

Running Head: CBT SELF-HELP: INFORMAL CARERS OF STROKE
SURVIVORS

Development and Feasibility Randomised Controlled Trial of Guided Cognitive
Behavioural Therapy (CBT) Self-Help for Informal Carers of Stroke Survivors

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ABSTRACT

Background: One-in-three carers of stroke survivors experience depression with no psychological treatments tailored to meet their needs, such as barriers to attending traditional face-to-face psychological services. A cognitive behavioural therapy (CBT) self-help approach may represent an effective, acceptable solution.

Methods: Informed by the MRC framework (2008) for complex interventions, six studies informed development, feasibility and piloting of a CBT self-help intervention for depressed carers of stroke survivors: *Study One:* Systematic review and meta-analysis of psychological interventions targeting depression and anxiety in carers of people with chronic health conditions; *Study Two:* Interviews to understand difficulties experienced by depressed and anxious carers; *Study Three:* Interviews to understand positive coping strategies used by non-depressed and non-anxious carers; *Study Four:* Drawing on results of Studies One to Three, iterative modelling to develop the CBT self-help intervention; *Study Five:* Feasibility randomised controlled trial to examine methodological and procedural uncertainties for a Phase III definitive trial; *Study Six:* Updated systematic review and meta-analysis.

Results: *Study One:* 16 studies identified for inclusion yielding small and medium effect sizes for depression and anxiety respectively, with trends for individually delivered treatments over shorter session durations to be more effective for depression. Six additional studies were included in Study Six, replicating Study One results; *Study Two:* Depressed and anxious carers experience difficulties adapting to the caring role, managing uncertainty, lack of support and social isolation; *Study Three:* Non-depressed and non-anxious carers utilise problem-focused coping strategies to gain balance and adapt to caring role, use assertiveness, seek social support and positive reinterpretation; *Study Four:* Developed a theory-driven CBT self-help intervention; *Study Five:* Recruited 20 informal carers in 10-months, representing 0.08% of invited carers randomised with high attrition in the intervention arm. Lack of GP recognition, gatekeeping and barriers to accessing psychological support identified as reasons for poor recruitment.

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Conclusions: A greater appreciation is required concerning barriers experienced by informal carers of stroke survivors to accessing support for depression and type of acceptable psychological support.

NOTES ON THESIS STRUCTURE

The protocols for Studies One and Five reported in Chapter Three and Chapter Seven respectively are presented in the form of manuscripts that have been published in peer reviewed scientific journals. The protocol for the systematic review and meta-analysis presented in Chapter Three (3.1 – 3.4 inclusive) has been published in *Systematic Reviews* (Woodford, Farrand, Richards & Llewellyn, 2013); and the protocol for the randomised controlled trial presented in Chapter Seven (7.1 – 7.4 inclusive) has been published in *Trials* (Woodford, Farrand, Watkins, Richards, & Llewellyn, 2014).

The main text pertaining to the protocols in Chapters Three and Seven are presented as a replication of the manuscript as per the School of Psychology's guidelines for the inclusion of papers in a thesis. In addition, a number of formatting adjustments have been made to the papers in order to integrate them into the thesis as a whole:

1. A global numbering system has been used throughout the thesis and this has been applied to the replicated published manuscripts.
2. American English has been changed to British English.
3. Figures, tables and appendixes within the published manuscripts are presented in appropriate places and their numbering has been changed in order to integrate them into the thesis as a whole.
4. In-text referencing has been reformatted to bring referencing in line with the American Psychological Association (APA) conventions for citing and referencing.
5. In-text seriation has been reformatted to reflect APA guidelines.
6. The reference sections of each paper have been collated into the single reference section at the end of the dissertation, again, reflecting APA conventions.
7. The abbreviation CBTsh has been changed to CBT self-help

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LIST OF ABBREVIATIONS

ASSIA	Applied Social Sciences Index and Abstracts
BAI	Beck Anxiety Inventory
BDI	Beck Depression Inventory
BI	Barthel activities of daily living index
CBS	Caregiver burden scale
CBT	Cognitive behavioural therapy
CCG	Clinical commissioning group
CENTRAL	Cochrane Central Register of Controlled Trials
CES-D	Center for Epidemiologic Studies-Depression Scale
CINAHL	Cumulative Index to Nursing and Allied Health Literature
CIS-R	Clinical interview schedule
CONSORT	Consolidated standards of reporting trials
CRD	Centre for Reviews and Dissemination
CSRI	Client Socio-Demographic and Service Receipt Inventory
DoH	Department of Health
EMBASE	Excerpta Medica DataBase
EQ-5D	EuroQol-5D
FAI	Frenchay activities index
GAD-7	Generalized Anxiety Disorder 7-item Scale
GDS	Geriatric Depression Scale
GHQ	General Health Questionnaire
GP	General practice
HADS-A	Hospital Anxiety and Depression Scale – Anxiety
HAMA	Hamilton Anxiety Rating Scale
IAPT	Improving Access to Psychological Therapies Programme
ICD-10	International Classification of Diseases-10
IPT	Interpersonal Psychotherapy
JW	Joanne Woodford
MBBS	Montgomery Borgatta Caregiver Burden Scale
MeSH	Medical Subject Headings
MRC	Medical Research Council
NHS	National Health Service
ONS	Office of National Statistics

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ORBIT	Outcome Reporting Bias in Trials classification system
PCRN	Primary Care Research Network
PF	Paul Farrand
PHQ-9	Patient Health Questionnaire-9
PICOS	Participants, Intervention, Comparator, Outcome, Study design
PROSPERO	International Prospective Register of Systematic Reviews
PTSD	Post-traumatic stress disorder
PWP	Psychological Wellbeing Practitioner
QALY	Quality-adjusted life-year
RCP	Royal College of Physicians
RCT	Randomised controlled trial
NETS	National Institute of Health Research Evaluation, Trials and Studies
SF-36	Short Form (36) Health Survey
SF-6D	Short Form-6 Dimension
SOC	Selection, Optimisation and Compensation Model
STAI-State	State-Trait Anxiety Inventory – State subscale.
TAU	Treatment-as-usual
TIA	Transient ischaemic attack
UK	United Kingdom
WSAS	Work and Social Adjustment Scale
ZBI	Zarit Burden Interview

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CHAPTER ONE: General Introduction

1.1 Background

1.1.1 The Prevalence and Impact of Informal Caregiving

Medical and healthcare advances have given rise to increases in life expectancy across the developed world (Christensen, Doblhammer, Rau & Vaupel, 2009). However, with an ageing population comes both a significant increase in people living with chronic physical health conditions (High, 2014) and the number of years people will live with poor health and disability (Jagger et al., 2007; Salomon, 2012). This poses a substantial challenge for the delivery of long-term healthcare within the community (Christensen et al., 2009; Dall et al., 2013; Lubitz, Cal, Kramarow, & Lentzner, 2003). As such, the demand for long-term home and community based care services has increased and is projected to further rise (Wittenberg, Comas-Herrera, Pickard, & Hancock, 2004). This has led to recent debate surrounding the reformation of healthcare services in order to ensure the sustainability and affordability of long-term care systems for older people (Malley et al., 2011) with projections of a 185% increase in long-term care expenditure in England by 2032 (Malley et al., 2011). The increased demand for long-term home and community based care has given rise to an increased reliance on informal carers as an alternative to formal care (Levine, Halper, Pelst, & Gould, 2010; van den Bery, Brouwer, & Koopmanschap, 2004; Wakefield, Hayes, Boren, Pak, & Davis, 2012).

Informal caregiving can be defined as provision of support by those in the close environment of the care recipient who are unpaid (Carretero, Garcés, Ródenas, & Sanjosé, 2009; Lutz & Young, 2010) and untrained (Carretero et al., 2009). Although informal carers are often family members, it is recognised that the term informal carer should also encompass non-family members such as partners, friends and neighbours (Levine, Halper, Pelst, & Gould, 2010). Typically long-term care is focused on the provision of nursing assistance with personal care, domestic responsibilities (Comas-Herrera et al., 2004) and emotional support (Carretero et al., 2009). Attempts to formally define the tasks involved in informal caregiving have identified five types of main activity (Hassink et al., 2011):

- Household activities.

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- ‘Instrumental activities of daily living’ (Lawton & Brody, 1969) such as managing finances and transportation.
- ‘Activities of daily living’, tending to focus on assisting with personal care (Katz, Ford, Roland, Jackson, & Jaffe, 1963).
- ‘Surveillance’, for example the person being cared for cannot be left alone.
- Medical tasks.

Although the operational definition of ‘informal carer’ concerns any unpaid, untrained person close to the care recipient providing support (Carretero et al., 2009; Lutz & Young, 2010), informal carers rarely identify with the role ‘carer’ (Cameron, Aggar, Robinson, & Kurrle, 2011). Family members often report feeling a ‘sense of duty’ (Cameron et al., 2011) or family obligation to support the care recipient (Weuest & Hodgins, 2011). Indeed, reluctance to identify with the term ‘carer’ is more common amongst family caregivers (Cooper, 2007). Further, some informal carers report the term ‘carer’ negatively impacts upon and threatens the identity of the person living with the long-term health condition (Knowles et al., 2015). Indeed, some informal carers have reported hiding the amount of support they provide to care recipients from others in order to protect the identity of the person receiving care (Moore & Gillespie, 2014). Additional factors contributing to informal carers resisting the ‘carer’ label concern fear of others expecting them to assume more caring responsibilities and the term overriding their identify as a ‘partner’ or ‘child’ (Knowles et al., 2015). Difficulties concerning informal carer identify are further complicated by the worldwide increase of the Baby Boomer generation being faced with the provision of informal care to their families (Guberman, Lavoie, Blein, & Olazabal, 2012). The Baby Boomer generation, those born between 1946 and 1964 (Moon & Dilworth-Anderson, 2014), are likely to simultaneously provide care to their children, parents and spouses, as well as potentially experiencing chronic health problem themselves (Moon & Dilworth-Anderson, 2014). Baby Boomers are potentially at an increased likelihood to experience identify conflicts in terms of balancing work expectations, as well as being a partner, a parent and caring for an older relative (Guberman et al., 2012). However, lack of identification with the term ‘carer’ can reduce informal carers’ ability to access and receive appropriate support (Cameron et al., 2011;

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Knowles et al., 2015). As such, whilst there is an increased reliance on informal carers as an alternative to formal care (Levine et al., 2010), carers are reluctant themselves to access currently available support (Cameron et al., 2011).

Consequently, there is a clear need to identify what type of support informal carers may consider appropriate and acceptable that recognises the unique difficulties carers experience (Krevers & Öberg, 2011).

Within the developed world it is projected that by 2050, 5.3% of the total population will be dependent on care (Harwood, Sayer, & Hirschfeld, 2004). Given the ageing population the old age dependency ratio, calculated by the population aged 65 and over divided by those aged between 20 to 64, is set to double by the year 2050 and triple by 2100 (Lee, 2011). Currently, 33.5% of adults over 50 years of age in high income countries have a first-degree relative with a serious physical health condition. Furthermore, 41.2% reported some degree of burden and 25.5% reported distress resulting from having a first-degree relative with a serious physical health condition (Shahly et al., 2013). Within the UK alone approximately 6.5 million adults provide informal care to someone, representing around 10% of the population (Office of National Statistics [ONS], 2013a). However, the percentage of adults providing informal care differs by age group with those aged between 50 and 64 years providing most care, with 24% of women and 17% of men providing informal care (ONS, 2013b).

The shift to outpatient treatment and subsequent increase in reliance on informal carers has led to the reduction in the use of home health care, nursing home care, shorter stays in hospital and less physician visits (van Houtven & Norton, 2004). However, the provision of informal care often results in substantial burden for the informal carer (Forster et al., 2014) meaning that potentially the healthcare costs are just being shifted somewhere else (Woodford, Farrand, Richards, & Llewellyn, 2013). Caregiver burden is a term used to describe the overall negative physical, emotional and financial consequences of being an informal carer (Mockus Parks & Novielli, 2000). Indeed, the provision of informal care is associated with increased mental health difficulties such as anxiety and depression (Coe & van Houtven, 2009; Pinguart & Sörensen, 2003a; Salva, Almeida, Davey, & Zarit, 2008); sleep problems (Rittman, Hinojosa, & Findley, 2009); a reduction in maintaining

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person relationships with family and friends (Rochette et al., 2007); restriction of participation in social and recreational activities (Mausbach et al., 2011; Rochette, Desrosiers, Bravo, Tribble, & Bourget, 2007), and poor quality of life (Godwin, Ostwald, Cron, & Wasserman, 2013; Parag et al., 2008).

Furthermore, informal caring is associated with poorer self-reported physical health (Legg, Weir, Langhorne, Smith, & Stott, 2013), psychosomatic, immunological and cardiovascular difficulties (Carretero et al., 2009) and reduced energy (Parag et al., 2008). Additionally, informal carers experience financial consequences such as being less likely to be in paid employment (Heitmueller, 2007) and if working, likely to be on lower incomes (Heitmueller & Inglis, 2007). Poor informal carer mental health is also associated with reduced quality of care and potentially abusive behaviour (Cooney, Howard, & Lawlor, 2006; MacNeil et al., 2009) and may also impact negatively on care recipient outcomes (Perrin, Heesacker, Stidham, Rittman, & Gonzalez-Rothi, 2008) including early institutionalisation (Carretero et al., 2009). Overall 30% of informal carers experience depression or anxiety (Davies, 1995) with higher levels of depression or anxiety experienced when the chronic physical health condition results in severe behavioural, cognitive and emotional impairment in the patient being cared for (van den Heuvel, White, Schure, Sanderman, & Meyboom-de Jong, 2001).

1.1.2 Informal Caregiving and Stroke

A stroke is a cerebrovascular event that can result in cognitive impairment (Douiri, Rudd, & Wolfe, 2013; Geerligs, Maurits, Renken, & Lorist, 2009); impairment of motor function (Langhorne, Coupar, & Pollock, 2009); emotional difficulties (Mukherjee, Levin, & Heller, 2006) and behavioural changes (Visser-Keizer, Meyboom-de Jong, Deelman, Berg, & Gerritsen, 2002). Indeed, 30-52% of informal carers of stroke patients experience high levels of depressive symptoms (Visser-Meily, Post, van de Port, van Heugten & van den Bos, 2008) from immediately following to 3-5 years post-stroke (Greveson, Gray, French, & James, 1991; Visser-Meily et al., 2008). Stroke prevalence rates currently stand at 2.4% for men and 2.2% for women within England (Townsend et al., 2012) with similar prevalence rates found in the United States (2.4% men; 2.7% women) (Jia, Zack, & Thompson, 2013). Although rates of stroke incidence and mortality across high-income countries is decreasing

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(Feigin et al., 2014) stroke remains the second leading cause of death and leading cause of disability worldwide (Feigin et al., 2014; Murray et al., 2012). An increase in post-stroke survival rates is resulting in an increase in stroke survivors returning to live in their homes (Reed et al., 2012) with around 80% of stroke survivors discharged into their home (Dobkin, 2005). Stroke survivors often have long-term disabilities that require different degrees of continued support and assistance (Kelly-Hayes et al., 2003) that tend to be provided by family members (Sumathipala, Radcliffe, Sadler, Wolfe, & McKeivitt, 2012). Often there is an assumption family members are able and willing to provide support to the patient in the home (Sisk, 2000). However this results in less professional support in terms of nursing and rehabilitation for both stroke survivors and carers (Ostwald, Davis, Hersch, Kelley, & Godwin, 2008).

Stroke onset is often sudden and leaves both the stroke survivor and informal carer unprepared for the consequences the stroke will place on them (Creasy, Lutz, Young, Ford, & Martz, 2013; Lutz & Young, 2010). Post-stroke effects are commonly physical, emotional (Creutzfeldt, Holloway, & Walker, 2012) and cognitive (Pinquart & Sörensen, 2003a; Schulz & Sherwood, 2008). Physical effects include an increased risk of falls and limitations in physical functioning (Lutz, Chumbler, & Roland, 2007); pain (Appelros, 2006; Jönsson, Lindgren, Hallström, Norrving, & Lindgren, 2006); fatigue (Appelros, 2006); post-stroke seizures and epilepsy (Berges et al., 2000); incontinence (Nakayama, Jorgensen, Pedersen, Raaschou, & Olsen, 1997) and spasticity (Wissel, Manack, & Brainin, 2013). Emotional difficulties include depression (Ayerbe, Ayis, Rudd, Heuschmann, & Wolfe, 2011; Johnson, Minarik, Nyström, Bautista, & Gorman, 2006; Lincoln et al., 2013); anxiety (Wai-Kwong, Grace, Vincent, Gabor, & Ka-Sing, 2013; Barker-Collo, 2007; Campbell Burton et al., 2013); and emotionalism (Hackett, Yang, Anderson, Horrocks, & House, 2010). Cognitive impairment encompasses memory deficits (Tatemichi et al., 1994) with approximately 23% of ischemic stroke survivors experiencing dementia (Desmond, Moroney, Sano, & Stern, 2002); communication problems such as dysphagia, dysarthria and aphasia (Flowers, Silver, Fang, Rochon, & Martino, 2013); deficits in executive function (Cumming, Marshall, & Lazar, 2013) and visual-spatial neglect (Appelros, Karlsson, Seiger, & Nydevik, 2002). Such post-stroke difficulties can cause disability with major impacts on performing

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activities of daily living, such as dressing, feeding (Mayo, Wood-Dauphinee, Côté, Durcan, & Carlton, 2002) and functional recovery (Cumming, Marshall, & Lazar, 2013). Around 69% of stroke survivors experiencing stroke related health difficulties require informal care and around 39% of stroke survivors without stroke related health difficulties also require informal care (Hickenbottom et al., 2002). Within England, Wales and Northern Ireland 42% of stroke survivors are considered independent in terms of functional ability. However, 22% have mild impairment, 14% moderate; 10% severe and 12% very severe indicating over 50% of stroke survivors will require some form of support and informal care (Royal College of Physicians [RCP], 2011).

Informal carers of stroke survivors are under significant burden (Rigby, Gubitz, & Phillips, 2009), with the prevalence of carer burden ranging from 28% within the first two months post-stroke (Bugge, Alexander, & Hagen, 1999; Ilse, Feys, de Wit, Putman, & de Weerd, 2008) and rising to 44% and 42% at six and 12 months post-stroke (Tooth, McKenna, Barnett, Prescott, & Murphy, 2005). Furthermore, increased carer burden has been found to be associated with increased neurological impairment, (Bugge et al., 1999); communication difficulties (Draper & Brocklehurst, 2007); physical dependence (Bugge, et al., 1999; McCullagh, Brigstocke, Donaldson, & Kalra, 2005); levels of functional ability (Bugge et al., 1999; Schulz & Sherwood, 2008; van Puymbroeck & Rittman, 2005); behavioural problems (Pinquart & Sörensen, 2003a) and anxiety and depression in the stroke survivor (Carod-Artal, Coral, Trizotto, & Moreira, 2009). However other studies have failed to find any association between carer burden and level of disability in the stroke survivor (Rigby et al., 2009; Robison, Fortinsky, Kleppinger, Shugrue, & Porter, 2009). Indeed, there is evidence to suggest that rather than relating to the needs of the person being cared for burden is associated with the informal carers' ability to adapt to the caring role (Garlo, O'Leary, van Ness, & Fried, 2010) with reviews indicating that for some informal carers' psychological health remains unchanged over time, whereas for others mental health declined or improved (Gaugler, 2010). Although there is inconsistent evidence in terms of factors that may contribute to increased informal carer burden, including depressive symptoms, it is clear that a large number of informal carers of stroke survivors require psychological support (Bakas, Austin, Okonkwo, Lewis, & Chadwick, 2002). Given the

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increases in reliance on informal carers, coupled with the recognition of high levels of burden and strain experienced, there have been calls for supporting informal carers in order to reduce the burden experienced (Carter, 2008). Furthermore, given the relationship between psychosocial functioning of the informal carer, quality of informal care provision and stroke severity and recovery (Perrin, Heesacker, Stidham, Rittman, & Gonzalez-Rothi, 2008) interventions for informal carers may not just improve mental health of the carer but also increase quality of care provided and impact on the recovery of stroke survivor themselves (Bakas et al., 2014; Perrin et al., 2008).

1.1.3 The Unmet Need

Despite the clear need to develop psychological treatments for informal carers of stroke survivors, the long-term emotional needs of informal carers have been neglected (Murray, Young, Forster, & Ashworth, 2003; Silva, Teizeira, Teizeira, & Freitas, 2013; Simon, Kumar, & Kendrick, 2008; 2009). Informal carers often report concerns about their need for emotional support and how these needs are not often addressed (Creasy et al., 2013) with content analyses of carer websites indicating that many informal carers seek information concerning psychological concerns, emotional support, relationship difficulties and stress management (Kernisan, Sudore, & Knight, 2010). Indeed, informal carers report the need for “counselling” type support (Krevers & Öberg, 2011) however only 3.1% of informal carers in the UK were found to have accessed counselling services, with percentages ranging from only 0.2% and 6.7% across other countries in Europe (Lamura et al., 2008).

As well as recognising the lack of availability of evidence based mental health treatments it is also important to recognise barriers to accessing treatment in order to provide support that is both accessible and acceptable to those who need support (Thorncroft & Tansella, 2014). Barriers to informal carers accessing support and information have included lack of time (Carretero et al., 2009; Eames, Hoffmann, Worrall, & Read, 2010; van Houtven, Oddone, & Weinberger, 2010); long waiting times making it difficult to plan appointments around caregiving (Beaver, Luker, & Woods, 2000); a feeling of guilt and duty of care (Sisk, 2000) and own physical health difficulties (van Houtven, Oddone, & Weinberger, 2010). Furthermore, a number of barriers to informal carers accessing support pertain to the lack of recognition of the difficulties associated

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in the caring role by health professionals (Arksey & Hirst, 2005). General practitioners and family doctors within primary care tend to provide referrals for practical support, as opposed to emotional support (Bulsara & Fynn, 2006; Greenwood, Mackenzie, Habibi, Atkins, & Jones, 2010) and when psychological support is provided within primary care it tends to be in the form of informal sharing as opposed to referral to mental health services (Bulsara & Fynn, 2006). Indeed carers of informal stroke survivors report that they receive little emotional support from general practitioners with support focused on the stroke survivor rather than themselves (Greenwood, Mackenzie, Harris, Fenton, & Cloud, 2011) alongside a lack of routine assessment of carer needs in Europe with services tending to be reactive as opposed to proactive (Lamura et al., 2008).

Although numerous studies have examined the provision of psychological support for informal carers of stroke survivors, there is also a lack of evidence in terms of effective interventions targeting the typical adverse consequences of caregiving such as depression, anxiety and burden (Brereton, Carroll & Barnston, 2007; Cheng, Chair, & Chau, 2014; Legg et al., 2011; Visser-Meily, van Heugten, Post, Schepers, & Lindeman, 2005). Overall limitations in terms of the existing evidence pertain to poor study quality (Brereton et al., 2007; Legg et al., 2011), such as a lack of randomised controlled trials alongside poor reporting (Bakas et al., 2014; Cheng, Chair, & Chau, 2014) and small sample sizes (Bakas et al., 2014; Bakas et al., 2014). In addition, most interventions are delivered during stroke survivor inpatient rehabilitation or within 6 months post-discharge to the home (Brereton et al., 2007). However, this period is one of major change for both the informal carer and the stroke survivor and more long-term interventions are required for later in the caregiving trajectory after stabilisation into the caregiving role has taken place (Perrin et al., 2010). Furthermore, studies examining informal carer interventions have tended not to include carers defined as having a disease state or ill health (e.g., depression) resulting in a reduced likelihood of being able to demonstrate the effectiveness of interventions (Legg et al., 2011). As such, there have been recommendations that future studies either recruit carers who are depressed or perform subgroup analysis on those participants who are depressed (Bakas et al., 2014). Despite the current overall poor evidence base,

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there is some evidence to suggest that informal carer interventions involving components such as problem solving, goal setting and stress management techniques are effective in terms of improving carer outcomes such as depression (Bakas et al., 2014; Cheng, Chair, & Chau, 2014; Visser-Meily et al., 2005).

1.1.4 A Potential Solution

Although there is a clear need for the development of evidence based treatments for depression in informal carers of stroke survivors traditional models of delivery, for example, face-to-face cognitive behavioural therapy (CBT), are unlikely to be suitable. Costs of traditional face-to-face psychotherapy are high, with demand exceeding the supply of therapists (Lovell, Richards, & Bower, 2003). Indeed, worldwide the majority of people with mental health difficulties, such as depression, are untreated (Kohn et al., 2004; Thornicroft, 2007) reflecting the global lack of provision of mental health services (Thornicroft & Tansella, 2014). A potential solution is the development of a CBT self-help intervention for depressed informal carers of stroke survivors. In order to increase access to psychological therapy CBT self-help is being widely implemented into mental health services globally (Clark, 2011; Gyani, Sahran, Layard, & Clark, 2013; Pilgrim & Carey, 2012; Rebello, Marques, Gureje, & Pike, 2014). This paradigm shift (Bennett-Levy et al., 2010) is marked by a movement away from traditional face-to-face psychotherapy delivered by mental health professionals towards CBT self-help supported by paraprofessional mental health workers following a stepped care system of delivery (Bower & Gilbody, 2005; Richards, 2012). The evidence base for CBT self-help for depression is well established, with several systematic reviews reporting medium to large effect sizes (Anderrson & Cuijpers, 2009; Coull & Morris, 2011; Farrand & Woodford, 2013; Gellatly et al., 2007; Hedman, Ljótsson, & Lindefors, 2012). Indeed, supported CBT self-help has been found to be as effective as traditional face-to-face psychotherapy for depression (Cuijpers, Donker, van Straten, Li, & Andersson, 2010).

There is currently no agreed definition as to what constitutes CBT self-help (Farrand & Woodford, 2013; Ridgway & Williams, 2011). However, it is commonly agreed that a defining characteristic of CBT self-help interventions is that CBT specific principles are communicated through the use of self-help

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materials rather than being delivered by a therapist. These materials are most commonly presented in a written or internet based format (Bennett-Levy, Richards & Farrand, 2010) but can also be delivered via audiotape, DVD (Ridgway & Williams, 2010) and more recently mobile phone applications (Donker et al., 2013b). CBT self-help materials are designed to provide the user with knowledge about their difficulties and provide them with skills and techniques to self-manage these difficulties (Williams, 2003). Some evidence suggests patients need guidance and motivation in the use of the self-help materials for the interventions to be most effective with supported CBT self-help yielding larger effect sizes than unsupported (Anderrson & Cuijpers, 2009; Gellatly et al., 2007). Although other meta-analyses have found effect sizes for written CBT self-help do not differ significantly by type of support, trends in the data would suggest minimal support and guidance over the telephone increases the effectiveness for depression CBT self-help treatments (Farrand & Woodford, 2013). Support can also be provided through a variety of mediums, for example face-to-face, telephone, email or skype (Ridgway & Williams, 2011). Support sessions are typically short in duration, lasting around 30 minutes (Richards & Whyte, 2011) with an average of 5.4 sessions being provided to support patient recovery (Richards & Borglin, 2011). Within England CBT self-help underpins the Improving Access to Psychological Therapies Programme (IAPT) in England (Clark, 2011; Richards & Borglin, 2011; Richards & Suckling, 2009) with a trained paraprofessional workforce, Psychological Wellbeing Practitioners (PWP), established to guide the use of the self-help materials.

Given that the demands of caring are often a barrier to attending therapy (Arksey et al., 2003; Arksey & Hirst, 2005), increased flexibility associated with the delivery of CBT self-help may potentially help to increase access to appropriate psychological support for informal carers of stroke survivors. For example, shorter sessions and options for telephone, email or Skype support may help overcome barriers to accessing support such as lack of time (Eames, et al., 2010); difficulties planning support around the caring role (Beaver, Luker, & Woods, 2000) and carer's own physical health difficulties (van Houtven et al., 2010). Furthermore, options for telephone or email support may provide a level of anonymity that may not be possible with therapy delivered face-to-face potentially overcoming barriers associating with feelings of guilt and duty of care

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(Sisk, 2000). Indeed, a recent review of interventions for informal carers of stroke survivors concluded that given time restrictions experienced by carers, interventions using a large number of lengthy face-to-face treatment sessions may not be suitable and indeed telephone or web support may be more acceptable (Bakas et al., 2014).

1.1.5 But Why Develop a New CBT Self-Help Intervention?

At present, CBT self-help interventions used within IAPT are targeted at a general mental health population. Recognising the demand for psychological therapy amongst physical health patients with comorbid mental health problems and their carers, the IAPT programme is currently being extended to include a focus on long-term physical health conditions and older adults (Department of Health [DoH], 2011a). However, an increasing body of evidence highlights a number of significant adaptations to the CBT self-help interventions used with IAPT are required prior to their application to other patient populations. For example, multiple sclerosis patients have reported that a general online CBT intervention for depression required adaptations to content, patient vignettes and intervention descriptors (Hind et al., 2009) prior to the intervention being acceptable. Specific treatment adaptations have also been required to ensure the acceptability of CBT self-help interventions for women with postnatal depression (O'Mahen et al., 2013; O'Mahen et al., 2014). Furthermore, in studies examining internet-based CBT self-help, high rates of attrition and low rates of treatment adherence are often reported (Christensen, Griffiths, & Farrer, 2009; Donkin et al., 2011). It has been proposed that rates of attrition may be reduced and adherence increased if the perspective of the population using the treatment is adopted when developing interventions (Ferwerda et al., 2013). Indeed, a trial of internet-based CBT for Irritable Bowel Syndrome (IBS) found patients who engaged in the programme spoke positively in terms of the IBS specific information provided (Tonkin-Crine, Bishop, Ellis, Moss-Morris, & Everitt, 2013). Moreover, informal cancer carers using a generic internet-based CBT intervention for depression criticised the programme for not being sufficiently focused on the needs of carers (Scott & Beatty, 2013). These conclusions have been supported in a focus group held with stroke survivors and their carers undertaken to develop the original PhD proposal. Whilst supporting the acceptability of a CBT self-help approach, stroke survivors and

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carers identified adaptations in language and patient vignettes as well as the need to tailor the CBT interventions to someone with caring needs.

Additionally, although CBT self-help has been found to be effective for depression (Coull & Morris, 2011; Gellatly et al., 2007; Farrand & Woodford, 2013) reviews of self-help interventions for people with physical health conditions have reported smaller effect sizes than those for anxiety and depression (Beatty & Lambert, 2013; Cuijpers, van Straten, & Andersson, 2008; Farrand & Woodford, in press; Matcham et al., 2014). Therefore, the benefits demonstrated in CBT self-help interventions developed for general mental health populations may not be generalisable to all populations. To date only five published studies have examined CBT self-help for depression within informal carer populations. Specifically, CBT self-help has been examined within carers of people with anorexia nervosa (Grover et al., 2011a; Grover et al., 2011b; Hoyle, Slater, Williams, Schmidt, & Wade, 2013), cancer (Scott & Beatty, 2013) and dementia (Kwok et al., 2014). Furthermore, mental health services for carers have been criticised for not being tailored to the unique difficulties carers experience (Krevers & Öberg, 2011; Lundh, 1999) such as managing behavioural problems (Pinquart & Sörensen, 2003a); physical impairments (Pinquart & Sörensen, 2003b) and cognitive decline (Vernooij-Dassen, Draskovic, McCleery, & Downs, 2011). Such criticisms have led to a call for the development of interventions focused on the provision of techniques to manage the difficulties of the caring role (Carretero et al., 2009). Indeed a recent review indicates informal caregiver interventions tailored to the specific needs of stroke informal caregivers are more effective than non-tailored interventions (Bakas et al., 2014). Therefore, it is clear that more research is required into both the effectiveness and acceptability of CBT self-help interventions for specific populations, such as carers.

1.1.6 Informing the Content of a New CBT Self-Help Intervention.

Over the last decade there has been growing recognition of the importance of understanding patients' experience when developing health resources (Kennedy & Rogers, 2002; Kennedy, Robinson, & Rogers, 2003) and healthcare policy (Nilsen, Myrhaug, Johansen, Oliver, & Oxman, 2006). A number of studies adopting both quantitative and qualitative methodology have investigated the factors contributing to caregiver burden. Although some

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longitudinal and cross-sectional studies have shown that increased levels of caregiver burden have been associated with increased levels of depression (Carod-Artel, Coral, Trizotto, & Moreira, 2009; Phillips, Gallagher, Hunt, Der & Carroll, 2009) results from systematic reviews in the area are inconsistent in terms of identifying additional factors (for example stroke survivor characteristics; physical strain; receipt of health and social support) that increase caregiver burden (Rigby et al., 2009). Therefore at present few studies have identified what specific aspects of the caregiving experience contribute to levels of caregiver burden. In addition, despite the consistent finding that elevated levels of depression and anxiety are related to increased levels of caregiver burden (Rigby et al., 2009), no studies to date have been conducted in terms of understanding the specific problems and difficulties experienced by informal carers of stroke survivors with elevated symptoms of anxiety and depression. Given the lack of research in terms of identifying the specific difficulties and challenges experienced by carers with elevated symptoms of depression and anxiety there is clear need to identify such difficulties and challenges to help inform some of the content of a new CBT self-help intervention. This will aid the development of an intervention whereby the unique needs of informal carers are taken into account, the neglect of which has hindered the development of effective informal carer interventions (Sørensen, Pinqart, & Duberstein, 2002; Wilkinson & Lynn, 2005). In addition, difficulties and problems experienced by carers may identify potential barriers to accessing support that may inform an appreciation of how best to deliver a CBT self-help intervention for carers.

As well as identifying difficulties experienced by patients when developing treatments, an appreciation of methods of coping with such difficulties is also important (Kennedy & Rogers, 2002; Kennedy, Robinson, & Rogers, 2003). Carers of stroke survivors have expertise in understanding and managing difficulties experienced within the caring role, with certain coping strategies (Perrin et al., 2008) and problem solving techniques (Grant, Elliott, Newman, & Bartolucci, 2001) helping to alleviate carers' levels of depression. Interventions helping carers with coping strategies and effective problem solving may therefore be effective in reducing carers' emotional distress (del-Pino-Basado, Frías-Osuna, Palomino-Moral, & Pancorbo-Hidalgo, 2011; Grant et al.,

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2001). Although various cross-sectional correlational studies indicate that the use of more active coping strategies and increased social support are associated with lower levels of depressive symptoms (van de Heuvel et al., 2001) weaknesses in the designs of these studies limit conclusions that can be made. Additionally a recent review of qualitative studies investigating coping strategies used by carers of stroke survivors (Greenwood, MacKenzie, Cloud, & Wilson, 2009) identified only four qualitative studies (Bakas et al., 2002; Burman, 2001; Denman, 1998; Peirce & Steiner, 2004) focused solely on the coping strategies used by carers of stroke survivors. Additionally, these studies have small sample sizes and fail to report participant mental health characteristics such as levels of depression or anxiety. Therefore, there is a clear need to identify the specific helpful coping strategies used by carers of stroke survivors to further feed into the development of a CBT self-help intervention, recognising such strategies may be useful to carers of stroke survivors experiencing emotional difficulties.

1.2 Overall Aim

The overall aim of this programme of research is to develop and refine a CBT self-help intervention for depressed informal carers of people with stroke that is both acceptable and feasible. This will be a two stage process following the revised Medical Research Council (MRC) framework for developing complex interventions (MRC, 2008; Craig, Dieppe, Macintyre, Michie, Nazareth, & Petticrew, 2008) consisting of development and test in a feasibility randomised controlled trial (RCT) comparing the new support CBT self-help intervention to usual care.

1.3 Thesis Structure

Chapter One has provided an outline of the prevalence and importance of the problem and an overview of the lack of effective and acceptable depression interventions for informal carers of stroke survivors. A potential solution in terms of a CBT self-help intervention was presented alongside reasons for developing an intervention tailored specifically to the needs of informal carers of stroke survivors. Finally, ways forward in terms of developing a tailored CBT self-help intervention were offered, primarily focusing on understanding both difficulties experienced by depressed informal carers of stroke survivors and positive coping strategies used by non-depressed carers.

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Chapter Two outlines the key methodological approaches utilised throughout the thesis. First, the MRC framework (MRC, 2000; 2008) is discussed alongside an appreciation of how the revised MRC framework (2008) was followed in order to develop and pilot the new CBT self-help intervention. Second, the specific methodological approaches used within the thesis are presented in detail and the choices of methodological approaches undertaken are justified.

Chapter Three (Study One) presents a systematic review and meta-analysis of psychological and psychosocial interventions for depressed and anxious informal carers of stroke survivors undertaken as the first stage of the development phase of the revised MRC framework (MRC, 2008). The aims of Study One were to identify the existing evidence base and identify potential intervention components associated with effectiveness to inform the development of CBT self-help intervention.

Chapter Four (Study Two) reports on a qualitative study utilising semi-structured interviews and a thematic analysis approach (Braun & Clarke, 2006). The study aim is to understand the specific difficulties experienced by depressed and anxious informal carers of stroke survivors and barriers to accessing support to further inform the development phase of the revised MRC framework (MRC, 2008). Psychological techniques were then identified from the literature that may target the difficulties experienced by informal carers of stroke survivors to further enhance the content of the CBT self-help intervention.

Chapter Five (Study Three) presents a further qualitative study adopting a positive psychology approach (Boiler et al., 2013; Layous et al., 2014; Mitchell et al., 2009) to understand positive coping strategies used by non-depressed and non-anxious informal carers through conducting semi-structured interviews. Again, psychological techniques were identified from the literature that may help depressed informal carers utilise positive coping strategies to further enhance the content of the CBT self-help intervention, further feeding into the development phase of the revised MRC framework (MRC, 2008).

Chapter Six (Study Four) was the final study conducted as part of the development phase of the revised MRC framework (MRC, 2008) and presents the use of modelling to synthesise the results of Study One, Two and Three to

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develop the CBT self-help intervention, PWP assessment and support protocol and associated training programme. As well as drawing upon previous study findings the CBT self-help intervention was developed closely with a lived experience steering committee, professional design company and further enhanced by incorporation common factors (Cahill et al., 2008).

Chapter Seven (Study Five) reports the findings of the feasibility RCT conducted to inform the feasibility and piloting phase of the revised MRC framework (MRC, 2008). The aims of the RCT were to examine the feasibility of study design, trial procedures and the acceptability of the new CBT self-help intervention. Results are discussed alongside limitations and future directions for research.

Chapter Eight (Study Six) places the programme of research undertaken in the context of an updated systematic review and meta-analysis of psychological and psychological interventions for informal carers of people with chronic physical health conditions. The review undertaken in Study One was completed in 2012 in order to inform the development of the CBT self-help intervention. As such, by the end of this programme of research the review results were out of date. In addition, all new research findings should be appreciated within the context of previously conducted relevant research (Clarke et al., 2010). The review undertaken in 2012 was updated until August 2014 in order to discuss the findings of this PhD in light of recent evidence.

Chapter Nine provides a summary of the thesis as a whole. In addition, the methodological strengths and limitations of the thesis are discussed, alongside a discussion of future research directions. Finally clinical implications of this programme of research are presented and conclusions drawn.

CHAPTER TWO: Methodological Approach

2.1 Introduction

In this chapter the methodological approaches utilised in the thesis will be outlined, alongside justifications for the use of the methods employed. First, an outline of MRC framework (MRC, 2000, 2008) for the development and evaluation of complex interventions will be presented. Second, an overview of the core methodological techniques employed within the thesis will be provided. Finally, each of the methodological techniques used will be described in detail, alongside justifications for their use. As such, this chapter will provide an overview and justification of the methodology used throughout the remainder of the thesis. Later chapters will present the specific methods followed within each study, along with results and detailed discussion of findings.

2.2 Medical Research Council Framework

As outlined in Chapter One, the overall aim of the thesis is to develop and refine an acceptable and feasible CBT self-help intervention for depressed informal carers of stroke survivors. The thesis follows a two-stage process informed by the revised MRC framework for the development and evaluation of complex interventions (Craig et al., 2008; MRC, 2008). Specifically, the development and feasibility and piloting phases of the MRC framework inform the structure of this thesis.

2.2.1 What is a Complex Intervention?

Complex interventions are defined as interventions that are comprised of multiple components (MRC, 2000; MRC, 2008). These components act independently, depend upon one another (Barley et al., 2012) and encompass external factors such as the context in which the intervention is delivered (Clark, 2013). Furthermore, such interventions incorporate the behaviours of those who deliver and receive the intervention and are designed to have an influence on some specified outcome (Campbell et al., 2007; Craig et al., 2008). Typically they are non-pharmacological interventions that attempt to change behaviour at either an organisational or individual level (Clark, 2013). Indeed, CBT self-help written materials have been previously defined in the literature as complex interventions (Lovell et al., 2008). The inherent complexity in terms of the relationship between components of complex interventions (Clark, 2013)

can make the design and evaluation of such interventions complex and difficult (Barley et al., 2012).

2.2.2 Why was the MRC Framework Developed?

Developing and evaluating complex interventions is challenging. Due to the difficulties in controlling for potential confounders, defining interventions, identifying suitable comparators and appropriate outcome measurements, evaluation methodologies that are too simplistic may be adopted or indeed researchers may shy away from evaluating complex interventions at all (Richards & Borglin, 2011). Commonly complex interventions are often poorly defined (Campbell et al., 2000) and trials of complex interventions tend not to identify the specific processes and mechanisms of action underlying the intervention (Campbell et al., 2007). As such, it can be difficult to interpret the findings of trials (Campbell et al., 2007). For example, if the trial results are negative it is difficult to judge whether the intervention itself is ineffective or whether the design, choice of comparators or outcome measurements may have been unsuitable (Campbell et al., 2007).

2.2.3 The MRC Framework (2000)

As a response to the difficulties in designing and evaluating complex interventions, the MRC published a framework to guide the development and evaluation of complex interventions (Campbell et al., 2000; MRC, 2000). The framework was designed to be a pragmatic approach to guide the development and evaluation of complex interventions encouraging the use of a variety of high quality experimental and non-experimental methods (Craig & Petticrew, 2013). The first iteration of the MRC framework was a stepwise approach; mirroring methods commonly used to develop and evaluate drugs (Campbell et al., 2000, MRC, 2000) and encompassed the following phases:

- Preclinical: The identification of evidence based theory to underpin the intervention to ensure the complex intervention proposed may result in the desired effect (Campbell et al., 2000).
- Phase I: Modelling in order to inform the specific theory based components of the intervention (Campbell et al., 2000).
- Phase II: An exploratory trial with the aim of examining the feasibility and acceptability of the intervention and inform methodological uncertainties such as definition of a suitable comparator;

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identification of suitable outcome measurements and investigation of other design uncertainties (Campbell et al., 2000).

- Phase III: A fully powered RCT to examine effectiveness of the intervention, with the design of the trial informed by the results of Phase II (Campbell et al., 2000).
- Phase IV: The implementation of the new intervention into practice if the results of Phase III are positive (Campbell et al., 2000).

The overall aim of the MRC framework was to develop a phased and structured approach to complex intervention design, development, evaluation and implementation in order to improve the quality and generalisability of complex interventions in healthcare (Campbell et al., 2000).

2.3.4 The Revised MRC Framework (2008)

Increasing evidence has highlighted a number of limitations in the original framework (Craig et al., 2008). For example, it was proposed that the framework could be strengthened by the provision of a greater emphasis on the use of modelling approaches to inform the development of complex interventions (Hardeman et al., 2005) and greater recognition that the development and evaluation of complex evaluations tends to be an iterative rather than sequential activity (Campbell et al., 2007). Additionally, the importance of understanding the context of the complex intervention was highlighted (Campbell et al., 2007). Context might include the wider social economic environment and background of participants, the prevalence of the health problem being targeted alongside the severity of the health problem as well as the wider health and social service systems the intervention is embedded within (Campbell et al., 2007). As such, it was posited that when developing and evaluating complex interventions it was essential that researchers both understand and report the context in which the intervention was developed and evaluated to enable others to apply the findings to their own context (Campbell et al., 2007). In response to these limitations and recommendations a revised framework was developed (Craig et al., 2008; MRC, 2008) which can be seen in Figure 2.1 and is described in more detail below.

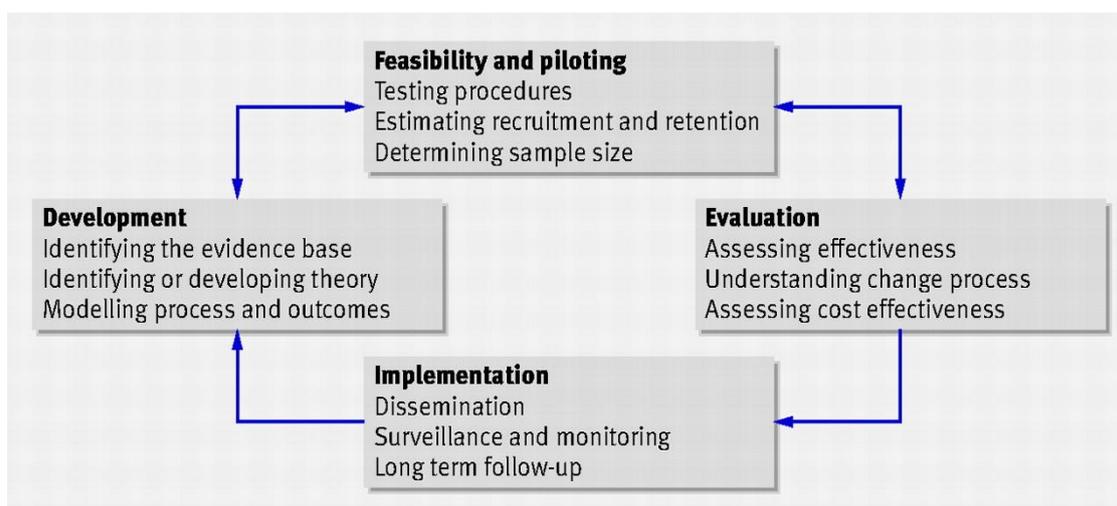


Figure 2.1. The revised MRC framework (Reprinted from Craig et al., 2008, p. 980).

2.3.4.1 Development. The overall aim of the new development phase identified in the revised MRC framework is to develop an intervention that maximises the likelihood the intervention will have a positive effect on outcomes (MRC, 2008; Craig et al., 2008).

- *Identifying the evidence base:* The existing evidence base should be identified through a systematic review (MRC, 2008; Craig et al., 2008). As well as identification of the current evidence base of an intervention it can also be possible through meta-analytic techniques to identify potential components associated with increased effectiveness to further inform the development of the intervention (Greaves et al., 2011).
- *Identify or develop the theory:* Understanding the theories underlying the potential process of change in the intervention will maximise the effectiveness of the intervention (MRC, 2008; Craig et al., 2008). Theory can be developed through primary research, for example understanding the views of key stakeholders as well as the identification of existing evidence and theory (MRC, 2008; Craig et al., 2008). Within the development phase the importance of using both quantitative and qualitative methodology has been highlighted (Richards & Borglin, 2011). For example, interviews may be held with patients and healthcare professionals to understand the needs and preferences for an intervention (Barley et al., 2012; Bradshaw et

al., 2012). Additionally, literature may be searched and experts contacted to identify appropriate theories to inform a theoretical understanding of the potential process underlying change (Carnes et al., 2013).

- *Modelling the intervention:* Specifically this refers to describing the expected processes underpinning the intervention (how the intervention is proposed to work) and outcomes (what the intervention is expected to change) of a complex intervention (MRC, 2008; Craig et al., 2008). This includes detailed definition of the specific components of the intervention, how these components may be related to one another and how these components relate to the desired outcomes of the intervention (Faes et al., 2010). Further primary research could be conducted within the modelling phase such as the use of Delphi studies to gain expert opinion as to the specific components of the intervention (Faes et al., 2010). Other techniques might include expert meetings, further qualitative studies with key stakeholders (Hardeman et al., 2006) or intervention mapping techniques (Michie, Johnston, Francis, Hardeman, & Eccles, 2008).

2.3.4.2 Feasibility and piloting. Poorly designed randomised controlled trials are common (Eldridge, Ashby, Feder, Rudnicka, & Ukoumunne, 2004). Furthermore, trials often report difficulties recruiting to target (McDonald et al., 2006; Sully, Julious, & Nicholl, 2013); high levels of attrition coupled with inappropriate handling of missing data (Peterson, Pirraglia, Wells, & Charlson, 2012) and non-compliance and difficulties delivering the intervention (Craig et al., 2008). As such, it is important to conduct a pilot study in order to examine the main methodological uncertainties and appreciate the acceptability of a complex intervention before conducting a full evaluation (Craig et al., 2008).

2.3.4.3 Evaluation. The primary aims of this phase are to assess the effectiveness of the intervention. The effectiveness of a complex intervention should ideally be examined using a RCT (MRC, 2008; Craig et al., 2008). In addition, this phase seeks to understand the processes underlying the complex intervention, for example through process evaluation (Oakley, Strange, Bonell, Allen, & Stephenson, 2006) and to assess the cost-effectiveness of the

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intervention (Craig et al., 2008; MRC, 2008). Additionally, a process evaluation may help assess fidelity to the intervention from both a delivery and patient compliance perspective. This will provide important data pertaining to the potential future implementation of the intervention (MRC, 2008).

2.3.4.4 Implementation. The implementation phase refers to methods to translate evidence into practice (MRC, 2008). First, this relates to the dissemination of results, not only through peer reviewed scientific journals but also using methods that will actively disseminate the results to policy makers (MRC, 2008). The importance of dissemination is relevant to both positive and negative trial results in order to reduce the bias of under reporting negative results and over publishing positive results (Chalmers & Glasziou, 2009). Additionally, it is essential that a detailed description of the intervention is disseminated to allow replication (Faes et al., 2010). Furthermore, it is important that this is timely as there are often large delays in the implementation of interventions from the time they were demonstrated to be efficacious (Grol, Bosch, Hulscher, Eccles, & Wensing, 2007). Finally, it is important to measure longer-term outcomes to determine the effectiveness of the intervention beyond the short-term changes measured within the original evaluation (MRC, 2008).

2.3.5 Impact of the MRC Framework

The MRC framework has been used to inform the development of a number of complex interventions including: depression and coronary heart disease programme (Barley et al., 2012); a healthy living intervention for people with early psychosis (Bradshaw et al., 2012); CBT self-help interventions for depression (Lovell et al., 2008); low intensity behavioural activation combined with physical activity promotion (Farrand et al., 2014); self-management for pain management in chronic musculoskeletal conditions (Carnes et al., 2013); collaborative care for depression (Richards et al., 2006) and diabetes self-management (Stuart, Whitlock, & Hearnshaw, 2006). Indeed, an increasing body of evidence suggests both the original and revised MRC frameworks have been utilised by researchers developing and evaluating a variety of complex interventions within healthcare (Craig & Petticrew 2013). It must however be noted that the MRC framework provides general guidance for researchers rather than a prescriptive set of methodological approaches that must be utilised within each phase. Furthermore, new models and evaluative

techniques are being continuously developed that may fit within the framework (Craig & Peticrew, 2013).

2.3 Overview of methodology utilised within the thesis

A series of studies have been conducted within the thesis to inform the development of a CBT self-help intervention for depressed carers of stroke survivors. This is followed by an initial examination of feasibility and acceptability within a feasibility RCT following the revised MRC framework (Craig et al., 2008; Campbell et al., 2008). Figure 2.2 provides a visual presentation of the main methods utilised to inform the development and feasibility phases of the MRC framework within this thesis.

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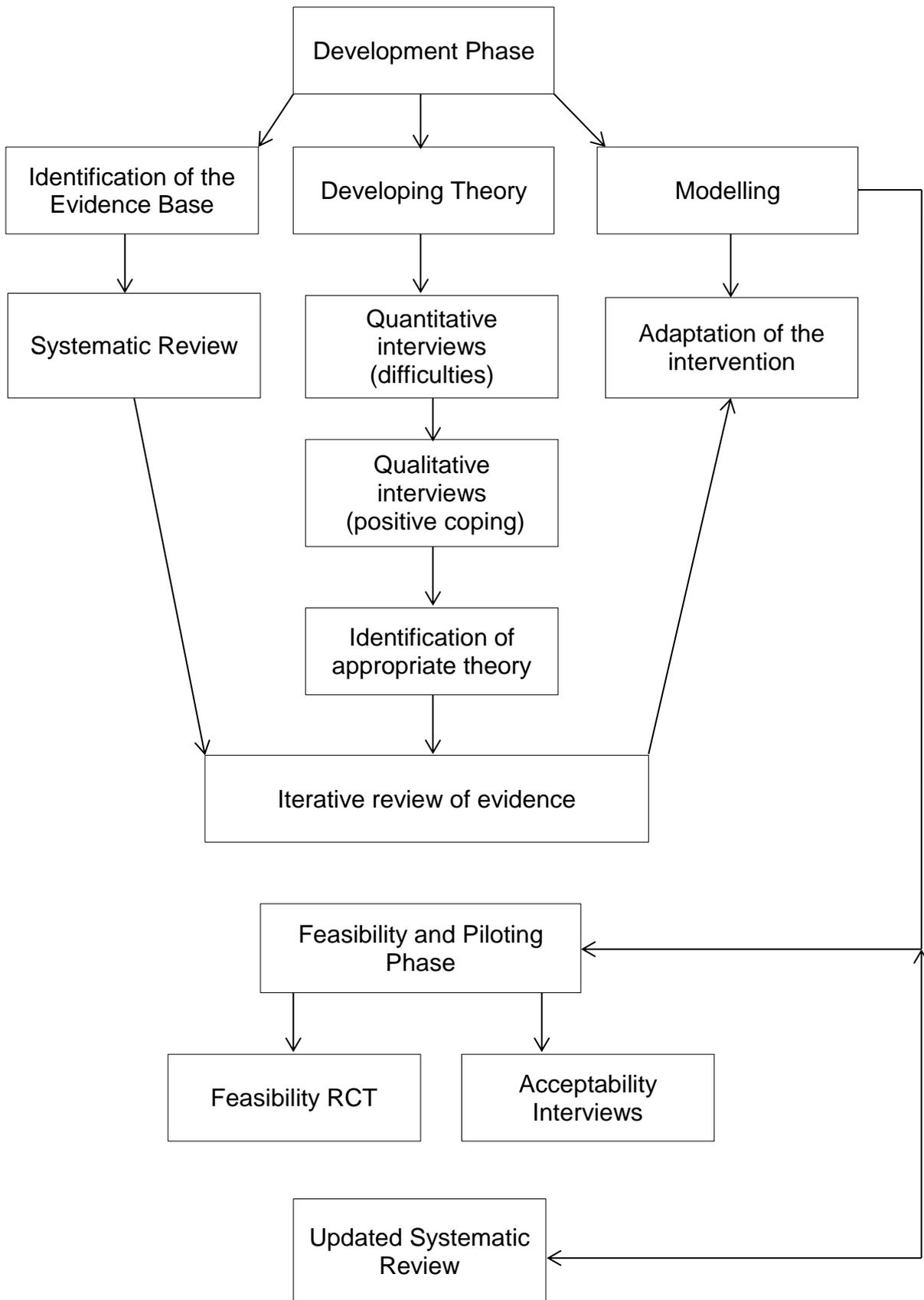


Figure 2.2. Main methods utilised to inform the development and feasibility phases of the MRC framework.

2.3.1 Development Phase

2.3.1.1 Identification of the existing evidence base. A systematic review and meta-analysis was conducted to identify the existing evidence base in terms of the effectiveness of psychological and psychosocial interventions for depressed and anxious carers of stroke survivors (Study One, Chapter Three). In addition, in order to place the findings of this research programme in context an updated systematic review and meta-analysis (Study Six, Chapter Eight) was conducted. This was done following guidance that all research should both begin and end with systematic reviews of the relevant evidence base (Clarke, Hopewell, & Chalmers, 2010).

2.3.1.2 Identification or development of theory. The identification or development of theory to inform intervention development proceeded in three main stages:

- *Stage One:* A further aim of the systematic review and meta-analysis was to identify specific theoretical components of interventions associated with effectiveness to further inform the theoretical framework underpinning the intervention (Study One, Chapter Three).
- *Stage Two:* Qualitative interviews were held with depressed and anxious informal carers of stroke survivors to identify the specific difficulties experienced by depressed and anxious carers. The aim of this study was to identify specific difficulties that could be targeted by the intervention. The main difficulties were identified and the literature was searched for appropriate psychological theories and techniques that may target these difficulties to help enhance and individualise the intervention (Study Two, Chapter Four).
- *Stage Three:* Qualitative interviews were held with non-depressed and non-anxious informal carers of stroke survivors to identify positive coping strategies utilised by informal carers. Positive coping strategies were identified from the interviews and again the literature was searched to identify psychological theories that may be incorporated into the intervention to help depressed carers utilise positive coping strategies used by carers without common mental health difficulties (Study Three, Chapter Five).

2.3.1.3 Modelling. Based on the findings from the systematic review and two qualitative studies, specific components of the intervention were identified. The components of the intervention were further enhanced by literature review and expert opinion in relation to the number, frequency, duration of sessions and the training programme for the PWP's supporting the intervention. In addition, in order to enhance the acceptability and relevance of the CBT self-help material two informal carers and one stroke survivor worked closely with the researcher to further inform the content and presentation of the CBT self-help materials (Study Four, Chapter Six).

2.3.2 Feasibility and Piloting Phase

A feasibility RCT was then conducted to examine the procedural and methodological uncertainties associated with the delivery of a high quality RCT and to determine whether the new intervention is acceptable to carers of stroke survivors (Study Five, Chapter Seven).

2.3.3 Placing the Research in Context

To place the findings of this programme of research in context (Clarke et al., 2010) an updated systematic review and meta-analysis was undertaken (Study Six, Chapter Eight).

The remainder of this chapter will present each of the methodological approaches used in each phase in more detail alongside justifications for the choice of each approach.

2.4 Systematic Review

As previously outlined, within the development phase of the revised MRC complex interventions framework (Craig et al., 2008; MRC, 2008), it is essential to identify the existing evidence base for similar interventions through systematic review. If a recent systematic review on the topic area already exists, it can be used to inform the development of the complex intervention. If not, a new review or updated search covering the period between the current and final search date included in the published systematic review should be conducted (Craig et al., 2008; MRC, 2008). This section outlines the following features associated with systematic reviews; what they are, main benefits, overview of the key stages when conducting alongside justifying use within this thesis.

2.4.1 What is a Systematic Review?

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A significant number of research papers are published every year to inform on-going research. However, given both the volume and varying quality of this research it can be difficult to make accurate decisions about the effectiveness, validity and relevance of particular healthcare interventions (Clarke, 2004). When conducted well, a systematic review can overcome problems with appraising large amounts of research by providing a structured step-by-step approach to identify, assess and pool statistically, if appropriate, relevant research evidence (Clarke, 2004). Additionally, in order to minimise the risk of conducting unnecessary primary research (Chalmers & Glasziou, 2009) identifying relevant existing systematic reviews, or conducting a new review, should be a prerequisite to conducting any new research (Clarke, 2004; MRC, 2008). A systematic review can therefore justify the new research both ethically and scientifically (Clarke et al., 2010) and is an essential experimental approach in evidence-based medicine (Sackett, Rosenberg, Gray, Haynes, & Richardson, 1996). Not only do systematic reviews provide retrospective evidence for the effectiveness of an intervention, but more importantly, can be used to design future studies and help formulate research agendas (Ioannidis, 2011). Systematic reviews are designed to answer a specific research question (Barza, Trikalinos, & Lau, 2009) and should have a clear protocol and transparent methodology that can be reproduced by others (Collins & Fauser, 2005). As such, a systematic review seeks to minimise bias and increase the validity of findings by applying a rigorous, structured way to identify, critically appraise and combine evidence relating to a particular research question (Aromataris & Riitano, 2014).

2.4.2 What are the Differences between a Systematic and Traditional Literature Review?

A systematic review differs from a traditional literature review, also known as a narrative review, in a number of ways (Uman, 2011). A traditional literature review is a mainly descriptive discussion of a particular topic area (Uman, 2011) normally written by experts using informal unstructured methods (CRD, 2009). It may form a part of a doctoral thesis by providing an overview and critical appraisal of the existing knowledge base pertaining to the topic of the thesis (Knopf, 2006). Additionally, traditional literature reviews are often published in peer reviewed scientific journals (Mulrow, 1987) and are normally

identified as reviews without a systematic approach to identify and synthesise evidence, rarely providing methods pertaining to how studies included are selected (Mulrow, 1987; Schmidt & Getzsche, 2005). Furthermore, traditional literature reviews tend to have a wider focus than a systematic review as they are not designed to answer a specific research question (Barza et al., 2009). A consequence of not using systematic approaches to identify and synthesise evidence is that traditional literature reviews are subject to reference bias, whereby the views and research of the authors of the review are overly cited (Oxman & Guyatt, 1993; Schmidt & Getzsche, 2005). Additionally, experts conducting a non-structured literature review are likely to bring their own personal research and clinical experience to appraising the literature and thus lack objectivity (Oxman & Guyatt, 1993) often using selective quotes to support their own theories (Greenhalgh, 1997). Literature reviews also often lack information relevant to clinicians and policy makers with the benefits and harms of particular treatments rarely being discussed (McAlister et al., 1999). Moreover, findings of literature reviews rarely reflect the findings of systematic reviews examining the same subject (Schmidt & Getzsche, 2005) and may omit evidence pertaining to the effectiveness of certain treatments resulting in recommending treatments that are ineffective or even harmful (Antman, Lau, Kupelnick, Mosteller, & Chalmers, 1992). By adopting a systematic review within this thesis the researcher aimed to overcome the bias and errors inherent in conducting a traditional literature review (Barza et al., 2009; Chalmers & Altman, 1995)

2.4.3 How do you Conduct a Systematic Review?

2.4.3.1 Setting the research question and development of a protocol. Before conducting a systematic review it is essential to formulate a concise research question (Counsell, 1997). The research question fundamentally guides the systematic review in terms of defining the inclusion and exclusion criteria, thereby informing both the search strategy and relevant data to be extracted from suitable studies (Counsell, 1997). When conducting a systematic review in health services research the question must be one that is important to patients, healthcare professionals, policy makers and researchers (Counsell, 1997). It may be important to consider the prevalence and impact of the condition of interest; how often the intervention would be likely to be used;

whether real uncertainty exists concerning the benefits of the intervention and the accessibility of data concerning the effectiveness of the intervention (Counsell, 1997). Although conducting systematic reviews can prevent unnecessary further primary research (Habre, Tramèr, Pöpping, & Elia, 2014), setting the wrong research question for a systematic review may also result in redundant and unusable findings (Chalmers & Glasziou, 2009). To minimise this possibility, a PICOS statement reflecting 'Participants'; 'Intervention'; 'Comparator'; 'Outcome' and 'Study design' (Barza et al., 2009; Counsell, 1997) is therefore typically used to formulate the research question, inclusion and exclusion criteria, and subsequent search strategy (Barza et al., 2009; Counsell, 1997).

Once a research question is set a clear research protocol should then be developed (Barza et al., 2009). There have been recent movements to increase the quality of systematic reviews by encouraging the registration of review protocols (Booth et al., 2012; Liberati et al., 2009; Moher et al., 2009). Specifically, the publication of review protocols is designed to decrease the frequency of review duplication and improve the conduct and reporting of systematic reviews to reduce bias and aid better interpretation of findings (Booth et al., 2012). As such, it is recommended that all reviews are registered on an international web-based system PROSPERO (Booth et al., 2012).

2.4.3.2 Literature search and screen. Once the protocol is established the next step is to formulate a search strategy, normally comprising of search terms relating to each element of the PICOS statement (Barza et al., 2009). In order to identify all of the available evidence it is essential that the search strategy is sensitive enough to find all relevant studies (Aromataris & Riitano, 2014). However, there is a fine line between sensitivity and specificity. Whereby, if a search strategy is too specific relevant studies may be omitted from the search results, whereas an overly sensitive strategy will yield a large number of irrelevant studies (Aromataris & Riitano, 2014). Typically, in order to search relevant electronic databases a sensitive and specific search strategy is formulated through the use of medical subject headings (MeSH) which are terms used by electronic databases to index and describe the content of each published paper (Aromataris & Riitano, 2014). However reliance on MeSH only is likely to lead to inconsistent results due to the lack of reliability in the

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consistency and accuracy of indexing (Portaluppi, 2007). Therefore search strategies should also be supplemented with free-text content (Aromataris & Riitano, 2014).

The primary method for identifying relevant literature is to search relevant electronic databases, for example MEDLINE, EMBASE (Barza et al., 2009), ISI Web of Knowledge, PsycINFO (Field & Gillett, 2010); CENTRAL and ASSIA (CRD, 2009). However, in order to ensure that the search is as comprehensive as possible, it is also important to search for white papers (CRD, 2009); clinical trial registers (Barza et al., 2009; CRD, 2009); hand-search the most relevant journals (Barza et al., 2009) and contact experts (Field & Gillett, 2010). Furthermore, reference lists and citation indexes of relevant papers should also be checked for further potentially eligible studies (Barza et al., 2009; CRD, 2009). Finally, existing systematic reviews of similar interventions should also be checked for additional studies (CRD, 2009). It is important to search additional sources other than electronic databases of published studies due to the potential of publication bias. This is the tendency for significant results to be published rather than non-significant or findings that do not support the research hypothesis (Rosenthal, 1979). In addition, in order to minimise language bias (i.e. positive results being more likely to be published in the English language (Egger et al., 1997b), there should be an attempt to identify studies in languages other than English (Centre for Reviews and Dissemination [CRD], 2009). If a study team does not have the facilities or budget for translator services the number of potential studies identified in languages other than English should at least be reported in the search results and the potential for language bias acknowledged (CRD, 2009). Finally, it is important to report the date searches were conducted to allow readers of systematic reviews to assess how up-to-date the research included within the review is (Beller, Chen, Wang, & Glasziou, 2013).

Once the initial search has been executed all search results are screened by a minimum of two reviewers in order to determine whether studies are potentially suitable for the review (CRD, 2009). The screening process involves comparing the titles and abstracts of all identified studies against the inclusion and exclusion criteria to assess their potential eligibility for inclusion within the review. Full papers are retrieved for studies that are identified as

potentially being suitable for inclusion from screening the title and abstract (CRD, 2009).

2.4.3.3 Full paper checks and data extraction. Full papers of potentially eligible papers are then checked for eligibility against the inclusion and exclusion criteria (Barza et al., 2009). To minimise errors and bias in the selection process, two separate reviewers should conduct full paper checks. In the event of any discrepancies a third reviewer or researcher unrelated to the research team is then contacted (CRD, 2009). In some cases, study reports may not contain all of the information required to come to a conclusion surrounding the eligibility of the study and therefore study authors should be contacted to try and obtain any missing information (CRD, 2009). Next, data of relevance to the review question is extracted from each eligible paper (Barza et al., 2009). In order to ensure that data extraction is consistent, unbiased and reliable, a standardised data extraction form should be used and data should be extracted by two reviewers (CRD, 2009). Typically the data extracted will relate to six areas (CRD, 2009):

- General study information (e.g., study title; authors; citation).
- Study characteristics (e.g., aim, design, recruitment).
- Participant characteristics.
- Intervention characteristics and settings.
- Outcome measurements.
- Results.

Additionally, a risk of bias assessment is an essential part of data extraction (Barza et al., 2009). The degree to which a systematic review can draw reliable conclusions is dependent upon the internal validity of the individual studies included within the review (Higgins & Altman, 2008). Internal validity relates to whether the study has been conducted in a way that is free from bias (Higgins & Altman, 2008). Bias can be defined as “a systematic error, or deviation from the truth, in results or inferences” (Higgins & Altman, 2008, p 82). Biases can lead to both overestimation and underestimation of the effect of an intervention and may account for variation in results between the studies included within a review (Higgins & Altman, 2008). As such, extracting relevant information pertaining to key sources of potential bias should assess the quality of the individual studies included. The Cochrane Risk of Bias Tool (Higgins &

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Altman, 2008) is a widely recommended way of examining the risk of bias of studies potentially eligible for a review (Lundh & Gøtzsche, 2008). Although other methods of risk of bias assessment exist, for example quality scales and checklists, these are not recommended as they are over simplistic (Higgins & Altman, 2008), have large variability in the weighting applied to specific items (Jüni, Witschi, Bloch, & Egger, 1999) and have rarely undergone testing concerning their reliability or validity (Armijo-Olivo, Stiles, Hagen, Biondo, Cummings, 2012). Instead, the Cochrane Risk of Bias Tool (Higgins & Altman, 2008) allows the evaluation of a number of domains that are related to the validity of a study's result: (a) sequence generation; (b) allocation concealment; (c) blinding of participants, personnel and outcome assessors; (d) incomplete outcome data; (e) selective outcome reporting and (f) other sources of bias.

The Cochrane Risk of Bias Tool provides guidelines to help reviewers make judgements as to whether there is 'low', 'unclear' or 'high' risk of bias in each domain (Higgins & Altman, 2008). Each domain in the tool relates to specific sources of bias that may influence the results of a randomised controlled trial. An adequate method of random sequence generation prevents selection bias in terms of the allocation of participants to study arms. Selection bias is also prevented through adequate allocation concealment, ensuring that forthcoming allocations cannot be predicted (Higgins & Altman, 2008). The blinding to study group of participants, personnel and outcome assessors is important to prevent performance bias, whereby there is a systematic difference between groups in the way in which participants behave, or how treatments are delivered (Higgins & Altman, 2008). Failure to blind may also result in detection bias, which refers to a systematic difference in the way outcomes are reported or measured, for example, study personnel may be more inclined to collect follow-up outcomes for one study group versus another group (Higgins & Altman, 2008). Blinding can also prevent attrition bias, for example, if a participant is aware of the group they are allocated to they may be more likely to drop out of the study leading to systematic differences in those who drop out of a study and those who do not drop out (Miller & Hollist, 2007). It should be noted however that blinding of participants and study personnel is not always possible due to the type of intervention being received, for example when the intervention consists of psychological interventions or a surgical treatment.

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Incomplete data may be due to attrition, when outcome data is not available due to study drop out or withdrawal. As such, incomplete data may also indicate possible attrition bias. Finally reporting bias may occur, where there are differences between the outcomes collected in a study and the outcomes reported, known as selective outcome reporting (Higgins & Altman, 2008). For example, study authors may be inclined to only publish outcomes that support the research hypothesis (Dwan et al., 2010).

A risk of bias assessment allows the review team to make a judgement as to the likely level of internal validity of the studies included within a review and what influence the presence of bias may have on the overall results of the review. Differences in risk of bias may explain variation in study results (Higgins & Altman, 2008). For example, studies with higher risk of bias may be associated with increased levels of effectiveness (e.g., Cuijpers, van Straten, Bohlmeijer, Hollon, & Anderson, 2010; Farrand & Woodford, 2013) and therefore potentially overestimate the effectiveness of an intervention (Higgins & Altman, 2008). In order to improve the internal validity of the studies included within a systematic review, and consequently the reliability of the conclusions that can be drawn, risk of bias may be included as part of the inclusion and exclusion criteria for the review. For example, studies with high risk of bias may be excluded from the review and possibly increase the validity of any conclusions that may be reached (Doi, Barendregt, & Mozurkewich; Verhagen, de Vet, de Bie, Boers, & van den Brandt, 2001).

2.4.3.4 Narrative synthesis (qualitative synthesis). Within a systematic review the narrative, or qualitative synthesis, of results pertains to the use of text to describe and summarise the principal findings of the review (Popay et al., 2006). Typically a narrative synthesis will include four main elements: (a) development of theory pertaining to how an intervention works and who it works for; (b) synthesising the findings of the included studies; (c) exploration of any relationships in the data; and (d) a quality appraisal (Popay et al., 2006). Typically a narrative synthesis will include both text and tables to present the data visually (Popay et al., 2006).

2.4.3.5 Meta-analysis (quantitative synthesis). If there are enough eligible studies the results of the studies can be pooled together using meta-analytical techniques (Glass, 1976) allowing a more accurate estimate of effect

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than that reported in an individual study alone (Doi et al., 2011). Although there may be multiple studies examining the effectiveness of an intervention, the sample sizes may be small with large confidence intervals around estimates of effect (Cafri, Kromrey, & Brannick, 2010) and may not reach statistical significance making it difficult to draw conclusions from these individual studies (Barza et al, 2009). A meta-analysis can overcome some of these problems in primary research by summarising, or pooling, the results of the multiple studies included within the review (Barza et al., 2009). Thereby increasing the power to detect small but meaningful effects, thereby providing a more precise estimate of the overall effectiveness of the intervention (Haidich, 2010).

The way in which data is pooled together within a meta-analysis depends upon the type of outcomes that are examined within the papers of interest (Barza et al., 2009). Some studies may report binary outcomes. A binary outcome measure has only two values and often relates to the presence or absence of a particular outcome (Altman, 1991). An example might be the number participants at the end of a trial that met diagnosis for depression, versus the number of participants who did not meet diagnosis for depression. Typically binary outcome data within a meta-analysis is pooled together by calculating the risk or odds ratio (Barza et al., 2009). When continuous data is examined within a meta-analysis a common way of pooling together the data from multiple studies is to calculate the standardised mean difference (Barza et al., 2009). Continuous data is data derived from a measure with possible values only restricted by the scale of measurement (Altman, 1991). An example is the measurement of severity of depressive symptoms using a standardised measurement of depression.

A further step of importance when conducting a meta-analysis is to reach a decision as to whether fixed or random effects models apply to the data (Barza et al., 2009). The fixed effect model presumes that any variability between the studies included within the meta-analysis is purely down to sampling error (Cafri et al., 2010) given that all participant samples in the studies are from the same population (Bazra et al., 2009). As such the summary estimate is simply calculated by weighting each study inversely proportionally to its variance (Bazra et al., 2009). If large variability is expected between the studies (for example there are expected differences between the

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populations included, variability in terms of the outcomes being measured or differences in the interventions included) then a random-effects model will be used (Barza et al., 2009). The random-effects model presumes that the true effect size of the intervention being examined is spread around the overall mean as the studies come from different populations with different mean effect sizes (Field & Gillet, 2010). This variance is known as heterogeneity (Bazra et al., 2009). As such, when pooling the results of studies the degree of heterogeneity is also taken into effect when calculating the weights of each study (Bazra et al., 2009). Typically, the random effects model is a more conservative test of overall effectiveness than the fixed-effect model (Bazra et al., 2009). If a fixed-effect model is used on heterogeneous, data confidence intervals will be narrower and results biased to overestimating significance (Cafri et al., 2010). Furthermore, the random-effects model is often recommended when the assumptions made about the underlying population the studies are drawn from are less stringent (Hedges & Vevea, 1998; Hunter & Schmidt, 2000).

The degree of statistical heterogeneity is typically determined by calculating the Q statistic (Ioannidis, Trikalinos, & Zintzaras, 2006). The Q statistic is the difference between the overall effect size derived under the fixed effect model and the sum of the weighted squared differences of the effect sizes for each individual study (Ioannidis et al., 2006). However, the Q statistic suffers from limitations of low power when there a few studies and overinflate power when a large number of studies are included within a review (Higgins, Thompson, Deeks & Altman, 2003). As such, the I^2 statistic is often preferred as it provides a percentage of the amount of variation expected due to heterogeneity rather than chance with 25%, 50% and 75%, considered low, moderate or high levels of heterogeneity respectively (Higgins et al., 2003). If significant levels of statistical heterogeneity exist then the random-effects model is adopted (Bazra et al., 2009). However, the decision to use a fixed or random-effects model should not only be based on the presence of statistical heterogeneity (Gagnier et al., 2012). There are a number of reasons why heterogeneity may still exist even if the level of statistical heterogeneity is found to be non-significant (Doi et al., 2011). Typically, heterogeneity can be classified as clinical or methodological heterogeneity (Gagnier et al., 2012).

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Clinical heterogeneity relates to differences in interventions; participants and outcome measurements utilised whereas methodological heterogeneity typically pertains to differences in the design and quality of the included trials (Gagnier et al., 2012). Therefore, if there are known differences between the included studies in relation to methodological or clinical factors researchers may still decide to adopt a random-effects model regardless of the degree of statistical heterogeneity found (Doi et al., 2011; Gagnier et al., 2012). However, if no statistical heterogeneity exists the effect sizes obtained using the fixed and random-effects models will be the same (Bazra et al., 2009).

Common statistics to compute the standardised mean difference are Cohen's *d* and Hedges' *g* (Lakrens 2013). Hedges' *g* is a preferred option commonly referred to as a 'corrected effect size' given its ability to correct for bias inherent in studies with smaller sample sizes (Lakrens, 2013). Hedges *g* has therefore been adopted for use within the meta-analysis conducted within this thesis. Cohen's (1988) effect size conventions are standardly used to report the magnitude of the overall effect size calculated within a meta-analysis with an effect size of 0.20 relating to a small effect; 0.50 a medium effect and 0.80 a large effect. Along with the effect size 95% confidence intervals should also be presented to measure the precision of results (Durlak et al., 2009; Gagnier et al., 2012). Larger confidence intervals represent less precise findings and may also highlight the presence of heterogeneity (Gagnier et al., 2012). As well as reporting the overall effect size and 95% confidence intervals forest plots are commonly used to present the results of a meta-analysis (Lewis & Clarke, 2001). A forest plot is a visual representation of the effect size and confidence intervals for each individual study and for the overall effect size and confidence intervals.

When there are clear methodological and clinical differences between the trials included within a review, and statistical heterogeneity exists, subgroup analysis or meta-regression can be conducted to examine potential explanations, or moderators, for variation between study findings (Lau, Ioannidis, & Schmid, 1997). However, even without the presence of statistical heterogeneity there may still be variables that influence the effect size and therefore moderator analysis may still be conducted (Gagnier et al., 2012). The systematic review conducted as part of the present thesis was designed to

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investigate the existing evidence base of psychological interventions for depression or anxiety for informal carers of stroke survivors and also identify potential intervention components associated with effectiveness. Intervention components associated with effectiveness can be used to help inform the development of the CBT self-help intervention. As such a number of planned subgroup analyses were conducted.

Moderator analysis should be planned a priori by identifying a set of covariates that may be expected to explain any variation in findings between individual studies (Gagnier et al., 2012). A subgroup analysis is conducted when examining categorical moderators (Lau et al., 1997). In order to conduct a subgroup analysis individual studies are separated into different groups on the basis of a particular study characteristic (category), for example, the chronic physical health condition of the care recipient. Separate meta-analyses are then performed for each group and the results between groups compared to examine whether the differences in effect size between these groups is statistically significant (Gagnier et al., 2012). Commonly a p-value of 0.10 is adopted to indicate that subgroup analyses are statistically significant (Lau et al., 1997). Meta-regression can be conducted to examine the effect of one or multiple independent variables, for example, date of publication, on the overall effect size (Thompson & Higgins, 2002). Meta-regressions are performed on continuous data or categorical data if each category is given a discrete value. Typically slope coefficients and confidence intervals are reported to describe meta-regression results (Lau et al., 1997).

Although moderator analyses are commonly conducted in meta-analyses it is important to note that the power of moderator analyses is often low due to the reduction in sample sizes included within each subgroup (Hedges & Pigott, 2001, 2004). Additionally, multiple comparisons are made when conducting moderator analyses, increasing the likelihood of Type I errors occurring (Cafri et al., 2010). When making multiple comparisons the probability increases that you will find at least one significant effect when no significant effects actually exist, known as a Type I error (Gelman, Hill, & Yajima, 2012). The limitations of making multiple comparisons can be minimised by amending the alpha level when conducting multiple comparisons and ensuring comparisons are limited and pre-planned (Cafri et al., 2010; Gagnier et al., 2012). Given these

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limitations, the results of moderator analyses should be used to form future research hypothesis as opposed to being considered conclusive evidence that are particular clinical or methodological factor is the reasons for differences between studies (Lipsey, 2003).

In order to examine the potential bias within a meta-analysis there are a number of statistical techniques that can be performed. Within a systematic review an assumption is made that the studies included within the review are only a sample of studies available from a wider population of 'possible studies' (Copas & Jackson, 2004, p 146). Publication bias refers to the greater likelihood of studies with significant results and larger sample sizes being published (Rosenthal, 1979). Publication bias results from researchers failing to submit non-significant and negative findings for publication (Dickersin, Min, & Meinert, 1992) and journal reviewers and editors being more likely to reject non-significant and negative findings (Hedges, 1984). Therefore, studies with non-significant and negative results are less accessible to the review team (Copas & Jackson, 2004). Despite efforts to minimise publication bias within the search and selection process previously detailed, publication bias is still likely to exist.

A number of statistical techniques are therefore available that can be applied to detect presence of publication bias. One such technique is the funnel plot where the different study effect sizes are plotted against sample sizes (Egger & Davey Smith, 1995). These plots can examine the presence of publication bias, alongside a number of other potential biases, such as English language bias, heterogeneity; poor design or clinical heterogeneity (Egger, Davy Smith, Schneider, & Minder, 1997). As previously discussed, the precision of an effect size will increase as the sample size of a study increases. As such, on a funnel plot, the results of smaller studies will be scattered at the bottom of the graph widely, whereas results from larger studies will spread more narrowly towards the top of the graph (Egger et al., 1997). If there is no bias then the funnel plot should be symmetrical, whereas the results will be asymmetrical if bias is present (Egger et al., 1997). The degree of publication bias can be calculated using Egger's Test of the Intercept (Sterne, Gavaghan, & Egger, 2000) and the trim and fill procedure (Duvel & Tweedie, 2000) can be used to calculate an effect size taking into account the potential for publication bias. A further way of examining the impact of publication bias is calculation of

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the 'fail-safe' number (Rosenberg, 2005). This refers to the number of non-significant, unpublished studies that would need to be included within the review for the overall results of the review to become non-significant. Typically the number of studies with a mean null result needed to reduce the combined significance level to >0.05 is calculated (Rosenthal, 1979). The larger the number of studies needed the more confidence a researcher can be in the conclusions of the meta-analysis (Rosenberg, 2005).

Outcome reporting bias is a further source of bias that can be investigated through statistical techniques. Reviews of RCTs have found that statistically significant outcomes are more likely to be reported in publications than outcomes that do not reach significance (Dwan et al., 2008). In order to take into account the likelihood of outcome reporting bias a sensitivity analysis can be conducted. First, it is important to assess the likelihood of outcome reporting bias within the review. This is undertaken by identifying the potentially eligible studies that were excluded from the review because they did not report one of the outcomes of interest (Dwan et al., 2010). It is important to assess how likely it is that these studies did measure the outcome of interest but failed to report the outcome in the trial paper. Second, if studies are suspected of collecting the outcome of interest but not reporting it, study authors should be contacted to gain copies of the trial protocols to examine whether selective outcome reporting did occur. The same procedure should be applied to studies included in the review that do not report one or more outcomes of interest. In order to determine the likelihood of outcome reporting bias, the ORBIT classification system has been developed (Kirkham et al., 2010). This allows studies to be classified as high, low, or no risk of outcome reporting bias. If any studies are rated as high risk then a sensitivity analysis, the maximum bias approach (Williamson & Gamble, 2007) should be adopted. A new treatment effect and confidence intervals are then calculated and compared against the original effect size found within the review to examine the robustness of findings (Dwan et al., 2010).

Other forms of sensitivity analysis to examine the robustness of findings include removing studies with small sample sizes from the analysis (CRD, 2009) and removing outlying studies with extreme effect sizes (Viechtbauer & Cheung, 2010). Running the analysis with each study removed one at a time,

thereby examining whether the level of significance and effect size remain similar regardless of which study is removed, can perform a further simple method of sensitivity analysis.

2.4.3.6 Reporting systematic reviews. In order to improve the reporting of systematic reviews and meta-analyses of health care interventions the Preferred Reporting Items for Systematic Reviews (PRISMA) statement provides a 27-item checklist covering the important items that should be reported in order to ensure transparent reporting (Liberati et al., 2009). In addition, the statement includes a four-phase flow diagram to improve the reporting of citation identification, screening, assessment of eligibility and inclusion in the final qualitative and quantitative synthesis (Liberati et al., 2009). The use of the PRISMA statement has led to an improvement in both the quality of reporting and quality of conduct of systemic reviews and meta-analyses (Panic, Leoncini, de Belvis, Ricciardi, & Boccia, 2013). As such, the PRISMA statement (Liberati et al., 2009) has been used to inform the reporting of the systematic review reported in Chapter Three.

2.4.4 Limitations of Systematic Reviews

Although there are clear benefits to conducting systematic reviews it is also important to consider their limitations. The results of meta-analyses should always be interpreted with caution as they are often found to be exaggerated when compared to larger trials performed (Ioannidis, 2005; Ioannidis, 2011). Furthermore, the strict protocols that must be followed when conducting a systematic review may not allow for a clear descriptions relating how a clinical concept has developed over time and therefore important information about interventions may be lost (Collins & Fauser, 2005). Additionally, the interpretation of systematic reviews and meta-analyses may not be without bias with particular stakeholder groups (for example, from industry, professional bodies, academics) potentially benefitting from the results of meta-analysis (Ioannidis, 2011). As such, potential biases must be taken into account when interpreting the results of any systematic review and meta-analysis. Finally, the time taken to publish systematic reviews from the date of the initial review search is often long and therefore reviews are often out-of date before they are available for other researchers, clinicians and policy makers (Beller et al., 2013).

2.4.5 Justification for the use of a Systematic Review within this Thesis

Little is known about psychological interventions that are effective in the treatment of anxiety and depression in carers of stroke survivors. Previous systematic reviews have been conducted to examine the efficacy of psychological and psychosocial interventions for carers of stroke survivors and other physical health conditions. However these have encompassed a variety of interventions targeting a number of different difficulties, such as burden, strain, quality of life and general psychological distress (Hopkinson, Brown, Okamoto, & Addington-Hall, 2012; Legg et al., 2011; Pinguart & Sörensen, 2006; Sörensen, Pinguart, & Duberstein, 2002; van Mierlo, Meiland, Van der Roest, & Dröes, 2012). As such, there have been no systematic reviews of interventions specifically targeting depression or anxiety in informal carers of stroke or other chronic physical health conditions. Therefore a systematic review will allow the examination of the evidence base for psychological and psychosocial treatments specifically targeting depressed or anxious carers, the first step of development of a new intervention following the revised MRC framework (MRC, 2008). In addition, moderator analysis may allow the identification of components of interventions associated with effectiveness that may help inform the theoretical framework of the intervention and specific therapeutic techniques to include within the intervention as well as additional treatment components such as format of delivery, number and length of sessions. The detailed methods, results, discussion and conclusion of the systematic review are presented in Chapter Three.

2.5 Qualitative Research Methodology

As previously discussed, an important element of the development phase of the revised MRC framework (MRC, 2008) is the identification of theory to inform the content of the complex intervention. Appropriate theories can be identified through conducting new primary research as well as using existing applicable evidence and theory in the literature (MRC, 2008; Craig et al., 2008). A qualitative approach to conducting new primary research is often used to identify or develop new theory when developing a new complex intervention (Barley et al., 2012; Bradshaw et al., 2012; Richards & Borglin, 2011) and was utilised within this thesis. This part of Chapter Two overviews the main features associated with qualitative healthcare research, in particular the main

approaches and data collection techniques alongside justification for the use of a qualitative approach within this thesis.

2.5.1 A Qualitative Approach to Healthcare Research

Traditionally, qualitative approaches have been used in the social sciences and anthropology but are being increasingly adopted within healthcare research (Pope & Mays, 1999) and psychology (Carrera-Fernández, Guàrdia-Olmos, & Peró-Cebollero, 2014). Similar to quantitative research, qualitative research asks questions about social phenomena, for example, people's experiences, or how they behave (Pope & Mays, 1999). However, a key distinction between qualitative and quantitative research is that qualitative research measures social phenomena through classification, for example, asking 'what', 'how' and 'why' questions (Pope & Mays, 1999, p 3). Qualitative research is concerned with understanding or explaining social phenomena and appreciates the context in which data is gathered and interpreted (Barbour, 2000). In contrast, quantitative research seeks to measure and explain phenomena through the use of numbers (Pope & Mays, 1999). An additional key distinction between the two approaches is that qualitative research is concerned with the study of people in their natural setting whereas quantitative research tends to be experimental (Pope & Mays, 1999).

The differences between qualitative and quantitative approaches are fundamentally based on each approach being grounded within distinct paradigms with differing philosophical underpinnings (Barbour, 1999). Although there are multiple definitions of the term 'paradigm' (Everest, 2014), a definition that identifies a paradigm as a group of basic beliefs concerning principles will be adopted (Guba & Lincoln, 2004). The four most common paradigms are positivist; interpretative or constructivist (Barbour, 1999); post-positivist and critical theory (Guba & Lincoln, 1994). Each paradigm has a distinct ontology, which refers to the assumption the paradigm makes about reality and subsequently what can be learned about reality (Guba & Lincoln, 1994). Additionally, each paradigm has a distinct epistemology, referring to the process of gaining knowledge about reality (Dew, 2007; Krauss, 2005).

- *Positivism*: The positivist paradigm posits that knowledge is acquired through the direct measurement of phenomena and is focused on the establishment of facts, or the 'truth' (Krauss, 2005). Additionally,

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positivism believes there is a single reality and science can observe and measure facts to gain knowledge objectively about this single reality (Krauss, 2005). As such, researchers adopting a positivist paradigm use quantitative research approaches.

- *Constructivism*: The constructivist or interpretative approach postulates that knowledge is established by understanding the personal meanings assigned to phenomena (Krauss, 2005). Therefore, the interpretative or constructivist approach theorises there is no objective truth but instead there are multiple realities that are constructed by those experiencing a particular phenomenon (Krauss, 2005) and is grounded in the use of qualitative approaches.
- *Post-positivism*: A post-positivist approach does assume that a reality exists, however it cannot be perfectly understood. As such an objective truth probably exists but findings are always subject to falsification (Guba & Lincoln, 1994). Methodology in post-positivism can include both qualitative and quantitative approaches (Guba & Lincoln, 1994).
- *Critical Theory*: This paradigm assumes that reality can be understood, however, it is shaped by social, political, economic and other factors, termed a 'historical reality' (Guba & Lincoln, 1994). As such, the researcher and participant interactions influence findings and therefore all results are 'value mediated' (Guba & Lincoln, 1994) and linked to historical structures. Critical theory inquiries can only be made through dialogue between the researcher and participant and will therefore always be qualitative in nature (Guba & Lincoln, 1994).

The epistemological position of the researcher should be used to inform the methodological (theoretical) approach and subsequent research methods (data sampling, collection, analysis) (Carter & Little, 2007).

The differing ontologies and epistemologies underlying qualitative and quantitative approaches to research have led to extreme discordance between the two research approaches (Bradley, Curry, & Devers, 2007; Pope & Mays, 1999). Indeed, qualitative research was previously absent from its inclusion as an evidence based approach to medicine (Britten, 2010). As such, in

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comparison with empirical quantitative research, quantitative researchers sometimes view qualitative findings with suspicion due to a perceived lack of rigour (Boulton, Fitzpatrick, & Swinburn, 1996) and consider it an 'unscientific' (Britten, 2010) and subjective approach (Everest, 2014). However, there have been significant movements towards a greater appreciation within healthcare research that qualitative and quantitative approaches complement one another and indeed can compensate for the limitations of each other (Barbour, 1999; Bryman, 2006). Examples of the complementary nature of quantitative and qualitative research include the collection of quantitative information during a focus group, or conducting a randomised controlled trial that included the collection of qualitative information regarding participants' experience of receiving the new intervention. Indeed, often qualitative research is used to inform research hypotheses (Carrera-Fernández et al., 2014), generate future quantitative research questions and also help to interpret quantitative research findings (Pope & Mays, 1999).

This "paradigm war" (Everest, 2014, p 11) has also been helped by an additional paradigm: pragmatism. However, some researchers consider pragmatism an approach, as opposed to a paradigm (Morgan, 2007). A quantitative approach considers the connection of theory and data to be deductive whereas a qualitative approach believes the connection to be inductive (Morgan, 2007). The pragmatic approach however posits that observations (e.g., qualitative approaches) can be converted into theories and then these theories can be examined through action (e.g., quantitative methods) and visa versa, referred to as 'mixed methods' (Morgan, 2007). Furthermore, the pragmatic approach is 'intersubjective' meaning that it does not propose that the relationship between a researcher and research completely objective or completely subjective, but rather a single reality does exist however individuals have their own interpretations of this reality (Morgan, 2007). Furthermore, pragmatism considers results to be 'transferable' rather than totally ground to context, or completely generalisable (Morgan, 2007). Instead with a pragmatic approach questions need to be asked concerning the degree of generalisability of findings to other setting (Morgan, 2007). Pragmatism places emphasis of the end result of research with the ultimate goal of improving the welfare of humans (Everest, 2014). Fundamentally it is concerned with using the research method

best suited to the research question (Barbour, 1999; Barbour, 2000) as opposed to being concerned with philosophical debates and can therefore include both qualitative and quantitative approaches (Everest, 2014).

The aim of Study Three (Chapter Four) within this thesis was to gain an appreciation of the specific difficulties experienced by depressed and anxious informal carers of stroke survivors that could be targeted by the intervention. A further aim of this study was to understand attitudes towards a CBT self-help intervention. Given the aims of the research are concerned with understanding the experience of informal caregiving and attitudes towards support, both questions concerning social phenomena, a qualitative approach would be best suited to these research aims. Additionally, the aim of Study Four (Chapter Five) was to adopt a positive psychological approach (Mitchell et al., 2009; Schueller, Kashdan, & Parks, 2014) in order to understand positive coping strategies utilised by informal carers that may also help inform the content of the CBT self-help intervention. Again, given the aim of this study was to gain an in-depth understanding of how informal carers 'behave' or cope with difficulties in the caring role a qualitative approach would be best suited to meet this aim.

2.5.2 Main Qualitative Theoretical (methodological) Approaches in Healthcare Research

There are a number of theoretical perspectives or methodological approaches (Carter & Little, 2007) that can be adopted, providing different frameworks to inform qualitative research (Pope & Mays, 1999). Within qualitative research, 'methodology' refers to the underlying principles and theoretical perspectives of a particular approach and 'methods' refer to the collection of data (Dew, 2007). For some qualitative researchers the theoretical perspective or methodological approach adopted is inseparably linked with the research methods used to collect data (Pope & Mays, 1999). However, for other qualitative researchers (for example, those adopting a pragmatic approach) the choice of research method used should be informed by the specific research question and the pragmatics of conducting the research (Pope & Mays, 1999). A number of theoretical approaches within qualitative research exist (see Creswell, 2007 for an overview) however this part of Chapter Two will focus on the three main approaches relevant to the research questions

examined within this thesis: (a) grounded theory; (c) thematic analysis and (c) framework.

2.5.2.1 Grounded Theory. Grounded theory is concerned with the generation or discovery of a theory rather than just a description of the meaning of a particular experience, or phenomenon, for a collection of individuals (Cresswell, 2007). The approach is embedded within symbolic interactionism, an approach that posits groups of people interact with one another to construct their realities from the symbols around them (Cutcliffe, 2000). As such, within symbolic interactionism understanding the symbolic meanings words, actions or objects have for a particular group of people is of importance and it seeks to understand how a particular group of people create their reality through their social interactions around these symbolic systems (Cutcliffe, 2000). Grounded theory seeks to describe behaviour and social processes through developing theory that is generated or discovered through the data of respondents, hence the term 'grounded' (Strauss & Corbin, 1998). Although there are multiple approaches to conducting grounded theory (e.g., Charmaz, 2006; Clarke, 2005; Glaser, 1992; Strauss, 1987) the two most common approaches can be termed systematic (Strauss and Corbin, 1990), or constructivist (Charmaz, 2006). The aim of the systematic approach is to explain a particular process or action through the development of a theory (Cresswell, 2007). Typically qualitative interviews are conducted in order to gain information concerning events or instances that form categories and these interviews continue until data saturation surrounding the categories is reached, meaning no new information is found about the category (Cresswell, 2007). As such, data is analysed as soon as it is collected and compared to the categories emerging from the data, an approach termed constant comparison (Cresswell, 2007). Initially 'open coding' is used whereby the researcher analyses each line of data and from the initial coding categories will emerge around the phenomenon of interest (Cresswell, 2007). In grounded theory there are three types of category: casual conditions (factors that cause the phenomenon); strategies (how people respond to the phenomenon); contextual conditions (situational factors) (Cresswell, 2007) and consequences (the outcome of using strategies). Hypotheses are drawn that describe how the categories in the model interrelate: the theory (Cresswell, 2007). The constructivist approach to grounded theory

(Charmaz, 2006) takes a social constructivist approach taking into account the diversity of people's situations and multiples realities. As such, the approach is concerned with the values and beliefs of individuals (Cresswell, 2006) and unearthing what things mean to respondents that can often be identified through the actions of respondents given actions can make implicit meaning explicit (Charmaz, 2004). The approach to coding the data is similar however less systematic and more flexible and interpretive than the traditional approach to grounded theory (Cresswell, 2007). Grounded theory is typically used when there is no theory to explain a particular process or models may exist but have been developed with different populations (Cresswell, 2007).

2.5.2.2 Thematic Analysis. Although thematic analysis is a distinct qualitative methodology, it has the flexibility of being used to analyse qualitative research using a variety of theoretical approaches (Braun & Clarke, 2006). It can fundamentally be used with any qualitative approach that generates themes, or categories (Holloway & Tordes, 2003). The approach is often used within psychology (Braun & Clarke, 2006) and a number of disciplines with a health focus (Braun & Clarke, 2014). It is a particularly useful approach if working within applied research and is not constrained to an underlying qualitative theory (Braun & Clarke, 2006; Braun & Clarke, 2014). However, if the researcher does have epistemological assumptions these should be made clear when reporting the qualitative analysis (Holloway & Tordes, 2003).

Thematic analysis comprises six phases that are outlined in Figure 2.3. Fundamentally, the methodology is concerned with the identification, analysis interpretation and reporting of themes, or patterns within the data, and is driven by the research question (Braun & Clarke, 2006). A theme is a pattern in responses or meaning captured within a set of data that is related to the research question (Braun & Clarke, 2006). A theme is not something that is defined by prevalence but instead is whether it appropriates something of importance to the research question (Braun & Clarke, 2006). Thematic analysis can be performed inductively, whereby the themes are driven by the data, with similarities to grounded theory (Braun & Clarke, 2006). In this case themes collated may not relate to the specific research questions and are not driven by the researcher's preconceptions formed by existing theory (Braun & Clarke, 2006). However, thematic analysis can also be deductive, or theoretical,

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whereby the analysis is driven by the researcher's theoretical concern (Braun & Clarke, 2006). A deductive approach tends to provide a less detailed analysis of the overall dataset and focused on specific aspects of the data (Braun & Clarke, 2006).

There are two levels of themes in thematic analysis: semantic or latent (Braun & Clarke, 2006). A latent theme is interpretative where the researchers theorise the significance and meanings of themes. Conversely, within the semantic approach the themes explicitly represent what participants said at the surface level and thus is descriptive as opposed to interpretive (Braun & Clarke, 2006). Typically, a constructivist approach will be more concerned with latent themes, whilst a realist approach is more concerned with semantic themes across the entire dataset; however combinations of the two approaches are possible (Braun & Clarke, 2006).

A clear advantage of thematic analysis is that it is more accessible to researchers due to not having to possess an in-depth understanding of a particular theoretical approach (Braun & Clarke, 2006). It is important to report your ontology (the assumptions you are making about reality) and associated epistemology (Braun & Clarke, 2006). However the research does not have to be linked to a particular theoretical approach.

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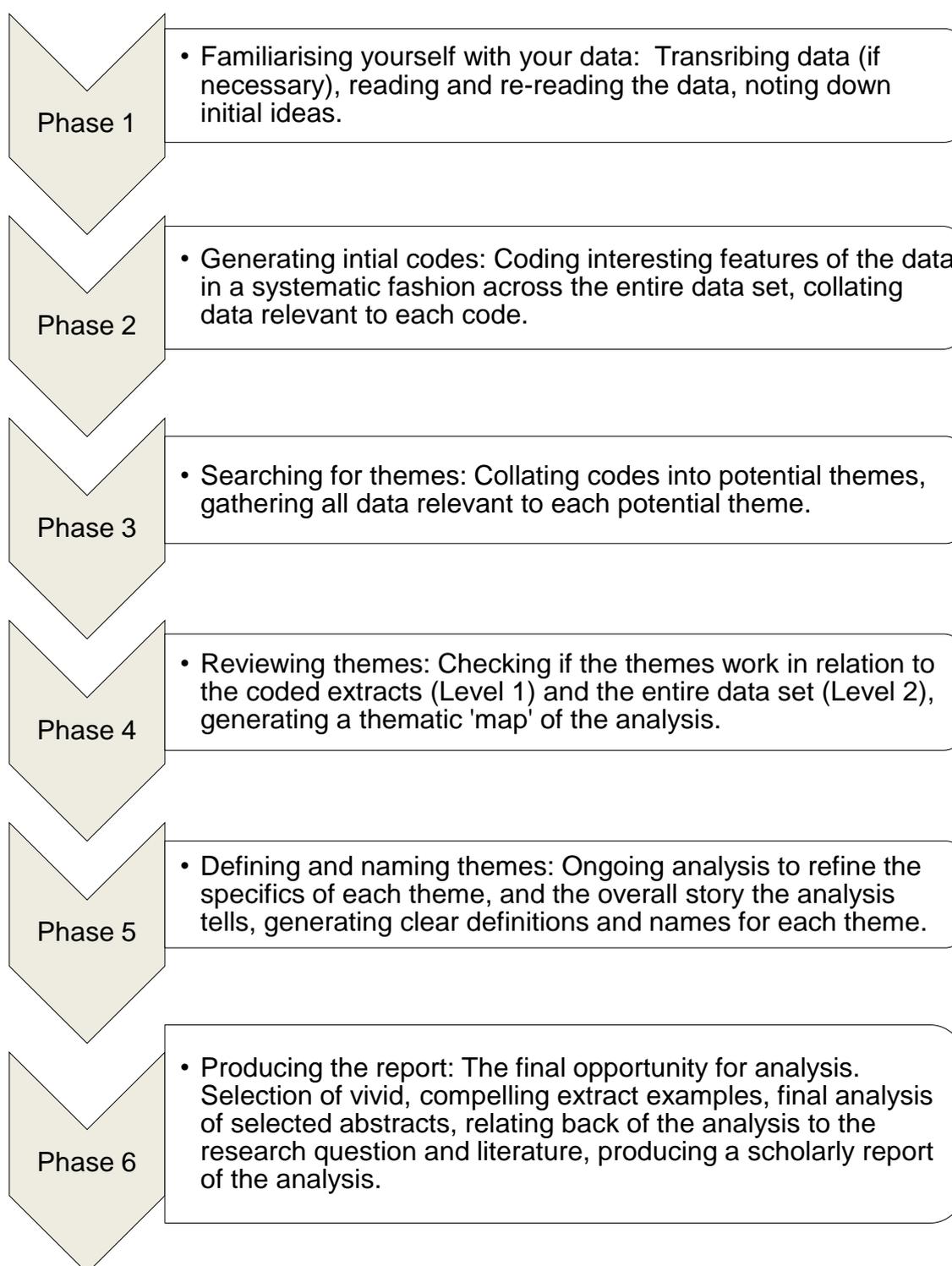


Figure 2.3. Phases of thematic analysis (adapted from Braun & Clarke, 2006, p. 87).

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Further benefits of the approach include that it is straightforward and easy to learn, especially for an inexperienced qualitative researcher (Braun & Clarke, 2006). Finally, you can use the approach to highlight differences as well as patterns within a data set (Braun & Clarke, the 2006). However, critiques of thematic analysis include that the analysis can be superficial and therefore it may only describe as opposed to interpret the data, especially if analysis is focused at the surface level (Smith & Firth, 2011). Additionally, a recurrence of a code is necessary in order to create a theme. As such, codes that are of importance, but do not reoccur, may be omitted by thematic analysis (Buetow, 2010). One way of overcoming this limitation is the use of 'saliency analysis' that can help enhance thematic analysis by assessing the importance of the code in terms of improving understanding of the research topic (Buetow, 2010). This approach therefore also allows codes that are not recurrent and do not form a theme to also be considered in the analysis if they are important to the topic of the research (Buetow, 2010).

2.5.2.3 Framework. The final approach to be discussed is one at complete contrast to purely inductive approaches such as grounded theory (Smith & Firth, 2011). The framework approach is concerned with how qualitative data can be managed and analysed as opposed to being a particular qualitative theoretical approach (Gale, Heath, Cameron, Rashid, & Redwood, 2013). As such, much like thematic analysis, it can be adopted to analyse any qualitative approach that generates themes and is neither purely inductive nor deductive (Gale et al., 2013) and can be viewed as a pragmatic and generic qualitative research approach (Smith, Bekker, Cheater, 2011). For example, a deductive approach could be adopted if the analysis is based on pre-existing theory. However analysis can also be inductive if new themes are generated that are not explained by a pre-existing theory (Gale et al., 2013). Primarily the approach provides a structure (framework) to identify important recurrent themes in data to illicit the development of a conceptual framework to understand the data collected (Smith & Firth, 2011).

Like other forms of qualitative analysis transcriptions are initially coded using 'open codes' if using an inductive approach. However, if using a purely deductive approach codes will have been pre-defined from existing literature (Gale et al., 2013). However, some open-coding may still occur if aspects of

the transcript cannot be explained a pre-defined code (Gale et al., 2013). A framework to analysing the data is created from the codes generated from initial transcripts and codes are grouped into specific categories (Gale et al., 2013). The categories and codes generated are then applied when analysing additional transcripts but new codes and categories are added if they arise (Gale et al., 2013). A spreadsheet is then used to summarise the data into the framework matrix. Within the matrix rows represent cases (normally an individual respondent) and columns represent codes with the summarised data in the cells of the matrix (Gale et al., 2013). The data is then interpreted by looking to develop patterns and relationship within themes to find meaning and explain the themes generated (Smith & Firth, 2011). Analysis of key themes can be conducted both over the entire data set but also as data is connected to individuals the contexts of each participant's response is preserved (Gale et al., 2013).

Some of the main advantages of adopting a framework approach are related to its pragmatic and straightforward approach to data management and analysis, especially when there are multiple team members (Gale et al., 2013). The structure of the framework can actually help researchers see patterns within the data (Gale et al., 2013). Furthermore, the approach is transparent (Pope, Ziebland, & Mays, 2000) as it clearly links the stages within the analysis to the data (Smith & Firth, 2011). However, the structure of the matrix can lead to the quantification of results which goes against the underlying epistemology of qualitative research (Gale et al., 2013). An additional concern may be that much like thematic analysis disconfirming cases may be lost if they do not recur enough to become themes (Buetow, 2010).

2.5.2.4 Paradigm and theoretical (methodological) approach adopted within this thesis. First, it is important to state that pragmatism was adopted as the underlying paradigm to Study Three and Four. This approach considers the relationship between the data to be intersubjective, as opposed to purely objective or subjective (Morgan, 2007) and that results are transferable rather than purely contextual or completely generalisable (Morgan, 2007). The emphasis of a pragmatic approach is the end result of the research and selecting the best research method to address the research questions (Everest, 2014). Second, a thematic analysis approach (Braun & Clarke, 2006) to

analysis and interpretation of the data was adopted. Although both studies were concerned with either identifying theories that might target difficulties experienced by informal carers or help elicit positive coping strategies the main aim of the research was to develop an in-depth understanding of difficulties experienced and coping strategies utilised and to map these onto existing evidence based psychological theories. As such a grounded theory approach was not considered suitable, as the aim was not to develop theory from data. Furthermore, grounded theory is a lengthy and rigorous process that is unnecessary given the pragmatic focus of the research question and time limitations of a PhD. Although a framework approach could have been utilised there were concerns surrounding how the structure may limit more rich interpretive data analysis and lead to the quantification of results and possibly miss important disconfirming cases. However, a thematic analysis approach remains pragmatic, structured and suitable for conducting qualitative research in a short timeframe. Adopting a latent approach to the interpretation of themes (Braun & Clarke, 2006) and saliency analysis (Buetow, 2010) to identify codes of importance that do not recur enough to form themes will help ensure an interpretive and rich analysis of the data.

2.5.3 Main Methods (data collection techniques) in Qualitative Healthcare Research

Although there is a multitude of methods, or ways of collecting qualitative data, the three most commonly used approaches are interviews, focus groups and observation (Pope & Mays, 1999). The use of interviews and focus groups will be the focus of the next part of this chapter as the two main approaches relevant to the research questions examined within Study Three and Four.

2.5.3.1 Interviews. There are three main types of interview: (a) structured; (b) semi-structured and (c) in-depth (Britten, 1995). A structured interview involves the administration of a structured questionnaire, often with fixed choice answers (Britten, 1995). A semi-structured questionnaire comprises of open-ended questions that are structured around areas to be explored in order to examine the research question (Britten, 1995). The open questions fundamentally define the subject areas that will then be explored in richer detail by the interviewer (Britten, 1995). An in-depth interview tends to only cover one or two areas but in rich detail, as such only one or two questions

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may be pre-defined and instead all subsequent questions are based on the answers from the respondent (Britten, 1995).

The limited structure within both semi-structured and in-depth interviews gives scope for the individual experience and perspectives of participants to be fully appreciated (Barbour, 2000). With both approaches the interviewer is aiming to probe into the research topic in detail by asking open-ended questions to explore respondents' answers and meanings as opposed to imposing their own assumptions (Britten, 1995). When conducting a qualitative interview it is important that the questions asked are open-ended, neutral, sensitive and clear (Patton, 1987) and therefore are designed to enable probing to develop a deeper understanding of a respondent's meaning (Britten, 1999). As such, probing in interviews can facilitate the clarification of responses and lead to enriched data collection (Barriball & While, 1994). Questions are likely to focus around behaviour or experience; opinions; feelings; knowledge and background (Britten, 1999). In order to explore meaning and build rapport with a respondent it is important to use the respondent's own language and therefore specific questions cannot be standardised. However, typically with semi-structured interviews there will be a list of questions or topics that the interviewer will aim to cover (Britten, 1995). Indeed as a qualitative interview study progresses, additional questions or topics may be added to the interview script or topic guide based on previous respondents and answers and new topics that may potentially emerge of importance and relevance to the interview question (Britten, 1995). Interview techniques are also particularly suitable when exploring sensitive topics areas that may not be suitable to discuss in a wider group (Gill, Stewart, Treasure, & Chadwick, 2008).

There is debate in the literature concerning whether semi-structured qualitative interviews or in-depth interviews can be conducted over the telephone. One side of this debate proposes that face-to-face contact is necessary to develop the rapport considered essential to gain the depth of information needed (Irvine, Drew, & Sainsbury, 2013). However, studies comparing interview transcripts generated from both telephone and face-to-face interviews have revealed no significant differences between the two approaches (Sturges & Hanrahan, 2004). Furthermore, there are multiple practical benefits to conducting telephone interviews including costs savings (Sturges &

Hanrahan, 2004) and increasing anonymity. Therefore telephone interviews may have benefits if discussing more sensitive topics (Kavanaugh & Ayres, 1998). Furthermore, some studies have found that it is more common for the respondent to ask more clarification questions in telephone interviews and also they are more likely to check with the interviewer that their responses were adequate (Irvine, Drew, & Sainsbury, 2013). Conversely however, researchers are less likely to provide verbal feedback to a respondent when conducting an interview over the telephone (Irvine et al., 2013). As such, it is important to recognise the potential limitations if using telephone interviews and also be aware that certain factors that can help increase rapport and thus provide more rich data may be less likely to be utilised when conducting telephone interviews.

2.5.3.2 Focus groups. A focus group can be defined as a group interview (Morgan, 1993) or a group discussion, focused around a particular topic of interest (Kitzinger, 1994). Although traditionally used within the marketing field, focus groups are now increasingly used in a variety of disciplines including health and education research (Kitzinger, 1994). Typically a focus group will consist of six to ten participants but may include up to 12 (Fitzpatrick & Boulton, 1996; Freeman, 2006) and will normally last between 1.5 to 2 hours (Fitzpatrick & Boulton, 1996; Freeman, 2006). A focus group will have a moderator or facilitator who looks to elicit the views, experiences and opinions of participants around certain topics pertaining to the research question that the participants discuss with one another (Fitzpatrick & Boulton, 1996). The moderator may be someone neutral who comes from the same culture as the group in order to seek a more mutual exchange whereas other researchers consider the moderators influence on the group dynamic and conversation part of the analysis (Lehoux, Poland, & Daudelin, 2006). Within a focus group it is important that participants respond to one another's responses and further clarification and exploration is also gained through questioning from the moderator (Freeman, 2006). As such the group interaction allows the clarification of group similarities and differences (Freeman, 2006). If conducting in-depth research, it is normal for multiple focus groups to be conducted (Fitzpatrick & Boulton, 1996).

The paradigm a researcher is working within influences how a focus group is used (Freeman, 2006). Constructivists tend to be more concerned with

the interaction between participants and examining group dynamics whereas realists are concerned with reducing selection bias within focus group participants and therefore increasing the generalisability of results (Freeman, 2006). From a realistic perspective, if convenience samples are used this may influence the group dynamic as people may know each other well and the pre-existing group dynamics may impact upon results and reduce generalisability (Krueger 1994). In addition, realists posit that groups should be homogenous in order to improve internal validity, which may mean performing multiple focus groups with different subgroups if the viewpoints of different stakeholders are required (Freeman, 2006). Also, people may be more willing to discuss certain topics if the group is more homogenous, for example a group with both doctors and patients may constrain discussion (Freeman, 2006). However, this is less important from a constructionist perspective as there is no true reality to be unearthed (Kitzinger, 1994) and the focus of the analysis is the discourse as opposed to understanding shared reality (Freeman, 2006). This perspective places less emphasis on the generalisability of data given that the findings are conceptual comprehensions of one of multiple realities that may exist (Freeman, 2006).

There are a number of benefits to using focus groups. For example, they can be quicker to conduct than multiple interviews (Fitzpatrick & Boulton, 1996) and can help researchers to understand the reality of a particular group of individuals (Fitzpatrick & Boulton, 1996). Group interaction allows for improved insight into the experiences and opinions of the participants (Barrett & Kirk, 2000). However, more sensitive topic areas may not be suitable for a group discussion and it can also be more difficult to probe responses in a focus group setting (Fitzpatrick & Boulton, 1996).

2.5.3.3 Methods (data collection techniques) adopted within this thesis. For both Study Three and Study Four a semi-structured interview approach to collecting data was adopted. Although focus groups would be a suitable method of data collection, concerns relating to the pragmatics of the approach were held due to the barriers experienced by carers of stroke survivors, such as lack of time (Carretero et al., 2009; Eames et al., 2010; van Houtven, Oddone, & Weinberger, 2010) or being unable to leave the person that they care for (Barrett & Kirk, 2000). Indeed, after liaising with the Stroke

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Association the researcher was advised that organising focus groups would be very difficult due to these pragmatic concerns. Additionally, working from a realist perspective ideally participants should not know one another (Krueger 1994). However, given that sampling techniques were based upon recruitment through stroke clubs in the same geographic area it would be likely that members of the group would have pre-existing relationships that may have influenced results. Finally, the topic of the focus groups, especially in terms of understanding the difficulties experienced by depressed carers and preferences for mental health support, is a sensitive topic area. There is evidence to suggest that a barrier to informal carers seeking help is a feeling of guilt and a sense of duty of care (Sisk, 2000).

As such using focus groups may have limited truthful dialogue. Therefore, for the following key reasons, semi-structured interviews were considered a more appropriate way of collecting data:

- Allow the development of a detailed appreciation concerning experience, feelings and knowledge, which are key aims of the research questions (Britten, 1999).
- Are suitable for potentially sensitive topics (Gill, Stewart, Treasure, & Chadwick, 2008).
- Can be conducted in peoples' homes; community settings or over the telephone thus overcoming pragmatic concerns.

The detailed methods, results, discussion and conclusion of Study Three and Study Four are presented in Chapters Four and Five respectively.

2.6 Modelling and Development of the CBT Self-Help Intervention

The final element of the 'development phase' of the revised MRC Framework (MRC, 2008) is the modelling stage. This refers specifically to describing the processes underpinning the intervention and defining the specific components of the intervention and how these components may relate to one another and the expected outcomes (Faes et al., 2010). As such, the overall aim of the modelling phase is to develop the specific CBT self-help intervention materials, PWP assessment and support protocol and accompanying PWP training programme. This process is an iterative one (Campbell et al., 2007) drawing upon the synthesised findings of Study One, Two and Three with the aim of developing a novel, evidence based, theoretically driven CBT self-help

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intervention individualised to the specific needs of depressed informal carers of stroke survivors.

The CBT self-help intervention was developed in accordance with the IAPT programme (Richards & Whyte, 2011, Richards et al., 2011) to deliver low-intensity CBT-based interventions for depression and anxiety. First, this was important as qualified PWPs trained in accordance with the IAPT national curriculum delivered the intervention. Second, the evidence base for the effectiveness of IAPT low intensity support (Richards & Borglin, 2011; Richards & Suckling, 2009) and CBT self-help in general is well established (Anderrson & Cuijpers, 2009; Coull & Morris, 2011; Farrand & Woodford, 2013; Gellatly et al., 2007). However, significant adaptations were made to the approach in order to tailor the intervention to the unique difficulties experienced by depressed informal carers of stroke survivors. This work consisted of the five phases detailed below:

2.6.1 Phase One

Integration of components associated with effectiveness identified from the systematic review and meta-analysis of psychological treatments for depression and anxiety experienced by informal carers of adults with chronic physical health conditions (Study Two, Chapter Three).

2.6.2 Phase Two

Incorporation of psychological theories that target the specific difficulties experienced by depression and anxious informal carers of stroke survivors gathered through semi-structured interviews (Study Three, Chapter Four).

2.6.3 Phase Three

Adoption of a positive psychological approach integrating psychological theories that help depressed informal carers utilise the positive coping strategies used by non-depressed anxious informal carers of stroke survivors as identified through semi-structured interviews (Study Four, Chapter Five).

2.6.4 Phase Four

Further refinement of the novel CBT self-help intervention was conducted through the development of examples and patient vignettes derived from the common difficulties and challenges identified in Study Three. It is important that the content of the intervention was relevant to informal carers of stroke survivors to increase engagement (Macdonald et al., 2007; Whittaker et al.,

2012). In addition, common factors highlighted to help establish, develop and maintain a therapeutic alliance (Cahill et al., 2008) were incorporated into the CBT self-help intervention given their association with positive therapeutic outcomes (Lambert & Barley, 2002; Martin, Garske, & Davis, 2000; Shirk & Karver, 2003). In order to ensure that the structure, format and appearance of the CBT self-help intervention was both acceptable and engaging, a lived experience steering committee of two carers and one stroke survivors also provided feedback during the development of the intervention.

2.6.5 Phase Five

Development of the assessment and support protocol for PWP's in order to support the delivery of the CBT self-help intervention and associated training programme. The assessment and support protocol was consistent with existing IAPT guidelines (Richards & Whyte, 2011). However, the initial assessment session was significantly adapted to ensure that questions were asked concerning the typical difficulties experienced by depressed informal carers of stroke survivors. Furthermore, the support protocol was further adapted to work with an informal carer population. A training programme was developed for PWP's on the basis of the new intervention and assessment and support protocols.

2.7 Feasibility Randomised Controlled Trial

The final study conducted in this thesis was a feasibility randomised controlled trial (RCT). Phase II of the revised complex interventions framework (MRC, 2008) is the 'feasibility and piloting stage' and is intended to examine procedural and methodological uncertainties (such as recruitment and retention rates and the acceptability of the intervention) before embarking on a full scale evaluation study (Craig et al., 2008; MRC, 2008). This part of Chapter Two explains what a feasibility study is, why they are important, how to report them, and the reasons for using a feasibility RCT in the thesis.

2.7.1 What are Feasibility Studies?

Phase II of the revised complex interventions framework (MRC, 2008) is concerned with undertaking a feasibility or pilot study. There is a lot of debate in the literature about the differences between feasibility and pilot studies (Abbott, 2014; Billingham, Whitehead, & Julious, 2013) with the terms often used interchangeably (Torgerson & Torgerson, unpublished manuscript).

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Essentially, both feasibility and pilot studies are preliminary studies that help inform the design and planning of definitive efficacy or effectiveness RCT's forming Phase III of the revised MRC framework (Abbott, 2014). Although the terms 'feasibility' and 'pilot' are used interchangeably there are some differences relating to the main objectives and outcomes of each type of study. However, preliminary studies often include features of both (Abbott, 2014). A widely accepted definition for feasibility and pilot studies (Billingham et al., 2013; Arain, Campbell, Cooper, & Lancaster, 2010) comes from the National Institute of Health Research Evaluation, Trials and Studies (NETS) programmes website. The NETS website defines a feasibility study as "pieces of research done before a main study in order to answer the question 'Can this study be done?'" (NETS, n.d.). A pilot study is defined as "a smaller version of the main study used to test whether the components of the main study can all work together" (NETS, n.d.). In contrast, a definitive efficacy or effectiveness RCT is designed to test a hypothesis relating to the efficacy or effectiveness of the new treatment undergoing investigation (Leon, Davis, & Kraemer, 2011).

The overall aim of a feasibility study is to assess the viability and practicality of conducting a definitive efficacy or effectiveness RCT (Abbott, 2004). A feasibility study is an important phase in the development of a new complex intervention and does not have to reflect the design of a definite RCT (Abbott, 2014) and indeed may be considered to reflect a 'proof of concept' study as used in pharmacological trials (Arain et al., 2010). A feasibility study does not have to include randomisation but if it does it will not have a primary clinical outcome measurement or power calculation to inform sample size (Arain et al., 2010). A pilot study however is more concerned with examining the suitability of the key procedural and methodological components necessary to conduct a definitive RCT and will normally mirror the planned RCT (Abbott 2014; Arain et al., 2010). A pilot can be either internal or external (Arain et al., 2010; Lancaster, Dodd, & Williamson, 2004). An internal pilot is one that is considered the first phase of a planned definitive RCT (Torgerson & Torgerson, unpublished manuscript) and are often required by funding bodies (Lancaster et al., 2004). As such, the results can be included in the final analysis of the main trial (Arain et al., 2010) as long as the aims and methods are the same as those subsequently used in the main trial (Charlesworth, Burnell, Hoe, Orrell, &

Russell, 2013). In contrast, with an external pilot a definitive RCT may not be planned at the end of the study and the results will be analysed and considered separate to any future RCT (Arain et al., 2010). As such they are considered as 'stand-alone' pieces of research (Lancaster et al., 2004). The key objectives of feasibility, pilot and efficacy or effectiveness trials can be found in Table 2.1.

2.7.2 Why Conduct a Feasibility or Pilot Study?

Setting up and delivering a high quality rigorous research project is challenging and relies on thorough preparation and planning (Gardner, Gardner, MacLellan, & Osborne, 2003). Furthermore, RCTs are expensive as well as labour and time intensive. As such it is important to evidence feasibility to funding bodies before embarking on a full-scale trial (Lancaster, Dodd, & Williamson, 2004). Indeed, conducting a feasibility or pilot study can increase the likelihood of success of a future definitive trial (Thabane et al. 2010). As such, clinical trials often fail to achieve their goals (Vickers, 2014). Some of the main difficulties believed to contribute to this failure are listed below:

- The complex and lengthy contractual and regulatory requirements for study approval, such as ethical and governance requirements often cause long delays to opening studies (Fudge, Redfern, Wolfe, & McKevitt, 2010; Kearney et al., 2014; Tcheremissine, Rossman, Castro, & Gardner, 2014).
- Recruitment into RCTs is challenging with trials rarely recruiting to target, often experiencing delays to starting recruitment and having to extend the trial recruitment period (McDonald et al., 2006). Under-recruitment leads to underpowered trials and subsequently further trials are required to examine the new intervention (Richards, Ross, Robens, & Borglin, 2014).
- Small trial sample sizes are not only due to under recruitment but also trials are commonly underpowered due a priori sample size calculations not being performed (Califf et al., 2012; Moher, Dulberg, & Wells, 1994).
- RCTs often contain complex trial protocols including protracted eligibility criteria and extensive test batteries (Fuks et al., 1998) that may contribute to poor recruitment and also increase the cost of conducting trials (Eapen et al., 2013). Indeed, a review of drug trials

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found that the work burden associated with administering trial protocols increased by 10.5% between 1999-2005 (Getz, Wenger, Campo, Seguire, & Kaitin, 2008).

- Endpoints are often poorly selected in terms of clinical relevancy and acceptability to patients and clinicians (Nichol, Bailey, & Cooper, 2010).
- The integration of clinical research into the daily routine of healthcare providers delivering the intervention itself is often challenging (Tcheremissine, Rossman, Castro, & Gardner, 2014). An associated problem concerns patient non-adherence to treatment protocols which although common is often poorly reported (Dodd, White, & Williamson, 2012). Patient adherence data can provide important information about barriers to adhering to the intervention and the acceptability of the intervention itself (Dodd, White, & Williamson, 2012).
- Low acceptability in terms of randomisation can occur. It is therefore important to assess the acceptability of randomisation and ensure that patients understand the justification for randomisation that is associated with increased acceptability (Kerr et al., 2004).
- Attrition is common, with reviews suggesting that 89% of RCTs published in high quality, high impact medical journals have at least some form of missing data and 18% were found to have attrition rates of over 20% (Wood, White, & Thompson, 2004).

These major challenges to conducting definitive RCTs, and therefore areas to be assessed regarding feasibility, can be classified under four categories (Thabane et al., 2010).

- *Process*: elements such as recruitment, retention, suitability of the eligibility criteria; accessibility of data collection methods or adherence rates.
- *Resources*: time and resource difficulties that may occur during the study, for example, the time taken to fill in data collection forms, time to mail out study information; availability of equipment; and the commitment of trial centres.

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- *Management*: human and data management issues, such as difficulties entering data onto data collection forms; whether important data values have been forgotten and the variability of data.
- *Scientific*: assessment of treatment effect and variance of effect.

Considering the multitude of challenges and difficulties that can be experienced when conducting a RCT, it is essential that the feasibility of carrying out a trial is fully examined before embarking on a definitive RCT (MRC, 2008).

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Table 2.1

Objectives of Feasibility, Pilot and Efficacy or Effective Randomised Controlled Trials (adapted from Abbott, 2014, p. 556).

Feasibility studies	Pilot studies	Efficacy or effectiveness trials
To determine the following:	To assess the following:	To investigate the following:
<ul style="list-style-type: none"> • Access to participants • Barriers to participating • Feasibility and suitability of assessment and outcome measures • Time and resources needed to carry out assessments • Willingness to be randomised • Need for stratification • Is the intervention deliverable in the setting? • Training needs and competence of therapists • Barriers to delivering the treatment in the healthcare setting • Clinician adherence to protocols • Acceptability of the intervention • Participant adherence to the intervention • Appropriateness of the target group for intervention • Risk of treatment contamination • Multisite issues such as generalisability of sites and participants; correlations among site clusters; differences between centres' commitment and willingness; barriers; differential loss to follow-up. 	<ul style="list-style-type: none"> • Whether recruitment and screening are working well • Recruitment rates • Randomisation processes • Selection bias • Effectiveness of blinding • Capacity and resources to carry out trial procedures • Access to equipment, space and other resources • Adequate time, intensity, dose, effects of interventions • Assessment procedures and timely and complete • Participant retention • Data completeness • Data variability • Treatment outcomes consistent with expectations and previous literature • Challenges faced by study sites and personnel. 	<ul style="list-style-type: none"> • The null hypothesis that treatment A is not more effective than a comparison.

2.7.3 Reporting Feasibility Randomised Controlled Trials

Feasibility and pilot studies are rarely published (Thabane et al., 2010), often due to journal editors being hesitant to publish pilot and feasibility studies due to perceived lack of rigour (Arain et al., 2010). However, the results of pilot and feasibility studies are essential in terms of the design and conduct of future definitive RCTs and thus researchers should attempt to publish findings (Thabane et al., 2010). They not only provide useful information for those who have conducted the preliminary study, but also for other researchers (Friedman, 2013). Indeed, results of preliminary studies are valuable if they do fail as they may prevent other researchers from making the same errors and can help identify important future research questions (Garnder et al., 2003). However, it is important that published reports do not mislead readers, for example by making claims concerning effectiveness, but instead are reported in terms of the key questions of uncertainty surrounding methodology, design and process (Friedman, 2013). Indeed, two errors are common regarding the reporting of preliminary studies. First, researchers report feasibility and pilot RCT outcomes in terms of effectiveness (Arain et al., 2010; Shanyinde, Pickering, & Weatherall, 2011). Second, inadequately powered RCTs are often framed as pilot studies (Arain et al., 2010). A recent review of pilot and feasibility studies found that just over half of the studies failed to report on any methodological or procedural objectives (Shanyinde, Pickering, & Weatherall, 2011).

When reporting a feasibility or pilot study the focus should be the assessment of feasibility in relation to clearly defined feasibility aims and objectives (Thabane et al., 2010). As such, the results of feasibility and pilot studies should mainly be descriptive (Lancaster et al., 2004; Lee, Whitehead, Jacques, & Julious, 2014) as opposed to reporting treatment outcomes (Abbott, 2014). Typically results will include participant flow, the baseline demographic and clinical characteristics of participants and data for each primary and secondary feasibility outcome. Effect sizes and confidence intervals can be reported in order to infer a cautious direction of effect rather than hypothesis testing (Lee et al., 2014). In some cases the variance of the outcome may be used to calculate the sample size for a future definitive RCT (Arain et al., 2010). However there is much debate in the literature regarding whether the results of feasibility and pilot trials can be used to determine the sample size of a definite

trial (Kraemer, Mintz, Noda, Tinklenberg, & Yesavage, 2006). Caution should therefore be applied to the use of pilot and feasibility studies when informing future definitive trial sample size calculations (Noordzij et al., 2010; Thabane et al., 2010). Typically, there are four potential overall outcomes for pilot or feasibility studies that should be reported (Thabane et al., 2010):

1. Stop;
2. Continue with modifications to the protocol;
3. Continue without modifications but close monitoring required;
4. Continue without modification.

2.7.3 Why use a Feasibility Randomised Controlled Trial in this Thesis?

2.7.4.1 Little evidence base for psychological interventions for informal carers. There is little evidence pertaining to the effectiveness of interventions targeting caregiving difficulties such as depression (Brereton et al., 2007; Legg et al., 2011; Visser-Meily, van Heugten, Post, Schepers, & Lindeman, 2005). Studies that have been conducted target a multitude of clinical outcomes such as distress, burden and general psychological wellbeing (Eldred & Sykes, 2008; Zarit & Femia, 2007). Furthermore, studies have tended not to include carers defined as having a disease state or ill health (e.g., depression) (Legg et al., 2011) and include highly heterogeneous carer populations (Zarit & Femia, 2007). As such, little is currently known about the effectiveness of informal carer interventions targeting depression in informal carers of stroke survivors.

2.7.4.2 Methodological uncertainties.

- Extreme variability exists in the interventions for informal carers in terms of content, delivery and setting (Eldred & Sykes, 2008). Therefore, little is known about what treatment components might be associated with effectiveness.
- Studies examining stroke carer interventions have focused on the first 6 months post-discharge from a hospital and therefore little is known about psychological interventions for carers in the long-term (Brereton et al., 2007).
- Methodological flaws in the existing carer intervention literature include small sample sizes and high levels of attrition (Eldred & Sykes, 2008; Thompson et al., 2007); lack of randomisation (Eldred & Sykes, 2008)

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and poor recruitment (Farran, 2001; Gallagher-Thompson, Solano, Coon, & Areán, 2003; Scott & Beatty, 2013). As such there are a number of uncertainties relating to feasibility of recruitment, likely attrition rates and the acceptability of randomisation.

- Uncertainty exists concerning the potential impact on recruitment and engagement of barriers experienced by informal carers such as lack of time (Eames et al., 2010); difficulties planning support around the caring role (Beaver, Luker, & Woods, 2000); carer's own physical health difficulties (van Houtven, Oddone, & Weinberger, 2010) and the tendency to seek treatment for the care recipient rather than themselves (Gallagher-Thompson et al., 2012).

2.7.4.3 Procedural uncertainties. The proposed intervention is designed to be delivered in IAPT services, supported by PWP. To date very few studies have been delivered within IAPT services (Farrand et al., 2014; Rhodes et al., 2014). As such it is important to examine procedural uncertainties relating to conducting research within this setting. Uncertainties include clinician adherence to research protocols, training needs and competence of therapists and barriers to delivering the intervention within IAPT services.

2.7.4.4 Little evidence base for CBT self-help for informal carers.

- Although the evidence base is well established for CBT self-help for mental health populations (Anderrson & Cuijpers, 2009; Coull & Morris, 2011; Farrand & Woodford, 2013), few studies have examined CBT self-help for informal carers (Grover et al., 2011a; Grover et al., 2011b; Holye et al., 2013; Scott & Beatty, 2013).
- Little is known about the acceptability of CBT self-help for a carer population with evidence suggesting CBT self-help interventions may not be acceptable for all populations without adaptation to specific needs (Hind et al., 2009). Given the intervention is a novel CBT self-help intervention for depressed carers of stroke survivors it is therefore important to examine the acceptability of the new intervention as well as patient and clinician fidelity and adherence. This will provide important information to potentially further refine both the CBT self-help treatment and PWP training programme.

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- Although CBT self-help interventions now have an established evidence base they are not without methodological problems themselves, including poor recruitment (Jones, O'Connor, Brelsford, Parsons, & Skirton, 2012; Hetherington, Matheson, & Robson; Hedman et al., 2011; Woodford, Farrand, Bessant, & Williams, 2011) and high levels of attrition (Christensen et al., 2009; Donkin et al., 2011; Farvolden, Denisoff, Selby, Bagby, & Rudy 2005; O'Mahen et al., 2013).

As such, it is important to consider these limitations in the CBT self-help literature and examine whether such difficulties impact on the feasibility of embarking on an RCT of the new CBT self-help treatment. The full study protocol, results and discussion of findings for the feasibility RCT can be found in Chapter Seven.

2.8 Chapter Summary

This chapter has explored the MRC framework and provided a more detailed outline in terms of the specific methodologies utilised within the thesis to inform the development and feasibility and piloting of the CBT self-help intervention for depressed carers of stroke survivors. In Chapter Three the researcher examines the existing evidence base for psychological and psychosocial interventions for informal carers of people with chronic physical health conditions experiencing depression and anxiety through systematic review and meta-analysis. The aim of Chapter Three is twofold:

- To explore the effectiveness of existing psychological and psychosocial interventions for informal carers of people with physical health conditions experiencing depression or anxiety.
- To examine specific components of psychological and psychosocial interventions for informal carers to identify potential components associated with effectiveness to inform the content of the new CBT self-help intervention.

CHAPTER THREE: Systematic Review and Meta-analysis

Psychological treatments for common mental health problems experienced by informal carers of adults with chronic physical health conditions (Protocol)

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3.1 Abstract

Background: Improved life expectancy is resulting in increased outpatient treatment of people with chronic physical health conditions and reliance on the provision of informal care in the community. However, those providing informal care are also associated with increased risk of experiencing common mental health difficulties such as depression and anxiety. Currently there is a lack of evidence-based treatments for such difficulties, resulting in poor health outcomes for both the informal carer and care recipient.

Methods/Design: Electronic databases will be systematically searched for randomised controlled trials examining the effectiveness of psychological interventions targeted at treating depression or anxiety experienced by informal carers of patients with chronic physical health conditions. Database searches will be supplemented by contact with experts, reference and citation checking and grey literature. Both published and unpublished research in the English language will be reviewed with no limitations on year or source. Individual, group and patient-carer dyad focused interventions will be eligible. Primary outcomes of interest will be validated self-report or clinician administered measures of depression or anxiety. If data allows a meta-analysis will examine (a) the overall effectiveness of psychological interventions in relation to

outcomes of depression or anxiety; (b) intervention components associated with effectiveness.

Discussion: This review will provide evidence on the effectiveness of psychological interventions for depression and anxiety experienced by informal carers of patients with chronic physical health conditions. In addition, it will examine intervention components associated with effectiveness. Results will inform the design and development of a psychological intervention for carers of people with chronic physical health conditions experiencing depression and anxiety.

PROSPERO registration number: CRD42012003114

Keywords: Caregivers, Chronic physical health condition, Depression, Anxiety, Treatment, Systematic review

3.2 Background

Advances in public health and medical technology have resulted in continued increases in life expectancy across developed countries (Christensen et al., 2009). Within the UK alone the number of adults aged over 80 years is projected to rise from 2.9 million adults in 2010 to 5.9 million in 2035 (ONS, 2012). These increases in life expectancy are presenting significant challenges to existing healthcare systems with regards to the management and treatment of patients with chronic or disabling illnesses (Christensen et al., 2009; Lubitz, Cai, Kramarow, & Lentzner, 2003). This is manifesting itself in an increased reliance on informal carers as a fundamental part of patient management which has become important following an increasing emphasis upon outpatient treatment of patients with chronic physical health conditions (Wakefield, Hayes, Boren, Pak, & Davis, 2012). Currently around 5 million people in the UK provide informal care to someone with a physical or mental health difficulty (National Health Service Information Centre [NHS IC], 2010).

The shift to outpatient treatment alongside a concomitant increase in the role of informal carer in patient management and treatment has led to a reduction in patient hospital and physician care as well as delaying the receipt of nursing home care (Van Houtven & Norton, 2004). However given demands associated with supporting the treatment and recovery of patients with a physical or mental health difficulty now being placed upon informal carers, the potential is that costs are simply being shifted elsewhere. Informal care is not

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only associated with greater risks of poor mental and physical health (Canniscio, 2002; Coe & van Houtven, 2009; Pinguart & Sørensen, 2003a; Shaw et al., 1997) but additional personal and societal costs arising from reductions in hours of paid work, restriction in social and recreational activities (Salva, Almeida, Davey, & Zarit, 2008) and sleep disturbances (Phillips et al., 2009). Additionally poor mental health in carers may also negatively impact on outcomes associated with the care recipient (Perrin, Heesacker, Stidham, Rittman, & Gonzalez-Rothi, 2008).

A clear need therefore exists to develop evidence based psychological interventions to support the long-term emotional needs of informal carers. However such long-term emotional needs of carers have been neglected across a range of chronic physical health conditions (Arksey & Hirst, 2005; Murray, Young, Forster, & Ashworth, 2003; Simon, Kumar, & Kendrick, 2008; Simon, Kumar, & Kendrick, 2009; Wilkinson & Lynn, 2005). Furthermore, services that do exist to provide emotional support are often inadequately developed and are generally not tailored to address the unique difficulties carers' experience (Lundh, 1999). Such difficulties may include the management of behavioural problems (Pinguart & Sørensen, 2003a), physical impairments (Pinguart & Sørensen, 2003b), cognitive decline (Vernooij-Dassen, Draskovic, McCleery, & Downs, 2011) and the development of communication techniques (Rosland & Piette, 2010). Developing interventions have however potentially been hindered given that the needs of carers often change dependent upon the course of the chronic physical health condition of the care recipient, the setting care is provided in and length of time care has been provided (Wilkinson & Lynn, 2005). Recognition of the unique and multifaceted needs of informal carers has led to the suggestion that multicomponent interventions are required (Brodady, Green, & Koschera, 2003; Wilkinson & Lynn, 2005).

A number of meta-analyses have been undertaken to identify factors associated with positive outcomes in informal carers, such as caregiver burden, knowledge, depression and symptoms of care recipients. Commonly such meta-analyses have included a large number of potential factors, such as respite and day care, knowledge and training, group- and individual-based interventions, type of setting and various caregiver characteristics (Sørensen, Pinguart, & Duberstein, 2002). Additionally they have focused upon a variety of

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specific patient carer groups such as stroke (Legg et al., 2011), cancer (Hopkinson, Brown, Okamoto, & Addington-Hall, 2012) and dementia (Brodaty et al., 2003; Van Mierlo, Meiland, Van der Roest, & Dröes, 2012). Far less attention has however been directed towards identifying specific psychological interventions that may be targeted at the treatment of depression and anxiety. Where this focus has been included within the meta-analysis as treatment moderators, psychological treatments mostly consistent with elements of cognitive behavioural therapy (CBT) have been identified to have a small effect on caregiver depression (Sörensen, Pinguart, & Duberstein, 2002; Pinguart & Sörensen, 2006). Furthermore, one review has identified cognitive reframing, a specific component commonly found within CBT, as an intervention component promising for depressed informal carers of dementia patients (Vernooij-Dassen et al., 2011).

To date little research has sought to identify specific intervention components utilised in interventions targeting depression and anxiety in carers of adults with chronic physical health conditions. Additionally, when such components have been identified through approaches such as systematic reviews, too little attention has then been paid to identifying the specific components associated with effectiveness (Cane, O'Connor, & Michie, 2012). Recent systematic reviews have therefore examined not only the overall effectiveness of interventions but also the specific intervention components associated with their effectiveness (Greaves et al., 2011; Lorencatto, West, & Michie, 2012).

This systematic review therefore seeks to examine both the overall effectiveness of psychological interventions for depressed or anxious carers and specific intervention components associated with effectiveness. The identification of effective intervention components utilised in interventions targeting depression and anxiety in carers of adults with chronic physical health conditions is an important next step to inform the future design and development of evidence-based treatments.

3.2.1 Objectives

First, to undertake a comprehensive systematic review and meta-analysis examining the effectiveness of psychological interventions targeted at treating emotional difficulties, such as depression or anxiety, across a range of

carer-care recipient populations. Second, to identify intervention components associated with effectiveness. The results of the systematic review will also be used to feed into the development of an evidence-based complex intervention for carers of people with chronic physical health conditions using the Medical Research Council's (MRC) guidance (Campbell et al., 2000; Craig et al., 2008).

3.3 Methods

The review will follow the Centre for Reviews and Dissemination (CRD) guidance on undertaking systemic reviews (CRD, 2009) and be reported to established criteria (Moher et al., 2009). The review is registered with the PROSPERO International Prospective Register of Systematic Reviews (registration number CRD42012003114).

3.3.1 Inclusion and Exclusion Criteria

3.3.1.1 Population. Eligible populations are informal adult (aged 16 years and older) carers of adults with chronic physical health conditions who are experiencing depression or anxiety. Formal diagnosis of depression or anxiety will not be required. No limitations will be placed on severity of depression or anxiety (though it is estimated carers will be depressed or anxious), length of time caring, chronic physical health condition of the person cared for, or relationship to person cared for. Informal carers will be defined as non-professionals who support people who are sick, infirm or disabled (Singleton et al., 2002). Commonly this group is made up of the patients' close family, however non-family informal carers will be eligible for inclusion. Given recognition that provision of care is dynamic and fluctuates from providing intensive assistance on a daily basis to more infrequent support no constraints will be placed on how much assistance informal carers provide (Szinovacz & Davey, 2007).

3.3.1.2 Interventions. The review will include psychological or psychosocial interventions that are targeted at depression or anxiety. There will be no limitation in terms of psychological theory informing the intervention, the person delivering the intervention or the setting in which the intervention is delivered. Group, one-to-one and unsupported interventions will be included. Interventions for the carer patient dyad will also be included as long as a target of the intervention is carer depression or anxiety.

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3.3.1.3 Comparators. Only studies comparing interventions with an inactive control will be considered. This may include: a waiting list control; treatment-as-usual (normally defined as standard care provided by a general practitioner/family doctor); no treatment and attention-controls. Interventions compared with another active intervention will not be eligible for inclusion.

3.3.1.4 Outcomes. Studies eligible for inclusion will have a primary or secondary outcome measurement of a validated self-report or clinician administered measure of depression or anxiety that elicits continuous data. Outcomes of caregiver burden and quality of life will also be examined. Dropout rates will also be recorded. Outcomes for any time period will be eligible for inclusion. However, in the case of studies reporting multiple time points the follow-up time point used for analysis will be the longest time point ≤ 6 months.

3.3.1.5 Study design. Only randomised controlled trials using a method of random sequence generation and allocation concealment assessed as low or unclear risk of bias using the Cochrane Collaboration's Risk of Bias tool (Higgins & Altman, 2008) will be included within the review.

3.3.2 Search Strategy

A comprehensive search will be conducted on the following electronic databases: Cumulative Index to Nursing and Allied Health Literature (CINAHL); Excerpta Medica DataBase (EMBASE); PsychInfo; Medline; Social Science Citation Index; Applied Social Sciences Index and Abstracts (ASSIA) and the Cochrane Central Register of Controlled Trials (CENTRAL). Reference lists and citations will be hand searched for all included studies to identify further studies. The results of the database searches will be analysed to identify journals that contain the largest number of included studies that will be hand searched for recent publications and conference abstracts (less than 12 months). Trial registers www.ClinicalTrials.gov and www.who.int/trialsearch/ will also be searched to identify on-going or unpublished trials. Experts in the field will be contacted to further identify unpublished or ongoing trials. An information specialist was consulted to build the search strategy using medical subject headings (MeSH). The Ovid MEDLINE search strategy can be found in Appendix 3.1.

3.3.3 Study Selection

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All titles and abstracts will be screened by JW and a second researcher. Full paper review to determine inclusion will be conducted independently by JW and PF. Cohen's Kappa will be calculated to determine agreement in selecting studies in accordance with the exclusion / inclusion criteria. Any discrepancies will be resolved by discussion with a third member of the research team involved in final decision making if consensus cannot be reached.

3.3.4 Data Extraction

Data extraction will be conducted by JW and a researcher not associated with the research team. Discrepancies will be discussed and if consensus is not reached discussion will be held with PF. A data extraction form specifically for this review has been developed upon guidance from the CRD (CRD, 2009).

To meet the second objective of the review there will also be a specific focus on extracting information relating to intervention components and patient characteristics in addition to the standard extraction of information (for example, identification features, study characteristics, primary outcome measurements, statistical approaches and primary results). Intervention components extracted from the data are partially based upon those used in a previous review examining intervention components associated with increased effectiveness in diet and physical activity interventions (Greaves et al., 2011). Specifically the following will be extracted: (a) theoretical framework (for example, cognitive therapy, behaviour therapy, interpersonal therapy, psychodynamic therapy); (b) behaviour change techniques (for example, problem solving, goal setting, relapse prevention) based on a taxonomy of 137 behaviour change techniques (Michie, Johnston, Francis, Hardeman, & Eccles, 2008); (c) mode of delivery (for example, individual face-to-face, telephone, email, group, unsupported self-help); (d) group size for group-based interventions; (e) clinician delivering treatment (for example, nurse, general practitioners, clinical psychologist); (f) training received by the clinicians delivering the treatment; (g) treatment intensity (for example, duration of treatment, number of sessions, length of sessions); (h) whether the treatment is manualised (yes or no); (i) measurement of treatment integrity (yes or no); and (j) treatment setting (for example, primary care, secondary care). In addition, specific characteristics will be extracted for both the carer (for example, age, ethnicity, severity of depression or anxiety at baseline, length of time caring, relationship to person cared for and receipt of

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formal care in the home) and the adult with the chronic physical health condition (for example, age, chronic physical health condition, severity of chronic physical health condition and mental health and other chronic physical health comorbidities). The data extraction form can be found in Appendix 3.2.

Intervention components will be extracted from published papers, however all authors will also be contacted to obtain trial protocols and treatment manuals associated with the delivery of the intervention to enable more detailed coding to take place. Interventions will be coded by JW and PF independently and discrepancies will be resolved through discussion and if required a third researcher will be consulted.

3.3.5 Methodological Quality

The Cochrane Collaborations' Risk of Bias tool (Higgins & Altman, 2008) will be adopted to appraise the methodological quality of the included studies. This will be undertaken independently by JW and a reviewer not associated with the research team. Ratings will be compared and any discrepancies discussed, and if consensus is not reached, further discussion will be held with PF. The tool will examine risk of selection, performance, attrition and reporting bias. To detect reporting bias attempts will be made to obtain study protocols for all included studies either via published protocols, trial databases or emailing the study authors. Comparisons will be made with the outcome measurements reported in the protocol and the paper. In addition, outcomes reported in the methods section will be compared with outcomes reported in the results section. In the event of discrepancies study authors will be contacted to identify potential reasons, such as changes to the study protocol, or to request missing data. In addition, the quality of primary outcome measures and whether a power calculation was conducted will be assessed. The quality of outcome measurements used will be examined in terms of reliability through internal consistency and test-retest reliability (Fitzpatrick, Davey, Buxton, & Jones, 1998). Only studies using outcome measurements of at least acceptable internal consistency and test-retest reliability (Cronbach's alpha .0.70) will be included (Fitzpatrick et al., 1998). All findings will be summarised within a table to allow easy comparison across studies.

3.3.6 Data Synthesis and Analysis

3.3.6.1 Effect size estimates. If possible with available data, a meta-analysis will be conducted using Comprehensive Meta-Analysis Version 2.0 (Borenstein, Hedges, Higgins, & Rothstein, 2005). Post-treatment between group standardised mean difference effect size will be calculated using Hedges' g from the outcomes relating to depression, anxiety, quality of life and caregiver burden separately. Where multiple time points are reported the longest follow-up time point will be taken ≤ 6 months. Means and standard deviations of post-outcome measurement scores will be requested from authors if not reported within the paper. Heterogeneity is expected and therefore a random-effect model will be used. In the event that there is no evidence of heterogeneity between studies a fixed-effect model will be selected. The presence of statistically significant heterogeneity will be examined using Cochran's test of heterogeneity (Q statistic) and the I^2 statistic will also be reported to quantify the degree of heterogeneity (Higgins & Thompson, 2002; Higgins, Thompson, Deeks, & Altman, 2003). I^2 values of heterogeneity will be considered low, moderate or high using cut offs of 25%, 50% and 75%, respectively (Higgins et al., 2003). If intention-to-treat data are available these will be used to calculate effect sizes, with completer used when intention-to-treat data are unavailable. With studies that compare two treatment conditions that are eligible for inclusion, comparisons will be analysed separately with the sample size within the control condition halved. Comparisons will be analysed separately with the sample size within the intervention arm halved when two control conditions are included.

3.3.6.2 Funnel asymmetry. Egger's Test of the Intercept (Egger, Davey Smith, Schneider, & Minder, 1997) will be used to examine funnel plot asymmetry to investigate possible publication bias and other potential sources of asymmetry (for example, language bias, potential inclusion of small studies with poor methodological rigour, heterogeneity) (Egger et al., 1997). Egger's Test of the Intercept will only be conducted if a minimum of ten studies is included within the meta-analysis (Sterne, Gavaghan, & Egger, 2000). The trim and fill procedure (Duval & Tweedie, 2000) will be used to calculate an effect size taking into account potential publication bias.

3.3.6.3 Sensitivity analysis. Sensitivity analyses will be undertaken to examine the extent to which results obtained may be influenced by the selective

reporting of outcomes. The maximum bias bound approach (Copas & Jackson, 2004; Dwan et al., 2010; Kirkham et al., 2010; Williamson & Gamble, 2007) will be adopted with new treatment effect and confidence intervals calculated by adding the bias bound value to the original pooled effect estimate to examine the robustness of findings (Williamson & Gamble, 2007). Further sensitivity analysis will also be conducted by temporarily dropping from the analysis: small studies ($n \leq 20$); unpublished studies; studies with high attrition ($>30\%$); and studies where outcome measurements of depression and anxiety are reported as primary or secondary outcome measurements to examine whether results remain consistent.

3.3.6.4 Moderator analysis. When number of studies addressing particular moderators permit, moderator analysis will be undertaken to examine intervention components, methodological and participant characteristics of studies associated with effectiveness. Specifically the following moderators will be examined: (a) chronic physical health condition of the care recipient; (b) theoretical framework (for example, cognitive therapy, behaviour therapy); (c) behaviour change techniques used (for example, problem solving, goal setting, relapse prevention); (d) mode of delivery (for example, individual face-to-face, telephone, group); (e) duration of treatment; (f) number of treatment sessions; (g) baseline severity of depression or anxiety; (h) diagnosis of depression or anxiety (yes or no); (i) recruitment setting. Moderators will be examined through subgroup analysis with standardised mean difference effect sizes calculated using Hedges' g statistic using a random-effects model. Q and I^2 statistics will also be reported as a measure of heterogeneity. Consistent with other meta-analyses (Farrand & Woodford, 2013; Hesser, Weise, Zetterqvist Westin, & Andersson, 2011) subgroup analyses will be considered statistically significant if a P value of ≤ 0.10 is obtained. In the event that there is not enough information in relation to components of interventions to support a meta-analysis (Lorenzatto et al., 2012) a narrative synthesis will be undertaken to summarise these findings.

3.4 Discussion

This review will examine the effectiveness of psychological interventions for informal carers of people with chronic physical health conditions experiencing depression or anxiety. Currently there is no comprehensive

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review of psychological interventions for informal carers that also systematically examines both the quality of available evidence and intervention components associated with effectiveness. Thereby this review seeks to examine gaps in the evidence base for future research and to map intervention components associated with effectiveness. The identification of specific intervention components associated with effectiveness will aid the translation of the existing evidence to the development of new interventions optimising these components. Thus, the mapping of such components is a first step towards developing a psychological treatment for informal carers that maximises the use of behavioural change techniques and delivery factors associated with effectiveness in order to meet objectives within Phase I of the MRC's guidance (Campbell et al., 2000; Craig et al., 2008) for developing complex interventions.

3.5 Amendments to the Original Protocol

During the initial stages of the review process a number of potential studies were identified targeting the broader concept of psychological distress or wellbeing, with some studies adopting depression or anxiety outcomes as distal or indirect outcomes of the intervention. This review was designed to investigate the effectiveness of psychological or psychosocial interventions that specifically target depression or anxiety. To aid with study selection the following guidelines were adopted to ensure only interventions that specifically targeted depression or anxiety were included:

- Studies were only included if a specific aim or objective of the treatment was to target depression or anxiety, and where depression or anxiety was defined as a primary endpoint.
- In studies where the target or primary endpoint of the intervention was unclear, study authors were contacted to clarify.
- Studies that considered reduction in depression or anxiety to be an indirect or distal target of the intervention were excluded from the review.

3.6 Results

3.6.1 Study Selection

A total of 10,083 possible studies were identified in total. No restriction was placed on earliest date of publication and the search was completed in December 2012. Database searches yielded 9,971 possible studies through

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searching the following databases: CINAHL (n=1,805); EMBASE (n=3,482); PsychInfo (n=1,025); Medline (n=2,491); Social Science Citation Index (n=214); ASSIA (n=310) and CENTRAL (n=644). Other review papers, reference lists, citation checks, www.ClinicalTrials.gov and www.who.int/trialsearch/ and contact with experts yielded an additional 111 studies. In addition, the following four journals were identified as containing the largest number of eligible studies (including those studies eligible but with missing data for inclusion within the meta-analysis) and were hand searched for recent publications and conference abstracts over the past 12 months:

1. American Journal of Alzheimer's Disease and Other Dementias.
2. The Gerontologist.
3. International Journal of Geriatric Psychiatry.
4. Journal of Clinical Psychology.

Hand searching journals yielded 1 additional possible study.

Of the 10,083 possible records identified from the initial title and abstract screen nine were dissertation abstracts that were potentially eligible for the review however due to time and funding limitations full dissertations were not reviewed (see Appendix 3.3). An additional 10 records were potentially relevant but published in a language other than English and therefore not included within the review due to lack of translation facilities (see Appendix 3.4). All titles and abstracts were screened by JW and one of two additional researchers otherwise unrelated to the research team.

In total 263 full text articles were assessed for eligibility by JW and one of two additional researchers otherwise unrelated to the research team. Cohen's Kappa was calculated to determine if there was agreement in selecting studies in accordance with the exclusion / inclusion criteria. There was substantial agreement between the researchers' judgements, $\kappa = .69$, $p < 0.000$. In the 22 cases where there was disagreement the third member of the research team also reviewed eligibility in accordance with the inclusion criteria and discussed with the research team to resolve. In all cases discrepancy was resolved. Additionally, in cases where it was unclear whether the study directly targeted depression or anxiety, or whether symptoms of depression or anxiety were considered a direct or indirect effect of the intervention, study authors were emailed for clarification. In 2 of these cases authors were either no longer

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contactable or failed to respond and were therefore excluded from the review. In total 247 studies were excluded from the review and 16 studies met the inclusion criteria and were included in the qualitative and quantitative data synthesis. See Figure. 3.1 for the study flow diagram and Table 3.1 for the main reasons for exclusion. See Appendix 3.5 for detailed reasons for study exclusion and study citations.

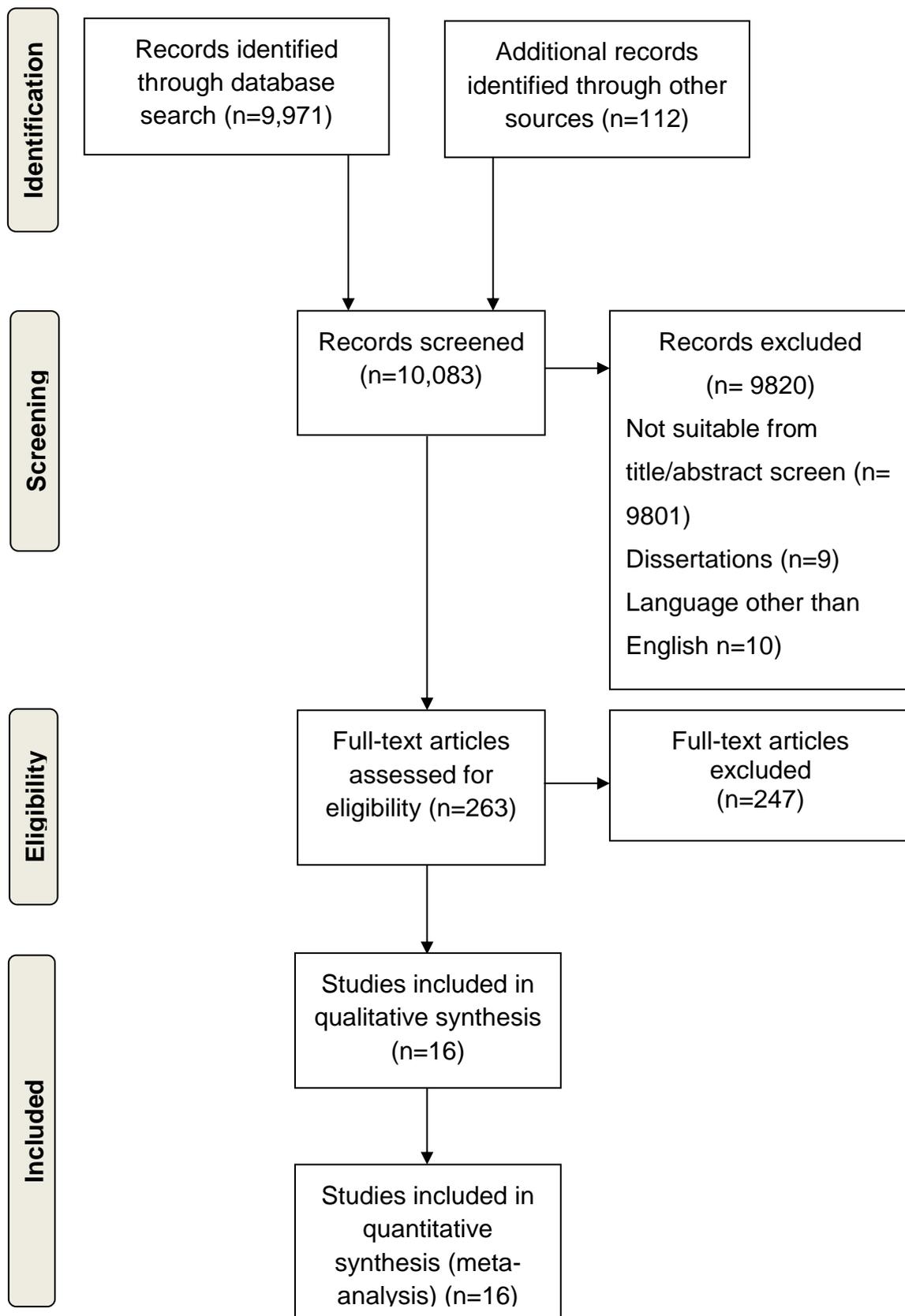


Figure 3.1. PRISMA 2009 (Moher et al., 2009) flow diagram

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Table 3.1

Reasons for Exclusion

Reason for exclusion	<i>n</i>
Depression and / or anxiety are not the primary target of the intervention or measured.	66
Not a psychological or psychosocial intervention	35
Depression and / or anxiety not the primary intervention target. Symptoms of depression and / or anxiety measured as a distal outcome.	32
Inappropriate comparator	23
Not an RCT	21
Treatment primarily focused on the patient rather than the carer.	15
Missing data	13
Secondary analysis	9
Treatment focused on the management of the behavioural and psychological symptoms of Dementia	4
Implementation study, not an RCT	3
Intervention aimed at patient symptom management, not a psychological or psychosocial intervention focusing on carer depression or anxiety	3
Inadequate randomisation	3
Multi-component rather than pure psychosocial or psychological intervention.	3
Lack of standardised measurement or low quality outcome measurement	3
Intervention target unclear, authors not contactable	2
Conference proceedings, authors unwilling to share data	2
Carers excluded if they suffered from major anxiety or depression	1
Duplicate	1
Mediation paper	1
Prevention	1
Not a chronic physical health condition	1
Targeted on the carer during patient transition to institutionalisation, therefore not focused on informal caring within the community.	1
The primary aims of the study pertain to feasibility and adherence to the intervention.	1
Care recipients not limited to those with a chronic physical health condition	1
Cost-effectiveness study	1
Carer depressive symptoms are examined as a potential moderator	1

3.6.2 Methodological Quality

Only randomised controlled trials (RCTs) were included within the review. In total, 21 studies were excluded from the review for not being RCTs. Furthermore, 3 studies were excluded due to using a method of random sequence generation or allocation concealment assessed as high risk of bias using the Cochrane Collaboration's Risk of Bias tool (Higgins & Altman, 2008). However, only 6 of the included studies provided details pertaining to the exact method of random sequence generation (Ågren, Evangelista, Hjelm, & Strömberg, 2012; Badger et al., 2011; Losada, Márquez-González, & Romero-Moreno, 2010; Márquez-González, Losada, Izal, Pérez-Rojo, & Montorio, 2007; Marriott, Donaldson, Tarrier, & Burns, 2000; Tremont, Duncan Davis, Bishop, & Fortinsky, 2008) and only 1 study provided details in terms of the method of allocation concealment (Marriott et al., 2000). As such, the majority of studies could be rated as unclear risk of bias (Higgins & Altman, 2008) in relation to random sequence generation and allocation. Half of the studies used a researcher blinded to condition to collect outcome data (n=8) however none of the studies stated that they used blinded data analysts. Blinding of participants to randomisation allocation was not feasible and therefore not expected given participants included within this review received an active psychological intervention compared mainly with treatment-as-usual or waiting list controls. As such the studies included within the review may be subject to performance bias.

The number of caregivers randomised into the studies ranged from 28 (Marriott et al., 2000) to 167 (Losada et al., 2010) with only 1 study (Marriott et al., 2000) reporting the use of a power calculation to determine sample size. Although the only study (Marriott et al., 2000) reporting the use of a power calculation yielded the lowest sample size in terms of caregivers randomised it is important to note that one control condition included within this trial was excluded from the review due to not meeting criteria for inclusion. Additionally, this was a dyadic intervention and therefore both caregivers and patients were randomised into the trial, however the sample size for the purpose of this review is only reported in terms of the number of caregivers randomised. Baseline imbalance in study arms on key demographics and other participant characteristics that may affect outcomes was not reported in any of the studies.

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In terms of attrition, 6 studies reported attrition >30% in at least one arm (Au et al., 2010; Hayley, Brown, & Levine, 1987; Losada et al., 2010; Lovett & Gallagher, 1988; Toseland, Blanchard, & McCallion, 1995; Toseland, McCallion, Smith, & Banks, 2004) and were rated unclear risk of bias and an additional 2 studies reported attrition >50% in at least one study arm (Márquez-González et al., 2007; Tremont et al., 2008) and were rated as high risk of bias. Finally, only 6 studies used intention-to-treat analysis raising the possibility of attrition bias. See Table 3.2 for the risk of bias ratings for all included studies.

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Table 3.2

Risk of Bias Table

Study	Random sequence generation	Random sequence allocation	Blinding (outcome collectors)	Blinding (data analysts)	Power	Baseline comparability	ITT	Attrition (%)	Outcome reporting bias
Agren et al., 2012	Low	Unclear	Unclear	Unclear	High	Low	Low	Low	Low
Akkerman & Ostwald, 2004	Unclear	Unclear	Low	Unclear	High	Unclear	High	Low	Low
Au et al., 2010	Unclear	Unclear	Unclear	Unclear	High	Low	High	Unclear	Low
Badger et al., 2007	Unclear	Unclear	Unclear	Unclear	High	Low	High	Low	Low
Badger et al., 2011	Low	Unclear	Unclear	Unclear	High	Low	Low	Low	Low
Haley et al., 1987	Unclear	Unclear	Low	Unclear	High	Low	Low	Unclear	Low
Kuijjer et al., 2004	Unclear	Unclear	Unclear	Unclear	High	Low	High	Low	Low
López et al., 2007	Unclear	Unclear	High	Unclear	High	Low	Low	Low	Low
Losada et al., 2010	Low	Unclear	Low	Unclear	High	Low	High	Unclear	Low
Lovett & Gallagher, 1988	Unclear	Unclear	Unclear	Unclear	High	Unclear	High	Unclear	Low
Márquez-González et al., 2007	Low	Unclear	High	Unclear	High	Low	Low	High	Low

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Marriott et al., 2000	Low	Low	Low	Unclear	Low	Low	High	Low	Low
Smith & Toseland, 2006	Unclear	Unclear	Low	Unclear	High	Unclear	Low	Low	Low
Toseland et al., 2004	Unclear	Unclear	Low	Unclear	High	Low	Low	Unclear	Low
Toseland et al., 1995	Unclear	Unclear	Low	Unclear	High	Low	High	Unclear	Low
Tremont et al., 2008	Low	Unclear	Low	Unclear	High	Unclear	Unclear	High	Low

Note. Risk of bias was assessed as low, unclear or high following guidelines outlined in the Cochrane Collaboration's Risk of Bias tool (Higgins & Altman, 2008). ITT; Intention-to-treat

3.6.2.1 Outcome reporting bias. Risk of bias resulting from missing or incomplete outcome reporting was conducted using the ORBIT classification system (Kirkham et al., 2010). Firstly, reasons for exclusion were re-examined to identify whether any eligible studies were excluded because they did not measure or report the outcome of interest. On re-examination, those papers were excluded for not reporting the main outcome of interest (depression or anxiety) were not designed to target these outcomes; as such they would not be expected to collect or report results pertaining to these outcomes of interest and were not considered at risk of outcome reporting bias.

In total 14 studies stated within their protocols that they measured at least one outcome of interest (depression or anxiety) however insufficient data was presented to be included in meta-analysis. In 9 cases, despite at least two attempts at contacting authors or co-authors, the authors did not respond to requests for data (Baldwin, Kleeman, Stevens, & Rasin, 1989; Finkel et al., 2007; Goldberg & Wool, 1985; Grant, 1999; Grant, Elliott, Weaver, Bartolucci, & Giger, 2002; Hartford, Wong, & Zakaria, 2002; Kurz et al., 2010; Viney, Crooks, & Walker, 1995; Wright, Litaker, Laraoa, & DeAndrade, 2001). In 4 cases authors were contacted however the data was no longer available (Elliot & Berry, 2009; Marziali & Donahue, 2006; Sutcliffe & Lerner; Winter & Gitlin, 2006). In 1 case the missing data was obtained and the study was included within the review (Haley et al., 1987). In line with the ORBIT classification system (Kirkham et al., 2010) studies stating that an outcome was analysed but insufficient data was reported to be included within the analysis are rated at low risk of bias.

Secondly, included studies were checked to examine whether any did not report on the primary outcomes of interest. Of the 16 studies included within the review 10 targeted and measured only depression, 1 targeted and measured anxiety and 5 targeted and measured both anxiety and depression. In the case of 2 studies (Badger et al., 2007; Toseland et al., 2004) both depression and anxiety were measured however the anxiety outcomes were not included within the review due to being of poor quality. An outcome matrix was constructed for those papers that did not report one of the primary outcomes of interest (n= 11) and the ORBIT classification system was applied to each of these studies and can be found in Table 3.3. In the case of 2 studies (Badger et

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al., 2007; Toseland et al., 2004) both depression and anxiety were measured however the anxiety outcomes were not included within the review due to being of poor quality.

In all cases, papers were classified as 'I' meaning it was clear that the outcome was not measured (Dwan et al., 2010; Kirkham et al., 2010) and therefore at no risk of outcome reporting bias (Table 3.3). In these cases there was no evidence to suggest the missing outcome measure was evidence of suspicion of outcome reporting bias as the intervention was not designed to target the missing outcome and therefore would not be expected to be measured.

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Table 3.3

Risk of Outcome Reporting Bias

Study	Missing outcome	ORBIT classification	Level of risk	Explanation for classification
Agren et al., 2012	Anxiety	I	No Risk	The only target of the intervention was depression. Anxiety was not an outcome of interest and would not be expected to be measured
Akkerman & Ostwald, 2004	Depression	I	No Risk	The only target of the intervention was anxiety. Depression was not an outcome of interest and would not be expected to be measured
Au et al., 2010	Anxiety	I	No Risk	The only target of the intervention was depression. Anxiety was not an outcome of interest and would not be expected to be measured
Badger et al., 2011	Anxiety	I	No Risk	The only target of the intervention was depression. Anxiety was not an outcome of interest and would not be expected to be measured
Kuijer et al., 2004	Anxiety	I	No Risk	The only target of the intervention was depression. Anxiety was not an outcome of interest and would not be expected to be measured
Losada et al., 2010	Anxiety	I	No Risk	The only target of the intervention was depression. Anxiety was not an outcome of interest and would not be expected to be measured
Lovett & Gallagher, 1988	Anxiety	I	No Risk	The only target of the intervention was depression. Anxiety was not an outcome of interest and would not be expected to be measured

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Márquez-González et al., 2007	Anxiety	I	No Risk	The only target of the intervention was depression. Anxiety was not an outcome of interest and would not be expected to be measured
Marriott et al., 2000	Anxiety	I	No Risk	The only target of the intervention was depression. Anxiety was not an outcome of interest and would not be expected to be measured
Tremont et al., 2008	Anxiety	I	No Risk	The only target of the intervention was depression. Anxiety was not an outcome of interest and would not be expected to be measured
Haley et al., 1987	Anxiety	I	No Risk	The only target of the intervention was depression. Anxiety was not an outcome of interest and would not be expected to be measured

Note. Risk of outcome reporting bias was assessed as no, low or high following guidelines outlined in the ORBIT classification system for missing or incomplete outcome reporting (Kirkham et al., 2010).

3.6.3 Study Characteristics

A total of 1,268 informal carers were randomised and 1,070 analysed (at the longest follow-up time point up to and including 6 months) in the 16 studies included within the review. Due to 3 studies (López et al., 2007; Lovett & Gallagher, 1988; Hayley et al., 1987) including more than 1 intervention condition 19 comparisons were included in total. More detailed study characteristics are presented below with selected study characteristics can be found in Table 3.4.

3.6.3.1 Participant characteristics. Overall the informal carers included within the review cared for patients with the following chronic physical health conditions: dementia (7 studies, 8 comparators, $n = 354$); cancer (4 studies, $n = 242$); mixed chronic health conditions (4 studies, 6 comparators, $n = 319$) and chronic heart failure (1 study, $n = 155$). Overall 9 studies were conducted in North America (Akkerman & Ostwald, 2004; Badger et al., 2007; Badger et al., 2011; Hayley et al., 1987; Lovett & Gallagher, 1989; Smith & Toseland, 2006; Toseland et al., 2004; Toseland et al., 1995; Tremont et al., 2008); 6 in Europe (Argen, Evangelista, Hjelm, & Strömberg, 2012; Kuijer, Buunk, De Jong, Ybema, & Sanderman, 2004; López et al., 2007; Losada et al., 2010; Márquez-González et al., 2007; Marriott et al., 2000) and 1 study in Asia (Au et al., 2010). The mean age of informal carers ranged from 49 years (Kuijer et al., 2004) to 73 years (Argen et al., 2012) with a mean of 73% of carers included within the review being female. Total length of time caring was reported in 11 studies and ranged from a mean of 1.6 years (Kuijer et al., 2004) to 5.4 years (Toseland et al., 2004). Only 1 study (López et al., 2007) reported receipt of formal care in the home, with 48.4% of participants receiving formal care in the home. The ethnic background of informal carers was only reported in 6 studies (Akkerman & Ostwald, 2004; Badger et al., 2007; Badger et al., 2011; Toseland et al., 1995; Toseland et al., 2004; Smith et al., 2006). In 1 study the exact relationship of the carer to care recipient was not reported, however only family caregivers were eligible for inclusion (Akkerman & Ostwald, 2004). In 4 studies the intervention was aimed at spouses and partners (Argen et al., 2012; Kuijer et al., 2004; Toseland et al., 1995, 2004) and both spouses, partners and adult children in an additional 4 studies (Au et al., 2010; Hayley et al., 1987; Lovett & Gallagher, 1988; Tremont et al., 2008). In 1 further study both spouses,

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partners and adult children were included however data was only available for adult children carers (Smith & Toseland, 2006). The 6 remaining studies also included other carers such as more distant family members and friends (Badger et al., 2007, 2011; López et al., 2007; Losada et al., 2010; Márquez-González et al., 2007; Marriott et al., 2000). The mean age of the care recipients ranged from 49.0 years (Kuijjer et al., 2004) and 80.8 years (Losada et al., 2010). The sex of the care recipients was reported in seven studies with a mean of 53% being female (Agren et al., 2012; Badger et al., 2007, 2011; Marriott et al., 2000, López et al., 2007). Due to multiple physical health conditions included within the review and variety of outcome measures used to assess the severity of the physical health condition data pertaining to severity of the physical health condition is not reported. Similarly care recipient mental health status and chronic physical health comorbidities were rarely reported and therefore were not extracted.

The baseline severity of depressive and anxious symptoms in informal carers was calculated where possible. In total 15 studies (18 comparators) measured depressive symptoms and four 4 measuring symptoms of anxiety (5 comparators). Within 14 of the studies measuring depression (17 comparators) 3 different validated outcome measurements for depression were adopted: Beck Depression Inventory I & II (BDI; Beck, Ward, Mendelson, Mock & Erbaugh, 1961; BDI-II; (Beck, Steer, & Brown, 1996); Centre for Epidemiological Studies: Depression Scale (CES-D; Radloff, 1977) and the Geriatric Depression Scale (GDS; Yesavage et al., 1983). Across these measures standard clinical cut offs for each measure were adopted to determine categories of severity level (mild; moderate; moderately severe and severe) to enable subgroup analysis. The remaining 1 study measuring depression (Toseland et al., 2004) used a measurement without standard clinical cut offs and the General Health Questionnaire-Severe Depression subscale (GHQ-Severe Depression; Goldberg & Hillier, 1979) and therefore baseline severity of depression could not be calculated for this study. In relation to anxiety 2 studies (3 comparators) used outcome measurements whereby standard clinical cut offs are available (Akkerman & Ostwald, 2004; López et al., 2007). These studies adopted 3 different validated outcome measurements for anxiety: Beck Anxiety Inventory (BAI, Beck et al., 1988), Hamilton Anxiety

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Rating Scale (HAMA; Hamilton, 1959) and the Hospital Anxiety and Depression Scale: Anxiety Subscale (HADS-A, Zigmund & Snaith, 1983). The 2 remaining studies measuring anxiety (Smith & Toseland, 2006; Toseland et al., 1995) used the State-Trait Anxiety Inventory (STAI; Spielberger, Gorsuch, Lushene, Vagg, & Jacobs, 1983) which does not have clinical cut offs and therefore baseline severity of anxiety could not be calculated for these studies. In relation to depressive symptoms subclinical symptoms at baseline were found in 5 studies (7 comparisons, $n = 317$) (Agren et al., 2012; Haley et al., 1987; Lovett & Gallagher, 1988; Marriot et al., 2000; Tremont et al., 2008). Mild symptoms of depression at baseline were found in 5 studies (5 comparators, $n = 269$) (Au et al., 2010; Badger et al., 2007; 2011; Kuijer et al., 2010; Toseland et al., 1995). Finally, moderate levels of depressive symptoms at baseline were found in 4 studies (5 comparators, $n = 344$) (López et al., 2007; Losada et al., 2010; Márquez-González et al., 2007; Smith & Toseland, 2006). In regards to anxiety, these 2 studies recruited carers with mild levels of anxiety at baseline (3 comparators, $n = 126$). Finally, it should be noted that none of the studies included within the review required a diagnosis of depression or anxiety determined by a standardised clinician or researcher administered interview for inclusion into the study.

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Table 3.4

Study Characteristics of Included Studies

Study	Carer characteristics	Care recipient characteristics	n	Intervention characteristics	Control	Primary outcome (s)	Follow-up	Recruitment
Agren et al., 2012	<p><i>Age (years):</i> I:67; C:73 <i>% female:</i> I:69.1; C: 80.9 <i>Length of time caring (years):</i> N/A <i>Relationship to care recipient:</i> Spouse/Partner <i>Baseline depression:</i> None/Minimal <i>Baseline anxiety:</i> N/A</p>	<p><i>Age (years):</i> I:69; C:73 <i>% female:</i> I:30.9; C:19.1 <i>LTC:</i> Chronic Heart Failure</p>	155	<p><i>Theory:</i> CBT <i>Dyadic:</i> Yes <i>Delivery:</i> Individual <i>Support:</i> Face-to-face <i>Duration:</i> 12 weeks <i>No. of Sessions:</i> 3 <i>Length of Sessions:</i> 60 minutes <i>Total Length of Sessions:</i> 180 minutes <i>Setting:</i> Not reported <i>Clinician:</i> Nurse <i>Training:</i> Not reported <i>Manualised:</i> Not reported <i>Treatment Integrity:</i> Not reported</p>	TAU	Depression (BDI-II)	PT 12 Months	Clinical
Akkerman & Ostwald, 2004	<p><i>Age (years):</i> 58.1 <i>% female:</i> 86 <i>Length of time caring (years):</i> 3.57 <i>Relationship to care recipient:</i></p>	<p><i>Age (years):</i> Not reported <i>% female:</i> Not reported <i>LTC:</i> Dementia (Alzheimer's)</p>	38	<p><i>Theory:</i> CBT <i>Dyadic:</i> No <i>Delivery:</i> Group <i>Support:</i> Face-to-face <i>Duration:</i> 9 weeks <i>No. of Sessions:</i> Unclear <i>Length of Sessions:</i></p>	WLC	Anxiety (BAI) Anxiety (HAMA)	PT	Community

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	Not reported <i>Baseline depression:</i> N/A <i>Baseline anxiety:</i> Mild			120 minutes <i>Total Length of Sessions:</i> Unclear <i>Setting:</i> Not reported <i>Clinician:</i> PI <i>Training:</i> Not reported <i>Manualised:</i> Not reported <i>Treatment Integrity:</i> Yes				
Au et al., 2010	<i>Age (years):</i> I: 56.9; C: 51.6 <i>% female:</i> 100% <i>Length of time caring (years):</i> I: 2.5; C: 3.0 <i>Relationship to care recipient:</i> Unclear <i>Baseline depression:</i> Mild <i>Baseline anxiety:</i> N/A	<i>Age (years):</i> Not reported <i>% female:</i> Not reported <i>LTC:</i> Dementia (Alzheimer's)	37	<i>Theory:</i> CBT <i>Dyadic:</i> No <i>Delivery:</i> Group <i>Support:</i> Face-to-face <i>Duration:</i> 13 weeks <i>No. of Sessions:</i> 13 <i>Length of Sessions:</i> 120 minutes <i>Total Length of Sessions:</i> 1,560 minutes <i>Setting:</i> Not reported <i>Clinician:</i> Clinical Psychologist <i>Training:</i> Not reported <i>Manualised:</i> Yes <i>Treatment Integrity:</i> Yes	WLC	Depression (CES-D)	PT	Mixed
Badger et al., 2007	<i>Age (years):</i> 51.7	<i>Age (years):</i> 54.1	75	<i>Theory:</i> IPT <i>Dyadic:</i> No	ATC	Depression (CES-D)	PT 10	Mixed

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	<p><i>% female:</i> 26.0%</p> <p><i>Length of time caring (years):</i> Not reported</p> <p><i>Relationship to care recipient:</i> Husband: 63%; Partner: 14%; Daughter: 17% Friend: 3% Other: 3%</p> <p><i>Baseline depression:</i> Mild</p> <p><i>Baseline anxiety:</i> N/A</p>	<p><i>% female:</i> 100.0</p> <p><i>LTC:</i> Cancer (Breast)</p>		<p><i>Delivery:</i> Individual</p> <p><i>Support:</i> Telephone</p> <p><i>Duration:</i> 6 weeks</p> <p><i>No. of Sessions:</i> 3</p> <p><i>Length of Sessions:</i> 34 minutes</p> <p><i>Total Length of Sessions:</i> 102 minutes</p> <p><i>Setting:</i> Home</p> <p><i>Clinician:</i> Psychiatric Nurse Counsellor</p> <p><i>Training:</i> Yes</p> <p><i>Manualised:</i> Yes</p> <p><i>Treatment Integrity:</i> Yes</p>				weeks
Badger et al., 2011	<p><i>Age (years):</i> 61.1</p> <p><i>% female:</i> 92.9</p> <p><i>Length of time caring (years):</i> Not reported</p> <p><i>Relationship to care recipient:</i> Spouse/significant other: 82.9%; Sibling: 4.2%; Daughter: 1.4%; Son: 1.4%;</p>	<p><i>Age (years):</i> 66.9</p> <p><i>% female:</i> 0.0</p> <p><i>LTC:</i> Cancer (Prostate)</p>	71	<p><i>Theory:</i> IPT</p> <p><i>Dyadic:</i> No</p> <p><i>Delivery:</i> Individual</p> <p><i>Support:</i> Telephone</p> <p><i>Duration:</i> 8 weeks</p> <p><i>No. of Sessions:</i> 4</p> <p><i>Length of Sessions:</i> 31 minutes</p> <p><i>Total Length of Sessions:</i> 124 minutes</p> <p><i>Setting:</i> Home</p> <p><i>Clinician:</i> Nurse or social worker</p> <p><i>Training:</i> Yes</p>	ATC	Depression (CES-D)	PT 16 weeks	Mixed

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	Friend/other:10 % <i>Baseline depression: Mild</i> <i>Baseline anxiety: N/A</i>			<i>Manualised: Yes</i> <i>Treatment Integrity: Yes</i>				
Haley et al., 1987	<i>Age (years): 56</i> <i>% female: Not reported</i> <i>Length of time caring(years): Not reported</i> <i>Relationship to care recipient: Mainly wife or daughter, percentages not reported</i> <i>Baseline depression: None/Minimal</i> <i>Baseline anxiety: N/A</i>	<i>Age (years): 54</i> <i>78.3</i> <i>% female: Not reported</i> <i>LTC: Dementia</i>		<u>Psychosocial Support</u> <i>Theory: Psychosocial Support</i> <i>Dyadic: No</i> <i>Delivery: Group</i> <i>Support: Face-to-face</i> <i>Duration: 15 weeks</i> <i>No. of Sessions: 10</i> <i>Length of Sessions: 90 minutes</i> <i>Total Length of Sessions: 900 minutes</i> <i>Setting: Not reported</i> <i>Clinician: PI & Clinical Psychology Graduate Student</i> <i>Training: Not reported</i> <i>Manualised: Yes</i> <i>Treatment Integrity: Not reported</i>	WLC	Depression (BDI)	PT	Mixed
				<u>Psychosocial Support & CBT</u> <i>Theory: Psychosocial</i>				

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Support & CBT
Dyadic: No
Delivery: Group
Support: Face-to-face
Duration: 15 weeks
No. of Sessions: 10
Length of Sessions: 90 minutes
Total Length of Sessions: 900 minutes
Setting: Not reported
Clinician: PI & Clinical Psychology Graduate Student
Training: Not reported
Manualised: Yes
Treatment Integrity: Not reported

López et al., 2007	<i>Age (years):</i> 53.9 <i>% female:</i> 86.8 <i>Length of time caring(years):</i> 5.3 <i>Relationship to care recipient:</i> Spouse: 33%; Child: 60.4%; Other: 6.6% <i>Baseline</i>	<i>Age (years):</i> 77.3 <i>% female:</i> 69.2 <i>LTC:</i> Mixed	91	<u>Traditional</u> <i>Theory:</i> CBT <i>Dyadic:</i> No <i>Delivery:</i> Individual <i>Support:</i> Face-to-face <i>Duration:</i> 8 weeks <i>No. of Sessions:</i> 8 <i>Length of Sessions:</i> 60 minutes <i>Total Length of Sessions:</i> 480 minutes <i>Setting:</i> Not reported	WLC	Depression (BDI-II) Anxiety (HADS-A)	PT	Mixed
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depression:
Moderate
Baseline
anxiety: Mild

Clinician: Social workers; nurses; doctors; and psychologists.
Training: Not reported
Manualised: Yes
Treatment Integrity: Not reported

Minimal Contact

Theory: CBT
Dyadic: No
Delivery: Individual
Support: Face-to-face
Duration: 8 weeks
No. of Sessions: 6
Length of Sessions: 3 x 90 minutes, 3 x 10 minutes
Total Length of Sessions: 290 minutes
Setting: Not reported
Clinician: Social workers; nurses; doctors; and psychologists.
Training: Not reported
Manualised: Yes
Treatment Integrity: Not reported

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Losada et al., 2010	<p><i>Age (years):</i> I:60.6; C:59.4 <i>% female:</i> I:81.7; C:84 <i>Length of time caring(years):</i> I:4.2; C:5.1 <i>Relationship to care recipient:</i> Spouse: I:40.2%; C:29.3%; Parent: I: 53.8%; C:65.4%; Other relative: I:6%;C:5.3% <i>Baseline depression:</i> Moderate <i>Baseline anxiety:</i> N/A</p>	<p><i>Age (years):</i> I:77.5; C: 80.8 <i>% female:</i> Not reported <i>LTC:</i> Dementia</p>	167	<p><i>Theory:</i> CBT <i>Dyadic:</i> No <i>Delivery:</i> Group <i>Support:</i> Face-to-face <i>Duration:</i> 12 weeks <i>No. of Sessions:</i> 12 <i>Length of Sessions:</i> 120 minutes <i>Total Length of Sessions:</i> 1,440 minutes <i>Setting:</i> Not reported <i>Clinician:</i> Psychologist and OT as co-therapist <i>Training:</i> Not reported <i>Manualised:</i> Yes <i>Treatment Integrity:</i> Not reported</p>	WLC	Depression (CES-D)	PT	Mixed
Lovett & Gallagher, 1988	<p><i>Age (years):</i> 59.3 <i>% female:</i> 83 <i>Length of time caring (years):</i> 2.5 <i>Relationship to care</i></p>	<p><i>Age (years):</i> 73.6 <i>% female:</i> Not reported <i>LTC:</i> Mixed</p>	107	<p><u>Behavioural Therapy</u> <i>Theory:</i> Behavioural <i>Dyadic:</i> No <i>Delivery:</i> Group <i>Support:</i> Face-to-face <i>Duration:</i> 10 weeks <i>No. of Sessions:</i> 10</p>	WLC	Depression (BDI)	PT	Community

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recipient:
Spouse: 55%;
Son/daughter/in
-law: 41%
Baseline
depression:
None/Minimal
Baseline
anxiety: N/A

Length of Sessions:
120 minutes
Total Length of
Sessions: 1,200
minutes
Setting: Not reported
Clinician: Pre or
postdoctoral
psychologists
Training: Not reported
Manualised: Yes
Treatment Integrity:
Not reported

Problem Solving
Theory: Problem
Solving
Dyadic: No
Delivery: Group
Support: Face-to-face
Duration: 10 weeks
No. of Sessions: 10
Length of Sessions:
120 minutes
Total Length of
Sessions: 1,200
minutes
Setting: Not reported
Clinician: Pre or
postdoctoral

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				psychologists <i>Training:</i> Not reported <i>Manualised:</i> Yes <i>Treatment Integrity:</i> Not reported				
Márquez-González et al., 2007	<i>Age (years):</i> I:58.1; C: 55.4 <i>% female:</i> 84.6 <i>Length of time caring(years):</i> 4.0 <i>Relationship to care recipient:</i> Spouse: 51.4%; Son: 40.0%; Other relative 8.6% <i>Baseline depression:</i> Moderate <i>Baseline anxiety:</i> N/A	<i>Age (years):</i> Not reported <i>% female:</i> Not reported <i>LTC:</i> Dementia	74	<i>Theory:</i> CBT <i>Dyadic:</i> No <i>Delivery:</i> Group <i>Support:</i> Face-to-face <i>Duration:</i> 8 weeks <i>No. of Sessions:</i> 8 <i>Length of Sessions:</i> 120 minutes <i>Total Length of Sessions:</i> 960 minutes <i>Setting:</i> Not reported <i>Clinician:</i> Psychologist <i>Training:</i> Not reported <i>Manualised:</i> Yes <i>Treatment Integrity:</i> Not reported	WLC	Depression (CES-D)	PT	Mixed
Kuijter et al., 2004	<i>Age (years):</i> I: 49.0); C:50.0 <i>% female:</i> I: 30.0; C: 32.0 <i>Length of time caring (years):</i> I: 1.6; C: 3.7 <i>Relationship to</i>	<i>Age (years):</i> I: 50.0; C: 49.0 <i>% female:</i> I: 70.0; C:68.0 <i>LTC:</i> Cancer (Mixed)	59	<i>Theory:</i> CBT <i>Dyadic:</i> Yes <i>Delivery:</i> Individual <i>Support:</i> Face-to-face <i>Duration:</i> 10 weeks <i>No. of Sessions:</i> 5 <i>Length of Sessions:</i> 90 minutes	WLC	Depression (CES-D)	PT	Mixed

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	<i>care recipient:</i> Spouse/Partner <i>Baseline</i> <i>depression:</i> Mild <i>Baseline</i> <i>anxiety:</i> N/A			<i>Total Length of</i> <i>Sessions:</i> 450 minutes <i>Setting:</i> Not reported <i>Clinician:</i> Psychologist <i>Training:</i> Not reported <i>Manualised:</i> Not reported <i>Treatment Integrity:</i> Not reported				
Marriott et al., 2000	<i>Age (years):</i> I:69.6; C:58.1 <i>% female:</i> I:64%; C:79% <i>Length of time caring (years):</i> I: 3.7; C:2.6 <i>Relationship to care recipient:</i> I: Spouse: 64.3%; Child: 21.4%; Sibling 14.3% C: Spouse 35.7%; Child: 57.1%; Sibling: 7.1% <i>Baseline depression:</i> (None/minimal) <i>Baseline anxiety:</i> N/A	<i>Age (years):</i> I: 28 76.6; C:77.7 <i>% female:</i> I: 71.0; C: 71.0 <i>LTC:</i> Dementia (Alzheimer's)	28	<i>Theory:</i> CBT <i>Dyadic:</i> Yes <i>Delivery:</i> Individual <i>Support:</i> Face-to-face <i>Duration:</i> 28 weeks <i>No. of Sessions:</i> 14 <i>Length of Sessions:</i> Unclear <i>Total Length of Sessions:</i> Unclear <i>Setting:</i> Not reported <i>Clinician:</i> Co-author <i>Training:</i> Not reported <i>Manualised:</i> Yes <i>Treatment Integrity:</i> Not reported	TAU	Depression (BDI)	PT 12 months	Clinical

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Smith & Toseland, 2006	<p><i>Age (years):</i> I: 54.0; C:54.9 <i>% female:</i> I: 77.4; C:96.7 <i>Length of time caring (years):</i>Not reported <i>Relationship to care recipient:</i> Child: 100.0% <i>Baseline depression:</i> <i>Baseline anxiety:</i></p>	<p><i>Age (years):</i> Not reported <i>% female:</i> Not reported <i>LTC:</i> Mixed</p>	61	<p><i>Theory:</i> Psychoeducation <i>Dyadic:</i> No <i>Delivery:</i> Group <i>Support:</i> Telephone <i>Duration:</i> 12 weeks <i>No. of Sessions:</i> 12 <i>Length of Sessions:</i> 90 minutes <i>Total Length of Sessions:</i> 1,080 minutes <i>Setting:</i> Home <i>Clinician:</i> Social worker <i>Training:</i> Yes <i>Manualised:</i> Yes <i>Treatment Integrity:</i> Yes</p>	WLC	<p>Depression (CES-D) Anxiety (STAI)</p>	PT	Mixed
Toseland et al., 2004	<p><i>Age (years):</i> I: 68.7; C:69.9 <i>% female:</i> I:66.7; C:70.8 <i>Length of time caring (years):</i> I: 4.5; C: 5.4 <i>Relationship to care recipient:</i> Spouse</p>	<p><i>Age (years):</i> I: 72.8; C: 72.5 <i>% female:</i> I: 27.5; C: 33.9 <i>LTC:</i> Mixed</p>	I: 105	<p><i>Theory:</i> Psychoeducation <i>Dyadic:</i> No <i>Delivery:</i> Group <i>Support:</i> Face-to-face <i>Duration:</i> 12 months <i>No. of Sessions:</i> 18 <i>Length of Sessions:</i> 120 minutes <i>Total Length of</i></p>	TAU	<p>GHQ- Severe Depression</p>	PT	Clinical

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	<i>Baseline depression: N/A</i>			<i>Sessions: 2,160 minutes</i>				
	<i>Baseline anxiety: N/A</i>			<i>Setting: Not reported</i>				
				<i>Clinician: Social Workers</i>				
				<i>Training: Yes</i>				
				<i>Manualised: Yes</i>				
				<i>Treatment Integrity: Yes</i>				
Toseland et al., 1995;	<i>Age (years): I: 56.0; C:51.0</i>	<i>Age (years): I:56.0; C:51.0</i>	86	<i>Theory: Problem Solving</i>	TAU	Depression (CES-D)	PT 6 months	Clinical
Blanchard et al., 1996	<i>% female: I:56.0; C:51.0</i>	<i>% female: Not reported</i>		<i>Dyadic: No</i>		Anxiety (STAI)		
	<i>Length of time caring(year): I:1.7; C:2.3</i>	<i>LTC: Cancer (Mixed)</i>		<i>Delivery: Individual Support. Face-to-face</i>				
	<i>Relationship to care recipient: Spouse: 100.0%</i>			<i>Duration: 6 weeks</i>				
	<i>Baseline depression: Mild</i>			<i>No. of Sessions: 6</i>				
	<i>Baseline anxiety: N/A</i>			<i>Length of Sessions: 60 minutes</i>				
				<i>Total Length of Sessions: 360 minutes</i>				
				<i>Setting: Not reported</i>				
				<i>Clinician: Oncology social worker</i>				
				<i>Training: Not reported</i>				
				<i>Manualised: Yes</i>				
				<i>Treatment Integrity: Yes</i>				
Tremont et al., 2008	<i>Age (years): I: 65.8; C: 61.0</i>	<i>Age (years): I:75.9; C:75.3</i>	60	<i>Theory: Family Treatment Model</i>	TAU	Depression (GDS)	PT	Mixed
	<i>% female: Not</i>	<i>% female: LTC:</i>		<i>Dyadic: No</i>				

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<p>reported <i>Length of time caring(years) :</i> I: 4.0; C:3.4 <i>Relationship to care recipient:</i> Not reported <i>Baseline depression:</i> None/Minimal <i>Baseline anxiety:</i> N/A</p>	<p>Dementia</p>	<p><i>Delivery:</i> Individual <i>Support:</i> Telephone <i>Duration:</i> 52 weeks <i>No. of Sessions:</i> 23 <i>Length of Sessions:</i> 1 x 60 minutes; 22 x 15-30 minutes. <i>Total Length of Sessions:</i> 720 minutes <i>Setting:</i> Home <i>Clinician:</i> Master's level therapists <i>Training:</i> Yes <i>Manualised:</i> Yes <i>Treatment Integrity:</i> Yes</p>
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Note. Carer Characteristics: I = intervention; C = control; baseline depression or anxiety only reported when depression and / or anxiety is a primary outcome and outcome measurements used have validated clinical cut off scores; Care Recipient Characteristics: LTC = Long-term condition; N: Number randomised, based on all participants randomised to treatment and control groups included within the review, therefore may differ from sample sizes included in the meta-analysis if ITT analysis not conducted and published numbers randomised if not all conditions within the paper were eligible for inclusion within the review; Intervention Characteristics: CBT = Cognitive Behavioural Therapy; IPT = Interpersonal Psychotherapy; Control: TAU = Treatment-as-usual; WLC = Waiting list control; ATC = Attention control; Primary Outcomes(s): BDI/BDI-II = Beck Depression Inventory; BAI = Beck Anxiety Inventory; HAMA = Hamilton Anxiety Rating Scale; CES-D = Center for Epidemiological Studies-Depression; HADS-A = Hospital Anxiety and Depression Scale – Anxiety subscale; STAI = State-Trait Anxiety Inventory; GHQ-Severe Depression = General Health Questionnaire – Severe Depression Subscale; GDS = Geriatric Depression Scale; Follow-up: PT = Post-treatment.

3.6.3.2 Intervention characteristics. In total, 12 included studies targeted only depression (14 comparisons, $n = 817$), a further 1 study only targeted anxiety ($n = 35$) and 3 studies targeted both depression and anxiety (4 comparisons, $n = 218$). A large number of studies ($n = 66$) were excluded as they targeted broader concepts such as caregiver burden, quality of life and general psychological distress and did not target or measure depression or anxiety. Furthermore, 32 studies measured depression or anxiety but considered potential reductions of these symptoms to be an indirect effect of the intervention. Within this review we were only interested in psychological or psychological interventions that targeted depression or anxiety

In total only 4 of the study authors provided full details of the treatment protocols in English relating to interventions used in 6 studies (Badger et al., 2007; 2011; Hayley et al., 1987; Toseland et al., 1995, 2004; Tremont et al., 2008). A further 2 treatment protocols were provided in Spanish (Losada et al., 2010; Márquez-González et al., 2007). Given the small number of studies included within the review ($n = 16$) and only 4 treatment manuals being provided in English it was not possible to extract behaviour change techniques utilised within all studies using the taxonomy of 137 behaviour change techniques (Michie, Johnston, Francis, Hardeman, & Eccles, 2008).

The theoretical approach underpinning the included interventions was predominantly based on CBT with 8 studies (9 comparators; $n = 565$) being explicitly CBT interventions. Other studies were based on techniques often used within a CBT approach such as problem solving (2 studies; $n = 96$); behavioural therapy (1 study, $n = 33$) and psychoeducation teaching CBT techniques (2 studies, $n = 166$). Only 1 study compared 2 psychosocial support groups with a waiting list control condition (Haley et al., 1987) with 1 group explicitly teaching CBT based skills and 1 group without (1 study, 2 comparators; $n = 41$). Only 3 studies used a different theoretical framework to CBT with two studies (Badger et al., 2007; 2011) using Interpersonal Psychotherapy ($n = 138$) and 1 study (Tremont et al., 2008) based on Family Systems Therapy ($n = 33$). Table 3.5 provides more detailed information pertaining to the theoretical approach underpinning each intervention and any additional conceptual frameworks listed informing treatment, along with the specific treatment components utilised in each treatment. In summary, mental

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health psychoeducation was commonly listed as an intervention component (15 studies; 18 comparators) and physical health psychoeducation relating to the physical health condition of the care recipient was also commonly included within treatments (11 studies, 13 comparators). Commonly included therapeutic techniques were problem solving (10 studies; 12 comparators); cognitive restructuring (10 studies, 11 comparators); stress management techniques (8 studies; 9 comparators) and activity scheduling (7 studies; 8 comparators). Additional modules commonly included pertained to providing carers with techniques to increase both social and professional support (12 studies; 14 comparators) and improving communication (9 studies; 11 comparators)

Overall, 13 studies were delivered to the carer individually (16 comparators, $n = 850$) and 3 studies were dyadic (3 comparators, $n = 220$). In total 8 studies were delivered to carers in one-to-one sessions with the therapist (9 comparisons, $n = 548$) and 8 studies used group based treatments (10 comparisons, $n = 522$). Mode of delivery included face-to-face (12 studies, 15 comparisons, $n = 838$) and telephone (4 studies, $n = 232$). Treatments were delivered over 6 weeks to 52 weeks with a mean of 16 weeks. The number of sessions ranged from 3 to 23 sessions with a mean of 9.7 sessions. Individual session duration ranged from 10 minutes to 120 minutes resulting in a total session duration over the course of treatment ranging from 102 minutes to 2,160 minutes (36 hours) with a mean of 830 minutes (13.8 hours).

The clinicians delivering the interventions varied from nurses (2 studies, $n = 233$); social workers (3 studies, $n = 232$); psychologists (6 studies, 7 comparators, $n = 352$); the Principal Investigator or co-author (3 studies, 4 comparators, $n = 102$) and studies using a mixture of healthcare professionals (2 studies, 3 comparators, $n = 161$). The setting of treatment delivery was rarely explicitly reported within studies, with the 4 studies reporting treatment setting delivering treatment in the carers' homes ($n = 232$). Training of those delivering the intervention was also only reported in 5 studies ($n = 337$) and only 8 studies measured treatment fidelity ($n = 465$). The majority of studies however did specify following a treatment manual or protocol (13 studies, 16 comparators, $n = 842$).

Interventions were compared to waiting-list control (9 studies, 12 comparators, $n = 546$), treatment-as-usual (5 studies, $n = 386$) and attention

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control (2 studies, $n = 138$) with patients recruited from community (2 studies, 3 comparators, $n = 97$), clinical (4 studies, $n = 353$) and mixed clinical and community settings (10 studies, 12 comparators, $n = 620$). No clinical diagnosis of depression or anxiety was required in informal carers for inclusion in the studies. It should be noted that 23 studies were excluded from the review for using inappropriate comparator conditions containing active ingredients.

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Table 3.5

Main Theoretical and Conceptual Components and Specific Treatment Components Utilised in Interventions

Study	Theoretical approach	Additional conceptual framework	Specific treatment components
Agren et al., 2012	CBT	Health Promotion Model (Pender, Walker, Sechrist, & Stromborg, 1988); Self-efficacy (Bandura, 1977)	Problem solving; cognitive restructuring; physical health condition psychoeducation; mental health psychoeducation; increasing social and professional support; lifestyle changes; communication techniques; role changes and transitions.
Akkerman & Ostwald, 2004	CBT		Stress management techniques including relaxation
Au et al., 2010	CBT		Problem solving; cognitive restructuring; physical health condition psychoeducation; mental health psychoeducation; stress management techniques including relaxation; activity scheduling; behavioural modification (dementia specific behaviours); increasing social and professional support; communication techniques.
Badger et al., 2007	IPT		Physical health condition psychoeducation; mental health psychoeducation; activity scheduling; increasing social and professional support; communication techniques; role changes and transitions. Focus on the four key relationship issues of grief, interpersonal role disputes, role transitions, and interpersonal deficits.

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Badger et al., 2011	IPT		Physical health condition psychoeducation; mental health psychoeducation; activity scheduling; increasing social and professional support; communication techniques; role changes and transitions. Focus on the four key relationship issues of grief, interpersonal role disputes, role transitions, and interpersonal deficits.
Kuijer et al., 2004	CBT	Perspective of equity theory (Walster, Walster, & Berscheid (1978))	Cognitive restructuring; perspective taking; physical health condition psychoeducation; mental health psychoeducation; increasing social and professional support; role changes / transitions.
Lopez et al., 2007	CBT	Transactional Theory Stress and Coping (Lazarus & Folkman, 1987)	Problem solving, cognitive restructuring; physical health condition psychoeducation; mental health psychoeducation; stress management techniques including relaxation; activity scheduling; increasing social and professional support; communication techniques.
Losada et al., 2010	CBT		Cognitive restructuring; mental health specific psychoeducation; activity scheduling; increasing social and professional support; exercise.
Lovett & Gallagher, 1988 (Problem Solving)	Problem Solving	Self-efficacy (Bandura, 1977)	Problem solving; mental health specific psychoeducation
Lovett & Gallagher, 1998 (Behavioural Activation)	Behavioural Activation	Self-efficacy (Bandura, 1977)	Mental health specific psychoeducation; activity scheduling; goal setting
Márquez-González et al., 2007	CBT		Problem solving; cognitive restructuring; mental health specific psychoeducation; stress management techniques including relaxation; activity scheduling; increasing social and professional support.

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Marriott et al., 2000	CBT		Physical health condition psychoeducation; mental health psychoeducation; stress management techniques including relaxation.
Smith & Toseland, 2006	Psychoeducation	Transactional Theory Stress and Coping (Lazarus & Folkman, 1987)	Problem solving; cognitive restructuring; perspective taking; physical health condition psychoeducation; mental health psychoeducation; stress management techniques included relaxation and guided imagery; increasing social and professional support; life style changes; communication techniques.
Toseland et al., 1995; Blanchard et al., 1996	Problem Solving		Problem solving; mental health psychoeducation.
Tremont et al., 2008	Family Systems Therapy	Psychosocial Transition (Tyhurst, 1958); Transactional Theory Stress and Coping (Lazarus & Folkman, 1987)	Problem solving; cognitive restructuring; reframing; physical health specific psychoeducation; mental health specific psychoeducation; behavioural modification (dementia specific behaviours); goal setting; increasing social and professional support; communication techniques; role changes/transitions.
Toseland et al., 2004	Psychoeducation	Transactional Theory Stress and Coping (Lazarus & Folkman, 1987)	Problem solving; cognitive restructuring; perspective taking; stress management techniques including relaxation and guided imagery; physical health specific psychoeducation; mental health specific psychoeducation; increasing social and professional support; life style changes; communication techniques.
Haley et al., 1987 (Psychosocial support)	Psychosocial support		Problem solving; physical health specific psychoeducation; mental health specific psychoeducation; behavioural modification (dementia specific behaviours); increasing social and professional support; life style changes;

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communication techniques.

Haley et al., 1987 (Psychosocial support plus CBT)

Psychosocial support plus CBT

Problem solving; cognitive restructuring; physical health specific psychoeducation; mental health specific psychoeducation; stress management techniques including relaxation; behavioural modification (dementia specific behaviours); increasing social and professional support; life style changes; communication techniques.

Note. CBT = Cognitive behavioural therapy; IPT = Interpersonal psychotherapy.

3.6.3.3 Outcome measurements. Only outcome measurements of depression or anxiety with at least acceptable internal consistency and test-retest reliability (Cronbach's $\alpha \geq 0.70$) were included within the review (Fitzpatrick, Davey, Buxton, & Jones, 1998). Only 3 studies were excluded on the basis of utilising inadequate measures of depression and or anxiety. One study included within the review (Badger et al., 2007) targeted both depression and anxiety. However this study also used an unvalidated measure of anxiety and therefore only depression outcomes were examined within this review. One study (Toseland et al., 2004) used the GHQ-28 (Goldberg & Hillier, 1979) and reported outcomes on the Severe Depression and Anxiety/Insomnia subscales. In the case of this study, only the GHQ-Severe Depression subscale was used in the meta-analysis as it has good convergent and divergent validity as both a categorical and dimensional measure of depression (Koeter et al., 1992). The Anxiety/Insomnia subscale was not included within the meta-analysis due to having no convergent or divergent validity as a categorical or dimensional measure of anxiety (Koeter et al., 1992). Outcome measurements utilised within the study and their internal consistency and test-retest reliability levels can be seen in Table 3.6.

In the 15 studies measuring depression the CES-D (Radloff, 1977) was used the most frequently (8 studies, $n = 522$) followed by the BDI (Beck et al., 1961) and BDI-II (Becket al., 1996) (5 studies, 8 comparators, $n = 375$). Additional depression measures included the GDS (Yesavage et al., 1983) (1 study, $n=33$) and the GHQ-Severe Depression subscale (Goldberg & Hillier, 1979) (1 study, $n = 105$). In relation to the 4 studies examining anxiety 1 study (Akkerman & Otswald, 2004) used both the BAI (Beck et al., 1988) and the HAMA (Hamilton, 1959) ($n = 35$). Additional studies used the HADS-A (Zigmond & Snaith, 1983) (1 study, 2 comparators, $n=91$) and the STAI (Spielberger et al., 1983) (2 studies, $n = 127$).

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Table 3.6

Quality of Outcome Measurements used in Included Studies

Outcome measurement	Number of studies	Internal consistency (Cronbach's alpha)	Test-retest reliability (Cronbach's alpha)
BAI	1	0.92 (Steer, Ranieri, Beck, & Clark, 1993)	0.75 (Beck, Epstein, Brown, & Steer, 1988)
BDI/BDI-II	5	0.79–0.90 (Beck, Steer, & Garbin, 1988)	0.93 (Beck, Steer, & Garbin, 1988)
CES-D	8	0.88 (Knight, Williams, McGee, & Olanan, 1997)	0.87 (Miller et al., 2008)
GDS	1	0.94 (Yesavage et al., 1983)	0.85 (Yesavage et al., 1983)
GHQ – Severe Depression	1	0.87 (Goldberg & Hillier, 1979)	0.85 (Vallejo, Jordán, Díaz, Comeche, & Ortega, 2007)
HADS-A	1	0.78–0.93 (Bjelland, Dahl, Haut, & Neckelmann, 2002)	0.89 (Spinoven et al., 1997)
HAMA	1	0.74 (Maier, Buller, Philipp, & Heuser, 1988)	0.97 (Kobak, Greist, Jefferson, Mundt, & Katzelnick, 1999)
STAI-State	2	0.81-0.95 (McDowell, 2006)	0.69-0.76 (McDowell, 2006)

Note. Outcome Measurement: BAI = Beck Anxiety Inventory; BDI = Beck Depression Inventory; CES-D = Center for Epidemiologic Studies-Depression Scale; GDS = Geriatric Depression Scale = GHQ-Severe Depression = General Health Questionnaire – Severe Depression subscale; HADS-A = Hospital Anxiety and Depression Scale – Anxiety; HAMA = Hamilton Anxiety Rating Scale; STAI-State = State-Trait Anxiety Inventory – State subscale.

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In regards to secondary outcomes of interest 6 studies measured carer burden using the Caregiver Burden Scale (CBS; Elmståhl, Malmberg, & Annerstedt, 1996) (1 study, $n = 137$); the Zarit Burden Interview (ZBI; Zarit, Reever, & Bach-Peterson, 1980) (4 studies, 5 comparators, $n = 251$) and the Montgomery Borgatta Caregiver Burden Scale (MBBS; Montgomery, Stull, & Borgatta, 1985) (1 study, $n = 105$). Only 3 studies included within the review examined quality of life using the Short Form (36) Health Survey (SF-36; Ware & Sherbourne, 1992) (2 studies, $n = 260$) and the Short From (20) Health Survey (Stewart, Hays & Ware, 1988) (1 study, $n = 66$).

All studies took outcome measurements immediately post-treatment (16 studies, 19 comparators, $n = 1,082$), with additional time points of 10 weeks post-treatment (1 study; $n = 68$); 4 months post-treatment (1 study, $n = 70$); 6 months post-treatment (1 study, $n = 66$) and 12 months post-treatment (2 studies, $n = 182$).

3.6.4 Meta-Analysis

On 3 occasions (Haley et al., 1987; Lopez et al., 2007; Lovett & Gallagher, 1988) studies reported 2 active interventions compared with 1 control condition. In these cases comparisons were analysed separately with the sample size within the control condition halved. In addition, in 1 study (Smith & Toseland, 2006) both adult child and spousal carers received the intervention however results were only reported in the paper for adult child carers. Study authors were contacted to try and obtain the data for spousal carers however the data was no longer available. As such, only data reported for adult child carers was included within the meta-analysis. The main meta-analysis is conducted on time points less than or equal to 6 months. Only post-treatment outcome measurements were analysed in this meta-analysis. Forest plots presenting effect sizes and 95% CIs are presented for the primary outcome measurements of depression and anxiety in Figure 3.2, 3.3 and 3.4.

3.6.4.1 Analysis by informal carer depressive symptoms. Although heterogeneity was expected analysis of heterogeneity was non-significant ($p = .08$, $Q = 11.45$, $I^2 = 0.00$) reflecting no heterogeneity. As such a fixed effect model was adopted for analysis. Studies targeting depression (15 studies, 18 comparators, $n = 1,035$) yielded a small-to-moderate effect size (Hedges' $g = -$

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0.30, 95% CI [-0.42, -0.17]) in comparison to the control using the fixed effects model (see Figure 3.2 for effect sizes and 95% CIs).

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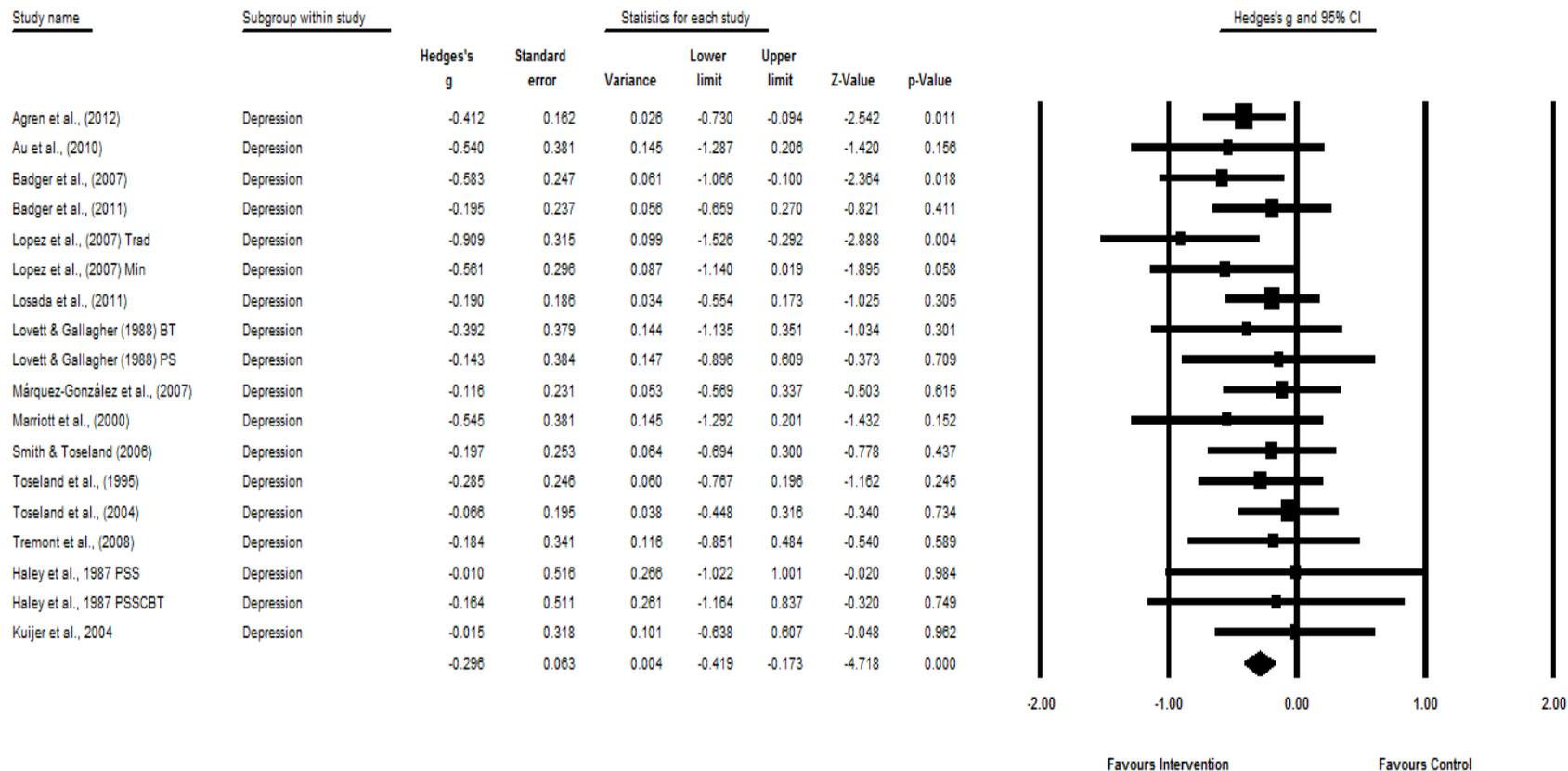


Figure 3.2. Effect sizes (Hedges' g) and 95% confidence intervals (Cis) for interventions targeting depression.

3.6.4.2 Analysis by informal carer anxiety symptoms. In the case of 1 study (Akkerman & Ostwald, 2004) both the Beck Anxiety Inventory (BAI) and Hamilton Anxiety Rating Scale (HAMA) were adopted as primary outcome measurements of anxiety symptoms. As such the meta-analysis was conducted with each outcome measurement separately.

BAI: When adopting of the BAI outcomes for Akkerman & Ostwald (2004) analysis of heterogeneity was non-significant ($p = .28$, $Q = 5.03$, $I^2 = 20.45$) reflecting low heterogeneity, as such a fixed effect model was adopted for analysis. In comparison to the control conditions employed across studies targeting anxiety (4 studies, 5 comparators, $n = 253$) a medium-to-large effect size was yielded (Hedges' $g = -0.71$, 95% CI [-0.96, -0.45]). Effect sizes and 95% CIs of the studies are plotted in Figure 3.3.

HAMA: When adopting the HAMA outcomes for Akkerman & Ostwald (2004) heterogeneity was larger, but remained non-significant ($p = .15$, $Q = 6.83$, $df = 4$, $I^2 = 41.44$) resulted in a medium-to-large effect size (Hedges' $g = -0.75$, 95% CI [-1.01, -0.50]). The effect sizes and 95% CIs of the studies are plotted in Figure 3.4.

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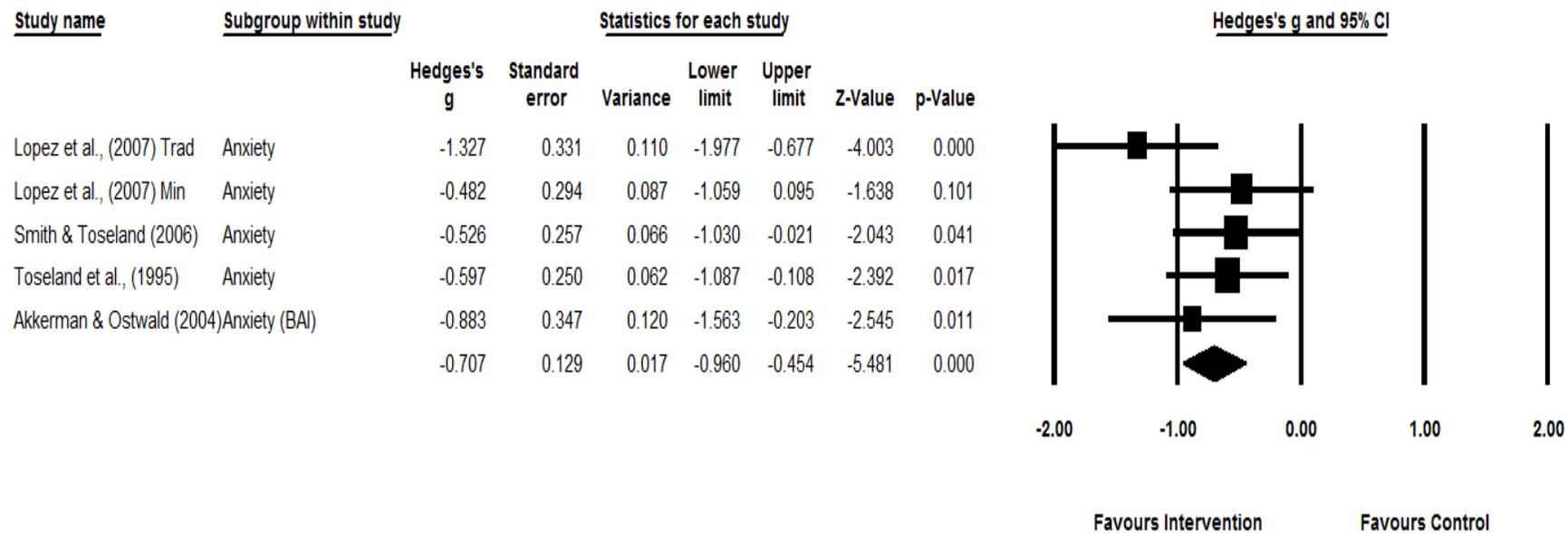


Figure 3.3. Effect sizes (Hedges' g) and 95% confidence intervals (Cis) for interventions targeting anxiety (BAI selected for Akkerman & Ostwald, 2004).

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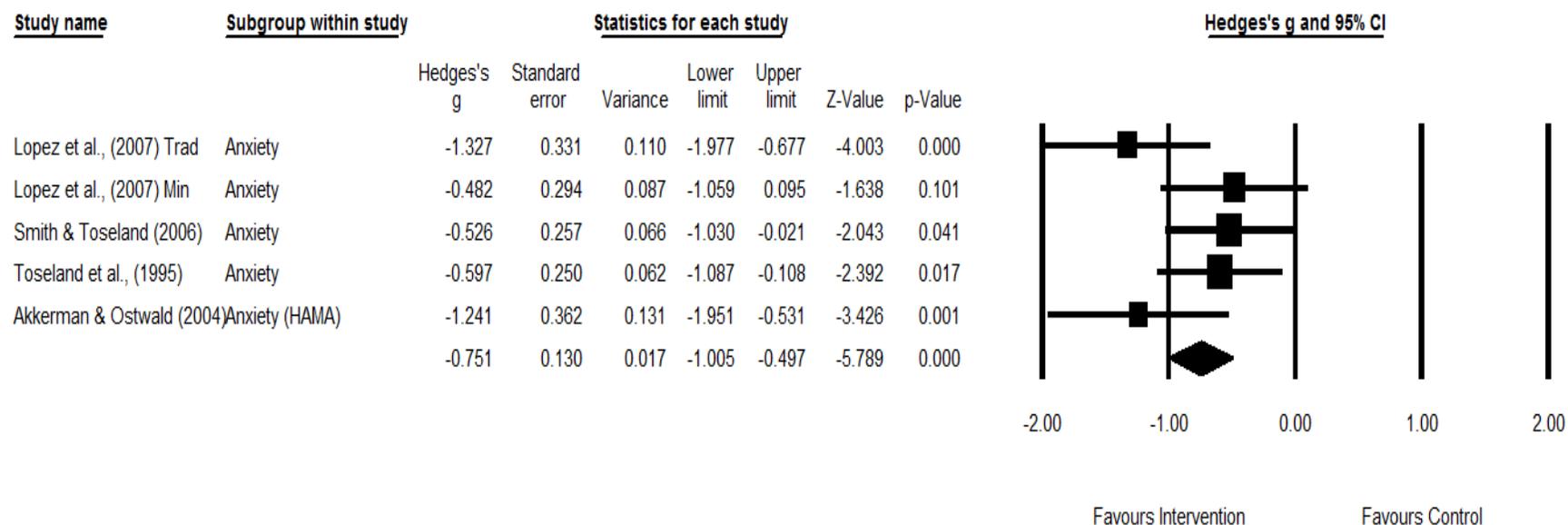


Figure 3.4. Effect sizes (Hedges' g) and 95% confidence intervals (Cis) for interventions targeting anxiety (HAMA selected for Akkerman & Ostwald, 2004).

3.6.4.3 Analysis by informal carer burden. One study (Toseland et al., 2004) adopted the Montgomery Borgatta Caregiver Burden Scale (MBBS) to measure carer burden, reporting the objective and subjective burden subscales separately. As such, the meta-analysis was conducted using each subscale separately.

MBBS-Objective Subscale: Analysis of was non-significant ($p = .55$, $Q = 4.92$, $I^2 = 0.00$) reflecting no heterogeneity. In comparison to the control conditions employed across studies measuring carer burden (6 studies, 7 comparators, $n = 493$) fixed effect meta-analysis resulted in a small effect size (Hedges' $g = -0.28$, 95% CI [-0.46, -0.10]).

MBBS-Subjective Subscale: Analysis of heterogeneity also non-significant ($p = .65$, $Q = 4.31$, $df = 6$, $I^2 = 0.00$), again reflecting no heterogeneity. The fixed effect meta-analysis resulted in a small effect size (Hedges' $g = -0.23$, 95% CI [-0.41, -0.05]).

3.6.4.4 Analysis by informal carer quality of life. Mental health and physical health component scores were reported in the 3 studies measuring carer quality of life (Argen et al., 2012; Toseland et al 1995; 2004). The meta-analysis was conducted using each component score separately.

Mental Health Component Scores: Analysis of heterogeneity was non-significant ($p = .71$, $Q = 0.65$, $df = 2$, $I^2 = 0.00$). In comparison to the control conditions employed across studies measuring carer quality of life (3 studies, $n = 326$) fixed effect meta-analysis resulted in a small effect size (Hedges' $g = -0.23$, 95% CI [-0.45, -0.01]).

Physical Health Component Scores: Analysis of heterogeneity was non-significant ($p = .17$; $Q = 3.56$, $df = 2$, $I^2 = 43.66$). Fixed effect meta-analysis resulted in a medium effect size (Hedges' $g = -0.44$, 95% CI [-0.74, -0.14]).

3.6.4.5 Publication bias. Egger's Test of the Intercept (Egger et al., 1997) was conducted to examine funnel plot asymmetry to investigate possible publication bias and other potential sources of asymmetry. A minimum of 10 studies are needed to be included within the meta-analysis for Egger's Test of the Intercept to be conducted (Sterne et al., 2000) therefore the test was conducted for those studies examining depressive symptoms only. Publication bias was not evident for depression ($\beta = -0.27$, $SE = 0.65$, $p = .69$) with Duval and Tweedie's trim and fill method (Duval & Tweedie) suggesting no studies to be missing to the right of the

mean. See Figure 3.5 for the Funnel Plot relating to outcome measurements of depression. Rosenthal's fail safe N (Rosenthal, 1979) was also conducted to estimate how many negative studies would need to be included to increase the p -value to above 0.05. Rosenthal's fail safe N indicated that an additional 82 studies with no effect were needed to result in a non-significant effect for depression and 37 additional studies with no effect to result in a non-significant effect for anxiety.

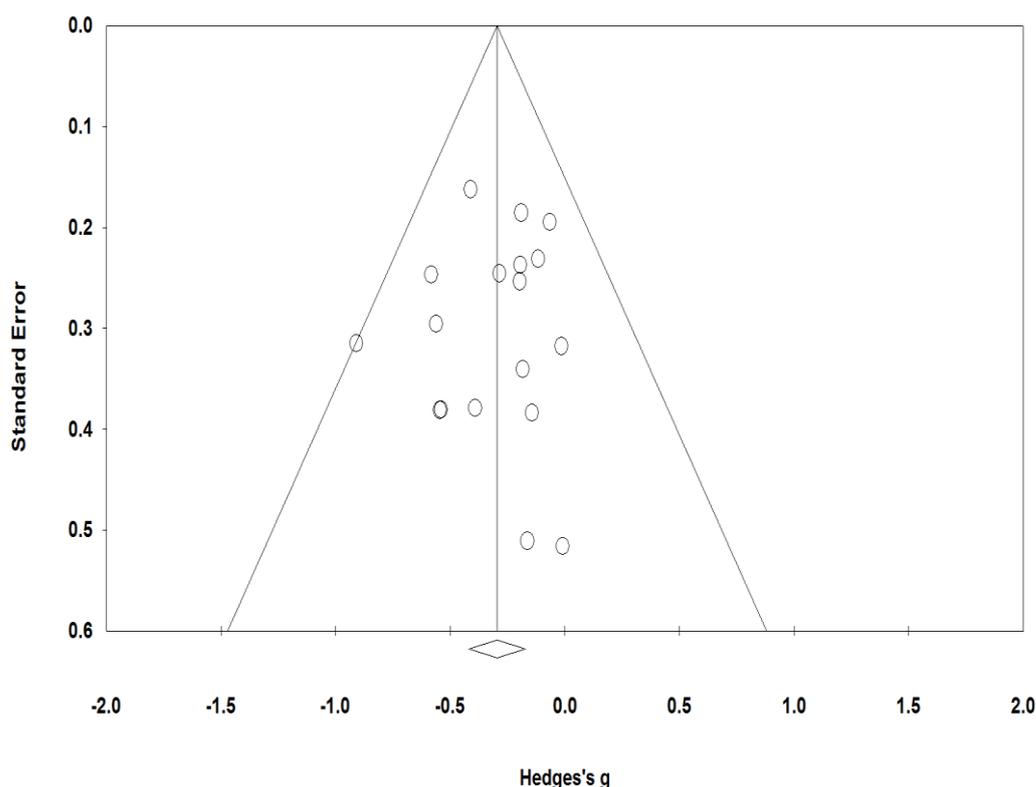


Figure 3.5. Funnel plot for interventions targeting depression

3.6.4.6 Sensitivity analysis. Maximum bias bound approach (Copas & Jackson, 2004; Dwan et al., 2010; Kirkham et al., 2010; Williamson & Gamble, 2007) was planned to examine the robustness of the original findings taking into account the potential for outcome reporting bias within the review. However, no studies were rated at high risk of outcome reporting bias and therefore this analysis was not conducted.

Sensitivity analysis was undertaken to examine the effect of high attrition (>30%) on the results. In relation to depression 7 studies (9 comparators) were identified as having high levels of attrition in at least one study arm (Au et al., 2010; Haley et al., 1987; Losada et al., 2011; Lovett & Gallagher, 1988; Márquez-González, 2007;

Toseland et al., 1995, 2004). When dropping studies with high levels of attrition from analysis (9 comparators, $n = 543$), heterogeneity remained non-significant in the resulting 8 studies ($p = .55$; $Q = 6.86$, $df = 8$, $I^2 = 0.00$) and fixed effect meta-analysis resulted in a small but increased effect size (Hedges' $g = -0.39$, 95% CI [-0.56, -0.22]). Only 1 study was identified as having high levels of attrition in at least one study arm for anxiety (Toseland et al., 1995). When this study was dropped from analysis (4 comparators, $n = 187$), heterogeneity remained non-significant in the resulting 3 studies ($p = .19$, $Q = 4.77$, $df = 3$, $I^2 = 37.0$) and fixed effect meta-analysis resulted in a slightly increased medium-to-large effect size for anxiety (Hedges' $g = -0.75$, 95% CI [-0.1.15, -0.39]).

Further sensitivity analysis was conducted by omitting each study from the meta-analysis to examine whether the effect size was biased by the inclusion of any particular study. The effect size for neither depression nor anxiety was significantly biased by the inclusion of any individual study, with the p -value remaining at $p = .0001$ regardless of which data set was removed.

Additional sensitivity analysis was planned by temporarily dropping from analysis small studies ($n \leq 20$); unpublished studies; and studies where outcome measurements of depression and anxiety are reported as primary or secondary outcome measurements to examine whether results remain consistent. These planned analyses were not possible as no included studies met these criteria.

3.6.4.7 Moderator analysis. Although the behaviour change techniques used within treatments were selected, a priori, as moderators this information was scarcely reported in the papers and treatment protocols were rarely received by the study team for them to be considered as moderators within the meta-analysis. As such, moderator analysis by use of specific behavioural change techniques was not possible. In addition, moderator analysis by diagnosis of depression or anxiety (yes or no) was originally planned however no studies included within the review formally diagnosed depression or anxiety. Moderator analysis was also planned by level of severity of the physical health condition experienced by the care recipient. Due to the inclusion of multiple physical health conditions within this review and different outcome measurements of severity this moderator analysis was not possible. Furthermore, moderator analysis was only performed on those studies measuring outcomes of depression (15 studies, 18 comparators) due to only 4 studies (5 comparators) targeting anxiety being included within the review.

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Results for all planned subgroup moderator analyses for studies targeting depressive symptoms can be seen in Table 3.7. Subgroup moderator analysis did not reveal any significant moderators of overall effect size for studies targeting depression. However, with respect to method of delivery there was a trend for treatments delivered individually to have a larger effect size to those treatments delivered in group setting ($Q = 3.25$, $df = 1$, $p = .07$). Furthermore, meta-regression was calculated to examine treatment duration, number of sessions, total session duration over the course of treatment and year of publication as predictors of effect size. All meta-regressions were non-significant ($p > .10$) except for total session duration over the course of treatment ($est = 0.01$, $z = 1.67$, $p = .09$). Interestingly, there was a trend for shorter session duration to have higher effect sizes than longer sessions.

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Table 3.7

Moderator Analyses of Associations between Clinical and Methodological Moderators on Effect Sizes (Hedges' g) for Studies Targeting Depressive Symptoms

Moderators	<i>n</i>	Hedges' <i>g</i>	95% CI	Q betw	<i>p</i>
Physical Health Condition				0.93	.82
<i>Dementia</i>	7	-0.22	-0.45, -0.00		
<i>Mixed Chronic Health Conditions</i>	6	-0.31	-0.54, -0.09		
<i>Cancer</i>	4	-0.30	-0.55, -0.04		
<i>Heart Failure</i>	1	-0.41	-0.73, -0.09		
Psychological Theory				2.70	.92
<i>Cognitive Behavioural Therapy</i>	8	-0.36	-0.53, -0.18		
<i>Interpersonal Therapy</i>	2	-0.38	-0.72, -0.05		
<i>Problem Solving</i>	2	-0.24	-0.65, 0.16		
<i>Psychoeducation</i>	2	-0.12	-0.42, 0.19		
<i>Behavioural Therapy</i>	1	-0.39	-1.14, 0.35		
<i>Family Systems</i>	1	-0.18	-0.85, 0.48		
<i>Psychosocial Support</i>	1	-0.01	-1.02, 1.00		
<i>Psychosocial Support + CBT</i>	1	-0.16	-1.16, 0.84		
Dyadic or Non-Dyadic				0.26	.61
<i>Non-Dyadic</i>	15	-0.28	-0.42, -0.14		
<i>Dyadic</i>	3	-0.36	-0.62, -0.09		
Method of Delivery				3.25	.07*
<i>Individual</i>	9	-0.40	-0.57, -0.23		
<i>Group</i>	9	-0.18	-0.36, 0.01		
Method of Support				0.00	.95
<i>Face-to-Face</i>	14	-0.29	-0.43, -0.15		
<i>Telephone</i>	4	-0.30	-0.42, -0.17		
Training				0.57	.45
<i>Not reported</i>	13	-0.33	-0.48, -0.18		
<i>Yes</i>	5	-0.23	-0.44, -0.02		
Intervention Fidelity				0.28	.60
<i>Not reported</i>	11	-0.33	-0.49, -0.16		
<i>Yes</i>	7	-0.26	-0.45, -0.07		
Manualised				0.07	.79
<i>Yes</i>	16	-0.29	-0.43, -0.15		
<i>Not reported</i>	2	-0.33	-0.61, -0.05		
Treatment Setting				0.00	.95
<i>Not reported</i>	14	-0.29	-0.43, -0.15		
<i>Home</i>	4	-0.30	-0.56, -0.05		
Clinician				4.87	.30
<i>Psychologist</i>	7	-0.19	-0.40, 0.02		
<i>PI/Co-author</i>	3	-0.31	-0.82, 0.21		
<i>Social Worker</i>	3	-0.16	-0.42, 0.09		
<i>Mix of health professionals</i>	3	-0.48	-0.80, -0.17		
<i>Nurse</i>	2	-0.46	-0.42, 0.09		

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Recruitment Setting					0.01	.99
	<i>Mixed</i>	12	-0.30	-0.46, -0.14		
	<i>Clinical</i>	4	-0.30	-0.50, -0.09		
	<i>Community</i>	2	-0.27	-0.80, 0.26		
Type of Control					0.29	.87
	<i>Waiting List</i>	11	-0.28	-0.46, -0.11		
	<i>Treatment-as-Usual</i>	5	-0.29	-0.49, -0.09		
	<i>Attention Control</i>	2	-0.38	-0.72, -0.05		
Severity of Depression at Baseline					0.03	.98
	<i>Subclinical</i>	7	-0.34	-0.57, -0.11		
	<i>Mild</i>	5	-0.32	-0.56, -0.08		
	<i>Moderate</i>	5	-0.31	-0.52, -0.10		
Follow-Up					15.81	.54.
	<i>Post-Treatment</i>	19	-0.30	-0.43, -0.18		
	10 weeks post-treatment	1	-0.58	-1.07, -0.1		
	4 months post-treatment	1	-0.20	-0.66, 0.27		
	6 months post-treatment	1	-0.29	-0.77, 0.20		
	12 months post-treatment	2	-0.39	-0.82, 0.03		

Note. Moderator analyses are based on a fixed effects model. *n* = number of comparators; CI – Confidence interval; *Q betw* = Homogeneity statistics across subgroups.

3.7 Discussion

This review extends the current evidence base by only including psychological or psychosocial interventions that specifically target depression or anxiety experienced by informal carers of people with chronic physical health conditions. Several clinical and methodological characteristics were included as moderators to examine their impact on overall effect size. Summarising the findings of the RCTs included within this meta-analysis resulted in a small-to-medium effect size for depression and a medium-to-large effect size for anxiety. No significant moderators were found, however there was a trend for treatments targeting depression delivered individually to have larger effect sizes (Hedges' $g = -0.40$) than those delivered in groups (Hedges' $g = -0.18$). Additionally, interestingly there was a trend for treatments that were shorter in total session duration to be more effective than those with longer total treatment session duration.

Within this current review larger effect sizes were found for both depression and anxiety symptoms in comparison with other reviews in the area (e.g., Brodaty & Arasaratnam, 2012; Cheng et al., 2014). Psychosocial interventions targeted at

training informal carers to manage the behavioural and psychological symptoms of physical health conditions, such as dementia, have only reported small effect sizes ($ES = 0.15$) on carer reactions such as bother, stress, distress and upset in dementia carers (Brodaty & Arasaratnam, 2012). Psychosocial interventions for carers of stroke survivors only had a small effect ($ES = 0.19$) on symptoms of depression (Cheng et al., 2014) and no effect on depression in cancer carers ($ES = 0.06$) (Northouse, Katapadi, Song, Lingling, Zhang & Wood, 2010). A further meta-analysis of psychosocial interventions for carers of stroke survivors have found no effect on depression for psychoeducation interventions ($ES = 0.20$) and for support and information provision ($ES = -0.06$) but did find a medium effect size ($ES = -0.61$) for interventions focused on the provision of skills for carers (Legg et al., 2011). In terms of anxiety symptoms comparisons were difficult to make as meta-analyses in the area tend to include multiple outcome measurements pertaining to worry, distress, distress and bother as opposed to only measuring symptoms of anxiety (e.g., Brodaty & Arasaratnam, 2012; Northouse et al., 2010) or did not find enough eligible studies to pool results (Vheng et al., 2014; Legg et al., 2011).

One potential explanation for finding larger effect sizes for depression and anxiety than other meta-analyses in the area may pertain to the restriction in the current review to only include psychological and psychosocial interventions that directly target depression or anxiety. Additionally, studies were only included that utilised high quality outcome measurements of depression or anxiety. Previous systematic reviews and meta-analyses of interventions for informal carers have included a variety of interventions, such as the provision of information and skills based training related to the caregiving role, for example lifting, assisting carer recipients with activities of daily living, personal care and medication management (e.g., Bakas et al., 2014; Northouse et al., 2010; Legg et al., 2011). Other interventions have focused on providing informal carers with skills in how to manage the behavioural and psychological symptoms of chronic health conditions such as dementia (Brodaty & Arasaratnam, 2012) with the aim of reducing the frequency of these behaviours and also reduce carer difficulties such as bother, distress and upset. Other common carer interventions may include case management, respite or day centre care (Gallagher-Thompson et al., 2007). The inclusion of a large variety of complex interventions based on a multitude of different therapeutic models and conceptual frameworks can limit the validity of making comparisons between these

interventions (Corry, Clarke, While, & Lalor, 2013). This may therefore account for the overall smaller effect sizes found in reviews of such carer interventions. In addition, although these carer interventions are often hypothesised to reduce negative carer outcomes such as depression and anxiety they are not designed to target these difficulties directly and often measure a variety of outcomes such as general psychological distress, burden, strain and quality of life. Previous criticisms of reviews of informal carer interventions have included the wide range of carer outcomes that are targeted (Brereton et al., 2007). Overall, it is interesting to note that despite the high prevalence of depression and anxiety experienced by informal carers of people with chronic physical health conditions only 16 studies were identified that directly targeted depression or anxiety. A large number ($n = 66$) were excluded from the review for not targeting depression or anxiety but rather targeted general distress, wellbeing or quality of life. Additionally, a number of studies ($n = 32$) were excluded as they considered reduction in symptoms of depression or anxiety to be an indirect or distal outcome of the treatment.

Restricting this current review to only include psychological or psychosocial interventions directly targeting depression or anxiety, utilising high quality outcome measures of depression or anxiety, may have reduced clinical heterogeneity by including studies with similar aims, targets, outcome measurements and interventions (Viechtbauer, 2007). Furthermore, restricting the meta-analysis to only high quality studies, with adequate randomisation allocation and concealment may have also reduced heterogeneity (Glasziou & Sanders, 2002). By imposing such restrictions to the inclusion criteria the dangers associated with over interpretation of results may have been reduced thus increasing confidence in the results (Thompson, 1994). Furthermore, given the increased rates of poor mental health in informal carers of people with chronic health conditions Canniscio, 2002; Coe & van Houtven, 2009; Pinqart & Sørensen, 2003a; Shaw et al., 1997) only including studies targeting depression or anxiety may also improve the relevance of the conclusions of the review to clinical settings (Thompson, 1994).

In regards to one of the main aims of the review to examine overall effectiveness of interventions targeting depression in informal carers of people with chronic physical health conditions, the results are not as encouraging as those reported in meta-analyses examining interventions for depression within the general population. For example, effect sizes of 0.71 (Ekers et al., 2014) to 0.87 (Cuijpers

van Straten, & Warmerdam, 2007a) have been found for behavioural activation; 0.71 for traditional CBT (Cuijpers et al., 2013); 0.55 (Huntley, Araya, & Salisbury, 2012) to 0.68 (Okumura & Ichikura, 2014) for group CBT; 0.54 for CBT self-help for depression (Farrand & Woodford, 2013); 0.63 for IPT (Cuijpers et al., 2011) and 0.40 for problem solving (Bell & D’Zurilla, 2009). However, results are not dissimilar to an effect size of 0.68 reported with transdiagnostic CBT based interventions for anxiety disorders (Reinholt & Krogh, 2014). One possible explanation for the effect size for depression being smaller than conventionally found in meta-analyses of psychological interventions for depression is that studies examining the effectiveness of psychological treatments for depression often restrict recruitment to participants meeting diagnostic criteria for major depressive disorder or a pre-determined level of psychological morbidity reflected by symptom severity scores related to the primary target(s) of the intervention. Within this review, none of the studies performed a standardised diagnostic interview pertaining to depression coupled with meeting diagnosis being a requirement for inclusion within the study. Although subgroup analysis by severity of depression at baseline was non-significant, it is important to note that in 7 of the included studies participants had subclinical levels of depressive symptoms at baseline. In a further 5 studies, participants had mild levels of depression at baseline and participants only reached moderate levels at baseline in 5 studies.

Given the low levels of psychological morbidity in the participants included within this review at baseline it is unsurprising that only a small-to-moderate effect size were identified for depression. Indeed, the effect size found within this meta-analysis is similar to the effect size of -0.35 found in a recent meta-analysis of psychotherapy for subclinical depression (Cuijpers et al., 2014). Such methodological limitations of including participants with subclinical or mild symptoms of depression are not uncommon in the behavioural medicine literature. Similar criticisms have been levied at studies examining traditional high intensity psychological treatments for cancer patients (Heron-Speirs, Harvey, & Baken, 2013; Sheard & Maquire, 1999) and low intensity treatments for a variety of chronic physical health conditions (Farrand & Woodford, in press). Risks of floor effects are significantly increased when including participants without elevated symptoms of the primary outcome measurement targeted by the treatment (Linden & Satin, 2007) and potentially underestimate the efficacy of the treatment under investigation. As such,

future interventions targeting depression in carers of people with chronic physical health conditions should look to recruit participants with elevated symptoms of depression and ideally meet diagnostic criteria for major depressive disorder. In terms of anxiety, all of the studies that met eligibility criteria for the review included participants with at least mild levels of anxiety symptoms.

A further aim of the review was to investigate components of interventions associated with effectiveness. Due to the small number of eligible studies, poor intervention descriptors within papers and lack of provision of intervention protocols from the study authors it was not possible to use specific intervention components and behavioural change techniques as potential moderators of effect. However, it is interesting to note that although type of psychological intervention was not a significant moderator the pooled effect sizes for interventions including skill building and problem solving components such as CBT (Hedges' $g=-0.36$); behavioural therapy (Hedges' $g=-0.39$) and IPT (Hedges' $g=-0.38$) had greater effect sizes than purely psychoeducational (Hedges' $g=-0.12$) and psychosocial support (Hedges' $g=-0.01$). Such findings are consistent with other reviews of interventions for informal carers that favour interventions including skill building components such as problem solving, stress management and goal setting rather than psychoeducational interventions alone (Bakas et al., 2014; Corry, While, Neenan, & Smith, 2014). As such, there appears to be greater support for the effectiveness of psychological interventions that incorporate active skill building and problem solving components.

A further interesting finding was the trend for individually delivered interventions to yield a medium effect size in comparison to only a small effect size for group based interventions. This finding is consistent with other reviews that have found that support groups for carers improve coping skills and confidence in the caring role but have no significant effect on wellbeing (Brereton et al., 2007). Indeed, studies examining the provision of group based psychosocial interventions for informal carers have concluded that negative results may be explained by the need to individually tailor psychological interventions for informal carers (Ulstein, Sandvik, Wyller, & Engedal, 2007).

A further trend was the finding that treatments with a longer duration of session time overall were less effective than those with shorter durations. Such findings are consistent with the finding that 5-9 sessions have the best evidence base for improving stroke carer outcomes (Bakas et al., 2014). Fewer sessions of

shorter duration would also potentially help minimise some of the specific barriers associated with accessing treatment experienced by informal carers, such as lack of time (Carretero et al., 2009; Eames et al., van Houtven et al., 2010).

A particular strength of this review is that the included studies provided support to informal carers over the long-term, with the total length of time ranging from a mean of 1.6 years (Kuijjer et al., 2004) to 5.4 years (Toseland et al., 2004). Previous studies examining support for informal carers has pertaining to the timing of included interventions (Brereton et al., 2007 with carer interventions often being delivered when the care recipients is in hospital or within the first 6 months of discharge home (Brereton et al., 2007). As such, the interventions included within this review recognise the longer-term emotional needs of informal carers of people with chronic physical health conditions.

It is also important to consider some additional limitations of the current informal carer intervention literature highlighted by this review. As found in other reviews of interventions for informal carers the majority of the studies had small sample sizes (Bakas et al., 2014; Corry et al., 2014; Brereton et al., 2007) with only one study undertaking a power calculation. Small sample sizes may increase the likelihood of making a Type II error, where no difference is found between the two groups but where however a difference does indeed exist (Kirkwood & Sterne, 2003). Therefore, it is important that future studies conducted are adequately powered to determine the effectiveness of informal carer interventions (Bakas et al., 2014).

An additional limitation is the lack of long-term follow up, with the majority of studies only taking outcome measurements post-treatment. Again, the lack of investigation of long-term outcomes is a common criticism of the informal carer intervention literature (Bakas et al., 2014). Finally, despite attempts to improve the quality of the included studies, studies were often rated as unclear risk of bias in relation to randomisation allocation, concealment, blinding of data collectors, lack of intention-to-treat analysis and high levels of attrition. Therefore, despite efforts to increase the quality of included studies, overall the study quality was at best unclear. Indeed, a commonly cited limitation of the carer intervention literature pertains to the poor overall quality of evidence (e.g., Bakas et al., 2014; Brereton et al., 2007; Cheng et al., 2014; Selwood, Johnston, Katona, Lykestsos, & Livingston, 2007). However, poor study quality is also a criticism of the wider evidence base for

psychological interventions for general mental health populations (Cuijpers, van Straten, Bohlmeijer, Hollon, & Andersson, 2010).

In addition, it was not possible to examine the effect that severity of the physical health condition experienced by the care recipient had on the overall effectiveness of interventions. This was due to studies examining multiple physical health conditions coupled with the use of multiple outcome measurements of conditions severity. Previous reviews have found larger effects of carer interventions for carers taking care of patients with moderate as opposed to mild dementia (Chien et al., 2011). Given the link between condition severity and higher levels of depression and anxiety in the informal carer (van den Heuvel, White, Schure, Sanderman, & Meyboom-de Jong, 2001) physical health condition severity may be an important moderator. As such, it is important that future studies measure physical health condition severity and attempt to standardise outcome measures used within specific physical health conditions to facilitate such comparisons (Clarke, 2007).

3.7.1 Limitations

Although little statistical heterogeneity between studies included within this review was found, clinical heterogeneity may still exist given the variability of participant's characteristics, characteristics of interventions and outcome measurement utilised (Gagnier, Moher, Boon, Beyene, & Bombardier, 2012). Furthermore methodological heterogeneity may exist due to different comparators included within the review and the varied quality of studies (Ryan, 2013). A further limitation pertains to the small sample sizes utilised within the studies included within the review. The inclusion of multiple studies with small sample sizes results in a significant potential for superrealization bias (Cronbach et al., 1980). Superrealization bias relates to research teams being able to more closely monitor the quality and delivery of interventions being delivered and may increase the likelihood of greater effect sizes than those that may be found in larger RCTs. As such, the effect size computed across a small number of studies with small sample sizes should be interpreted with caution (Flather, Farkouh, Pogue, & Yusuf, 1997). Additionally, a small number of studies coupled with small sample sizes may have resulted in the moderator analyses performed being underpowered (Hedges & Pigott, 2004) which is a common limitation of meta-analyses of psychological interventions (Cafri et al., 2010). Furthermore, moderator analysis is correlational rather than causal data (Viechtbauer, 2007) and the precision of measurement of

heterogeneity reduces when small numbers of studies are included within such analyses (Viechtbauer, 2005, 2007). However, the findings of the moderator analyses may help form research questions to be examined through future primary research (Cooper, 1998).

It is also important to note the possibility of publication bias (Rosenthal, 1979) due to the failure to access unpublished dissertations and find unpublished data to include within the meta-analysis. A further limitation pertains to the failure to include potentially eligible studies published in languages other than English. Indeed, within this review ten studies were identified as being potentially eligible for inclusion that was published in a language other than English. Reviews of studies published in English compared to other languages highlights differences in design and analytical approach (Moher et al., 1996) with positive studies more likely to be published in English (Egger et al., 1997). However, it is important to highlight that reviews examining the impact of language bias on meta-analyses have found that the exclusion of trials not published in English has little effect on the overall level of effectiveness (Jüni, Holenstein, Sterne, Bartlett, & Egger, 2002; Morrison et al., 2012).

Finally, results of the meta-analysis may have been overestimated due to only including non-active comparators. A large number of studies ($n=23$) were excluded due to a lack of suitable condition control. Studies were commonly excluded due to comparing the experimental intervention to a minimal support control condition or an active comparator. In particular, problem solving interventions were often compared to information only control conditions that are considered bona fide treatment alternatives to problem solving (Malouff, Thorsteinsson, & Schutte, 2007). Within the informal carer literature there is debate concerning what are suitable control conditions (Schulz et al., 2009). Indeed, for some informal carer populations routine standard care may not exist or researchers may experience difficulty in defining a suitable attention control (Elliot, 2007). When compared with waiting list controls or treatment-as-usual effect sizes for depression trials tend to be large, whereas medium effect sizes are in general found when comparing to attention control conditions and small effect sizes when comparing to active comparators or minimal support (Mohr et al., 2014). As such, there is the potential that the effect sizes within this review have been overestimated and inclusion of a wider range of control

conditions (e.g., active comparators and minimal support) may have resulted in a smaller overall effect size.

3.7.2 Implications

Overall, there is some evidence to suggest that psychological and psychosocial interventions are effective for the treatment of anxiety and cautious support the treatment of depression in informal carers of people with chronic physical health conditions. In relation to anxiety it is important to note that only four studies were eligible for inclusion, with small sample size and therefore it is important not to over interpret these results. In regards to depression, although the effect size was smaller than those found in meta-analyses of psychological and psychosocial interventions in the general population it is important to consider the potential for floor effects, small sample sizes and overall poor quality study design reporting. Overall, it is clear that larger, higher quality randomised controlled trials of interventions targeting depression and anxiety in informal carers of people with chronic physical health conditions that examine long-term outcomes are warranted. Furthermore, it is important that future research is targeted at informal carers who are experiencing clinical levels of depression or anxiety or meet diagnostic criteria for these common mental health conditions. Additionally, it is important for interventionists to provide more detailed and clear information in publications concerning the conceptual framework underlying the intervention and treatment components utilised. Indeed, this is a common criticism of complex intervention descriptors in the wider literature (Glasziou, Meats, Heneghan, & Shepperd, 2008). Finally, the finding that no studies examining psychological and psychosocial interventions targeting depression in carers of stroke survivors met inclusion criteria for this review was of particular importance to this programme of research. This further highlights the importance of developing a psychological intervention designed to specifically target depression in carers of stroke survivors.

3.7.3 Executive Summary

This present review clearly identified a number of trends associated with effectiveness within the existing evidence base for interventions targeting depression and anxiety in informal carers. These findings will be used to inform the content of the new CBT self-help intervention. Specifically, the review found support the adoption of a CBT based intervention, of short duration, delivered to informal carers on an individual basis. A summary of the main findings and how these will be used

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to inform the development of the present CBT self-help approach for depressed informal carers of stroke survivors can be seen in Table 3.8.

Table 3.8

Main finding from the systematic review and meta-analysis to inform the CBT self-help intervention

Main Findings	Informing the CBT self-help intervention
Treatments delivered to informal carers individually (Hedges' $g = -0.40$) yielded a larger effect size than group based interventions (Hedges' $g = -0.18$).	The CBT self-help intervention will be delivered to carers individually.
Shorter overall session duration was associated with an increased effect size ($est = 0.01, z = 1.67, p = .09$).	This finding supports using a guided CBT self-help approach whereby session duration is limited to approximately 35 minutes per session (Richards & Whyte, 2011).
Treatments that were based on a CBT (Hedges' $g = -0.36$), problem solving (Hedges' $g = -0.24$) and behaviour therapy (Hedges' $g = -0.39$) had larger effect sizes than psychosocial (Hedges' $g = -0.12$) and psychoeducational (Hedges' $g = -0.01$) based interventions.	This finding supports the adoption of a CBT based self-help approach. Possible techniques that may be utilised in the intervention could include problem solving and behavioural techniques.
There was no difference in effect size between interventions delivered face-to-face (Hedges' $g = -0.29$) and over the telephone (Hedges' $g = -0.30$).	The CBT self-help approach could be guided either face-to-face or over the telephone,

3.8 Conclusions

Firstly, it is important to note that one of the main aims of the review, to investigate intervention components and behavioural change techniques associated with effectiveness was not possible. Therefore, it was difficult to fully meet the aim of mapping intervention components associated with effectiveness (Greaves et al., 2011; Michie et al., 2008) to inform Phase I MRC guidance for the development and evaluation of complex interventions (Campbell et al., 2000; Craig et al., 2008). Overall however, there is some support for the use of psychological and psychosocial interventions that include components to develop skills and are problem focused such as CBT (Laidlaw & McAlpine, 2008) and are delivered to

informal carers individually rather than in group settings. Overall there is some support in terms of implementation of psychological and psychosocial interventions into wider mental health service developments to address the unmet long-term emotional needs of informal carers of people with chronic physical health conditions. However further research is required to address the methodological limitations highlighted within this review.

In Chapter Four the researcher moved onto the next stage of the development phase of the revised MRC complex interventions framework (MRC, 2008) and examined the specific difficulties and challenges experienced by depressed or anxious informal carers of stroke survivors through semi-structured interview.

CHAPTER FOUR: The provision of informal care to stroke survivors: A qualitative investigation of difficulties experienced by depressed or anxious informal carers of stroke survivors.

4.1 Background

4.1.1 Overall Aims

This chapter reports the second study informed by the development phase of the revised MRC framework (MRC, 2008). The study specifically focuses on the identification of appropriate theories to inform the development of the CBT self-help approach. As discussed in Chapter Two this study was designed to:

- Identify specific difficulties experienced by depressed or anxious informal carers of stroke survivors through the use of semi-structured qualitative interviews that could be targeted by the intervention.
- Identify psychological theories that may target these specific difficulties in order to help both enhance and individualise the CBT self-help intervention.
- Use the specific difficulties identified to enhance the content of the self-help material in terms of vignettes and the use of appropriate language to further facilitate engagement with the intervention (Lovell et al., 2008; MacDonald, Mead, Bower, Richards & Lovell, 2007).

4.1.2 Existing Literature

It is well documented that the provision of informal care to stroke survivors can result in increased burden and strain (Ilse, Feys, de Wit, Putman, & Weerd, 2008) alongside mental health difficulties such as depression (Visser-Meily et al., 2008) and anxiety (Balhara, Verma, Sharma, & Mathur, 2012) in the informal carer. Factors contributing to caregiver burden in informal carers of stroke survivors have been investigated using both quantitative and qualitative approaches (Pinquart & Sörensen, 2003). Several longitudinal and cross-sectional quantitative studies have shown that increased levels of caregiver burden are associated with increased incidence of elevated depressive symptoms (Carod-Artel, Coral, Trizotto, & Moreira, 2009; Phillips et al., 2009). However, results from systematic reviews in the area are inconsistent in terms of identifying additional factors such as stroke survivor characteristics; physical strain; receipt of health and social support) that increase caregiver burden (Rigby et al., 2009). Furthermore, although there is evidence to suggest an association between factors such as stroke severity (Bugge et al., 1999;

Draper & Brocklehurst, 2007) and level of burden and strain, little research examines the specific features of the stroke survivors' condition that cause informal carers difficulties (Bugge et al., 1999). Indeed, a criticism of interventions aimed at alleviating carer problems is that they do not target problems that cause carers the most difficulty (Scholte op Reimer, de Haan, Pijnenborg, Limburg, & van den Bos, 1998).

Given the limitations of the existing literature in terms of understanding factors that contribute to informal strain, burden and general psychological wellbeing there have been calls for more qualitative research in the area (Bugge et al., 1999). A number of qualitative studies have been conducted to examine the experience of being an informal carer of a stroke survivor. However, a recent systematic review of qualitative studies examining challenges and methods of coping in the caring role has highlighted that the majority of studies conducted formed part of another research project. Therefore the interviews were not focused on gaining an in-depth understanding of the caring role (Greenwood et al., 2009). As such, the qualitative studies conducted rarely focused on understanding the experience of carers and therefore any difficulties and challenges identified within the analysis were subsidiary to the wider research question with studies also having small sample sizes (Greenwood et al., 2009). Therefore, there is currently a lack of studies aimed at eliciting an in-depth understanding of the experience of caring for a stroke survivor (Bäckström & Sundin, 2009; Bäckström, Asplung, & Sundin, 2010) and understanding the specific challenges and difficulties faced by informal carers of stroke survivors (Greenwood et al., 2009). Finally, to the best of the researcher's knowledge, no qualitative research has been conducted to identify and understand the specific difficulties and challenges experienced by carers with elevated symptoms of depression and anxiety. There is a clear need therefore for research to identify the difficulties and challenges experienced by carers with common mental health difficulties in order to help inform the content and target of the self-help material.

4.2 Methods

4.2.1 Study Aim

To gain a detailed understanding of the difficulties, challenges and problems experienced by depressed and anxious informal carers of stroke survivors.

4.2.2 Study Design

4.2.2.1 Underlying paradigm. Pragmatism was adopted as the underlying research paradigm whereby respondent's accounts were considered intersubjective and transferable and accepted as having some meaning in reality (Morgan, 2007).

4.2.2.2 Theoretical framework. A thematic analysis approach (Braun & Clarke, 2006; Pope, Ziebland & Mays, 2000) was adopted in order to identify patterns of meanings across the data set.

4.2.2.3 Data collection. Data was collected through semi-structured interviews with the interview schedule (Appendix 4.1) targeted at understanding the difficulties, challenges and problems faced by carers of stroke survivors and preferences for emotional support. In order to focus the interview schedule on emerging themes it was adapted and analysed as interviews took place. For example, additional focus in the interview schedule was placed on barriers for accessing support as it became clear that informal carers were experiencing a larger number of difficulties gaining access to both practical and emotional support for their difficulties. All interviews were conducted by JW and lasted between 52 and 105 minutes.

4.2.2.4 Sampling. A purposive sample was used with participants recruited from community based stroke and carer organisations throughout the United Kingdom (The Stroke Association; Different Strokes; Carers UK; Headway and Unite Devon). Purposive sampling refers to the pre-selection of a group with specific characteristics or features of relevance to the specific research question of interest (Pope & Mays, 1999). Within this study, the set of characteristics of interest were being an adult informal carer of a stroke survivor experiencing elevated symptoms of depression or anxiety. A benefit to this approach to sampling is the approach ensures some similarity between participants included and allows for generalisations to be made to a wider population featuring similar characteristics (Sharma, 1997). Recruitment continued until it was felt that saturation was met concerning understanding the difficulties, challenges and problems faced by depressed and anxious carers of stroke survivors.

4.2.2.5 Participants.

Participation inclusion criteria.

- Informal carer of a stroke survivor.
- Aged 16 years or over.

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- Male or female.
- Displaying mild to moderate levels of depression relating to a score between 5-23 on the PHQ-9 (Kroenke, Spitzer, & Williams, 2001) or mild to severe levels of anxiety as indicated by a score between 5-21 on the GAD-7 (Spitzer, Kroenke, Williams, & Löwe, 2006).

Participant exclusion criteria.

- Scored two or more on the suicidality question on the PHQ-9.
- Consuming above 31 units of alcohol for men and 22 for women per week.
- Dependent on street drugs, as defined by using street drugs every day.
- Current / past psychosis or bipolar disorder.
- A hearing or reading impairment that would prevent them from taking part in a qualitative interview.

4.2.2.6 Procedure. Interested participants were referred to the researcher and telephoned to discuss the study brief. Participants were then sent the following via the post: study invitation letter; participant information sheet; consent form and questionnaire. The questionnaire consisted of the following: (a) basic demographics (date of birth; gender; ethnicity; relationship status; yearly household income; highest level of academic qualification; work status); (b) mental health (history of bipolar disorder or psychosis; units of alcohol consumed per week; use of street drugs; level of depressive symptoms assessed with the PHQ-9 (Kroenke et al., 2001); level of anxiety symptoms, assessed with the GAD-7 (Spitzer et al., 2006); and (c) experience of caring (length of time in the caring role; relationship to the stroke survivor; whether lived with the stroke survivor; receipt of help services in the home; hours of help services received in the home; hours per week caring for the stroke survivor). Once questionnaires and consent forms were returned via the post JW advised participants of their eligibility for the study.

4.2.2.7 Setting of data collection. Dependent on participant preference, interviews were conducted over the telephone or face-to-face in the participants' home or a convenient community based setting.

4.2.2.8 Data analysis. Thematic analysis was used to analyse the interview transcripts. All interviews were audio recorded and transcribed verbatim by the researcher. The researcher transcribed all the data as transcription can be seen as an essential phase of data analysis within qualitative research allowing the

researcher to develop a thorough understanding of the data (Braun & Clarke, 2006). Further familiarisation was made with the raw data by reading and re-reading the transcripts. Reading the transcripts was conducted in an immersive and active way, searching for meanings and patterns within the data (Braun & Clarke, 2006). Initial codes were identified across the entire data set in order to then start to organise the data into meaningful groups. An inductive, data driven approach was adopted towards coding. Once the entire data set was coded and collated, codes were sorted into potential themes. For example, examining how different codes might be combined in order to form a theme (Braun & Clarke, 2006). Following the identification of themes and subthemes they were further refined by re-reading the collated extracts for each theme in order to identify whether they represent a meaningful pattern (Braun & Clarke, 2006). When themes were decided upon, the entire data set was then re-read to ensure the themes accurately represented the data set as a whole. The process of analysis involved the researcher repeatedly reading and coding the entire data set. The supervisor reviewed and discussed the initial themes and subthemes generated in multiple research meetings, informing the additional refinement of the themes generated. Finally, when the researcher and supervisor agreed that themes represented significant patterns repeated both across and within transcripts, the themes and sub-themes were agreed upon, fully defined and named (Braun & Clarke, 2006). Where possible participant's own language was used to name and describe themes. NVIVO9 and NVIVO10 (QSR International, 2010; 2012) software was used to assist with the data analysis in terms of initial coding, grouping of codes and generation of themes within and across the data set.

4.2.2.9 Ethical considerations. The study was approved by the University of Exeter Psychology Ethics Committee (Application 2010/506). NHS Ethics was not required as all participants were recruited from community settings. All data was stored securely and confidentiality, in line with the Data Protection Act (Parliament, 1998). Informed consent for participation was obtained.

4.3 Results

4.3.1 Participants

Recruitment flow of participants through the study, including withdrawals from the study can be seen in Figure 4.1 with a final sample of 19 participants included in the analysis (see Table 4.1 for participant characteristics). In addition, selected details of the sample, with pseudonyms adopted and ages provided in bandings to

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protect confidentiality, are provided in Table 4.2. This was done to aid interpretation of selected quotations used within the text to further describe generated themes and subthemes.

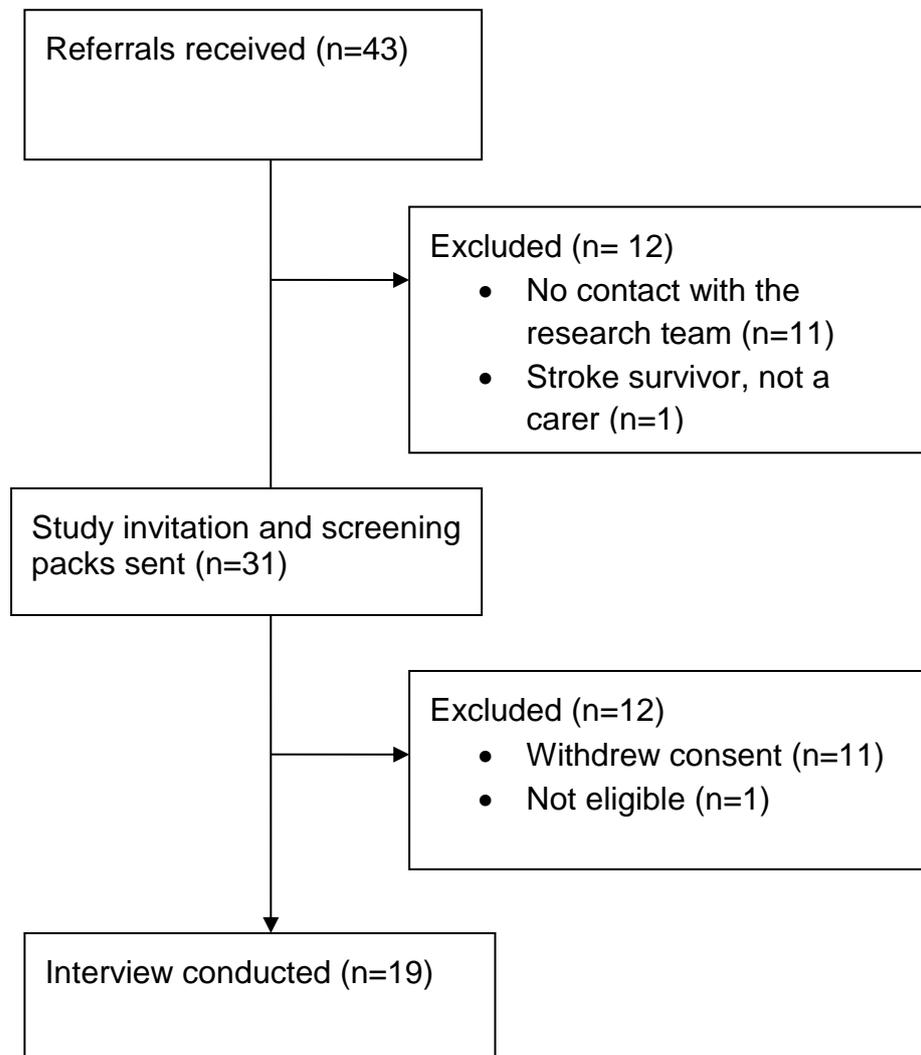


Figure 4.1. Recruitment flow

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Table 4.1

Participant Characteristics

Characteristic	<i>n</i>	%
Sex		
Male	2	10.5
Female	17	89.5
Ethnicity		
White British	18	94.7
Irish	1	5.3
Relationship Status		
Married	15	78.9
Live-In-Partner	2	10.5
Live-Out-Partner	1	5.3
Single	1	5.3
Annual Household Income		
£0-£9,999	2	10.5
£10,000-£19,999	6	31.6
£20,000-£29,999	5	26.3
£30,000-£39,000	1	5.3
£80,000-£89,999	1	5.3
£90,000-£99,999	1	5.3
Missing	3	15.8
Employment Status		
Retired	7	36.8
Full time caregiver	6	31.6
Working, full-time	3	15.8
Working, part-time	2	10.5
Homemaker	1	5.3
Highest Level of Education		
O Levels / GCSEs	5	26.3
NVQ/GNVQ	4	21.1
A Levels / AS Levels	1	5.3
First Level Degree	1	5.3
Postgraduate Certificate / Diploma	5	26.3
Master's Degree	2	10.5
Missing	1	5.3
Relationship to Stroke Survivor		
Spouse / Partner	15	78.9
Son/ daughter	1	5.3
Granddaughter	1	5.3
Father / Mother	1	5.3
Other relative	1	5.3

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Mean Hours Provision of Care per Week

More than 30 hours	12	63.2	
20 to 30 hours	1	5.3	
10 to 20 hours	3	15.8	
5 to 10 hours	2	10.5	
Missing	1	5.3	
	Mean	SD	Range
Mean age	57.3	15.6	21.4-76.9
Mean Units of Alcohol Consumed Per week	5.4	6.7	0-21
Mean PHQ-9 Score	9.2	5.0	1-20
Mean GAD-7 Score	8.1	4.8	2-21
Mean Years Caring	4.9	5.3	0.4-22.3
Mean Hours of Help Services Received in Home per Week	5.7	10.0	0-37

Table 4.2

Details of Sample

Name	Age	Relationship to stroke survivor	Length of time in caregiving role
Simon	50 - 60	Spouse / Partner	5 years, 2 months
Fern	20 - 30	Granddaughter	4 months
Corinne	60 - 70	Spouse / Partner	4 years, 2 months
Bettie	50 - 60	Spouse / Partner	1 year, 1 month
Aida	50 - 60	Spouse / Partner	1 year, 3 months
Maude	60 - 70	Spouse / Partner	10 years
Leanne	70 - 80	Spouse / Partner	12 years, 6 months
Ivy	60 - 70	Spouse / Partner	1 year
Matilda	30 - 40	Other relative	3 years, 1 month
Karina	50 - 60	Mother	5 years, 2 months
Alana	60 - 70	Spouse / Partner	1 year, 8 months
Gerald	70 - 80	Spouse / Partner	22 years, 3 months
Clarissa	70 - 80	Spouse / Partner	7 years
Celina	60 - 70	Spouse / Partner	6 years
Frances	60 - 70	Spouse / Partner	1 year, 1 month
Maryanne	50 - 60	Spouse / Partner	3 years, 7 months
Clare	50 - 60	Spouse / Partner	1 year, three months
Amy	50 - 60	Daughter	3 years, 7 months
Harriett	50 - 60	Spouse / Partner	2 years, 7 months

Note. Names changes and ages provided in bandings to protect confidentiality.

4.3.2. Qualitative Analysis

Three key themes emerged from the data concerning key difficulties experienced by depressed and or anxious informal carers of stroke survivors: “Difficulties adapting to the caring role”; “Uncertainty” and “Lack of support”. A number of subthemes were derived from these major themes (Table 4.3).

Table 4.3

Major Themes and Subtheme

Major themes	Subthemes
Difficulties adapting to the caring role	Giving up roles and life goals of value and importance
	Changes in relationships
	“A prisoner in your own home”
	Assuming new roles and responsibilities
	Lack of balance
Uncertainty	No light at the end of the tunnel
	Worry about the stroke survivor
Lack of support	Lack of information
	Social isolation
	Health and social care

4.3.2.1 Theme One. Difficulties adapting to the caring role. A significant difficulty reported by depressed or anxious carers of stroke survivors related to problems adapting to their new role as a carer and the consequences of this difficult life transition. Five subthemes were generated pertaining to difficulties that were experienced trying to adapt to the caring role.

Subtheme One: Giving up roles and life of goals of value and importance. In order to manage the demands of the caring role many carers reported giving up previous roles and goals of importance and value to them, for

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example those related to work, plans for retirement and education. A number of significant impacts resulted from giving up such goals, such as social isolation, boredom with the caring role, loss of independence and feeling as if there was no life outside the caring role:

It is hard, I'm not going to say it isn't because I mean I've always worked, right up to the day he had his stroke and suddenly I haven't got that anymore so I haven't got a life outside of caring." (Maude)

As well as roles of importance a number of goals and values of importance were also given up. For example, carers felt unable to pursue previously valued activities such as sporting interests, seeing friends, hobbies or other activities they used to enjoy.

"That's another thing that you have to learn to deal with is that acceptance of what it is and perhaps, perhaps even after all this time I still haven't really accepted what it is. I don't like this life ... I suppose, it's getting by, it's not really living, it's not a life, it's not a life I would have ever, we came here to do all the lovely things that <county> has to offer, and it's like having your nose rubbed in it." (Celina).

Difficulties around activities previously carried out with the stroke survivor were also reported, such as no longer being able to go on holiday, to restaurants, or for walks. A number of reasons for giving goals were reported, for example financial restrictions due to giving up work and resultant loss of income; lack of time; the physical difficulties experienced by the stroke survivor; the stroke survivors loss of motivation; anxiety around leaving the stroke survivor on their own and lack of time. They reported feeling trapped in the caring role and unable to change the situation in order to pursue things of value and importance to them. However, this feeling of being trapped led to feelings of resentment for having to give up so much, which in turn led to feelings of guilt for holding resentment towards the person they are caring for:

"You start resenting; resentment's a good one, everything that you've given up and everything that you're doing." (Aida)

Subtheme Two: Changes in relationships. Significant changes in relationships were reported both in terms of stroke survivor and relationships with other family members and friends. In terms of changes in the relationship with the stroke survivor communication difficulties were often mentioned as contributing

factors. Due to difficulties with communication carers reported feeling as if they were living as separate people, with a lack of understanding of one another, leading to frustration and anger from both the carer and stroke survivor. Further contributing factors to changes in relationships were reported in terms of mood difficulties and personality changes experienced by the stroke survivor. A number of carers described the stroke survivor's personality changing and a sense of loss around losing the person that they once were. They spoke about how they assume the role of the carer changing the dynamics of the relationship, for example comparing the role to that of parenthood as opposed to being a spouse or child.

"It's almost as if when mum had her stroke and dad got dementia, it's a dreadful thing to say, but it's almost as if I lost them then, because they're not the way they used to be at all, they're completely different and I've had to sort of take over as the adult to look after two children that, they behave like children ... you lose the people they were, which is an awful thing to say. I do think that's a terrible thing to say but it's the only way I can describe the way I feel about them now. That makes me feel guilty as well. Very guilty." (Karina)

"I mean the person I married has gone, he's not the same person that I married, that person has gone, so you're mourning for the person that you've lost, and you've now got another person, you've come home with a completely different person and so I find that quite difficult because you know you're mourning for the person that's gone and that person's no longer there and now you've got someone else." (Alana)

As well as changes in the relationship with the stroke survivor carers also described difficulties in changes in relationships with other people. For example, the demands of the caring role placed strains on relationships with other significant people, such as partners and children, resulting in arguments:

"I have to accept that it's damaging my family and it's damaging my relationship and I need to step back in some ways and put my own family first and I think that's an incredibly difficult thing to do." (Matilda)

Subtheme Three: "A prisoner in your own home". A loss of independence and freedom were reported as significant difficulties within the caring role. Carers felt that they were no longer able to do things spontaneously or activities they used to do, resulting in a sense of boredom and having no life outside of the caring role:

"It's the fact that your life is not your own anymore. That's the hardest thing. You know you're just ... you're just completely and utterly controlled by caring for somebody else." (Bettie)

"It feels like I'm a prisoner in my own home. You feel as if you're a prisoner and you can never get up in the morning and say 'I think I'll just go here' or 'I'll just go there'. You have to organise everything a week before because you have to book people and sometimes I book a day off and it's a day where it's blowing a gale and you can't say 'well I'm not going to go out today in that'. I've got to go because everything's been arranged so you're really tied, you feel like a prisoner in your own home." (Alana)

Furthermore, when carers were able to take time out from the caring role they felt a sense of guilt in terms of not being with the stroke survivor and that they should be doing more for the stroke survivor. Additionally, they reported worry around something happening to the stroke survivor if they took time out and fear of being blamed by others if they did take time out.

"I'm on carers allowance and I feel that if I do that [leave the stroke survivor at home] and something happens to him and I'm not there then I'll get into trouble because I should have been there looking after him. And it's just the anxiety that something will happen to him while I'm not there. So I don't believe in leading a life of my own, I lead his life." (Maryanne)

Indeed, some carers experienced difficulties with other family members criticising them for taking time out of the caring role. A further contributing factor to the sense of loss of independence and freedom was the 'twenty-four-seven' nature of the caring role, with references made to the caring role "as a prison sentence". Carers felt trapped by this role and unable to change it and reported anxiety around leaving the stroke survivor. A number of carers also reported that the stroke survivor felt anxious being left on their own resulting in the carer feeling unable to leave the stroke survivor. Carers also reported feeling resentment towards the stroke survivor due to the lack of independence and freedom resulting from the caring role.

Subtheme Four: Assuming new roles and responsibilities. Significant difficulties were experienced by carers in terms of taking on new roles and responsibilities around the caring role and taking on new tasks that were previously the responsibility of the stroke survivor. For example, they reported having to take on tasks such as managing finances, housework, cooking, gardening and DIY as

well as learning care related tasks. The responsibility of taking on new roles and responsibilities was described as overwhelming and carers felt pulled in different directions contributing to feelings of not being able to cope and not doing a good enough job.

"Everything seemed to be just on my shoulders and there are times when I don't want it, I don't want to have this responsibility, it wasn't mine, I don't want it, take it back you know please somebody please come and take it away" (Aida)

Carers reported difficulties in having to make all the decisions, which was especially the case when assuming roles that the stroke survivor had previously been responsible for. In addition, they found making decisions that used to be joint decisions difficult and missed having someone else to discuss major decisions with. They also found the responsibility of decision making overwhelming and found themselves questioning their own judgement.

"I feel I'm pulled in so many different directions that I don't do any of them well and I don't always feel like that but then it does, it does come sometimes out of the blue and I just feel that I'm doing everything very badly and I just can't cope." (Matilda).

Subtheme Five: Lack of balance. Carers reported difficulties with trying to balance the caring role with other activities. In general they felt that they did not have time for activities outside the caring role and that responsibilities of the caring role were constant with little opportunity for a break:

"I get tired obviously and you never get time for yourself to sit and relax. I mean I don't necessarily want to go out, I just want a couple of hours with nothing to do but you have to run the whole house". (Leanne)

"It does take over your life because I'm not doing all the things that I like to do. I'm not doing the things that I probably would have enjoyed doing before (Alana)."

"I think, I don't know really, it's just, just daily, it's just always there in front of you, that I don't ever feel, I never feel happy, I can't remember what feeling happy is." (Celina)

Lack of time for themselves led to carers reporting difficulties with exhaustion and fatigue. Furthermore, feeling stuck in the caring routine led participants to report

feelings of boredom and that their life was mundane with little life existing outside the caring role. They also reported feeling anxious about deviating from the routine of the caring role with a fear that they would forget important aspects of the caring role, such as medication regimes. Furthermore, carers felt so overstretched by the caring role that they did not have the time or energy to do things for themselves outside of the caring role.

However, they also spoke about how having a routine around the caring role was helpful. For example, planning and organisation around medication and caring regimes were important in order to get through everything during the day and spoke about how deviation from the routine could lead to the whole day falling apart.

"If I go out of the routine I'd never cope with it. You know like his medication. It starts from 6 o'clock in the morning and then through certain hours during the day and it continues right through until he goes to bed at night and he has his last tablet then. And I've got to be in that routine." (Maude)

Additionally, they spoke about how stroke survivors themselves welcomed the routine and felt anxious if the routine was deviated from:

"Well [stroke survivor's] very, he likes things done at a certain time and in a certain way and if you change that routine everything else seems to fall apart during the day" (Alana)

4.3.2.2 Theme Two. Uncertainty. A further key difficulty experienced by carers was a feeling of uncertainty with respect to the future, the health of the stroke survivor and lack of information about the caring role. Three main subthemes related to uncertainty.

Subtheme One: No light at the end of the tunnel. Carers frequently reported have a lack of hope for the future. Lack of hope centred mainly on not seeing how the caring role was going to change and the health of the stroke survivor. They spoke about how stroke was a long-term condition and they saw no end to the caring role and had concerns over how long they could manage:

"You, it was just life was a muddle and I was in this tunnel. I couldn't see an end. I couldn't see an end. And I'm not sure I can really see an end now." (Clarissa)

"I suppose the way I look at it at the moment is it's a long dark tunnel and there's no light at the end of the tunnel at all." (Alana)

A number of carers felt a lack of hope relating to the progress the stroke survivor was going to make, especially when the progress that the stroke survivor had made was slowing down, or the health of the stroke survivor was deteriorating. Uncertainty about the long term prognosis of the stroke survivor or not knowing what long-term recovery may be made contributed to this sense of hopelessness for the future.

"I think the thing with stroke is its forever. Whereas if somebody gets an illness like MS or a friend of mine, her husband's just been diagnosed with myeloma, and I think that's terminal, she can see an end to her situation. She's going through a bad time, but she can see an end to it, and that's my problem, I can't. That sounds really horrible but we're here to be honest and that's how I feel." (Celina)

Furthermore, carers reported feelings of hopelessness were not helped by negative comments made by health professionals about the prognosis for the stroke survivor. Additionally, uncertainty around their own health in the future was frequently reported, with concerns about what would happen to the stroke survivor if they became sick or died themselves.

Subtheme Two: Worry about the stroke survivor. Uncertainty around the health of the stroke survivor and their ability to perform specific activities led to reports of worry and anxiety. They reported being uncertain about being able to leave the stroke survivor alone, for example if the stroke survivor suffered a fall, an epileptic fit, or indeed another stroke or transient ischaemic attack (TIA).

"He had his stroke ten years ago but I was never told that a side effect of the stroke could be epilepsy and we were out in the garden and [stroke survivor] said 'I'm going, I'm going' and I thought 'where's he going, he can't walk anywhere' and I could see he was slipping and I went over and grabbed him, lowered him down and then he went into a full epileptic fit. Which terrified me. I was out in the garden screaming for people to help me and there was nobody around. And I found that very traumatic. Had I been warned about it I could have read up about it". (Maude)

Such anxieties led carers to report an overwhelming feeling of responsibility and protectiveness for the stroke survivor resulting in behaviours such as constant monitoring. In some cases they reported specific situations that had contributed to these feelings of anxiety and worry, for example where they had left the stroke

survivor and they had fallen or suffered a fit. Carers reported that they would blame themselves if something did happen to the stroke survivor if they were left alone, or were concerned that others (e.g., family members) would blame them.

"I suppose you think that if anything happened to him then people would blame you and think 'oh where were you when this happened?' So you're aware that people might think that you weren't paying attention and you weren't giving him your full attention. If anything happened to [stroke survivor] in the night or anything they'd blame me for it. I often think that. (Alana).

In some cases the stroke survivor's own level of anxiety influence the carer's behaviour, for example they reported that they could not leave the stroke survivor as the stroke survivor was scared of being left alone. Furthermore carers reported uncertainty around how to manage if the stroke survivor did experience physical setbacks, such as a fall or fit. For some this led them feeling unable to cope with the stroke survivor outside the home, with the impact that they reported being more isolated and unable to leave the house. Additionally, difficulties were reported in terms of worrying about how to deal with communication, mood and personality changes outside the home, for example if the stroke survivor was verbally aggressive to someone in public.

Subtheme Three: Lack of information. A major contributing factor to uncertainty around the caring role related to lack of information, especially from health care professionals. Many carers reported feeling ill-equipped for the caring role, especially in terms of the practical implications and likely impact on their life, impacting on their ability to adapt to the caring role. They reported health professionals assumed that they would adopt the role of carer but without providing any information about what to expect and how to actually care for someone who has had a stroke:

"Everybody is different and the level of care is different but I think it would be nice if somebody had taken the time to sit down and say 'You do realise that your life is going to change dramatically'. I mean I am bright enough to know that my life was going to change, but I don't think I ever realised quite how much it was going to change. And how big a change obviously [stroke survivor] has to cope with every day. And his frustrations and his anguish at being disabled and not being able to do anything for himself. And I think that none of that was talked about." (Bettie).

Some carers felt they were not provided with enough information about the secondary health complications post-stroke, such as epileptic fits, communication difficulties, hallucinations and changes in mood. This led to an uncertainty around how to deal with these difficulties when experienced by the stroke survivor. Furthermore, they reported being provided with little information in terms of prognosis from health care professionals and also no information in terms of where to go to form support, leading to further uncertainty about the future and how to manage within the caring role. In contrast, others reported feeling overwhelmed with the number of leaflets they provided when the stroke occurred and were uncertain what information would relate to their specific situation. Carers felt overwhelmed by the provision of information in these circumstances, leading to them not reading the information.

4.3.2.3 Theme Three: Lack of Support. A constant theme throughout the interviews was the lack of support carers felt they received. This was both in terms of social support from family and friends and also health and social care. Although in general, carers reported lack of support from health care professionals there were some disconfirming cases that are reported below. There were two main subthemes in terms of lack of support:

Subtheme One: Social isolation. Carers reported feeling more socially isolated and less supported, especially as time went on. A lack of understanding about the caring role and effects of stroke were reported in terms of both family and friends:

“I tend to not get too involved with people because it hurts to hear, I know it sounds horrible, but it hurts to hear how wonderful a time they’re all having. And I don’t think mine’s much good ... sometimes it’s very hard to stomach people going on about how they’re always going out here there and everywhere and you know we’re lucky if we go out once every two weeks somewhere for a meal” (Celina)

This lack of understanding resulted in less support being provided and contributed to difficulties in the caring role. For example, family members and friends were unable to understand the changes experienced such as no longer being able to go on holiday, financial restrictions or not being able to participate in social activities as they had previously. Some carers also reported difficulties with family

members not believing that they were doing enough for the stroke survivor they cared for and criticising their ability to care.

Carers felt isolated due to the changes in their role, for example no longer working and communicating with colleagues and friends. In addition, the constraints in time of the caring role and being confined to the house led to carers feeling unable to socialise with their friends as they would have in the past. Over time they felt that their friends were drifting away:

"You've got a lot of backup at the beginning, a lot of family friends, everyone's there and it's like bereavement, it's like anything big that happens. In an emergency everyone's there and they all drift away, the phone calls stop and I think you feel more isolated, you feel like you're on your own." (Aida)

In addition, carers felt that they did not want to burden friends and relative with the difficulties of the caring role and found themselves avoiding phone calls or not speaking with friends and family about their problems.

Subtheme Two: Health and social care. Carers frequently referred to difficulties with accessing health and social care, in terms of support for both themselves and the long-term care of the stroke survivor. Often carers discussed not being offered carer assessments, or even being aware that they were available. Furthermore, they spoke about being told incorrect information about benefits available and also spoke about guilt asking for social support:

"I became sort of, I'm completely ... what's the word I want ... I can't think ... dependent on social services money now I'm not earning. A carers allowance is fifty-five pounds a week. You're expected to work twenty-four hours seven days a week for that. I think it's a pittance really for what you've paid into the system all your life but I don't like having to ask for it, its, you know it's horrible." (Bettie).

In terms of long-term care of the stroke survivor carers spoke about frustration with services only being provided for a short-term post-stroke. They reported feeling that long-term care would have resulted in the stroke survivor making more improvements resulting in fewer burdens for themselves. Furthermore, due to the lack of long-term care the responsibility for motivating the stroke survivor to continue with rehabilitation exercises fell on the carer, resulting in further strain and burden:

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"I actually got [stroke survivor] some more physiotherapy to try and help her, but that consisted of the lady coming on three occasions and recognising that [stroke survivor] had limitations on walking gave [stroke survivor] some exercises too. And on the third visit she said 'right well that's up to you now [stroke survivor] to keep it going' and you just feel so frustrated and I know there is a constraint upon money and constraint on professional's time but sometimes you think 'if a bit more time had been spent on [stroke survivor] when she first came out then I think a lot of the problems that we've got now five years on may not have been there.'" (Simon)

Carers also felt that longer-term their difficulties were increasing and therefore although assistance is provided immediately after the stroke there are increasing needs long-term, especially if the condition of the stroke survivor is deteriorating. Carers felt that they had to fight all the time to gain support which they found exhausting and led to further feelings of frustration. They also reported difficulties in terms of general practitioner recognition of the impact of the caring role and provision of appropriate support:

"I mean if we go to GP surgeries like I have done, two or three occasions I've mentioned it [difficulties with mood] nobody actually says 'how are you managing' and that's all you need. You just feel that it's a 'oh well what do you expect' and 'get on with it'. You need someone to stop and say 'how is this person really coping' and unless you actually spell it out for them and sometimes when you do it's just 'oh well, here's another prescription'."
(Maryanne)

Although on the whole carers felt that there was a lack of long-term care, a number of carers reported that the immediate care post-stroke was supportive and that their general practitioners provided on-going support and care:

"We've had excellent support from the local hospital, we've had lots of physiotherapy there, they couldn't have done more for him. Because they recognised that he's doing everything that he can to help himself, and it's just been fantastic" (Maryanne)

"Our GP has been fantastic, we've been really lucky, and I don't know where we would have been without him really." (Bettie)

4.3.2.4 Barriers to accessing emotional support. Although not an original focus of the interviews, carers identified a number of barriers to accessing psychological support.

The stroke survivor: Some carers felt that accessing emotional support for themselves would be difficult because the stroke survivor did not like outside support. Additionally, carers felt that face-to-face support may be difficult due to the stroke survivor not liking to be left alone, or not being able to be left alone. They also felt that they had to put on a brave face for the stroke survivor as they are responsible for their care.

"I haven't really tried to get any support ... Probably because [Stroke survivor] doesn't want any. He'd be dead against any outside intervention." (Corinne).

"You just don't talk about it": A further theme was one of keeping things to themselves and not wanting to admit failure. Carers expressed not feeling happy expressing their emotions and felt that expressing they were experiencing difficulties would be an admission of failure. As a carer they felt that it was their 'duty' to get on with the caring role and something they 'should' be doing and therefore not complaining.

"I think that's why a lot of the carers don't come to the fore because they just take on board the role, looking after a child, or a wife, or husband, whatever it happens to be, and just thinking 'well it's part of my family, I've got to do this.'" (Simon).

"It didn't happen to me": A related theme was guilt concerning asking for support and help when they were not the one who had experienced a stroke. Carers referred to difficulties with feeling resentment for the caring role but then guilt as they were not the one who had the stroke. This resulted in carers feeling that they did not have any cause to complain or seek support for themselves. They also felt guilty in terms of accessing support for themselves when such little support was available for the stroke survivor.

"I felt very guilty because, another thing that you feel is that you can't feel those feelings, you can't feel resentment because it didn't happen to you, you think 'well I didn't have the stroke' and 'why am I moaning, why am I complaining because it didn't happen to me.'" (Aida).

4.4 Discussion

The results of Study Two add to the existing literature on difficulties experienced by carers of stroke survivors (e.g. Bakas et al., 2002; Bugge et al., 1999; Greenwood, et al., 2009; Pinguart & Sörensen, 2003a, Pinguart & Sörensen, 2003b) by providing a detailed account of the difficulties experienced by carers experiencing mild-moderately severe levels of depression or anxiety. Findings clearly demonstrate that informal carers of stroke survivors with elevated symptoms of depression and anxiety have particular difficulties in terms of adapting to the caring role, hopelessness and worry, social isolation and lack of support. A key aim of Study Two was to identify psychological theories and techniques that may target these specific difficulties in order to help both enhance and individualise the CBT self-help intervention and this will be discussed below. Psychological theories refer to a set of ideas or models that explain a particular phenomenon (for example a set of processes that result in changed behaviour) that has been confirmed by experimental studies (Michie & Abraham, 2004). Psychological techniques are defined as components of an intervention designed to change behaviour (Michie et al., 2011).

4.4.1 Adapting to the Caring Role

Results from Study Two suggest that carers of stroke survivors struggle with adapting to the caring role, with specific difficulties around changing roles, relationships, responsibilities, adapting life goals and dealing with loss. Such findings suggest that a useful framework for working with carers may be the model of successful aging (Baltes, 1991; 1997) that helps people to maximise levels of functioning despite experiences of loss (Boerner & Jopp, 2007). During the lifespan people experience changes to their functional ability (Baltes & Smith, 2003) and in order to overcome functional losses need to adapt. This adaptation is an essential component of successful aging (Baltes &, 1996; Baltes & Baltes, 1990). The 'selection, optimisation and compensation' model of successful ageing is focused on the maximisation of gains, goals and outcomes that are desired, whilst minimising losses, goals and outcomes, that are undesirable (Baltes et al., 1999). Definitions of gains and losses are influenced by cultural and personal factors as well as age (Baltes et al., 1999).

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The framework has three components: (a) selection; (b) optimisation; (c) compensation (SOC) and helps people to select goals that can still be achieved and uses alternative ways of achieving these goals through optimisation and selection (Baltes, 1991; 1997). Selection refers to the reduction in the number of goals someone has in order to allow more focused energy and motivation to be aimed at more important goals or to select new goals in light of awareness of limitations. There are two types of selection: Elective and loss-based selection (Freund & Baltes 1998). Elective selection is driven by motivation and involves selecting goals from a number of different possibilities. Loss-based selection is when specific means or resources to achieve desired outcomes are not available (Freund & Baltes 1998). The process of selection will sometimes mean that old goals may need to be given up and other goals that are attainable selected. Optimisation is where the highest level of functioning is worked towards given the new limitations in resources (for example in the case of carers' time, financial restrictions, being more confined to the house). Compensation is where new limitations are recognised and alternative means of working towards goals are taken (Baltes, 1997; Freund & Baltes, 1998). For example, if old methods of achieving goals are no longer available people will search for alternative methods to achieve the goal. Alternatively people may change goals as a response to the loss of means to achieve their goal (Baltes, Staudinger, & Lindenberger, 1999). This also fits with findings suggesting that higher levels of wellbeing are reported when people are able to disengage from unattainable goals and replace these with new more achievable goals (e.g., Wrosch, Miller, Scheier & de Pontet, 2007; Wrosch, Scheier, Carver & Schulz, 2003).

The SOC model has been used to explain participation in career and family life with experimental study indicating that those who use SOC strategies have lower levels of job related stressors and therefore less work and family life conflict (Baltes & Heydens-Gahir, 2003). Furthermore, adopting SOC strategies have been found to be adaptive for older adults, resulting in higher levels of wellbeing despite reduction in resources (Jopp & Smith, 2006). Additionally, patients with depression have been demonstrated to display significantly lower SOC scores on admission to inpatient care, in comparison to when in remission and a population-based control condition (Weiland, Dammermann, & Stoppe, 2011). Research into older adults with osteoarthritis (Gignacm Cott, & Badley, 2000) and Alzheimer's disease (Rapp, Krampe, & Baltes, 2006) has also used the SOC model to adapt to living with

physical health conditions. Indeed, the SOC framework has been used to support people with chronic disabilities and is easily adapted into the problem solving approach inherent in CBT (Laidlaw & McAlpine, 2008). As such, the use of a goal setting psychological technique based on goal setting theory (e.g., Locke & Latham, 2006) with goal adaptation following the SOC model may represent a suitable adaptation to the CBT self-help intervention.

4.4.2 Lack of balance

An additional clear finding from Study Two is that due to the restrictions of the routine of the caring role and subsequent disengagement from previous activities of value, carers are not getting an opportunity to engage in behaviours associated with an improvement in mood (Hopko, Lejuez, Ruggiero, & Eifert, 2003). Behaviour theory postulates that the primary trigger of a depressive reaction is an environmental stressor (Lewinsohn et al., 1985). Such stressors may include failure to achieve goals or experiencing a physical illness (Dimidjian et al., 2011). Such stressors result in a change in the way people behave, for example giving up work, stopping previously enjoyed activities, and other regular behaviours (Dimidjian et al., 2011). This avoidant behaviour leads to people disengaging from activities that would normally provide them with positive reinforcement (e.g., pleasure, satisfaction and sense of achievement) due to the initial relief experienced by disengaging from activities that may be perceived as difficult or aversive (see Hopko et al., 2003; Jacobson, Martell & Dimidjian, 2001). Indeed, avoidance behaviours are common in depression and serve as a function to cope with depressive symptoms (Jacobson, Martell, & Dimidjian, 2001). Consequently avoidance is negatively reinforced, resulting in increased avoidance and less opportunity to engage in positively reinforcing activities (Lewinsohn, 1974), reducing the experience of positive affect and maintaining depression.

Behavioural activation (BA) is a psychological treatment informed by behavioural theory that can be used as a stand-alone treatment for depression (Jacobson et al., 2001; Lejuez et al., 2001) though it is also used as a component of cognitive behavioural therapy (Dimidjian et al., 2011). Although there are a number of different behavioural activation approaches (see Hopko et al., 2003) the underlying premise is that behavioural avoidance is targeted by reintroducing activity into peoples' lives thus increasing the opportunity for accessing positively reinforcing activities (Hopko et al., 2003) that helps overcome negative reinforcing actions that

have maintained avoidance behaviours (Richards, 2010). Therefore using behavioural activation (see Hopko et al., 2003) may increase carers' engagement in rewarding activities thus reducing symptoms of low mood. This may also help to reduce carers' feelings of social isolation. In addition, behavioural activation is a well-established treatment for depression (Ekers, Richards, & Gilbody, 2008; Ekers et al., 2014) and is used as a low intensity CBT technique (Richards, 2010).

4.4.3 Problem solving

Additionally, it is clear from findings that carers struggle with a number of difficulties surrounding the responsibility of the caring role, effective decision making and the new tasks and activities they have to undertake. Furthermore, carers experience difficulties with changes in resources (e.g., lack of time, finance, conflicting demands) causing difficulties in engaging with previously valued goals and activities. There is clear evidence to suggest a strong association between depression and deficits in problem-solving ability (Nezu, 1987). Studies indicate that depressed participants are less able to generate multiple solutions to interpersonal problems and the strategies that are produced are less effective than those generated by non-depressed participants, with similar results were found in relation to making decisions (Nezu, 1987). Problem-solving theory and supporting research has long been considered a potential method of behavioural change (S'Zurilla & Goldfried, 1971). A variety of therapeutic techniques have been developed based on problem solving theory and problem solving therapy is commonly used a therapeutic technique within CBT (Nezu, 2004).

In general, problem solving therapy provide patients with a systematic way of identifying problems, generating potential solutions, choose the most appropriate solution likely to be successful, develop a concrete plan to execute the solution, test out the solution and evaluate the success of the solution (Cuijpers, van Straten, & Warmerdam, 2007b). In addition, problem solving therapy has a well-established evidence base for treating depression (Cuijpers et al., 2007b; Bell & D'Zurilla, 2009). As such problem solving (see Nezu, 2004) may help carers identify solutions to the difficulties they encounter within the caring role. Facilitation of adaptive and effective problem solving when dealing with difficult and stressful situations may reduce levels of depression as well as the worry and anxiety often reported by carers (see Bell & D'Zurilla, 2009).

4.4.4 Limitations

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First, trustworthiness of the data was not established due to the time and resource limitations experienced in conducting a PhD and the short timeframe to develop the CBT self-help intervention. As such, the level of confidence that can be held in the analysis has been limited. Establishing trustworthiness is an assessment of quality within qualitative research ensuring findings represent the reality of participants (Johnson & Waterfield, 2004). Steps to establish trustworthiness could have included triangulation by observation (Lietz, Langer & Furman, 2006) whereby a researcher not associated with the team performs a brief analysis of the data and compares the results against the initial results (Russell & Kelly, 2002). Additionally participants could have been sent summaries of study findings to comment on the accuracy of the data analysis (Johnson & Waterfield, 2004).

An additional limitation concerns the lack of structured clinical interview to determine a diagnosis of depression or anxiety. As such, there is a possibility that although carers were psychologically distressed, with elevated symptoms of depression and anxiety, their experiences may not represent a clinically depressed or anxious informal carer population.

A further limitation relates to the varied length of time participants had spent in the caring role, ranging from 4 months to 22.3 years with a mean duration of 4 years and 9 months. Therefore, the majority of informal carers were in the 'long-lasting adaptation at home' phase (Cameron & Gignac, 2008). However, little research has been conducted examining the long-term recovery trajectory post-stroke (Arntzen, Borg, & Hamran, 2014) or longitudinal changes in the impact of caregiving (Gaugler, 2010). Longitudinal adjustment in informal carers of stroke survivors may be curvilinear as opposed to linear and as such complex trajectories are expected (Gaugler, 2010). For example, significant health transitions may occur during the trajectory following events such as falls, hospitalisations and other critical illnesses. Therefore stroke informal carer outcomes will differ around these life transition events (Gaugler, Roth, Haley, & Mittelman, 2008). Therefore carers interviewed may have been at very different time points along the caring trajectory with no details taken surrounding whether any key health transitions had recently taken place that may have impacted upon carer experience. As such, a future study may wish to purposively sample informal carers of stroke survivors who had been in a caring role for a similar length of time, thus increasing the homogeneity of the sample. A further modification may include only recruiting informal carers providing support to stroke

survivors with low, or high, levels of stroke severity. Indeed, there is some evidence to suggest that there is a relationship between increased carer burden and increased neurological, physical, functional (Bugge et al., 1999) and behavioural impairment (Pinquart & Sörensen, 2003a). As such, limiting the sample to those caring for stroke survivors with a more specific level of post-stroke severity may further increase the similarity of the sample and improve generalisability of results to carers of stroke survivors in a similar situation.

Finally, the study recruited from community based stroke and carer organisations, therefore participants may not be representative of carers not already engaged in community based organisations, further limiting the generalisability of findings.

4.4.5 Executive Summary

Study Two successfully identified a number of key difficulties experienced by depressed and anxious carers of stroke survivors. Subsequently, a number of psychological techniques to be utilised within the CBT self-help intervention, to target the identified difficulties, have been posited. First, carers find it difficult to adapt to the new roles, relationships and responsibilities accompanying the provision of informal care. Subsequently, former roles, relationships and responsibilities are lost, leading to carers no longer engaging in goals and activities of importance and value. The 'selection, optimisation and compensation' model (Baltes et al., 1999) represents a model that may be integrated into the CBT self-help intervention to assist carers in adapting to the caring role. Specifically the model assists people in maximising their achievements of goals, despite the experience of loss (Boerner & Jopp, 2009), and may help carers select and achieve goals despite their new limitations. The 'selection, optimisation and compensation' model could be integrated into a goal setting approach, currently used as a CBT self-help intervention (Farrand & Foord, 2013). Second, carers have very little time for themselves outside the caring routine. Therefore, carers disengage from previous activities of value and importance, losing the opportunity to engage in behaviours associated with improved mood (Hopko et al., 2003). Behavioural activation represents a psychological technique that reintroduces activities, increasing access to positively reinforcing activities that bring pleasure, satisfaction and achievement (Hopko et al., 2003). As such, behavioural activation is an additional technique that will be utilised in the CBT self-help intervention. Finally, carers experience difficulties

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in making decisions and are overwhelmed by the responsibility of the caring role and news tasks accompanying caregiving. Subsequently, an additional psychological technique that will be utilised in the CBT self-help intervention is problem solving (Nezu, 2004). Problem solving helps people work through problems in a systematic and structured way (Cuijpers et al., 2007b) and reduces depression and anxiety experienced in stressed situations (Bell & D’Zurilla, 2009).

Table 4.4

Main findings from the qualitative investigation of difficulties experienced by depressed or anxious informal carers of stroke survivors to inform the CBT self-help intervention

Main Findings	Informing the CBT self-help intervention
Carers experience difficulties adapting to the caring role, including giving up roles and goals of importance, without replacing these activities with new, or adapted, goals of similar value and importance	The ‘selection, optimisation and compensation’ model (SOC; Baltes, 1991; 1997) will be integrated into the CBT-self-help intervention, using a goal setting technique, to help carers select goals they can still achieve despite the significant limitations placed on their life providing care.
Carers experience difficulties with gaining balance in their life and give up activities outside of the caring role. As such, carers are not gaining the opportunity to engage in activities that may provide them with a sense of pleasure or achievement.	Behavioural activation (Hopko et al., 2003) will be adopted as a specific technique within the CBT self-help intervention, to assist carers in re-engaging with activities outside the caring role and increase the opportunity for positive reinforcement.
Problems were encountered by carers concerning decision making, undertaking new activities and tasks and problem solving.	Problem solving (Nezu, 2004) will be used a technique within the CBT self-help intervention to support carers in terms of overcoming difficulties they may experience carry out new tasks and responsibilities.

4.5 Conclusions

By providing a clear account of the difficulties experienced by carers of stroke survivors experiencing mild-moderately severe levels of depression or anxiety Study Two has identified three psychological techniques that could be used within the CBT self-help intervention: (a) goal setting with goal adaptation following the SOC model; (b) behavioural activation; and (c) problem solving. The identification of effective psychological interventions that map onto the difficulties experienced by carers of stroke survivors provide the first step towards development of a psychological treatment for carers.

In Chapter Five the researcher continued working within the development phase of the revised MRC complex interventions framework (MRC, 2008) and examined the positive coping strategies utilised by non-depressed and non-anxious informal carers of stroke survivors through semi-structured interview.

CHAPTER FIVE: Coping with the provision of informal care to stroke survivors: A qualitative investigation of positive coping strategies utilised by non-depressed and non-anxious informal carers of stroke survivors.

5.1 Background

5.1.1 Overall Aims

This present chapter presents results of the third study conducted to inform the development phase of the revised MRC framework (MRC, 2008). Study Three focused on the identification of further appropriate theories to enhance the content of the new CBT self-help approach for informal carers of stroke survivors. As outlined in Chapter Two, this study was designed to:

- Identify positive coping strategies used by non-depressed and non-anxious informal carers of stroke survivors through the use of semi-structured interviews.
- Search the literature in order to identify psychological theories that may be incorporated into the intervention to help depressed carers utilise positive coping strategies used by carers without depression or anxiety.

5.1.2. Existing Literature

Although provision of informal care to stroke survivors is associated with burden, strain, depression and anxiety (Ilse et al., 2008; Visser-Meily et al., 2008; Balhara et al., 2012) some informal carers report more positive consequences of the caregiving role, such as increased self-esteem (Kruithof, Visser-Meily, & Marcel) improved relationships and providing their lives with a sense of meaning (López, López-Arrieta, & Crespo, 2005). In addition, an association between carers adopting approach-coping and problem-focused coping strategies and reduction of carer burden has been found, with calls for interventions to be based on helping informal carers develop coping strategies such as problem solving and assertiveness (del-Pino-Basado et al., 2011; Yeung, Lui, Ross & Murrells, 2007). Other studies have found that active coping strategies are associated with positive outcomes in relation to informal carer burden and depression (van Puymbroeck & Rittman, 2005; Visser-Meily et al., 2009). Given the clear association between informal carers' ability to adopt positive coping strategies and reduced levels of burden and depression there have been calls to gain a greater appreciation of how informal carers cope and adapt

to the caring situation that may inform the content of effective psychological interventions (Garlo et al., 2010).

However, there is currently a lack of qualitative research aimed at gaining a detailed appreciation of the specific coping strategies adopted by informal carers (Greenwood et al., 2009). Furthermore, although quantitative research has identified the types of coping strategies used by carers, there have been proposals for more in-depth qualitative investigations of the experience of coping in the caring role (Quinn, Murray, & Malone, 2014). Indeed, a recent systematic review and meta-synthesis found only one qualitative study seeking to gain an understanding of the specific coping strategies utilised by informal carers of stroke survivors (Quinn et al., 2014). Existing studies have tended to focus on understanding the general experience of being a carer of a stroke survivor rather than aiming to gain a detailed appreciation of how informal carers cope with the caring role (Quinn et al., 2014). It is therefore important for more studies to be conducted in order to understand how carers cope with the caring role in order to investigate how these coping mechanisms may be facilitated in carers who are struggling to cope with the caring role (Quinn et al., 2014).

Given the limitations of the existing literature, a clear need was identified for further research in order to identify positive coping strategies utilised by informal carers of stroke survivors. In order to gain an understanding of the more positive aspects of the caring role a positive psychology approach (Bolier et al., 2013; Mitchell et al., 2009; Schueller et al., 2014) was adopted. Positive psychology was born out of criticisms pertaining to the field of psychology focusing on the negatives when treating mental health difficulties (Seligman & Csikszentmihalyi, 2000). Instead the goal is the promotion of wellbeing as the pathway are strategies that promote positive thoughts, behaviours or feelings, as opposed to targeting changing maladaptive patterns of behaviour or negative thinking (Schueller et al., 2014). Indeed, the development of positive coping strategies may protect people from the development of mental health difficulties (Layous, Chancellor, & Lyubomirsky, 2014). Recently there have been calls for translating positive psychology interventions into treatments for people with depression (Layous, Chancellor, Lyubomirsky, Wang, & Doraiswamy, 2011) and to be translated into self-help materials to increase access (Schueller & Parks, 2014). Whilst the CBT self-intervention will be targeted at reducing depression and addressing negative patterns of behaviour, thoughts and

feelings (and therefore not a positive psychology intervention per se) it is hoped that adopting a positive psychology approach to promote more positive behaviours will further strengthen the CBT self-help approach.

5.2 Methods

5.2.1 Study Aim

To gain an in-depth understanding of the positive coping strategies used by non-depressed and non-anxious informal carers of stroke survivors.

5.2.2 Study Design

5.2.2.1 Underlying paradigm. As used in Study Two (Chapter Four) pragmatism was adapted as the underlying research paradigm.

5.2.2.2 Theoretical framework. Consistent with Study Two, a thematic analysis approach was adopted (Braun & Clarke, 2006).

4.2.2.3 Data collection. Data was collected through semi-structured interviews, using an interview schedule (Appendix 5.1) targeted at understanding the positive coping strategies used by carers of stroke survivors. Modification of the interview schedule took place iteratively as the interviews took place. For example, carers displayed difficulties in identifying specific coping strategies utilised with amendments made to the interview schedule to focus on difficulties and challenges experienced in the caring role and what carers did in these situations to help manage. All interviews were conducted by JW and lasted between 48 and 90 minutes.

5.2.2.4 Sampling. A purposive sample was used with participants recruited from community based stroke and carer organisations throughout the United Kingdom (The Stroke Association; Different Strokes; Carers UK; Headway and Unite Devon). Consistent with Study Two, purposive sampling was used to identify adult informal carers of stroke survivors who considered themselves to be coping well with the caring role, and not experiencing symptoms of depression or anxiety. Pre-selection of groups with characteristics of relevance to the research question (Pope & Mays, 1999) may improve the validity and generalisability of findings (Sharma, 1997). Recruitment was stopped once it was felt saturation was reached concerning positive coping strategies experienced by non-depressed and non-anxious carers of stroke survivors.

5.2.2.5 Participants.

Participant inclusion criteria.

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- Informal carer of a stroke survivor.
- Aged 16 years or over.
- Male or female.
- Displaying none-to-mild levels of depressive symptoms relating to a score between 0-9 on the PHQ-9 (Kroenke, Spitzer & Williams) or none-to-mild levels of anxiety as indicated by a score between 0-9 on the GAD-7 (Spitzer, Kroenke, Williams & Löwe, 2006).

Participant exclusion criteria.

- Scored two or more on the suicidality question on the PHQ-9;
- Consuming above 31 units of alcohol for men and 22 for women per week;
- Dependent of street drugs, as defined by using street drugs every day;
- Current / past psychosis or bipolar disorder;
- A hearing or reading impairment that would prevent them from taking part in a qualitative interview.

5.2.2.6 Procedure. Potentially interested participants were referred to the researcher and telephoned in order to discuss the study background and procedure. If interested, participants were sent the following in the post: study invitation letter; participant information sheet; consent form and questionnaire. The questionnaire was the same as the questionnaire used in Study Two. Once the consent forms and questionnaires were received in the post JW advised participants as to their eligibility for the study and arranged interviews with eligible participants.

5.2.2.7 Setting of data collection. Dependent on participant preference, interviews were conducted over the telephone or face-to-face in the participants' home or a convenient community based setting.

5.2.2.8 Data analysis. All interviews were audio recorded and transcribed verbatim by JW. The same thematic analysis approach was used as Study Two. NVIVO9 and NVIVO10 (QSR International, 2010; 2012) software were used to assist with the data analysis in terms of initial coding, grouping of codes and generation of themes within and across the data set.

5.2.2.9 Ethical considerations. The study was approved by the University of Exeter Psychology Ethics Committee (Application 2010/506). NHS Ethical approval was not required as all participants were recruited from community settings. All data

was stored securely and confidentiality, in line with the Data Protection Act (Parliament, 1998). Informed consent for participation was obtained.

5.3 Results

5.3.1 Participants

The recruitment flow of participants through the study, including withdrawals, can be seen in Figure 5.1.

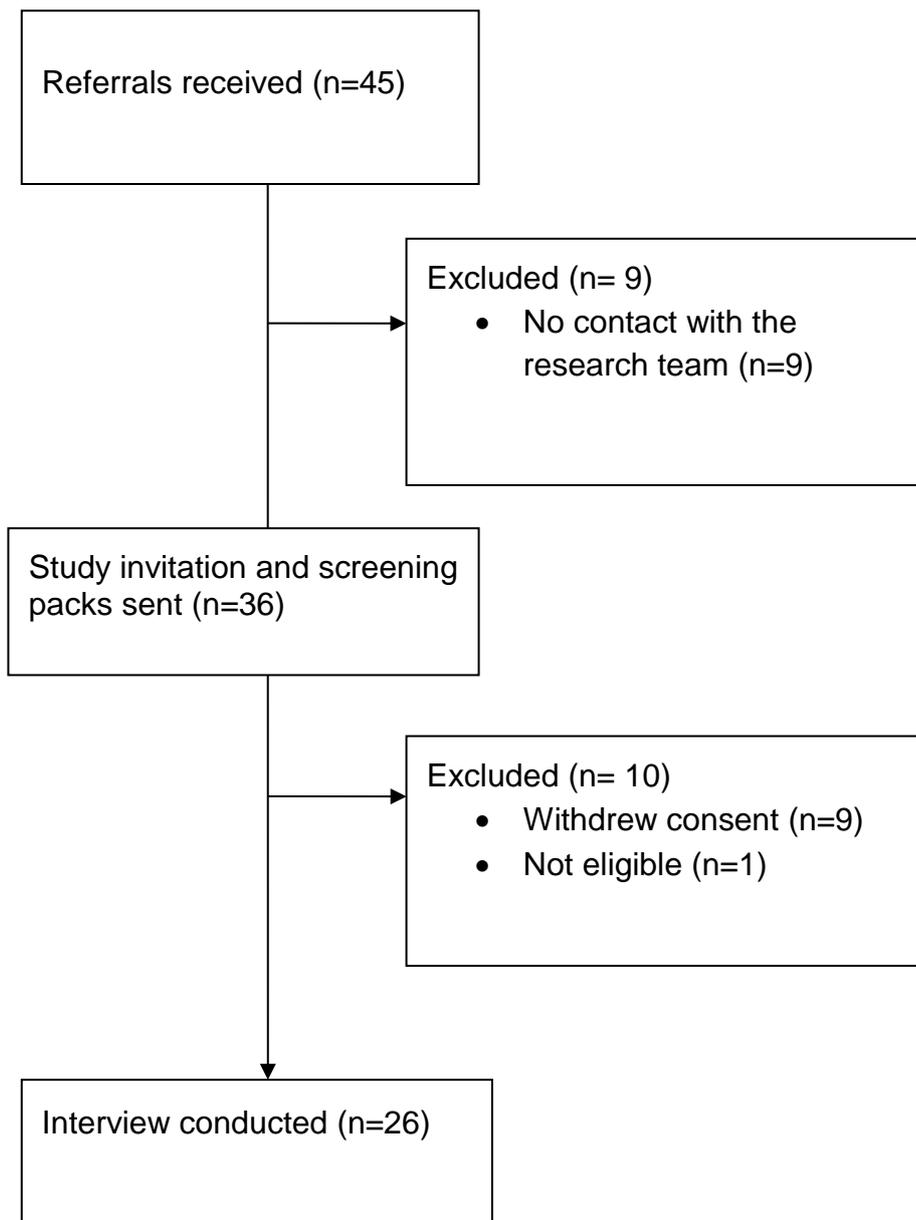


Figure 5.1. Recruitment flow

CBT SELF-HELP: INFORMAL CARERS OF STROKE SURVIVORS

A final sample of 26 twenty-six participants was included in the analysis (see Table 5.1 for participant characteristics). In addition, selected participant characteristics are presented (Table 5.2) to aid interpretation of quotes to support themes generated in the analysis, with names changes and ages provided in bandings to protect confidentiality.

CBT SELF-HELP: INFORMAL CARERS OF STROKE SURVIVORS

Table 5.1

Participant Characteristics

Characteristic	n	%
Sex		
Male	3	12
Female	23	88
Ethnicity		
White British	24	92
Irish	1	4
White and Asian	1	4
Relationship Status		
Married	18	69
Widowed	4	15
Live-In-Partner	3	12
Single	1	4
Annual Household Income		
£0-£9,999	1	4
£10,000-£19,999	10	38
£20,000-£29,999	10	38
£30,000-£39,000	2	8
£40,000-£49,999	1	4
Missing	2	8
Employment Status		
Full time caregiver	9	35
Retired	8	31
Homemaker	3	12
Working, part-time	3	12
On disability or extended medical leave	1	4
Student	1	4
Working, full-time	1	4
Highest Level of Education		
None	6	23
O Levels / GCSEs	8	31
NVQ/GNVQ	1	4
A Levels / AS Levels	3	12
First Level Degree	3	12
Postgraduate Certificate / Diploma	4	15
Master's Degree	1	4
Relationship to Stroke Survivor		
Spouse / Partner	22	85
Son/ daughter	3	12
Friend	1	4

CBT SELF-HELP: INFORMAL CARERS OF STROKE SURVIVORS

Mean Hours Provision of Care per Week

More than 30 hours	15	58
20 to 30 hours	4	15
10 to 20 hours	5	19
Under 5 hours	2	8

	<i>M</i>	<i>SD</i>	Range
Mean age	63.5	13.7	18-81
Mean Units of Alcohol Consumed Per week	3.6	6.8	0-28
Mean PHQ-9 Score	2.1	2.2	0-8
Mean GAD-7 Score	1.2	1.2	0-5
Mean Years Caring	6.5	3.7	0.3-14.2
Mean Hours of Help Services Received in Home per Week	1.1	2.1	0-7

Table 5.2

Details of Sample

Name	Age	Relationship to the stroke survivor	Length of time caring
Diane	70-80	Spouse / Partner	4 years, 3 months
Sandra	50-60	Spouse / Partner	1 year, 6 months
Janice	70-80	Friend	1 year, 6 months
Rose	70-80	Spouse / Partner	6 months
Nicole	60-70	Spouse / Partner	2 years, 3 months
Helen	50-60	Spouse / Partner	1 year, 3 months
Rebecca	70-80	Spouse / Partner	7 years, 6 months
Teresa	60-70	Spouse / Partner	7 years, 3 months
Judy	70-80	Spouse / Partner	4 years, 9 months
Peggy	60-70	Spouse / Partner	3 months
Charles	70-80	Spouse / Partner	12 years
Nancy	70-80	Spouse / Partner	6 years, 9 months
Mary	70-80	Spouse / Partner	6 years, 7 months
Jessica	60-70	Spouse / Partner	12 years, 5 months
Ann	60-70	Daughter	3 years
Grace	60-70	Spouse / Partner	2 years, 1 month
Henry	16-20	Son	7 years, 3 months
Karen	70-80	Spouse / Partner	4 years, 2 months
Emily	60-70	Spouse / Partner	9 months
Janet	60-70	Spouse / Partner	4 years, 5 months
Charlotte	60-70	Spouse / Partner	5 years, 8 months
Joyce	40-50	Spouse / Partner	7 years, 7 months
Edith	70-80	Spouse / Partner	14 years, 2 months
Peter	80-90	Spouse / Partner	11 years, 1 month
Emma	50-60	Daughter	5 years, 8 months
Hazel	60-70	Spouse / Partner	11 years

Note. Pseudonyms used and ages provided in bandings in order to protect confidentiality.

5.3.2 Qualitative Analysis

Five key themes emerged from the data concerning key positive coping strategies used by non-depressed and non-anxious informal carers of stroke survivors: “Balance”; “Adapting to the caring role”; “Push, push, push”; “Seeking social support” and “Looking for the positives” with subthemes derived (Table 5.3).

Table 5.3

Major Themes and Subthemes

Major themes	Subthemes
Balance	“Time for me” Planning Keeping up activities
Adapting to the caring role	Acceptance Prior experience Adapting activities and finding new activities
“Push, push, push”	“I’m the carer from hell” Assertiveness
Seeking social support	Actively seeking support and advice Social comparison
Seeing things in a different light	Looking for the positives Laughter / humour

5.3.2.1 Theme One. Balance. Seeking balance in their lives was a significant coping strategy reported by non-depressed and non-anxious carers of stroke survivors. Three subthemes were generated in terms of how some type of balance was maintained in carers’ lives.

Subtheme One: “Time for me”. Although carers recognised that a significant difficulty was trying to balance the caring routine with other activities they emphasised the importance of trying to find time for gaining the opportunity for a break from the caring role. Carers reported that often this would be a short break but

this was still important to maintain in order to gain space to think, to reflect, problem solve, relax and switch off from the responsibilities of caring:

“This may sound very strange, having the dog and just walking away from it for half an hour, even if I just went out in the field at the back ... it was just time on my own and I think you’ve got to have a break. It might only be for half an hour but it’s that break of you looking after somebody else, it just takes that edge off of it.” (Emily).

“I think the biggest thing is to have some time for yourself you know. Even if it’s just a couple of hours each week”. (Judy).

Having time for themselves helped carers maintain some form of independence and freedom. There was a recognition that it was important to try and balance the needs of stroke survivor and the needs of the carer and that time out of the caring role was important to maintain carers own health and therefore continue caring for the stroke survivor. In order to gain time for a break they used a number of resources including respite, day care, stroke clubs, community, groups, family and friends:

“I think respite is the best thing on this planet frankly ... just for that week or ten days you are not getting up at the crack of dawn, you are not thinking ‘first thing I’ve got to is get him up, wash him, blah blah blah’ and you suddenly find yourself, the day seems so free and long, you feel quite strange. Even though you’ve probably got a decorator in or something you still feel terribly free. That’s the word, free.” (Nancy).

Although use of respite and day care centres was a clear strategy used by some carers there were also disconfirming cases whereby carers felt that they would not be able to enjoy their free time as they would feel guilty for putting the stroke survivor into respite as the stroke survivor would not be happy:

“I would never bung him into respite with a lot of dribbling, I couldn’t bear it for him. And he would hate it. And I know some operate like that but then I couldn’t stand the guilt, we talked about that earlier, I couldn’t stand the guilt of him being dumped in a circle I just could not. I wouldn’t then enjoy my burst of freedom. (Jessica).

Subtheme Two: Planning. Having some form of routine around the caring role was really important in order to facilitate planning and organisation. Planning was an important strategy in order to get everything done that they needed to:

"I think first you should get yourself into a routine. I really can't express, your medication, your whole day, you really got to set yourself a timetable because if you don't you'll be running round like headless chicken all day." (Emily).

"I'm very tidy and clean and organised and I like ... well everything in its place and that includes him (laughter)". (Nancy).

However, whilst it was recognised that having a routine and planning was important to get the tasks associated with the caring role done planning actually led carers to be able to facilitate some form of balance in their lives. Carers planned their routine in order to ensure they were getting a break, doing activities for themselves and activities with the stroke survivor. Carers voiced that planning activities also allowed them to prioritise activities in order to get a break, or do activities for themselves. As such, they were not just planning around the stroke survivor, but planning around themselves. In addition, planning was also important in order to do activities together with the stroke survivor, for example, if going out for a meal transportation, parking, choosing somewhere with good disabled access were all key considerations:

"I plan a lot as to what I am going to do each day so that again in the hope that by planning and I can see how each day is going to work out. I can perhaps have a clear slot during the afternoon or early evening, which will be mine." (Nicole)

Planning was also considered helpful by carers in order to schedule activities to look forward to.

"I think it's the thought that I've got a holiday coming up. I think having something to look forward to is helpful. We were a bit disappointed, especially my husband, because we actually had something booked for the weekend before we came out of hospital so we had to cancel that and had really been looking forward to that. So I think having a holiday to look forward to is something for both of us to take our minds off things." (Peggy).

Subtheme 3: Keeping up activities. In order to cope with the caring role carers reported the importance of keeping up activities of value and importance to them, such as hobbies, socialising with friends, sport and exercise and other interests and activities that they enjoy. Carers spoke about keeping up activities providing a sense of enjoyment and independence. They also felt continuing

activities helped provide energy and to keep them going in the caring role. Keeping up activities helped carers feel that they had a life outside the caring role and although they recognised that their lives had changed trying to keep up with activities outside the caring role helped maintain some sense of normality. As well as keeping up their own hobbies and interests they also kept up interests with the stroke survivor which was recognised as being important for both the stroke survivors own health and also their relationship:

“I mean we're going to the theatre on Thursday with friends, we're all coming back here for a takeaway, and Friday we're going to a charity quiz with our friends across the road, Saturday we're going to the [city's name] literary festival I think if I can work up the energy by then and then we're going out for dinner with friends on Saturday night, we have a busy life. And that helps me.” (Jessica).

“I go out with my husband a lot. Like today I've been out, I took him out personally because I think he'll settle down for an hour when we come in if I do something like that because it's boring for him as well. It can be boring for him and more so because I'm doing jobs and filling the time, so really I endeavour to then take him with me as much as I can.” (Karen).

Keeping up activities also allowed carers the chance to relax, escape and distance themselves from the demands of the caring role. Carers who continued to work, spoke of the importance of working in order to maintain their sense of identify and to provide a break from the routine of the caring role:

“I suppose my escapism is reading. I've always been a great reader and I belong to a book club, that's another thing I do, but I've always read and read and read and you know you get into a good book and I'm lost and away”. (Jessica).

“Almost from the outset you were very conscious about not just becoming 'a carer' and that you need to retain your own true identity, your own self-identity, and going to work meant that you could go back to being yourself, people just saw you as who you were in your role and they didn't know what was going on so that was that was really helpful.” (Joyce).

4.3.2.2 Theme Two: Adapting to the caring role. Carers spoke about a number of positive coping strategies utilised to help adapt to the role of being a carer. Although carers recognised that their lives had changed they utilised various

techniques to help adapt to this significant life transition. Three subthemes were generated pertaining to adapting to the caring role:

Subtheme One: Acceptance. Acceptance of the situation they were in was common amongst the carers. Carers spoke about how acceptance takes time and over time you learn to live with the changes caring imposes on your lives and recognising that things cannot be changed. They spoke about taking each day at a time and “just getting on with it”.

“I suppose by just being honest about it you know, there’s nothing I can do about it we’ve just got to take each day at a time and get on with it.” (Ann).

“You just have to accept it and carry on as best you can and adapt really.” (Sandra).

“I have no choice and I mean what can one do, one can hardly sort say ‘oh you’ve had a stroke I’m going to pack up my rucksack and go.’ You can’t do that.” (Nancy).

For some carers the ageing process was a facilitator in terms of acceptance, citing that life would have changed anyway by virtue of getting older. Acceptance of the caring role was easier if their life situation had not drastically changed, for example, the carer and stroke survivor had already slowed down, or if carers had not left the house much before the stroke, or the tasks and responsibilities of the caring role were not new ones.

“Plus we’re getting old you see and you forget about it. It was his birthday ... it was his birthday and he’s 76 and I’m 75 this year so we haven’t done badly not really and we manage.” (Rose).

“We’re both in our 70s, well [stroke survivor] 78 next month so yeah we’re not young. You never know what you are going to be like when you’re older. It just, is one of those things. If it was a younger person yes I am sure it would hit a lot harder.” (Diane).

Another facilitator for acceptance was the ‘sense of duty’ carers felt to care for their loved one. Spouses felt that it was their duty to care for the stroke survivor with some stating that they were not a carer but a partner, a wife or husband:

“To me you’re not a carer, you’re a wife, and it doesn’t matter what’s thrown at you, I’m sure if it was the other way round he would do it for me. So I don’t look at it as care, I’m his wife and unfortunately he’s ended up like this and you just look after him”. (Charlotte).

Subtheme Two: Prior experience. Adaptation to the caring role was further facilitated by prior experience. For example, having worked in a caring profession, previous experience of providing informal care to others, or indeed, if the stroke survivor had experienced other chronic conditions before the stroke. Prior experience helped in two main ways. First, it helped carers with the practical aspects of caring for someone with a stroke, enhancing carers ability to problem solve around care related tasks. Second, helping prepare carers emotionally, carers knew what to expect and recognised immediately how different life was going to be. Although becoming a carer for a loved one was still a huge transition carers with prior experience recognised that drawing on upon what they had learnt previously was a successful way of coping and managing the caring role.

“I mean the thing is because I was a physiotherapist before it wasn’t such a shock as it might be to some other people. I’m perfectly capable of caring for somebody. I know how to handle someone who’s had a stroke which is a big advantage, so I knew what he should be doing, and I was keen to encourage that. So I wasn’t fazed by him coming home, I was perfectly happy for him to come home and help him in any way he needed.” (Helen).

“As soon as he had the stroke I knew life was going to change so I did go out and proactively find groups to join. He belongs to one this morning, goes to Different Strokes this afternoon and he goes to a speech class which is now going to come to an end at [hospital’s name] and he goes to a day centre.” (Mary).

Subtheme Three: Adapting activities and finding new activities. Although carers acknowledged that there were some activities they and the stroke survivor could no longer do, they pro-actively came up with new ways of being able to carry on activities that they enjoyed or were important to them. Alternatively carers found completely new activities that they could do within the limitations of the caring role and the impact of the stroke. Typical limitations included limited time, limited finance and the physical health difficulties of the stroke survivor. However carer’s problem solved around these limitations by adapting activities so they could still manage them. As well as adapting activities for themselves carers also adapted activities for the stroke survivor in order to be able to carry on doing things together. Adapting activities helped maintain a sense of normality and helped carers try to maintain the same relationship they had with the stroke survivor prior to the stroke. Finding new

meaningful activities for the stroke survivor to do was also considered important for the stroke survivors' wellbeing.

"We became Travel Lodge fans, because they do the nine pound specials. So we would plan holidays. We managed to do [country name] on one-hundred-and-twenty quid, just because it was another country." (Joyce).

"We used to walk for pleasure, rucksack walking, proper walking, and holiday walking with rucksacks. Well obviously we can't do that but we still do a lot. We do try to walk every day albeit a mile or less with his walker moaning because he gets tired (laughter)." (Nancy).

In addition, some carers recognised that they had lost roles that used to be important to them, for example having to give up work. Carers reported finding alternative activities that could give them a similar sense of value, for example, running stroke clubs, getting involved in research and attending classes:

"To be part of that research project at [city name] university made one feel valued, it made one feel like an intellectual human being again." (Rebecca).

4.3.2.3 Theme Three: "Push, push, push". The third theme relates to being proactive. Carers took direct action in terms of motivating the stroke survivor and gaining support from healthcare professionals as well as social care. Two subthemes related to "push, push, push".

Subtheme One: "I'm the carer from hell". First, carers recognised that the person they cared for lacked motivation and confidence, both common post-stroke complications. As such, carers utilised a number of strategies in order to push the stroke survivor. Second, carers spoke about the importance of observing the stroke survivor in order to recognise what tasks they could do, and then letting them. They would encourage stroke survivors to do certain activities, and instil the stroke survivor with confidence and reassurance that they could do the activity. This helped with keeping the stroke survivor active, independent and also carers would occupy the stroke survivor with activities that would also help the carer, for example, dusting, washing up, mixing cake dough or making a cup of tea. They also felt it was important to encourage the stroke survivor to keep on doing things for themselves so that the carer did not slip into the role of being a 'slave' or a 'nurse' to the stroke survivor, or for the stroke survivor to slip into the mind-set of "*I'm disabled I need everything doing for me*" (Teresa).

“I let him do what he can, there’s very little now but if there’s a little bit of washing up, if it’s only like a couple of cups, a couple of plates, then he can stand at the sink for five minutes and do that. I don’t think I’ve got many cups and plates now that haven’t been chipped but I let him do it because if I stop doing it, letting him do it, then he would you know ... there’d be nothing he can do.” (Rebecca).

Carers particularly pushed stroke survivors around rehabilitation exercises and keeping up activities. They recognised that this was good for the physical and mental health of the stroke survivor but also gave them a break from the caring role. In addition, if the stroke survivor was still doing activities carers recognised this provided the stroke survivor with things to talk about which was important for communication and their relationship. Whilst some carers used gentle encouragement other carers were more assertive with their approaches to motivating the stroke survivor to do things.

“I’m the carer from hell ... If you are passive, very passive, believe you me you end up as a servant. I have this vision of upstairs downstairs and being summoned but I think the strong women survive. I really believe that because only by pushing and pushing, because they were quite happy retreating to a shell. I think [stroke survivor’s] idea of a perfect day to be honest would be not to get up.” (Nancy).

Carers also recognised the importance of the stroke survivor keeping up mobility and trying to make a better recover, or to not decline, in order for the stroke survivor to stay at home for longer, rather than ending up in a care home.

“I’d said to him ‘well, look you’ve got to be able to walk because if you become immobile I simply won’t be able to cope’ and I used that as a thing to say. He’d say ‘I really don’t want to do this today’ and I would say ‘well it’s so important, you must be mobile, if you don’t keep mobile I won’t be able to look after you at home.’” (Rebecca).

Subtheme Two: Assertiveness. Carers frequently spoke about lack of provision of adequate health and social care, both in terms of the needs of the stroke survivor and their own needs. However, in order to overcome barriers to accessing health and social care carers were assertive, demanding and would not take ‘no’ from professionals as an answer. Carers spoke about the importance of being aware of what support they were entitled to and getting it. In some cases they

provided examples such as being given an inappropriate appointment time with a consultant and requesting it to be changed, rather than just accepting. Other carers took very direct action such as changing consultants, GP surgeries and even moving to a new catchment area for better health care. Overall carers would not put up with inadequate care and support and would fight until suitable care and support was provided.

"I probably nagged the consultants quite a bit. In fact one apparently, [Stroke survivor] had to have a lumbar puncture because he got meningitis before he was discharged because of the drain in his head, they can cause an infection, and apparently there was a doctor who was doing the lumbar puncture who actually said to [Stroke survivor] 'if this ever happens to me, I hope I have a wife who fights like yours has'. I hope I wasn't too aggressive with them. But I didn't let them rest." (Jessica).

I got really cross one time because I'd gone in to [the hospital] and [Stroke survivor] was quite upset and he said 'they just want me out of here, they think I'm putting it on' and I left a message on the ward for the consultant to phone me. And he didn't. So I phoned his secretary and I explained that I'd left this message and she said 'it's very unlike him' and I have to be honest and say up to this point I did not like the consultant, I find him pompous, rude and very condescending. So I hadn't been surprised that he hadn't been bothered to ring me. But about quarter of an hour later he did ring me." (Teresa).

However, carers did report that it could be difficult having to fight all the time and become confrontational towards all professionals:

"It was like a continual, if you can call it confrontation, fight, all the time ... and it makes you nasty, it changes your personality because since you've had it all the time. The minute you'd approach somebody like that [consultant], you're looking for a confrontation because you know you're going to get it, because you find with the vast majority of people you cannot talk things over rationally." (Charles).

Additionally, in some cases, despite pushing adequate support was not available and carers paid for additional support privately, which is a luxury only some can afford:

"I jumped up and down and shouted very loudly that he really did need some more physiotherapy but they would give him instructions about what to do but

his memory for them was nil ... so there was no point in him being given lists of exercises ... I found I was under such strain I couldn't remember half of them either so in the end I found a private physiotherapist, at vast expense, so that was costing me sixty pounds a week, that was really the attendance allowance money and she came to him every week and she was absolutely wonderful with him and really pushed him." (Rebecca).

Additionally, carers actively sought help and support from health and social care. They looked for support and asked for it and expressed the importance of not shying away from help and support when you need it. Carers recognised that they were ill-equipped in the beginning for the caring role however actively looked for information in order to improve their understanding about stroke and what support was available. Typically they utilised a number of resources in order to find out information about what support was available, including asking health professionals, social services, community groups and other carers in a similar position.

"I think it's important that you know what's out there, it's no good sitting in the house saying 'there's nothings out there' because there is, but if you want it." (Charlotte).

"I'm quite dominant, and quite a leader, so I want to know the facts and I want to be given the facts and I will take the lead if I don't get somebody to show me. But there must be hundreds of carers and spouses of stroke who shrivel up and shrink in the background and have to put up with things because they don't realise that is more help out there" (Edith).

4.3.2.4 Theme Four: Social support. Carers spoke about the importance of social support from stroke clubs, family, friends and neighbours. Social support was important practically, emotionally and also important to facilitate social comparison. Two subthemes related to social support:

Subtheme One: Actively seeking support and advice. Carers spoke about the importance of actively seeking support from a variety of people socially. Some used stroke clubs, carer groups and the Stroke Association and found this support helpful in facilitating contact with people in a similar situation. Carers used these avenues to ask for advice and tips about the caring role. In addition, it was important to actively seek out people in a similar situation who would have more understanding of the situation. For example, some carers spoke about how whilst they had their own friends, it was important to also make new friends who would understand better

the limitations the stroke had put on their life and ability to do certain activities. Other carers did not attend the stroke groups but did find that stroke clubs gave them a break from the caring role as the stroke survivor would be well looked after during that time. As such, support from people in a similar situation was helpful both practically and emotionally.

“The groups have been a big thing to us, they really have been a big help to us, and we’ve made lots of friends. We can always phone one another if we need to chat. But the groups I think is our biggest thing because we’ve still got our old friends but they don’t understand your change of life, and there’s lots of things you can’t do, that you use to do, and you can’t go places that you used to and they don’t fully understand that.” (Charlotte).

However, carers also emphasised that it was important to both ask and accept help from family and friends. Some carers spoke about providing friends and family members with information about the consequences of stroke in order to help facilitate understanding. Again, contact with family and friends was considered important for both the provision of practical and emotional support. However, it was also recognised that you could not over rely on the support of family and friends and there was a fine balance between seeking appropriate help and support and over dependence on them. For some carers, family members did not live locally however the keeping in contact via the phone or Skype was important. Just knowing that their family were there to support if they needed them to be was enough.

“Talk to other people, if you’ve got friends they’re there for the good and the bad. Ok you can’t go on and on forever and ever but friends actually want to help. Don’t shut them out and don’t bore them to death either. But don’t shut them out.” (Jessica).

“I ring my sister up every day, which I never, I mean I used to ring my sister every so often but since [Stroke survivor] had his stroke I do talk to her every day because it’s nice just to have somebody you can talk to and that I guess is something that I do now that I didn’t do, that I do because it’s helpful”.
(Helen).

Subtheme Two: Social comparisons. Many carers found it helpful to know other stroke survivors, carers and people with other chronic health conditions in order to compare their own situation to the situation of others. Carers were making both downward and upward social comparisons (Festinger, 1954). Downward

comparisons were made with people who carers considered to be worse off than themselves. This strategy helped carers to feel better about their own situation, realising that things could be worse.

“I was speaking to my brother-in-law last night and he drifted off completely because of this dementia, he suddenly started to talk about something that must have happened over fifty years ago. And I thought well if he's like that this during the day how does my sister put up with it, at least I don't have dementia to cope with ... The only place she (sister) goes is if she's got a doctor's appointment or a hospital appointment. She doesn't even go shopping. And I thought that's far worse than me, at least I can go out with dog or I've got a hobby or I can drive I can go shopping if I need to be. And so yes I do think about that. I think thank goodness.” (Nicole).

“There's so many unfortunate, well unfortunately the other two people I speak to their partners are forties and fifties and they've had severe strokes and that's a bit scary because when [Stroke survivor] was in hospital he was the oldest on the ward and you're thinking it's younger and younger people having these strokes and one lady, they've got a child and she's two and a half so that must be so difficult. So when you hear other people's problems you think gosh mine are not quite so bad.” (Emily).

Carers also used upward comparisons to people who they considered better off, or managing better than themselves. This served to motivate and inspire carers to manage in the caring role and to also further encourage the stroke survivor. Carers looked to learn from other carers and stroke survivors who were doing well in order to improve their own situations. This technique also helped instil a sense of hope that things could get better.

“I mean that woman's a saint (leader of stroke club). I mean she really is, she's fantastic and I think because she's so strong and because <stroke survivor> is quite disabled and I use her as a my yard stick I mean when I see her making it, I go home and say to [Stroke survivor] ‘you can do it, come on’.” (Nancy).

“I think I learnt a lot from one of my sister-in-laws because one of my brother-in-laws has multiple sclerosis, and she was really brilliant. A lot older than me but I think I learnt a lot from her...she did do everything for him, I mean she had carers, she had to have carers because he couldn't do anything for

himself, but they were always so cheerful and they were always sort of made ... But she made the best of her life and so did he, he was always cheerful he never moaned and I think will learnt a lot from her, them.” (Charlotte).

4.3.2.5 Theme Five: Seeing things in a different light. Carers that were interviewed were optimistic and hopeful about their future, which was achieved by seeing negatives in a different, positive light. They looked to positively reinterpret situations in order to see something good in their situation. There were two subthemes relating to this theme:

Subtheme One: Looking for the positives. Carers actively looked for the good in their situations, searching for something positive in bad situations. They had hope for the future and belief that things would get better and recognised the importance of maintaining hope for the future. Carers would actively look for what they had to be thankful for in their lives, for example, supportive family, grandchildren, and focusing on what the stroke survivor could do.

“You've just got to go with it, make the most of what you've got. I truly believe that. And I'm not a bit religious, I don't believe in a word of it, but I just think you make the most of what you've got. We've got you know wonderful kids; our grandchildren are the joy of my life, that's been a great help. So yeah, you just get on and are thankful really for what you've got. And if there's worse to come you have to face it you.” (Jessica)

“I think my natural persona is a cup half full. I like to see positives in things and I think at a time like that you hang onto every positive that you can, such as wow he managed to hold the flannel today, or you know he's not fallen over forgetting that half his body doesn't work.” (Joyce).

Some carers looked at the positive things that had come out of the situation of their loved one having a stroke and becoming a carer. For example, they referred to being able to help at stroke clubs and being able to give something back to others in need and the sense of reward that was felt by helping others.

“In fact we actually help other people. We have today, we've just been out with other stroke survivors to the seaside, we've just arrived back and I was helping others as well as my husband. So you know you must try and focus on how you can do things for other people who are not as well off as you.” (Edith).

Subtheme 2: Laughter / humour. A further strategy carers used to make difficult situations less daunting was the use of humour. Humour helped carers and stroke survivors alike to cope with negative situations, to get them through tough times and provided them with a sense of comfort.

“I think we both work on being able to laugh at ourselves as much as anything and you cannot afford to take it too seriously”. (Joyce).

“At the moment he’s wearing Ladies Tenner’s, ones with pretty little purple flowers on because we couldn’t get the male ones. Not that he’s bothered about it I mean we’ve been laughing about it.” (Rose).

5.4 Discussion

The results of Study Three add to the existing literature on positive coping strategies used by carers (Quinn et al., 2014; van Puymbroeck & Rittman, 2005; Visser-Meily et al., 2009) by providing a detailed account of the specific coping strategies utilised by informal carers of stroke survivors to manage the caring role. Findings clearly demonstrate that informal carers use a number of active, problem focused strategies such as actively seeking balance in their lives, planning, adapting activities and building upon prior experience. Encouragement and motivation of the stroke survivor and actively seeking support, including being assertive with healthcare professionals were also identified as key strategies. In addition, carers actively seek and accept social support for practical advice and emotional support and use both upwards and downwards social comparison to help them assess their situation. Finally, carers use positive reinterpretation to reframe negative situations, also facilitated by the use of laughter and humour. The second aim of Study Three was to identify psychological theories on techniques that might help depressed informal carers of stroke survivor utilise some of these positive coping strategies.

5.4.1 Psychological Theories or Techniques to Facilitate Positive Coping

5.4.1.1 Problem Focused Coping. First, taking into account the multidimensional coping inventory (Carver, Scheier, & Weintraub, 1989) it is clear that informal carers were adopting a number of problem focused coping strategies. Problem focused coping encompasses a number of strategies, such as taking active steps to cope with a difficulty in a logical manner and planning in order to develop strategies to best overcome difficulties (Carver et al., 1989). In Study Two it was identified that carers struggle with a number of difficulties pertaining to the tasks of the caring role, coping with changes in resources (e.g., lack of time and finance) and

find it difficult to continue to engage in meaningful valued goals and activities. As such problem solving technique (Nezu, 2004) was identified as an appropriate technique to utilise with the CBT self-help intervention. It is clear that positive coping informal carers were utilising problem focused coping or problem solving as a general coping strategy (D'Zurilla & Nezu, 1990). Indeed, the presence of effective problem solving skills has been found to be associated with less depressive symptoms when experiencing stressful events (Nezu, Nezu, Saraydarian, Kalmar & Ronan, 1986). The findings of Study Three therefore support the use of problem solving as a specific technique to be utilised within the CBT self-help intervention.

5.4.1.2 Adapting to the Caring Role. One of the main coping techniques identified in Study Three related to carers being able to adapt previous activities to enable both the carer and stroke survivor to continue new activities within the limitations of the caring role and consequences of stroke. Additionally, they found new activities that they could do within the limitations of the caring role and the impact of the stroke. As such, non-depressed and non-anxious carers of stroke survivors appear to be using the model of successful aging (Baltes, 1991; 1997) by adapting goals to their new life situation. As discussed in Chapter Three (Study Two) the selection, optimisation and compensation (SOC) model has been found to be a strategy used within the aging process in order to help people maximise levels of functioning despite experiences of loss (Boerner & Jopp, 2007). There were clear examples in Study Three of carers selecting goals that could still be achieved but using alternative methods of achieving these goals. Indeed, similar findings indicate older adults with osteoarthritis (Gignacm Cott, & Badley, 2000) and Alzheimer's Disease (Rapp, Krampe, & Baltes, 2006) adapt to living with the consequences of their conditions using the SOC model. As such, the findings of Study Three support building in support around goal adaptation into the new CBT self-help intervention.

5.4.1.3 Balance. Seeking balance was a significant coping strategy reported by non-depressed and non-anxious carers of stroke survivors. Specifically carers achieved balance by planning and organising their schedules in order to make time for breaks and time for activities on their own, with the stroke survivor and with others. Remaining engaged in these activities of value and importance was seen as an essential method of coping with caring role. This finding is in contrast to Study Two where carers found themselves disengaging from previous activities of value and not getting time for a break from the caring role. Behavioural activation (Hopko

et al., 2003) was identified as a strategy to help facilitate re-engagement with activities that would provide carers with positive reinforcement (e.g., a sense of pleasure, satisfaction and sense of achievement). Again, this supports the use of a behavioural activation treatment to support those carers struggling with balancing the routine of the caring role with remaining engaged in previously valued activities.

5.4.1.4 Emotion-focused coping. It was also clear from the findings of Study Three that carers utilised a number of emotion-focused coping strategies (Carver et al., 1989), such as seeking emotional support, positive reinterpretation and acceptance. Actively seeking social support was a regularly adopted coping strategy utilised by non-depressed and non-anxious carers. Social support provided emotional support, the opportunity for positive reinterpretation of the caring situation by focusing on the positive aspects of the caring role. As such, it is important for the CBT self-help intervention to help facilitate engagement in community stroke and carer groups and to emphasise the importance of involving others. Whilst involvement of others is down to patient choice, the patient vignettes used in the CBT self-help intervention could be written in a manner to encourage seeking support from others. Furthermore, information could be provided in the materials relating to national sources of community support for stroke survivors and carers. In addition, techniques such as problem solving, goal setting and behavioural activation are all focused on facilitating re-engagement with rewarding and meaningful activities that may also help reduce carers' feelings of social isolation. Moreover, the psychological wellbeing practitioners supporting the intervention work within a collaborative care model (Gilbody, Bower, Fletcher, Richards & Sutton, 2006) and therefore can support depressed carers in terms of assessing support from health, social and community organisations.

5.4.1.5 Social comparison theory. Non-depressed and non-anxious carers used social comparison as a coping strategy, which has been found to facilitate self-evaluation self-evaluation (Festinger, 1954). The theory posits that people use social information in order to evaluate their own situation (Festinger, 1954). Carers engaged in upward comparisons, comparing their situation to those who were coping well and downward comparisons, comparing their situation to those they felt were worse off than themselves. Making upward social comparisons has been found to provide inspiration and hope (Collins, 1996). Additionally, downward comparisons (Wills, 1981) have been found to improve mood (Gibbons & Gerrand, 1989; Parker,

Page, & Hooke, 2013) and improve self-esteem (Wills, 1981). Indeed, there is evidence to suggest that downward social comparisons improve mood in people with elevated levels of depressive symptoms (Gibbons, 1986). As such, this provides further support for the CBT self-help intervention to help facilitate engagement in community stroke and carer groups and to emphasise the importance of involving others in order to potentially facilitate social comparisons.

5.4.2 Limitations

Due to time and resource limitations trustworthiness of the data was not established thereby reducing the level of confidence that can help in the analysis. Methods of establishing trustworthiness may include another researcher not associated with the research performing analysis of the data and comparing to the initial results, or participants could have been sent summaries of findings to comment on the accuracy of the data (Johnson & Waterfield, 2004, Lietz et al., 2006). Furthermore, all carers were engaged in stroke clubs or carer community organisations that as demonstrated from the interview findings were a strong source of emotional, social and practical support. As such, positive coping strategies utilised within this group may not be generalisable to those informal carers who do not actively engage in community support networks. Additionally, as found in study two, the majority of the studies were in the 'long-lasting adaptation at home' phase (Cameron & Gignac, 2008) and the length of time informal carers had been in the caring role varied substantially, ranging from 4 months to 14.2 years with a mean duration of 6 years and 5 months. As such, homogeneity of the sample may be increased in the future by purposively sampling informal carers who have been in a caring role for a similar length of time. Additionally, homogeneity may be increased further by limiting the sample to informal carers providing support to stroke survivors with a similar level of post-stroke impairment.

5.4.3 Executive Summary

Study Three highlighted a number of positive coping strategies adopted by non-depressed and non-anxious carers of stroke survivors to help manage the caregiving role. Identification of positive coping strategies facilitated the identification of a number of psychological techniques to be integrated into the new CBT self-help intervention. First, non-depressed and non-anxious carers were clearly using a number of problem focused coping strategies (Carver et al., 1989), such as planning and problem solving, to overcome any difficulties experienced. As such, the

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adoption of a problem solving technique (D’Zurilla & Nezu, 1990), identified in Study Two, is further supported. Second, non-depressed and non-anxious carers reported adapting previous activities and engaging in new activities, taking into account limitations of the caring role and the experience of stroke. This further supports the integration of the ‘selection, optimisation and compensation’ model (Baltes et al., 1991, 1997) identified in Study Two into a goal setting approach. Third, carers in Study Three activity sought balance in their lives, for example planning and organising time for breaks and their own activities. This further supports the use of behavioural activation (Hopko et al., 2003) as an additional psychological technique within the CBT self-help intervention. Forth, carers utilised a number of emotion-focused coping techniques (Carver et al., 1989) such as actively seeking emotional support, acceptance and positive reinterpretation of difficult situations. As such, the CBT self-help intervention will actively encourage carers to seek social support and will also provide information concerning community stroke and carer support organisations. Further PWPs follow a collaborative care model (Gilbody et al., 2006) and will therefore support carers to access (if required) support from health, social and community organisations. Encouragement of social support may also help facilitate carers to make upward and downward social comparisons (Festinger, 1954) that non-depressed and non-anxious carers made to further facilitate coping within the caring role. Finally, assertiveness was identified as a coping strategy aiding carers in successfully accessing health and social care. Again, a collaborative care model (Gilbody et al., 2006) may help carers access appropriate health, social and community based support.

Table 5.4

Main findings from the qualitative investigation of positive coping strategies utilised by non-depressed and non-anxious informal carers of stroke survivors to inform the CBT self-help intervention

Main Findings	Informing the CBT self-help intervention
Non-depressed and non-anxious carers adapted activities and engaged in new activities, within the limitations of the	Integration of the ‘selection, optimisation and compensation’ model (SOC; Baltes, 1991; 1997) into the CBT-self-help

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caring role and experience of stroke	intervention, using a goal setting technique
Carers were found to strike a balance by planning and organising time for breaks and activities outside of the caring role	Supported the use of behavioural activation as a key psychological technique to be adopted in the CBT self-help intervention.
Carers demonstrated assertiveness, for example by actively seeking social and healthcare support	National sources of support from stroke and carer specific national community based organisations will be included within the intervention. Adoption of a collaborative care model (Gilbody et al., 2006) will also support carers to access social and healthcare support.
Active seeking of social support was a common coping strategy, providing emotional support and the opportunity for positive interpretation of difficult situations.	Encouragement to seek social support will be provided within the CBT self-help materials. Further, national sources of support from stroke and carer specific national community based organisations may further facilitate social support.
Carers found making both upward and downward social comparisons with others in similar situations helpful.	Encouragement of social support within the CBT self-help interventions may facilitate the opportunity for carers to make social comparisons.

5.5 Conclusions

First, the generation of a clear account of the positive coping strategies used by non-depressed and non-anxious carers of stroke survivors in Study Three confirms the use of the three psychological techniques identified in Study Two. Specifically (a) goal adaptation and setting; (b) behavioural activation and (c) problem solving were identified further supporting their use within a developed CBT self-help intervention. Second, Study Three has clearly identified that actively seeking social and emotional support are key techniques used by non-depressed

and non-anxious carers of stroke survivors. As such, it is of importance that the CBT self-intervention adopts a collaborative care model to help facilitate access to appropriate support. Additionally, the materials should encourage actively seeing support from family, friends and community-based organisations in order to facilitate social support, reduce social isolation and facilitate social comparison. The identification of positive coping strategies typically utilised by non-depressed and non-anxious carers of stroke survivors therefore represents the second step towards the development of an individualised, theory-driven CBT self-help intervention for informal carers of stroke survivors.

In Chapter Six the researcher moved to the final stage of the development phase of the revised MRC complex interventions framework (MRC, 2008) and used modelling techniques in order to integrate the findings of Study One, Two, and Three to develop the CBT self-help intervention.

CHAPTER SIX: Development of the Supported CBT Self-Help Intervention

6.1 Background

6.1.1 Overall Aims

This chapter reports on the fourth and final study conducted as part of the development phase of the revised MRC framework (MRC, 2008). As previously outlined in Chapter Two this study was designed to:

- Develop the specific CBT self-help intervention materials.
- Develop the PWP assessment and support protocol.
- Develop the accompanying PWP training programme.

This process was an iterative one, drawing upon the combined findings of Study One, Two and Three in order to develop an evidence-based, theory driven CBT self-help intervention targeted at the specific difficulties experienced by informal carers of stroke survivors.

6.1.2 Introduction

CBT self-help interventions have the potential to improve access to depression treatment for informal carers of stroke survivors. However tailoring existing CBT self-help approaches to the unique difficulties experienced by informal carers of stroke survivors may be required to improve both the effectiveness and acceptability of the treatment (Farrand & Woodford, in press; Hind et al., 2010). Existing informal carer psychological interventions have been criticised for not being tailored to the unique difficulties experienced by informal carers (Krevers & Öberg, 2011; Lundh, 1999) with evidence suggesting that interventions tailored to the specific difficulties experienced by informal carers are more effective than generic interventions (Bakas et al., 2014). Furthermore, there is increasing recognition of the importance of involving patients in the design, delivery and evaluation of interventions (Gagnon et al., 2011; Greenhalgh, 2009).

Specifically, qualitative approaches were used in Study Two and Study Three to collect in-depth knowledge concerning the experience of providing informal care to a stroke survivor. This chapter describes how these findings were incorporated into developing an individualised CBT self-help approach for depressed informal carers of stroke survivors. A team of researchers, a professional design company with experience in the design of written patient information and a lived experience steering committee comprising of two informal carers and one stroke survivors

contributed to the development of the intervention. Whilst a number of different written CBT self-help materials exist (e.g., Lovell & Richards, 2008; Williams, 2006; 2009; 2012) the CBT self-help intervention was developed in line with current low intensity materials and models, specifically those used within IAPT (Lovell & Richards, 2008; Richards & Whyte, 2011, Richards et al., 2010). Being informed by materials within IAPT was important given the PWP's supporting the intervention were already trained in delivering low-intensity treatments following IAPT guidelines (Richards et al., 2011) and the established evidence base for IAPT (Richards & Borglin, 2011; Richards & Suckling, 2009) and CBT based self-help (Anderrson & Cuijpers, 2009; Coull & Morris, 2011; Farrand & Woodford, 2013; Gellatly et al., 2007). As such, this chapter focuses on describing the adaptation and enhancement of existing CBT self-help intervention materials taking into consideration the findings from Studies One, Two and Three.

6.2. Methods

6.2.1 Phase One

6.2.1.1 Systematic review and meta-analysis of psychological treatments for depression and anxiety experienced by informal carers of adults with chronic physical health conditions. Methods and results were reported in Study One (Chapter Three). RCTs of psychological and psychosocial treatments for depressed or anxious informal carers of adults with chronic physical health conditions were identified with database search and expert contact. As well as examining the overall effectiveness of interventions specific intervention components associated with effectiveness were identified through moderator analysis to further inform the development of the new CBT self-help intervention for depressed informal carers of stroke survivors. Intervention components found to be associated with effectiveness were mapped onto the new CBT self-help intervention to further inform content.

6.2.2 Phase Two

6.2.2.1 Identification of psychological theories that target the specific difficulties experienced by depressed and anxious informal carers of stroke survivors. Semi-structured interviews were held with 19 depressed or anxious informal carers of stroke survivors to identify specific difficulties and challenges experienced in the caring role. Full methods and results are reported in Study Two (Chapter Four). Psychological theories were identified from the literature that may

target the main difficulties and challenges identified as commonly experienced by depressed informal carers of stroke survivor. Identified psychological theories were used to further inform the content of the individualised CBT self-help intervention.

6.2.3 Phase Three

6.2.3.1 Identification of psychological theories that help depressed informal carers utilise positive coping strategies used by non-depressed anxious informal carers of stroke survivors. Semi-structured interviews were held with 26 non-depressed and non-anxious informal carers of stroke survivors to identify positive coping strategies that are utilised in the caring role (methods reported in Study Three, Chapter Five). In order to further enrich the new CBT self-help intervention, psychological theories that may help depressed informal carers employ these positive coping strategies were identified and used to further inform the content of the intervention.

6.2.4 Phase Four

6.2.4.1 Further refinement of the novel CBT self-help intervention. Findings from phases one to three were discussed in supervisory meetings to inform the content and format of the CBT self-help intervention developed by JW and PF. Patient vignettes were developed from the findings of Study Two to ensure the material was relevant to informal carers of stroke survivors with depression to help facilitate engagement with the material (Macdonald et al., 2007; Whittaker et al., 2012). Whilst writing the materials, emphasis was placed on the incorporation of common factors (Cahill et al., 2008) known to increase therapeutic alliance and improve outcome of psychological interventions (Lambert & Barley, 2002; Martin, Garske, & Davis, 2000; Shirk & Karver, 2003). This phase included working closely with a lived experience committee, consisting of two informal carers and one stroke survivor and also a professional design company with previous experience of developing CBT self-help materials (Farrand et al., 2014).

6.2.5 Phase Five

6.2.5.1 Development of an assessment and support protocol and accompanying training programme for PWP. To support the new CBT self-help intervention, assessment and support protocols were developed in line with existing IAPT guidelines (Richards & Whyte, 2011). These protocols were adapted to fit delivery of the new intervention alongside the development of supporting PWP training programme.

6.3 Results

6.3.1 Phase One

6.3.1.1 Systematic review and meta-analysis of psychological treatments for depression and anxiety experienced by informal carers of adults with chronic physical health conditions. Due to the small number of studies eligible for inclusion within the review alongside treatment protocols being rarely received from study authors, it was not possible to conduct the planned moderator analysis in terms of identifying behavioural change techniques (Greaves et al., 2011; Lorencatto, West, & Michie, 2012) associated with the effectiveness of psychological treatments for depression and anxiety experienced by informal carers of stroke survivors. However, the systematic review and meta-analysis did provide an overview of the existing evidence based common psychological components included within informal carer interventions and there were some trends suggesting certain intervention components were associated with an increased effect size. The key findings and how these were incorporated into the CBT self-help intervention are illustrated in Table 6.1.

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Table 6.1

Incorporation of Key Findings from Study One (systematic review and meta-analysis) into the CBT Self-help Intervention

Trends in the data identified in study one	Incorporation into the CBT self-help programme
<p>Individual treatments have a larger effect size than group based treatments (e.g., Agren et al., 2012; Badger et al., 2007; 2011; Kuijjer et al., 2004; Lopez et al., 2007; Marriott et al., 2000; Toseland et al., 1995; Tremont et al., 2008).</p>	<ul style="list-style-type: none"> • The CBT self-help intervention was designed to be delivered individually to informal carers as opposed to within a group setting.
<p>Interventions with shorter total session duration have larger effect sizes than those with longer session duration (e.g., Argen et al., 2012; Au et al., 2010; Badger et al., 2007; 2011; Lopez et al., 2007; Toseland et al., 1995).</p>	<ul style="list-style-type: none"> • Short sessions were utilised in line with current IAPT guidelines (approximately 35 minutes per session; Richards & Whyte, 2011).
<p>CBT based treatments more effective than purely psychosocial or psychoeducational interventions (e.g., Agren et al., 2012; Akkerman & Otswald, 2004; Au et al., 2010; Kuijjer et al., 2004; Lopez et al., 2007; Losada et al., 2011; Lovett & Gallagher, 1988; Márquez-González et al., 2007; Marriott et al., 2000; Toseland et al., 1995).</p>	<ul style="list-style-type: none"> • CBT was the main underlying theory of the intervention. The intervention introduces the CBT model and in order to facilitate the development of an understanding of how we think, feel and behave interact and maintain depression and by changing how we feel or changing how we act can help people to reverse the vicious cycle of depression. Carers explore the specific cognitions, behaviours and physical feelings they are experiencing to gain a better understanding of their problem (Appendix 6.1, Introduction Booklet, p. 7 – 9). The CBT model is reiterated within each of the specific techniques utilised within the intervention (Appendix 6.2, Behavioural Activation Booklet, p. 4; Appendix 6.3, Goal Setting Booklet, p. 3; Appendix 6.4, Problem Solving Booklet, p. 3). • All strategies to address carers' problems with low mood and depression were based on the CBT model throughout the intervention. As per standard CBT interventions the treatment was structured, time-limited, homework driven and supplemented by patient

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	<p>worksheets throughout.</p> <ul style="list-style-type: none">• Clear, specific, positive and achievable aims were set at the beginning of the intervention (Appendix 6.1, Introduction Booklet, p. 10 – 11).• Clear rationales were provided for each of the specific techniques utilised within the intervention (Appendix 6.2, Behavioural Activation Booklet, p. 1-4; Appendix 6.3, Goal Setting Booklet, p. 1-3; Appendix 6.4, Problem Solving Booklet, p. 1-3).
<p>Interventions incorporating active skill building and problem solving components yield larger effect sizes (e.g., Agren et al., 2012; Akkerman & Otswald, 2004; Au et al., 2010; Kuijer et al., 2004; Lopez et al., 2007; Losada et al., 2011; Lovett & Gallagher, 1988; Márquez-González et al., 2007; Marriott et al., 2000; Toseland et al., 1995).</p>	<ul style="list-style-type: none">• Specific techniques incorporated into the intervention will be problem-focused and skills based. Specifically, behavioural activation, goal setting and problem solving were chosen as CBT based techniques to inform the intervention (Appendix 6.2, Behavioural Activation Booklet; Appendix 6.3, Goal Setting Booklet, Appendix 6.4, Problem Solving Booklet).
<p>The majority of interventions included mental health psychoeducation (see Table 3.4; Chapter Three).</p>	<ul style="list-style-type: none">• Psychoeducation, concerning what is depression and low mood, was incorporated into the intervention, including information of common symptoms, possible causes and the effect of depression (Appendix 6.1, Introduction Booklet, p. 4 – 6).• Specifically, information was provided concerning the caring experience and depression to help carers understand that depression is a common difficulty experienced by informal carers of stroke survivors and to gain an understanding of common problems carers may experience adapting to the caring role that may contribute to the experience of depression (Appendix 6.1, Introduction Booklet, p. 3).
<p>The majority of interventions included psychoeducation concerning the physical health condition of the person being cared for (see Table 3.4; Chapter Three).</p>	<ul style="list-style-type: none">• Clear information was incorporated concerning stroke, for example common difficulties experienced by stroke survivors post-stroke (Appendix 6.1, Introduction Booklet, p. 19 – 20).

Note. CBT = Cognitive behavioural therapy

6.3.2 Phase Two

6.3.2.1 Identification of psychological theories that target the specific difficulties experienced by depressed and anxious informal carers of stroke survivors. Identification of psychological theories that target the specific difficulties experienced by depression and anxious informal carers of stroke survivors were gathered through semi-structured interviews in Study Two (Chapter Three). Results identified three psychological theories that specifically targeted some of the unique difficulties experienced by informal carers of stroke survivors that provide the critical components underlying the adaptation of the CBT self-help approach:

- Selection, optimisation and compensation model (SOC; Baltes, 1991; 1997).
- Behavioural activation (Hopko, Lejuez, Ruggiero, & Eifert, 2003; Jacobson, Martell & Dimidjian, 2001; Lewinsohn, 1974).
- Problem solving (Nezu, 2004; Bell & D'Zurilla, 2009).

In addition, there were a number of specific difficulties identified that could be further targeted by the intervention, including:

- Lack of information concerning secondary health complications post-stroke.
- Lack of access to stroke and carer specific support.

These key findings and how they were incorporated into the CBT self-help intervention are illustrated in Table 6.2.

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Table 6.2.

Incorporation of Key Findings from Study Two (qualitative Interviews with depressed and anxious informal carers of stroke survivors) into the CBT Self-Help Intervention.

Key findings from study two	Incorporation into the CBT self-help programme
<p>Carers of stroke survivors struggle with adapting to the caregiving role, specifically around changing roles and giving up previously held life goals and activities of value and importance. Carers were found to often give up previously held goals completely, without replacing them with new goals, or to give up activities of value and importance, without identifying adaptations informing how they might still be able to work towards these activities. This heightened the sense of loss carers experienced by assuming the caring role. The 'Selection, Optimisation and Compensation' model (SOC; Baltes, 1991; 1997) was identified as a model that may help carers select goals that can still be achieved despite changes to their functional ability and the new limitations imposed on their life by the caregiving role.</p>	<ul style="list-style-type: none"> • Goal setting was selected as an appropriate intervention to help carers continue working towards achieving goals that are important to them (Appendix 6.3, Goal Setting Booklet). • Psychoeducation was provided concerning how when becoming a carer the barriers and difficulties experienced as a result of the new caring role may lead to carers giving up previously held goals of value and importance. The SOC model was introduced by explaining that some goals may still be achieved, though some goals may need to be completely changed if they are no longer achievable (selection) but carers may need to think about different ways of achieving them given the constraints of the caring role (optimisation) and may need to be adapted (compensation) to take account of the caring role. (Appendix 6.3, Goal Setting Booklet, p. 2). For example, in the booklet the carer and stroke survivor in the vignette presented previously regularly went on long walks together, but the stroke survivor was now in a wheelchair, so this was an activity that had been given up. Instead the carer selected going on a walk somewhere wheelchair friendly for just 30 minutes once a week (Appendix 6.3, Goal Setting Booklet, p. 23). • The impact of giving up activities and goals of importance and value was described using the vicious cycle of depression model (Appendix 6.3, Goal Setting Booklet, p. 3). For example, a carer stops an activity of importance, they experience less sense of achievement, meaning or purpose in life, this may lead to thoughts such as 'life has no purpose' that may lead to feeling fatigued, irritable and resentful, the carer may snap at their partner, and their mood may worsen. This illustration was designed to demonstrate to carers how giving up certain roles, goals and activities due to the caring role may lead to difficulties with low mood and depression.

Carers of stroke survivors struggle with a lack of balance within their lives, bound by the caring routine with no time for activities outside of the caring role or for a break. When carers did engage in activities for themselves they often felt guilty. In addition, carers often reported feeling resentful about having to give up activities, which in turn made them feel guilty. As such, carers were not gaining an opportunity to engage in behaviours that are associated with an improvement in mood, for example, activities that provide pleasure, satisfaction or a sense of achievement. As such, behavioural activation was chosen as a suitable technique for carers who were struggling with such difficulties.

- Specific setbacks that carers may experience with working through the goal setting treatment were focused around difficulties carers may have with selection, optimisation and compensation. For example, carers may have to give up old goals but they can still select new goals of importance and value by examining the values of the old goal and selecting new achievable activities that provide similar values. Additional setbacks included how carers might be able to identify changes in resources due to the caring role (e.g., lack of finance and time) and think of ways of still working towards goals in light of changes in resources (e.g., asking for support, finding time) (Appendix 6.3, Goal Setting Booklet, p. 14-15).
- Conventionally, low intensity behavioural activation protocols (Lovell & Richards, 2008; Richards, 2010; Richards & Whyte, 2011) are based on a simple model of depression whereby patients disengage from a number of activities within their lives. However, informal carers experience difficulties because their routine is full of activities around the caring role, normal routine and necessary activities concerning the provision of care and running a household. As such, they tend to be doing few activities for themselves that may provide them with a sense of enjoyment, satisfaction or achievement. Therefore a key adaptation was to recognise this within the behavioural activation booklet. The cycle of low mood and reducing activity is introduced to carers and linked to specific difficulties experienced by carers when doing fewer activities outside of the caring role (Appendix 6.2, Behavioural Activation Booklet, p. 4).
- A key adaptation to the standard low intensity behavioural activation protocol adopted within IAPT (Lovell & Richards, 2008; Richards, 2010; Richards & Whyte, 2011) is the introduction of a '*My Starting Point Diary*' to enable carers to write down all of the activities they are doing during the week (Appendix 6.2, Behavioural Activation Booklet, p. 7-8). Additionally, carers are encouraged to write down the type of activity 'routine, necessary or pleasurable' next to each activity they do during the day. This is designed to help carers visually identify the lack of balance within their lives. For example, carers may be able to see that their days are full of routine and necessary activities within the caring role which is illustrated by the sample worksheet used within the patient vignette

(Appendix 6.2, Behavioural Activation, p. 23-24) and recognised by the carer “*I explained that I had noticed that I was doing a lot of routine activities around the house and the only thing I did during the week that was pleasurable was watching TV, and I didn’t really enjoy that anyway*” (Appendix 6.2., Behavioural Activation Booklet, p. 27).

- An additional change was the incorporation of a step whereby the carer identifies what areas of life are important to them, adapted from the Brief Behavioural Activation Treatment for Depression: Revised Treatment Manual (BATD-R, Lejuez, Hopko, Acierno, Daughters, & Pagoto, 2011). Carers give up a lot of activities that were previously of value and importance to them. Therefore it was considered an important step for carers to identify what areas of life were important to them so that activities they start to build in their lives are associated with these important areas of life (Appendix 6.2, Behavioural Activation Booklet, p. 9-10).
- The feelings of resentment and guilt that are commonly experienced by informal carers of stroke survivors were acknowledged within the technique, including an emphasis on how it is important for informal carers to take care of themselves, not only for them but for the person they are caring for too: “*As a carer you may have found yourself focusing on the needs of the person you care for. This can make you feel that things of importance to you are being neglected, which may then lead to feelings of guilt for having such thoughts. It is important to remember depression in either the carer or stroke survivor can increase the likelihood depression will occur in the other. Therefore it is very important that you seek to take care of yourself, for the benefit of both you and the person you care for*” (Appendix 6.2, Behavioural Activation Booklet, p.12).
- Common difficulties that may be experienced when using behavioural activation were tailored towards the caring role. For example, carers may not understand why they need to become ‘more active’ when they are doing so much already. A further difficulty carers often experience is being overwhelmed by large, difficult and new tasks, tips were provided in terms of how to break these down. A final adaptation concerned how to identify time and space for new activities. Carers were encouraged to think about ‘how important’ or what ‘priority level’

	<p>they gave to the activities they were doing, for example, carers may find that they are doing routine activities that could be left to make space for activities for themselves (Appendix 6.2., Behavioural Activation Booklet, p. 22).</p>
<p>Carers of stroke survivors experience difficulties surrounding the responsibility of the caring role, effective decision-making and undertaking new tasks and activities. This is further compounded by changes in resources such as lack of time, lack of finance, and competing demands. This in turn leads to difficulties in engaging with activities of value and importance. As such, problem solving was posited as a technique that may help informal carers of stroke survivors with these difficulties.</p>	<ul style="list-style-type: none">• Problem solving was selected as an appropriate intervention to help carers overcome difficulties relating to managing new tasks and responsibilities and re-engaging with activities of value and importance (Appendix 6.4, Problem Solving Booklet).• The rationale for problem solving was introduced in relation to difficulties within the caring role. For example, a difficult life event (e.g., a loved one having a stroke) or day-to-day problems that are hard to resolve may be experienced. The carer experiences distress, is overwhelmed and stressed, leading to difficulties with concentration, finding it hard to make decisions, or cope effectively with the problem or event, leading to mood worsening (Appendix 6.4, Problem Solving Booklet, p. 3).• Current IAPT problem solving approaches (e.g., Farrand & Foord, 2013) use the seven steps of problem solving that train users in the application of problem based skills. However, evidence suggests that problem-solving interventions are more effective if they also provide training in a positive problem orientation (Bell et al., 2009). This includes helping the patient to identify that the problem is ‘solvable’, of relevance and a challenge (Bell et al., 2009). As such, an important adaptation to the current low-intensity problem solving approach was to add a step to allow carers to categorise their problems into those that are ‘not important’; ‘important and can be solved’ and ‘important but cannot be solved’. Carers would then focus on working on problems that were both important and solvable. In order to help carers identify which problems were most important carers identified areas of life that were important to them so that problems they work on solving are associated with these important areas of life.
<p>Informal carers experienced difficulties concerning worry and uncertainty. These were often hypothetical worries, for example, “what if the stroke survivor falls if I leave them alone”. Carers found this</p>	<ul style="list-style-type: none">• “Worry time” was incorporated into the problem solving technique following Cuijper’s problem solving model (Cuijpers, 2004) (Appendix 6.4, Problem Solving Booklet, p. 19-21). To help carers manage problems they identified as important, but not solvable.

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worry overwhelming and it prevented them from engaging in certain activities.

Carers experienced difficulty in gaining information concerning common post-stroke health complications leading to feelings of worry, uncertainty and anxiety.

Lack of support

- Information was provided concerning the following common post-stroke difficulties: depression; anxiety; fatigue, seizures and epilepsy, sleep-disordered breathing, emotionalism (Appendix 6.1, Introduction Booklet, p. 19-20). Providing this information was designed to normalise these post-stroke health complications and also provide information about how to gain help is experiencing problems and encouragement to speak to the PWP who may also be able to provide support and help.
 - Incorporation of national sources of support from stroke and carer specific national community based organisations including: “Different Strokes”; “Stroke Association”; “Headway”; “Stroke Foundation”; “Connect”; “Carers Trust” and “Carers Direct” (Appendix 6.1. Introduction Booklet, p. 23-26).
 - Encouragement of gaining support in using the intervention with friends and family is encouraged within the intervention. Specifically this is done through using examples of how social support has been gained in the patient vignettes e.g., *“Tim (PWP) spoke to me about the importance of support and I recognised I really missed my old friends. I showed them the information on caring, stroke and goal setting in the booklets and this helped them to understand how our lives have changed. We have now been able to find some new activities to all do together”* (Appendix 6.1, Introduction Booklet, p. 14).
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Note. CBT = Cognitive behavioural therapy; PWP = Psychological wellbeing practitioner; SOC = Selection, optimisation and compensation.

6.3.3 Phase Three

6.3.3.1 Identification of psychological theories that help depressed informal carers utilise positive coping strategies used by non-depressed anxious informal carers of stroke survivors. A positive psychology approach (Bolier et al., 2013; Mitchell et al., 2009) was adopted in Study Three (Chapter Four) to identify positive coping strategies utilised by non-depressed and non-anxious informal carers of stroke survivors. Results identified a number of positive coping strategies typically utilised by informal carers of stroke survivors:

- Goal adaptation.
- “Striking a balance”.
- “Push, Push, Push” – actively seeking social and healthcare support and actively pushing and motivating the stroke survivor.
- Social comparison.
- Actively seeking social support.

These key findings and how they were incorporated into the CBT self-help intervention are illustrated in Table 6.3.

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Table 6.3

Incorporation of Key Findings from Study Three (qualitative interviews with non-depressed and non-anxious informal carers of stroke survivors) into the CBT Self-Help Intervention

Key findings from study three	Incorporation into the CBT self-help programme
<p>Carers utilised a number of positive coping strategies in order to adapt to the caring role. Although carers recognised that there were some activities that they were no longer able to do, carers focused on identifying new activities they could still do within the limitations of the caring role and also identified new ways to enable them to continue with certain activities. As such, it was clear that non-depressed and non-anxious carers were adopting the SOC model in order to adapt goals to their new life situation, for both themselves and the stroke survivor.</p>	<ul style="list-style-type: none"> • As outlined in Table 6.2, goal setting was selected as an appropriate intervention to help carers continue working towards achieving goals that are important to them (Appendix 6.3, Goal Setting Booklet,). The SOC model was incorporated to help carers adapt activities to take account of the caring role (Appendix 6.3, Goal Setting Booklet, p. 2). • Successful adaptation of goals were presented in the patient stories, with examples informed by the findings of Study Three e.g., <i>“I am now working towards Brian and I going away on a mini-break which will be easier as the Carers Trust put me in touch with Travel Quest who specialise in holidays for disabled people and their families. I was also able to organise a sitting service and have started to volunteer in a local charity shop one morning a week. I am starting to feel a lot more like the old me again!”</i> (Appendix 6.3, Goal Setting Workbook, p. 23). • Positive coping strategies identified in Study Three were incorporated into the Introduction Booklet to provide informal carers with depressed with ‘tips from the field’ that they may be able to incorporate into their lives e.g., <i>“You may have noticed yourself that there are activities you used to enjoy, or things you value that you feel you can no longer do now you are a carer. This is very common but many carers spoke about adapting their goals or activities to accommodate their new role as a carer and finding this a helpful way of coping”</i> (Appendix 6.1, Introduction Booklet, p. 22).
<p>Striking a balance was a significant coping strategy reported by carers. Carers planned and organised their</p>	<ul style="list-style-type: none"> • As outlined in Table 6.2, behavioural activation was selected as an appropriate intervention to help carers gain balance in their lives (Appendix 6.2, Behavioural Activation Booklet). In addition, goal setting and problem solving are also

routine to enable them to take breaks from the caring role and continue activities for both themselves and with the stroke survivor and friends and family. As such, findings from Study Three supported the used of behavioural activation as a key psychological technique to be adopted in the CBT self-help intervention.

problem-focused interventions that may help carers identify ways to make time for themselves outside of the caring role (Appendix 6.3, Goal Setting Booklet; Appendix 6.4 Problem Solving Booklet). Study Three clearly identified that non-depressed and non-anxious informal carers use various problem focused coping strategies that are all inherent with a behavioural activation, goal setting, and problem solving approach.

- Informal carers in Study Three identified that they used planning and prioritisation of activities on order to make space for activities for themselves, or to take a break. As such, a setback listed within the Behavioural Activation booklet was how to make time and space. Prioritisation of activities was provided as a technique that carers could adapt e.g., *“You may also be able to find some time by thinking about how ‘important’ or what ‘priority level’ you consider the tasks you are currently doing to be. Some people when feeling low find themselves doing lots of tasks that are not necessarily important but can help distract themselves from difficult feelings or situations. For example, doing the ironing for an hour to avoid arguing with the person you care for. You might find it helpful to look through the activities you are currently doing and rate how important these activities are. If certain activities are not as important you may be able to replace these with other activities to help you regain some balance”* (Appendix 6.2, Behavioural Activation, p. 22). An example of prioritisation of activities is also provided in the patient story *“Stephanie (PWP) also asked me to think about some of the routine activities I did around the house and how important I considered them to be. This made me realise I often did lots of easier activities around the house that I didn’t really need to do, but I did them to keep myself busy and was putting off more difficult tasks* (Appendix 6.2, Behavioural Activation, p. 30).
- The importance of both balance and finding ‘time for me’ were listed under strategies for carers to cope with the caring role e.g., *“A number of carers mentioned the importance of striking a balance between different types of activity. You may have found yourself that the routine of being a carer is really tough. Therefore it is important to try and find things that both you and the stroke survivor enjoy and value”* (Appendix 6.1, Introduction Booklet, p. 22).

“Push, Push, Push” – actively seeking social and healthcare support and actively pushing and motivating the stroke survivor.

- Successful examples of striking balance were also provided within the patient recovery story: *“My friend Zoe also suggested she come around for a coffee instead of me trying to get out. This was really nice and my gran enjoyed having Zoe over too. I also realised that when the carers came round I didn’t just leave them to it and would be doing some of the caring tasks they should be doing. I started to leave the carers to get my gran ready and managed to grab 15 minutes to do something else”* (Appendix 6.2, Behavioural Activation, p. 31).
 - Various examples were provided throughout the booklets in relation to the importance of ‘time for me’ and not feeling guilty about taking a break or doing an activity just for themselves e.g., *“Another strategy mentioned was trying to take time out from the caring role, even if this is only for a few minutes each day ... In Part 4 we mentioned that if depression or low mood increase in the stroke survivor depression or low mood may increase in the carer, and vice versa. It is therefore important to remember that taking care of your own mental health is of benefit to the stroke survivor as well”* (Appendix 6.1, Introduction Booklet, p. 22).
 - As previously highlighted in Table 3.2 national sources of support from stroke and carer specific national community based organisations were added to the Introduction Booklet including: “Different Strokes”; “Stroke Association”; “Headway”; “Stroke Foundation”; “Connect”; “Carers Trust” and “Carers Direct” (Appendix 6.1. Introduction Booklet, p. 23-26).
 - Encouragement to seek support from the PWP was provided throughout the booklets e.g., *“Remember your PWP is there to help you if you find yourself struggling with identifying activities”* (Appendix 6.2, Behavioural Activation Booklet, p. 12).
 - Within the patient stories, incorporation of the stroke survivor within homework activities is encouraged, for example, in the Goal Setting Booklet (Appendix 6.3) one of the main goals was to go on wheelchair friendly walks with the stroke survivor.
 - “Push, Push, Push” was incorporated in the tips for carers sections in the Introduction Booklet e.g., *“Some carer spoke to us about difficulties with the stroke survivor they cared for experiencing low levels of motivation. Carers spoke about how trying to push the stroke survivor, within their capabilities, helped*
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Actively seeking social support	<p><i>overcome such difficulties</i>” (Appendix 6.1, Introduction Booklet, p. 22).</p> <ul style="list-style-type: none">• The strategies for coping from carers of stroke survivors also encompassed the importance of gaining support from family, friends and stroke survivors. Additionally, this section encouraged carers to think about how they might like support from others, who they might want to ask and also whether they could think about showing friends and family sections from the CBT self-help programme (Appendix 6.1, Introduction Booklet, p. 21).• Encouragement to seek social support from friend, family and stroke organisations was also provided within the patient case studies e.g., “<i>Charlotte (PWP) also helped me get in touch with a charity called Connect especially for people with aphasia. I was able to get some really great advice about how to communicate with Mary (stroke survivor) and our relationship is much better now. I also shared this advice with some of our friend and they come around again now too</i>” (Appendix 6.1, Introduction Booklet, p. 18).
Social comparison	<ul style="list-style-type: none">• The benefits of social comparison were included within the strategies for coping from carers of stroke survivors section of the Introduction Booklet e.g., “<i>Sometimes carers reported it helpful to be around other people in a similar situation and to share their stories. This seems of benefit in two may ways. First simply sharing your story with others can help, and sometimes it can result in receiving some helpful and practical advice. Also talking to other carers and stroke survivors can help make you more aware of the different type of difficulties faced by others, and this can sometimes help you to consider your difficulties in different ways</i>” (Appendix 6.1, Introduction Booklet, p.21).• In addition, each of the “Care and Relative Recovery Stories” incorporated into the booklets provided examples of how carers may overcome depression and instil hope. Carers using the programme may seek inspiration and motivation from these recovery stories.

Note. CBT = Cognitive behavioural therapy; PWP = Psychological wellbeing practitioner; SOC = Selection, optimisation and compensation.

6.3.4 Phase Four

6.3.4.1 Integration of finding to inform the intervention. Findings from Phases I-III were used to adapt currently available CBT self-help materials into a unique self-help intervention for depressed informal carers of stroke survivors.

Overview of the CBT self-help intervention. Five separate booklets were developed, taking into account the results of Phases I-III and an overview of contents is provided in Figure 6.1:

1. Introduction to the intervention.
2. Behavioural Activation – informed in part by the CBT self-help manual for behavioural activation used within IAPT (Lovell & Richards, 2008; Richards, 2010; Richards & Whyte, 2011) and the Brief Behavioural Activation Treatment for Depression: Revised Treatment Manual (BATD-R, Lejuez, Hopko, Acierno, Daughters, & Pagoto, 2011).
3. Goal Setting – informed in part by the CBT self-help manual for goals setting developed for use within IAPT (Farrand & Woodford, 2013) utilising the simple **Specific, Measureable, Achievable, Relevant and Time specific (S.M.A.R.T)** model.
4. Problem Solving – adapted from a problem-solving manual developed by Cuijpers (2004) and elements from the CBT self-help manual for problem solving developed for use within IAPT (Farrand & Foord, 2013).
5. Relapse Prevention – this booklet was developed specifically for the study and was not based on existing CBT self-help materials.

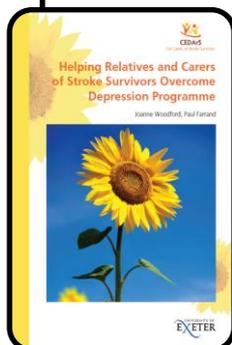
Development of the CBT self-help materials was both interactive and collaborative involving a multitude of stakeholders. Drafts of each Booklet were developed and subsequently refined on the basis of the findings from Phases I-III as well as feedback by the principal supervisor (PF); the lived experience steering committee, consisting of two informal carers and one stroke survivor and the professional design company Dowling Design (<http://www.dowling.biz/>). In addition, feedback on the CBT self-help materials was sought from three Associate Lecturers on the IAPT Low Intensity Programme at the University of Exeter (Hayley Foord; Kat Rayson & Faye Small) who are all experienced in delivering, teaching and developing CBT self-help materials.

Format of the CBT self-help intervention. The CBT self-help intervention was designed to be delivered over a maximum of one assessment and up to 12

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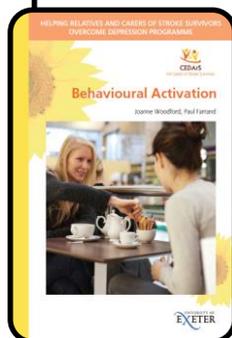
support sessions with the PWP. Assessment sessions were designed to last approximately 35 minutes with support sessions lasting between 25 and 35 minutes, in line with current IAPT guidance (Richards & Whyte, 2008). Limitations on the number and length of support sessions are defining characteristics of low-intensity CBT (Bennett-Levy & Farrand, 2010) and are supported by the findings of Study One within this thesis indicating that shorter total session length duration is more effective in reducing depressive symptoms in carers than longer treatments (e.g., Argen et al., 2012; Au et al., 2010; Badger et al., 2007; 2011; Lopez et al., 2007; Toseland et al., 1995). The treatment was designed to be single strand (Richards et al., 2010) meaning that one specific technique utilised in the intervention was supported at one time. However, carers were able to use more than one CBT based self-help technique over the course of the treatment.

During the initial assessment carers were introduced to the CBT self-help intervention through provision of the Introduction Booklet (Appendix 6.1). The intervention was designed so that carers could choose with support from the PWP, which CBT technique (behavioural activation; goal setting; problem solving) they felt best suited their particular difficulties. During the first support session the carer was given the specific booklet containing the particular technique they had decided to use. In the final support session the Relapse Prevention Booklet (Appendix 6.5) was introduced to the carer.



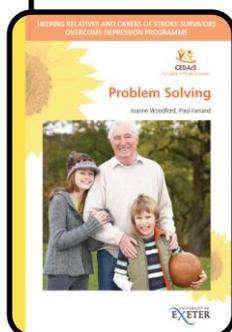
Introduction

Psychoeducation: depression and the caring experience
Introduction to the CBT model
Setting aims for treatment
Introducing carer recovery stories pertaining to the three main interventions (behavioural activation; goal setting and problem solving)
Psychoeducation: common physical and emotional complications in stroke survivors
Positive coping strategies used by carers of stroke survivors
National sources of support (stroke and carer specific NHS and community support services)



Behavioural Activation

Psychoeducation: activity in the caring role
Psychoeducation: theory behind behavioural activation
Identification of current activities.
Identification of what things in life are important to the informal carer
Identification of activities that have been given up since becoming a carer
Organisation of activities that have been given up by level of difficulty
Planning activities
Common difficulties experienced when using behavioural activation
Carer recovery story



Problem Solving

Psychoeducation: problems and the caring role
Psychoeducation: theory behind problem solving
Identification things in life are important to the carer
Identification of current problems
Categorisation of problems into 'not important'; 'important and can be solved' and 'important but cannot be solved'.
Using the seven-steps to problem solving for important problems that can be solved.
Worry time for important problems that cannot be solved.
Common difficulties experienced using problem solving.
Carer recovery story



Figure 6.1. Content of the CBT Self-Help Intervention

Integration of common factors. One of the defining features of CBT self-help is that CBT specific principles are communicated through the use of self-help materials rather than being delivered by a therapist (Farrand & Woodford, 2013). As such, CBT self-help materials are required to convey more than just information but allow patients to set goals, learn and develop CBT based skills, and develop knowledge concerning the prevention of relapse in the future (Richardson & Richards, 2006). The specific CBT techniques are known as 'specific factors' (Richardson & Richards, 2006) and inform the general content of

the CBT self-help intervention (see Figure 6.1). However, there are a number of 'common factors' evident across all types of psychotherapy (Richardson & Richards, 2006). These are essential to the establishment, development and maintenance (Cahill et al., 2008) of a therapeutic relationship and contribute to improved therapy outcome (Lambert & Barley, 2002; Martin, Garske, & Davis, 2000; Norcross, 2002; Shirk & Karver, 2003). Indeed, many patients attribute interpersonal concepts such as 'talking to someone' as reasons for improvement in depression (Rogers, Oliver, Bower, Lovell & Richards, 2004). Although the materials are designed to be supported by PWPs, given the time-limited nature of supported self-help, there may be less opportunity for the development of a therapeutic relationship utilising common factors (Richardson & Richards, 2006). It is important to ensure that the self-help materials themselves foster the therapeutic alliance through the integration of common factors (Richardson, Richards, & Barkham, 2010). Given the significance of common factors (Cahill et al., 2008; Norcross, 2002; Richardson & Richards, 2006) the authors ensured that common factors were incorporated into the self-help materials. Table 6.4 provides an overview of key common factors and some examples of how they were integrated into the self-help materials following previously developed guidelines to identifying common factors within CBT self-help materials (Barazzzone, Cavanagh, & Richards, 2012; Richardson & Richards, 2006; Richardson et al., 2010).

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Table 6.4

Common Factors Integrated into the CBT Self-Help Programme based on the Common Factors Model for Self-Help Books
(Richardson et al., 2010, p. 71)

Common factor	Incorporation into the CBT self-help programme
<i>Establishing the relationship</i>	
Being accessible	<ul style="list-style-type: none"> • CBT self-help materials were developed closely with the lived experience steering group in order to ensure that the language used, layout and graphics were accessible and acceptable to informal carers of stroke survivors. • Personal difficulties experienced by depressed informal carers explored in Study Two were used to inform the patient vignettes to enable informal carers to relate to the material, to improve accessibility. • The CBT self-help materials were designed by a professional design company with prior experience of developing accessible CBT self-help materials. • The use of technical jargon was minimised throughout the booklets.
Generating a belief in recovery	<ul style="list-style-type: none"> • Hope that recovery from depression is possible was generated through the patient vignettes. First, brief vignettes for patients using each of the three CBT based techniques are provided in the Introduction Booklet (Appendix 6.1). These vignettes briefly introduce the three carers who have used the three interventions (Sarah, Goal Setting; Louise, Behavioural Activation, and Tom, Problem Solving) and provide information on how each carer has worked through the intervention successfully in order to generate hope in recovery. Within each booklet, these patient vignettes are further developed, demonstrating in more detail how recovery from depression is possible. • Positive coping strategies identified in Study Three are included within the Introduction Booklet to demonstrate the techniques some carers have used to successfully manage the caring role and generate hope that positive coping within the caring role is possible. • Finally, positive comments concerning recovery from depression are interwoven throughout the booklets, for example “there are tools and techniques that can help you overcome and cope with these difficulties” (Appendix 6.1, Introduction Booklet,

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Generating a belief in the helpfulness of the materials	<p>p.3) and “Behavioural Activation helps you break this vicious cycle by starting to do activities you have stopped doing again. This puts the cycle into reverse and things start to improve” (Appendix 6.2, Behavioural Activation Booklet, p. 4).</p> <hr/> <ul style="list-style-type: none">• Clear examples of how the techniques might work are provided within each of the booklets. Diagrams are used explaining how each technique can help with the vicious cycle of depression.• Information about the authors (JW & PF) is listed towards the end of each booklet under ‘About the Authors’ including working for the University of Exeter, academic history within the development of CBT self-help materials, training mental health professionals in supporting CBT self-help materials and clinical experience.• In addition, the three members of the steering committee are also introduced at the end of each booklet. Photos were requested not to be used by steering committee due to concerns surrounding physical appearance. However, detail is provided about their experiences of being a carer and stroke survivor and belief in the intervention may be further generated by carers understanding that the materials were developed alongside people with lived experience of the difficulties they are experiencing themselves.• Further belief in the helpfulness of the interventions is generated through the use of patient vignettes that have successfully used the interventions and recovered from depression.
Empathy, warmth and genuineness	<hr/> <ul style="list-style-type: none">• Direct empathy statements are used throughout the materials. For example, “<i>This can make you feel like your problems are increasing which is understandable overwhelming, distressing and can make thing seem very difficult to manage</i>” (Appendix 6.4, Problem Solving Booklet, p. 2) and “<i>Such difficult thoughts around resentment, guilt and loss are very common and understandably very distressing</i>” (Appendix 6.4, Goal Setting Booklet, p. 1).• The case studies were written in the first person. This technique may help readers identify with the material and increase the realism of the patient vignettes. This has been identified previously as a technique that may also communicate empathy to the reader (Richardson et al., 2010). For example through statement such as “<i>There just didn’t seem to be any purpose in life anymore and Brian and I seemed to have lost any hope we had for the future</i>” (Appendix 6.4, Goal Setting Booklet,

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- p. 16).
- The recognition of the impact of depressive symptoms and the restraints of the caring role on ability to work through the treatments are also recognised throughout: *“It can take time to start to feel better again. A loss of enjoyment or pleasure out of certain activities is very common in depression and you may be achieving activities but not experiencing pleasure. This can be the same for feeling satisfaction or a sense of achievement. Many carers we have worked with also report that they can often feel guilty when starting to do activities again for themselves. However in the long term they report that this becomes better and they see the benefits of balance again, for both themselves and the person they care for”* (Appendix 6.2, Behavioural Activation Booklet, p. 18).
 - The examples used within the intervention are informed from the understanding gained concerning informal carers’ difficulties in Study Two. The language and examples used are relevant to informal carers of stroke survivors to increase engagement further within the materials (Whittaker et al., 2012).
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- Negotiation of goals
- Aims for treatment are set within the Introduction Booklet. The term ‘aims’ rather than ‘goals’ was used due to ‘goal setting’ being a specific technique utilised within the intervention and to avoid confusion. Guidelines are provided to enable carers to set specific aims, that strive towards achieving something and are realistic. Examples are used to help guide carers in setting aims for treatment. There is a worksheet for carers to write down their aims for treatment, with methods of measuring whether they are obtaining the aim alongside space to write down the date so progress can be monitored over time (Appendix 6.2, Introduction Booklet, p. 9-10).
 - The goal setting booklet is focused around setting goals and uses the S.M.A.R.T model to ensure that goals set are specific, measureable, achievable, relevant and time specific. Worksheets are included to help carers’ track and measure progress.
 - Additionally, within each of the main techniques there is a worksheet that helps carers to identify what areas of life are important to them (Appendix 6.2, Behavioural Activation Booklet, p. 9-10; Appendix 6.3, Goal Setting Booklet, p. 6-7, Appendix 6.4, Problem Solving Booklet, p. 4-5). Carers are encouraged to think
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about the areas of life that are most important to them and are provided with prompts such as ‘relationships’; ‘roles and responsibilities’; ‘social and leisure activities’; ‘health’; ‘finances’ and ‘religious or spiritual life’. Each intervention is set around activities that are of value and importance. For example, if using Behavioural Activation carers are encouraged to select activities that are associated with areas of life that are important and of value to them.

Collaborative framework

- The interventions include multiple homework exercises with accompanying worksheets to assist them in working through the techniques utilised within the intervention. Carers are encouraged to work through each step of the technique through undertaking homework activities. For example, the Behavioural Activation intervention includes a ‘My Starting Point Diary’ to record activities the carer is currently undertaking (Appendix 6.2, Behavioural Activation Booklet, p. 7-8).
 - Statements encouraging carers to work through the intervention in their own time and at their own pace are included throughout the booklets, for example *“Sometimes it can be really difficult to identify ‘least difficult activities. One thing you could try is breaking down some of the activities you have identified in the ‘medium; and ‘most difficult; categories”* (Appendix 6.2, Behavioural Activation Booklet, p. 14).
 - The Introduction Booklet introduces the carer to the role of the PWP in supporting the intervention to emphasise the collaborative nature of the intervention and how the PWP is there to support and guide the carer through using the techniques: *“You’ll either meet with your PWP face-to-face or speak with them over the telephone on a regular basis over the coming months. How you would like to work is up to you. Your PWP will act a bit like a coach or personal trainer and help you to understand and use the techniques in the programme”* (Appendix 6.1, Introduction Booklet, p. 2).
 - A collaborative framework is further developed by encouraging the carer to speak with their PWP if they are experiencing difficulty: *“If you find yourself struggling to write your goals according to the S.M.A.R.T features remember your PWP is there to help you”* (Appendix 6.3, Goal Setting Booklet, p. 12). This technique is also used in the patient vignettes whereby in each of the stories the carer is working through the intervention with the support of their PWP
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Guidance	<ul style="list-style-type: none">• Throughout the materials the carer is addressed directly through the use of the first and second person that may further generate a collaborative framework and encourage the carer to work through the materials.• Clear rationales in terms of each technique utilised within the intervention are provided and linked to typical difficulties experience by carers of stroke survivors as generated by Study Two.• Step-by-step instructions in terms of how to work through each technique are provided throughout. Carers are reminded to speak with their PWP if they have difficulties using any of techniques.• Instructions in term of how to use each step of the techniques are provided in the patient vignettes, alongside sample worksheets.
Developing the relationship	
A secure base	<ul style="list-style-type: none">• Clear rationales for each technique will help carers to understand the techniques better and feel confident and secure in their use.• The academic, training and clinical backgrounds of the authors may help readers feel confident in the use of the interventions.• It is emphasised within the booklets that each of the techniques used are evidence based: <i>“Goal setting is an evidence based treatment for low mood or depression. Research has shown it to be effective, especially for people who have gone through a major life change like becoming a carer of a stroke survivor”</i> (Appendix 6.3, Goal Setting Booklet, p. 1).• The patient vignettes are positive, showing how carers have worked through the techniques successfully.• Carers are encouraged to use their PWP to support and guide them: <i>“Whilst working through the programme you will be supported by your Psychological Wellbeing Practitioner, or PWP. Your PWP is a mental health professional who has been specially trained to help support carers and relatives of stroke survivors experiencing depression work through this programme”</i> (Appendix 6.1, Introduction Booklet, p. 2).
Feedback	<ul style="list-style-type: none">• Carers are encouraged to work through the techniques, testing them out and writing down how they progressed by using the homework materials.• Example feedback from the PWP is provided within the patient vignettes, for

example “Tim and I also spoke about setting new goals. I had spoken a lot in our first session together about how I found giving up work really hard. Tim explained that a useful question to ask yourself when setting new goals to replace those you had to give up was to ask yourself what you valued, or what was important about your old goal” (Appendix 6.3, Goal Setting Booklet, p. 8).

- The carers in the patient vignettes also provide feedback concerning how they found using the techniques: *“I managed to do the activities but I found reading really hard. I used to be able to read loads but it was really difficult to concentrate. I also still found myself feeling exhausted. Stephanie (PWP) explained this was really normal and that things would get easier over time. Though I noticed speaking to my friend Zoe really helped lift my mood” (Appendix 6.2, Behavioural Activation Booklet, p. 31).*

Responsiveness

- Three different techniques and three different patient vignettes were chosen in order to reflect the different types of difficulties that carers may experience (as identified by Study Two) to enable carers to choose a technique that best reflected their own situation and difficulties. The recovery stories were designed around carers of different genders (male and female); different ages (24, 45 and 72 years old) with different relationships to the stroke survivor (grandchild, husband and wife). In addition, the effect of the stroke on the stroke survivor was also different in each vignette. For example, one stroke survivor had aphasia and memory difficulties, another was confined to a wheelchair and another stroke survivor was very dependent on their carer and had experienced multiple falls. As such, the patient vignettes were designed to be of relevance to different carers experiencing different types of difficulties and challenges.
- Carers are encouraged to identify what their own needs and difficulties are, for example, using the vicious cycle of depression within the Introduction booklet in order to identify the specific symptoms of low mood and treatment they are experiencing (Appendix 6.1, Introduction Booklet, p. 6-8).

Maintaining the relationship

Rupture prevention and repair

- Each booklet includes a section on common difficulties experienced with each technique that is specifically linked to being a carer of a stroke survivor. Techniques are provided in terms of how to work through these typical setbacks.

- Throughout the descriptions of the techniques, difficulties are also anticipated and solutions suggested: *“However, reaching your goal may not always be possible in the time frame you have set yourself. You might need to break the goal down further. Sometimes you might need more resources or time to achieve your goals. Not always being able to reach your goals is perfectly normal and to be expected. However write down why you are unable to achieve your goals in the ‘comments’ box and what may have got in the way of you achieving your goal. You can discuss this with your PWP who can help you to think about ways of making your goal more achievable”* (Appendix 2.3, Goal Setting Booklet, p. 12).
 - Carers are encouraged to speak with their PWP if they experience any difficulties or setbacks whilst using the techniques.
 - A relapse prevention booklet is provided to all carers (Appendix 6.5, Staying Well Booklet), recognising that it is important to stay well in the future, but setbacks, challenges and difficulties in life are normal and if low mood or depression is experienced again techniques can be used to help.
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- Flexibility
- Carers are given a choice of interventions to use dependent on the specific difficulties they are experiencing and which intervention carers identify with the most: *“You won’t use all of the techniques, but rather you’ll pick one that seems most suited to the difficulties you are currently experiencing. If you have any problems in deciding which technique to work with, your PWP will be able to help you”* (Appendix 6.1, Introduction, pp 2).
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Note. JW = Joanne Woodford; PF = Paul Farrand; PWP = Psychological wellbeing practitioner

6.3.5 Phase Five

6.3.5.1 Development of the PWP assessment and support protocol and accompanying training programme. The training programme was developed by JW, who has trained PWPs on the Low-Intensity IAPT Postgraduate Certificate at the University of Exeter and PF, who is the Low Intensity IAPT Course Director. The training programme was designed to provide ‘top up’ training to already qualified PWPs who had been trained in the national curriculum supporting the IAPT programme in order to deliver low-intensity CBT-based interventions for depression and anxiety (Department of Health, 2008; 2011a). The training programme was designed as a one day workshop that consisted of the following:

1. Introduction to the study.
2. The experience of caring for a stroke survivor (delivered by one of the lived experience steering committee).
3. Stroke: Causes; treatment; signs / symptoms and effects (delivered by the Exeter Stroke Support (Early Supported Discharge) Team Leader).
4. Intervention training (delivered by JW).

The accompanying PowerPoint training slides can be found in Appendix 6.6. The training was also accompanied by a CEDArS Trial PWP Handbook, available on request due to length (77 pages). The intervention training was focused on enabling the PWPs to develop an understanding of the main adaptations made to the existing CBT self-help techniques. In addition, some adaptations were made to the standard low intensity assessment protocol (see Appendix 6.7). Specifically these additions encompassed:

- Including the research trial when explaining the role of a PWP.
- Making the collaborative care role of the PWP explicit.
- Explaining the potential for depression to co-exist when being a carer of a stroke survivor explicit.
- Gather clear information around the difficulties experienced within the caring role.
- Gather informal information concerning activities of value and importance the carer has stopped.

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- Gather information pertaining to the impact of depression on the relationship with the stroke survivor (e.g., communication) and role changes (e.g., work, retirement plans and education).
- Explicitly ask how the carer has managed the transition to the caring role, for example loss and acceptance.
- Formulation of a problem statement that includes reference to the caring role.
- Provide the Introduction Booklet, explain the CBT model and set aims of treatment if possible. Homework should be to read the patient vignettes and decide on treatment.
- Ensure that when arranging the next session emphasis is placed on the barriers that can be experienced accessing support (e.g., lack of time, financial constraints, guilt) with appropriate support around problem solving these difficulties.

Further changes were also made to the standard low-intensity support protocol (see Appendix 6.8) as follows:

- Including the research trial when explaining the role of a PWP.
- Making the collaborative care role of the PWP explicit.
- Explaining the potential for depression to co-exist when being a carer of a stroke survivor explicit.
- Ascertain whether there have been any changes in the relationship between the caring role, thoughts, behaviours and physical feelings experienced, and impact of the carer's life.
- Review the carer's use of, and any changes, to support received as a carer (e.g. carer / stroke support groups, GP, social services).
- Review any new understanding about extent to which psychological and difficulties experienced within the caring role may be linked.

The low-intensity assessment and support protocols were designed to enable examination of PWP adherence to the protocol.

6.4 Discussion

This chapter describes the modelling phase of the development of a CBT self-help intervention for depressed informal carers of stroke survivors prior to progressing to the feasibility and piloting phase of the revised MRC complex interventions framework (MRC, 2008). Three separate studies were conducted and

findings were synthesised in order to develop a novel CBT self-help intervention driven by theory. This new CBT self-help intervention was designed to specifically meet the unique difficulties experienced by depressed informal carers of stroke survivors.

6.4.1 Limitations

The use of a CBT self-help intervention was decided a priori, prior to embarking on the PhD. First, this was due to the PhD being funded by an external funder (The Dunhill Medical Trust) and as such in order to gain funding, a full research proposal was developed specifying the development of a CBT based self-help intervention. Second, in terms of feasibility there was limited scope in relation to departing from the CBT self-help model utilised within England. For example, the planned feasibility RCT was to be run within existing IAPT services and PWP, trained in supporting CBT self-help, were planned to deliver the treatment.

As such, there is the possibility that important difficulties experienced by informal carers of stroke survivors that require support have been omitted from the development of the treatment due to being out of scope for this particular research study. For example, in Study Two it was clear that informal carers experienced significant difficulties with relationships and communication, role transitions and social isolation. There is the possibility that an Interpersonal Psychotherapy (IPT) approach might be suited to support informal carers with such difficulties. IPT is an evidence based (Cuijpers et al., 2011) psychological intervention for depression whereby the focus of treatment is on interpersonal problems, such as grief, role transition, relationship difficulties or social isolation (Lipsitz & Markovitz, 2013). In addition, Study One conducted as part of this thesis identified that IPT might be an effective treatment for informal carers experiencing depression. However, to date few IPT based self-help interventions have been developed (see Dagöö et al., 2014; Donker et al., 2013a) and PWPs are not currently trained to support IPT based interventions. The development of a self-help intervention based on a model other than CBT was not feasible within the limitations of a PhD.

In addition, Study Two identified difficulties with anxiety and worry. Although difficulties with worry are partially integrated with the inclusion of 'Worry Time' as a technique within 'Problem Solving' anxiety and worry were key themes elicited within Study Two by depressed and anxious informal carers of stroke survivors. Typically anxieties concerned fear of leaving the stroke survivor alone, fear of falls and other

health complications and anxiety concerning what might happen in the future. Such anxieties led to behaviours such as constant monitoring of the stroke survivor and disengaging from activities that may further heighten anxiety (e.g., leaving the house). However, it was decided not to develop a combined self-help intervention for anxiety and depression due to lack of evidence for CBT self-help interventions targeting both anxiety and depression (Farrand & Woodford, 2013). As such, difficulties with anxiety are not specifically targeted within the developed CBT self-help intervention.

A further limitation pertains to the lack of formal involvement of additional key stakeholders in the development of the intervention. For example, a Delphi study could have been conducted to attempt to gain consensus from key stakeholders (e.g., PWP, stroke healthcare professionals and GPs) concerning elements of the intervention design and delivery (Moscovice, Armstrong, Shortell, & Bennett, 1977; Evans, Rogers, & McGraw, 2004).

Finally, there was a lack of involvement from informal carers of stroke survivors within the development process to further inform the content of the material, use of language and general layout. Although the lived experience committee of two carers and one stroke survivor provided feedback throughout the development of the material all three members had academic backgrounds and were possibly not representative of the wider informal carer population.

6.5 Conclusions

A novel CBT self-help intervention was successfully developed for depressed informal carers of stroke survivors. Utilisation of the revised MRC framework (MRC, 2008) has allowed the development of a complex intervention informed by existing evidence, recognised psychological theories and tailoring intervention to the unique needs of informal carers of stroke survivors. In the following chapter the researcher moves onto the feasibility and piloting stage of the revised MRC framework (MRC, 2008) whereby the feasibility and acceptability of the new CBT self-help intervention will be examined in Study Five.

CHAPTER SEVEN: Feasibility Randomised Controlled Trial

Supported cognitive-behavioural self-help versus treatment-as-usual for depressed informal carers of stroke survivors (CEDARs): study protocol for a feasibility randomised controlled trial.

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7.1 Abstract

Background: Increased life expectancy has resulted in a greater provision of informal care within the community for patients with chronic physical health conditions. Informal carers are at greater risk of poor mental health, with one in three informal carers of stroke survivors experiencing depression. However, currently no psychological treatments tailored to the unique needs of depressed informal carers of stroke survivors exist. Furthermore, informal carers of stroke survivors experience a number of barriers to attending traditional face-to-face psychological services, such as lack of time and the demands of the caring role. The increased flexibility associated with supported cognitive behavioural therapy self-help (CBT self-help), such as the ability for support to be provided by telephone, email, or face-to-face, alongside shorter support sessions, may help overcome such barriers to access. CBT self-help, tailored to depressed informal carers of stroke survivors may represent an effective and acceptable solution.

Methods/Design: This study is a Phase II (feasibility) randomised controlled trial (RCT) following guidance in the MRC Complex Interventions Research Methods Framework. We will randomise a sample of depressed informal carers of stroke survivors to receive CBT self-help supported by mental health paraprofessionals, or treatment-as-usual. Consistent with the objectives of assessing the feasibility of trial

design and procedures for a potential larger scale trial we will measure the following outcomes: a) feasibility of patient recruitment (recruitment and refusal rates); (b) feasibility and acceptability of data collection procedures; (c) levels of attrition; (d) likely intervention effect size; (e) variability in number, length and frequency of support sessions estimated to bring about recovery; and (f) acceptability of the intervention. Additionally, we will collect data on the diagnosis of depression, symptoms of depression and anxiety, functional impairment, carer burden, quality of life, and stroke survivor mobility skill, self-care and functional ability, measured at four and six months post-randomisation.

Discussion: This study will provide important information for the feasibility and design of a Phase III (effectiveness) trial in the future. If the intervention is identified to be feasible, effective, and acceptable, a written CBT self-help intervention for informal carers of stroke survivors, supported by mental health paraprofessionals, could represent a cost-effective model of care.

Trial registration: Current Controlled Trials ISRCTN63590486.

Keywords: Randomised controlled trial, Cognitive behavioural therapy (CBT), Self-help, Depression, Stroke, Informal caregivers.

7.2 Background

Technological advances in healthcare have resulted in increased life expectancy across the developed world (Christensen et al., 2009). However, such increases have led to significant challenges, with excessive demand placed upon the provision of treatment and care of patients with chronic physical health conditions (Christensen et al., 2009; Wakefield, Hayes, Boren, Pak, & Davis, 2012). This has resulted in an increased reliance on informal care within the community for people with chronic physical health conditions (Wakefield et al., 2012). However, increased provision of informal care places informal carers at greater risk of poor mental and physical health (Canniscio et al., 2002; Coe & van Houtven, 2009; Pinquart & Sörensen, 2003a) accompanied by reduced opportunity for paid employment and social activity (Salva, Almeida, Davey, & Zarit, 2008). On average, 30% of informal carers experience depression (Davies, 1995). Rates are even higher when the chronic physical health condition causes significant behavioural, cognitive, and emotional impairment in the patient being cared for (van den Heuvel, de White, Schure, Sanderman, & Meyboom-de Jong, 2001). Significant forms of impairment are experienced with stroke (Visser-Keizer, Meyboom-de Jong, Deelman, Berg, &

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Gerritsen, 2002), with 30 to 68% of informal carers of stroke survivors experiencing depression from the time of the initial stroke to three years post-stroke (Berg, Palomäki, Lönnqvist, Lehtihalmes, & Kaste, 2005; Visser-Meily, Post, van de Port, van Heugten, & Bos, 2008). Given such a high prevalence of depression, demand for accessible evidence-based psychological interventions targeted at informal carers of stroke survivors is high.

Although evidence-based psychological treatments for depression exist (Cuijpers et al., 2013) the costs of service delivery are high, with demand for treatment exceeding the capacity of therapists, resulting in long waiting lists (Lovell, Richards, & Bower, 2003) and limited access (Kazdin & Blasé, 2011). Additionally, informal carers experience specific barriers to accessing primary care services (Arksey & Hirst, 2005). Barriers have included a lack of recognition of the difficulties associated with the caring role by health professionals (Arksey & Hirst, 2005), with general practitioners more likely to provide practical support rather than referral for formal psychological treatment. Additionally, interventions are predominantly focused on the stroke survivor rather than the informal carer (Bulsara & Fynn, 2006; Greenwood et al., 2011). The long term psychological needs of informal carers of stroke survivors have therefore been largely neglected, making it difficult for informal carers to access evidence-based psychological therapies (Murray, Young, Forster, & Ashworth, 2003; Simon, Kumar, & Kendrick, 2008; 2009).

To improve access to evidence-based psychological therapies, there have been movements towards the use of supported cognitive behavioural therapy self-help (CBT self-help) for the treatment of mild to moderate depression and anxiety disorders (Bennett-Levy, Richards, & Farrand, 2010). Meta-analyses of supported CBT self-help provide evidence that it is an efficacious treatment for depression and anxiety (Coull & Morris, 2011; Farrand & Woodford, 2013; Gellatly et al., 2007; Lewis, Pearce, & Bisson, 2012). Furthermore, when compared with traditional CBT no significant difference in overall effect size was found, suggesting supported CBT self-help and traditional CBT are comparable treatments for both depression and anxiety (Cuijpers et al., 2010). CBT self-help is not delivered by a therapist, rather CBT specific principles are communicated to the patient through the use of self-help materials, commonly in a written or internet-based format (Bennett-Levy, Richards, & Farrand, 2010). Guidance and motivation appear to increase effectiveness (Gellatly et al., 2007) although the need for support differs across mental health conditions

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(Farrand & Woodford, 2013). To further increase access, support is provided in a variety of ways including telephone, email, or face-to-face (Bennett-Levy, Richards, & Farrand, 2010). Because the demands of caring are often a barrier to attending therapy (Arksey & Hirst, 2005; Arksey et al., 2003), the increased flexibility associated with the delivery of CBT self-help may increase access to appropriate psychological support for informal carers of stroke patients.

Although CBT self-help interventions are available for depression, evidence highlights that significant adaptations to interventions may be required prior to application to different depressed populations, for example, to those with depression co-morbid to a physical health condition (Hind et al., 2009). Additionally, although CBT self-help appears effective for common mental health difficulties, reviews of CBT self-help interventions for people with physical health conditions are less promising (Beatty & Lambert, 2013; Cuijpers, van Straten, & Andersson, 2008; Matchan et al., 2014). This raises the possibility that benefits demonstrated in general CBT self-help interventions for adult depression may not generalise to medical populations that have depression as a secondary co-morbidity or informal carers of people with physical health conditions. Indeed, mental health services for carers have been criticised for not being tailored to address the unique difficulties informal carers experience (Lundh, 1999). Such difficulties include informal carers managing behavioural problems (Pinquart & Sörensen, 2003a), physical impairments (Pinquart & Sörensen, 2003b) and cognitive impairment (Germain et al., 2009), all of which are experienced by informal carers of stroke survivors (van den Heuvel et al., 2001). To the best of our knowledge, only three published studies have examined CBT self-help for depression within informal carer populations, specifically carers of people with anorexia nervosa (Grover et al., 2011a; Grover et al., 2011b) and cancer patients (Scott & Beatty, 2013). It is therefore clear that more research is required into both the effectiveness and acceptability of CBT self-help interventions for the treatment of depression in informal carers of patients with chronic physical health conditions.

Over the last decade there has been a growing recognition of the importance of understanding patients' experiences when developing health resources (Kennedy & Rogers, 2002; Kennedy, Robinson, & Rogers, 2003) and healthcare policy (Nilsen, Myrhaug, Johansen, Oliver & Oxman, 2006). Reflecting this recommendation, a new written CBT self-help intervention has been developed specifically targeted at

depressed informal carers of stroke survivors (Woodford & Farrand, 2013). The content was informed through a series of qualitative studies to understand the specific difficulties and challenges experienced by depressed informal carers of stroke survivors, and helpful coping strategies used by currently non-depressed informal carers. The new CBT self-help intervention recognises and targets the difficulties commonly experienced by informal carers of stroke survivors identified through the qualitative studies. Additionally, helpful coping strategies used by currently non-depressed informal carers were used to further inform and adapt the content of written CBT self-help intervention. Recognising such strategies may provide a useful aid to informal carers experiencing emotional difficulties (Mackenzie & Greenwood, 2012). This study seeks to examine the feasibility of running a definitive randomised controlled trial (RCT) to examine the effectiveness and acceptability of this specially adapted CBT self-help intervention.

7.2.1 Study Aims and Objectives

We will conduct a feasibility phase II RCT (Craig et al., 2008; Thabane et al., 2010) comparing a written CBT self-help intervention for depressed informal carers of stroke survivors supported by paraprofessional mental health workers (Psychological Wellbeing Practitioners; PWPs) with treatment-as-usual (TAU). Outcomes will assess a number of methodological and procedural uncertainties that require investigation prior to designing and applying for funding for a Phase III trial. Therefore the following four questions will be addressed: For informal carers of stroke survivors receiving CBT self-help in a fully powered phase III trial, what would be the estimates of likely recruitment and retention rate; estimates of the range of effect sizes; feasibility and acceptability of data collection methods and instruments; and acceptability and structure of the treatment procedures to participants?

7.3 Methods/Design

7.3.1 Study Design

We will conduct a single blind parallel group feasibility RCT comparing CBT self-help for depressed informal carers of stroke survivors (intervention group) with TAU (control group). This protocol follows CONSORT (Schulz et al., 2010) and SPIRIT (Chan et al., 2013) guidelines for reporting clinical trial protocols.

7.3.2 Setting

We will recruit participants over a six-month period through primary care services, specialist stroke healthcare settings, and community organizations in the

counties of Cornwall and Dorset (South-West England). Participants will be treated within primary care mental health services commissioned under the Improving Access to Psychological Therapies program (IAPT; Clark, 2011).

7.3.3 Participant Inclusion Criteria

Eligible participants will be self-identified informal carers of stroke survivors at a minimum of two months post home discharge (relating to the time of the most recent stroke), aged 16 and over. We will recruit participants meeting the 10th revision of the International Statistical Classification of Diseases and Related Health Problems (ICD-10) criteria for major depression as determined by the Clinical Interview Schedule (CIS-R) (Lewis, Pelosi, Araya, & Dunn, 1992) and who score between 10 and 22 on the Patient Health Questionnaire-9 (PHQ-9) (Kroenke, Spitzer, & Williams, 2001). To reflect standard practice participants will be eligible to participate in the study whether or not they are currently receiving antidepressant medication, however the dose must have been stable for at least one month prior to recruitment into the study. All participants need to be able to read in English in order to engage with the written CBT self-help intervention.

7.3.4 Participant Exclusion Criteria

Potential participants with post-traumatic stress disorder (PTSD), psychosis, bipolar disorder, current substance or alcohol abuse, or who are acutely suicidal will be excluded from participation in the study, in addition to those currently receiving formal psychotherapy for their depression.

7.3.5 Recruitment Settings and Procedure

A number of recruitment techniques will be utilised including letter mail-out, the use of brochures, posters and flyers, advertisement in newsletters, and direct referral from healthcare professionals. Such multifaceted recruitment techniques have been successfully used to recruit informal carers of people with dementia (Whitebird et al., 2011). Details of the recruitment strategies to be used within each recruitment setting are detailed below.

7.3.5.1 Primary care. Participants will be recruited by searching GP records, a strategy successfully employed within other depression trials (Kuyken et al., 2010; Richards et al., 2013; Watkins et al., 2011). First, practice staff will search general practice electronic case records for stroke survivors. Practice staff will subsequently manually screen these records to identify stroke survivors who have a known informal carer. Practice staff will send a study invitation pack to all identified informal

carers inviting them to take part, including an invitation letter, patient information sheet, and reply slip. Informal carers will reply directly to the research team to express whether they would like to be contacted to discuss the research in more detail either by using the reply slip or calling the research team directly. Additionally, GPs will be able to directly refer suitable informal carers to the study team and study posters will be displayed in practice reception rooms to further advertise the study.

7.3.5.2 Specialist stroke care settings. We will also recruit participants from clinical acute and community based stroke healthcare settings, for example acute stroke units, stroke rehabilitation units, community early discharge, and rehabilitation teams. Stroke research nurses and community stroke healthcare professionals will approach informal carers seen within these settings and provide brief details about the study and a study invitation pack. If interested, informal carers can either consent for their contact details to be sent to the research team or reply directly to the research team themselves.

7.3.5.3 Community outreach. Participants will also be recruited through a variety of community based stroke and informal carer charities such as the Stroke Association, Different Strokes, and community stroke clubs and groups. Groups and charities interested in supporting the study will be provided with brochures and flyers advertising the study to hand out to informal carers. The research team will also endeavour to give presentations to members of stroke and informal carer groups to further advertise the research program. Additionally, the study will be advertised in stroke and informal carer charity newsletters.

7.3.6 Reasons for Non-Participation

All study invitation packs will also include anonymised reply slips with space for writing reasons for nonparticipation and researchers will ask participants for reasons from those who verbally decline. It will be made clear that researchers will not be trying to persuade participants to reconsider their decision. This information will provide further information in terms of the feasibility of recruitment and acceptability of the intervention.

7.3.7 Screening, Baseline and Informed Consent

A researcher will speak to all informal carers of stroke survivors about the study in more detail. If interested in participating in the study, informal carers will be asked to provide verbal consent for a telephone screen to be conducted against the inclusion criteria to confirm the current level of depressive symptoms, length of time

carers, and any history of PTSD, psychosis, bipolar disorder, and current substance or alcohol abuse. If eligible to participate, dependent upon preference, the potential participant will be invited to attend a full screening appointment via the telephone or face-to-face, to confirm a diagnosis of major depression using the CIS-R. If eligible, the full baseline assessment will be undertaken. Potential participants will be required to provide full written informed consent before the full screening appointment or baseline can take place. Once the full baseline assessment has taken place, participants will be randomised (see Figure 7.1).

7.3.8 Randomisation and Allocation Concealment

We will randomly allocate eligible participants to one of the two study arms - supported CBT self-help or TAU - using a web-based randomisation service at the Peninsula Clinical Trials Unit which will be concealed from the research team. We will use minimisation to ensure balance between arms in relation to site in order to assist with efficient study management (East Dorset, West Dorset, North Cornwall, and South Cornwall) and factors that may affect the outcomes: PHQ-9 score (Moderate: PHQ-9 score 10 to 14; Moderately Severe: PHQ-9 score 15 to 22) and sex (male or female). The minimisation algorithm will contain a stochastic element to maintain a degree of unpredictability when allocating. In order to preserve the blinding of research personnel, participants will be informed as to which study arm they have been allocated by a researcher not otherwise associated with the study.

7.3.9 Sample Size

No formal power calculations are usually undertaken in feasibility RCTs (Arain et al., 2010). Instead a sufficient sample size to calculate the critical parameters relating to the feasibility outcomes in the trial, for example recruitment and attrition rates (Arain et al., 2010), should be used. As such, we will use the recommended sample size of 30 participants per arm for feasibility studies (Browne, 1995) consistent with the median sample size found in both feasibility and pilot RCTs (Billingham et al., 2013). This will provide a reasonable indication of the likely sample size required for a larger trial (Thabane et al., 2010; Lancaster, Dodd, & Williamson, 2004).

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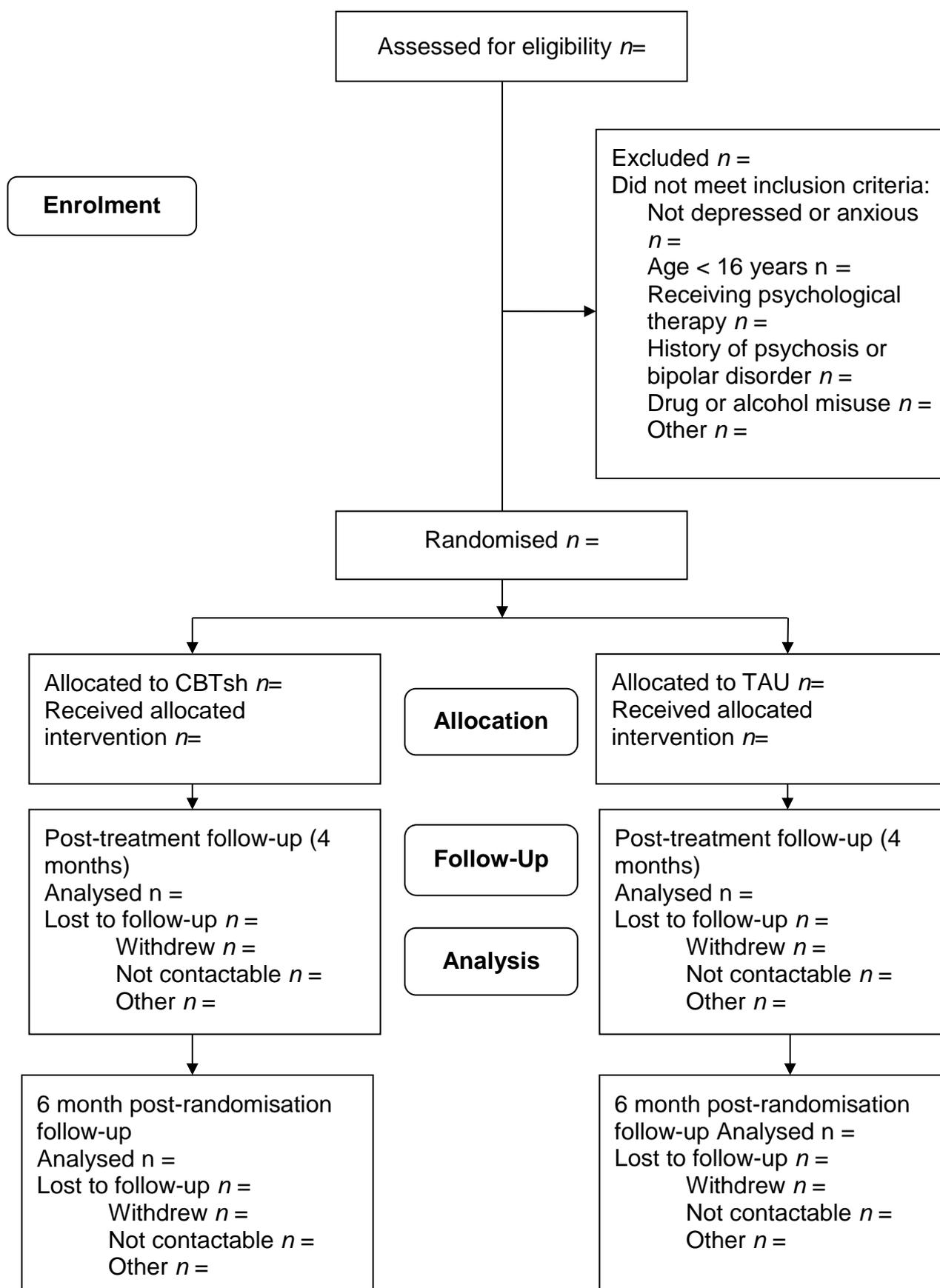


Figure 7.1. CONSORT diagram

7.3.10 Treatments

7.3.10.1 Intervention. Participants will receive one assessment session and up to twelve support sessions. Limiting the number of sessions used to support the intervention is identified as one of the characteristics associated with low-intensity CBT (Bennett-Levy & Farrand, 2011). The number of support sessions received will be decided collaboratively between the PWP and participant. The initial assessment session will be of 35 minutes duration, with subsequent sessions lasting between 25 and 35 minutes each. During their first assessment session participants will receive the CBT self-help introduction Booklet specifically developed for the trial (Woodford & Farrand, 2013). The assessment session will mainly comprise a client centred assessment to understand the difficulties experienced by the participant alongside the provision of information concerning the impact of depression, the impact of the caring role on mood, and the CBT approach. Participants will also be provided with more information about each of the three possible interventions (behavioural activation, problem solving, and goal setting) by the PWP, supplemented by the introduction Booklet (Woodford & Farrand, 2013). During the first support session participants will be provided with an additional Booklet detailing the particular CBT self-help intervention they wish to use (behavioural activation, problem solving, or goal setting). Subsequent support sessions will provide guidance and encouragement around the use of the chosen CBT self-help intervention. All assessment and support sessions will follow a structured treatment support protocol (Richards & Whyte, 2011) adapted to fit the needs of carers that were identified within the treatment development phase. Assessment and support sessions will be provided either face-to-face, over the phone, or through a combination of both methods as determined by participants' preference. All participants will receive relapse prevention during their final support session, again guided by a relapse prevention Booklet developed for the study.

Those providing support will be qualified PWPs trained in accordance with the curriculum supporting the Improving Access to Psychological Therapies Programme (Department of Health, 2008; 2011a) to deliver low-intensity CBT-based interventions for depression and anxiety (Richards, Chellingsworth, Hope, Turpin, & Whyte, 2011). PWPs will also receive an additional one-day training session delivered by JW, alongside a carer of a stroke survivor and a stroke healthcare professional. Consistent with IAPT supervision guidance for the PWP workforce

(Turpin & Wheeler, 2011), PWPs will be provided with weekly case management supervision to provide advice and support by an experienced mental health professional within the service. Case management supervision will be delivered to predetermined protocols ensuring all participants are brought to supervision at pre-set times during treatment or when they display particular clinical characteristics and risk (Richards et al., 2011). PWPs supporting the intervention will also be provided with group clinical supervision by an IAPT clinical educator once a month. This supervision will focus on the discussion of cases and ongoing clinical skills development, will last approximately 45 minutes, and be provided for the duration of the treatment phase of the trial.

7.3.10.2 Control - treatment-as-usual. Participants randomised to the control condition will receive usual care delivered by their general practitioner or other healthcare provider. In general, this may include a consultation with their general practitioner, the prescription of antidepressant medication, or a referral to a mental health service for psychological intervention.

7.3.11 Blinding

The study is single blind, with the research staff conducting outcome assessment interviews remaining blind to group allocation. Participants will be reminded not to disclose the arm they have been randomised to during contact with the researcher throughout the duration of the trial. To maintain blinding of the outcome assessor, acceptability interviews will be conducted by a researcher not otherwise associated with the study. Due to the nature of the intervention, participant and clinician blinding is not possible.

7.3.12 Outcome Measurements

7.3.12.1 Feasibility outcome measurements. The feasibility of participant recruitment will be examined including numbers assessed for eligibility; numbers eligible; reasons for ineligibility; reasons for nonparticipation and numbers randomised. Additionally comparisons will be made between recruitment settings and recruitment techniques.

The relative levels of diagnosis of depression between treatment arms at post-treatment (four months) will be determined using the CIS-R.

The feasibility and acceptability of data collection processes will be investigated through the number of missing items and follow-up rates relating to the

clinical outcome measurements likely to be used in a Phase III trial. Additionally, we will examine levels of attrition through treatment and study drop-out rates.

The range of number, length, and frequency of support sessions required to bring about recovery from depression, defined as a score of ≤ 9 on the PHQ-9, as per current IAPT guidance (Department of Health, 2011b) will also be reported.

The acceptability of the treatment will be examined through reasons reported for not attending support sessions, reasons for withdrawal from treatment and acceptability interviews will be conducted at four months post-randomisation.

PWP adherence to the protocol will be examined using audio tapes of treatment sessions. Levels of PWP adherence to the protocol will be judged by a member of academic staff involved in delivering PWP training on an accredited PWP training programme. A randomly selected sample of 20% recorded treatment sessions for each PWP in the study will be assessed for levels of adherence.

7.3.12.2 Clinical outcome measurements. A number of clinical outcome measurements have been included to examine the feasibility of the proposed data collection process, estimates of relative levels of diagnosis of depression between arms at post-treatment and the range of number, length, and frequency of support sessions required to bring about recovery from depression. The CIS-R will be used to assess diagnosis of depression and the PHQ-9 will be taken to measure depression severity. Symptoms of anxiety will be measured using the Generalised Anxiety Disorder 7-item Scale (GAD-7; Spitzer, Kroenke, Williams, & Löwe, 2006) and levels of functional impairment will be measured using the Work and Social Adjustment Scale (WSAS; Mundt, Marks, Shear, & Greist, 2002). Stroke survivors' mobility skill and self-care will be examined with the Barthel Activities of Daily Living Index (BI; Mahoney & Barthel, 1965). The measure will be completed by the informal carer on behalf of the stroke survivor. Discrepancies arise between stroke survivor and informal carer assessment of stroke survivor functional ability, with carers rating patients as more disabled (Knapp & Hewison, 1999). However, such disagreement has been found to be associated with increased carer burden (Knapp & Hewison, 1999) and is therefore of interest to collect. Stroke survivors' level of functional impairment will be measured through the Frenchay Activities Index (FAI; Holbrook & Skilbeck, 1983). The measure will be completed by the informal carer on behalf of the stroke survivor. Due to bias found when using proxy scores on the FAI (Tooth, McKenna, & Smith, 2003) results will be interpreted with caution. However

the use of proxy measurements on the FAI are considered suitable for research purposes (Chen, Hsieh, Mao, & Huang, 2007). Carer burden will be measured using the Caregiver Burden Scale (CBS; Elmstahl, Malmberg, & Annerstedt, 1996). We will also measure informal carer quality of life using both the Short Form (36) Health Survey (SF-36; Ware & Sherbourne, 1992) and the EuroQol-5D (EQ-5D; Brooks, 1996). Finally, health and public service use will be collected using an adapted version of the Client Socio-Demographic and Service Receipt Inventory (CSRI; Chisholm et al., 2000). The version of the CSRI for use in this study has been adapted from the original CSRI (Chisholm et al., 2000) and a further version developed for informal carers of stroke survivors (Patel, Knapp, Evans, Perez, & Kalra, 2004).

7.3.12.3 Demographics. Several background and socio-demographic variables will be collected at screening for informal carers and stroke survivors.

The collected variables for an informal carer: source of referral; age; gender; ethnic background; relationship status; relationship to stroke survivor; employment status; yearly household outcome; highest level of academic qualification; length of time caring; whether lives with the stroke survivor; provision of care before the stroke; receipt of support services in the home; hours of support services received in the home per week, and hours of caring per week.

The collected variables for a stroke survivor: age; gender; ethnic background; relationship status; employment status; date of first stroke; date of most recent stroke; type of first stroke (ischemic, haemorrhage, transient ischemic attack (TIA)); type of most recent stroke, (ischemic, haemorrhage, TIA) and whether the stroke survivor is aphasic.

7.3.13 Data Collection

Dependent upon participant preference, the researcher will collect data either over the telephone or face-to-face at screening, baseline, four months and six months post-randomisation. The adapted CSRI will be collected via post due to the potential for unblinding as the measure includes information about the receipt of psychological treatment. A summary of outcomes collected at each time point can be seen in Table 7.1.

7.3.14 Acceptability of the Intervention

7.3.14.1 Study objectives and design. We will conduct a sub study to examine the following question: what are participants' views on the acceptability of

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CBT self-help? Semi-structured interviews will be conducted with all participants randomised to receive CBT self-help to examine the acceptability of the new intervention. Open-ended questions will be asked around participants' impressions of supported CBT self-help; the relevance and suitability of the intervention for carers and relatives of stroke survivors; receiving support; specific interventions used; perceived benefit and impact of the intervention; difficulties experienced using the intervention; continued use of self-help strategies; and recommendations for future development. The topic guide has been partially informed by a previous qualitative study investigating the acceptability of online-based CBT self-help for depressed patients with multiple sclerosis (Hind et al., 2009). Non-attendees and poor attendees will also be asked about reasons for dropping out of the intervention and to consider what a more acceptable intervention may look like. Interviews will be semi-structured and conducted over the telephone. Interviews are anticipated to last between 45 and 90 minutes, however the duration may be shorter for those categorised as non-attendees and poor attendees.

7.3.14.2 Sampling. All participants allocated to receive the intervention will be invited to participate. Dependent upon attendance of support sessions, participants will be categorised into one of the following: (a) non attendees, defined as not attending any sessions; (b) poor attendees, defined as attending the assessment session and then terminating treatment before reaching a shared decision with the PWP to be discharged from treatment; or (c) completers, defined as those who engage in treatment until a shared decision is made with the PWP to terminate treatment.

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Table 7.1

Study Clinical Outcome Measures by Time Point

Outcome Measure	Telephone Screen	Full Eligibility Screen	Baseline	Weekly during treatment	Post-treatment (4 months)	6 months post-randomisation
Demographics (informal carer)						
Demographics (stroke survivor)						
PHQ-9						
GAD-7						
CIS-R						
WSAS						
CBS						
BI						
FAI						
SF-36						
EQ-5D						
Health and public service use						

Note: PHQ-9 = Patient Health Questionnaire-9; GAD-7 = Generalised Anxiety Disorder 7-item Scale; CIS-R = Clinical Interview Schedule; WASAS = Work and Social Adjustment Scale; CBS = Caregiver Burden Scale; BI = Barthel Activities of Daily Living Index; FAI = Frenchay Activities Index; SF-36 = Short Form (36) Health Survey; EQ-5D = EuroQol-5D.

7.3.15 Statistical Analysis

7.3.15.1 Quantitative. Data analysis will mainly be descriptive and address the primary outcomes relating to the feasibility of conducting a future definite RCT. Participant flow will be summarised following the CONSORT diagram (Schulz et al., 2010). Recruitment and attrition rates (both treatment and study dropouts) will be calculated, along with 95% confidence intervals. Protocol deviations, along with reasons and number of missing items on questionnaires will be reported. The mean and standard deviation for each outcome measurement will be reported at baseline, four, and six months. The mean and standard deviation will also be reported for the number, length, and frequency of support sessions required to bring about recovery.

7.3.15.2 Health Economics. Estimates of cost-effectiveness will not be possible due to the design reflecting a feasibility RCT. However the feasibility and acceptability of collecting outcome measurement relating to health-related quality of life and patient NHS and social support use will be examined. Processes for estimating costs of delivering the intervention will also be tested. The Short Form-6 dimension (SF-6D; Brazier, Roberts, & Deverill, 2002) will be used to gain measures of utility from 11 items of the SF-36 covering 6 dimensions (physical functioning, social functioning, role limitations, mental health, vitality, and pain). Both the SF-6D and EQ-5D will be used to determine quality-adjusted life years (QALYs) due to floor effects found when using the SF-6D and ceiling effects with the EQ-5D in different study populations (Brazier, Roberts, Tsuchiya, & Busschbach, 2004). In addition, although both the SF-36 and EQ-5D appear to respond to changes in depression, the agreement between utility changes is low (Gerhards et al., 2011). These procedures will inform the economic evaluation plan for the design of a future phase III RCT.

7.3.15.3 Qualitative. The five-stage framework approach (Pope, Ziebland, & Mays, 2000) will be used to analyse the verbatim notes and transcribed digital recordings from the interviews. Trustworthiness of the analysis will be established by the use of triangulation by observation, whereby completed analyses conducted by JW will be sent to one other researcher and a member of the lay steering committee to discuss whether the analysis reflects the generated themes (Lietz, Langer, & Furman, 2006). Once the second analysis is complete participants will be sent a summary of the findings to confirm whether the analysis represents accurately their experiences of the intervention (Lietz et al., 2006).

7.3.16 Ethical Approval

We will conduct the trial in accordance with the Helsinki Declaration to safeguard the welfare and rights of participants. Ethical approval was received by the National Research Ethics Committee South West for Cornwall and Plymouth on 24 May 2013. REC Reference number: 13/ SW/0018. The Data Protection Act will be followed at all times with all data securely stored and anonymised.

7.4 Discussion

This feasibility RCT has been designed to explore important feasibility questions that can be used to inform the design and funding application of a possible future definitive (Phase III) RCT. Furthermore, detailed exploration of the acceptability of the new CBT self-help intervention will inform future treatment iterations.

A supported CBT self-help intervention, tailored to the needs of informal carers of stroke survivors, may represent an effective and accessible psychological intervention for depression. As well as improving mood, supported CBT self-help may also improve informal carers' quality of life and reduce carer strain and burden. Furthermore, improvements in carer depression may also improve recovery outcomes in stroke survivors themselves and represent a cost-effective model of care both nationally and internationally.

7.4.1 Trial Status

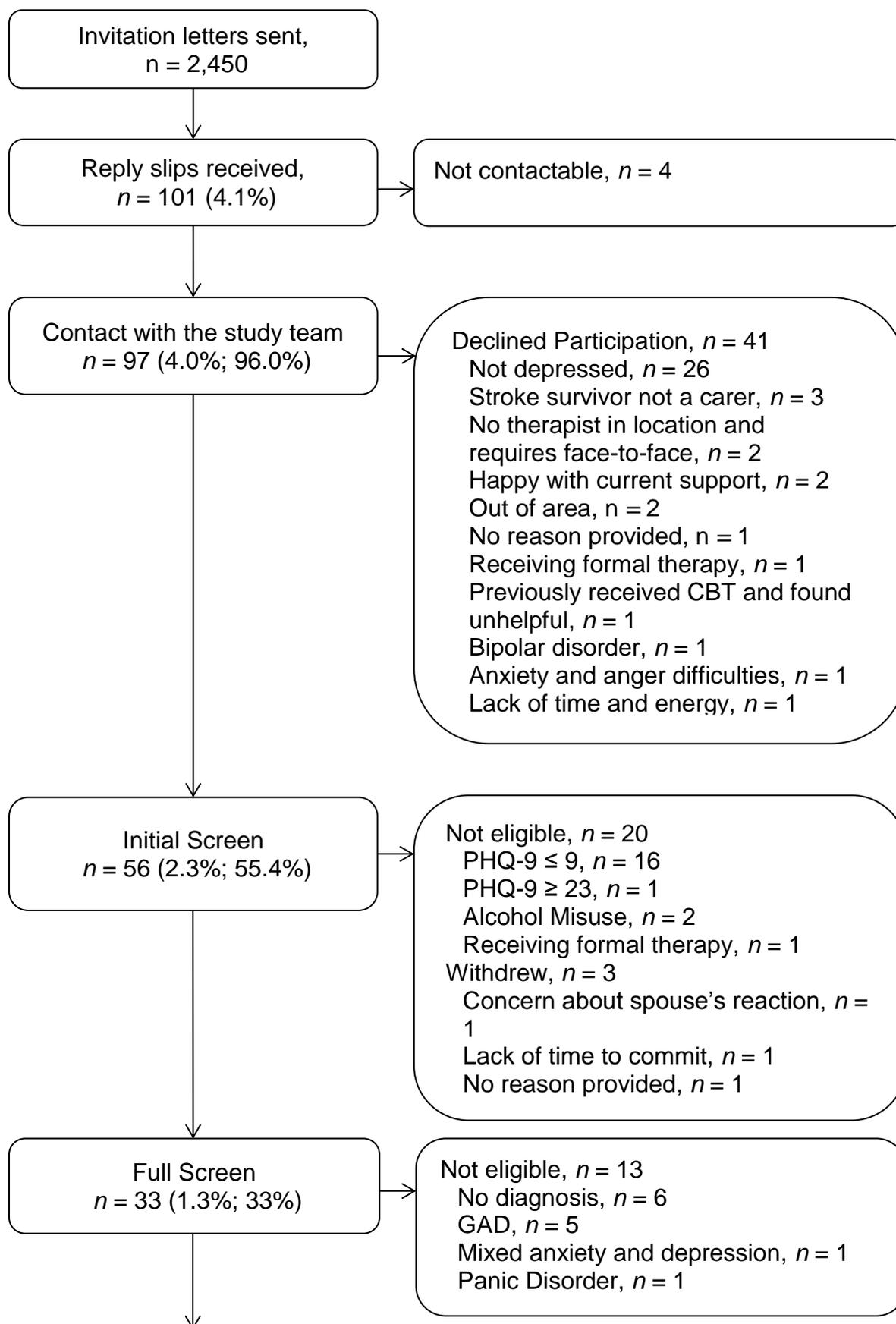
Recruitment commenced in September 2013.

7.5 Results

7.5.1 Participant Flow

The CONSORT (Schulz et al., 2010) flow chart for the feasibility RCT can be found in Figure 7.2. Recruitment and delivery of the supported CBT self-help intervention took place between August 2013 to November 2014. Post-treatment data collection at four months post-randomisation continued until October 2014. Due to the timeline for recruitment being extended from 6 months to 10 months as a result of slow recruitment into the study, 6 month outcome measures were only collected for 9 participants.

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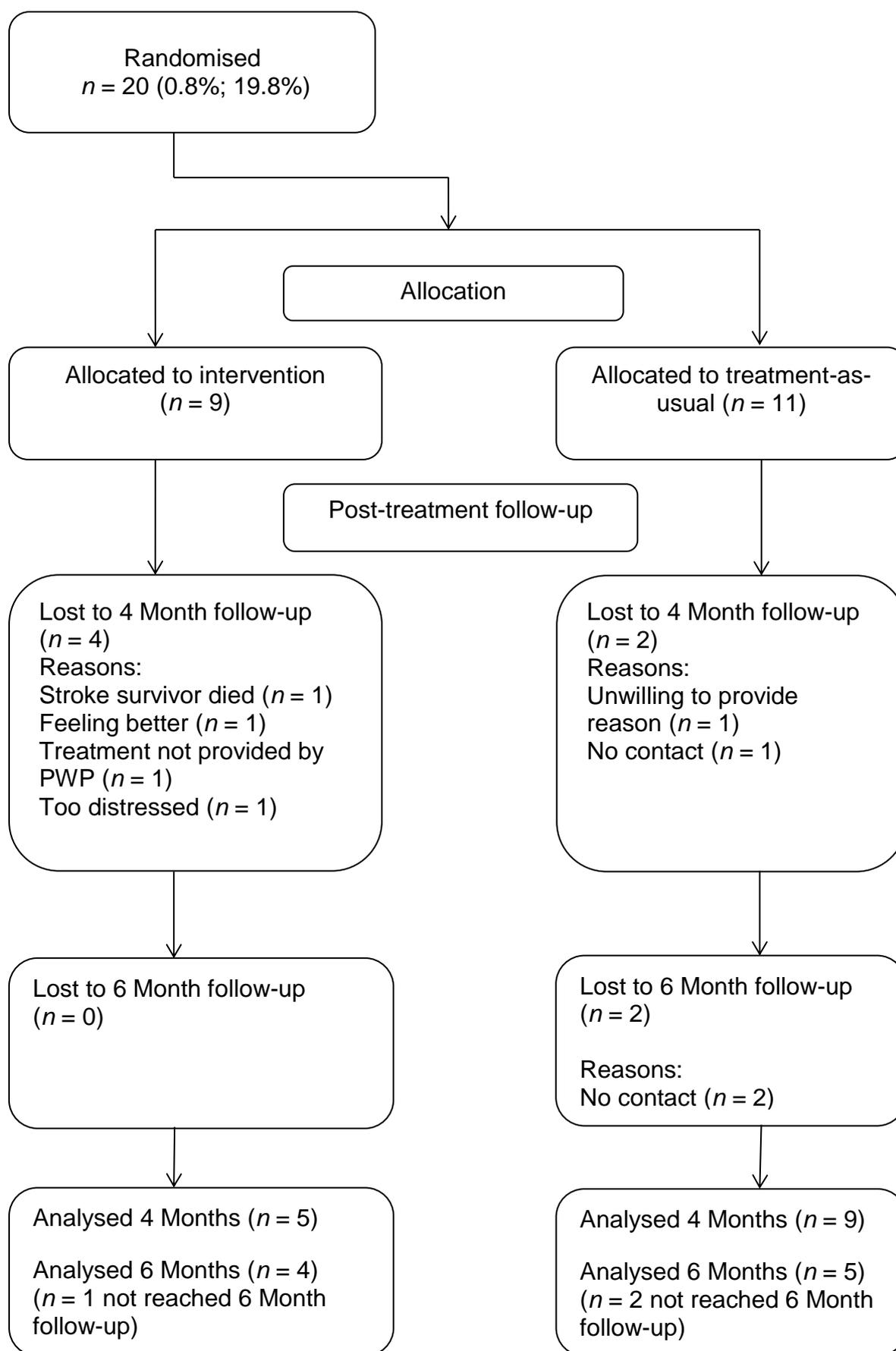


Figure 7.2. Participant Flow

7.5.2 Participant Recruitment

During the 10 month recruitment period (August 2013 to May 2014) only 20 participants were recruited into the trial. As shown in Figure 7.2 despite a total of 2,450 participant invitation letters being sent via primary care recruitment (GP mail out) and specialist stroke care settings, recruitment rates were poor with an overall randomisation rate of 0.8% (20/2450).

7.5.3 Participant Recruitment Source

The majority of referrals were received through primary care ($n = 75$; Table 7.2). Table 7.2 demonstrates stage of enrolment by source of recruitment and indicates the most successful method of recruitment in terms of randomisation rate was community outreach, with 75% of informal carers approached being randomised into the study. However, only 4 informal carers in total were referred into the study through community outreach. The success rates of each method of recruitment are discussed in more detail in the following sections.

Table 7.2

Stage of Enrolment by Source of Recruitment

Source of recruitment, n (%)	Initial interest ($n = 101$)	Initial screen ($n = 56$)	Full screen ($n = 33$)	Randomised ($n=20$)	Randomisation rate (%)
Primary Care	75 (74.0)	46 (82.1)	28 (84.8)	15 (75.0)	20.0
Stroke specialist healthcare settings	8 (8.0)	6 (10.7)	2 (6.1)	2 (10.0)	25.0
Community outreach	4 (4.0)	3 (5.4)	3 (9.1)	3 (15.0)	75.0
Press coverage	1 (1.0)	0 (0.0)	0 (0.0)	0 (0.0)	0.0
Word of mouth	2 (2.0)	1 (1.8)	0 (0.0)	0 (0.0)	0.0
Unknown	11 (11.0)	0 (0.0)	0 (0.0)	0 (0.0)	0.0

7.5.3.1 Primary care recruitment

Prevalence rates. In total 6,104 stroke survivors were identified in the initial practice database search and 2,055 informal carers were subsequently identified to be invited into the study across the 34 GP practices involved in the study (Table 7.3). Assuming a 2% point prevalence rate for stroke in the South West of England (Department of Health, 2011c) it was anticipated that 6,890 stroke survivors would be identified (Table 7.3). However, only 86% (6104/6890) of the expected number of stroke survivors were identified through the general practice database search. In addition, the number of stroke survivors identified as having an informal carer or relative who could be invited into the study ranged from 7% (20/283) to 100% (135/135). Overall 34% of stroke survivors were identified as having an informal carer or relative (2055/6104) who could be invited into the study. Based on a conservative estimate of 50% of stroke survivors requiring informal care (Hickenbottom et al., 2002) 3,052 informal carers should be identified for invitation into the study based on the number of identified stroke survivors (n=6104). Therefore, overall only 67.33% of anticipated informal carers were invited into the study. In total 75 informal carers showed initial interest from primary care recruitment, yielding an initial response rate of 4% (75/2055). From these 75, only 15 participants were randomised into the trial, yielding a total randomisation rate of 0.7% (15/2055) for primary care recruitment.

Target population. English Indices of Multiple Deprivation 2010 (Department for Communities and Local Government, 2011) were used to approximate the socio-demographic background of the study population targeting by GP mail-out (Figure 7.3). Indices of Multiple Deprivation are an overall calculation based on indicators such as income, employment and education. Indices were calculated for each GP practice area. The recruited 34 GP practices indicate an even distribution of practices from the least to most deprived areas within the South West of England.

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Table 7.3

Number of Stroke Survivors and Informal Carers Identified by GP Practice Database Search Compared with the Number of Stroke Survivors and Informal Carers Anticipated to be Identified Based on Stroke and Informal Care Provision Prevalence Rates.

Practice	Location	GP list size	No. of stroke survivors identified	No. expected stroke survivors (2.0%)	No. of carers identified	No. expected carers (50% of stroke survivors expected)	No. expected carers (50% of stroke survivors identified)	% of stroke survivors identified as having an informal carer
A	Cornwall	11,600	283	232	20	116	142	7.1%
B	Cornwall	13,000	204	260	96	130	102	47.1%
C	Cornwall	9,574	192	191	31	96	96	16.2%
D	Cornwall	4,800	76	96	32	48	38	42.1%
E	Cornwall	10,470	105	209	42	105	53	40.0%
F	Cornwall	5,030	94	101	16	50	47	17.0%
G	Cornwall	7,945	132	159	37	79	66	28.0%
H	Cornwall	6,300	166	126	56	63	83	33.7%
I	Cornwall	14,472	253	289	21	145	127	8.3%
J	Cornwall	10,609	154	212	29	106	77	18.8%
K	Cornwall	9,750	100	195	50	98	50	50.0%
L	Cornwall	7,742	271	155	54	77	136	19.9%
M	Cornwall	6,950	67	139	30	70	34	44.8%
N	Cornwall	8,700	64	174	37	87	32	57.81%
O	Cornwall	18,237	346	365	36	182	173	10.4%
P	Cornwall	6,971	113	139	60	70	57	53.1%
Q	Cornwall	12,200	167	244	100	122	84	59.9%

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R	Cornwall	8,741	183	175	101	87	92	55.2%
S	Dorset	15,785	219	316	130	158	110	59.3%
T	Dorset	9,786	135	196	135	98	68	100.0%
U	Dorset	12,381	344	248	77	124	172	22.4%
V	Dorset	31,560	607	631	323	316	304	53.2%
W	Dorset	4,879	117	98	47	49	59	40.2%
X	Dorset	7,838	186	157	38	78	93	20.4%
Y	Dorset	6,150	103	123	25	62	52	24.3%
X	Dorset	9,675	167	194	30	97	84	18.0%
AA	Dorset	6,350	68	127	27	64	34	39.7%
AB	Dorset	7,263	134	145	30	73	67	22.4%
AC	Dorset	13,000	258	260	102	130	129	39.5%
AD	Dorset	8,262	132	165	52	83	66	39.4%
AE	Dorset	11,700	293	234	68	117	147	23.2%
AF	Dorset	9,100	51	182	8	91	26	15.7%
AG	Dorset	3,700	72	74	66	37	36	91.7%
AH	Dorset	14,000	248	280	49	140	124	19.8%
Totals		344,520	6104	6,890	2,055	3,445	3,052	33.7%

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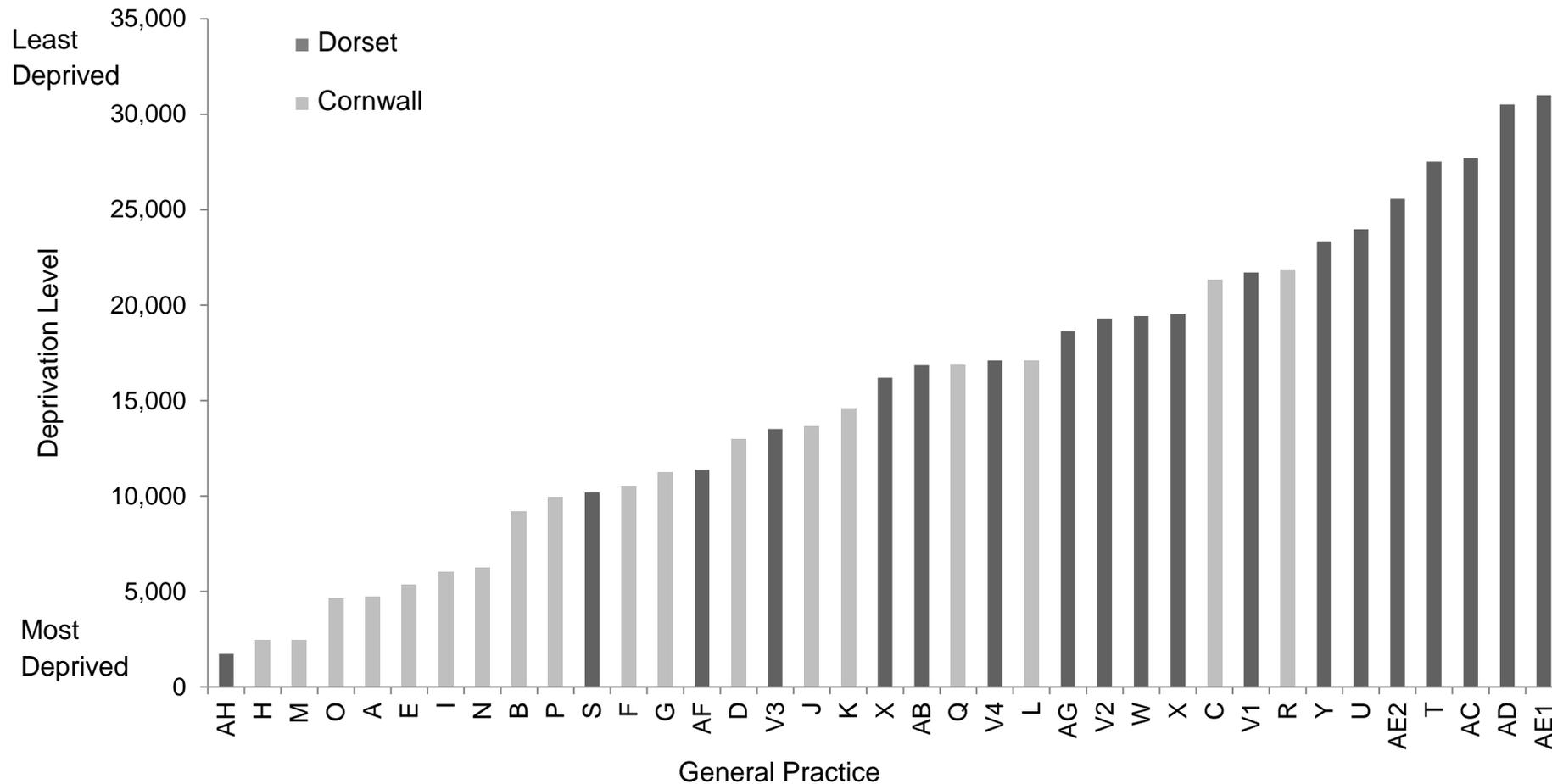


Figure 7.3. English Indices of Multiple Deprivation 2010 by general practice

7.5.3.2 Specialist stroke care setting recruitment. Stroke specialist recruitment took place between August 2013 and March 2014 and was stopped earlier than GP recruitment due to inclusion criteria of 2 months post-home discharge. Four stroke hospital wards recruited informal carers of stroke survivors (1 hospital in Cornwall, and 4 in Dorset) and 1 community stroke practitioner and 1 speech and language therapist also agreed to hand out participant information packs. Over the course of the study, stroke wards supporting the study admitted approximately 1,520 stroke survivors. Of these stroke survivors, it is anticipated that 50% (n=760) would have an informal carer or relative who could have been invited into the study. However, as shown in Table 7.4 only 395 informal carers were provided with participation invitation packs. As such, only 52% of potential informal carers were invited into the study (395/760). Additionally, Hospital One refused to supply informal carers on the ward with participant information packs and Hospital Four failed to distribute any participant information packs. Regular meetings were held with the Stroke Research Network (SRN) and Stroke Ward research nurses to investigate difficulties with recruitment. The main reason reported for not handing out participant information packs were stroke nurses concerns regarding causing any additional distress to the informal carers by mentioning the possibility of experiencing depression. In regards to Hospital Four the ward sister agreed it was an important study but failed to commit staff to recruit into the study.

It is also important to note that as the study was primarily supported by the Primary Care Research Network (PCRN), rather than the SRN service support costs (monetary reimbursement for research activities over and above standard care provided to patients) were not allocated for a specialist stroke care setting recruitment. Overall 8 informal carers showed initial interest in the study that were recruited in stroke specialist settings, meaning an initial response rate of 2% (8/395). In total 2 participants recruited from stroke specialist settings were randomised, yielding a randomisation rate of 0.5%.

Table 7.4

Stroke Specialist Healthcare Recruitment.

Stroke specialist healthcare setting	Face-to-face	Post	Telephone	Ward packs	Total	Number of stroke admissions (8 months)
Hospital One	8	0	42	0	50	480
Hospital Two	13	47	0	168	228	480
Hospital Three	10	0	0	100	110	320
Hospital Four	0	0	0	0	0	240
Community Stroke Practitioner	6	0	0	0	6	N/A
Speech & Language	1	0	0	0	1	N/A
TOTALS	38	47	42	268	395	1,520

7.5.3.3 Community outreach recruitment. In total 30 different stroke and informal carer specific community organisations agreed to support the study with recruitment across the counties of Cornwall and Dorset. Groups included stroke community organisations such as the Stroke Association, Different Strokes and independent stroke clubs; Carer Forums, community day centres and the Alzheimer’s Society. In total, community organisations distributed 284 information packs and 699 posters and leaflets advertising the study. The 284 information packs are not included in the total number of invitation letters sent ($n = 2,450$) (Figure 7.2) as it cannot be known that community organisations definitely distributed the information packs they received from the study team. In total 4 informal carers returned a reply slip indicating initial interest in the study, yielding a response rate of 1% (4/284) (Table 7.2). Of these 4 informal carers, 3 were randomised into the study, yielding a randomisation rate of 1% (3/284).

7.5.3.4 Taking into account the prevalence of depression. Overall response rates and subsequent randomisation rates were very poor. However, the recruitment strategy adopted did not target informal carers with known difficulties with depression and low mood. As such, it is also important to calculate response rates taking into account the prevalence of depression expected in the population targeted. Depression rates in informal carers of stroke survivors range from 30%-68% immediately to three years post-stroke (Berg et al., 2005; Visser-Meily et al., 2008), as such, a conservative estimate of 30% was adopted for this study. Overall 2,450 invitation packs were sent to informal carers of stroke survivors, taking a 30% prevalence rate of depression 735 informal carers would have been expected to be depressed. In total 101 informal carers returned reply slips, yielding a revised response rate of 14% (101/735). In total, 20% were eventually randomised into the trial yielding a revised randomisation rate of 3% (20/735) taking into account the prevalence of depression.

7.5.3.5 Informal carer reasons for non-participation. All study invitation packs included anonymised reply slips with space for writing reasons for non-participation. In total, 376 reasons for non-participation were received, yielding a response rate of 15% (376/2450). The reasons for non-participation were coded and the results are presented in Table 7.5 with informal carers often providing more than one reason for not participating in the research and a total of 555 reasons for non-participation coded. In total 55% of responses related to informal carers feeling that they did not need support for low mood or depression as they were coping well with the caring role. However, 33% of reasons for non-participation related to barriers to being able to access further support. Finally, 8% of reasons for non-participation related to procedural concerns, for example the invitation was sent incorrectly or the stroke survivor responded rather than the carer.

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Table 7.5

Reasons for Non-Participation

Category	Subcategory	<i>n</i>	%
Coping well	Not low / depressed	123	22.2
	Stroke survivor has made a good recovery and no / little care is required	86	15.5
	Coping well with the caring role	55	9.9
	Good support from others	39	7.0
	TOTAL	303	54.6
Barriers to accessing support	Lack of time	33	6.0
	Own poor physical health	27	4.9
	Low mood / depression is not associated with the stroke	14	2.5
	Does not consider self to be a carer	12	2.2
	The problem is lack of health care, social care and practical support	11	2.0
	"I cope because I have to"	10	1.8
	Gets low / depressed, but is able to cope	10	1.8
	Stroke survivor cares for the carer	8	1.4
	Difficulty talking about personal issues	7	1.3
	Too old	6	1.1
	More help is needed at the beginning, now it's too late	6	1.1
	Experienced depression in the past, but not currently depressed	6	1.1
	Reaction of the stroke survivor	6	1.1
Stroke survivor is depressed and needs support, not the carer	6	1.1	

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	Talking won't help	5	0.9
	Depression should be dealt with yourself	4	0.7
	Lack of energy	3	0.5
	Sense of duty	2	0.4
	Cannot cope with any questions	1	0.2
	Low mood / depression not severe enough	1	0.2
	Previous help from GP made things worse	1	0.2
	Guilt	1	0.2
	Hearing difficulties	1	0.2
	Not being treated for depression and therefore doesn't feel support is appropriate	1	0.2
	Receiving antidepressant medication	1	0.2
	TOTAL	183	33.0
Procedural	Stroke survivor responded, not the carer	16	2.9
	Invitation sent incorrectly	15	2.7
	Thought research was for the stroke survivor	6	1.1
	Stroke survivor died	4	0.7
	Stroke incidentally diagnosed and research therefore not applicable	2	0.4
	No longer a carer	1	0.2
	TOTAL	44	7.9
	No point to the research	3	0.5
	No reason provided	22	4.0

7.5.4 Baseline Characteristics

Baseline demographic and clinical characteristics of participants randomised into the trial are presented in Table 7.6. Chi-squared tests were conducted to examine differences in categorical variables between the intervention and control conditions revealing no significant differences. Independent samples t-tests were conducted to examine differences in continuous variables between the intervention and control conditions, again revealing no significant differences. As such, minimisation to ensure balance between arms was successful.

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Table 7.6

Participant Clinical and Demographic Characteristics at Baseline

Informal Carer Characteristics	All participants (<i>n</i> = 20)	Condition		<i>p</i>
		Intervention (<i>n</i> = 9)	Control (<i>n</i> = 11)	
Female (%)	65	67	64	.63
Age, M (SD)	62.88 (10.26)	59.18 (10.84)	65.91 (9.14)	.15
Ethnic Background (%)				
White British	95	100	91	.55
Irish	5	0	9	
Relationship Status (%)				
Married / Partner	90	89	91	.56
Not in a relationship	5	11	0	
Widowed	5	0	9	
Relationship to Stroke Survivor (%)				
Spouse / Partner	85	89	82	.65
Son / Daughter	10	11	9	
Father / Mother	5	0	9	
Employment Status (%)				
Retired	60	44	73	.28
Full time carer	30	44	18	
Employed, full time	5	0	9	
Employed, part time	5	11	0	
Yearly Household Income (%)				
£0 to £9,999	10	0	18	.10
£10,000 to £19,999	35	56	18	
£20,000 to £29,999	30	11	46	
£30,000 to £39,999	5	0	9	

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	Missing	20	33	9	
Highest Level of Academic Qualification (%)					
	None	35	33	36	
	Secondary education	25	22	27	
	Post-Secondary education	25	33	18	
	University level education	15	11	18	
Living With the Stroke Survivor (%)		95	100	91	
Time Caring in Years M (SD)		8.19 (9.32)	6.56 (6.98)	9.53 (11.04)	.49
PHQ-9, M (SD)		15.00 (3.11)	15.56 (3.57)	14.55 (2.77)	.49
GAD-7, M (SD)		11.65 (4.02)	13.00 (4.39)	10.55 (3.50)	.18
Primary Diagnosis (CIS-R)					
	Mild Depression	15	11	18	.50
	Moderate Depression	80	78	82	
	Severe Depression	5	11	0	
Secondary Diagnosis (CIS-R)					
	GAD	60	56	64	.53
	Mixed Anxiety and Depression	35	33	36	
	Specific Phobia	5	11	0	
CIS-R Distress Score		22.45 (6.14)	22.56 (7.23)	22.36 (5.46)	.95
WSAS		23.74 (9.93)	25.89 (9.45)	21.80 (10.44)	.39
CBS		2.89 (0.53)	2.88 (0.60)	2.89 (0.49)	.98
BI		13.90 (5.08)	15.22 (3.35)	12.70 (6.18)	.14
FAI		12.36 (6.93)	12.22 (7.59)	12.48 (6.68)	.94
SF-36 Physical Health Component		55.30 (22.54)	58.68 (25.48)	52.53 (20.66)	.56
SF-36 Mental Health Component		44.53 (14.03)	42.71 (15.14)	46.01 (13.61)	.61
EQ-5D VAS		57.63 (19.39)	58.00 (16.02)	57.22 (23.60)	.28
<i>Stroke Survivor Characteristics</i>					
Female (%)		35	22	45	.27
Age, M (SD)		67.94 (11.96)	68.63 (10.31)	67.37 (13.64)	.82

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Ethnic Background (%)					
	White British	95	89	100	.26
	Filipino	5	11	0	
Relationship Status (%)					
	Married / Partner	90	89	91	.90
	Widowed	10	11	9	
First Stroke Type (%)					
	Ischemic	45	67	27	.21
	Haemorrhagic	40	22	55	
	TIA	15	11	18	
	Unknown				
Most Recent Stroke Type (%)					
	Ischemic	10	11	9	.50
	Haemorrhagic	15	11	18	
	TIA	25	11	36	
	Not applicable	50	67	36	
Aphasic (%)					
		50	56	45	.65

Note: % reported as whole numbers; means, standard deviations and p-value reported to 2 decimal places

PHQ-9 = Patient Health Questionnaire-9; GAD-7 = Generalised Anxiety Disorder 7-item Scale; CIS-R = Clinical Interview Schedule; WASAS = Work and Social Adjustment Scale; CBS = Caregiver Burden Scale; BI = Barthel Activities of Daily Living Index; FAI = Frenchay Activities Index; SF-36 = Short Form (36) Health Survey; EQ-5D VAS = EuroQol-5D Visual Analogue Scale; TIA = transient ischaemic attack.

7.5.5 Study Attrition

In total 6 participants dropped out of the trial prior to the 4 month post-randomisation follow-up, yielding an overall attrition rate of 30% (6/20). Overall, 4 participants dropped out of the intervention meaning the attrition rate in the intervention arm was 44% (4/9). The attrition rate in the control condition was 18% (2/11). Therefore participants were more likely to drop out of the intervention condition than the control condition with an OR of 3.6 (95% CI: 0.48, 27.11). Study attrition at six months is not reported due to 3 participants having not reached the 6 month follow-up time point at the time of study write up.

7.5.6 Feasibility and Acceptability of Data Collection Procedures

7.5.6.1 Incomplete Outcomes. Overall, no negative comments were made by trial participants when collecting outcome measurements. Due to the time constraints of the caring role full baseline and follow-up assessments tended to be conducted over two sessions, each lasting approximately 30 minutes each. Cases where there was missing demographic or clinical data is presented in Table 7.7. As can be seen, 11% of informal carers were unwilling to provide information pertaining to their annual household income. Some informal carers reported being unsure of their annual income as it tended to comprise of various benefits or were unwilling to provide the data due to fears of benefits received being taken away. One participant at baseline was only able to complete the Clinical Interview Schedule (CIS-R) due to levels of fatigue and it was not possible to arrange another assessment to complete the additional measures at baseline. At 4 months the Barthel Activities of Daily Living Index (BI) and Frenchay Activities Index (FAI) were not completed by 2 participants, again due to levels of fatigue. Overall however the majority of participants were able to complete all outcome measures at screen, full baseline and 4 month follow-up demonstrating high levels of feasibility and acceptability of the outcome measurement battery. In relation to the FAI at baseline there were 5 cases whereby 2 items were missing and 1 case where 1 item was missing of the 15 item FAI scale, yielding a missing item rate of 4% (11/300). In the 5 cases whereby 2 items were missing this was due to an error with the data collection form whereby two questions had been missed due to printing error. In the remaining case whereby 1 item was missing, this was due to data collection error whereby the item was missed by the researcher. There were no other missing items in the study, again

demonstrating that the data collection procedures used within the trial were acceptable and feasible.

Table 7.7

Incomplete Outcome Measurements

Outcome	Time point	Total <i>n</i>	Missing <i>n</i>	% of total sample
Income	Initial Screen	56	6	11%
First stroke type	Initial Screen	56	7	13%
WSAS	Baseline	20	1	5%
CBS	Baseline	20	1	5%
BI	Baseline	20	1	5%
FAI	Baseline	20	1	5%
CBS	4 months	14	1	7%
BI	4 months	14	2	14%
FAI	4 months	14	2	14%

Note. Total *n* = total number of participants; missing *n* = number of participants with missing data; WASAS = Work and Social Adjustment Scale; CBS = Caregiver Burden Scale; BI = Barthel Activities of Daily Living Index; FAI = Frenchay Activities Index.

7.5.6.2 Blinding. The researcher was unblinded 6 times during the course of the trial. In the majority of cases this was due to accidental disclosure by participants of information that revealed allocation, despite being reminded as per the data collection protocol not to discuss allocation at the beginning of the assessment. In 2 cases, unblinding occurred due to clinical queries from the PWP's providing treatment. Although PWP's had been fully trained in the research protocol, alongside the provision of a trial handbook, including the importance of maintaining blinding, the researcher was also responsible for the project management of the trial and resolving any difficulties experienced by the services supporting the trial. As such, the feasibility of being the main contact for resolving any service related difficulties and maintaining blindness throughout the trial was low.

7.5.7 Outcomes

7.5.7.1 Clinical outcomes. As a feasibility RCT the efficacy of an intervention with a comparator should not be examined through traditional statistical techniques (Abbott, 2014). Therefore the point estimate of effect and confidence intervals were calculated for each of the main clinical outcomes. The means, standard deviations and Hedges' *g* effect size each with 95% CIs and can be seen in Table 7.8 for each clinical outcome collected. Cohen's (1988) effect size conventions are used to interpret the magnitude of effect sizes calculated with an effect size of 0.20 relating to a small effect; 0.50 a medium effect and 0.80 a large effect. At 4 months follow-up a large effect size was found in favour of the CBT self-help intervention for depression, anxiety and overall distress as measured by the PHQ-9, GAD-7 and CIS-R respectively. There was no significant group difference in those participants no longer meeting diagnosis for depression (CIS-R) at 4 months comparing the intervention ($n=4/5$; 80%) to the control condition ($n=4/9$; 44%) with an OR of 0.20 (95% CI: 0.02, 2.58). At 6 months $3/4$ (75.0%) participants in the intervention condition no longer met diagnosis for depression and $5/5$ (100%) of participants no longer met diagnosis. The OR could not be calculated due to the small sample size. Overall, given the very small sample size few conclusions can be made concerning the effectiveness of the CBT self-help intervention and results should be interpreted with caution.

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Table 7.8

Means, SDs, and Effect Sizes (Hedges' *g*) Including 95% CIs for Clinical Outcome Measures

Outcome measure	Condition	Baseline			Post-treatment			Between-group effect size (Post-treatment)		6 months			Between-group effect size (6 months)	
		<i>n</i>	Mean	SD	<i>n</i>	Mean	SD	<i>g</i>	95% CI	<i>n</i>	Mean	SD	<i>g</i>	95% CI
PHQ-9	Intervention	9	15.56	3.57	5	7.00	3.24	-1.31	-2.44 to -0.18	4	5.75	6.45	-0.79	-2.01 to 0.44
	Control	11	14.55	2.77	9	13.44	5.15			5	10.60	4.62		
GAD-7	Intervention	9	13.00	4.39	5	4.00	2.74	-1.27	-2.40 to -0.14	4	4.50	5.92	-0.43	-1.62 to 0.75
	Control	11	10.55	3.50	9	9.78	4.84			5	7.20	5.26		
CIS-R Distress	Intervention	9	22.56	7.23	5	13.00	10.42	-1.10	-2.21 to 0.00	4	10.25	12.69	-0.53	-1.72 to 0.66
	Control	11	22.36	5.46	9	22.33	6.28			5	16.40	8.08		
WSAS	Intervention	9	25.89	9.45	5	14.55	12.53	-0.40	-1.43 to 0.64	4	15.31	11.01	0.06	-1.11 to 1.23
	Control	10	21.80	10.44	9	19.44	10.94			5	14.75	6.27		
CBS Total	Intervention	9	2.88	0.60	5	2.65	0.64	0.05	-0.99 to 1.09	4	2.56	0.68	0.02	-1.15 to 1.18
	Control	10	2.89	0.49	8	2.61	0.75			5	2.55	0.48		
<i>CBS General Strain</i>	Intervention	9	3.21	0.63	5	2.90	0.82	-0.01	-1.05 to 1.03	4	2.72	0.73	-0.29	-1.46 to 0.89
	Control	10	3.23	0.51	8	2.91	0.73			5	2.90	0.38		
<i>CBS Isolation</i>	Intervention	9	3.37	0.75	5	3.07	1.12	0.33	-0.71 to 1.38	4	2.83	0.96	0.16	-1.01 to 1.33
	Control	10	3.20	0.65	8	2.71	0.93			5	2.67	0.85		
<i>CBS-Disappointment</i>	Intervention	9	3.07	0.87	5	2.92	0.41	0.12	-0.92 to 1.16	4	2.90	0.74	0.41	-0.78 to 1.59
	Control	10	3.04	0.62	8	2.83	0.82			5	2.60	0.58		
<i>CBS-Emotional Involvement</i>	Intervention	9	2.19	0.91	5	2.13	0.69	0.24	-0.80 to 1.29	4	2.17	0.58	0.24	-0.94 to 1.41
	Control	10	2.19	1.09	8	1.88	1.07			5	1.93	1.09		
<i>CBS-Environment</i>	Intervention	9	1.93	0.52	5	1.60	0.72	-0.64	-1.71 to 0.43	4	1.67	0.54	-0.65	-1.86 to 0.56
	Control	10	2.23	0.35	8	2.08	0.68			5	2.07	0.55		

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BI	Intervention	9	15.22	3.35	5	16.20	5.40	-0.75	-1.85 to 0.35	4	14.00	6.68	-0.77	-1.99 to 0.45
	Control	10	12.70	6.18	7	12.14	4.67							
FAI Total	Intervention	9	12.22	7.59	5	17.20	10.08	-0.42	-1.49 to 0.65	4	16.00	11.40	-0.49	-1.68 to 0.70
	Control	10	12.48	6.68	7	13.57	6.29							
<i>FAI Domestic</i>	Intervention	9	2.44	4.53	5	4.00	4.74	-0.12	-1.19 to 0.94	4	3.50	5.69	-0.32	-1.50 to 0.86
	Control	10	2.50	2.83	7	3.43	3.82							
<i>FAI Leisure / Work</i>	Intervention	9	6.15	1.90	5	7.60	3.44	-0.73	-1.83 to 0.36	4	7.00	2.71	-0.66	-1.87 to 0.55
	Control	10	5.23	1.97	7	5.57	1.72							
<i>FAI Outdoor</i>	Intervention	9	3.63	2.76	5	5.60	3.05	-0.29	-1.36 to 0.77	4	5.50	4.80	-0.38	-1.56 to 0.80
	Control	10	4.75	3.60	7	4.57	3.36							
EQ5D VAS	Intervention	9	57.22	23.60	5	65.00	12.75	-0.17	-1.19 to 0.86	4	65.50	18.56	-0.58	-1.77 to 0.62
	Control	10	58.00	16.02	9	61.67	21.07							
SF-36 Physical Health Component	Intervention	9	58.68	25.48	5	57.00	19.86	-0.45	-1.49 to 0.59	4	58.13	20.15	-0.24	-1.41 to 0.93
	Control	11	52.53	20.66	9	47.40	19.94							
SF-36 Mental Health Component	Intervention	9	42.71	15.14	5	57.75	11.00	-0.38	-1.41 to 0.65	4	59.35	21.48	0.14	-1.03 to 1.31
	Control	11	46.01	13.61	9	52.18	14.90							
<i>SF-36 Physical Functioning</i>	Intervention	9	66.11	39.59	5	63.00	30.12	-0.14	-1.17 to 0.88	4	61.25	39.45	-0.07	-1.24 to 1.10
	Control	11	62.27	33.12	9	57.78	35.80							
<i>SF-36 Role Limitations (Physical)</i>	Intervention	9	61.11	32.74	5	62.50	28.30	-0.57	-1.62 to 0.47	4	68.75	21.04	-0.55	-1.74 to 0.65
	Control	11	50.57	22.27	9	47.92	21.19							
<i>SF-36 Role limitations (Emotional)</i>	Intervention	9	55.56	22.82	5	75.00	17.68	-0.53	-1.57 to .51	4	77.08	21.92	0.20	-0.98 to 1.37
	Control	11	53.03	15.49	9	64.81	18.06							
<i>SF-36 Vitality</i>	Intervention	9	30.56	17.24	5	35.00	21.92	-0.66	-1.71 to 0.39	4	42.19	24.14	-0.34	-1.52 to 0.84
	Control	11	23.30	18.98	9	23.61	12.41							

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<i>SF-36 Mental Health</i>	Intervention	9	38.89	15.16	5	61.00	8.22	-0.22	-1.25 to 0.81	4	65.00	15.81	-0.05	-1.22 to 1.12
	Control	11	53.18	17.79	9	57.78	15.83							
<i>SF-36 Social Functioning</i>	Intervention	9	45.83	27.24	5	60.00	16.30	0.08	-0.94 to 1.11	4	53.13	35.90	0.50	-0.69 to 1.69
	Control	11	54.55	31.76	9	62.50	31.87							
<i>SF-36 Bodily Pain</i>	Intervention	9	60.83	24.72	5	54.50	10.37	-0.61	-1.66 to 0.44	4	53.75	14.93	-0.08	-1.25 to 1.09
	Control	11	54.09	22.23	9	43.33	19.57							
SF-36 General Health	Intervention	9	46.67	17.32	5	48.00	18.91	-0.35	-1.38 to 0.69	4	48.75	18.87	-0.23	-1.40 to 0.94
	Control	11	43.18	18.07	9	40.56	20.68							
SF-36 Health Transition	Intervention	9	50.00	17.68	5	55.00	20.92	-0.09	-1.12 to 0.93	4	50.00	28.87	0.21	-0.96 to 1.39
	Control	11	61.36	23.35	9	52.78	23.20							

Note. SD = Standard deviation; *g* = Hedges' *g*; CI = confidence interval; PHQ-9 = Patient Health Questionnaire-9; GAD-7 = Generalised Anxiety Disorder 7-item Scale; CIS-R = Clinical Interview Schedule; WASAS = Work and Social Adjustment Scale; CBS = Caregiver Burden Scale; BI = Barthel Activities of Daily Living Index; FAI = Frenchay Activities Index; SF-36 = Short Form (36) Health Survey; EQ-5D VAS = EuroQol-5D Visual Analogue Scale; TIA = transient ischaemic attack.

7.5.7.2 Health Economics

Health and public service data was collected using an adapted version of the Client Socio-Demographic and Service Receipt Inventory (CSRI; Chisholm et al., 2000) and a further version developed for informal carers of stroke survivors (Patel, Knapp, Evans, Perez, & Kalra, 2004). Baseline health and public service data is presented in Table 7.9. The feasibility of using an adapted version of the Client Socio-Demographic and Service Receipt Inventory was examined. In total, participants completed the measure at baseline, yielding a completion rate of 90% (18/20); 7 participants completed at 4 month follow-up, yielding a completion rate of 50% (7/14) and 8 completed the questionnaire at 6 month follow-up, with a completion rate of 89% (8/9).

In relation to missing cases of data at baseline, 7 questionnaires had a photocopying error and were missing questions relating to outpatient appointment and accident and emergency use for the stroke survivor. Two participants failed to fill out questions relating to stroke survivor service use (40 items). An additional two carers failed to fill out questions relating to the amount of time per week they performed a variety of care related tasks to the stroke survivor (28 items). At 4 months and 6 months 1 questionnaire was received with missing questions relating to outpatient appointment and accident and emergency use for the stroke survivor.

Overall, the response rate to filling out the health and public service use was poor at follow-up. A number of questionnaires had comments written on them pertaining to difficulties experienced by carers quantifying how much care they provided, or how much contact they had with various health and public services. A number of carers felt that certain caring tasks were performed 24/7 and it was therefore difficult for carers to estimate how many hours of each care related task they performed.

Originally, the questionnaire was designed to be sent in the post but completed with the carer over the telephone with a researcher not otherwise associated with the study. This was to ensure that JW remained blind to group allocation as some questions related to psychological service use. However, due to resource limitations it was not possible to find someone to follow-up carers on the telephone. Given the complexity of health and public use questionnaires future studies may wish to ensure researchers not blind to treatment allocation are resources in order to support participants completing such measures.

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Table 7.9

Health and Public Service Use

Service	<i>n</i>	%	No. of contacts		Duration of contacts (minutes)	
			<i>M</i>	<i>SD</i>	<i>M</i>	<i>SD</i>
Service use for Carer (3 months) (<i>n</i> = 18)						
Antidepressant medication (%)	7	38.9%				
Psychological therapy (%)	0	0.0%				
Seen GP (%)	15	83.3%	3.00	1.89	10.00	3.40
Seen Practice Nurse	5	27.8%	2.40	2.60	10.80	8.40
Seen community nurse	0	0.0%				
Seen Psychiatric nurse	1	5.6%	3.00		30.00	
Social worker	2	11.1%	2.00	1.40	30.00	
Helpline	3	16.7%	3.00	1.00	40.00	43.60
Benefits for Carer (3 months) (<i>n</i> = 18)						
In receipt of state benefits	14	77.8%				
<i>Carers allowance</i>	6	33.3%				
<i>Income support</i>	1	5.6%				
<i>Disability Premium</i>	1	5.6%				
<i>Disability living care component</i>	3	16.7%				
<i>Disability living mobility component</i>	3	16.7%				
<i>Housing benefit</i>	2	11.1%				
<i>Council tax benefit</i>	3	16.7%				
<i>State pension</i>	8	44.4%				
Care provision to stroke survivor (3 months) (<i>n</i> = 18)						
	<i>n</i>	%	No. hours per week		No. weeks in 3 months	
			<i>M</i>	<i>SD</i>	<i>M</i>	<i>SD</i>
Personal care	13	72.2%	14.80	22.40	11.10	3.30
Transportation	15	83.3%	9.40	6.30	11.70	1.10
Preparing meals	17	94.4%	14.60	9.20	11.80	0.80
Housework	17	94.4%	8.50	6.00	11.10	2.50
DIY	9	50.0%	1.90	1.50	11.10	2.45
Gardening	10	55.6%	4.40	4.40	10.10	3.90
Outings	13	72.2%	7.20	5.50	11.20	2.10
Social and emotional support	14	77.8%	73.10	82.10	11.30	2.90
Benefits forms	7	38.9%	1.60	1.60	4.80	4.90
Medical appointments	15	83.3%	3.50	4.40	8.00	4.30
Occupational therapy	6	33.3%	5.30	2.30	10.80	2.70
Physiotherapy	7	38.9%	4.60	2.50	9.70	4.40
Finance	13	72.2%	2.00	1.30	10.60	3.10
Hospital Use Stroke Survivor (3 months) (<i>n</i> = 18)						
Stay in a residential care home	1	5.6%				

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Hospital day treatment	2	11.1%		
Outpatient appointment ^a	3	27.2%		
Accident & Emergency ^a	1	9.0%		
			Number of appointments	
Other Service Use Stroke Survivor (3 months) (<i>n</i> = 16)	<i>n</i>	%	<i>M</i>	<i>SD</i>
GP appointment	11	68.8%	3.40	2.80
GP telephone	6	37.5%	3.80	4.20
Practice nurse appointment	6	37.5%	2.80	2.20
Practice nurse telephone	2	12.5%	2.00	1.40
Repeat prescription request	14	87.5%	4.60	3.50
Physiotherapy	4	25.0%	4.50	4.00
Occupational therapy	2	12.5%	3.00	3.00
Speech and language	1	6.3%	2.00	
Health visitor	1	6.3%	2.00	
Geriatrician	0	0.0%		
Psychologist	1	6.3%	1.00	
Chiropodist	6	37.5%	2.30	1.50
Chiropractor	0	0.0%		
Osteopath	0	0.0%		
Dentist	7	43.8%	1.60	0.80
Optician	6	37.5%	1.30	0.50
Day hospital	1	6.3%	32.00	
Social club	3	18.8%	3.30	2.50
Social worker	1	6.3%	3.00	
Benefits for stroke survivor (3 months) (<i>n</i> = 17)			<i>n</i>	%
In receipt of state benefits	15	88.2%		
<i>Carers allowance</i>	1	5.9%		
<i>Income support</i>	1	5.9%		
<i>Disability premium (income support)</i>	1	5.9%		
<i>Severe disability premium (income support)</i>	1	5.9%		
<i>Council tax benefit</i>	7	41.2%		
<i>State pension</i>	11	64.7%		

Note. ^a*n* = 11

7.5.8 Variability in Number, Length and Frequency of Support Sessions Estimated for Recovery

Table 7.10 provides individual sessions detail for the four participants who completed treatment prior to completion of this thesis. Overall, participants spent an average of 7 weeks on a waiting list between randomisation and the initial assessment session. It was expected; due to IAPT specification (Department of Health, 2004) that participants should be seen within 28 days of randomisation into the study. However, as can be seen in Table 7.10 one participant was on the waiting list for 18.5 weeks. This was picked up by the study team and investigated. It was discovered that the PWP in question was prioritising service patients above study participants. After liaising with the PWP's Service Lead this issue was resolved and the participant was seen by the PWP. Participants received an average of 4 support sessions that is in line with the average of 5.4 sessions being provided to support patient recovery in IAPT nationally (Richards & Borglin, 2011). The average session duration was 30.8 minutes, again in line with IAPT guidelines for low intensity treatment delivery (Richards & Whyte, 2011). One participant requested discharge prior to PHQ-9 and GAD-7 scores reaching below caseness, as defined by a PHQ-9 score of below 10 and a GAD-7 score of below 8. The remaining 3 participants scored below thresholds for caseness on the PHQ-9 and GAD-7 at discharge, with an average of 4 sessions required to bring about recovery.

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Table 7.10

Individual Session Information and Clinical Outcomes for Participants Receiving the CBT Self-Help Intervention

Outcome	Participant				Mean (SD)
	One	Two	Three	Four	
Intervention	Behavioural Activation	Problem Solving	Behavioural Activation	Goal Setting	-
Delivery	Face-to-Face	Telephone	Telephone	Telephone	-
Date of Randomisation	18/09/2013	20/09/2013	05/09/2013	26/02/2014	-
Date of First Assessment	16/10/2013	16/10/2013	13/01/2014	20/03/2014	-
Time from Randomisation to Assessment (Weeks)	4.00	3.71	18.57	3.14	7.36 (7.48)
Number of Sessions	3	3	6	4	4.00 (1.41)
Number of DNAs	0	0	2	0	0.50 (1.00)
Reason for discharge	Participant cancelled the 4th session scheduled on the 14/01/2014 due to feeling better.	Participant reported in the third session that was feeling much better and wished to be discharged.	Participant reached recovery, mutual decision to discharge	Participant reached recovery, mutual decision to discharge	-
Date of Discharge	14/01/2014	23/12/2013	11/06/2014	15/05/2014	-
Total Length of Session (weeks)	12.86	9.71	21.29	8.00	12.96 (5.90)

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Average Length of Session (minutes)	31.67	31.67	30.00	30.00	30.83 (0.96)
Primary Diagnosis Baseline (CIS-R)	Moderate Depressive Episode	Moderate Depressive Episode	Mild Depressive Episode	Moderate Depressive Episode	-
Secondary Diagnosis Baseline (CIS-R)	Mixed Anxiety and Depression	Generalised Anxiety Disorder	Mixed Anxiety and Depression	Generalised Anxiety Disorder	-
Primary Diagnosis 4 Months (CIS-R)	None	Generalised Anxiety Disorder	None	None	-
Secondary Diagnosis 4 Months (CIS-R)	None	Mixed Anxiety and Depression	None	None	-
Primary Diagnosis 6 Months (CIS-R)	None	None	None	Mild Depressive Episode	-
Secondary Diagnosis 6 Months (CIS-R)	None	None	None	Generalised Anxiety Disorder	-
PHQ-9 Baseline	20	12	11	17	15.00 (4.24)
PHQ-9 Assessment	27	7	14	16	16.00 (8.29)
PHQ-9 Session 1	24	6	12	13	13.75 (7.50)
PHQ-9 Session 2	24	4	10	12	12.40 (8.39)
PHQ-9 Session 3	-	-	9	9	9.00 (5.20)
PHQ-9 Session 4	-	-	7	-	-
PHQ-9 Session 5	-	-	4	-	-
PHQ-9 4 Months	4	5	11	5	6.25 (3.20)
PHQ-9 6 Months	0	4	4	15	5.75 (6.45)
GAD-7 Baseline	15	12	6	9	10.50 (3.87)

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GAD-7 Assessment	19	14	7	10	12.50 (5.20)
GAD-7 Session 1	20	4	6	11	10.25 (7.14)
GAD-7 Session 2	19	4	5	6	8.50 (7.05)
GAD-7 Session 3	-	-	6	3	4.50 (2.12)
GAD-7 Session 4	-	-	4	-	-
GAD-7 Session 5	-	-	3	-	-
GAD-7 4 Months	2	4	5	1	3.00 (1.83)
GAD-7 6 Months	0	4	1	13	4.50 (5.92)
WSAS Baseline	15	13	26.25	35	22.31(10.27)
WSAS Assessment	26	16	35	28	26.25 (7.85)
WSAS Session 1	23	15	28	26	23.00 (5.72)
WSAS Session 2	29	16	24	28	24.25 (5.91)
WSAS Session 3	-	-	19	23	21.00 (2.83)
WSAS Session 4	-	-	21	-	-
WSAS Session 5	-	-	16	-	-
WSAS 4 Months	0	4	27.5	26.25	14.44(14.46)
WSAS 6 Months	7.5	6.25	17.5	30	15.31(11.01)

Note. Patient Health Questionnaire-9; GAD-7 = Generalised Anxiety Disorder 7-item Scale; CIS-R = Clinical Interview Schedule; WASAS = Work and Social Adjustment Scale

7.5.9 Acceptability of the Intervention

7.5.9.1 Acceptability interviews. Only 3 out of the 5 participants who were randomised to the intervention group and remained in the trial at 4 months follow-up were interviewed. One participant did not have time to be interviewed and 1 participant was still receiving the intervention. As such, planned thematic analysis using the framework approach (Pope, Ziebland, & Mays, 2000) and subsequent examination of trustworthiness (Lietz et al., 2006) was not possible. Findings from each acceptability interview are summarised in Table 7.11.

Overall, participants reported that the support was useful and effective. Specifically, behavioural activation was well received as a simple, easy to understand intervention that helped the participants recognise that their life revolved around the caring role with little balance and opportunity to take a break or to do activities they enjoyed. The behavioural activation approach facilitated carers recognising how many roles around the caring routine they were doing and to re-organise their schedules to allow time and space for other activities. The self-help intervention materials themselves were also considered well formatted, concise, easy to read and useful to refer back to. However, there were also comments that the materials were too long and more space was required on the behavioural activation diary due to the many tasks that comprise of a carers typical day. It was additionally noted that all the case studies represented stroke survivors who had stabilised in terms of their recovery and were not making further progress. Therefore a case study including a stroke survivor who was still making good progress would also be beneficial and help facilitate identification with the material for informal carers in this particular situation.

On the whole support from the PWP was well received, with the PWPs considered experts in CBT, understanding, emphatic, non-judgemental and well suited to provide support. However, one carer did identify that the PWPs knowledge and understanding of stroke was limited and greater knowledge of the consequences of stroke would have been beneficial. However, both of the participants who received telephone support would have preferred face-to-face support, however face-to-face support was not an option due to the location of the PWP. The participant who received the intervention but was not interviewed also expressed to the researcher when collecting outcome measures that face-to-face support would have been in preference to the telephone support received. In addition, one

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participant felt the support sessions were mainly involved around the collection of outcome measures and an additional participant felt that instructions concerning homework were repeated too much. One participant felt that small group behavioural activation sessions may be beneficial as would allow carers to share experiences, and help one another overcome any difficulties with working through the intervention. Being able to speak with other carers who had found the intervention useful would help instil hope and also the intervention would feel less daunting. This echoed feedback from another participant who felt that speaking with someone who had used the intervention before would also instil hope and help the carer to recognise that other carers experience similar difficulties.

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Table 7.11

Participant Acceptability Interviews

Participant	Intervention	Positive feedback	Areas to improve	Ideas for the future
One	Behavioural Activation	<ul style="list-style-type: none"> • Helped participant to realise how much they were doing for other people, how much caring dominated their life, and how they were putting others before their own needs. • Helped the participant to prioritise activities for themselves. • Helped the participant to recognise not to let past experiences and thoughts dominate the present and to live life. • Support was non-judgemental. • Feedback from the PWP was useful. • Regular appointments were helpful. • The materials were concisely written and little had to be remembered. • The case studies were relevant and the participant could identify with the 	<ul style="list-style-type: none"> • Too much written material. • Would prefer support to be more practical. • Written materials too long. 	<ul style="list-style-type: none"> • It is difficult to find time to write down what you are doing during the day when caring, and then difficult to remember at the end of the day to write in the diary - use of a dictaphone may help with this. • The participant felt that she was given lots of information about the research however they still felt that they didn't really know what to expect from the intervention. It would be good to have someone to speak to who had used the intervention before. This would be useful as it could help instil hope and help the carer feel positive about the intervention and also recognise that other carers also feel the same way.

		<p>difficulties experienced by the carers depicted in the vignettes.</p> <ul style="list-style-type: none"> • Face-to-face was of benefit due to hearing difficulties. 		
Two	Problem Solving	<ul style="list-style-type: none"> • Useful to have the Booklet to refer back to. • Can read the Booklet in your own time. • The Booklet was well laid out and having different sections made it easy to read. • No difficulties in using the technique. • Useful to break problems down into the three categories: 'Not Important' 'Important and can be solved' and 'Important but cannot be solved' and will continue to do this in the future. 	<ul style="list-style-type: none"> • Disliked telephone support. More local face-to-face treatment would be preferred, for example at a local GP surgery. Time and distance to travel was a barrier to receiving support, particularly to fit around part-time work commitments. • The case studies could be improved by having an example of a stroke survivor who was making progress. All the case studies included stroke survivors who were no longer making a recovery and it would be beneficial to have an example whereby the stroke survivor was making a good recovery (as per the situation of this particular participant). 	<ul style="list-style-type: none"> • The PWP was clearly an expert in PWP but more understanding of the consequences of stroke would be beneficial. It was clear that the PWP had only received theoretical training in stroke and had no practical experience. The participant was unclear who should deliver the treatment as they felt that the PWP was the correct person in terms of the expertise in CBT but a stroke nurse would be more appropriate in terms of the knowledge surrounding stroke. • Support would be better provided face-to-face in the local GP practice with more flexibility around appointment times. • Support should be offered earlier to carers. At the end of the 6 weeks of early discharge support received

		<ul style="list-style-type: none"> • It was felt that the sessions with the PWP mainly comprised of filling out questionnaires rather than providing support. • Questions seemed closed around outcomes rather than asking open questions around the carers' experience. • The PWP did not have an in-depth understanding of the consequences of stroke and the participant felt that the PWP did not have an understanding of the difficulties the participant was describing in relation to the stroke survivor. 	<p>by the stroke survivor would be a good time to receive support. This would also help carers to feel less isolated knowing that other people have similar problems and that there is support and hope. Support could be offered in the hospital setting for example. Carers focus on the stroke survivor and therefore do not go to the GP for their own needs. Therefore information about what sort of support could be offered in the hospital setting so carers are aware of the support available without having to go to their GP.</p> <ul style="list-style-type: none"> • Would have liked to have received Booklets on all three of the interventions to examine other techniques that might be beneficial.
3	Behavioural Activation	<ul style="list-style-type: none"> • Was very useful and a catalyst to look at life from a different angle and to move away from the "hum drum" routine of the caring role. Helped recognise that whole routine was around caring, which was making 	<ul style="list-style-type: none"> • Disliked the orange and red font. Black would be better with colour around the edges, and would help things stand out more. • More space devoted to each day in the diary would be helpful as it was • Was sceptical initially, due to there being a lot of support offered for carers but unless someone has been a carer the participant was sceptical that the person provided support could really understand and help. The

the participant very tired. However, the intervention helped the participant realise that even things such as calling a friend for 10 minutes, reading a book or the newspaper can provide a much needed break.

- The intervention helped highlight the difficulties the participant was experiencing.
- Working through the intervention in 'doses' was helpful and made it less daunting. Leaving the intervention for a couple of days and going back to it eventually helped the participant realise the intervention was something that could be helpful and relevant.
- The intervention helped the participant concentrate and earmark activities they enjoyed and how to re-organise time to fit these activities in. Although very simple the participant felt that when you have been

hard to fit in all the tasks the participant was doing.

- The PWP had a habit of repeating themselves in terms of telling the participant what to do. The participant felt the PWP was padding out the session and they found it tedious. Although recognising that some people might need to be told more than once, the participant felt in this case there was not need to be told what to do three times.
- Would have preferred face-to-face support, at least initially. Meeting someone face-to-face helps you to relate to them better and the early part of the programme was difficult and daunting and meeting someone face-to-face would have helped with this. Telephone support could then be provided.

idea of filling out the diary was particularly daunting and felt that it was not something they could cope with doing. Small groups, with 3-4 carers only, led by PWPs might be less daunting. Other carers could provide encouragement and advise and carers could share experiences and help one another work through any difficulties experienced working through the intervention. Speaking with other carers who have found the intervention useful would instil more hope and working through the intervention would feel less daunting.

- Wanted the PWP to direct in what intervention to use at the beginning. The participant was daunted at the beginning and despite reading the case studies had no idea which intervention would be best. Would prefer the PWP as an expert to tell them what to do.

doing the same thing for four years it can be very difficult to recognise that you have got yourself into a rut and BA helped recognise this.

- BA was an easy technique to understand and use.
 - Writing down everything the participant did during the week was helpful and facilitated the participant to question why they were doing particular activities and recognise where a break could be taken.
 - May be useful in the future if symptoms return as provides an easy process to go through again to help with symptoms of low mood and depression.
 - Clearly laid out written material.
 - Examples were concise and helped to keep the programme together.
 - Easy to follow.
 - PWP obviously an expert and well placed to provide the support.
-

7.5.10 Ethics and Governance Procedures

NHS ethical approval for the study was received in February 2013. Originally, it was anticipated that recruitment into the study would begin in April 2013. As such, two months were planned to obtain separate local Research and Development site specific approval from each NHS trust recruiting or treating patients in the trial, which cannot be gained until NHS Ethical approval is received. First, at the time of ethical approval only one IAPT service had agreed to support the study however an additional site was needed. Two IAPT services had been approached to support the study however one was unable to support due to capacity concerns and the other IAPT service, although initially expressing interest had to withdraw support in February 2013 due to service restructuring. As such, the second IAPT site was not confirmed until April 2013. Local site-specific approval for this service was not received until July 2013. The main reason for this delay was that the Director who originally approved support for the study organised a sabbatical during the approval process meaning that negotiations to support the study had to start again. In addition, excess treatment costs (ETCs) needed to be negotiated and approved. ETCs are the difference in cost between the delivery of the new treatment in the trial and standard care (Kearney et al., 2014) and in this case referred to PWP time to deliver the new treatment, and are covered by the NHS Trust or Clinical Commissioning Groups (CCG). It took one month to gain approval for ETCs which also further contributed to delays in gaining site specifically approval for this IAPT site.

In the case of the other IAPT site agreement to support the study was received in September 2012 and negotiations concerning ETCs and site specific approval began in October 2012. Further significant difficulties were experienced concerning ETC approval. First, the Research Manager for the NHS Trust who was fundamental in the initial negotiations left the Trust in March 2013. The NHS Trust stated at this time that they considered the cost of PWPs delivering the treatment to be research costs, rather than ETCs and should therefore be covered by the Funder. The Senior Manager for Finance and Performance for the Department of Health was contacted by the researcher in April 2014 and confirmed that PWP time on the trial was an ETC that should be funded by the NHS through normal commissioning arrangements. The researcher communicated this information to the Trust. However in May 2013 the researcher was informed that the Research and

Governance Department and the local CCG were merging and no longer accepting ETCs. The CCG also argued that IAPT services were national and therefore ETCs should be covered by national, rather than local, budgets. Due to significant difficulties with the CCG recognising that ETCs should be covered by their budget it was eventually negotiated that the IAPT service would include study participants as standard patients and thus still receive payment for treating these participants. Due to this significant delay site specific approval for this IAPT site was not gained until July 2013. As such, recruitment into the study did not begin until August 2013 equating to a 4 month delay.

7.5.11 Barriers to Clinical Delivery of the Intervention in the Health Care System

7.5.11.1 PWP attrition. Over the course of the study 2 PWPs dropped out, one in each site. One PWP dropped out in Dorset due to ill-health and the second dropped out in Cornwall following promotion into a more senior role and no longer have capacity to support the study. A replacement for the PWP in Dorset was found and trained; the PWP in Cornwall was not replaced due to lack of capacity of existing staff.

7.5.11.2 PWP location. Four PWPs supported the delivery of the new intervention initially, with 2 PWPs located in Dorset and 2 in Cornwall. As a result of 1 PWP dropping out of the study in Cornwall, from February 2014 only 1 PWP covered Cornwall from this point onwards. As a result of slow recruitment informal carers across the counties of Dorset and Cornwall were invited into the study, rather than only recruiting in the location of the trial PWPs. As such, telephone support was the only option available to the majority of carers enrolled in the study. Two potential participants refused to participate due to face-to-face support not being available and additionally, as previously discussed, all 3 participants receiving telephone support would have preferred face-to-face support.

7.5.11.3 PWP's adherence to protocols. PWP adherence to the protocol was planned to be examined using audiotapes of treatment sessions. In total, 16 low-intensity assessment and treatment sessions were delivered over the course of the trial (excluding the participant still currently in treatment). However, only 2 assessments and 1 support session were taped during the course of the study yielding a 19% compliance rate to the protocol. In 7 cases the PWP reported that the tape recorder did not work and therefore sessions were not recorded. However,

the PWP failed to report the technical fault to the research team despite clear instructions in training, clinical supervision and repeated communication, reminding PWPs of the importance of taping sessions. The remaining 6 sessions were purportedly not taped due to NHS Trust IT issues concerning gaining approval for the software to download recordings being installed on laptops. However, a clear Standard Operating Procedure concerning the protocol for recording and downloading treatment sessions had been approved by the Trust prior to recruitment beginning. Communication with the Service Lead highlighted that the PWPs had been instructed to record treatment sessions and therefore this was clear deviation from the protocol as opposed to an IT related issue.

7.6 Discussion

This study examined the feasibility of conducting an RCT comparing a CBT self-help intervention for depressed informal carers of stroke survivors with treatment-as-usual. Significant difficulties were experienced in relation to recruitment; high levels of attrition in the intervention arm; insufficient data concerning acceptability of the intervention and noteworthy issues concerning therapist adherence to protocol and conducting a research trial in existing IAPT services. Although initial examination of effect sizes show some promise for the CBT self-help intervention no conclusions can be drawn due to the low sample size. Overall the results indicate that proceeding at this stage to a definitive Phase III RCT is not currently feasible or appropriate given the significant feasibility issues highlighted. The key difficulties relating to lack of feasibility will be discussed in further detail.

7.6.1 Recruitment

Recruitment rates were low with only 20 participants recruited over a 10 month recruitment period with an overall randomisation rate of 0.8%. Even when taking into account a 30% prevalence rate of depression (Berg et al., 2005; Visser-Meily et al., 2008) the overall randomisation rate was only 3%. A multi-faceted recruitment strategy was adopted within this study in order to examine the feasibility of recruiting informal carers from varying recruitment settings. Additionally, this approach was chosen to overcome previous criticisms of the caregiving literature for using convenience based sampling methods such as identifying carers already engaged in health and social services that may result in enrolment biases (Whitebird et al., 2011). Furthermore, previous recruitment strategies into intervention trials for

informal carers of stroke survivors have tended to use strategies such as advertisement on carer and stroke websites (Smith et al. 2012); rehabilitation services (Draper et al., 2007; Wilz & Narskova, 2007) and stroke units (Franzen-Dahlin et al., 2008). However the feasibility of recruitment through primary care settings, where patients presenting with depression are commonly seen (Faghri, Boisvert, & Faghri, 2010) has not been examined in informal carers of stroke survivors.

Despite adopting multiple strategies to recruit participants into the present study recruitment rates in all three recruitment settings (primary care, stroke specialist healthcare and community outreach) were low. Although difficulties recruiting into depression trials are well documented (see Hughes-Morley, Young, Waheed, Small, & Bower, 2015) recruitment rates experienced in the present study are significantly lower than those found in depression trials conducted with a general mental health population using GP mail-out. For example, 23% of patients invited into a study examining collaborative care for depression expressed initial interest with 11% found eligible and randomised (Richards et al., 2013). Overall, response rates to general mail-outs are around 15% (Richards et al., 2009). However, as previously highlighted (Chapter Three) alongside additional reviews (Bakas et al., 2014; Corry et al., 2014; Brereton et al., 2007) trials examining informal carer interventions often have small sample sizes. Indeed, other trials recruiting informal carers have experienced significant difficulties. For example, a strategy based on recruitment of informal carers from stroke units recruited only 39 carers over a four year period (Draper et al., 2007). Five factors have therefore contributed to poor recruitment within Study Five

7.6.1.1 GP recognition. Only 34% of stroke survivors were identified as having an informal carer or relative who could be invited into the study. This is significantly lower than the conservative estimate of 50% of stroke survivors expected to require some level of informal care (Hickenbottom et al., 2002; RCP, 2011). No restrictions were placed on severity of stroke or amount of informal care provided within the inclusion criteria and GPs were instructed to initially search for stroke survivors and subsequently identify and invite any relative or known informal carer of a stroke survivor, regardless of the level of impairment experienced by the stroke survivor.

Research suggests that GPs lack confidence in being able to identify informal carers within practice, require guidance in how to identify carers and lack confidence in providing support to carers (Greenwood et al., 2010). Indeed, only 6% of GPs in the UK surveyed were found to have a specific carers register (Greenwood et al., 2010), with a lack of sufficient information systems to aid GPs in identifying informal carers (Simon and Kendrick, 2001). Furthermore, informal carers and care recipients may not have the same GP or even be registered within the same practice, making identification of informal carers more difficult (Greenwood et al., 2010). Additionally, research suggests that there is a lack of recognition of the difficulties associated within the caring role by health professionals (Arksey & Hirst, 2005) limiting subsequent referral to appropriate support (Bruce & Paterson, 2000). Further research is required to examine the potential factors contributing to GP being unable to identify as many informal carers of stroke survivors that would be suggested by prevalence rates.

7.6.1.2 Gatekeeping. There is evidence to suggest GPs screen out patients from depression trials for reasons other than those included within the exclusion criteria (Jenkinson et al., 2014). Common reasons for screening out patients include the patient having a comorbid health condition, being disabled or frail and making assumptions that the patient would not cope with the research (Jenkinson et al., 2014). Further research has identified that GPs make a therapeutic decision as to whether or not the patient requires the intervention on offer when screening patients for potential depression trials (Fairhurst & Dowrick, 1996). Furthermore, GPs have been found to make judgements about a person's ability to benefit from psychological interventions when making decisions concerning referral into psychological services (Stavrou, Cape & Barker, 2009) which may also translate to the research setting. Additionally, literature suggests health practitioners tend to disempower older adults and make decisions for them, considering them unable to make their own decisions concerning receipt of health care services (Benbow, 2012). Consequently, fewer carers may have been identified by GPs than anticipated within this study due to GPs making decisions on behalf of patients concerning their eligibility and suitability to receive CBT self-help. Future studies may wish to ask GPs to record reasons for excluding participants to examine these potential factors (Jenkinson et al., 2014).

Similarly, only 30% of stroke survivors were identified as having an informal carer to be invited into the study within specialist stroke healthcare settings. Reasons for not inviting carers into the study were mainly concerned with stroke healthcare professionals not wanting to cause more distress for the informal carer. Indeed, other depression trials have experienced significant difficulties with recruitment due to referring health professionals viewing potential participants as vulnerable and concerned that entry into a depression trial would cause more burden and increase levels of distress (Hughes-Morley et al., 2015). Interestingly, concerns voiced by stroke healthcare professionals regarding fear of causing increased distress were not mirrored by some informal carers who stated within the reason for non-participation slip that support had been offered too late.

Finally, although 30 community stroke and carer organisations agreed to support the study in terms of handing out study invitations, leaflets and displaying posters it was noted that some community group leaders may also have been gatekeeping. Some community organisations, although agreeing to support the study, made comments to the researcher such as “*Most carers, and from my own experience, do not have much spare time or energy. Don't hold your breath!*” and “*I'll hand out the leaflets but I doubt anyone will be interested*”. Indeed, other studies investigating depression interventions for older populations have experienced similar difficulties with community contacts acting as gatekeepers (Shellman & Mokel, 2010). Further investigation and consideration of potential gatekeeping by referring healthcare professionals and community contacts is therefore required.

7.6.1.3 Carer barriers to accessing support. As well as fewer carers being invited into the study than anticipated, only 4% of carers expressed interest in the trial, with an initial screen rate of 2% and overall randomisation rate of 0.8%. Significantly, barriers experienced by carers to accessing support may potentially explain poor uptake. First, reasons for non-participation collected included factors such as; (a) lack of time; (b) own physical health difficulties; (c) not identifying as a carer; (d) not attributing depression to the stroke; (e) coping because ‘I have to’; (f) difficulty talking about personal problems and (g) fear of the stroke survivor finding out.

Interestingly, reasons for non-participation were consistent with barriers to accessing support identified within a general carer population and general depression population. Lack of time and energy is a consistent barrier to accessing

support identified within the caregiving literature (Arksey et al., 2003; Arksey & Hirst, 2005). Furthermore, carers do not always recognise themselves as being 'carers' and instead consider caring for a loved one their duty and responsibility (Whitebird et al., 2011). However this can also impact on lack of GP recognition if carers do not identify themselves as such (Cameron, et al., 2011).

There is also the possibility that symptoms of low mood and depression may conflict with carers' identity and personal goals. Previous research has identified conflict between identity and depressive symptoms to be a significant factor in delaying help-seeking behaviour in depression (Farmer, Farrand & O'Mahen, 2012). Family members of someone with a physical health problem commonly feel a sense of obligation to care and support the person with the physical health problem (Weuest & Hodgins, 2011). This may be accompanied by beliefs that they should be able to cope with the caring role and it is their duty to provide care. Indeed, this sense of duty has been found to lead to guilt in terms of acceptance of professional support from GPs by dementia informal carers under elevated levels of stress (Bruce, Paley, Underwood, Roberts & Steed, 2002). Carers' sense of obligation and duty may be important constructs of their identity and personal goals with symptoms of low mood and depression conflicting with this identity and potentially leading to a significant barrier to accessing help and support. Depression may threaten an individual's perceived ability to perform the caring role and thus challenge their identity and delay help-seeking behaviour. Indeed, it is reported in the literature that carers often delay help-seeking until a crisis point has been met (Bruce et al., 2002; Bulsara & Fynn, 2006)

A related concept is that of 'candidacy', a term that refers to how someone perceives their eligibility for receipt of healthcare services, which is something negotiated within interactions between healthcare providers and individuals (Gask et al., 2012). An individual's identity is core to the concept of candidacy and an individual's identity is maintained by interactions with others (Gask et al., 2012). For example, previous negative experiences with healthcare providers can threaten an individual's identity and have a negative impact on subsequent health seeking behaviours. It was clear from Chapter Four that carers experience significant difficulties accessing support from GPs, other healthcare professionals and social support services. The wider literature has identified a clear association between levels of depression and anxiety and increased number of carers' unmet needs

across a number of domains such as the provision of information, health care services, work and social as well as psychological support (Girgis et al., 2012). This also links to the finding that GPs report having limited access to services for informal carers to refer to and insufficient knowledge about services that could be accessed (Greenwood et al., 2010). There is also evidence suggesting that services considered important to informal carers of stroke survivors are not received (Krevers & Öberg, 2011; Dorze & Signori, 2010). As such, carers' previous negative experience of trying to access support may impact on their ability to seek help for their low mood and depression.

Further research has identified that patients may not enrol in depression trials if they are experiencing remission in symptoms or feel that they are coping with depression, in order to protect their state of wellness (Dowrick, Hughes, Hiscock, Wigglesworth, & Walley, 2007; Van Der Weele et al., 2012). Additionally, older adults have been found to view depression as an inevitable consequence of aging, which may also present a barrier to accessing psychological treatment (Law, Laidlaw, & Peck, 2010). Indeed, older adults have been found to recognise difficulties with their mood but use terms such as 'sad' or 'lonely' as opposed to explicitly using the term depression and considering being 'sad' as something different to depression that can be addressed without an intervention (van der Welle et al., 2012).

It is important to recognise the stigma associated with depression (Keeley, West, Tutt, & Nutting, 2014; Thornicroft & Tansella, 2014). Stigma remains a significant issue worldwide with clear negative consequences in terms of accessing mental health care (Thornicroft, 2008) and a barrier to recruiting into depression trials (Hughes-Morley et al., 2015). Furthermore, there is evidence to suggest that depression stigma may be a particular challenge in terms of mental health treatment seeking among older adults (Connor et al., 2010; Park & Unützer, 2011; Hall & Reynolds, 2014). Indeed, older adults declining participation into depression trials have considered 'giving in to' depression as a weakness (van der Welle et al., 2012). Further investigation and consideration of barriers preventing help-seeking behaviour in depressed informal carers of stroke survivors is therefore required.

7.6.1.4 A non-assertive recruitment approach. Within this present study healthcare professionals or community workers provided potential participants with study information through the post. The researcher only contacted potential

participants if they responded to the letter of invitation. Ethical approval was received for practice staff or clinical studies officers within the Primary Care Research Network (PCRN) to follow-up patients over the telephone if they did not respond to the initial invitation on the basis that a successful method of improving recruitment is to provide reminders over the telephone to non-responders (Watson & Togerson, 2006). However, due to both practice and PCRN capacity limitations telephone follow-up with non-responders was not feasible. Furthermore, although the researcher attempted to attend community stroke and carer events this was limited in terms of time, distance and budget. The researcher was based in Devon however the trial was conducted across the counties of Dorset and Cornwall.

Previous carer intervention studies have successfully utilised more assertive and collaborative community engagement to recruit informal carers, such as the attendance of community groups, seminars, large public events and community service providers (Whitebird et al., 2011). However, much time needs to be invested into community collaborations in order for recruitment to be successful and an advantage is to have existing relationship with the population being recruited (Austrom, Bachman, Altmeye, Gao, & Farlow, 2010). Although the researcher had strong links with the Stroke Research Network and stroke groups within the county of Devon very few links were held in Cornwall and Dorset. As such, there is the possibility that the lack of ability to follow-up non-responders and lack of existing relationship with community based organisations contributed to poor response rates in the present trial.

7.6.1.5 The prevalence of depression. The number of informal carers anticipated to be eligible for the present trial was based on a 30% prevalence rate of depression in this group (Berg et al., 2005; Visser-Meily et al., 2008). However, a key limitation within the depression prevalence literature for informal carers is the reliance on global levels of psychological distress as opposed to making specific diagnosis (Livingston, Manela, & Katona, 1996). Indeed, the overall rate of depression in carers of elderly people living at home has been found to be 15% (Livingston et al., 1996) when making specific depression diagnoses in accordance with the International Classification of Diseases, 10th Revision (ICD-10, WHO, 1992). Recruiting informal carers meeting Diagnostic and Statistical Manual of Mental Disorders (DSM-IV) criteria for a mood, anxiety, or adjustment disorder was

found to be very difficult with only 28 informal carers of dementia patients recruited over a two year period (Wiprzycha, Mackenzie, Khatri, & Cheng, 2011).

Within the current study 13 participants were excluded from the study. These participants screened above caseness for IAPT services as defined by a PHQ-9 score of 10 or above (DOH, 2011b) but failed to meet diagnosis for depression. As such, these participants may have been considered suitable for a low-intensity treatment through IAPT but did not meet the strict inclusion criteria for the current study in terms of meeting diagnostic criteria for depression. As such, further investigation is warranted in terms of whether prevalence rates of depression are as high as indicated by the present literature based on elevated depressive symptoms and whether this may have impacted on recruitment rates into the present trial. Further consideration may also be necessary in terms of whether individuals need to meet diagnosis for depression for trials of self-help interventions that in practice would be delivered to individuals who may not meet diagnostic criteria of Major Depression Disorder.

7.6.2 Attrition

The overall attrition rate in the current study was 30%. However 44% of participants dropped out of the intervention arm, with drop out from this arm significantly higher than with the control. This is similar to the finding in Chapter Three (Study One) that six studies reported attrition >30% in at least one arm (Au et al., 2010; Hayley et al., 1987; Losada et al., 2010; Lovett & Gallagher, 1988; Toseland et al., 2004; Toseland et al., 1995) and an additional two studies reported attrition >50% in at least one arm (Márquez-González et al., 2007; Tremond et al., 2008). Due to the small sample size it is difficult to draw any conclusions from the data concerning attrition. However high rates of attrition found in this study may indicate further lack of acceptability of the CBT self-help intervention and barriers to informal carers accessing support for depression.

7.6.3 Limitations

Some elements of feasibility could have been examined through more simple study designs as opposed to running an RCT which can be difficult and time consuming (Shanyide et al., 2011). For example, a greater understanding of the acceptability of the intervention and recruitment into the intervention may have been gained by running a single armed study (Shanyide et al., 2011). Although only having one study arm would not have allowed investigation of elements such as

randomisation rates or maintenance of researcher blinding, given the significant delays experienced in terms of gaining research governance approvals and excess treatment costs some of the significant unknowns could have been examined through alternative methodologies that would have been less labour and time intensive.

A further limitation pertains to the lack of gathering in-depth reasons for non-participation. Although the study collected written responses indicating reasons for non-participation, a more thorough qualitative investigation may have provided an in-depth understanding of the barriers to participating in the study and greater detail concerning the acceptability of the proposed intervention; help-seeking behaviour and barriers to accessing support. Furthermore, potential research related barriers such as difficulties with randomisation (Carey et al., 2001); trust of the study team (Hughes-Morley et al., 2015) or misunderstanding about the research itself (Barnes et al., 2012) may have been highlighted.

Additionally, there was no formal exploration into GP and stroke healthcare professional reasons as to why so few informal carers were identified in comparison to prevalence rates, and warrant further investigation. Finally, significant difficulties were experienced by virtue of the research being conducted in two large geographical areas some distance from the base of the researcher. Should the researcher have been located nearer to the main study sites some of the difficulties pertaining to lack of relationships with stroke and community services, inability to adopt a more assertive outreach recruitment strategy and PWP protocol non-adherence issues may have been managed more successfully.

7.6.4 Future Research

Future research involving the recruitment of informal carers of stroke survivors may seek to interview potential participants who decline participation within the study. Eliciting more in-depth qualitative reasons for non-participation may provide researchers with a greater understanding concerning barriers to research participation; barriers to accessing psychological treatment; and the acceptability of the intervention under investigation. Qualitative research provides the opportunity to further understand complex barriers and facilitators to recruitment experienced within depression trials that may both increase future recruitment rates and aid researchers in developing more acceptable treatments for depression (Hughes-Morley et al., 2015).

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Informal carers recruited within this programme of research were predominantly long-term carers, however the range was wide (mean=8.19 years (SD=9.32)). As such, the majority of informal carers were in the “long-lasting adaptation at home” (Cameron & Gignac, 2008). However, little research has examined the long-term recovery trajectory post-stroke (Arntzen, Borg, & Hamran, 2014) or longitudinal changes in impact of caregiving (Gaugler, 2010). There have been suggestions that longitudinal adjustment in informal carers of stroke survivors is curvilinear as opposed to linear and as such complex trajectories are expected. For example, significant health transitions may occur during the trajectory, for example, falls, hospitalisations, other critical illnesses, and therefore stroke informal carer outcomes will differ around these life transition events (Gaugler, Roth, Haley, & Mittelman, 2008). Given the potential for a curvilinear form of adjustment (Gaugler, 2010) it may be difficult to make generalisations from informal carers recruited at different time points and without measures of key life transitions. Indeed, this has been posited as general limitation of the stroke carer research (Greenwood et al., 2009). As such, future studies including carers with differing lengths of time within the caring role may seek to measure recent significant health transitions. An alternative future research direction could be to minimise recruitment to carers who have been caring for a more similar length of time, to create a more homogeneous sample. Indeed, the ‘Timing It Right’ framework suggests informal carer needs for support change throughout the caring trajectory (Cameron & Gignac, 2008), and as such different types of support may be required at different stages post-stroke (Cameron, Nagliem Silver, & Gignac, 2013). Further, some evidence suggests a relationship between increased carer burden and depression with increased neurological, physical, functional (Bugge et al., 1999) and behavioural impairment (Pinquart & Sörensen, 2003a) in the stroke survivor. As such, future studies may also seek to recruit informal carers who are providing care to stroke survivors with similar levels of impairment, thus improving homogeneity. Further, restriction to providing an intervention to carers at a similar stage in the care continuum (Cameron & Gignac, 2008), caring for someone with similar levels of post-stroke impairment (Bugge et al., 1999) may allow for a more targeted and acceptable intervention, that will possibly improve recruitment rates.

Finally, the present trial experienced significant difficulties relating to conducting the trial within existing IAPT services. Significant difficulties were

experienced gaining NHS governance, resulting in substantial delays to commencing recruiting. PWP attrition and PWP lack of adherence to trial protocols, for example, taping support sessions was also experienced. Further, PWP location resulted in only telephone support being offered to participants, with acceptability data suggesting face-to-face support would have been preferred by those who received the intervention. Additionally, the researcher was based in Devon; however the trial was conducted across the counties of Dorset and Cornwall. Although the researcher attempted to adopt a more assertive recruitment approach (for example attending stroke and carer events) this was restricted due to limitations in terms of time, distance and budget. Integration of research into existing healthcare providers is difficult (Tcheremissine et al., 2014). Indeed, a recent study conducted within an existing IAPT service experienced significant difficulties with PWP deviation from protocol and high staff turnover (Pentecost et al., in press). As such, future studies may seek to employ trial PWPs directly, a strategy that may overcome difficulties with integrating research within existing healthcare services (Tcheremissine et al., 2014) and reduce the need to navigate complex research governance procedures (Fudge et al, 2010; Kearney et al., 2014). However, it should be noted that such an approach to research is less pragmatic and conducting research outside of real-world treatment settings may reduce the external validity of the trial results (Rothwell, 2005; Thorpe et al., 2009). Finally, future studies should seek to ensure a research team is located in the area of recruitment to allow for a more assertive recruitment approach.

7.7 Conclusions

This study was conducted as Phase II of the revised complex interventions framework (MRC, 2008) and designed to examine procedural and methodological uncertainties associated with running a definitive Phase III trial in the future. After conducting a feasibility RCT researchers should make a decision to stop due to the main study not being feasible, continue but with protocol modifications or continue without modifications (Thabane et al., 2010). Considering the substantial feasibility concerns highlighted by this trial, especially in concerns to significant difficulties with recruitment, it is clear that a Phase III RCT is not feasible or warranted at the current time. However, the current study has raised significant questions concerning:

- Lack of recognition of carers by healthcare professionals.

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- Gate keeping by healthcare professionals and community organisations.
- Barriers to accessing support experienced by informal carers.
- The acceptability of the CBT self-help intervention in its current form.

As such, following the revised MRC framework (MRC, 2008), there a number of future research directions, that could now be taken to address these new uncertainties. Chapter Nine will provide a full discussion concerning some of these future research ideas. In the following chapter (Chapter Eight) the programme of research undertaken will be placed in the context of an updated systematic review and meta-analysis of psychological and psychological interventions for informal carers of people with chronic physical health conditions.

CHAPTER EIGHT: Updated Systematic Review and Meta-Analysis

8.1 Aims

To place the feasibility RCT in the context of an updated systematic review and meta-analysis. This follows guidance that all clinical trials should both begin and end with systematic reviews of the pertinent evidence base (Clarke et al., 2010).

8.2 Background

Study One (Chapter Three) comprised of a systematic review and meta-analysis examining the evidence base for psychological and psychosocial interventions for depressed and anxious informal carers of people with chronic physical health conditions. The review search was completed in December 2012 with no limitations placed on the earliest date of publication. The systematic review and meta-analysis was conducted in line with the development phase of the revised MRC complex interventions framework (MRC, 2008). As well as examining the existing evidence base for psychological and psychosocial interventions for depressed and anxious informal carers of people with chronic physical health conditions a further aim of the study was to examine potential intervention components associated with effectiveness that might further inform the content of the new CBT self-help intervention for depressed informal carers of stroke survivors.

Further guidance suggests that when an RCT of a new intervention is conducted the findings should be appreciated within the context of previously conducted relevant research (Clarke et al., 2010). One method of doing this is to update an existing systematic review and meta-analysis with the findings from the new trial or alternatively appreciate the findings of the RCT in light of an up-to-date systematic review and meta-analysis (Clarke et al., 2010). The original systematic review and meta-analysis conducted in Study One only included studies published up to and including December 2012 and as is now out of date. As such, the review was updated with a search conducted from January 2013 until 15th August 2014 in order to gain an appreciation of the updated evidence base. The feasibility RCT was not included within the updated review as unpublished data due to the primary aims pertaining to feasibility outcomes as opposed to the reduction of depressive and anxious symptoms. Methods for conducting the updated systematic review and meta-analysis were identical to those used in Study One (Chapter Three).

8.3 Results

There is little guidance concerning how to report updated systematic reviews and meta-analyses (Stovold, Beecher, Foxlee, & Noel-Storr, 2014). However, results will be presented as follows:

- An overview of the study selection process for updated review conducted between January 2013 and August 2014.
- Study flow for the original and updated review combined.
- Presentation of detailed information pertaining to the clinical and methodological characteristics of the new studies identified by the updated review.
- Overall meta-analytic results for the original and new review combined.

The discussion will focus on how the inclusion of the new studies identified impacted on the findings of the original review.

8.3.1 Study Selection

A total of 2,347 additional possible studies were identified in total by the updated search conducted from January 2013 to August 2014. Database searches yielded 2,336 possible studies through searching the following databases: CINAHL (n=382); EMBASE (n=673); PsychInfo (n=261); Medline (n=498); Social Science Citation Index (n=80); ASSIA (n=43) and CENTRAL (n=399). Other review papers, reference lists, citation checks, www.ClinicalTrials.gov and www.who.int/trialsearch/, hand-checking journals and contact with experts yielded an additional 11 studies. Of the 2,347 possible records identified, one was a dissertation abstract (McLain et al., 2013) and one was published in a language other than English (Ryynanen, Nousiainen, Soini, & Tuominen, 2013) and therefore excluded. In total, 35 full text articles were assessed for eligibility by JW. Due to limitations in resources and time there were no other researchers available to parallel assess for studies for eligibility, although a second review is currently in process to aid future publication. In total 29 studies were excluded from the review with 6 studies meeting the inclusion criteria and included in the updated systematic review and meta-analysis. The updated study flow diagram following Cochrane guidance for reporting updated systematic reviews and meta-analyses (Stovold, Beecher, Foxlee, & Noel-Storr, 2014) including results from the original meta-analysis can be seen in Figure 8.1. The main reasons for study exclusion and reasons for study exclusion (Table 8.1) and study citations

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relating to the studies excluded from the updated review (Appendix 8.1) are presented.

Table 8.1

Reasons for Exclusion

Reason for exclusion	<i>n</i>
Inappropriate comparator	7
Depression and / or anxiety not the primary target of the intervention or measured.	6
Depression and / or anxiety not the primary target of the intervention. Symptoms of depression and / or anxiety are measured as a distal outcome	3
Not an RCT	3
Intervention target unclear, authors not contactable	2
Not a psychological or psychosocial intervention.	2
Treatment primarily focused on the patient rather than the carer	2
Inadequate randomisation	1
Missing data	1
Prevention	1
The treatment is focused on how to manage the behavioural and psychological symptoms of dementia	1

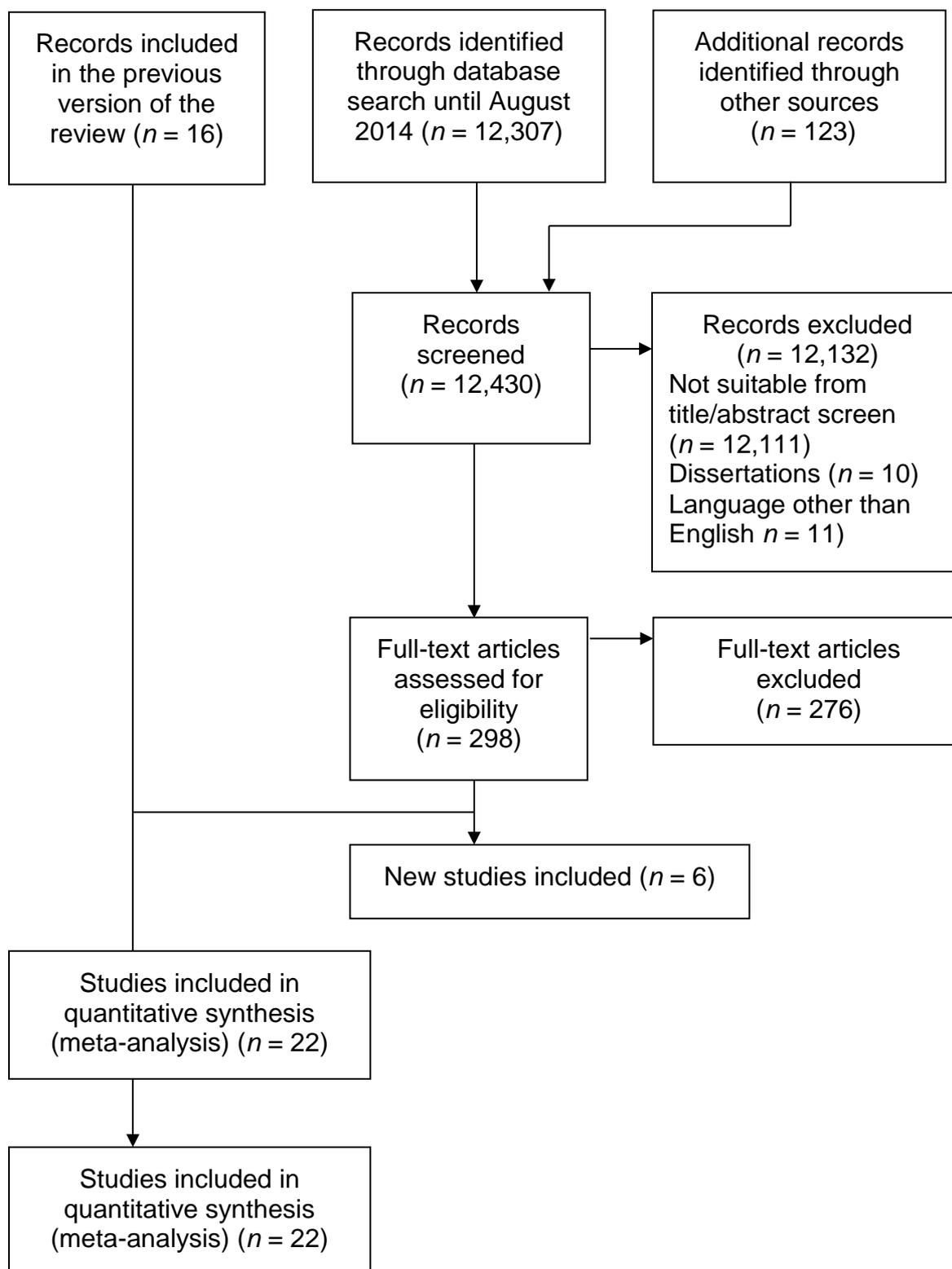


Figure 8.1. Adapted study flow diagram (Stovold et al., 2014).

8.3.2 Methodological quality

Only 1 study was excluded from the updated review due to inadequate randomisation. Overall, the quality of studies included in the updated review was higher than the studies included in the original review (Table 8.2). In total, 4 out of the 6 newly included studies provided details concerning the exact method of random sequence generation (Bruvik, Allore, Ranhoff, & Engedal, 2013; Garand et al., 2014; Livingston et al., 2013; Martindale-Adams, Nichols, Burns, Graney, & Zuber, 2013; Tremont et al., 2014). However, only 1 study (Livingston et al., 2013) provided details relating to the method of allocation concealment. Blinding of outcome assessors was reported in 4 studies (Au, Wong, Leung, Lueng, & Wong, 2014; Bruvik et al., 2013; Livingston et al., 2013; Tremont et al., 2014). However no studies reported the use of data analysts blind to participant randomisation. The number of carers randomised into the studies ranged from 60 (Au et al., 2014) to 260 (Livingston et al., 2013) with four studies reporting power calculations (Bruvik et al., 2013; Livingston et al., 2013; Martindale-Adams et al., 2013; Tremont et al., 2014). This is in contrast to the original review where only 1 study (Marriott et al., 2000) that reported the use of a power calculation to determine sample size. Furthermore, only 1 study reported attrition >30% in at least one arm (Garand et al., 2014). Additionally, 5 out of the 6 studies used intention-to-treat analysis reducing the possibility of attrition bias.

8.3.3 Outcome Reporting Bias

The ORBIT classification system (Kirkham et al., 2010) was used to assess risk of bias resulting from missing or incomplete outcome reporting. Six studies were excluded from the updated search for not measuring at least one outcome of interest (anxiety or depression) (see Appendix 8.1). However, these studies were not expected to measure these outcomes as the interventions were not designed to target anxiety or depression. In addition, 1 study reported within their protocol that depression and anxiety were measured (Shum, Lui, Law, & Fong, 2014). However insufficient data was presented to be included in the meta-analysis with attempts at contacting the authors failing. In 1 case the missing data was obtained and the study was included within the update review (Garand et al., 2014). Of the included studies, 4 studies targeted and measured depression and the remaining 2 studies targeted and measured both anxiety and depression. An outcome matrix was developed for the four studies that only targeted depression and the ORBIT

classification system was applied to each of these studies. In all cases studies were classified as 'I' meaning it was clear that the outcome was not measured (Dwan et al., 2010; Kirkham et al., 2010) and therefore at no risk of bias (Table 8.3). As such, there was no evidence suggesting that the new studies included within the updated review were at risk of outcome reporting bias, as found in Study One (Chapter Three).

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Table 8.2

Risk of Bias Table

Study	Random sequence generation	Random sequence allocation	Blinding (outcome collectors)	Blinding (data analysts)	Power	Baseline comparability	ITT	Attrition (%)	Outcome reporting bias
Au et al., 2004	Unclear	Unclear	Low	Unclear	High	Low	High	Low	Low
Bruvik et al., 2013	Low	Unclear	Low	Unclear	Low	Unclear	Low	Low	Low
Garand et al., 2014	Low	Unclear	High	Unclear	High	Low	Low	Unclear	Low
Livingston et al., 2013	Low	Low	Low	Unclear	Low	Unclear	Low	Low	Low
Martindale-Adams et al., 2013	Unclear	Unclear	Unclear	Unclear	Low	Unclear	Low	Low	Low
Tremont et al., 2014	Low	Unclear	Low	Unclear	Low	Low	Low	Low	Low

Note. Risk of bias was assessed as low, unclear or high following guidelines outlined in the Cochrane Collaboration's Risk of Bias tool (Higgins & Altman, 2008). ITT; Intention-to-treat.

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Table 8.3

Risk of Outcome Reporting Bias

Study	Missing outcome	ORBIT classification	Level of risk	Explanation for classification
Au et al., 2014	Anxiety	I	No Risk	The only target of the intervention was depression. Anxiety was not an outcome of interest and would not be expected to be measured.
Bruvik et al., 2013	Anxiety	I	No Risk	The only target of the intervention was depression. Anxiety was not an outcome of interest and would not be expected to be measured.
Martindale-Adams et al., 2013	Anxiety	I	No Risk	The only target of the intervention was depression. Anxiety was not an outcome of interest and would not be expected to be measured.
Tremont et al., 2014	Anxiety	I	No Risk	The only target of the intervention was depression. Anxiety was not an outcome of interest and would not be expected to be measured.

Note. Risk of outcome reporting bias was assessed as no, low or high following guidelines outlined in the ORBIT classification system for missing or incomplete outcome reporting (Kirkham et al., 2010).

8.3.4 Study Characteristics

A total of 1,027 informal carers were randomised and 957 analysed (at the longest follow-up time point ≤ 6 months) within the 6 new studies. As such, a total of 2,295 were randomised and 2,027 analysed within the 22 studies included within the updated review.

Selected study characteristics for the additional studies included within the updated review can be found in Table 8.4. Each of the 6 newly included studies included carers of dementia patients or in the case of 1 study (Garand et al., 2013) mild cognitive impairment or early dementia. As such, the revised review includes 13 studies (8 comparators) examining the effectiveness of psychological or psychosocial interventions for dementia in total. The additional studies were conducted in the following locations: North America ($n = 3$; Garland et al., 2014; Martindale-Adams et al., 2013; Tremont et al., 2014); Europe ($n = 2$; Bruvik et al., 2013; Livingston et al., 2013) and Asia (Au et al., 2014). The mean age of carers ranged from 55 years (Au et al., 2014) to 65 years (Martindale-Adams et al., 2013) with a mean of 77% of carers being female. Length of time caring was only reported in 3 studies (Au et al., 2014; Martindale-Adams et al., 2013; Tremont et al., 2014). The ethnic background of participants was reported in 4 studies (Garand et al., 2014; Livingston et al., 2013; Martindale-Adams et al., 2013; Tremont et al., 2014). In 1 study only spousal informal carers were included (Garand et al., 2014), 3 studies include spouses and adult child carers were included (Au et al., 2014; Martindale-Adams et al., 2013; Tremont et al., 2014) and in 2 cases spouses, adult children and others were included (Bruvik et al., 2013; Livingston et al., 2013). The age of care recipients was reported in all studies and ranged from a mean age of 74 years (Garland et al., 2014) to 80 years (Au et al., 2014). The gender of care recipients was reported in 3 studies (Garland et al., 2014; Martindale-Adams et al., 2013; Tremont et al., 2014) with a mean of 37% of care recipients being female. Overall participant characteristics were very similar to the original review with the only notable exception being that in the original review 52.5% of care recipients were female.

Baseline levels of depressive symptoms were reported in all 63 additional studies using three different validated outcome measures for depression: Centre for Epidemiological Studies: Depression Scale (CES-D; Radloff, 1977 ; Hospital Anxiety and Depression Scale: Depression Subscale (HADS-D; Zigmond and Snaith 1983).;

and the Geriatric Depression Scale (GDS; Yesavage et al., 1982-1983). Adopting standard clinical cut offs for depression, subclinical symptoms at baseline were found in two studies (Bruvik et al., 2013; Livingston et al., 2013) and mild symptoms were found at baseline in the remaining four studies (Au et al., 2014; Garand et al., 2014; Martindale-Adams et al., 2013; Tremont et al., 2014). As such subclinical depressive symptoms in baselines were found in 7 studies (9 comparisons, $n = 737$) and mild symptoms were found in 9 studies (9 comparators, $n = 806$) within the updated review.

In regards to anxiety, 1 study (Livingston et al., 2013) used the Hospital Anxiety and Depression Scale: Anxiety Subscale (HADS-A; Zigmond and Snaith 1983) and informal carers were mildly anxious at baseline. The additional new study examining anxiety (Garland et al., 2014) used the State-Trait Anxiety Inventory (STAI, Spielberger et al., 1983) which does not have clinical cut offs and therefore baseline severity of anxiety could not be calculated. As a result, 3 studies overall in the updated review recruited carers with mild levels of anxiety at baseline (4 comparators, $n=351$). As found in the original review, no studies included any standard diagnosis interview to determine a probable diagnosis at baseline or follow-up of a major depressive disorder or anxiety disorder.

8.3.5 Intervention Characteristics

Detailed information concerning specific treatment components utilised in each of the new studies is provided in Table 8.5. In total, 4 of the additional studies targeted only depression and 2 studies targeted anxiety and depression. One study was based on CBT (Livingston et al., 2013); 2 studies were based on problem solving (Bruvik et al., 2013; Garand et al., 2014); 1 study on behavioural activation (Au et al., 2014), 1 study on family systems therapy (Tremont et al., 2014) and the final study used a psychosocial approach (Martindale-Adams et al., 2013)

Overall, 5 new studies were delivered to the carer individually ($n = 762$) and 1 consisted of a mix of dyadic and non-dyadic session ($n = 195$). Five studies were individual interventions ($n = 608$) and 1 utilised a group based format ($n = 154$). Method of support included face-to-face (2 studies, $n = 420$), telephone (3 studies, $n = 464$) and mixed telephone and face-to-face (1 study, $n=73$). Treatments were delivered over 4 weeks to 52 weeks with a mean of 27.5 weeks. The number of sessions ranged from 6 to 16 with a mean of 10.6 sessions. Individual session duration ranged from 15 minutes to 90 minutes with a mean of 536 minutes (8.9

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hours). Clinicians delivering the treatments within the new studies included nurses and occupational therapists (1 study, $n = 195$); social workers (1 study, $n = 73$); psychology graduates (1 study, $n = 225$) and masters-level psychologists (2 studies, $n = 404$). Setting of delivery was home based in 5 studies ($n = 762$). Therapist training was reported in 5 studies ($n = 897$); 3 studies measured treatment fidelity ($n = 548$) and 5 studies reported the use of a treatment protocol ($n = 803$). In total, 4 studies used a treatment-as-usual control ($n = 634$) and 2 used an attention-control ($n = 323$). Clinical recruitment settings were used in 4 studies ($n = 512$) and 2 recruited from mixed clinical and community setting ($n = 445$).

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Table 8.4

Study Characteristics

Study	Carer characteristics	Care recipient characteristics	<i>n</i>	Intervention characteristics	Control	Primary outcome (s)	Follow-up	Recruitment
Au et al., 2014	<p><i>Age (years):</i> I: 58.1; I:55.1 <i>% female:</i> I:78.6; C:77.4 <i>Length of time caring (years):</i> I:3.2; C:3.3 <i>Relationship to care recipient:</i> Spouse: I:42.9%; C:35.5% Children: I:53.6%; C:45.2% Children-in-laws: I:3.6%; C:12.9% Relatives: I:0.0%; C:6.5% <i>Baseline depression:</i> Mild <i>Baseline anxiety:</i> N/A</p>	<p><i>Age (years):</i> I:80.1; C:79.9 <i>% female:</i> Not reported LTC: Dementia</p>	60	<p><i>Theory:</i> Behavioural <i>Dyadic:</i> No <i>Delivery:</i> Individual <i>Support:</i> Telephone <i>Duration:</i> 4 weeks <i>No. of Sessions:</i> 6 <i>Length of Sessions:</i> 20 minutes <i>Total Length of Sessions:</i> 120 minutes <i>Setting:</i> Home <i>Clinician:</i> Not reported <i>Training:</i> Not reported <i>Manualised:</i> Yes <i>Treatment Integrity:</i> Not reported</p>	TAU	Depression (CES-D)	PT	Clinical
Bruvik et al., 2013	<p><i>Age (years):</i> 63.5 <i>% female:</i> 77.0% <i>Length of time caring (years):</i> Not reported <i>Relationship to care recipient:</i> Spouse: 53.0%; Children: 40.0%; Other: 7.0% <i>Baseline depression:</i> None/Minimal</p>	<p><i>Age (years):</i> 78.4 <i>% female:</i> I: 52.0; C:55.0 LTC: Dementia</p>	23 0	<p><i>Theory:</i> Problem Solving <i>Dyadic:</i> Mixed <i>Delivery:</i> Mixed <i>Support:</i> Face-to-face <i>Duration:</i> 12 months <i>No. of Sessions:</i> Unclear <i>Length of Sessions:</i> Unclear <i>Total Length of Sessions:</i> Unclear</p>	TAU	Depression (GDS)	PT	Mixed

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	Depression <i>Baseline anxiety: N/A</i>			<i>Setting: Local authority Clinician: Nurses & OTs Training: Yes Manualised: Yes Treatment Integrity: Not reported</i>				
Garand et al., 2014	<i>Age (years): I: 66.4; C: 63.4 % female: I:77.7; C:78.3 Length of time caring (years): Not reported Relationship to care recipient: Spouse: I:86.1; C:64.8 Baseline depression: Mild Baseline anxiety: N/A</i>	<i>Age (years): I:74.1; C:76.2 % female: I:33.3;C:37.8 LTC: MCI and Dementia</i>	73	<i>Theory: Problem Solving Dyadic: No Delivery: Individual Support: Face-to-face and telephone Duration: 17 weeks (approx.) No. of Sessions: 9 Length of Sessions: 6 x 90 minutes, 3 x 45 minutes Total Length of Sessions: 675 Setting: Home Clinician: Social worker Training: Yes Manualised: Yes Treatment Integrity: Yes</i>	ATC	Depression (CES-D) Anxiety (STAI)	1 month 3 months 6 months 12 months	Clinical
Livingston et al., 2013	<i>Age (years): I:62.0; C: 56.1 % female: I:67.0; 62.0% Length of time caring (years): Not reported Relationship to care recipient: Spouse/partner: I:45.0%; C:36.0%; Child: 41.0%;</i>	<i>Age (years): I: 79.9; C:78.0 % female: I: 57.0; C: 59.0 LTC: Dementia</i>	26 0	<i>Theory: CBT Dyadic: No Delivery: Individual Support: Face-to-face Duration: 14 weeks No. of Sessions: 8 Length of Sessions: Unclear Total Length of Sessions:</i>	TAU	Depression (HADS-D) Anxiety (HADS-A)	PT 8 months	Clinical

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	48.0%; Other: 14.0%; 16.0% <i>Baseline depression:</i> None/Minimal <i>Baseline anxiety:</i> Mild			Unclear <i>Setting:</i> Patient preference, often home <i>Clinician:</i> Psychology graduates <i>Training:</i> Yes <i>Manualised:</i> Yes <i>Treatment Integrity:</i> Yes				
Martindale-Adams et al., 2013	<i>Age (years):</i> I:66.2; C: 65.0 <i>% female:</i> I: 81.8; C: 85.7 <i>Length of time caring (years):</i> I: 4.1; C: 4.1 <i>Relationship to care recipient:</i> Spouse: I: 72.7; C: 71.4; Child: I: 23.4; C: 22.1 <i>Baseline depression:</i> Mild <i>Baseline anxiety:</i> N/A	<i>Age (years):</i> I: 77.5; C: 77.3 <i>% female:</i> I: 17.0; C: 11.7 <i>LTC:</i> Dementia	15 4	<i>Theory:</i> Psychosocial Support <i>Dyadic:</i> No <i>Delivery:</i> Group <i>Support:</i> Telephone <i>Duration:</i> 52 weeks <i>No. of Sessions:</i> 14 <i>Length of Sessions:</i> 60 minutes <i>Total Length of Sessions:</i> 840 minutes <i>Setting:</i> Home <i>Clinician:</i> Masters Level <i>Training:</i> Yes <i>Manualised:</i> Not reported <i>Treatment Integrity:</i> Not reported	TAU	Depression (CES-D)		Clinical
Tremont et al., 2014	<i>Age (years):</i> 62.7 <i>% female:</i> 78.0% <i>Length of time caring (years):</i> 3.7 <i>Relationship to care recipient:</i> Spouse: 51.0%; Child:42.0% <i>Baseline depression:</i> Mild	<i>Age (years):</i> 78.1 <i>% female:</i> 59% <i>LTC:</i> Dementia	25 0	<i>Theory:</i> Family Treatment Model <i>Dyadic:</i> No <i>Delivery:</i> Individual <i>Support:</i> Telephone <i>Duration:</i> 26 weeks <i>No. of Sessions:</i> 16 <i>Length of Sessions:</i> 1 x	ATC	Depression (CES-D)	PT	Mixed

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Baseline anxiety: N/A

60 minutes; 15 x 15-30 minutes

Total Length of Sessions:
510

Setting: Home

Clinician: Masters level therapists

Training: Yes

Manualised: Yes

Treatment Integrity: Yes

Note: Carer Characteristics: I = intervention; C = control; baseline depression or anxiety only reported when depression and / or anxiety is a primary outcome and outcome measurements used have validated clinical cut off scores; Care Recipient Characteristics: LTC = Long-term condition; N: Number randomised, based on all participants randomised to treatment and control groups included within the review, therefore may differ from sample sizes included in the meta-analysis if ITT analysis not conducted and published numbers randomised if not all conditions within the paper were eligible for inclusion within the review; Intervention Characteristics: CBT = Cognitive Behavioural Therapy; Control: TAU = Treatment-as-usual; ATC = Attention control; Primary Outcomes(s): CES-D = Center for Epidemiological Studies-Depression; GDS = Geriatric Depression Scale; STAI = State-Trait Anxiety Inventory; HADS-D = Hospital Anxiety and Depression Scale – Depression subscale; HADS-A = Hospital Anxiety and Depression Scale – Anxiety subscale; Follow-up: PT = Post-treatment.

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Table 8.5

Intervention Characteristics

Study	Theoretical approach	Additional conceptual framework	Specific treatment components
Au et al., 2014	Behavioural Activation		Activity scheduling; relaxation; physical health specific psychoeducation; mental health specific psychoeducation; increasing social and professional support; developing adaptive coping styles.
Bruvik et al., 2013	Problem Solving		Problem solving; activity scheduling; physical health specific psychoeducation; mental health specific psychoeducation.
Garland et al., 2014	Problem Solving		Problem solving; activity scheduling; physical health specific psychoeducation; mental health specific psychoeducation.
Livingston et al., 2013	CBT		Cognitive restructuring, reframing; physical health specific psychoeducation, mental health specific psychoeducation; behavioural management (dementia specific behaviours); relaxation; assertiveness; increasing social and professional support.
Martindale-Adams et al., 2013	Psychosocial support		Dementia behaviour management; assertiveness; communication techniques; grief; physical health specific psychoeducation; mental health specific psychoeducation; problem solving; relaxation.
Tremont et al., 2014	Family Systems Therapy	Psychosocial Transition (Tyhurst, 1958); Transactional Theory Stress and Coping (Lazarus & Folkman, 1987)	Problem solving; cognitive restructuring; reframing; physical health specific psychoeducation; mental health specific psychoeducation; behavioural modification (dementia specific behaviours); goal setting; increasing social and professional support; communication techniques; role changes/transitions.

8.3.6 Outcome Measurements

The outcome measurements used to measure depression and anxiety can be seen in Table 8.6 alongside levels of internal consistency and test-retest reliability. No studies in the updated review were excluded due to utilising inadequate measures of depression or anxiety.

Table 8.6

Outcome Measurements for Depression and Anxiety

Outcome measurement	Number of studies	Internal consistency (Cronbach's alpha)	Test-retest reliability (Cronbach's alpha)
CES-D	4	0.88 (Knight, Williams, McGee, & Olaman, 1997)	0.87 (Miller et al., 2008)
GDS	1	0.94 (Yesavage et al., 1983)	0.85 (Yesavage et al., 1983)
HADS-D	1	0.82–0.90 (Bjelland, Dahl, Haut, & Neckelmann, 2002)	0.86 (Spinhoven et al., 1997)
HADS-A	1	0.78–0.93 (Bjelland et al., 2002)	0.89 (Spinhoven et al., 1997)
STAI-State	1	0.81-0.95 (McDowell, 2006)	0.69-0.76 (McDowell, 2006)

Note. CES-D = Center for Epidemiological Studies-Depression; GDS = Geriatric Depression Scale; HADS-D = Hospital Anxiety and Depression Scale – Depression subscale; HADS-A = Hospital Anxiety and Depression Scale – Anxiety subscale; STAI = State-Trait Anxiety Inventory;

8.3.7 Updated Meta-Analysis

Overall 22 studies (25 comparators) were included within the updated meta-analysis. The main meta-analysis is conducted on time points less than or equal to 6 months. Only post-treatment outcome measurements were analysed in this meta-analysis. Forest Plots for the main outcome measures (depression and anxiety) are reported in Figures 8.2 - 8.4.

8.3.7.1 Depressive symptoms. There was non-significant heterogeneity ($p = .73$, $Q = 18.53$, $I^2 = 0.00$) and therefore the fixed effect model was used for the analysis. A small effect size (Hedges' $g = -0.25$, 95% CI [-0.34, -0.16]) was found for depression (21 studies, 24 comparators, $n = 1,992$), (see Figure 8.2 for effect sizes and 95% CIs). This was similar to the effect size of Hedges' $g = -0.30$ (95% CI: -0.42, -0.17) found in Study One.

8.3.7.2 Anxiety symptoms. One study (Akkerman & Ostwald, 2004) adopted both the BAI (Beck et al., 1988) and HAMA (Hamilton, 1959) as primary outcome measurements of anxiety symptoms. As such effect sizes were conducted separately using each outcome measurement.

BAI: Analysis of heterogeneity was significant ($p = .06$, $Q = 12.18$, $I^2 = 50.73$) and therefore the random-effects model was used for the analysis. A medium effect size (Hedges' $g = -0.64$, 95% CI [-0.91, -0.38]) was found for anxiety (6 studies, 7 comparators, $n = 551$). This was comparable to the effect size of Hedges' $g = -0.71$ (95% CI: -0.96, -0.45) found in Study One. The effect sizes and 95% CIs of the studies are plotted in Figure 8.3.

HAMA: Analysis of heterogeneity was significant ($p = .02$, $Q = 14.85$, $I^2 = 59.58$) and therefore the random-effects model was used for the analysis. A medium effect size (Hedges' $g = -0.69$, 95% CI [-0.99, -0.39]) was found for anxiety (6 studies, 7 comparators, $n = 551$). This was comparable to the effect size of Hedges' $g = -0.75$ (95% CI: -1.01, -0.50) found in Study One. The effect sizes and 95% CIs of the studies are plotted in Figure 8.4.

8.2.7.3 Informal carer burden. One study (Toseland et al., 2004) adopted the Montgomery Borgatta Caregiver Burden Scale (MBBS; Montgomery et al., 1985) to measure carer burden, reporting the objective and subjective burden subscales separately. As such, the meta-analysis was conducted using each subscale separately.

MBBS-Objective Subscale: Analysis of heterogeneity was non-significant ($p = .58$, $Q = 6.58$, $I^2 = 0.00$) and therefore a fixed-effect model was used for the analysis. A small effect size (Hedges' $g = -0.22$, 95% CI [-0.36, -0.09]) was found for carer burden (8 studies, 9 comparators, $n = 897$). This was similar to the effect size of Hedges' $g = -0.28$ (95% CI: -0.46, -0.10) found in Study One.

MBBS-Subjective subscale: Analysis of heterogeneity was non-significant ($p = .72$, $Q = 5.35$, $I^2 = 0.00$) and therefore a fixed-effect model was used for the analysis. A small effect size (Hedges' $g = -0.20$, 95% CI [-0.33, -0.07]) was found for carer burden (8 studies, 9 comparators, $n = 897$). This was similar than the effect size of Hedges' $g = -0.23$ (95% CI: -0.41, -0.05) found in Study One.

8.3.7.4 Informal carer quality of life. Mental health and physical health component scores were both reported in three studies (Argen et al., 2012; Toseland et al., 1995; 2004) and two studies reported overall quality of life (Livingston et al., 2013; Tremont et al., 2014). As such, the meta-analysis was conducted using the mental and physical health component score separately combined with the two studies measuring overall quality of life included within each analysis.

Mental health component score: Analysis of heterogeneity was non-significant ($p = .92$, $Q = 0.91$, $I^2 = 0.00$) and therefore a fixed-effect model was used for the analysis. A small effect size (Hedges' $g = -0.20$, 95% CI [-0.34, -0.06]) was found for quality of life (5 studies, 5 comparators, $n = 792$). This was comparable to the effect size of Hedges' $g = -0.23$ (95% CI: -0.41, -0.01) found in Study One.

Physical health component score: Analysis of heterogeneity was non-significant ($p = .11$, $Q = 7.48$, $I^2 = 46.49$) and therefore a fixed-effect model was used for the analysis. A small effect size (Hedges' $g = -0.31$, 95% CI [-0.51, -0.11]) was found for depression (5 studies, 5 comparators, $n = 792$). This was lower than the effect size of Hedges' $g = -0.44$ (95% CI: -0.74, -0.14) found in Study One.

8.3.7.5 Publication bias. A minimum of 10 studies need to be included within the meta-analysis for Egger's Test of the Intercept to be conducted (Sterne, Gavaghan, & Egger, 2000). Therefore the test for publication bias was only conducted for those studies examining depressive symptoms. Publication bias was not evident for depression ($\beta = -0.72$, $SE = 0.49$, $p = .15$) with Duval and Tweedie's trim and fill method (Duval & Tweedie) suggesting 1 study to be missing to the right of the mean (see Figure 8.5). Rosenthal's fail safe N (Rosenthal, 1979) indicated that an additional 176 studies with a null effect were needed to result in a non-significant effect for depression.

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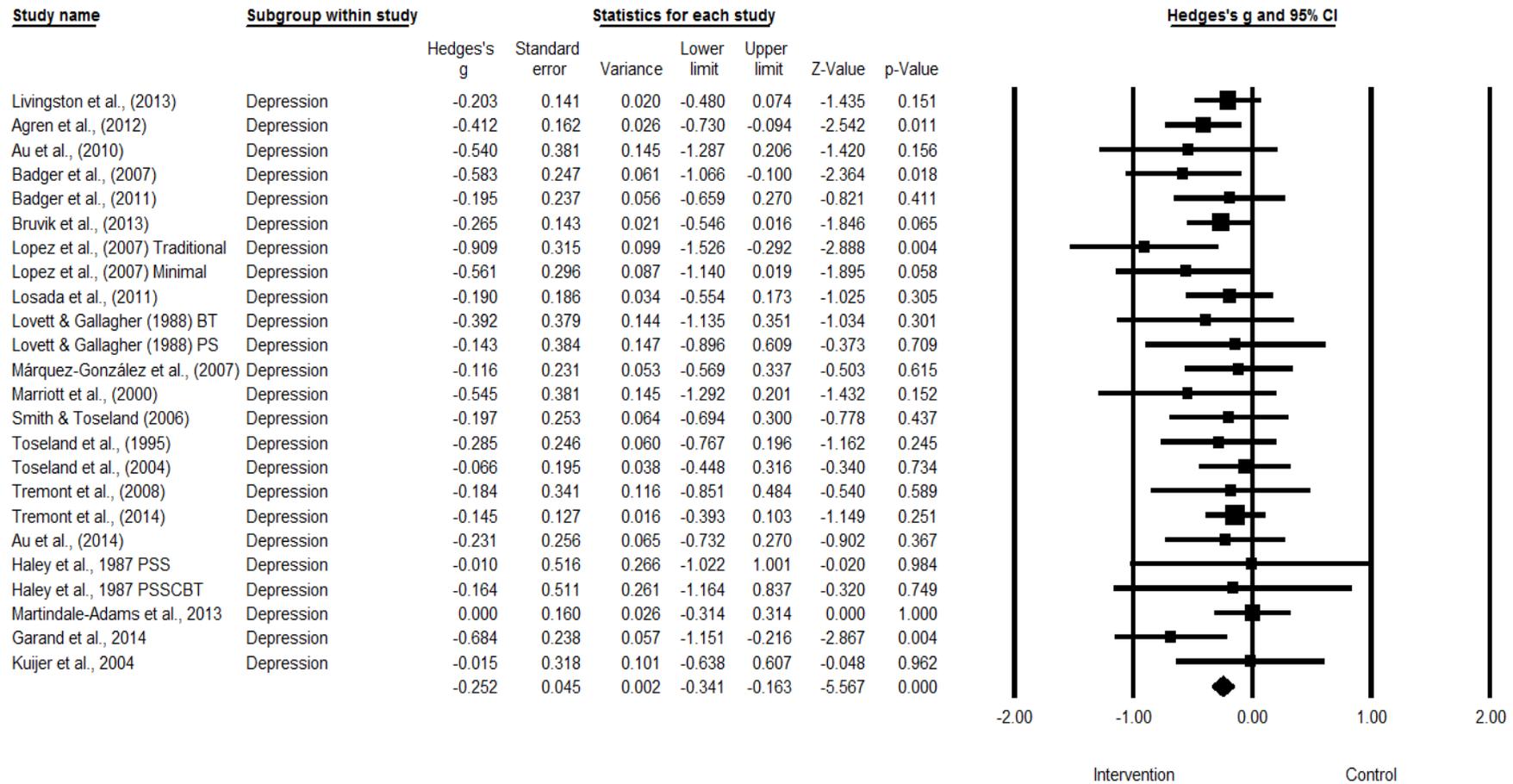


Figure 8.2 Effect sizes (Hedges' g) and 95% confidence intervals (CIs) for interventions targeting depression

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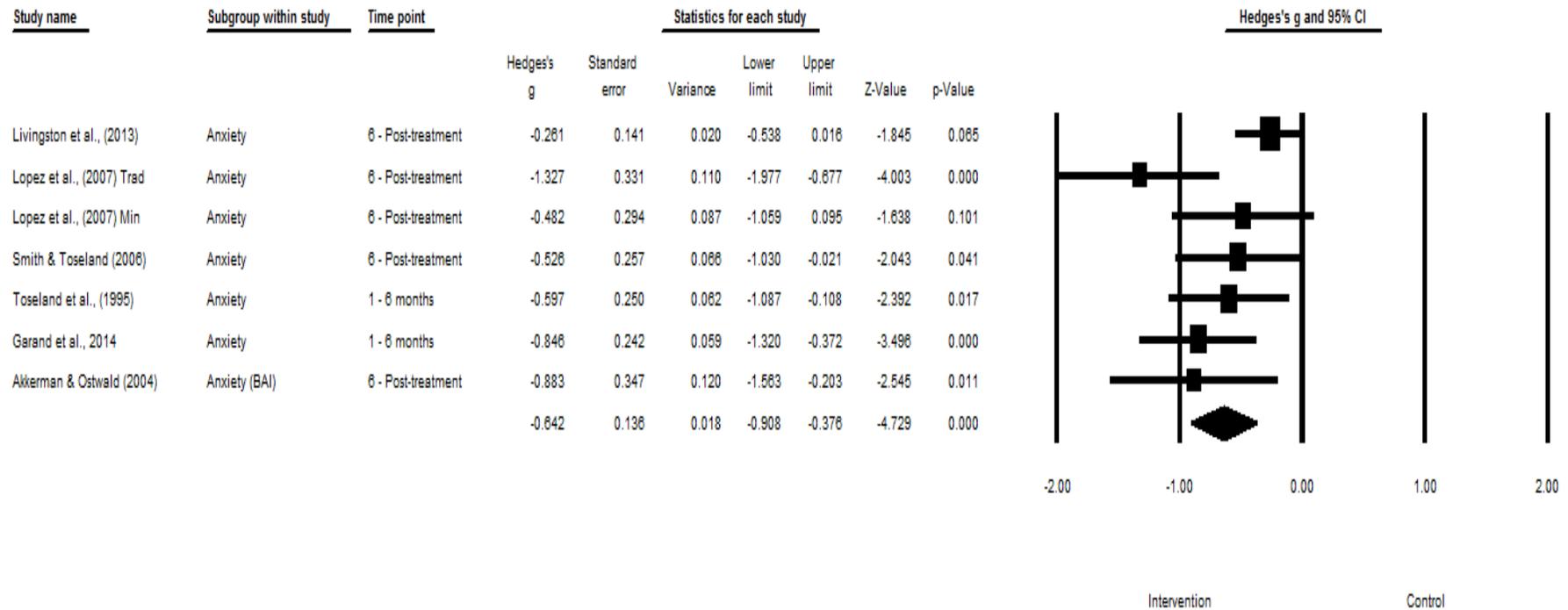


Figure 8.3 Effect sizes (Hedges' g) and 95% confidence intervals (CIs) for interventions targeting anxiety (BAI selected for Akkerman & Ostwald, 2004).

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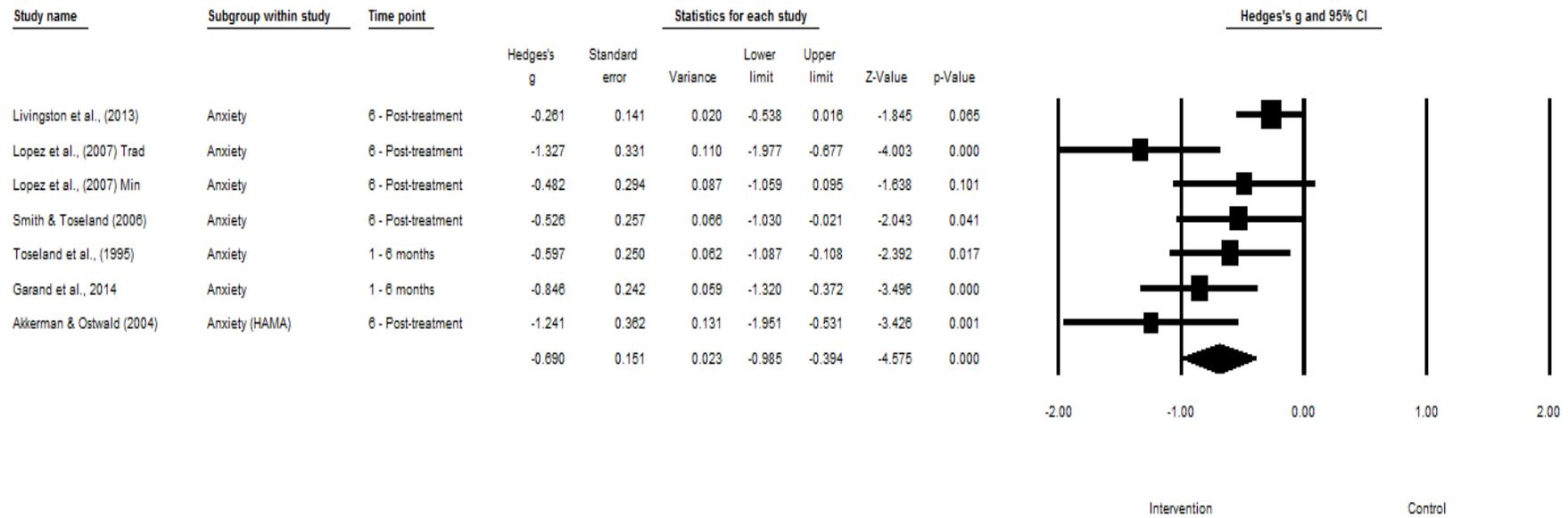


Figure 8.4 Effect sizes (Hedges' g) and 95% confidence intervals (CIs) for interventions targeting anxiety (HAMA selected for Akkerman & Ostwald, 2004).

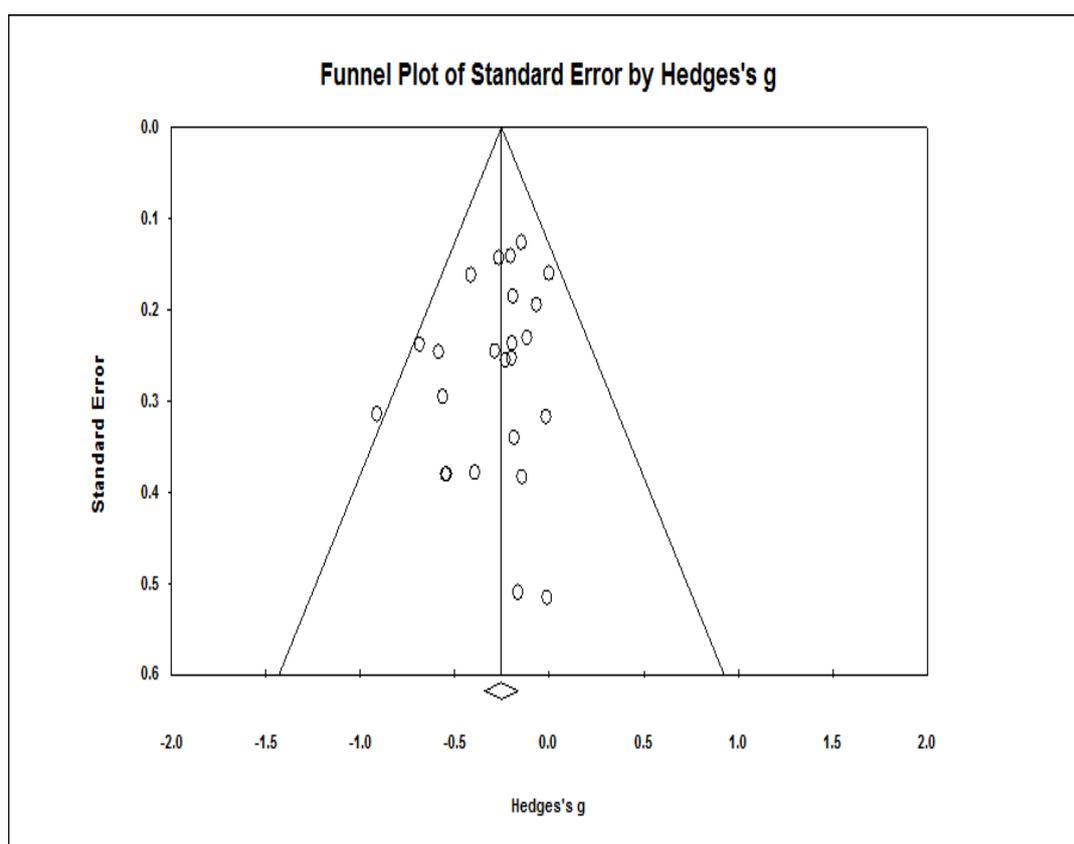


Figure 8.5. Funnel plot examining the presence of publication bias

8.3.7.6 Sensitivity analysis. The revised systematic review identified 8 studies (10 comparators) examining depression, with high levels of attrition in at least one study arm (Au et al., 2010; Garland et al., 2014, Haley et al., 1987; Losada et al., 2011; Lovett & Gallagher, 1988; Márquez-González, 2007; Toseland et al., 1995, 2004). When these 8 studies were dropped from analysis the fixed effect meta-analysis resulted in a small effect size (Hedges' $g = -0.25$, 95% CI [-0.36, -0.15]).

8.3.7.7 Moderator analysis. Moderator analysis was only performed on those studies measuring outcomes of depression (21 studies, 24 comparators) due to only 6 studies (7 comparators) targeting anxiety being included within the review. The updated subgroup analysis did not reveal any significant moderators of overall effect (Table 8.7). However, as in Study One, there was a trend for individually delivered treatments to have a larger effect size than group-based treatments ($Q = 3.25$, $df = 1$, $p = .17$). There was also a trend for face-to-face treatments to be more

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effective than those delivered over the telephone ($Q = 4.50$, $df = 2$, $p = .11$). Meta-regression was calculated to examine treatment duration, number of sessions, total session duration over the course of treatment and year of publication as predictors of effect size. There was a trend for treatments using fewer total number of treatment sessions to have larger effect sizes than treatments using larger number of sessions ($est = 0.0$, $z = 1.72$, $p = .08$). Similarly session lengths of shorter duration had significantly larger effect sizes than longer sessions ($est = 0.02$, $z = 2.05$, $p = .04$). This is further supported by the trend for total session duration over the course of treatment to favour shorter rather than longer treatment session duration ($est = 0.0$, $z = 1.50$, $p = .13$).

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Table 8.7

Moderator Analyses of Associations between Clinical and Methodological Moderators on Effect Sizes (Hedges' g) for the Studies Targeting Depressive Symptoms

Moderators	<i>n</i>	Hedges' <i>g</i>	95% CI	<i>Q betw</i>	<i>p</i>
Physical Health Condition				2.03	.57
<i>Dementia</i>	13	-0.21	-0.32, -0.10		
<i>Mixed Chronic Health Conditions</i>	6	-0.31	-0.54, -0.09		
<i>Cancer</i>	4	-0.30	-0.55, -0.04		
<i>Heart Failure</i>	1	-0.41	-0.73, -0.09		
Psychological Theory				6.01	.54
<i>Cognitive Behavioural Therapy</i>	9	-0.31	-0.46, -0.17		
<i>Interpersonal Therapy</i>	2	-0.38	-0.76, -0.00		
<i>Problem Solving</i>	4	-0.34	-0.55, -0.14		
<i>Psychoeducation</i>	2	-0.12	-0.42, 0.19		
<i>Behavioural Therapy</i>	2	-0.28	-0.70, 0.13		
<i>Family Systems</i>	2	-0.15	-0.38, 0.08		
<i>Psychosocial Support</i>	1	-0.01	-1.02, 1.00		
<i>Psychosocial Support + CBT</i>	2	-0.02	-0.32, 0.29		
Dyadic or Non-Dyadic				0.72	.70
<i>Non-Dyadic</i>	20	-0.24	-0.34, -0.14		
<i>Dyadic</i>	3	-0.36	-0.62, -0.09		
<i>Combination</i>	1	-0.27	-0.55, 0.02		
Method of Delivery				3.56	.17
<i>Individual</i>	13	-0.32	-0.44, -0.20		
<i>Group</i>	10	-0.13	-0.29, 0.03		
<i>Combination</i>	1	-0.27	-0.55, 0.02		
Method of Support				4.50	.11
<i>Face-to-Face</i>	16	-0.27	-0.39, -0.16		
<i>Telephone</i>	7	-0.17	-1.15, -0.22		
<i>Combination</i>	1	-0.17	-0.32, -0.03		
Training				1.41	.23
<i>Not reported</i>	14	-0.32	-0.47, -0.18		
<i>Yes</i>	10	-0.21	-0.32, -0.10		
Intervention Fidelity				0.01	.93
<i>Not reported</i>	14	-0.26	-0.38, -0.13		
<i>Yes</i>	10	-0.25	-0.38, -0.12		
Manualised				2.66	.26
<i>Yes</i>	21	-0.27	-0.37, -0.17		
<i>Not reported</i>	3	-0.31	-0.65, 0.04		
Treatment Setting				0.59	.44
<i>Not reported</i>	15	-0.29	-0.35, -0.09		
<i>Home</i>	9	-0.22	-0.41, -0.16		

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Clinician					5.68	.46
<i>Qualified Psychologist</i>	9	-0.14	-0.28, 0.01			
<i>PI/Co-author</i>	3	-0.31	-0.82, 0.21			
<i>Social Worker</i>	4	-0.29	-0.56, -0.03			
<i>Mix of health professionals</i>	3	-0.52	-0.93, -0.10			
<i>Nurse</i>	3	-0.37	-0.56, -0.18			
<i>Psychology graduates</i>	1	-0.20	-0.48, 0.07			
<i>Not reported</i>	1	-0.23	-0.73, 0.27			
Recruitment Setting					0.00	1.00
<i>Mixed</i>	14	-0.26	-0.35, -0.16			
<i>Clinical</i>	8	-0.25	-0.40, -0.10			
<i>Community</i>	2	-0.27	-0.80, 0.26			
Type of Control					0.98	.61
<i>Waiting List</i>	11	-0.28	-0.46, -0.11			
<i>Treatment-as-Usual</i>	9	-0.22	-0.34, -0.09			
<i>Attention Control</i>	4	-0.36	-0.63, -0.08			
Severity of Depression at Baseline					0.35	.84
<i>Sub-clinical</i>	9	-0.28	-0.43, -0.13			
<i>Mild</i>	9	-0.24	-0.40, -0.09			
<i>Moderate</i>	5	-0.33	-0.59, -0.07			
Follow-Up					5.54	.59
<i>Post-Treatment</i>	23	-0.24	-0.33, -0.15			
<i>10 weeks post-treatment</i>	1	-0.58	-1.07, -0.01			
<i>3 months post-treatment</i>	1	-0.38	-0.84, -0.08			
<i>4 months post-treatment</i>	1	-0.20	-0.66, 0.27			
<i>6 months post-treatment</i>	2	-0.49	-0.88, -0.10			
<i>8 months post-treatment</i>	1	-0.22	-0.51, 0.07			
<i>12 months post-treatment</i>	3	-0.54	-0.93, -0.15			

Note: Moderator analyses are based on a fixed effects model. *n* = number of comparators; CI – Confidence interval; *Q betw* = Homogeneity statistics across subgroups.

8.4 Discussion

This review extends Study One by providing an updated appreciation of the evidence base for psychological or psychosocial interventions that specifically target depression or anxiety experienced by informal carers of people with chronic physical health conditions. The updated meta-analysis found a small-to-medium effect size for depression (Hedges' $g = -0.25$) and a medium-to-large effect size for anxiety (Hedges' $g = -0.64$ and -0.69), similar to the findings in the original review. The trend for treatments targeting depression delivered individually to have larger effect sizes than those delivered in group settings remains. This provides further support for the development of an individually delivered CBT self-help intervention within this thesis.

Furthermore, there was a trend for treatments delivered face-to-face to be more effective than those delivered over the telephone. This finding is in contrast to other findings in the general mental health population literature. No differences have been reported for low intensity CBT treatments delivered over the telephone compared to face-to-face for depression or anxiety in IAPT services unless patients had high levels of symptom severity, when face-to-face treatment was more effective (Hammond et al., 2012). Further, a recent systematic review and meta-analysis of CBT self-help interventions found larger effect size associated with telephone delivery (Farrand & Woodford, 2013). Findings are similar for traditional CBT delivered over the telephone in comparison with face-to-face treatment for depression (Mohr et al., 2012) and meta-analytic results show promise for telephone delivered CBT for depression and anxiety (Bee et al., 2008). However, currently few studies of varying quality exist examining the efficacy of telephone delivered psychological therapy (Bee et al., 2008) and user acceptability has been found to be heterogeneous (Bee, Lovell, Lidbetter, Easton, & Gask, 2010). Given the smaller effect size for telephone support found in this present review, coupled with low levels of acceptability for telephone support found in Study Six (feasibility RCT) the efficacy and acceptability of telephone delivered interventions for informal carer populations warrant further investigation. Furthermore, future research should be conducted to examine whether face-to-face interaction is an important component for supporting informal carers or those with chronic physical health conditions.

Interesting, shorter treatment session duration was significantly associated with larger effect sizes coupled with a trend for treatments with fewer sessions being more effective than treatments with larger numbers of sessions. Again, this supports

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the choice of a CBT self-help approach which is characterised by sessions that are typically short in duration (Richards & Whyte, 2011) with an average of 5.4 sessions being provided to support patient recovery within the IAPT programme (Richards & Borglin, 2011). Such findings are similar to a recent meta-analysis indicating that less therapist contact time is associated with larger effect sizes for CBT delivered to people with chronic physical health conditions for the reduction of physical health symptoms (Muller & Yardley, 2011). Furthermore, there have been calls for stroke carer interventions to give more consideration to the required dosage of sessions as a large number of treatment sessions may not be feasible for informal carers with very little time (Bakas et al., 2014).

With respect to anxiety, the results of the review highlight a medium-to-large effect size, similar to transdiagnostic CBT based interventions for anxiety (Reinholt & Krogh, 2014). However, the effect size for depression remains less encouraging than meta-analyses examining depression interventions in the general population (e.g., Cuijpers et al., 2007a; Ekers et al., 2014; Farrand & Woodford, 2013). However, as found in Study One, none of the additional studies recruited participants meeting diagnostic criteria for major depressive disorder, with the 6 additionally included studies recruiting participants with subclinical or mild levels of depressive symptoms. Consequently, the studies included within the updated meta-analysis remain at risk of floor effects (Linden & Satin, 2007). The decision to recruit participants with elevated symptoms of depression and meet diagnostic criteria for major depressive disorder within the feasibility RCT within this thesis (Study Six) was therefore supported.

It is of further importance to highlight that although type of psychological intervention was not a significant moderator, the pooled effect sizes for interventions including skill building and problem solving components such as CBT (Hedges' $g = -0.31$); behavioural therapy (Hedges' $g = -0.28$) and problem solving (Hedges' $g = -0.34$) yielded larger effect sizes than purely psychoeducational (Hedges' $g = -0.12$) and psychosocial support (Hedges' $g = -0.01$). As such, the updated review further supports the decision to develop a CBT self-help intervention utilising active skill building components such as behavioural activation, goal setting and problem solving.

The methodological quality of the additional studies within the revised systematic review and meta-analysis was higher than those included in Study One.

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Sample sizes within the studies added to the updated review were larger, with all but one study calculating a power calculation. Indeed the 6 new studies provided an additional 957 participants for inclusion in the analysis, compared with the original sample size of 1,070 (on the basis of ≤ 6 month outcomes). In addition, risk of bias was lower with studies more likely to report adequate randomisation allocation, blinding of data analyses and lower levels of attrition. As such, the updated review suggests that the quality of informal carer psychological research is improving. This is possibly responding to the commonly cited limitation of the carer intervention literature pertaining the poor quality of evidence (e.g., Bakas et al., 2014; Brereton et al., 2007; Cheng et al., 2014; Selwood et al., 2007) and increased adherence to trial reporting guidelines increasingly requested by journal editors (Turner, Shamseer, Altman, Schulz, & Moher, 2012).

Finally, it is important to note that all 6 additional studies added to the updated review were psychological interventions for informal carers of dementia patients (Au et al., 2014; Bruvik et al., 2013; Garland et al., 2014; Livingston et al., 2013; Martindale-Adams et al., 2013; Tremont et al., 2014). Two psychological interventions for carers of stroke survivors were identified in the search, however both utilised active control comparators whereas only studies comparing interventions with inactive controls (treatment-as-usual, wait list control, attention control) were eligible for inclusion. We therefore excluded these from the analysis (Ostwald et al., 2014; Pfeiffer et al., 2014). As such, to-date there have been no RCTs using non-active treatment controls of psychological treatments specifically targeting depression or anxiety in informal carers of stroke survivors except the feasibility RCT conducted as part of this thesis.

Overall, this updated meta-analysis provides tentative support for the psychological treatment of depression in informal carers of people with chronic physical health conditions, with some evidence to suggest effectiveness for the treatment of anxiety. Importantly, trends in the data continue to provide cautious support for the choice of intervention components utilised within the CBT self-help intervention developed as part of this thesis. Furthermore, it highlights that more recent informal carer interventions are failing to target informal carers meeting diagnostic criteria for common mental health difficulties or clinical levels of depressive or anxious symptoms. Finally, the updated review indicates that to the best of the researcher's knowledge no other RCTs examining psychological

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treatments that specifically target depression in informal carers of stroke survivors has been conducted to date.

CHAPTER NINE: General Discussion

9.1 Background

The final chapter presents a general discussion of the thesis as a whole and aims to:

- Provide a summary of the thesis as a whole.
- Discuss the overall limitations of the research.
- Appreciate the possible clinical implications of the findings.
- Provide an overview of potential future research directions in consideration of the revised MRC guidelines for the development of complex interventions (MRC, 2008).
- Draw overall conclusions pertaining to the research informing this thesis.

9.2 Thesis Summary

Overall this thesis presents a series of six separate but interrelated studies informed by the development, feasibility and pilot phases of the revised MRC framework (MRC, 2008). The aim of these studies being to develop and pilot a CBT self-help intervention for depressed informal carers of stroke survivors. The development phases encompassed four studies in order to:

- (a) Identify the existing evidence base;
- (b) Develop and identify appropriate theory to inform the components of the intervention;
- (c) Modelling the intervention.

A feasibility RCT was then conducted to examine uncertainties pertaining to the feasibility and acceptability of the proposed intervention. Finally, an updated systematic review and meta-analysis was conducted to place the research in current context. The findings of each chapter will now be summarised.

9.2.1 Chapter One

This chapter sets the scene for the thesis. The research is placed in the context of worldwide increasing life expectancy (Christensen et al., 2009), the concomitant growth in people with chronic physical health conditions (High, 2014) and resultant reliance on informal carers within the community (Levine et al., 2010; Wakefield et al., 2012). The significant burden experienced by informal carers (Forster et al., 2014) with one-in-three experiencing depression or anxiety (Davies, 1995) is discussed alongside the increased burden experienced by informal carers

providing support to care recipients with cognitive, behavioural and emotional impairment (van den Heuvel et al., 2001), which are all common post-stroke impairments. However, the chapter also outlines that the long-term emotional needs of informal carers have been neglected (Silva et al., 2013) and informal carers experience significant barriers to accessing support (Arksey & Hirst, 2005). As such, CBT self-help was proposed as a potential solution due to: (a) a well-established evidence base (Coull & Morris, 2011; Farrand & Woodford, 2013; Gellatly et al., 2007); (b) global implementation (Clark, 2001; Pilgram & Carey, 2012; Rebello et al., 2014); and (c) flexible and accessible delivery (Bennett-Levy, Richards & Farrand, 2011). Finally the potential need to adapt existing CBT self-help interventions to increase acceptability for specific patient populations (Farrand & Woodford, in press; Hind et al., 2009) and tailor support to the unique difficulties experienced by informal carers (Krevers & Öberg, 2011) was outlined. Overall Chapter One established the rationale underlying the development of a new CBT self-help intervention for informal carers of stroke survivors.

9.2.2 Chapter Two

A detailed overview of the methodological approaches adopted within the thesis was presented in order to follow the revised MRC framework (MRC, 2008) guidance concerning the development of complex interventions. The main methodological approaches (systematic review and meta-analysis; semi-structured qualitative interviews; thematic analysis; intervention modelling and feasibility RCT) utilised within the thesis were described in detail, alongside justification for their use.

9.2.3 Chapter Three

The methodology and findings of Study One, a systematic review and meta-analysis of psychological and psychosocial interventions for depressed and anxious informal carers of people with chronic physical health conditions are presented. Study One was conducted as the first stage of the development phase of the revised MRC framework (MRC, 2008) in order to identify the existing evidence base. Furthermore, the review aimed to identify potential components associated with increased effectiveness to further inform the development of the intervention (Greaves et al., 2011). Study One identified evidence to support the use of psychological and psychosocial interventions for the treatment of anxiety and cautious support for the treatment of depression in informal carers of people with chronic physical health conditions. However, the review also highlighted several

significant limitations of the current evidence base, including the potential of floor effects due to recruiting informal carers with subclinical levels of depression; small sample sizes and poor reporting of study design. Some support was found in terms of developing a psychological intervention for carers that included skill-building components such as CBT, problem solving and behavioural activation, that is delivered individually rather than in group setting and comprises of shorter overall treatment duration.

9.2.4 Chapter Four

The methodology and results of Study Two are reported. Study Two was conducted within the second stage of the development phase of the revised MRC framework (MRC, 2008) in order to identify appropriate theories to further inform the development. Semi-structured qualitative interviews were held with depressed and anxious informal carers of stroke survivors in order to understand the specific difficulties and challenges experienced as well as barriers to accessing appropriate support. Thematic analysis (Braun & Clarke, 2006) revealed that carers experienced significant difficulties with adapting to the caring role including uncertainty and lack of social and professional support. Literature was reviewed to identify appropriate psychological techniques that could be implemented within the CBT self-help intervention to target the unique difficulties experienced by depressed informal carers of stroke survivors. In particular goal adaptation and setting, behavioural activation and problem solving featured prominently in this literature review.

9.2.5 Chapter Five

The methodology and findings of Study Three are presented. Study Three further informed the development phase of the revised MRC framework (MRC, 2008) and was designed to further identify appropriate theories to enhance the new CBT self-help intervention. Study Three adopted a positive psychology approach (Boiler et al., 2013; Layous et al., 2014; Mitchell et al., 2009) by identifying positive coping strategies utilised by non-depressed and non-anxious informal carers of stroke survivors through semi-structured interviews. Thematic analysis (Braun & Clarke, 2006) revealed that non-depressed and non-anxious carers of stroke survivors adopted a variety of active and adaptive coping strategies. Strategies included adapting goals, striking a balance between the routine of caring and other activities of value and importance, actively seeking social support and the benefits of social comparison and assertiveness with both the stroke survivor and health and social

care organisations. Results supported the use of goal adapting and setting, behavioural activation and problem solving within the intervention. However findings also identified that the intervention should place emphasis on encouraging informal carers to increase levels of social support. For example, by engaging in community based organisations.

9.2.6 Chapter Six

Study Four, the final study encompassing the development phase of the revised MRC framework (MRC, 2008), is presented in Chapter Six. Study Four represented the modelling phase, utilising a comprehensive iterative process, drawing upon the results of Study One, Two and Three, in order to develop the specific CBT self-help materials and accompanying PWP assessment, support and training protocol. A self-help intervention was developed by adapting existing CBT self-help materials on the basis previous study findings, as well as working closely with a lived experienced steering committee, a professional design company and also comprehensively integrating common factors (Cahill et al., 2008) associated with improved therapy outcome (Lambert & Barley, 2002; Martin et al., 2000; Norcross, 2002; Shirk & Karver, 2003).

9.2.7 Chapter Seven

The research programme moved on from development into the feasibility phase of the revised MRC framework (MRC, 2008). This chapter reports on findings from the feasibility RCT trial conducted to examine the feasibility of trial design, associated trial procedures and the acceptability of the CBT self-help intervention. Significant difficulties were experienced in relation to recruitment, high levels of attrition in the intervention arm, minimal acceptability data, poor PWP adherence to trial protocols and problems conducting the trial within IAPT services. Potential reasons for poor recruitment include lack of GP recognition; gatekeeping by health care professionals; barriers to accessing support experienced by informal carers of stroke survivors; and the over estimation of prevalence rates of depression. As such, Chapter Seven concluded that moving into a Phase III RCT is not feasible or justified at this present time.

9.2.8 Chapter Eight

Chapter Eight placed the findings of Studies One to Seven in the context of an updated systematic review and meta-analysis. The updated systematic review and meta-analysis provided further support for the intervention components utilised in the

treatment (e.g., CBT, problem solving, behavioural activation, fewer treatment sessions, shorter session duration). Finally, the researcher will discuss the overall strengths and limitations of the methodological approaches utilised within the thesis, discuss clinical implications and outline a series of recommendations for future research.

9.3 Strengths of the Thesis

A significant strength of this thesis was embedding the programme of research within the revised MRC framework (2008). The iterative, flexible process guiding intervention development enabled the researcher to develop an evidence and theory based intervention that was further enhanced by the difficulties identified by informal carers of stroke survivors that needed to be targeted by the intervention. As such an intervention that was both driven by empirical evidence and patient centeredness was successfully developed. The modelling process allowed clear mapping of the key intervention components to enable evaluation in the future (Bradshaw et al., 2012). Furthermore, utilising a structured, theoretically driven, approach to development also facilitated the development of treatment manuals, therapist protocols, therapist training programme and a comprehensive therapist training programme that is associated with the increased likelihood of successful implementation into clinical practice (Bradshaw et al., 2012).

A further strength of this PhD was both starting and ending with a systematic review and meta-analysis. New research should not be embarked upon without taking into account evidence from existing relevant systematic reviews, or conducting a new one (Chalmers & Glasziou, 2009; Clark & Horton, 2010). Additionally, all new research should be presented in the context of an updated systematic review in order to allow the relevance of findings to be judged by readers (Chalmers & Glasziou, 2009). The initial systematic review and meta-analysis (Study One) justified conducting the research (Clarke et al., 2010) by identifying that the existing evidence base for psychological interventions for carers is methodologically poor and to date, no psychological interventions specifically targeting depression in informal carers of stroke survivors have been conducted. The updated review placed the programme of research conducted for this thesis in context, providing further justification for the treatment components utilised with the intervention. Furthermore, the updated review highlighted that no other RCTs

examining psychological interventions for depressed carers of stroke survivors have been conducted to date.

Additionally, this PhD actively involved patients in the development of the CBT self-help intervention. The importance of involving patients in the development of health research is well documented (Gagnon et al., 2011). First, this programme of research derived patient perspectives primarily through qualitative research. This was to understand: (a) the specific difficulties and challenges experienced by depressed and anxious informal carers of stroke survivors; (b) barriers to accessing support for difficulties; and (c) positive coping strategies utilised by non-depressed and non-anxious informal carers of stroke survivors. Such an approach resulted in the development of an intervention of relevance to informal carers; specifically targeting difficulties experienced being a carer of a stroke survivor. This helps to overcome previous criticism that psychological interventions are not tailored to the unique difficulties experienced by informal carers (Krevers & Öberg, 2011). It is essential that the content of interventions is relevant to users in order to increase engagement (Macdonald et al., 2007; Whittaker et al., 2012). Second, a lived experience steering committee was consulted during the intervention development process in order provide feedback on the design and content of the intervention materials, further enhancing the patient-centred nature of development.

Furthermore, Study Four presented a systematic and structured approach to modelling relevant evidence based and theory driven intervention components to adapt existing CBT self-help approaches. Currently there is little guidance in terms of how to approach the development of complex interventions in a theory informed and structured way (Procheret et al., 2014). The approach used in Chapter Four may represent a model that could be used within future CBT self-help approach adaptations for other populations. Furthermore, this approach overcomes some of the previous criticism of the informal carer intervention research would not grounding interventions in theory (Gallagher-Thompson & Coon, 2007).

Research is often considered 'wasteful' due to lack of consideration regarding essential elements of trial design and procedural factors (Chalmers & Glasziou, 2009) with many trials failing to achieve their goals (Vickers, 2014). A clear strength of this programme of work was the undertaking of a feasibility RCT, designed to reduce the risk of conducting evaluation studies of unacceptable, unfeasible and poorly designed interventions (Faes et al., 2010). Indeed, Study Five clearly

highlighted that the movement to Phase Three (evaluation) of the revised MRC framework (MRC, 2008) is not currently justified. However, the difficulties experienced within the feasibility RCT have raised important future questions concerning GP recognition; professional gatekeeping; barriers to accessing support and the acceptability of a CBT self-help intervention for depressed informal carers of stroke survivors. These will be discussed in more depth later in this chapter under future recommendations for research.

9.4 Limitations of the Thesis

Specific limitations of each study conducted have been addressed throughout. As such the researcher will now focus on the most significant limitations of the thesis as a whole.

The first limitation is concerned with the development of the CBT self-help intervention. Although the identification of informal carer difficulties and positive coping strategies to be targeted by the intervention was achieved through qualitative interviews in Study Two and Three, the selection of intervention techniques and adaptation of the intervention was informed by expert knowledge, rather than taking a systematic intervention mapping approach (Michie, Johnston, Francis, Hardeman, & Eccles, 2008). A more systematic approach could have been adopted by systematically mapping the difficulties and positive coping strategies to be targeted by the intervention, and then to systematically identify all psychological theories and associated behavioural change (intervention) techniques that could target these identified constructs (Michie & Prestwich, 2010). An alternative approach would have been to map the CBT self-help intervention post-development and identify all behavioural change techniques that are utilised within the programme. By failing to utilise a comprehensive mapping approach not all of the mechanisms that may affect treatment outcomes were identified (Schulz et al., 2010). Future research could utilise intervention mapping, whereby the developed CBT self-help intervention could be mapped onto known behaviour change techniques (Michie et al., 2008; Michie & Prestwich, 2010). Both approaches were out of scope for the PhD given time constraints.

Additionally, although a small lived experience steering committee was established to inform the development of this programme of research, it was not possible to seek their involvement until the study had started and the protocol developed. Furthermore, one carer became chronically ill during the study and

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involvement was limited to email correspondence. As such, a more comprehensive model of public involvement could have been adopted whereby a partnership with the public was developed prior to embarking on the research with in-depth consultation and collaboration throughout the programme of research (Kaltoft et al., 2014). Indeed, poor engagement of participants and healthcare professionals in developing research questions led to inappropriate intervention design and trial design (Chalmers & Glasziou, 2009). As such enhanced public involvement in terms of the identification of important research questions, designing the intervention as well as managing and undertaking some elements of the research (Fitzgibbon, Baille, Simon, & Nelson, 2014) may have resulted in the development of a more acceptable intervention for depression in informal carers of stroke survivors.

The final limitation relates to the researcher adopting an intrapsychic (individualistic) approach, common in psychology. This is opposed to a macro-socio approach taken with sociology that emphasises the importance of appreciating the wider social systems of the population of interest (Côté, & Schwartz, 2002). A sociological approach to mental health postulates that wellbeing is influenced by the underlying structural and social processes of a community (Pearlin, 1989). For example, mental health is influenced by wider factors such as inequality, the historical and political context and economics (Horwitz, 2007). As such, the underlying social conditions of a population either enhance or impact negatively on psychological wellbeing (Horwitz, 2007). Indeed, the individualistic approach to the development of self-management interventions in chronic illness (e.g., Lorig et al., 2001) has been criticised for failing to appreciate social variables that impact on the experience of living with a chronic physical health condition (Newbould, Taylor, & Bury, 2006). Consequently, there have been calls for a greater appreciation of the sociological and economic characteristics of a community in order to develop acceptable and effective treatment for people with chronic physical health conditions (Newbould, Taylor, & Bury, 2006).

Indeed, this programme of research clearly highlighted in Study Two that informal carers struggled with accessing practical, medical and financial support. Furthermore, reasons for non-participation provided in Study Seven echo difficulties with accessing support calling for more practical, financial and health care support. This reflects the general literature highlighting the fragmented nature of health and social care within the UK (Ling et al., 2012). This PhD was conducted between 2011

and 2014. During this time significant political changes occurred to the detriment of welfare support provision, such as the abolition of community care grants and the Welfare Reform Act (Parliament (2012) that made significant cuts to social security payment and placed additional restrictions in eligibility and level of carers allowance (Carers UK, 2014). The financial impact of caring is significant with 45% and 44% of carers cutting down on essential food and heating respectively, 19% unable to afford rent and mortgage payments, 44% ended up in debt to pay basic bills and 53% report that money worries were effecting their health (Carers UK, 2014). As such, taking the social-political context into consideration may resulted in a greater understanding of potential barriers to accessing care, priorities for providing support carers and the development of a more acceptable intervention. Neglect of the social-political context may also relate to adopting the revised MRC framework (MRC, 2008). Criticisms of the framework relate to its focus on intervention specific components (e.g., intervention content, mode of delivery, dosage) with limited focus on other important social, human, political and other contextual components (Clark, 2013; MacKenzie, O'Donnell, Halliday, Sridharan, & Platt, 2010).

9.5 Future Research Directions

The revised MRC framework (MRC, 2008) is designed to be iterative as well as phased (Craig & Petticrew, 2013). As such, the framework allows researchers to move backwards and forwards within the cyclical process of the MRC framework (Faes et al., 2010). Findings from the feasibility RCT (Study Five) clearly indicated a decision to stop, rather than to progress to a Phase III RCT at this time (Thabane et al., 2012). However, rather than abandoning the research programme in its entirety the framework allows researchers to move back to previous phases, reflecting on what has been learnt and how the research can be moved forward. The researcher will now discuss some of the potential research directions informed by this programme of research.

Study Five revealed a number of significant barriers to accessing support experienced by informal carers of stroke survivors, as indicated by the poor recruitment rate and reasons for non-participation. Although research exists relating to barriers to accessing support in general primary care services experienced by informal carers (Arksey et al., 2003; Arksey & Hirst, 2005) to the best of the researcher's knowledge there have been no research studies conducted to date aimed at understanding the specific barriers carers may experience accessing

support for depression. As such, future research could return to the development phase of the revised MRC framework (MRC, 2008) in order to examine barriers to accessing support for depression in more detail. An investigation of potential barriers to seeking help for mental health difficulties experienced by informal carers of stroke survivors could inform the development of an approach that may encourage informal carers to accept support for their difficulties (Cameron et al., 2011).

A further future research question concerns whether depression should be the target of a psychological intervention for carers of stroke survivors. As highlighted in both Study One (Chapter Three) and Study Six (Chapter Eight), existing studies examining psychological treatments for informal carers have not targeted a depressed carer population. Given the significant difficulties recruiting informal carers into this trial, further research needs to be conducted to examine whether depression is an appropriate target for carer psychological intervention research. One potential way forward would be to develop a positive psychology intervention, aimed at increasing psychological wellbeing (Schueller, Kashdan, & Parks, 2014). Instead of focusing on reductions in depression or levels of distress positive psychological interventions focus on building positive outcomes, as opposed to reducing negative outcomes (Schueller et al., 2014). Future research could seek to ground informal carer interventions within a positive psychological intervention framework that would be hypothesised to overcome barriers to accessing support such as lack of recognition of depressive symptoms (Woodford et al., 2011) and stigma (Keeley, West, Tutt, & Nutting, 2014; Schomerus, Matschinger, & Angermeyer, 2009; Thornicroft & Tansella, 2014). Further research could also examine the acceptability of different treatment settings, for example, basing intervention in community organisations and social support networks may be more acceptable than accessing support within mental health service (McClay, Morrison, McConnachie, & Williams, 2013).

An additional area of future research is concerned with the clear finding in study Two (Chapter Four) that informal carers of stroke survivors experience significant difficulties adapting to the caring role, associated with feelings of loss for both the stroke survivor and previous life roles. Loss of the stroke survivor was associated with post-stroke complications such as personality changes, emotional difficulties and communication impairment. A growing area of interest within the dementia informal carer literature concerns the experience of anticipatory grief,

estimated to be experienced by between 47% and 71% of informal dementia carers (Chan, Livingston, Jones, & Sampson, 2013). Anticipatory grief is concerned with losses that have occurred, losses that are occurring in the present and losses that are anticipated in the future (Frank, 2008). As such, informal carers of dementia patients are hypothesised to experience more significant feelings of loss than informal carers of people with other chronic physical health conditions (Frank, 2008). A related concept is that of ambiguous loss (Boss, 1999), for example the person is physically present but psychologically absent. The experience of anticipatory grief and ambiguous loss has been posited as key difficulties experienced by informal carers of dementia patients (Frank, 2008). As such, a further area for potential future research is to examine whether anticipatory grief and ambiguous loss are experienced by informal carers of stroke survivors, given the cognitive, communication and emotional, and personality changes common post-stroke. If found to be a difficulty also experienced by informal carers of stroke survivors there is the possibility that an IPT approach for depression, whereby the focus of treatment is on interpersonal problems, such as grief, role transition, relationship difficulties or social isolation (Lipsitz & Markovitz, 2013), may represent a suitable way of supporting informal carers of stroke survivors.

9.6 Clinical Implications

In accordance with the evidence-based medicine approach it is important that research evidence should inform clinical decisions concerning patient care (Sackett, Rosenberg, & Gray, 1996). Although the new CBT self-help intervention was not found to be acceptable or feasible there are still clear implications concerning clinical practice and healthcare policy arising from the research programme.

Findings from Study Five (Chapter Seven) indicate lack of GP recognition of informal carers of stroke survivors, a finding supported by previous research (e.g., Greenwood et al., 2010; 2011). Given the high levels of burden, strain and mental health difficulties experienced by informal carers of stroke survivors (Rigby et al., 2009; Visser-Meily et al., 2008) clear guidelines should be developed to help general practitioners recognise, record, and provide access to appropriate support services to informal carers of stroke survivors.

A further implication for clinical practice relates to the significant barriers to accessing support experienced by informal carers of stroke survivors. Health professionals working with informal carers of stroke survivors, or their care

recipients, should be made aware of these significant barriers in order to attempt to provide support that recognises and takes account of these barriers in order to improve access to support.

Finally, results from the systematic review and meta-analysis indicate cautious support for the use of CBT and IPT based psychological interventions for depressed and anxious informal carers. As such, there should more efforts to translate psychological interventions for depressed and anxious informal carers into existing care systems.

9.7 Conclusions

This research programme suggests that despite the high prevalence of emotional difficulties experienced by informal carers of stroke survivors little is currently known concerning what an acceptable psychological intervention for carers of stroke survivors might look like. This PhD has highlighted significant barriers to informal carers accessing support to mental health interventions. Future research should focus on gaining an in-depth appreciation of barriers to accessing support for mental health difficulties; approaches to increasing help-seeking behaviour and the development of acceptable interventions. As such, the research programme informing this PhD has made a significant contribution to the literature in terms of starting to outline significant feasibility issues concerned with working with an informal stroke carer population that can be used to directly inform future research directions in the field.

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APPENDICES

Appendix 3.1: Ovid MEDLINE search strategy

Ovid MEDLINE(R) 1946 to September Week 4 2012

Search Conducted 10th October 2012

- 1 caregivers/ (18,698)
- 2 (carer\$ or caregiver* or care giver\$ or care-giver\$ or caregiver-oriented or relative* or family or families or spouse\$ or husband\$ or wife or wives or partner\$ or parent\$ or mother\$ or father\$ or adult\$ or dyad\$).ti,ab. (2,306,260)
- 3 exp parents/ (65,102)
- 4 family/ (57,951)
- 5 1 or 2 or 3 or 4 (2,341,496)
- 6 (caring or caregiv\$ or care-giv\$ or looking after or long term care or caring for or living with or at home or home car\$ or family support\$ or family car\$ or families living or informal car\$).ti,ab. (112,905)
- 7 5 and 6 (60,286)
- 8 exp Counseling/ (30,688)
- 9 exp Cognitive Therapy/ (13,525)
- 10 exp Behavior Therapy/ (47,698)
- 11 exp Psychotherapy/ or exp Psychotherapy, Multiple/ or exp "Imagery (Psychotherapy)"/ or exp Psychotherapy, Group/ or exp Psychotherapy, Brief/ or exp Psychotherapy, Rational-Emotive/ (141,550)
- 12 exp Bibliotherapy/ (311)
- 13 cognitive restructuring.ti,ab. (463)
- 14 cognitive reframing.ti,ab. (51)
- 15 behavio\$ activation.ti,ab. (911)
- 16 activity scheduling.ti,ab. (14)
- 17 problem solving.ti,ab. (10,311)
- 18 (cCBT or iCBT or computer\$ or online or ehealth or e-health or telephone or teletherapy or telehealth or technology).ti,ab. (380,124)
- 19 (Selfhelp or self help or selfmanag\$ or self manage\$ or selfadminister\$ or self administer\$).ti,ab. (29,744)
- 20 (cognitive or CBT or behavio\$ or therap\$ or psychotherapy or psychodynamic or counseling or counselling or group or treatment\$ or intervention\$ or program\$ or

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psychoeducation or psycho education or education or training or manag\$ or support\$ or psychosocial or rehabilitation).ti,ab. (6,456,654)

21 8 or 9 or 10 or 11 or 12 or 13 or 14 or 15 or 16 or 17 or 18 or 19 or 20 (6,699,948)

22 exp Depression/ (67,563)

23 exp Depressive Disorder/ (74,735)

24 (depression or depressive or depressed or melancholi\$ or dysphori\$ or dysthymi\$ or low mood).ti,ab. (256,054)

25 exp Anxiety/ (49,977)

26 exp Anxiety Disorders/ (61,318)

27 (anxiety or anxious or stress or worry).ti,ab. (447,272)

28 22 or 23 or 24 or 25 or 26 or 27 (715,625)

29 7 and 21 and 28 (8,234)

30 exp Randomized Controlled Trial/ (338,627)

31 exp Clinical Trial/ (699,240)

32 meta-analysis/ (36,848)

33 "review"/ (1,742,840)

34 Random Allocation/ (76,053)

35 (randomi?ed controlled trial\$ or RCT or random allocation or randomly allocated or allocated randomly or trial or systematic review or review or meta-analysis).ti,ab. (1,043,085)

36 30 or 31 or 32 or 33 or 34 or 35 (2862890)

37 29 and 36 (2,314)

Appendix 3.2: Data extraction form

Study Identification Features		
Unique Study Identifier		
Title		
Authors		
Year of Publication		
Citation		
Publication Type		
Country of Origin		
Funding Source		
Study Characteristics		
Aims and Objectives		
Design		
Inclusion/Exclusion Criteria		
Recruitment		
Randomisation	Sequence Generation	
	Type	
	Allocation Concealment	
	Implementation	
Blinding	Data Collectors	
	Data Analysts	
Participant Characteristics		
Mental Health Condition		
Method of Assessment / Diagnosis of Depression		
Method of Assessment / Diagnosis of Anxiety		
Severity of Depression at Baseline		
Severity of Anxiety at Baseline		
Age		

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Ethnicity	
Length of time caring	
Relationship to Care Recipient	
Receipt of Formal Care in the Home	
Physical Health Condition of Care Recipient	
Age of Care Recipient	
Severity of Physical Health Condition of Care Recipient	
Intervention Components	
Theoretical Components	
Behaviour Change Techniques	
Mode of Delivery	
Clinician Delivering Treatment	
Duration of Treatment	
Number of Sessions	
Length of Sessions	
Treatment Setting	
Type of Control Condition	
Outcome Measurements	
Primary Outcome Measurements	
Name of Primary Outcome Measurement	
Quality of Primary Outcome Measurement	
Length of Follow-up	
Secondary Outcome Measurements	
Name of Secondary Outcome Measurement	
Quality of Secondary Outcome Measurements	
Length of Follow-up	

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Statistical Techniques		
Power Calculation		
Method of Dealing with Missing Data		
Baseline Comparability		
Participant Flow		
Randomised to Intervention		
Randomised to Control		
Lost to Follow-Up Intervention ¹		
Lost to Follow-Up Control ¹		
Analysed Intervention ²		
Analysed Control ²		
Results³		
Intervention	Outcome Measurement	
	Pre-Treatment Means	
	Pre-Treatment Standard Deviation	
	Pre-Treatment Number Analysed	
	Post-Treatment Means	
	Post-Treatment Standard Deviation	
	Post-Treatment Number Analysed	
Control	Outcome Measurement	
	Pre-Treatment Means	
	Pre-Treatment Standard Deviation	
	Pre-Treatment Number Analysed	
	Post-Treatment Means	
	Post-Treatment Standard Deviation	
	Post-Treatment Number Analysed	
Additional Comments		

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¹Numbers lost to follow-up to be reported at each time point measured; ²Numbers analysed to be reported for each time point measured; ³Results to be extracted for each primary outcome measurement at each follow-up time point

Appendix 3.3: Full dissertations not reviewed

Authors	Year	Citation
Arguello	2005	Dissertation Abstracts International: Section B: The Sciences and Engineering. Vol.65(10-B),2005, pp. 5386.
Beck	2001	Dissertation Abstracts International: Section B: The Sciences and Engineering. Vol.61(10-B), Apr 2001, pp. 5551.
Cakov	2003	Dissertation Abstracts International: Section B: The Sciences and Engineering. Vol.63(10-B), Apr 2003, pp. 4892.
Lancer	2007	Dissertation Abstracts International: Section B: The Sciences and Engineering. Vol.68(3-B),2007, pp. 1931.
Lindstrom Bremer	2007	Dissertation Abstracts International Section A: Humanities and Social Sciences. Vol.68(6-A),2007, pp. 2676.
Lindstrom	2010	Dissertation Abstracts International: Section B: The Sciences and Engineering. Vol.71(6-B),2010, pp. 3596.
Mccartney	2008	Dissertation Abstracts International: Section B: The Sciences and Engineering. Vol.69(2-B),2008, pp. 1334.
Varona	2001	Dissertation Abstracts International: Section B: The Sciences and Engineering. Vol.61(8-B), Feb 2001, pp. 4434.
Woods	2008	Dissertation Abstracts International Section A: Humanities and Social Sciences. Vol.68(9-A),2008, pp. 4021.

Appendix 3.4: Studies in language other than English not reviewed

Authors	Language
Ferre-Grau et al., 2012	Spanish
Fuillerat, 2012	Spanish
Geschke et al., 2012	German
Guerrero Caballero et al., 2008	Spanish
Hori et al., 2009	Japanese
Imanipour, Heydari, Seyedfatemi, & Haghani, 2012	Farsi
Losada Baltar, Izal Fernández de Trocóniz, Montorio	Spanish
Cerrato, Márquez González, & Pérez Rojo, 2004	
Sta'm-Rad, Montani, & L'association des	French
Psychologues en Gérontologie (Apsygé), 2009	
Van Heugten, Visser-Meily, & Beusmans, 2006	Dutch
Yoo, Jeon, & Yang, 2007	Korean

Note. Please see references for full citations

Appendix 3.5: Detailed reasons for study exclusion and study citations

No	Authors, year	Reason for exclusion
1	Mahoney, Tarlow, & Jones, 2003	Inappropriate comparator
2	Gallagher-Thompson, Gray, Dupart, Jimenez, & Thompson, 2008	Inappropriate comparator
3	Toseland, Rossiter, Peak, & Smith, 1990	Inappropriate comparator. Pseudo-randomised controlled trial.
4	Hebert et al., 2003	Inappropriate comparator
5	Joling et al., 2012	Aim to prevent depression or anxiety. Those meeting diagnosis for depression or anxiety excluded.
6	Aakhus, Engedal, Aspelund, Selbaek, 2009	Care recipients are not restricted to those with a chronic physical health condition
7	de Rotrou et al., 2011	Carers excluded if they suffered from major anxiety or depression, although reduction in depressive symptoms the primary aim of the intervention
8	Monti, Vanacore, Bartorelli, & Giubilei, 2012	Conference proceedings, authors unwilling to share data
9	Park, Sung, Lee, & Park, 2012	Conference proceedings, authors unwilling to share data
10	Nichols et al., 2008	Cost-effectiveness only paper
11	Brodaty, Gresham, & Luscombe, 1997	Depression and / or anxiety are not the primary target of the intervention or measured.
12	Carter, 2006	Depression and / or anxiety are not the primary target of the intervention. Depressive symptoms are measured as a distal outcome.
13	Mittelman, Ferris, Shulman, Steinberg, & Levin, 1996	Depression and / or anxiety are not the primary target of the intervention. Depressive symptoms are measured as a distal outcome. Active control
14	Mittelman et al., 1993	Depression and / or anxiety are not the primary target of the intervention. Depressive symptoms are measured as a distal outcome. Active control
15	A'Campo, Wekking, Spliethoff-Kamminga, Le Cessie, & Roos, 2010	Depression and / or anxiety are not the primary target of the intervention. Depression is measured as a distal outcome.
16	Forster & Young, 1996	Depression and / or anxiety are not the primary target of the intervention or measured.
17	Clark, Rubenach, & Winsor, 2003	Depression and / or anxiety are not the primary target of the intervention or measured.
18	Pakenham, Dadds, & Lennon, 2002	Depression and / or anxiety are not the primary target of the intervention or measured.
19	Perren, Schmid, & Wettstein, 2006	Depression and / or anxiety are not the primary target of the intervention or measured.

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20	Nobili et al., 2004	Depression and / or anxiety are not the primary target of the intervention.
21	Stolley, Reed, & Buckwalter, 2002	Depression and / or anxiety are not the primary target of the intervention.
22	Huang, Shyul, Chen, Chen, & Lin, 2003	Depression and / or anxiety are not the primary target of the intervention.
23	Hinchliffe, Hyman, Blizard & Livingston, 1995	Depression and / or anxiety are not the primary target of the intervention or measured.
24	Gitlin, Winter, Dennis, Hodgson, & Hauck, 2010	Depression and / or anxiety are not the primary target of the intervention. Depression is measured as a distal outcome.
25	Gitlin et al., 2008	Depression and / or anxiety are not the primary target of the intervention. Carer depressive symptoms are examined as a potential moderator only.
26	Gitlin, Corcoran, Winter, Boyce, & Hauck, 2001	Depression and / or anxiety are not the primary target of the intervention or measured.
27	Gitlin, Hauck, Dennis, & Winter, 2005	Depression and / or anxiety are not the primary target of the intervention or measured. Long term follow up of Gitlin et al., 2003.
28	Guerra, Ferri, Fonseca, Banerjee, & Prince, 2011	Depression and / or anxiety are not the primary target of the intervention or measured.
29	Zanettia, Metitiera, Bianchettia, & Trabucchia, 1998	Depression and / or anxiety are not the primary target of the intervention. Depression is measured as a distal outcome. Not a randomised controlled trial.
30	Gitlin et al., 2003	Depression and / or anxiety are not the primary target of the intervention or measured.
31	Martin-Cook, Remakel-Davis, Svetlik, Hynan, & Weiner, 2003	Depression and / or anxiety are not the primary target of the intervention. Depression is measured as a distal outcome.
32	Martin-Cook, Davis, Hynan, & Weiner, 2005	Depression and / or anxiety are not the primary target of the intervention. Depression is measured as distal outcome.
33	Chien & Lee, 2008	Depression and / or anxiety are not the primary target of the intervention or measured.
34	Carnevale, Anselmi, Busichio & Millis, 2002	Depression and / or anxiety are not the primary target of the intervention or measured.
35	Moniz-Cook et al., 2008	Depression and / or anxiety are not the primary target of the intervention. Depression is measured as a distal outcome. Active comparator
36	Northouse, Kershaw, Mood, & Schafenacker, 2005	Depression and / or anxiety are not the primary target of the intervention or measured.
37	Northouse et al., 2007	Depression and / or anxiety are not the primary target of the intervention or measured

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38	Oktay & Volland, 1990	Depression and / or anxiety are not the primary target of the intervention or measured
39	Manne & Badr, 2008	Depression and / or anxiety are not the primary target of the intervention or measured.
40	Signe & Elmståhl, 2008	Depression and / or anxiety are not the primary target of the intervention or measured.
41	Heinrichs et al., 2012	Depression and / or anxiety are not the primary target of the intervention or measured.
42	Gavrilova et al., 2009	Depression and / or anxiety are not the primary target of the intervention or measured.
43	Gitlin, Winter, Dennis, Hodgson, & Hauck, 2010	Depression and / or anxiety are not the primary target of the intervention or measured.
44	Bakas et al., 2009	Depression and / or anxiety are not the primary target of the intervention. Depression is measured as a distal outcome.
45	Baucom et al., 2009	Depression and / or anxiety are not the primary target of the intervention or measured.
46	Bevans et al., 2010	Depression and / or anxiety are not the primary target of the intervention or measured. Not a randomised controlled trial.
47	Bourgeois, Schulz, Burgio, & Beach, 2002	Depression and / or anxiety are not the primary target of the intervention. Depression is measured as a distal outcome.
48	Budin et al., 2008	Depression and / or anxiety are not the primary target of the intervention or measured.
49	Bultz, Specia, Brasher, Geggie, & Page, 2000	Depression and / or anxiety are not the primary target of the intervention. Overall distress is targeted and measured however depression and anxiety subscales of the POMS are reported as distal outcomes.
50	Campbell et al., 2007	Depression and / or anxiety are not the primary target of the intervention. Depression and anxiety subscales of the POMS-SF are also reported as distal outcomes.
51	Carnevale, Anselmi, Johnston, Busichio, & Walsh, 2006	Depression and / or anxiety are not the primary target of the intervention or measured.
52	Cummings, Long, Peterson-Hazan & Harrison, 1999	Depression and / or anxiety are not the primary target of the intervention or measured. Not a randomised controlled trial.
53	Corbeil, Quayhagen, & Quayhagen, 1999	Depression and / or anxiety are not the primary target of the intervention or measured.
54	Derdiarian, 1989	Depression and / or anxiety are not the primary target of the intervention or measured.
55	Dias et al., 2008	Depression and / or anxiety are not the primary target of the intervention or measured.
56	Draper et al., 2007	Depression and / or anxiety are not the primary target of the intervention or measured.
57	Ducharme et al., 2011	Depression and / or anxiety are not the primary

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		target of the intervention or measured.
58	Eloniemi-Sulkava et al., 2001	Depression and / or anxiety are not the primary target of the intervention or measured.
59	Evans, Matlock, Bishop, Stranahan, & Pederson, 1988	Depression and / or anxiety are not the primary target of the intervention or measured.
60	Franzén-Dahlin, Larson, Murray, Wredling & Billing	Depression and / or anxiety are not the primary target of the intervention or measured.
61	Fung & Chien, 2002	Depression and / or anxiety are not the primary target of the intervention or measured.
62	Garand et al., 2002	Depression and / or anxiety are not the primary target of the intervention or measured. Active comparator.
63	Gerdner, Buckwalter, & Reed, 2002	Depression and / or anxiety are not the primary target of the intervention or measured.
64	Given et al., 2006	Depression and / or anxiety are not the primary target of the intervention. Depression is measured as a distal outcome.
65	Glueckauf, Ketterson, Loomis, & Dages, 2004	Depression and / or anxiety are not the primary target of the intervention or measured. Not a randomised controlled trial.
66	Gonyea, O'Connor, & Boyle, 2006	Depression and / or anxiety are not the primary target of the intervention or measured.
67	Gormley, Lyons, Howard, 2001	Depression and / or anxiety are not the primary target of the intervention or measured.
68	Heinrich & Schag, 1985	Depression and / or anxiety are not the primary target of the intervention. Depression and anxiety symptoms are measured as a distal outcome. Inadequate randomisation.
69	Hepburn et al., 2005	Depression and / or anxiety are not the primary target of the intervention. Depression and anxiety are measured as distal outcomes. Results from two
70	Kayser, Feldman, Borstelmann, & Daniels, 2010	Depression and / or anxiety are not the primary target of the intervention or measured.
71	Lewis, Hobday, & Hepburn, 2010	Depression and / or anxiety are not the primary target of the intervention or measured.
72	Locke et al., 2008	Depression and / or anxiety are not the primary target of the intervention or measured.
73	Mahler & Kulik, 2002	Depression and / or anxiety are not the primary target of the intervention or measured.
74	Martín-Carrasco et al., 2009	Depression and / or anxiety are not the primary target of the intervention or measured.
75	Oken et al., 2010	Depression and / or anxiety are not the primary target of the intervention. Depression symptoms are measured as a distal outcome. Active comparator.
76	Porter et al., 2009	Depression and / or anxiety are not the primary target of the intervention. POMS used to measure

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		psychological distress however depression and anxiety subscales are not reported.
77	Roberts et al., 1999	Depression and / or anxiety are not the primary target of the intervention or measured.
78	Schure et al., 2006	Depression and / or anxiety are not the primary target of the intervention or measured.
79	Schwiebert & Myers, 1994	Depression and / or anxiety are not the primary target of the intervention or measured.
80	Scott, Halford, & Ward, 2004	Depression and / or anxiety are not the primary target of the intervention or measured.
81	Senanarong et al., 2004	Depression and / or anxiety are not the primary target of the intervention or measured.
82	Shaw et al., 2011	Depression and / or anxiety are not the primary target of the intervention or measured.
83	Shaw et al., 2012	Depression and / or anxiety are not the primary target of the intervention or measured.
84	Shields & Rousseau, 2004	Depression and / or anxiety are not the primary target of the intervention or measured.
85	Spijker et al., 2011	Depression and / or anxiety are not the primary target of the intervention. Depression is measured as a distal outcome.
86	Toseland, Labrecque, Goebel, & Whitney, 1992	Depression and / or anxiety are not the primary target of the intervention. Depression and anxiety symptoms are measured as a distal outcome
87	Ulstein, Sandvik, Wyller, & Engedal, 2007	Depression and / or anxiety are not the primary target of the intervention or measured.
88	van den Heuvel, de Witte, Nooyen-Haazen, Sanderman, & Meyboom-de Jong, 2000	Depression and / or anxiety are not the primary target of the intervention or measured.
89	van den Heuvel et al., 2002	Depression and / or anxiety are not the primary target of the intervention or measured.
90	Zarit, Anthony, & Boutselis, 1987	Depression and / or anxiety are not the primary target of the intervention or measured.
91	Lenz, & Perkins, 2000	Depression and / or anxiety are not the primary target of the intervention. Depressive symptoms are measured as a distal outcome.
92	Chang, 1999	Depression and / or anxiety are not the primary target of the intervention. Depressive symptoms are measured as a distal outcome.
93	Hebert, Leclerc, Bravo, Girouard, & Lefrancois, 1884	Depression and / or anxiety are not the primary target of the intervention. Depression and anxiety symptoms are measured as a distal outcome.
94	Saarijärvi, 1992	Depression and / or anxiety are not the primary target of the intervention. Depressive symptoms are measured as a distal outcome.
95	Saarijärvi, Alanen, Rytökoski, Hyyppä,	Depression and / or anxiety are not the primary target of the intervention. Depressive symptoms are

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	1992	measured as a distal outcome.
96	Woods et al., 2012	Depression and / or anxiety are not the primary target of the intervention. Depression and anxiety symptoms are measured as a distal outcome.
97	Pierce, Steiner, Khuder, Govoni, & Horn, 2009	Depression and / or anxiety are not the primary target of the intervention. Depressive symptoms are measured as a distal outcome.
98	Toseland, Rossiter, & Labrecque, 1989	Depression and / or anxiety are not the primary target of the intervention or measured.
99	Secker & Brown, 2005	Depression and / or anxiety are not the primary target of the intervention. Depressive symptoms are measured as a distal outcome.
100	Quayhagen et al., 2000	Depression and / or anxiety are not the primary target of the intervention. Depression and anxiety symptoms are measured as a distal outcome.
101	Backhaus, Ibarra, Klyce, Trexler, Malec, 2010	Depression and / or anxiety are not the primary target of the intervention or measured.
102	Clark & Lester, 2000	Depression and / or anxiety are not the primary target of the intervention or measured.
103	Cohen & Kuten, 2006	Depression and / or anxiety are not the primary target of the intervention or measured.
104	Porter et al., 2012	Depression and / or anxiety are not the primary target of the intervention or measured. Follow-up paper from Porter et al., 2009
105	Schwartz et al., 1998	Depression and / or anxiety are not the primary target of the intervention or measured.
106	Hepburn et al., 2001	Depression and / or anxiety are not the primary target of the intervention. Depression is measured as a distal outcome.
107	Gallagher-Thompson et al., 2010	Depression and anxiety are not targets of the intervention. Although depressive symptoms are measured it is explicitly stated that the intervention not designed to target depression.
108	Toseland, McCallion, Smith, Huck, Bourgeois, & Garstka, 2001	Duplicate of Toseland, McCallion , Smith, & Banks, 2004
109	Faes et al., 2011	Depression and / or anxiety are not the primary target of the intervention. Depression and anxiety are measured as distal outcomes.
110	Morano & King, 2010	Implementation study, not a randomised controlled trial.
111	Nichols, Martindale-Adams, Burns, Graney, & Zuber, 2011	Implementation study, not a randomised controlled trial.
112	Callahan et al., 2011	Implementation study, not a randomised controlled trial.
113	Labrecque, Peak, & Toseland, 1992	Inadequate randomisation

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114	Thompson & Meddis, 1990	Inadequate randomisation
115	Brodaty & Gresham, 1989	Inadequate randomisation
116	Burns, Nichols, Martindale-Adams, Graney, & Lummus, 2003	Inappropriate comparator
117	Forducey et al., 2012	Inappropriate comparator
118	Gallagher-Thompson et al., 2007	Inappropriate comparator
119	Gallagher-Thompson & Steffen, 1994	Inappropriate comparator
120	Glueckauf et al., 2012	Inappropriate comparator
121	Mittelman et al., 1995	Inappropriate comparator
122	Waldorff et al., 2012	Inappropriate comparator
123	Rivera, Elliott, Berry, & Grant, 2008	Inappropriate comparator
124	Schulz et al., 2009	Inappropriate comparator
125	Smith, Egbert, Dellman-Jenkins, Nanna, & Palmieri, 2012	Inappropriate comparator
126	Gendron, Poitras, Dastoor, & Perodeau, 1996	Inappropriate comparator
127	Elliott, Brossart, Berry, & Fine, 2008	Inappropriate comparator
128	Elliot, Berry, & Grant, 2009	Inappropriate comparator
129	Gallagher-Thompson et al., 2003	Inappropriate comparator
130	Hartke & King, 2003	Inappropriate comparator
131	King et al., 2012	Inappropriate comparator
132	Belle et al., 2006	Inappropriate comparator
133	Eisdorfer et al., 2003	Inappropriate comparator
134	Mittelman, Roth, Coon, & Haley, 2004	Inappropriate comparator, follow-up of Mittelman et al., 1995
135	Sherwood et al., 2012	Intervention aimed at patient symptom management, not a psychological or psychosocial intervention focusing on carer depression or anxiety
136	Kurtz, Kurtz, Given, & Given, 2005	Intervention aimed at patient symptom management, not a psychological or psychosocial intervention focusing on carer depression or anxiety
137	Martire, Schulz, Keefe, Rudy, & Starz, 2007	Intervention target unclear, authors not contactable
138	McCorkle, Siefert, Dowd, Robinson, & Pickett, 2007	Intervention target unclear, authors not contactable

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139	Kozachik et al., 2001	Intervention target unclear, authors not contactable
140	Elliott, Burgio, & Decoster, 2010	Mediation paper
141	Finkel et al., 2007	Missing data, authors did not respond to request
142	Grant, 1999	Missing data, authors did not respond to request
143	Grant, Elliott, Weaver, Bartolucci, & Giger, 2002	Missing data, authors did not respond to request
144	Goldberg & Wool, 1985	Missing data, authors did not respond to request
145	Kurz, Wagenpfeil, Hallauer, Schneider-Schelte, & Jansen, 2010	Missing data, authors did not respond to request
146	Hartford, Wong, & Zakaria, 2002	Missing data, authors not contactable
147	Viney, Crooks, Walker, 1995	Missing data, authors not contactable
148	Wright, Litaker, Laraia, & DeAndrade, 2001	Missing data, authors not contactable
149	Baldwin et al., 1989	Missing data, authors not contactable
150	Winter & Gitlin, 2006	Missing data, data no longer available
151	Marziali, & Donahue, 2006	Missing data, no longer available
152	Sutcliffe, & Lerner, 1988	Missing data, no longer available
153	Elliot & Berry, 2009	Missing data, no longer available
154	Wolff et al., 2010	Multi-component rather than pure psychosocial or psychological intervention. 18 months follow-up of Wolff et al., 2009
155	Onor et al., 2007	Multi-component rather than pure psychosocial or psychological intervention.
156	Wolff et al., 2009	Multi-component rather than pure psychosocial or psychological intervention.
157	Broadbent, Ellis, Thomas, Gamble, & Petrie, 2008	No standardised measurement of anxiety
158	Beauchamp, Irvine, Seeley, & Johnson, 2005	No standardised measurement of depression.
159	Wei et al., 2012	Not a chronic physical health condition.
160	Newcomer, Yordi, DuNah, Fox, & Wilkinson, 1999	Not a psychological or psychosocial intervention.
161	Jansen et al., 2011	Not a psychological or psychosocial intervention.
162	Björkdahl, Nilsson, & Sunnerhagen, 2007	Not a psychological or psychosocial intervention.
163	Burgener, Bakas, Murray, Dunahee, Tossey, 1998	Not a psychological or psychosocial intervention.

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164	Burton & Gibbon, 2005	Not a psychological or psychosocial intervention.
165	Charlesworth et al., 2008a	Not a psychological or psychosocial intervention.
166	Chu, Edwards, Levin & Thomson, 2000	Not a psychological or psychosocial intervention.
167	Dellasega & Zerbe, 2002	Not a psychological or psychosocial intervention.
168	Dennis, O'Rourke, Slattery, Staniforth, & Warlow, 1997	Not a psychological or psychosocial intervention.
169	Forster et al., 2009	Not a psychological or psychosocial intervention.
170	Fortinsky, Kuldorff, Kleppinger, & Kenyon-Pesce, 2009	Not a psychological or psychosocial intervention.
171	Innes, Selfe, Brown, Rose, & Thompson-Heisterman, 2012	Not a psychological or psychosocial intervention.
172	Jepson, McCorkle, Adler, Nuamah, & Lusk, 1999	Not a psychological or psychosocial intervention.
173	Kalra et al., 2004	Not a psychological or psychosocial intervention.
174	Korn et al., 2009	Not a psychological or psychosocial intervention.
175	Kwak, Montgomery, Kosloski, & Lang, 2001	Not a psychological or psychosocial intervention.
176	Lai, Li, & Lee, 2011	Not a psychological or psychosocial intervention.
177	Larson et al., 2005	Not a psychological or psychosocial intervention.
178	Kidd, Zauszniewski, & Morris, 2011	Not a psychological or psychosocial intervention.
179	Logiudice et al., 1999	Not a psychological or psychosocial intervention.
180	Mackenzie, Wiprzycka, Hasher, & Goldstein et al., 2007	Not a psychological or psychosocial intervention.
181	Melis et al., 2009	Not a psychological or psychosocial intervention.
182	Mignor, 2000	Not a psychological or psychosocial intervention.
183	Mokuau, Braun, Wong, Higuchi, & Gotay, 2008	Not a psychological or psychosocial intervention.
184	Perrin et al., 2010	Not a psychological or psychosocial intervention.
185	Ripich, ZioL, & Lee, 1998	Not a psychological or psychosocial intervention.
186	Schoenmakers, Buntinx, & Delepeleire, 2010	Not a psychological or psychosocial intervention.
187	Quayhagen, & Quayhagen, 1989	Not a psychological or psychosocial intervention.
188	Bass, Clark, Looman, McCarthy, & Eckert, 2003	Not a psychological or psychosocial intervention.
189	Montgomery, Kwak,	Not a psychological or psychosocial intervention.

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	Kosloski, & O'Connell Valuch, 2011	
190	Judge et al., 2011	Not a psychological or psychosocial intervention.
191	Pillemer & Suito, 2002	Not a psychological or psychosocial intervention.
192	Li et al., 2012	Not a psychological or psychosocial intervention. Care recipients hospitalised.
193	Li et al., 2003	Not a psychological or psychosocial intervention. Care recipients hospitalised.
194	Charlesworth et al., 2008b	Not a psychological or psychosocial intervention. Duplicate of Charlesworth et al., 2008a.
195	Toseland & Smith, 1990	Not a randomised controlled trial
196	Gallagher-Thompson, Arean, Rivera, & Thompson, 2001	Not a randomised controlled trial
197	Greene & Monahan, 1989	Not a randomised controlled trial
198	King, Hartke, & Denby, 2007	Not a randomised controlled trial
199	Kuzu et al., 2005	Not a randomised controlled trial
200	Allen, 2009	Not a randomised controlled trial
201	Moniz-Cook, Agar, Gibson, Win, & Wang, 1998	Not a randomised controlled trial
202	Ott, Kelber, & Blaylock, 2010	Not a randomised controlled trial
203	Turner et al., 2012	Not a randomised controlled trial
204	Villareal-Reyna Mde, Salazar-González, Cruz-Quevedo, Carrillo-Cervantes, & Champion, 2010	Not a randomised controlled trial
205	Wilkins, Castle, Heck, Tanzy, & Fahey, 1999	Not a randomised controlled trial
206	Wilz, & Barskova, 2007	Not a randomised controlled trial
207	Schultz, Smyrnios, Grbich, & Schultz, 1993	Not a randomised controlled trial
208	Kahan, Kemp, Staples, & Brummel-Smith, 1985	Not a randomised controlled trial
209	Cox et al., 2012	Not a randomised controlled trial.
210	Lewis et al., 2009	Not a randomised controlled trial.
211	Marziali & Garcia, 2011	Not a randomised controlled trial.
212	Whitlatch, Judge, Zarit, & Femia, 2006	Not a randomised controlled trial.
213	Leutz et al., 2002	Not a randomised controlled trial.
214	Donorfio, Vetter, &	Not a randomised controlled trial.

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	Vracevic, 2010	
215	Coon, Thompson, Steffen, Sorocco, & Gallagher-Thompson, 2003	Primary outcome measure low test-retest reliability
216	Gitlin et al., 2003	Secondary analysis
217	Farran et al., 2007	Secondary analysis from Farran et al., 2004.
218	A'Campo, Wekking, Spliethoff-Kamminga, Stijnen & Roos, 2012	Secondary analysis of A'Campo et al., 2010
219	Mittelman, Haley, Clay, & Roth, 2006	Secondary analysis of Mittelman et al., 1996 and Mittelman, Roth, Coon, & Haley, 2004
220	Mittelman, Roth, Clay, & Haley, 2007	Secondary analysis of Mittelman et al., 1996 and Mittelman, Roth, Coon, & Haley, 2004.
221	Roth, Mittelman, Clay, Madan, & Haley, 2005	Secondary analysis of Mittelman et al., 1996 and Mittelman, Roth, Coon, & Haley, 2004.
222	Mittelman, Roth, Haley, & Zarit, 2004	Secondary analysis of Mittelman, Roth, Coon, & Haley, 2004
223	Steiner et al., 2008	Secondary analysis of Pierce, Steiner, Khuder, Govoni, & Horn, 2008.
224	Berry, Elliott, Grant, Edwards, & Fine, 2012	Secondary analysis of Rivera, Elliott, Berry, & Grant, 2008 and Elliott, Berry, & Grant, 2009.
225	Gaugler, Roth, Haley, & Mittelman, 2008	Targeted on the carer during patient transition to institutionalisation, therefore not focused on informal caring within the community.
226	Herman et al., 2006	The primary aims of the study pertain to feasibility and adherence to the intervention, therefore outcomes related to efficacy not reported.
227	Hepburn, Lewis, Tornatore, Sherman, & Bremer, 2007	The treatment is focused on how to manage the behavioural and psychological symptoms of Dementia, although a primary outcome is symptoms of depression and anxiety.
228	Farran et al., 2004	The treatment is focused on how to manage the behavioural and psychological symptoms of Dementia, although a primary outcome is depressive symptoms. Additionally, an active comparator is used.
229	Buckwalter et al., 1999	The treatment is focused on how to manage the behavioural and psychological symptoms of Dementia, although a primary outcome is depressive symptoms. Additionally, an active comparator is used.
230	Ostwald et al., 1999	The treatment is focused on how to manage the behavioural and psychological symptoms of Dementia
231	Teri et al., 2005	The treatment is focused on how to manage the behavioural and psychological symptoms of Dementia
232	Mittelman, Brodaty, Wallen & Burns, 2008	Treatment primarily focused on the patient rather than the carer.

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233	Teri, 1994	Treatment primarily focused on the patient rather than the carer.
234	Teri, Logsdon, Uomoto, & McCurry, 1997	Treatment primarily focused on the patient rather than the carer.
235	Nezu, Nezu, Felgoise, McClure, & Houts, 2003	Treatment primarily focused on the patient rather than the carer.
236	Callahan et al., 2006	Treatment primarily focused on the patient rather than the carer.
237	Clare et al., 2010	Treatment primarily focused on the patient rather than the carer.
238	Egan, Clavarino, Burridge, Teuwen, & White, 2002	Treatment primarily focused on the patient rather than the carer.
239	Giesler et al., 2005	Treatment primarily focused on the patient rather than the carer.
240	Gitlin et al., 2006	Treatment primarily focused on the patient rather than the carer.
241	Graff et al., 2007	Treatment primarily focused on the patient rather than the carer.
242	Huijbregts, McEwen & Taylor, 2009	Treatment primarily focused on the patient rather than the carer.
243	Johnston et al., 2007	Treatment primarily focused on the patient rather than the carer.
244	Li et al., 2012	Treatment primarily focused on the patient rather than the carer.
245	Mant, Carter, Wade, & Winner, 2000	Treatment primarily focused on the patient rather than the carer.
246	Rawl et al., 2002	Treatment primarily focused on the patient rather than the carer.
247	Chambers & Connor, 2002	Usability study. Not a randomised controlled trial.

Note. Please see references for full citations

Appendix 4.1: Interview schedule for Study Two (interviews with depressed and anxious informal carers of stroke survivors)

For the purposes of tape please could you confirm full name. Thank-you for agreeing to be interviewed today. The purposes of today's interview are twofold:

- To understand your experience of being a stroke survivor, for example the challenges and difficulties you may have experienced and ways in which you have found helpful and also unhelpful in coping with these difficulties.
- To understand your preferences as to how emotional support could be provided to carers of stroke survivors.

The results will be used to develop as psychological treatment for carers of stroke survivors experiencing emotional difficulties such as low mood, depression or anxiety.

The interview will last around 1 hour (possibly a little longer, or a little shorter). I would like you to answer the questions in your own words and in your own time. If at any point in time you change your mind and don't want to continue that's fine, just say stop. Or if there is a question you don't want to answer we can skip the question.

Everything that you tell me in the interview will be confidential.

1. Can you tell me a little about some of the challenges you have faced since XX experienced a stroke?
 - a. From answers here funnel down around the type and nature of the difficulties / challenges
 - b. Ascertain whether the type and nature of difficulties / challenges have changed over time, specifically to ascertain:
 - i. Some of the difficulties faced immediately after XX experienced a stroke
 - ii. Some of the difficulties faced once XX was back home?
 - iii. Some of the difficulties faced a few months after XX was back home?
2. Can tell me about a recent difficult situation and what was going through your mind at the time? (This point try and funnel around thoughts – can do this from the answers elicited above - funnel down as if an assessment).
3. Can you tell me a little bit about how you feel XX is coping? (emotional and practical impact of the stroke)
4. What strategies have you found helpful in the way you have cared for XX?

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5. What strategies have you found unhelpful in the way you have cared for XX?
6. What type of support do you feel would have been helpful in your role as being a carer?
 - a. Try and ascertain both emotional and practical support.
7. What types of barriers have you experienced in accessing support for your difficulties?
8. One evidence based intervention for depression or low mood and anxiety is cognitive behavioural therapy. Traditionally this is delivered face-to-face by a therapist. There is also another type of cognitive behavioural therapy called self-help. You have someone to support and guide you in using the materials and cognitive behavioural techniques yourself. This can be supported by lots of different types of people – professionals or non-professionals. It can also be supported in lots of different ways – by email, telephone, face-to-face or in groups. The materials can also be presented in lots of different ways for example in workbooks or the internet. In what ways would you prefer a cognitive behavioural self-help intervention to be delivered?
 - a. What kind of support would you generally want from treatment?
 - b. Where and when would you want this type of support to be provided
 - c. Who do you think would be suitable to provide this type of support?
9. Have you received any support for your difficulties? If so, what type of support have you received for your difficulties?
 - a. How helpful has this support been and why?
 - b. How unhelpful was this support and why?
 - c. What could be changed about this support to make it better?
10. What type of additional information do you think would be helpful when adjusting to becoming a carer of a stroke survivor?

Appendix 5.1: Interview schedule for Study Three (interviews with non-depressed and non-anxious informal carers of stroke survivors)

For the purposes of tape please could you confirm full name. Thank-you for agreeing to be interviewed today. The purposes of today's interview are twofold:

- To understand your general experience of being a stroke survivor
- Carers also often adopt a range of coping strategies to help them manage this major life change. Some carers report specific ways of adapting to a caring role which they have found helpful. The aim of this study is to develop a better understanding of coping strategies used by carers of stroke survivors

The results will be used to develop as psychological treatment for carers of stroke survivors experiencing emotional difficulties such as low mood, depression or anxiety.

The interview will last around 1 hour (possibly a little longer, or a little shorter). I would like you to answer the questions in your own words and in your own time. If at any point in time you change your mind and don't want to continue that's fine, just say stop. Or if there is a question you don't want to answer we can skip the question.

Everything that you tell me in the interview will be confidential.

1. Can you tell me a little but about your experience of becoming a carer for XX?
2. Can you tell me a little bit about how you feel XX is coping? (emotional and practical impact of the stroke)
3. What strategies helped you cope with becoming a carer?
 - a. What were some of the strategies you used immediately after XX had a stroke?
 - b. What were some of the strategies you used once XX was back home?
 - c. Have the strategies you have used since XX returned home changed? If so, how have they changes?
4. What strategies were unhelpful when you become a carer?
 - a. What were some of the unhelpful strategies you used immediately after XX had a stroke?

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- b. What were some of the unhelpful strategies you used once XX was back home?
- c. What difficulties have you experienced whilst caring for XX?
- d. In what ways have these difficulties changed over time?
5. Can you tell me a little bit about the types of thoughts you have experienced whilst caring for XX?
6. What sorts of thoughts have helped you overcome some of the difficulties faced when caring for XX?
7. What types of activities have helped you overcome some of the difficulties faced when caring for XX?
8. What additional practical strategies have helped you care for XX?
9. What social support networks have helped you cope with being a carer? In what ways have these social support networks helped you?
10. What type of information did you find helpful when adjusting to become a carer? Why type of information do you feel would be helpful when adjusting to become a carer of a stroke survivor?
11. Is there any additional help or support you have found useful in adjusting to become a carer of a stroke survivor? Is there any additional help or support that you feel would be useful in helping adjust to become a carers of a stroke survivor? If yes, can you tell me a little about what this help would ideally look like?

Appendix 6.1: Introduction Booklet



Helping Relatives and Carers of Stroke Survivors Overcome Depression Programme

Joanne Woodford, Paul Farrand



Well done for taking the first steps to help overcome your low mood or depression. Seeking help for your low mood and depression can be one of the most difficult steps to make. This is especially so when you are a busy carer or relative of a stroke survivor with very little time for yourself.

The 'Helping Relatives and Carers of Stroke Survivors Overcome Depression Programme' is based on a psychological treatment, known as Cognitive Behavioural Therapy (CBT). This treatment has been shown to help many people with depression.

The booklets have been developed very closely with carers and relatives of stroke survivors experiencing similar difficulties to you. They are therefore targeted at overcoming the unique difficulties and challenges carers of stroke survivors with depression experience.

HOW DOES THE PROGRAMME WORK?

Whilst working through the programme you will be supported by your Psychological Wellbeing Practitioner, or PWP. Your PWP is a mental health professional who has been specially trained to help support carers and relatives of stroke survivors experiencing depression work through this programme.

The programme includes three different techniques that have been shown to help people overcome difficulties with depression:

- Goal Setting
- Behavioural Activation
- Problem Solving

You won't use all of the techniques, but rather you'll pick one that seems the most suited to the difficulties you are currently experiencing. If you have any problems in deciding which technique to work with, your PWP will be able to help you. You can find out a little bit more about each of the techniques by reading the 'Carer and Relative Recovery Stories' in Part 3 of this booklet.

You'll either meet with your PWP face-to-face or speak with them over the telephone on a regular basis over the coming months. How you would like to work is up to you. Your PWP will act a bit like a coach or personal trainer and help you to understand and use the techniques in the programme.

Working through the programme does involve time and commitment and you'll have homework to complete in between support sessions. From our discussions with carers during the development of this programme we also know that finding time when you are busy caring for a stroke survivor can be really tough. Therefore take your time, remember you are in control of how much you do. Working through the techniques little but often can be really helpful.

Sometimes progress will be slow and setbacks will happen, this is perfectly normal and to be expected. If you find yourself facing difficulties please speak with your PWP. They are specially trained to help people overcome setbacks and difficulties with using the techniques in these booklets.

UNDERSTANDING LOW MOOD AND DEPRESSION

The Caring Experience and Depression

Low mood and depression are very common emotional difficulties experienced by carers. Around 1 in 3 carers are likely to experience such difficulties.

Strokes often happen completely out of the blue and with every stroke being different the future can often seem very uncertain with no real guideline or template to follow to help with recovery. Understandably you may feel your entire life has been turned upside down and have little hope for the future. These are difficulties many of the carers we have worked with to develop this programme have talked to us about.

Becoming a carer of a stroke survivor involves many major life changes. You may have found yourself having to give up certain activities, goals, and things that you value, for example, work, education, plans for retirement, social activities and hobbies. Some carers we have spoken to have reported feeling resentment towards the stroke survivor due to having to give up so much they previously valued. However this resentment is often mixed up with guilt around having these difficult feelings. As a carer you may have experienced thoughts like 'Why am I moaning, why am I complaining, the stroke didn't happen to me'. From our work with carers having such thoughts is perfectly normal.

As a carer you may have found your day has become filled with activities around caring for the stroke survivor, looking after the home and finances. Understandably carers often feel like it is a huge struggle to hold everything together and feel like they are not doing a good enough job. With such little time carers also often find themselves feeling very isolated and confined to the house with little support from others.

It is important to remember that these difficulties are very common and understandable with seeing a loved one experience a stroke and experiencing such major life changes. However, there are tools and techniques that can help you overcome and cope with these difficulties.

Exactly what is Depression?

Depression or low mood are experienced by people in different ways. But there are a number of common signs and symptoms that people may experience that are listed below:



WHAT CAUSES DEPRESSION?

Although there are a lot of theories about what causes depression mental health experts still don't know the cause.

Some people think that depression is triggered by difficult and stressful life events. Others argue that some people have personality traits which can make them more likely to experience depression, for example being over self-critical or viewing the world negatively. Others argue that depression is caused by low levels of a chemical called serotonin in the brain.

Although we don't know what causes depression and low mood, it is likely that a combination of these things contribute.

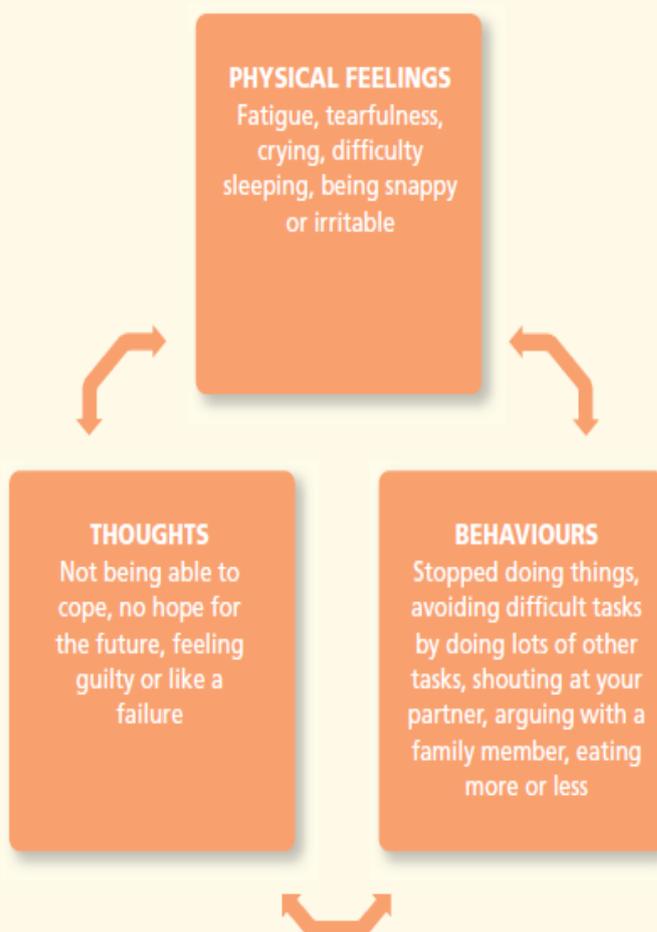
The Effect of Depression

When thinking about the different signs and symptoms of depression that people may experience it can be useful to think about how depression impacts us in three ways:

- **Physical Feelings:** You may experience physical feelings such as changes in appetite, tearfulness, exhaustion or restlessness.
- **What we think:** You may experience thoughts such as 'I can't cope'; 'I can't do anything right'; 'I'd be better off dead'.
- **How we behave:** You may also experience changes in the way you behave, such as stopping seeing friends, stopping activities you previously enjoyed or valued. Or you might have found yourself doing lots of other activities to try and avoid difficult tasks or feelings.

You may notice that the common symptoms of depression listed on page 4 fall into these three categories. We know that each of these areas impact on one another – like a 'vicious cycle' or a 'downward spiral'. An example of this can be seen on the next page.

The impact of low mood or depression



Depression impacts each of these three areas and one thing leads to another. You may find yourself feeling fatigued or having difficulty sleeping. This may lead to thoughts about not being able to cope which may lead you to snap or shout at the person you are caring for. This in turn may make you feel guilty and you might find yourself leaving the room and avoiding speaking with the person you are caring for.

It is important to remember each of these three areas, your physical feelings, thoughts and behaviours, all impact on and reinforce one another. This 'vicious cycle' or 'downward spiral' can be really difficult to break out of. This is what can keep depression or low mood going.

HOW DOES YOUR DEPRESSION AND LOW MOOD IMPACT YOU?

It can be really helpful to have a think about how your depression or low mood is impacting on you. So why not try to develop your own 'vicious cycle' or 'downward spiral'?

Using the diagram opposite try and think about the following:

- What physical feelings are you experiencing?
- What have you stopped doing? Or what have you started doing more of?
- What thoughts are you experiencing?

Have a go at completing this for yourself. If you struggle however don't worry as your PWP will help you.

GETTING OUT OF THE VICIOUS CYCLE

Cognitive Behavioural Therapy (CBT) is an evidence based treatment for depression and low mood which works by focusing on either helping you to change the way you behave or the way you think. Because your physical feelings, thoughts and behaviours are all linked in the vicious cycle of depression, if you can improve one of these areas the other areas will also be improved.

The focus of the three techniques used in this programme will help you change some of the ways that you behave. This will in turn help you with the difficult thoughts and physical feelings you are currently experiencing.

It is completely up to you which technique you would like to work with. The 'Carer and Relative Recovery Stories' in Part 3 of this booklet talk about the three techniques (Behavioural Activation, Goal Setting and Problem Solving) in some more detail. However, if you struggle to decide which technique is best suited to your current difficulties your PWP can help explain more about these techniques to help you to decide.

BEHAVIOURS

THOUGHTS

PHYSICAL FEELINGS

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AIMS FOR TREATMENT

Before we start on the treatment it can be really helpful to think about what you would like to achieve over the coming months. It is important to remember the following things when setting your aims for treatment:

Be Specific

Try and make your aims for treatment specific. Although you might want to set aims such as 'feel able to cope' or 'feel better' it can be hard to know whether you have managed to achieve these aims. Instead, have a think about how you would know if you were coping better, or feeling better. For example, what sorts of things might you be doing if you were feeling or coping better?

e.g. 'I will speak with a friend twice a week' or 'I will go swimming once a week' or 'I will have confidence when speaking to the care agency and be more assertive about the care my partner may require'

Strive towards achieving something

It can be tempting to write down aims such as 'shout at my partner less' or 'eat less'. However it is more helpful when our aims are more positive.

e.g. 'I will talk to my partner calmly' or 'I will eat a healthy dinner at least four times a week'

Realistic

It is important to try and set aims that will be realistic to achieve over the next few months. They may be things you have stopped doing for a long time, or things you would like to do in the future.

On the next page try and think of three aims for treatment. Your PWP can help you with this if you are struggling. Then say how well you are achieving these aims at the moment by rating them between '0' meaning 'not at all' and '6' meaning you can achieve the aim at 'anytime'. Over the next few months you and your PWP will revisit these aims to see how you are getting on.

Three aims for treatment



Today's Date _____

Aim 1

I can do this now (circle a number):

0	1	2	3	4	5	6
Not at all		Occasionally		Often		Anytime

Today's Date _____

Aim 2

I can do this now (circle a number):

0	1	2	3	4	5	6
Not at all		Occasionally		Often		Anytime

Today's Date _____

Aim 3

I can do this now (circle a number):

0	1	2	3	4	5	6
Not at all		Occasionally		Often		Anytime

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CARER AND RELATIVE RECOVERY STORIES

Sometimes people find it helpful to read about other carers and relatives of stroke survivors who have experienced and overcome low mood or depression.

Each of the following carers has used a different technique in the programme to help overcome their difficulties. These stories have been developed very closely with carers and relatives of stroke survivors who have experienced difficulties with depression or low mood.

You may want to read each story in full over the following pages, or you may just want to read the story about using a technique that seems appropriate for your current situation.

If you are having difficulty deciding which technique to use your PWP will explain each of the treatments to you in some more detail to help you decide which one might be best for you.

Additional details about how each carer or relative has worked through the techniques can also be found within each of the specific booklets.

Sarah found herself really struggling with having to give up so much when she became a carer for her husband.

She no longer felt like she had anything to work towards anymore, except being a carer. She therefore decided to use the 'Goal Setting' booklet to help her to identify the goals she could still work towards now she was a carer but also to identify some new goals that were of value to her. You can find Sarah's recovery story on page 13.

Louise really struggled with the routine of the caring role looking after her gran and finding any time for herself.

She found many caring and household tasks really overwhelming and found herself putting off really difficult tasks. Louise also felt that she had stopped lots of activities she used to really enjoy. She felt that she couldn't do a lot of these activities now she was a carer.

Therefore Louise decided to use the 'Behavioural Activation' booklet to help her with getting more balance back into her life. You can find Louise's recovery story on page 15.

Tom found caring for his wife Mary really overwhelming.

He found it difficult to manage with the personality changes and communication difficulties Mary had experienced since her stroke. Tom also found himself having difficulty with the new tasks he had to perform around the house and really struggled taking up offers of support from his family.

Tom decided to use the 'Problem Solving' booklet to help him actively work towards solutions to these difficulties. You can find Tom's recovery story on page 17.

SARAH

My husband Brian suffered his first stroke three years ago when he was 49, it was so sudden, completely out of the blue and it turned our whole life upside-down. The stroke left him paralysed in the right hand side of his body and he was wheelchair bound. It soon became apparent that I couldn't work and look after my husband, so I had to cut short a good career to care for him full time.

Still three years later I was struggling to hold everything together. At the beginning Brian was really determined to overcome the stroke, but over time he made little improvement. He had exercises to do but didn't seem to be bothered with them anymore and put no effort in. He seemed to have given up hope, and so had I. Just before I sought help for my low mood Brian told me that often when he went to bed at night he hoped he wouldn't wake up in the morning. That devastated me.

I never felt like I was doing a good enough job for Brian. My old career was really rewarding but I didn't receive any praise or acknowledgement for the caring tasks I carried out for my husband or around the home. I had no idea whether I was doing a good job and found myself questioning everything I did for Brian and every decision I made. Brian spent most of his time sitting in a chair watching the TV and I felt that it must be my fault that he didn't want to do anything anymore. We also had to give up on so many activities that we used to enjoy together: travelling, meals out, walking.

It felt like a prison sentence, for both of us.

We used to have a great circle of friends, who were really supportive at the beginning but had drifted away over time. They didn't seem to understand that we couldn't do the things we used to do with them. The phone calls had pretty much stopped before I started the overcoming depression programme and I felt so alone.

I had never felt like this before in my life. I would find myself crying over the smallest of things. I was exhausted all the time but despite that I still couldn't sleep. I would lie in bed a lot wishing that our life was the same as it used to be. All I could manage was to care for my husband and I didn't even feel like I was doing that properly. I really wanted to try and get better but I had no idea where to start.

I went to speak to my GP about how I was feeling and he recommended that I saw a Psychological Wellbeing Practitioner who saw me at the GP Practice. At first I was pretty sceptical. I had lost so much and I saw no way of getting anything that resembled our old life back. However my PWP, Tim, helped me work through the 'Goal Setting Booklet'. He spoke to me about how focusing on goals can be really helpful for people with depression, especially if they had gone through a huge life change like I had. Tim explained to me that it can be possible to still work towards some of the goals I had, but in different ways to take account of the changes I had experienced. He also spoke about how I may need to change some of my old goals, but if they are still of value and importance to me then this can be really helpful with overcoming low mood. Tim also explained that sometimes you may need to let go of old goals, but that it was important to try to replace these with new goals that had a similar purpose and meaning to my old goals.

Things are looking much better now. I've been able to get some more balance in my life again - a bit of the old me is back!

Brian and I have been able to find wheelchair friendly walks and we're even planning a mini break away. Tim spoke to me about the importance of support and I recognised that I really missed my old friends. I showed them the information on caring, stroke and goal setting in the booklets and this helped them understand how our lives have changed. We have now been able to find some new activities to all do together. I have also been able to start doing some of my old hobbies again after being able to arrange some respite. Although I have had to change the way in which I work towards some of my goals to fit in with my new life style I now feel that I am actually achieving something for me and that I am more than just a carer. Brian seems to be doing a lot better too now with his own mood as a lot of the goals I set involved both of us.



LOUISE

I am 24 years old and had been looking after my gran for about a year and a half before I got help for my low mood. My gran needs a lot done for her. We have carers that come in to help wash her in the morning and get her ready for bed in the evening but everything else is down to me. My day starts at about 6am and I don't seem to finish until late in the evening. Each day was mapped out for me, I found it an enormous weight and the responsibility was just overwhelming.

The routine of caring for my gran really got me down but I was scared of ever coming out of the routine we had, I worried about things like 'What if I forget something really important like her medication?' or 'What if she fell if we went somewhere outside the house together'. If I ever changed the routine everything else seemed to fall apart during the day. I seemed to be stuck in the role; it was so hard to see a way of changing it or ever leaving it. I had terrible thoughts like 'when will my gran die so I can be free from all of this. These thoughts made me feel really guilty.

I found myself becoming more and more confined to the house and had stopped doing many of the things that I used to enjoy. Nothing really seemed to interest me anymore either. I once had a really bad experience when I tried to leave my gran on her own for a few hours so I could meet some friends for a drink. I thought it would be ok to leave her but when I came back I found her lying in the garden. She had tried to do some gardening and fell. She could have been there for hours. I felt I couldn't leave her anymore and became really worried about what might happen to her if I did. My friends still called me to ask me to come out, but I always said no, I just didn't bother seeing them anymore and I had recently started to ignore their phone calls completely. I also found myself getting really behind with so much around the house.

The garden was a real mess, really overgrown. It made me feel so guilty as my gran used to love her garden and sitting out there.

I had no idea where to start with the garden and I was so tired I just couldn't bring myself to even think about sorting it out. I also felt that I had no real future. I had to give up my plans to go to university.

The thoughts I had about wondering when my gran will die really scared me. Of course I didn't really want her to die, I love her so much. I just wished I could get back to normal and stop feeling the way I did but I had no idea how to stop it. I wanted to get support but I was worried about how I could leave my gran whilst I got help. I couldn't afford to get more care in. I felt so trapped.

Eventually I decided that I just couldn't go on anymore feeling the way I did so I searched on the internet for help with depression. I came across the local NHS service and saw that they took self-referrals and also could support people over the telephone, so I didn't have to find someone to care for my gran. I phoned up and they made me a telephone appointment with my PWP Stephanie. We decided to work through the 'Behavioural Activation' booklet. At first I was really uncertain. It didn't seem to make sense as I was doing so much already. My day never seemed to stop! However Stephanie explained to me that it is really important to try and get a balance of different types of activity and pretty much all I was doing was caring for my gran. At first it was really difficult to identify times in the day where I could fit anything else in! Stephanie helped me to problem solve around this, by identifying activities I was doing that were low priority, and replacing these with other activities to help get some more balance. It was tough but we managed it and I started doing activities for me again, like getting my hair cut and reading. Stephanie also helped me work out how to break huge tasks down, like sorting out the garden. This made things much less overwhelming and manageable.

My life feels much more balanced now; I even get the opportunity to see my friends sometimes!



TOM

I'm 72 years old and my wife Mary had her stroke two years ago. The day we returned home from hospital it was like someone completely different came home with me. She had been changed so much from the stroke. I felt my wife was gone and I still felt I was mourning for her.

Mary suffers from aphasia and has a lot of memory difficulties too. Her personality seemed to have changed since the stroke as well. I found it really difficult to understand her and she sometimes gets really angry, throws things and swears. I used to lose my patience with her and I would often shout back at her or leave the room out of frustration. Before the stroke Mary was one of the most placid people I had ever met but it was like she had become a different person. I had started to give up even trying to communicate with her. We were living like separate people, just sitting in front of the TV and no longer talking.

I also found it embarrassing going out anywhere with Mary. I had a really bad experience when we went to a restaurant and she got really angry because they didn't have what she wanted to eat on the menu and she swore at the waitress. She just didn't seem to understand that she couldn't have whatever she wanted. We had pretty much stopped going out at all before I sought help. Our grandchildren would often offer to come and sit with Mary so I could get a break but I would always turn them down. I was so worried she might get angry and swear at them.

We also used to have friends over but they didn't really understand her communication difficulties and often they would just talk to me and ignore Mary completely. It was so upsetting to see so I had stopped letting them come round.

I also had to give up a lot of the things I used to do.

I used to play bowls, go to local football matches, but just didn't feel like I had time for any of those activities anymore. I felt so isolated. Not only did I not see my friends but I didn't even have the relationship I used to with my own wife.

I also found a lot of the tasks around the house really difficult. I had never done the housework, the cooking, the washing, the cleaning before. Mary had done everything. Most of the time I felt so overwhelmed. I had felt like this once before when I was made redundant about 30 years ago, but I managed to pull myself out of it. This time I just didn't seem to be able to. I was so worried about whether Mary would be taken away from me. What if they think I can't cope and they put her in a home?

One week I dropped Mary off at her stroke club. I often would drop Mary off and not speak with anyone else. I didn't want the other carers thinking I couldn't cope. However by this point everything had just got so overwhelming I broke down in tears to one of the other carers. The carer told me he had experienced similar problems and seen someone at his GP surgery who had really helped him overcome his difficulties with low mood. At first I was really unsure. I couldn't really see how talking to someone could help overcome any of my problems. They just seemed unsolvable. However, I went to the appointment anyway and met with Charlotte, my PWP who supports people like me work through self-help programmes for depression. We eventually decided to work on a treatment called 'Problem Solving'. It seemed like a really practical approach and definitely wasn't 'just talking'. I had so many overwhelming problems and difficulties in my life and it seemed like a really good way of trying to cope and manage with them. It was really hard work. Some of the problems I just didn't see a way out of but with Charlotte's help we were able to identify potential solutions and work towards them.

I had also stopped doing a lot of things that were of importance and value to me but didn't see a way of doing these activities now I was a carer. However I was able to problem solve around some of these activities too. Obviously we couldn't solve everything but I am now able to play bowls again and now I have accepted my grandchildren's offer of sitting with Mary and I can get the chance to see our local football team play. Charlotte also helped me get in touch with a charity called Connect especially for people with aphasia. I was able to get some really great advice about how to communicate with Mary and our relationship is much better now. I also shared this advice with some our friends and they come around again now too.

I won't pretend the process was easy. I still have down days. But things are starting to look much more positive now.



UNDERSTANDING COMMON COMPLICATIONS IN STROKE

Many of the carers we have worked with to develop this programme have spoken about difficulties gaining information surrounding the common health complications and difficulties stroke survivors' experience. A number of carers have also spoken about not being aware that some of these health complications quite common, leading them to feel very alone and anxious about the stroke survivor. Lack of information can therefore contribute to the levels of distress you may feel.

We have put together some information about some of the common health difficulties and complications stroke survivors may experience that carers have told us about. At the end of this booklet, in Part 6, we have listed a number of organisations that provide further advice, help and support around how to manage these difficulties.

Depression

One-in-three carers of people with stroke experience difficulties with depression or low mood which is similar to the rates experienced by the stroke survivors themselves. It is common that depression in one increases the likelihood depression will occur in the other. As such it is important both you and the stroke survivor you care for seek to take care of yourselves and try to find help if the stroke survivor you care for mood has also dropped. You may want to encourage the person you care for to speak with their GP about their difficulties as there are psychological and medical treatments available that may help.

Anxiety

One-in-three stroke survivors will experience difficulties with anxiety. For example, they may fear having another stroke, or that performing certain activities may lead to a stroke, or they may have anxiety around performing certain activities due to the physical difficulties they experience. This can also greatly impact you as a carer and the activities you can do together. Again, remember to encourage the person you care for to speak with their GP as there are psychological and medical treatments that can be effective to treat post-stroke anxiety.

Fatigue

Over half of stroke survivors will experience fatigue. This can be very difficult for both stroke survivors and carers to manage and may impact on the stroke survivors' ability to do many activities. It is important to remember fatigue is very common and you are not alone. However, there are techniques that can help manage post-stroke fatigue that can be found on the 'Stroke Association' website. Also your PWP will be aware of a number of ways that stroke survivor fatigue can be accommodated within any intervention you may seek for your depression. So if this is a difficulty for you make sure you raise it with them.

Seizures and Epilepsy

A number of carers of stroke survivors have spoken to us about difficulties with post-stroke seizures and epilepsy. Understandably seeing the person you care for have a seizure or epileptic fit is very distressing and a highly anxiety provoking situation. It is important to remember that seizures and epilepsy post-stroke are quite common.

Sleep-Disordered Breathing

Another anxiety provoking and distressing experience is sleep-disordered breathing. This is where the stroke survivor has long pauses in their breathing multiple times an hour. A number of carers spoke about how they would fear the worst when the stroke survivor stopped breathing and this led to difficulties sleeping. It is important to remember that over 50% of stroke survivors experience difficulties with sleep-disordered breathing. However, it is also important to speak with your health care providers as there are treatments available or a referral could be made to a sleep centre.

Emotionalism

Emotionalism is when the stroke survivor either cries or laughs uncontrollably and often for no apparent reason. Again, this is a common difficulty with one-in-ten stroke survivors experiencing emotionalism. Understandably this can be distressing for both the stroke survivor and carer. Many carers have spoken to us about feeling that uncontrollable crying was due to something they had done or how they can find emotionalism embarrassing. It is important to remember that this is a common post-stroke complication. Remember to speak with family and friends about how this is common which can help with difficult situations. Again, there are treatments available so encourage the person you care for to speak with their GP or stroke healthcare professional.

Whilst all of these post-stroke health complications can be understandably distressing and difficult to manage it is important to remember that you are not alone and they are experienced by many stroke survivors. The organisations listed in Part 6 will be able to provide more information about these difficulties and how to manage them. If you struggle to find organisations to help you speak with your PWP who may be able to put you in touch with further support.

STRATEGIES FOR COPING FROM CARERS OF STROKE SURVIVORS

As well as working with carers and relatives to identify common difficulties experienced to inform the development of this programme we have also identified a number of strategies that carers and relatives find helpful in supporting day-to-day difficulties and coping with the caring role. These may be strategies that you would like to try out yourself.

SUPPORT FROM FAMILY, FRIENDS AND STROKE ORGANISATIONS

Some carers spoke about how it was helpful to have support from those close to them. This was both in terms of practical support, for example helping with caring for the stroke survivor, and also emotional support and having someone to talk to. Some also spoke about support from stroke clubs and groups in terms of providing information, practical advice and helping them feel that they were not alone. However, getting others involved isn't for everyone, or you may not feel ready to take this step yet. Don't worry if this is the case. If you think you might find support from others helpful have a think about who you might want to ask, or you could think about showing them some of the sections of this programme. Also Part 6 lists a number of stroke and carer organisations that run groups nationally that may be able to provide you with this type of support if you feel this might be helpful.

COMPARING MY SITUATION WITH OTHERS

Sometimes carers reported it helpful to be around other people in a similar situation and to share their stories. This seems to be of benefit in two main ways. First simply sharing your story with others can help, and sometimes it can result in receiving some helpful practical advice. Also talking to other carers and stroke survivors can help make you more aware of the different type of difficulties faced by others, and this can sometimes help you to consider your difficulties in different ways.

BALANCE

A number of carers mentioned the importance of striking a balance between different types of activity. You may have found yourself that the routine of being a carer is really tough. Therefore it is important to try and find things that both you and the stroke survivor enjoy and value. If you are interested in finding out ways of trying to get more balance in your life you may want to look at the 'Behavioural Activation' booklet.

TIME FOR ME!

Another strategy mentioned was trying to take time out from the caring role, even if this is only for a few minutes each day. The 'Behavioural Activation' technique looks at ways to make more time in your busy caring role to have time for yourself. 'Goal Setting' and 'Problem Solving' are also techniques that can help around difficulties making more time for yourself outside the caring role. In Part 4 we mentioned that if depression or low mood increases in the stroke survivor depression or low mood may also increase in the carer, and vice versa. It is therefore also important to remember that taking care of your own mental health is of benefit to the stroke survivor as well.

'PUSH, PUSH, PUSH'

Some carers spoke to us about difficulties with the stroke survivor they care for experiencing low levels of motivation. Carers spoke about how trying to push the stroke survivor, within their capabilities, helped overcome such difficulties. They spoke about the importance of continuing to push the stroke survivor to do exercises, or tasks around the house, or activities around self-care, helping them to strike more of a balance within the caring role. Many carers also spoke about how adopting a 'push, push, push' attitude with health care professionals was also helpful in terms of gaining adequate support.

ADAPTING GOALS

Carers spoke to us about adapting activities and goals so that they could still be achieved in their new life situation, for both themselves and the stroke survivor. You may have noticed yourself that there are activities you used to enjoy, or things you value that you feel you can no longer do now you are a carer. This is very common but many carers spoke about adapting their goals or activities to accommodate their new role as a carer and finding this a helpful way of coping. If you are interested in adapting your goals or setting new goals to work towards now you are a carer you may find the 'Goal Setting' technique helpful.

OTHER SOURCES OF SUPPORT

Many carers and relatives we have worked with to develop this programme have spoken about how it can often be really difficult to find help, support and advice around stroke and caring.

However a number of the carers we have worked with have spoken about the benefits of seeking external support, for both them and the stroke survivor they care for. We have therefore listed a number of organisations that carers and relatives of stroke survivors have found helpful in supporting day to day issues with caring for stroke survivors and practical difficulties that you might encounter.



Different Strokes
Tel: 01908 317618 or 0845 130 7172
Email: info@differentstrokes.co.uk
Website: www.differentstrokes.co.uk

Different Strokes helps stroke survivors of working age to optimise their recovery, take control of their own lives and regain as much independence as possible by offering 'rehabilitative services', information and advice.

Different Strokes currently does this by:

- Organising a national network of weekly exercise classes
- Providing practical, easy to use information for the recovering stroke survivor
- Offering a 'StrokeLine' telephone service so that younger stroke survivors can speak to other younger stroke survivors (01908 317618 or 0845 130 7172)
- Keeping stroke survivors informed, through newsletters, an interactive website and other means, of developments relevant to them



Stroke Association
Helpline: 0303 3033 100
Website: www.stroke.org.uk

Stroke Association is the UK's leading stroke charity. They campaign to improve stroke care, and support people to make their best possible recovery. The Stroke Association funds world-class research to develop new treatments and ways to prevent stroke. They are here for everyone affected by stroke. Please call their Helpline on 0303 3033 100 or visit www.stroke.org.uk for more information.



Headway
Free, confidential helpline: 0808 800 2244
Email: helpline@headway.org.uk
Website: www.headway.org.uk

Headway is a charity set up to give help and support to people affected by brain injury. A network of local Groups and Branches throughout the UK and Channel Islands offers a wide range of services, including rehabilitation programmes, carer support, social re-integration, community outreach and respite care. The services available will vary, depending on local needs and resources.

Support from Headway includes:

- A free, confidential helpline (0808 800 2244; helpline@headway.org.uk)
- A comprehensive website (www.headway.org.uk), including a section dedicated to caring for someone with a brain injury (www.headway.org.uk/caring.aspx)
- An award-winning range of publications and factsheets, including the BMA award-winning booklet *Caring for someone with a brain injury*
- A network of more than 100 groups and branches across the UK

OTHER SOURCES OF SUPPORT



Stroke Foundation
Website: www.strokefoundation.com

StrokeFoundation.com is dedicated to providing the most up-to-date and comprehensive information about stroke. Their mission is to educate the public and healthcare community about the serious medical condition of a stroke.

The Stroke Foundation endeavour to keep StrokeFoundation.com up to date with all the latest news and information and hope that StrokeFoundation.com acts as a spring-board from which further information, help and advice can be found.



Connect
St Alphege Church, King's Bench Street
London SE1 0QZ
Tel: 020 7367 0840
Email: info@ukconnect.org

Connect is a charity for people with aphasia (sometimes known as dysphasia). We offer counselling for people with aphasia and carers from a trained counsellor who has aphasia.

People with aphasia can get involved in a range of activities. Connect call these 'Access to Life' services because they support people to become re-connected with life again.

We offer:

- Peer-led conversation groups
- Befriending
- Training healthcare workers about aphasia
- Aphasia hubs
- Drop-in



Carers Trust, 32–36 Loman Street
London SE1 0EH
Tel: 0844 800 4361, Fax: 0844 800 4362
Email: info@carers.org
Website: www.carers.org

Carers Trust is the UK's largest charity for carers. With local Network Partners they work to improve support, services and recognition for carers in communities across the UK. Carers Trust offer practical help, both in and outside the home, desperately needed breaks, information and advice.

To find your nearest Network Partner, call 0844 800 4361 or visit www.carers.org. Carers Trust also helps carers through interactive websites www.carers.org and www.youngcarers.net.



Carers Direct
Free, confidential helpline: 0808 802 0202

Carers Direct is the official website designed to help carers get the help and support they need as a carer. Carers Direct offer all the information you should need to get the financial help you're entitled to, as well as advice on getting a break from caring, going to work and much more.

You can call Carers Direct on 0808 802 0202 for free, confidential information and advice for carers. Lines are open 9am to 8pm Monday to Friday (except bank holidays), 11am to 4pm at weekends. Calls are free from UK landlines and mobiles.

You can also visit the following website:
<http://www.nhs.uk/CarersDirect/Pages/CarersDirectHome.aspx>

CEDARS LIVING EXPERIENCE GROUP

As well as interviewing a number of carers and relatives of stroke survivors the treatment booklets were also developed closely with the three members of the CEDArS Lived Experience Group.

A little about Celia

I am the sole carer for my partner who had a stroke 2 years ago at the age of 59. By the time he was correctly diagnosed with a stroke (2 weeks later) he had suffered more than one and consequently has damage in different areas. His main problems are weakness down the right hand side and extensive neurological damage. The latter took some time and a lot of research to ascertain exactly what the problems were. Initially it was a huge shock to both of us, but I bore the brunt of it as he seemed immune from worries of the present or the future.

I obtained an MA in Social Care quite late in life, after getting a degree in Politics at 42. I immersed myself in working as a frontline Social Worker with Care Leavers, aged 16-21 and helped develop the team, as the legislation for committing to this age group was new. I also helped write some of Exeter City Councils' policy on Homelessness. When my partner had his stroke I changed to part time work so that I could be his carer but found it hard to fully commit to either task. I left work after 15 months and made his rehabilitation my goal. Initially I channelled myself into basic household tasks for him-later expanding this to the outside world: using a bus pass; ordering and collecting his prescriptions; buying things in a shop etc. I think the trickle of progress has encouraged me and helped me refrain from thinking 'what was', as I cannot change that. Being involved with this project activates my brain, utilises my academic skills and hopefully keeps me at the forefront of stroke advances so that I can continue our long road ahead.

A little about Hilary

For the first fourteen years of our marriage I was a mother of three children, and a housewife, as well as doing the occasional job as for instance, a barmaid. Our youngest daughter was born profoundly deaf, as a result of which I became interested in education. I helped out at Holiday Playschemes and helped organise and run Toy Libraries for disabled children. This led me to do an English A level when I was 34, then to get a B.Ed degree when I was 38. For a few years I worked as a Care Assistant in a Hostel for people recovering from mental illness, eventually getting a job as an English teacher when I was 44 years of age.

Life with David has obviously been very difficult since his stroke, but my experiences in life have given me a certain amount of patience, something that is greatly needed in our situation. I can communicate in British Sign Language, but David, sadly, can't. He tried to learn over twenty years ago but found it impossible to remember which hand to use, and/or which sign meant what. Anyway, it would be almost impossible to use British Sign Language as he only has the one hand now, so his iPad, with its Grid Player 'qwerty' keyboard, and space for words to be typed, is absolutely invaluable, and has 'saved our lives' nearly every day for over five years now.

A little about David

David studied psychology at University, became a Social Worker, which job he did for many years, ending up as an Assistant Manager, then became a University lecturer in Social Work. He had a severe stroke at the age of 65, caused by a clot, mostly caused by more than 40yrs of smoking even though he had given up 7 years before. The damage was in the left brain which left him with great difficulty in forming and saying words - despite sessions of speech therapy and regular exercises the damage remains very severe. David can't use the telephone, he finds social situations very frustrating (so avoids them a lot of the time!), and gets very miserable when I can't understand what he's trying to say. Another effect of the stroke was to partially paralyse his right hand, particularly the thumb and index finger, making fine movements impossible, such as cutting up food and typing. Again, despite various methods, exercises and devices the damage remains severe. Just to aggravate his disabilities, his hearing, which has been deteriorating over the last twenty years, has got even worse, limiting his social activities even more, especially in public with a lot of background noise.

In David's words: "Unlike some stroke victims, I have been lucky enough to have been nourished and protected by Hilary through our 48 years of marriage. Even so, our lives have been irreversibly damaged by the stroke, compounded by the poor hearing and compensations are hard to find. After five years I routinely get dark moods, depressed, enraged and desperate, and this has put a heavy load on Hilary as my prime carer."

ABOUT THE AUTHORS



Joanne Woodford is an Associate Research Fellow within the Mood Disorders Centre at the University of Exeter with a special interest in developing and improving access to evidence based psychological interventions for people with depression, especially for carers and relatives of people with physical health difficulties, such as stroke. Joanne has previously co-developed an online CBT self-help treatment for postnatal depression and contributed to the development of a treatment for people with chronic physical health conditions. Joanne is also involved in several educational programmes directed at training mental health professionals in the skills required to support patients in the use of CBT self-help materials.



Dr Paul Farrand is a Senior Lecturer within the Mood Disorders Centre and Director of Psychological Wellbeing Practitioner training within Clinical Education, Development and Research (CEDAR) at the University of Exeter. His main clinical and research interests are in the area of low intensity cognitive behavioural therapy (CBT), especially in a self-help format. Based upon his research and clinical practice he has developed a wide range of written self-help treatments for depression and anxiety.



CBT SELF-HELP: INFORMAL CARERS OF STROKE SURVIVORS



The **Dunhill Medical Trust**

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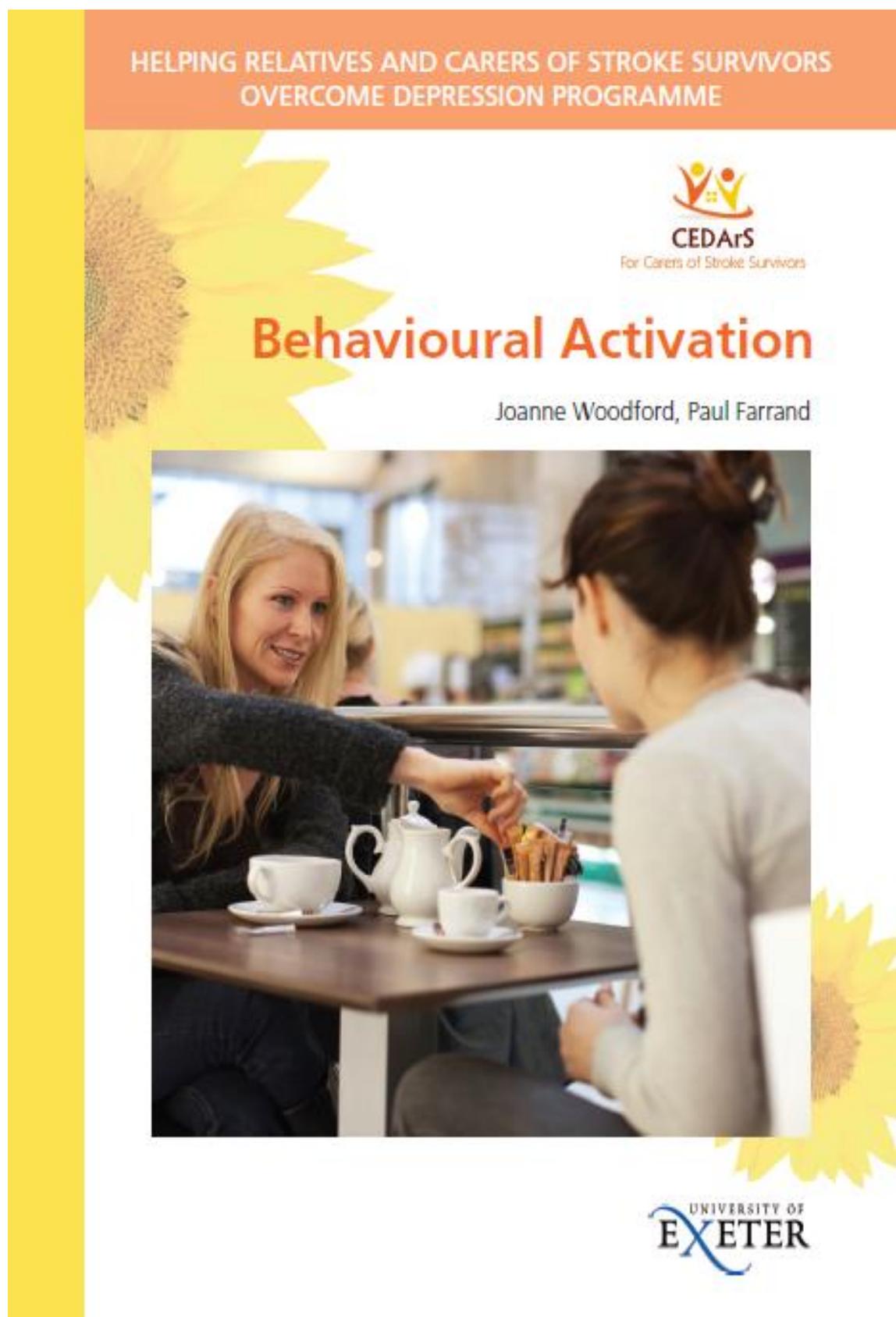
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Appendix 6.2: Behavioural Activation Booklet



WHAT IS BEHAVIOURAL ACTIVATION?

Behavioural activation is an evidence based treatment for low mood or depression. A lot of research has shown it to be effective and many people tell us how helpful they find it with lifting their low mood or depression.

Activity in the Caring Role

When we are feeling low we often stop doing, or avoid a lot of activities we used to do. We may not get any enjoyment out of things we used to find pleasurable and important tasks may feel overwhelming and difficult to concentrate on. Many carers we have spoken with to develop this programme have experienced such difficulties themselves.

You learnt in the 'Introduction Booklet' that how you behave, what you think and how you feel physically all impact on one another in a 'vicious cycle' or 'downward spiral'. Some symptoms of depression may cause you to stop doing activities you used to do, or make you increase certain activities. For example, you might stop doing activities you used to enjoy because you can't concentrate on them and feel fatigued, this may lead you to think negative thoughts around hopelessness or helplessness.

When we go through a major life change like becoming a carer we may also stop certain activities because tasks around the caring role take over. Your days may be packed with activities focused around caring for the stroke survivor leading you to give up a number of activities you previously valued. Many carers who helped develop this programme talked about how each day seems mapped out for them.

Carers also talked about how they feel a sense of guilt if they do any sort of activity which is just for them, and outside of caring for the stroke survivor.

Therefore both your depression and your role as a carer may be impacting on the types of activity that you are currently doing.



STRIKING A BALANCE

There are three main types of activity in our lives:

Routine

e.g. dressing the person you care for, housework, cooking, gardening, food shopping

Necessary

e.g. medical appointments, giving the person you care for medication, calling your social worker, paying a bill

Pleasurable

e.g. reading, swimming, seeing friends, going to a stroke club or carers meeting

We know that it is really important to get a balance of these three different types of activity in our life

Currently you may be focusing on just one or two of these activity types. Or you may find that everything is so overwhelming and exhausting right now you have stopped doing lots of different activities. To help overcome your low mood it is important to try and increase what you are doing in each area you are neglecting.

This probably sounds really overwhelming. However with behavioural activation you are in control at all times. You will start off by doing things that you have stopped doing at the level you choose and then slowly build these up. Also you are encouraged to choose activities that are relevant to your own life and priorities.

You might be wondering how you can do some of the activities you have stopped because of the impact of the caring role. Your PWP is there to help you problem solve around these difficulties and help you to find activities that you can do.

HOW DOES BEHAVIOURAL ACTIVATION WORK?

When people are feeling low or depressed they often stop doing the things they used to do. This is especially the case when the caring role itself feels so overwhelming.

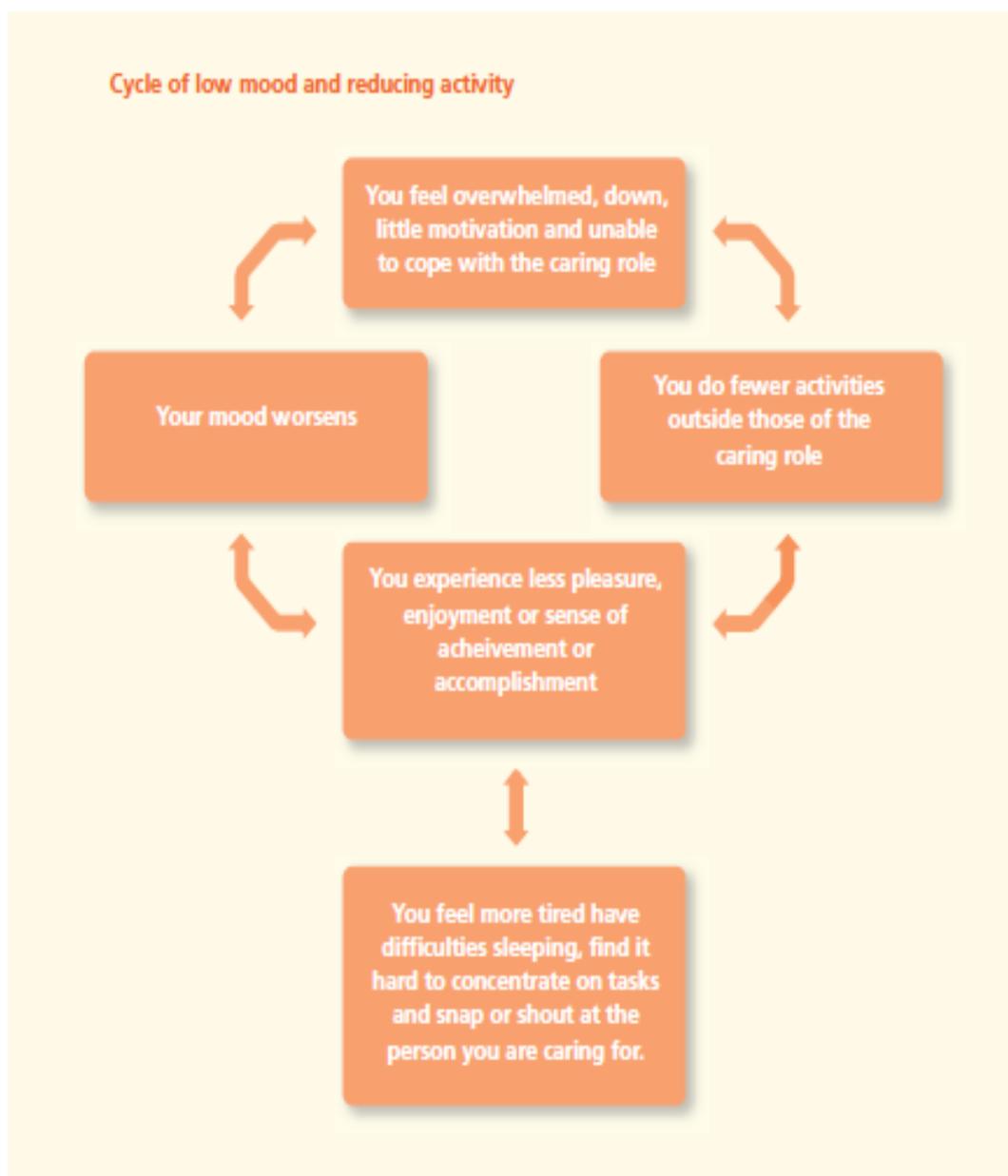
At first, doing less of certain things may make you feel better. You may feel relief around not picking up the phone to a friend or seeing the GP for your own health problems. Or you may feel better about not mowing the lawn.

Doing less of certain activities is a normal 'self-defence' type coping response, especially if you are already feeling exhausted and overwhelmed by the tasks of caring.

Overtime you may find yourself doing less and less of these activities due to this initial sense of feeling better by avoiding these tasks. In the long term however, stopping doing certain activities can have a negative effect on your mood:

- You may not perform roles or activities that are of value or importance to you
- You may no longer be doing any activities that you enjoy
- Tasks that need to be done may pile up and feel unmanageable
- You may find yourself becoming more isolated from friends and family

Feeling worse will make it more likely that you want to do less and less, which in turn makes you feel even worse – like the 'vicious cycle' or 'downward spiral' we spoke about in the 'Introduction Booklet'. You can see this vicious cycle of low mood and reducing activity on the next page.



Behavioural Activation helps you break this vicious cycle by starting to do activities you have stopped doing again. This puts the cycle into reverse and things start to improve.

We know being a carer means it can be really difficult to find the time to do certain activities and the routine of being a carer can be really overwhelming. Therefore it can be helpful to start off with doing just a little at a time.

If you need them to your PWP can help you work out ways to find time and identify activities you can do to start regaining balance in your life.

STEP 1: WHAT ARE YOU CURRENTLY DOING?

Behavioural Activation works by following four simple steps. Your PWP will help you work through these steps if you need them to.

Over the next week use the blank 'Worksheet A: My Starting Point Diary' to record what you are doing. This may feel a little overwhelming. Often carers start early in the morning with caring tasks and feel like they don't stop until the evening.

However it's not necessary to write down everything you do. Instead fill in a couple of the main activities for the morning, afternoon and evening. Or you could try grouping together lots of different activities, for example 'getting my partner ready for the day' will involve lots of tasks but you don't need to list them all separately.

There are three main types of activity that we do in our lives: routine, pleasurable and necessary:

Routine

These are activities that you do on a regular basis. For example dressing your partner, cooking, dusting or food shopping.

Necessary

These are activities that are often very important with a negative consequence if they are not done. For example giving the person you care for medication or organising Carers Allowance.

Pleasurable

These are activities that you used to enjoy before you started to feel low. Or they may be activities you have stopped doing since becoming a carer. They may also be activities you haven't done before but you think you might enjoy and would like to try. What people find enjoyable is very individual. What one person really enjoys, another person might dislike. However, some examples might include seeing friends, going out for dinner, exercise, reading the newspaper or listening to music.

When writing down activities you are doing it can be really helpful to provide the following details:

'What' are you doing – i.e. 'Getting my partner up'

'Where' are you doing it - i.e. 'Bedroom'

'Who' you are with – i.e. 'My partner'

'Type' of activity – i.e. 'R' for 'routine', 'N' for 'necessary' or 'P' for 'pleasurable'

Types of activity often overlap a lot, for example gardening may be something pleasurable and routine. Just try and put down the type of activity you think fits best.

We know from speaking with carers that they often find themselves doing lots of 'routine' tasks – recording the type of activity will help identify whether this is a pattern you are also experiencing.

At the end of each day it can also be helpful to write down comments about how the day went. For example, were there particular times of the day you felt better or worse? Were there particular activities that made you feel better or worse? Were there any people that made you feel better or worse?

Putting in as much detail in as possible will really help when you next speak with your PWR. However, we know that both depression and being a carer can make us feel exhausted and overwhelmed therefore try to do as much as you can but don't worry if you can't fill out everything.

RECORD WHAT YOU ARE CURRENTLY DOING

Worksheet A: My Starting Point Diary

		Monday	Type	Tuesday	Type	Wednesday	Type
Morning	What						
	Where						
	Who						
	What						
	Where						
	Who						
Afternoon	What						
	Where						
	Who						
	What						
	Where						
	Who						
Evening	What						
	Where						
	Who						
	What						
	Where						
	Who						
Comments							

STEP 2: WHAT IS IMPORTANT TO ME IN MY LIFE?

The next step is to think about things in life that are really important to you. This can help you identify activities to start doing again that are of importance or value to you. These are the same activities that help give your life purpose and meaning.

Caring for your
loved one

Your children or
grandchildren

Your Partner

Cooking nice meals

Seeing friends

Happiness

Although you may have many things that are important to you first of all try and think about five or so things that are really important to you right now. You can always come back to other things that are important in your life later.

Remember to write down what is important to you, rather than the things you feel you 'should' write down.

Use 'Worksheet B: What is really important to me in my life' to record the things you have identified.

Worksheet B: What is really important to me in my life?



List the five most important things in your life right now below:

1	
2	
3	
4	
5	

Helpful Hint: Sometimes people find it helpful to think about the following areas in their life:

- Relationships
- Roles and responsibilities
- Social and leisure activities
- Health
- Finances
- Religious or spiritual life

STEP 3: IDENTIFYING ACTIVITIES

The next step is to start to think about the different types of activities you have given up since becoming a carer and starting to feel down.

It is important that your daily routine includes activities that are of **importance** or **value** to you. Therefore try to identify activities in the areas of life you identified as important in Step 2.

It can also be useful to think about activities you would like to **start doing** for the first time too. Carers often find it difficult to do certain activities they did before becoming a carer, however there may be different activities you could start doing instead.

Remember to try and think about activities in the three main areas of your life: **routine**; **pleasurable** and **necessary**.

You can use 'Worksheet C: Identifying Activities' to write down a few activities in each category. Sometimes it can be difficult to think about activities to write down but you don't have to do this all at once - you might find it helpful to come back to it a few times.



Some Helpful Tips

Some activities will fall into more than one category. Just try to put the activity where you feel it fits best.

How you behave influences how you think and feel. Therefore make sure you select activities that you value and are of importance to you. These activities may help bring you a sense of pleasure, achievement, satisfaction or accomplishment.

As a carer you may have found yourself focusing on the needs of the person you care for. This can make you feel that things of importance to you are being neglected, which may then lead to feelings of guilt for having such thoughts. It is important to remember depression in either the carer or stroke survivor can increase the likelihood depression will occur in the other. Therefore it is very important that you seek to take care of yourself, for the benefit of both you and the person you care for.

Try asking yourself the following questions?

- What things have I stopped doing?
- What important things have I been putting off?
- What hobbies would I like to take up?
- Is there a particular physical activity I would like to start?
- Is there a course I would like to do or a group I would like to join?

You may find it helpful to look over your aims for treatment to try and identify activities you might want to do.

You may feel there are certain activities you have stopped doing or would like to do that are not possible to do now you are a carer. This is perfectly normal, especially when you are feeling depressed. However, even if you don't think you can do these activities anymore still write them down. Your PWP will be able to help you identify ways in which you might be able to achieve these activities in Step 4.

Remember your PWP is there to help you if you find yourself struggling with identifying activities.

STEP 4: ORGANISING ACTIVITIES BY HOW DIFFICULT THEY ARE

Next we will use **Worksheet D** to put the activities you listed in **Worksheet C** into an order of how difficult you feel they are.

Some activities may feel too difficult to achieve right now. That's absolutely fine as you will focus on the easier activities first of all.

STEP 4A

For each activity in 'Worksheet C', think about how difficult you would find it to do currently and try to put them into the following categories:

'Least Difficult' – Activities that may feel challenging right now but you think you could probably manage to do in the next week or so.

'Medium Difficult' – Activities that you think you would find really difficult to do right now, but not impossible.

'Most Difficult' – Activities that you feel would be impossible to do at the moment.

Sometimes it can be really difficult to identify 'least difficult' activities. One thing you could try is breaking down some of the activities you have identified in the 'medium' and 'most difficult' categories down.

Here are some examples that might help:

- 'Go for a drink with my friend Sarah' could be broken down into steps such as 'Ask my daughter if she can sit with my husband for an hour'; 'phone my friend Sarah to see when she is free'.
- 'Organise Carers Allowance' might be broken down into steps such as 'Phone the Carer's Allowance Unit for a claim pack' or 'organise an appointment at the Citizen's Advice Bureau' or 'find the paperwork I need to fill in the form' or 'Fill in 4 pages of the claim pack'.

Remember to write these smaller activities or steps into **Worksheet C**.

STEP 5: PLANNING

The final step is to begin putting activities from your 'least difficult' section into 'Worksheet E: My Next Steps Diary' on the next page.

It is important to try and get a mix of 'routine', 'pleasurable' and 'necessary' activities into your week.

Since becoming a carer you may have found yourself doing lots of routine and necessary activities, mostly around the caring role. Therefore it is important to also plan into your diary the types of activities you have stopped doing. For example, if you are doing lots of routine caring tasks but have stopped doing pleasurable and necessary activities try and fit some of these activities into your week.

It might seem overwhelming to add more activities to your busy schedule. However we know getting more of a balance between these different types of activities can really help lift your mood. Achieving just two or three activities to begin with can be enough. If you feel you can achieve more than this over the next week that's great too!

If you are struggling to find space to fit in these activities please speak with your PWP and they can help you problem solve around this difficulty. We know that this can be a common difficulty carers experience so we have added some more helpful tips to the 'Common difficulties with Behavioural Activation' section of this booklet on page 21.

When you come to do the activities they may seem harder than you first imagined. This is very normal and not a problem at all. Try to do what you can and make a note of any difficulties you experience in the 'comments' section in your 'My Next Steps Diary'. It is also important to try and make a note of activities you enjoyed too, or where you noticed your mood lift. You can discuss this when you next see your PWP.

IMPORTANT

Although you should try to start off with activities from the 'least difficult' list it is important to look at your 'necessary' activities. As 'necessary' activities have consequences if they are not done, these activities may need to be prioritised, even if they are under your 'most difficult' heading.

For example, you may have an important overdue bill to pay. If this is the case think about ways you could manage it. You may want to ask family or friends for help. Or perhaps it might be easier to break the task down, for example: 'find the bill'; 'find the number you need to call'; 'get your bank details together'; 'make the call to pay the bill'. You could also speak to your PWP who will also be able to help you overcome barriers to getting these necessary tasks done.

Putting Planned Activity into Action

When you have planned your activities for next week in your diary it is time to start to do the activities. Remember to try and write down 'what' you are doing, 'when' and 'where' you are doing the activity, and 'who' you are doing the activity with. Being really specific about the activities you have planned can help you to achieve them.

Remember to try and spread your activities out over the week. Try not to overload yourself on one particular day.

Over time you will be able to start to include some of the activities you saw as more difficult. If all goes well you will start to see more balance in your life over the coming weeks.



Things to Remember

Don't expect too much too soon

Some weeks you may find things are quite easy to achieve. Other weeks might be a real struggle. Also as a carer things may happen as part of the caring role that get in the way of you being able to achieve some of the activities you have set. This is really normal and to be expected. Remember your PWP will be learning how best to support you and help you overcome any difficulties you might experience. Also you are learning how to get more balance in your life, and feel better.

Don't expect to feel better immediately

It can take time to start to feel better again. A loss of enjoyment or pleasure out of certain activities is very common in depression and you may be achieving activities but not experiencing pleasure. This can be the same for feeling satisfaction or a sense of achievement. Many carers we have worked with also report that they can often feel guilty when starting to do activities again for themselves. However in the long term they report that this becomes better and they see the benefits of trying to get some balance again, for both themselves and the person they care for.

Don't forget you are in control

You should go at the speed you want. No one is going to put you under pressure to go any quicker than you want to. Also remember that you are not alone, your PWP is there to help and support you throughout.

Worksheet E: My Next Steps Diary

My Starting Point Diary

		Monday	Type	Tuesday	Type	Wednesday	Type
Morning	What						
	Where						
	Who						
	What						
	Where						
	Who						
Afternoon	What						
	Where						
	Who						
	What						
	Where						
	Who						
Evening	What						
	Where						
	Who						
	What						
	Where						
	Who						
Comments							

COMMON DIFFICULTIES WITH BEHAVIOURAL ACTIVATION

I am doing so much already? Why do I need to become more active?

Many carers told us they are on the go from morning to night trying to juggle many things around the caring role. However, they also reported a sense of boredom, no longer doing anything for themselves and spending days not even getting out of the house.

Rather than withdrawing from the world altogether you may have found your life is very active. It is likely that most of these activities are routine and necessary activities around caring and other household tasks. However, it is really important for you to get positive feedback from things in your environment that are rewarding as this can help lift your mood. You can get this feedback from:

- a sense of pleasure or enjoyment
- a sense of satisfaction
- a sense of achievement or accomplishment

If you find yourself mainly doing only one type of activity you will not be getting this type of positive feedback from the environment you are in.

Therefore try and get a balance of routine, pleasurable and enjoyable activities. As a carer it may not be possible to get a complete balance. However trying to make sure you do activities that bring you a sense of pleasure, satisfaction and achievement is really important and will help to lift your mood. In turn this will actually help you care for your loved one even more.

I have so many new overwhelming tasks to do; I just don't know where to start!

You may find yourself doing a lot of tasks around caring, but you may also be putting off big important tasks too. Carers we have worked with often talk about difficulties taking on lots of overwhelming tasks they have never had to manage before, for example, dealing with financial arrangements, gardening or cooking.

Remember one way of working through big overwhelming tasks is to break them down. You could try thinking about steps you need to take to complete a task and planning these activities separately in your diary. Other tasks can be broken down into smaller tasks. A task like gardening can include many different activities, for example mowing the lawn, raking the leaves, weeding a flower bed, watering the plants.

If possible it can be helpful to try and get support from others. Are there friends or family who could help you with some of these more overwhelming tasks? You may also find it helpful to speak to some of the organisations listed in the 'Introduction Booklet' about sources of support too. Many of the carers we have worked with have found the organisations listed really helpful in terms of providing support, advice and information. Remember there are others there to help you if you want it.

If you find yourself struggling with working out how to break down big overwhelming tasks remember to speak with your PWP. They are trained to help carers overcome these types of difficulties.

How can I make time and space for the things I want to do?

With so many responsibilities carers often find it hard to make time for other activities, especially activities for themselves. Carers describe a sense of guilt around taking time just for them and find it difficult to leave the person they are caring for, or to get someone else to be with the stroke survivor whilst they get a break.

These types of feelings are very normal and experienced by many carers. However, for your mood to improve it is important that you try to fit in some activities that will provide you with a sense of pleasure, satisfaction or achievement.

You may be able to make time for yourself by talking to friends or family to get support. You could also try talking to social services about a sitting service, or some respite.

You may also be able to find some time by thinking about how 'important' or what 'priority level' you consider the tasks you are currently doing to be. Some people when feeling low find themselves doing lots of tasks that are not necessarily important but can help distract themselves from difficult feelings or situations. For example, doing the ironing for an hour to avoid arguing with the person you care for.

You might find it helpful to look through the activities you are currently doing and rate how important these activities are. If certain activities are not as important you may be able to replace these with other activities to help you regain some balance.

If you are struggling to make time and space for other activities outside the caring role, bring this up with your PWP and they will be able to help problem solve around these difficulties.

I've had to stop doing so much! How do I identify activities that are achievable for me now I am a carer?

The carers we have worked with to develop this programme have spoken to us a lot about having to give up many activities because of the caring role. Often these are activities they used to enjoy, for example, going on holiday, sporting activities or seeing friends. Carers talk about having little time, financial restrictions, not being able to leave the person they are caring for and the stroke survivors' physical difficulties contributing to having to give up these activities. Some activities you used to do may now feel unachievable. Or sometimes it may be that your current situation means you have to give up on some of these activities. If you find you have had to give up certain activities it is important to try and replace them with activities that bring the same value or purpose as the activity that you've had to give up.

You can try to ask yourself the following questions?

- What activities can I no longer do now I am a carer?
- What was important to me about that activity? What did I value about that activity?
- What other activities could I do that would bring me the same value but I can do as a carer?

You may find it helpful to brainstorm around these questions to try and identify some new activities that you could work towards that will provide you with similar values to the activities you have had to give up.

If you are experiencing difficulties identifying achievable activities, speak to your PWP who will be able to help you.

LOUISE'S RECOVERY STORY

I was 24 when I first got help for my low mood. I had been caring for my gran for about a year and a half and was really struggling. I found the routine of the caring role an overwhelming responsibility. I never seemed to have time for myself and had become more and more confined to the house, never having time off, seeing friends or doing the other activities I used to enjoy. I was also completely overwhelmed by so many activities around the house that were new to me, the housework seemed to be piling up and the garden was a mess.

I decided to look on the internet to see if there was any help out there and I came across a local NHS service who took self-referrals. I also noticed that they could support me over the telephone which was a massive help too because I couldn't leave my gran or afford to pay for anyone to look after her.

I phoned them up and they arranged a telephone appointment with a PWP called Stephanie 10 days later. I was really nervous about talking to a complete stranger over the telephone but knew that I really needed some help. During the phone call Stephanie asked me questions about 'what I was doing more or less of', the 'thoughts running through my head' and also what sorts of 'physical symptoms' I was experiencing. She also asked me a lot about the impact of the caring role, especially the impact on my relationships with others and on my own hobbies and interests. At first I found this quite difficult, especially around some of the thoughts I was experiencing about wondering when my gran was going to die so I could be free from the responsibility of caring. Stephanie was really reassuring however and explained that these types of difficult thoughts can be very common when caring for someone.

Stephanie explained that many carers feel overwhelmed and find themselves doing less activities for themselves, or activities they used to enjoy. She also told me being overwhelmed by the responsibility of lots of new tasks is also really common. But she also said that these difficulties were common when people were feeling depressed too. Stephanie spoke about the vicious cycle of depression and how when we are feeling low we may find ourselves experiencing physical symptoms such as exhaustion and fatigue, which may make us stop doing certain activities like big overwhelming tasks, which may lead us to thinking that we're a failure or can't cope. I found it really helpful to understand that some of the difficulties I was experiencing were not just due to the caring role, but actually symptoms of depression too.

At the end of the session Stephanie explained that she was going to send an 'Introduction Booklet' to me in the post that would explain the experience of caring and depression in some more detail and also some treatments that we could work through.

I had my first telephone support call the following week. Stephanie first recapped the previous week and then asked me what I thought about the information in the 'Introduction Booklet' and whether any of the treatments seemed particularly helpful. I told Stephanie that the 'Behavioural Activation' treatment seemed to suit me because I had stopped quite a few activities that I used to do and also found a lot of the tasks I was responsible for were really overwhelming and I was putting them off. However, I also explained that I was concerned because my days were already so full with activities I wasn't totally sure how increasing what I was doing would help, or how I could possibly fit anything else in.

Stephanie went through how behavioural activation worked and explained how stopping doing certain activities will have made me feel better in the beginning. I know I found it a relief not having to speak with a friend on the phone, or tackle the mess in the garden. However, she described how in the long term this can have a negative effect on your mood. For example, you might stop doing things you used to enjoy, or big tasks may pile up and become unmanageable, just how the garden had for me. She also explained it was really important to do activities that provide us with a sense of pleasure, satisfaction, achievement or accomplishment. However by avoiding activities of value or importance to me meant that I was getting less opportunity for such positive feedback.

I recognised that I no longer did anything that I found enjoyable and never seemed to get a sense of achievement out of any of the tasks I did.

Most of the time I felt disinterested in things I used to enjoy and many tasks around the house seemed completely unachievable anyway.

Stephanie explained that with behavioural activation we would try to work out ways of reintroducing activities of value and importance to me into my life so that I could start to get positive feedback again. She also said that carers often struggled at first to find time and space to reintroduce these activities into their lives but there were ways around this she could help me with.



Over the next week I kept track of the type of activities that I was doing.

The first step was to think about what I was currently doing during the week and use the 'Worksheet A: My Starting Point Diary' to record this.

Louise's Starting Point Diary

		Monday	Type	Tuesday	Type	Wednesday	Type
Morning	What	Getting gran ready, mainly	R	Getting gran ready, mainly	R	Getting gran ready,	R
	Where	in the bedroom and		in the bedroom and		mainly in the bedroom	
	Who	bathroom with some help		bathroom with some help		and bathroom with some	
	Who	from the carers		from the carers		help from the carers	
	What	Housework (cleaning	R	Housework (cleaning	R	Medical appointment at	N
	Where	getting lunch ready)		getting lunch ready)		GP surgery for my	
Who	kitchen, on my own		kitchen, on my own		gran		
Afternoon	What	Exercises with gran in the	R	Took gran to stroke club	R	Washing clothes and	R
	Where	lounge		and did the supermarket		sheets in the kitchen	
	Who			shop			
	What	TV in lounge with gran	P	Housework, upstairs	R	Nap, lounge	N
	Where						
	Who						
Evening	What	Getting gran ready for	R	Getting gran ready for	R	Getting gran ready for	R
	Where	bed, bathroom and		bed, bathroom and		bed, bathroom and	
	Who	bedroom, carers there to		bedroom, carers there to		bedroom, carers there	
	Who	help for 20 minutes		help for 20 minutes		to help for 20 minutes	
	What	Sleep, bedroom	R	Sleep, bedroom	R	Sleep, bedroom	R
	Where						
Comments	What	I noticed although TV is		Exhausted all day		Getting gran to the GP	
	Where	pleasant, I don't really				and back was really	
	Who	enjoy it and we just watch				though	
	Who	what gran wants to					
	Who						
	Who						

CBT SELF-HELP: INFORMAL CARERS OF STROKE SURVIVORS

I had to think about the types of activity I was doing and Stephanie described the three different types of activity in our lives: routine, necessary and pleasurable. Stephanie pointed out carers often find themselves doing lots of the same type of activity and neglecting other activities but it was important to try and get more of a balance.

Day	Thursday	Type	Friday	Type	Saturday	Type	Sunday	Type
	Getting gran ready, mainly in the bedroom and bathroom with some help from the carers	R	Getting gran ready, mainly in the bedroom and bathroom with some help from the carers	R	Getting gran ready, mainly in the bedroom and bathroom with some help from the carers	R	Getting gran ready, mainly in the bedroom and bathroom with some help from the carers	R
	Housework (cleaning getting lunch ready), kitchen, on my own	R	Housework (cleaning getting lunch ready), kitchen, on my own	R	Housework (cleaning getting lunch ready), kitchen, on my own	R	Housework (cleaning getting lunch ready), kitchen, on my own	R
	Collect gran's new prescriptions in town, with gran	N	Exercise with gran in the lounge	R	Washing clothes and sheets in the kitchen	R	Washing clothes and sheets in the kitchen	R
	TV in lounge with gran	P	Housework, upstairs	R	TV in lounge with gran	P	Nap	N
	Getting gran ready for bed, bathroom and bedroom, carers there to help for 20 minutes	R	Getting gran ready for bed, bathroom and bedroom, carers there to help for 20 minutes	R	Getting gran ready for bed, bathroom and bedroom, carers there to help for 20 minutes	R	Getting gran ready for bed, bathroom and bedroom, carers there to help for 20 minutes	R
	Sleep, bedroom	R						
			All seem to be doing is routine stuff				Exhausted! Even the nap didn't help	

Stephanie also asked me to try and brainstorm the five or so things that were the most important to me in my life, so we could try and get me to do more activities in these areas and to fill in the 'Worksheet B: What is really important to me in my life?'.

Over the next week I kept track of the type of activities that I was doing and had a think about what was really important in my life.



Worksheet B: What is really important to me in my life?

List the five most important things in your life right now below:

1	My relationship with my friends
2	Caring for my gran
3	My education
4	My health and exercise
5	My future career

The next time I spoke with Stephanie over the telephone we chatted about what I had found during the week using the 'Starting Point Diary'.

I explained that I had noticed that I was doing a lot of routine activities around the house and the only thing I did during the week that was pleasurable was watching TV, and I didn't really enjoy that anyway. Stephanie explained that this was something many carers noticed. We then started to work through Worksheet C together, 'Identifying Activities' that were of value and importance to me that I had stopped doing, and also activities I wanted to start doing.

Working through the sheet I noticed that I was putting off some tasks that I found really overwhelming, like paying bills, speaking to social services, cleaning the car and sorting out the garden. I also noticed there were lots of activities I used to enjoy that I had stopped doing. They just didn't seem possible anymore.

Worksheet C : Identifying activities

Under each type of activity write down what you want to be able to achieve.

<p>Routine e.g., getting your partner dressed, cooking, dusting, food shopping, having a shower, washing your hair, walking the dog, or ironing</p>	<p>Pleasurable e.g., giving the person you care for medication, attending medical appointments, paying a bill, getting an M.O.T for the car, organising Carers Allowance</p>	<p>Necessary e.g., seeing friends, going out for dinner, exercise, reading the newspaper or listening to music.</p>
<p><u>Sorting out the garden</u></p> <p>_____</p> <p><u>Clean the car</u></p> <p>_____</p>	<p><u>Pay the water bill</u></p> <p>_____</p> <p><u>Speaking to social services about respite</u></p> <p>_____</p> <p>_____</p> <p>_____</p> <p>_____</p> <p>_____</p> <p>_____</p> <p>_____</p> <p>_____</p> <p>_____</p>	<p><u>Speaking to my friend Zoe on the phone</u></p> <p>_____</p> <p><u>Going for a coffee with friends</u></p> <p>_____</p> <p><u>Riding my bike</u></p> <p>_____</p> <p><u>Reading</u></p> <p>_____</p> <p><u>Starting a course</u></p> <p>_____</p> <p><u>Go to the cinema</u></p> <p>_____</p> <p><u>Get my hair cut</u></p> <p>_____</p>

CBT SELF-HELP: INFORMAL CARERS OF STROKE SURVIVORS

Also as I was now unable to go to university I really wanted to start a course but even that seemed impossible. Stephanie told me that many carers identify these same sorts of patterns – that they stop doing lots of things they enjoy and find certain difficult tasks really overwhelming. She also said that people often identify activities that they would like to do that seem impossible right now but there are ways of achieving these activities. I started filling in 'Worksheet D: Organising activities as to how difficult they are'. Stephanie explained that sometimes it can be really difficult to identify 'least difficult' tasks but there were ways of breaking down tasks into steps or smaller activities.

As I broke down some of the more difficult tasks, such as sorting out the garden, and paying the water bill, they started to seem a little bit more manageable. I also thought about some of the first steps I needed to make to find a course I could potentially do from home, that wouldn't be too demanding.

Worksheet D: Organising activities by how difficult they are

Least difficult	Medium difficult	Most difficult
Speaking to my friend Zoe on the phone	Pay the water bill	Going for a coffee with friends
Reading	Riding my bike	Starting a course
Cut the hedge back near the gate	Speaking to social services about respite	Go to the cinema
Weed one flower bed	Rake the leaves in the garden	Get my hair cut
Look up some courses online	Speak to the college about courses I can do from home	Sorting out the garden
Find the water bill	Mow the front lawn	Clean the car
Get my bank account details together		Mow the back lawn
Pay the water bill online		

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Next I started to plan some activities into my diary to try out over the next week using 'Worksheet E: My Next Steps Diary'. At first it seemed really daunting as I was doing so much already. However, Stephanie and I discussed how to plan in activities and I realised that there were other activities I could do whilst my gran was watching TV.

Louise's Next Steps Diary

		Monday	Type	Tuesday	Type	Wednesday	Type
Morning	What	Getting gran ready, mainly	R	Getting gran ready,	R	Getting gran ready,	R
	Where	in the bedroom and		mainly in the bedroom and		mainly in the bedroom	
	Who	bathroom with some help		bathroom with some help		and bathroom with some	
		from the carers		from the carers		help from the carers	
	What	Housework (cleaning,	R	Housework (cleaning	R		
	Where	getting lunch ready),		getting lunch ready),			
	Who	kitchen, on my own		kitchen, on my own			
Afternoon	What	Exercises with gran in the	R	Took gran to stroke club	R	Find the water bill in the	N
	Where	lounge		and did the supermarket		lounge	
	Who			shop			
	What	Call my friend Zoe,	P	Housework, upstairs	R	Nap lounge	N
	Where	kitchen					
	Who						
Evening	What	Getting gran ready for	R	Getting gran ready for	R	Getting gran ready for	R
	Where	bed, bathroom and		bed, bathroom and		bed, bathroom and	
	Who	bedroom, carers there to		bedroom, carers there to		bedroom, carers there	
		help for 20 minutes		help for 20 minutes		to help for 20 minutes	
	What	Sleep, bedroom	R	Sleep, bedroom	R	Sleep, bedroom	R
	Where						
	Who						
Comments		I enjoyed speaking with		Exhausted all day			
		Zoe					

CBT SELF-HELP: INFORMAL CARERS OF STROKE SURVIVORS

Stephanie also asked me to think about some of the routine activities I did around the house and how important I considered them to be. This made me realise I often did lots of easier activities around the house that I didn't really need to do, but I did them to keep myself busy and I was putting off more difficult tasks. We started by just planning three activities for the week, to call my friend Zoe, to find the water bill and read some of my book.

e	Thursday	Type	Friday	Type	Saturday	Type	Sunday	Type
	Getting gran ready, mainly in the bedroom and bathroom with some help from the carers	R	Getting gran ready mainly in the bedroom and bathroom with some help from the carers	R	Getting gran ready, mainly in the bedroom and bathroom with some help from the carers	R	Getting gran ready, mainly in the bedroom and bathroom with some help from the carers	R
	Housework (cleaning getting lunch ready), kitchen, on my own	R	Housework (cleaning getting lunch ready), kitchen, on my own	R	Housework (cleaning getting lunch ready), kitchen, on my own	R	Housework (cleaning getting lunch ready), kitchen, on my own	R
	Collect gran's new prescriptions in town, with gran	N	Exercises with gran in the lounge	R	Washing clothes and sheets in the kitchen	R	Washing clothes and sheets in the kitchen	R
	TV in lounge with gran	P	Housework, upstairs	R	Read my book, bedroom	P	Nap	N
	Getting gran ready for bed, bathroom and bedroom, carers there to help for 20 minutes	R	Getting gran ready for bed, bathroom and bedroom, carers there to help for 20 minutes	R	Getting gran ready for bed, bathroom and bedroom, carers there to help for 20 minutes	R	Getting gran ready for bed, bathroom and bedroom, carers there to help for 20 minutes	R
	Sleep, bedroom	R						
					Reading was hard. I found it difficult to concentrate but managed a bit			

The next time I spoke with Stephanie I discussed how I got on.

I managed to do the activities but I found reading really hard. I used to be able to read loads but it was difficult to concentrate. I also still found myself feeling exhausted. Stephanie explained this was really normal and that things would get easier over time. Though I noticed speaking to my friend Zoe really helped lift my mood.

Over the coming weeks I kept planning in activities and things started to get easier. Stephanie helped me to problem solve ways of making time for activities for me. I noticed that I rushed around the supermarket each week whilst gran was at stroke club so instead I started online shopping and did something for me, like get my hair cut, whilst gran was at stroke club. My friend Zoe also suggested she come round for a coffee instead of me trying to get out. This was really nice and my gran enjoyed having Zoe over too. I also realised that when the carers came round I didn't just leave them to it and would be doing some of the caring tasks they should be doing. I started to leave the carers to get my gran ready and managed to grab 15 minutes to do something else.

Over time I managed to get some of the really big tasks done too, like the garden. It took time but breaking down sorting out the garden into smaller tasks really helped.

It was really satisfying seeing the garden start to take shape and now gran and I can enjoy it together.

I won't pretend that I don't feel overwhelmed at all anymore. The caring role is still tough and some weeks are harder than others. However, now I have a little bit more balance, I really feel my mood has lifted. Also as my mood is lifting some activities are easier to do than they were before which is saving me time too! I can now identify where I might be able to make time for important activities for me and have arranged a sitting service so I can go out and see my friends sometimes.

CEDARS LIVING EXPERIENCE GROUP

As well as interviewing a number of carers and relatives of stroke survivors the treatment booklets were also developed closely with the three members of the CEDARS Lived Experience Group.

A little about Celia

I am the sole carer for my partner who had a stroke 2 years ago at the age of 59. By the time he was correctly diagnosed with a stroke (2 weeks later) he had suffered more than one and consequently has damage in different areas. His main problems are weakness down the right hand side and extensive neurological damage. The latter took some time and a lot of research to ascertain exactly what the problems were. Initially it was a huge shock to both of us, but I bore the brunt of it as he seemed immune from worries of the present or the future.

I obtained an MA in Social Care quite late in life, after getting a degree in Politics at 42. I immersed myself in working as a frontline Social Worker with Care Leavers, aged 16-21 and helped develop the team, as the legislation for committing to this age group was new. I also helped write some of Exeter City Councils' policy on Homelessness. When my partner had his stroke I changed to part time work so that I could be his carer but found it hard to fully commit to either task. I left work after 15 months and made his rehabilitation my goal. Initially I channelled myself into basic household tasks for him-later expanding this to the outside world: using a bus pass; ordering and collecting his prescriptions; buying things in a shop etc. I think the trickle of progress has encouraged me and helped me refrain from thinking 'what was', as I cannot change that. Being involved with this project activates my brain, utilises my academic skills and hopefully keeps me at the forefront of stroke advances so that I can continue our long road ahead.

A little about Hilary

For the first fourteen years of our marriage I was a mother of three children, and a housewife, as well as doing the occasional job as for instance, a bar-maid. Our youngest daughter was born profoundly deaf, as a result of which I became interested in education. I helped out at Holiday Playschemes and helped organise and run Toy Libraries for disabled children. This led me to do an English A level when I was 34, then to get a B.Ed degree when I was 38. For a few years I worked as a Care Assistant in a Hostel for people recovering from mental illness, eventually getting a job as an English teacher when I was 44 years of age.

Life with David has obviously been very difficult since his stroke, but my experiences in life have given me a certain amount of patience, something that is greatly needed in our situation. I can communicate in British Sign Language, but David, sadly, can't. He tried to learn over twenty years ago but found it impossible to remember which hand to use, and/or which sign meant what. Anyway, it would be almost impossible to use British Sign Language as he only has the one hand now, so his iPad, with its Grid Player 'qwerty' keyboard, and space for words to be typed, is absolutely invaluable, and has 'saved our lives' nearly every day for over five years now.

A little about David

David studied psychology at University, became a Social Worker, which job he did for many years, ending up as an Assistant Manager, then became a University lecturer in Social Work. He had a severe stroke at the age of 65, caused by a clot, mostly caused by more than 40yrs of smoking even though he had given up 7 years before. The damage was in the left brain which left him with great difficulty in forming and saying words - despite sessions of speech therapy and regular exercises the damage remains very severe. David can't use the telephone, he finds social situations very frustrating (so avoids them a lot of the time!), and gets very miserable when I can't understand what he's trying to say. Another effect of the stroke was to partially paralyse his right hand, particularly the thumb and index finger, making fine movements impossible, such as cutting up food and typing. Again, despite various methods, exercises and devices the damage remains severe. Just to aggravate his disabilities, his hearing, which has been deteriorating over the last twenty years, has got even worse, limiting his social activities even more, especially in public with a lot of background noise.

In David's words: "Unlike some stroke victims, I have been lucky enough to have been nourished and protected by Hilary through our 48 years of marriage. Even so, our lives have been irreversibly damaged by the stroke, compounded by the poor hearing and compensations are hard to find. After five years I routinely get dark moods, depressed, enraged and desperate, and this has put a heavy load on Hilary as my prime carer."

ABOUT THE AUTHORS



Joanne Woodford is an Associate Research Fellow within the Mood Disorders Centre at the University of Exeter with a special interest in developing and improving access to evidence based psychological interventions for people with depression, especially for carers and relatives of people with physical health difficulties, such as stroke. Joanne has previously co-developed an online CBT self-help treatment for postnatal depression and contributed to the development of a treatment for people with chronic physical health conditions. Joanne is also involved in several educational programmes directed at training mental health professionals in the skills required to support patients in the use of CBT self-help materials.



Dr Paul Farrand is a Senior Lecturer within the Mood Disorders Centre and Director of Psychological Wellbeing Practitioner training within Clinical Education, Development and Research (CEDAR) at the University of Exeter. His main clinical and research interests are in the area of low intensity cognitive behavioural therapy (CBT), especially in a self-help format. Based upon his research and clinical practice he has developed a wide range of written self-help treatments for depression and anxiety.





CBT SELF-HELP: INFORMAL CARERS OF STROKE SURVIVORS



The Dunhill Medical Trust

This trial is funded by The Dunhill Medical Trust, a member of the Association of Medical Research Charities (AMRC) and a National Institute for Health Research (NIHR) recognised non-commercial partner.

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Research Statement:

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Appendix 6.3: Goal Setting Booklet

HELPING RELATIVES AND CARERS OF STROKE SURVIVORS
OVERCOME DEPRESSION PROGRAMME



CEDArS

For Carers of Stroke Survivors

Goal Setting

Joanne Woodford, Paul Farrand



UNIVERSITY OF
EXETER



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WHAT IS GOAL SETTING?

Goal setting is an evidence based treatment for low mood or depression. Research has shown it to be effective, especially for people who have gone through a major life change like becoming a carer of a stroke survivor.

Becoming a carer may mean you need to change or revise the goals that you set yourself. Goal setting can help you to find new ways of working towards your goals, which take into account the caring role. Or it can help you decide on new and realistic goals you want to achieve now you are a carer. Goal setting is a technique that puts you in charge, helping you to plan how to achieve your goals and work towards them in a structured way.

Goals and Caring

Becoming a carer of a stroke survivor is a major life change, or life transition. Many carers we have worked with have spoken about how their whole life feels like it has been turned upside down. You may have found yourself giving up many aspects of life, or goals, for example, your job, plans for retirement, friends and interests. This sense of loss around valued goals is understandably distressing.

Some carers we have worked with have also spoken about feeling a sense of loss around the stroke survivor they care for, for example, some stroke survivors may experience changes in their personality and mood. This may lead to you feeling like the stroke survivor is a different person and you have lost the person they previously were. Also, the stroke survivor may have physical disabilities that place restrictions on what you can now do together; leading you to feel like you can no longer do many of these previously valued activities. From our discussion with carers such activities might include going on holiday, going out for a meal or visiting friends.

You may find yourself experiencing difficult thoughts such as 'I can no longer achieve anything now I am a carer' or 'since my partner had a stroke we have had to give everything up'. Such thoughts may lead to a sense of hopelessness or helplessness and you may feel that things will never get better, or that you can't do anything that you used to do anymore because you need to care for your partner, relative or friend. From our work with carers such thoughts are very common.

Carers have also spoken to us about difficult feelings around resentment for the person they care for due to the restrictions that they are now experiencing on their life. Such feelings of resentment then often lead to guilt around having such thoughts. You may also feel guilt around pursuing previously valued goals now the person you care for has had a stroke and you may feel like you should be caring for the stroke survivor, rather than pursuing things for yourself. Such difficult thoughts around resentment, guilt and loss are very common and understandably very distressing.

Getting Back on Track

When we are feeling low or depressed the extent to which we feel our life is limited by the caring role may not actually match what we are able to achieve. The new barriers and difficulties you experience as a carer may make you feel that you are unable to work towards your goals. But there are things that you can do to help reduce these limitations and help you to work towards the things you would like to achieve.

You may find that you can still achieve some of the things that you want to, but you may need to think about different ways to do them. Some goals can be adapted to take into account your caring role. Other goals will need to be completely changed but you may be able to select new goals to work towards that are still of value and importance to you.

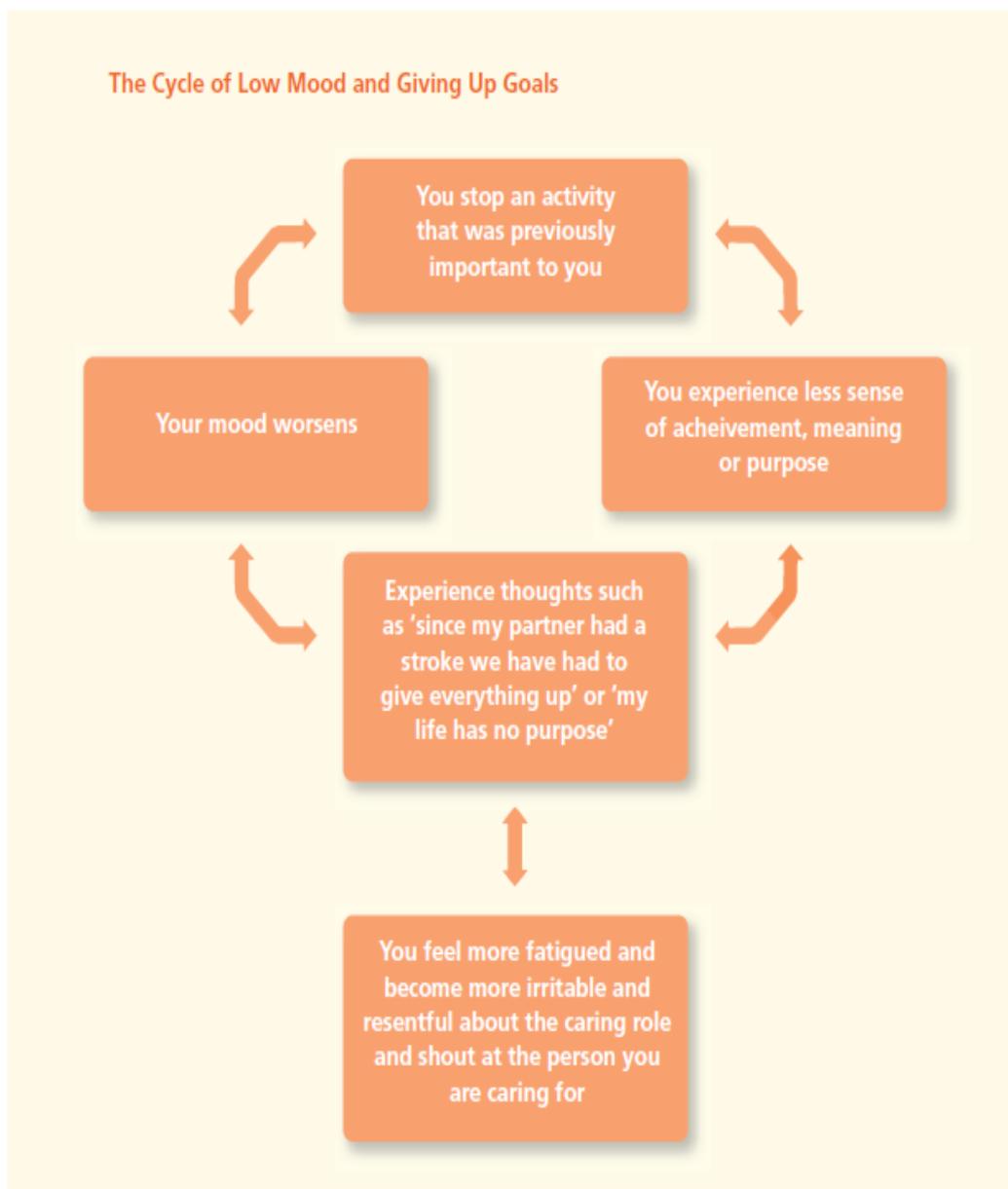
This probably sounds overwhelming. You may have stopped working towards goals for a while now. Experiencing difficulties with fatigue or exhaustion are common in low mood and depression and coupled with the demands of the caring role the idea of working towards goals or trying to set new ones may sound really difficult. However, with goal setting you are in charge. You can start by only working on a couple of goals that are achievable in the short term. You are also encouraged to pick goals that are of importance to you.

HOW DOES GOAL SETTING WORK?

Low mood or depression can make us withdraw from a lot of things we would normally do. The demands of the caring role may also force us to stop working towards certain goals and values. We may not feel we have the time or resources to work towards certain goals now we are a carer.

However, working towards and achieving goals or carrying out valued and important activities are important to our wellbeing. They provide our life with a sense of meaning, purpose or achievement and help lift our mood. Giving up goals that are important to us can therefore cause us distress and make us feel worse. Feeling worse can then make you want to do less and less, which in turn makes you feel even worse – like the 'vicious cycle' or 'downward spiral' we spoke about in the 'Introduction Booklet'.





It is also important to remember that sometimes you may continue to try to work towards or hold goals that are no longer achievable now you are a carer. This can also have difficult consequences, such as feeling hopeless or helpless. Although you may need to give up some goals you can set new ones that are still of value and importance to you. Although it will be difficult to give up these goals in the beginning this will cause less distress in the longer term.

With goal setting we can break this vicious cycle by starting to work towards goals again. This will put the cycle in reverse and things will start to improve.

STEP 1: THE THREE RULES OF GOAL SETTING

There are three simple rules to help you set realistic goals and make the first steps towards getting your life back on track.

Rule 1: Set Three Goals

Being a carer can be very overwhelming and exhausting. In addition, the symptoms of low mood and depression may mean that you are struggling with low energy and feeling tired. Therefore it is important to only set yourself a few goals to begin with. You will check how you are getting on with your goals regularly so they can be revised, or you can set new ones.

Rule 2: Focus upon Short Term Goals

It is important to be able to notice when you achieve goals that you set for yourself. Setting short term goals initially will help you do this. Many of the carers we have worked with have spoken to us about how they often feel that they are not achieving anything outside caring tasks. Therefore it is important to set short term goals that you can reach to help give you a sense of achievement.

Rule 3: Set Positive Goals

As we are talking about getting your life back on track it is important to think positively about your goals. It is helpful to think about what you can achieve rather than things you would like to stop or reduce. For example, 'find out some useful communication strategies to use with the person I care for' is better than 'stop arguing with the person I care for'. Or 'call my friend once a week' is better than 'stop ignoring the phone when it rings'.



WHAT ARE SHORT, MEDIUM AND LONG TERM GOALS?

Short-term goals

These are goals that you think you could achieve in the next few days or weeks. For example, wash the car, ring a friend or read a chapter of a book.

Medium-term goals

These are goals that you think you could achieve in the coming weeks or months. For example, go swimming once a week, clean the house or go out for the day with the person you care for.

Long-term goals

These are goals that you would like to achieve in the future but may take more than a few months to achieve. Some examples could include: meeting more carers of stroke survivors, going on holiday with the person care for or doing some voluntary work.

STEP 2: WHAT IS IMPORTANT TO ME IN MY LIFE?

The next step is to think about things in life that are really important to you. This can help you identify activities to start doing again that are of importance or value to you. These are the same activities that help give your life purpose and meaning.

Caring for your loved one

Your children or grandchildren

Your Partner

Cooking nice meals

Seeing friends

Happiness

Although you may have many things that are important to you first of all try and think about five or so things that are really important to you right now. You can always come back to other things that are important in your life later.

Remember to write down what is important to you, rather than the things you feel you 'should' write down.

Use 'Worksheet A: What is really important to me in my life' to record the things you have identified.

Worksheet A: What is really important to me in my life?



List the five most important things in your life right now below:

1	
2	
3	
4	
5	

Helpful Hint: Sometimes people find it helpful to think about the following areas in their life:

- Relationships
- Roles and responsibilities
- Social and leisure activities
- Health
- Finances
- Religious or spiritual life

STEP 3: WHAT ARE MY GOALS?

Next try and write down what your goals are. These can be short, medium or long-term goals. So that you are working towards goals of importance and value it may be useful to set goals linked to the areas of life you identified as important in Step 2.

You may also want to look at the aims you set yourself for treatment and use 'Worksheet A: My Aims for Treatment' in the 'Introduction Booklet' to write these and any other goals you may have down.

When people are feeling low and have the pressure of caring for someone they may feel there are certain goals or activities that are not possible to do anymore. Even if you don't think you can do these activities anymore try and write them down. Your PWP will be able to help you to identify ways in which you might be able to achieve these goals.

It is important to try and think of as many goals as you can. Sometimes it can be difficult to think of the goals you would like to achieve straight away so take your time. You may have given up on your goals for a while now and therefore it might be tricky to come up with more than a couple of goals. It will become easier to think of more goals as you start to work through the goal setting booklet.

Remember you will only start to work on three goals to begin with but it can be useful to think about a few goals you would like to achieve before starting to set and plan working towards your goals.

HINT: BREAKING MEDIUM AND LONG-TERM GOALS DOWN

Short term goals can sometimes be difficult to set. If you struggle to set short term goals you can look at breaking medium or longer term goals down into steps or smaller activities.

For example, you may have a goal to be able to go swimming again once a week. Achieving this goal may mean following a number of steps. Such steps might include finding out what times the local swimming pool is open; speaking to the stroke survivor you care for about you taking this time out of the caring role; finding someone to be with the stroke survivor whilst you go swimming.

STEP 4: SETTING S.M.A.R.T GOALS

Setting S.M.A.R.T Goals is a useful way to help us to achieve the goals we are aiming towards. You can use 'Worksheet C: Setting S.M.A.R.T Goals' to help you develop your goals according to the following features.

S is for Specific

It is important to set specific goals. If possible try to set the following:

- What date will I try out my goal?
- What time will I try out my goal?
- What resources do I need to achieve my goal?
- Do I need help from anyone else to achieve my goal?

M is for Measureable

It is really important to be able to measure goals so that you know when you have achieved your goal. To make your goal measurable think about how long you might do a certain activity for, and how many times you might do this activity over a specific timeframe. For example, 'My partner and I will go for a 10 minute walk two days a week next week'.

A is for Achievable

It is important not to pick things that you are currently doing, yet it is also important to make sure the goals you pick are achievable. If you select goals you cannot achieve then you will set yourself up to fail.

R is for Relevant

Try to set goals that are directly relevant to your life. Goals should be of importance and relevance to you, so that when you achieve them they have some purpose or meaning. Think about goals that would really make a difference in your life that you would like to be able to do again. This will help you to get your life back on track.

T is for Time Specific

Set a time by which you would like to achieve your goals. Initially don't seek to set more than three short term goals to focus on your recovery. However, over time you will be able to set a mixture of short, medium and long-term goals.

Worksheet C: Setting S.M.A.R.T Goals



Write your original goal here:

Refine your goal according to S.M.A.R.T:

Specific	Try to make sure your goal is as specific as possible. Ensure that it includes dates, times, resources etc., that you will need to achieve your goal.	
Measureable	Next ensure that your goal is measurable. You may need to think about rewording your goal so that you can measure it.	
Achievable	Is your goal achievable? Is it possible to achieve your goal in the next couple of weeks? If not, think about breaking your goal down.	
Relevant	Remember to ensure your goal is relevant to your life now. Will achieving the goal make a difference to you now? Is it important, of value and meaningful? If not, try to adapt the goal so it is.	
Time Specific	Try to set a time by which you want to achieve your goal. If this is a short-term goal this may be within the next week or not. If not, go back to 'achievable' again and think about how to adapt your goal to make it achievable in the next week or two.	

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STEP 5: STARTING TO WORK TOWARDS YOUR GOALS

Now it is time to start to think about setting your own goals. Take a look at 'Worksheet B: My Goals' and try to pick 3 short-term goals that you think are achievable over the next week or two.

As you start to achieve your shorter term goals you will then be able to move onto working towards your medium and long-term goals.

Next fill out 'Worksheet C: Setting S.M.A.R.T Goals' for each of these goals to make sure they contain all the S.M.A.R.T features.

If you find yourself struggling to write your goals according to the S.M.A.R.T features remember your PWP is there to help you.

STEP 6: REVIEWING YOUR PROGRESS

It is really important for you to record how well you have worked towards your goals each week. This will enable you and your PWP to review your progress and help you to continue to reach your goals. You can use 'Worksheet D: My Goal Progress' to help record how you are getting on.

It is great when you are able to reach your goals. Remember to write down in the 'comments' box in 'Worksheet D: My Goal Progress' when you are able to reach your goals. Try and write down how this made you feel and what helped you reach your goal.

However, reaching your goal may not always be possible in the time frame you have set yourself. You might need to break the goal down further. Sometimes you might need more resources or time to achieve your goals. Not always being able to reach your goals is perfectly normal and to be expected. However write down when you are unable to achieve your goals in the 'comments' box and what may have got in the way of you achieving your goal. You can discuss this with your PWP who can help you to think about ways of making your goal more achievable.



Worksheet D: My Goal Progress



Write your goal here:

Write your goal here:		
Today's date	<p>I can do this now (circle a number):</p> <p>0 1 2 3 4 5 6</p> <p>Not at all Occasionally Often Anytime</p>	<p>Comments</p> <hr/> <hr/> <hr/> <hr/> <hr/> <hr/>
Review 1 date	<p>I can do this now (circle a number):</p> <p>0 1 2 3 4 5 6</p> <p>Not at all Occasionally Often Anytime</p>	<hr/> <hr/> <hr/> <hr/> <hr/> <hr/>
Review 2 date	<p>I can do this now (circle a number):</p> <p>0 1 2 3 4 5 6</p> <p>Not at all Occasionally Often Anytime</p>	<hr/> <hr/> <hr/> <hr/> <hr/> <hr/>
Review 3 date	<p>I can do this now (circle a number):</p> <p>0 1 2 3 4 5 6</p> <p>Not at all Occasionally Often Anytime</p>	<hr/> <hr/> <hr/> <hr/> <hr/> <hr/>
Review 4 date	<p>I can do this now (circle a number):</p> <p>0 1 2 3 4 5 6</p> <p>Not at all Occasionally Often Anytime</p>	<hr/> <hr/> <hr/> <hr/> <hr/> <hr/>

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COMMON DIFFICULTIES WITH GOAL SETTING

How do I select new goals that are of importance to me?

Becoming a carer of a stroke survivor is a huge life transition. There are many changes we may experience in terms of the roles we have (e.g., giving up work; taking on all the household responsibilities); our relationships (e.g., seeing less of friends; relationship with the stroke survivor changing) and our hobbies and interests (e.g., no longer being able to travel). There may be other changes you have noticed too but we know from our work with carers to develop this programme that these are common changes carers experience.

Such changes can be really difficult. You may have noticed that there are a number of activities you really valued and were of importance to you that have now changed, or you feel you can no longer do now you are a carer.

Although sometimes such changes mean that we have to give up some of our old goals, the values of the old goal may still be important to us:

e.g. 'I have had to give up my career but I miss the sense of achievement I got from my job and being able to get out of the house'

e.g. 'We can no longer travel abroad, but I miss seeing new places, meeting new people and getting out of the house'

However, it is important to see if you can gain similar values from other area of your life.

You can try to ask yourself the following questions:

- What goals can I no longer work towards now I am a carer?
- What was important to me about that goal? What did I value about that goal?
- What other activities could I do that would bring me the same value but I can do as a carer?

You may find it helpful to brainstorm around these questions to try and identify some new goals or activities you could work towards that will provide you with similar values to the goals you have had to give up.

How can I adapt the way I work towards goals?

As a carer you may have noticed that it is difficult to work towards some goals due to the changes that accompany being a carer. For example, you may now have less time to pursue certain goals, you may have experienced financial changes that mean working to certain goals is now difficult, or you may have less energy than you did previously.

When you select a goal to work towards it is important to consider the changes in resources, such as time and money, and think about ways you can still work towards the goal taking into account these changes. Think about the limitations but think about alternative ways of still achieving these goals taking into account the limitations you are now experiencing.

For example, think about what you need to achieve your goal:

- Do you need time to work towards the goal?
- Do you need to sort care out for the person you care for?
- Do you need to travel to a certain location?
- Do you need to ask for support and help from others to pursue your goal?



SARAH'S RECOVERY STORY

I am 45 years old and my husband Brian had his stroke three years ago which left him wheelchair bound. I had to give up work to care for Brian and I missed this very much, especially the socialising and the sense of achievement I got out of my job. Brian quickly lost motivation for trying to improve and slowly stopped doing his physio exercises. I tried to motivate him at the beginning but found myself giving up too. Our friends started to drift away and we stopped doing all the things we used to enjoy such as meals out, walking and travelling. It seemed as if our friends didn't really understand that we couldn't do a lot of things that we used to do with them anymore, or what it was like being a carer. There just didn't seem to be any purpose in life anymore and Brian and I seemed to have lost any hope we had for the future.

I really started to notice my mood worsen. I was tearful a lot of the time and the smallest thing would make me cry. My sleep was really affected too and I would sit up at night thinking about how our life used to be and wishing it was the same now. I eventually decided to see my GP as I felt I couldn't go on anymore. My GP recommended I saw a Psychological Wellbeing Practitioner (PWP) who would be able to meet with me at the practice. I was very sceptical at first. I just couldn't see any way of getting my old life back.

I met with my PWP, Tim, about two weeks later. We spoke about my low mood, tearfulness and difficulty sleeping. We also spoke about the things I was doing more and less of, especially a lot of the things I had stopped doing since becoming a carer. We also spoke about the thoughts I had running through my head, especially at night time and how I was managing to deal with being a carer. Tim mentioned the transition people go through when they become a carer and how often carers give up many things in their life that they previously valued, such as work, plans for retirement, travelling, socialising and hobbies. It was really helpful to hear that difficulties adjusting to becoming a carer were quite common. However, Tim also spoke about how giving up on goals and activities that are important to us can also affect our mental health. It was really helpful to understand more about the vicious cycle of depression and how my low mood was being maintained. Tim gave me an 'Introduction Booklet' to take away and read for homework and told me to have a read of the recovery stories to decide on which technique I would like to work on with him.

I met with Tim again the following week and I explained to him that I thought goal setting sounded useful. It was interesting to think about how it may be possible to still work towards some of my old goals, but that I may need to think about different ways to achieve them now that I am a carer. It was also useful to think about how I could set new goals for myself that were achievable now I was a carer but would still be of importance and value to me.

I started with thinking about the things that were important and of value to me. I found this quite easy and realised that most of the important things were around my relationship with Brian and friends, work and my fitness and I noted these down on 'Worksheet A: What is really important to me in my life?'

Sarah's Worksheet A: What is really important to me in my life?

List the five most important things in your life right now below:

1	My relationship with my Brian
2	Work
3	My relationship with my my friends
4	Keep fit, swimming, walking
5	Being a good carer for Brian

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Next Tim and I went through the three rules for goal setting together. I then brainstormed some short, medium and long-term goals that I wanted to work towards and wrote them into 'Worksheet B: My Goals'. At first I struggled a little with finding any short-term goals, but Tim explained to me that medium and long-term goals could be broken down into steps and these steps could become short-term goals that would help me work towards longer term goals. This really helped to make goal setting less overwhelming and made me feel like I could actually achieve some of my goals.

Tim and I also spoke about setting new goals. I had spoken a lot in our first session together about how I found giving up work really hard. Tim explained that a useful question to ask yourself when setting new goals to replace those you had to give up was to ask yourself what you valued, or what was important about your old goal. For me, socialising, getting out of the house and a sense of achievement when completing big tasks were important things for me about work. I knew I couldn't go back to work but thought about how I might be able to set new goals that would have a similar value for me. I decided that I might be able to volunteer somewhere half-a-day a week. This would get me out of the routine of caring and the house, help me socialise and definitely give me some more purpose outside the caring role. So I set finding a role volunteering as a new long-term goal. I knew that this would be a really hard goal to work towards but Tim said that that we could look at breaking this goal down into shorter-term steps to help me work towards this goal.



SARAH'S GOALS

Worksheet B

Short-Term Goals	Medium Term Goals	Long-Term Goals
<p>To go on regular walks somewhere wheelchair friendly with Brian</p> <p>Speak to the stroke club about wheelchair friendly walks</p> <p>Go for a walk somewhere with Brian</p> <p>Go swimming</p> <p>Phone my friend Wendy and speak to her about coming over to understand more about what becoming a carer of a stroke survivor was like.</p> <p>Invite Wendy over to read the information on stroke survivors and becoming a carer and how our lives have changed.</p> <p>Speak to Brian about the idea of me volunteering for a charity once a week.</p> <p>Search for local volunteering positions on the internet and in the newspaper</p>	<p>Go for a meal out with Brian</p> <p>Invite our friends Wendy and Chris round for dinner</p> <p>Go to the theatre with Brian</p> <p>Start doing physio exercises with Brian again</p> <p>Organise the garage</p> <p>Organise someone to sit with Brian so I can speak with some local charities about volunteering.</p> <p>Apply for local volunteering positions.</p>	<p>Volunteer half a day a week for one of the local charity shops.</p> <p>Have a group of friends who are also carers</p> <p>Go on holiday with Brian</p>

Next I picked three short-term goals to work towards

I decided that it would be good to do something with Brian so I picked 'Go for a walk somewhere with Brian'. I also wanted to do something for just me and also to start to help my friends understand the life changes Brian and I had gone through so I decided to work on 'go swimming' and 'Phone my friend Wendy and speak to her about coming over to understand more about what becoming a carer of a stroke survivor was like.'

In the support session, with Tim's help, I started setting my first three goals to the S.M.A.R.T criteria. As I started to do this the goals became much clearer. This also made them much more manageable and less overwhelming.



Worksheet C: Setting S.M.A.R.T Goals

Write your original goal here:

To go on regular walks somewhere wheelchair friendly with Brian.

<p>Specific</p>	<p>Try to make sure your goal is as specific as possible. Ensure that it includes dates, times, resources etc., that you will need to achieve your goal.</p>	<p>To go on regular walks somewhere wheelchair friendly with Brian.</p> <p>Speak to the stroke club about wheelchair friendly walks and go on some walks next week with Brian.</p>
<p>Measurable</p>	<p>Next ensure that your goal is measurable. You may need to think about rewording your goal so that you can measure it.</p>	<p>Speak to the stroke club about wheelchair friendly walks and go on some walks next week with Brian.</p> <p>Speak to the stroke club about wheelchair friendly walks and go for 3 walks a week that last at least 30 minutes by the end of next month.</p>
<p>Achievable</p>	<p>Is your goal achievable? Is it possible to achieve your goal in the next couple of weeks? If not, think about breaking your goal down.</p>	<p>Speak to the stroke club about wheelchair friendly walks and go for 3 walks a week that last at least 30 minutes by the end of next month.</p> <p>Speak to the stroke club about wheelchair friendly walks and go for 3 walks this week that last at least 30 minutes.</p>
<p>Relevant</p>	<p>Remember to ensure your goal is relevant to your life now. Will achieving the goal make a difference to you now? Is it important, of value and meaningful? If not, try to adapt the goal so it is.</p>	<p>Speak to the stroke club about wheelchair friendly walks and go for 3 walks this week that last at least 30 minutes.</p>
<p>Time Specific</p>	<p>Try to set a time by which you want to achieve your goal. If this is a short-term goal this may be within the next week or not. If not, go back to 'achievable' again and think about how to adapt your goal to make it achievable in the next week or two.</p>	<p>Speak to the stroke club when we meet on Wednesday about wheelchair friendly walks and go for 3 walks this week that last at least 30 minutes.</p>

As I made each goal S.M.A.R.T I transferred each of them to Worksheet C.

I was quite confident of achieving my first goal: 'Speak to the stroke club when we meet on Wednesday about wheelchair friendly walks and go for 3 walks this week that last at least 30 minutes'. Brian had spoken about how he missed not being able to go out for walks. However this is something I would really enjoy too. We had both been ramblers and we missed being outside. I had also heard people at the stroke club talk about wheelchair friendly walks nearby so I felt that this was achievable.

However, after speaking with Brian I realised that going out three times a week wasn't currently achievable. Brian had not been out much for a long time and felt this would be too much for him. Instead we decided to try going for a walk once a week to begin with and we were both confident that this would be more achievable. I therefore revised my goal and wrote it on top of Worksheet C to include this new information.

In my next meeting with Tim we spoke about how I had got on with my goals. Two of them had worked really well. It was hard to get the wheelchair in and out of the car but we both really enjoyed the walk. I also managed to show my friend Wendy some of the information on having a stroke and becoming a carer from the 'Introduction Booklet'. This was really helpful and Wendy seemed to start to understand the effects stroke had on our lives. However, I hadn't been able to reach the third goal of going swimming once a week for an hour. Tim explained that it was great that I had managed the first two goals and looked at problem solving around my difficulty with going swimming. I had experienced some problems finding someone to sit with Brian whilst I went swimming as I hadn't thought that the children might not be free to sit with him when the swimming pool was open. Tim and I brainstormed some ideas and I decided to look at asking Wendy whether she could sit with Brian instead this week, especially now she had a better understanding of what had happened. Tim was also really helpful in suggesting I try contacting some stroke charities for advice about the difficulties I had getting the wheelchair in the car. He suggested there may be help for this.

Tim then discussed with me the idea of setting new goals now I had managed two of my goals. I decided that I wanted to continue walking with Brian once a week but to go for longer than 30 minutes. I decided to increase this to 45 minutes. I had already discussed this with Brian and he wanted to try to go out for longer. I also decided I wanted to start working towards my longer term goal of starting some voluntary work for half a day a week. I really missed work. Especially socialising with different people and getting out of the house.

I knew that I couldn't go back to work but I felt that volunteering would get me out of the house for a bit, away from the caring role and I'd be able to meet lots of new people and extend my social circle a bit. Tim and I brainstormed the steps I would need to follow in order to reach this goal and I started with the two short term goals of 'Have a conversation on Tuesday this week with Brian about how I would like to do some volunteering work' and 'Ring social services on Wednesday about what respite or sitting service they could organise'.

During the following weeks things got better and better. Brian and I were getting out regularly together and both our moods were improving. Tim continued to help me revise my goals each week and I continued to meet them. By the end of the treatment I felt like my life was much more balanced. Our friends understood our difficulties more and were much more supportive. I am now working towards Brian and I going away on a mini-break which will be easier as the Carers Trust put me in touch with Travel Quest who specialise in holidays for disabled people and their families. I was also able to organise a sitting service and have started to volunteer in a local charity shop one morning a week. I am starting to feel a lot more like the old me again!

Worksheet C: Sarah's Goal Progress

Write your goal here:

~~Speak to the stroke club about wheelchair friendly walks and go for 3 walks this week that last at least 30 minutes.~~

Speak to the stroke club about wheelchair friendly walks and go 1 walk this week that lasts at least 30 minutes.

<p>Today's date</p>	<p>I can do this now (circle a number):</p> <p>0 1 2 3 4 5 6</p> <p>Not at all Occasionally Often Anytime</p>	<p>Since Brian had his stroke and I became his carer we haven't been for any walks apart from up to the shop. It will be good to see if we can both manage this.</p>
<p>Review 1 date</p>	<p>I can do this now (circle a number):</p> <p>0 1 2 3 4 5 6</p> <p>Not at all Occasionally Often Anytime</p>	<p>It wasn't too bad! The walk we were recommended was really quite easy. Getting Brian in and out the car was hard work but it was worth it!</p>

CEDARS LIVING EXPERIENCE GROUP

As well as interviewing a number of carers and relatives of stroke survivors the treatment booklets were also developed closely with the three members of the CEDArS Lived Experience Group.

A little about Celia

I am the sole carer for my partner who had a stroke 2 years ago at the age of 59. By the time he was correctly diagnosed with a stroke (2 weeks later) he had suffered more than one and consequently has damage in different areas. His main problems are weakness down the right hand side and extensive neurological damage. The latter took some time and a lot of research to ascertain exactly what the problems were. Initially it was a huge shock to both of us, but I bore the brunt of it as he seemed immune from worries of the present or the future.

I obtained an MA in Social Care quite late in life, after getting a degree in Politics at 42. I immersed myself in working as a frontline Social Worker with Care Leavers, aged 16-21 and helped develop the team, as the legislation for committing to this age group was new. I also helped write some of Exeter City Councils' policy on Homelessness. When my partner had his stroke I changed to part time work so that I could be his carer but found it hard to fully commit to either task. I left work after 15 months and made his rehabilitation my goal. Initially I channelled myself into basic household tasks for him-later expanding this to the outside world: using a bus pass; ordering and collecting his prescriptions; buying things in a shop etc. I think the trickle of progress has encouraged me and helped me refrain from thinking 'what was', as I cannot change that. Being involved with this project activates my brain, utilises my academic skills and hopefully keeps me at the forefront of stroke advances so that I can continue our long road ahead.

A little about Hilary

For the first fourteen years of our marriage I was a mother of three children, and a housewife, as well as doing the occasional job as for instance, a bar-maid. Our youngest daughter was born profoundly deaf, as a result of which I became interested in education. I helped out at Holiday Playschemes and helped organise and run Toy Libraries for disabled children. This led me to do an English A level when I was 34, then to get a B.Ed degree when I was 38. For a few years I worked as a Care Assistant in a Hostel for people recovering from mental illness, eventually getting a job as an English teacher when I was 44 years of age.

Life with David has obviously been very difficult since his stroke, but my experiences in life have given me a certain amount of patience, something that is greatly needed in our situation. I can communicate in British Sign Language, but David, sadly, can't. He tried to learn over twenty years ago but found it impossible to remember which hand to use, and/or which sign meant what. Anyway, it would be almost impossible to use British Sign Language as he only has the one hand now, so his iPad, with its Grid Player 'qwerty' keyboard, and space for words to be typed, is absolutely invaluable, and has 'saved our lives' nearly every day for over five years now.

A little about David

David studied psychology at University, became a Social Worker, which was a job he did for many years, ending up as an Assistant Manager, then became a University lecturer in Social Work. He had a severe stroke at the age of 65, caused by a clot, mostly caused by more than 40yrs of smoking even though he had given up 7 years before. The damage was in the left brain which left him with great difficulty in forming and saying words - despite sessions of speech therapy and regular exercises the damage remains very severe.

David can't use the telephone, he finds social situations very frustrating (so avoids them a lot of the time!), and gets very miserable when I can't understand what he's trying to say. Another effect of the stroke was to partially paralyse his right hand, particularly the thumb and index finger, making fine movements impossible, such as cutting up food and typing. Again, despite various methods, exercises and devices the damage remains severe. Just to aggravate his disabilities, his hearing, which has been deteriorating over the last twenty years, has got even worse, limiting his social activities even more, especially in public with a lot of background noise.

In David's words: "Unlike some stroke victims, I have been lucky enough to have been nourished and protected by Hilary through our 48 years of marriage. Even so, our lives have been irreversibly damaged by the stroke, compounded by the poor hearing and compensations are hard to find. After five years I routinely get dark moods, depressed, enraged and desperate, and this has put a heavy load on Hilary as my prime carer.

ABOUT THE AUTHORS



Joanne Woodford is an Associate Research Fellow within the Mood Disorders Centre at the University of Exeter with a special interest in developing and improving access to evidence based psychological interventions for people with depression, especially for carers and relatives of people with physical health difficulties, such as stroke. Joanne has previously co-developed an online CBT self-help treatment for postnatal depression and contributed to the development of a treatment for people with chronic physical health conditions. Joanne is also involved in several educational programmes directed at training mental health professionals in the skills required to support patients in the use of CBT self-help materials.



Dr Paul Farrand is a Senior Lecturer within the Mood Disorders Centre and Director of Psychological Wellbeing Practitioner training within Clinical Education, Development and Research (CEDAR) at the University of Exeter. His main clinical and research interests are in the area of low intensity cognitive behavioural therapy (CBT), especially in a self-help format. Based upon his research and clinical practice he has developed a wide range of written self-help treatments for depression and anxiety.

Appendix 6.4: Problem Solving Booklet

HELPING RELATIVES AND CARERS OF STROKE SURVIVORS
OVERCOME DEPRESSION PROGRAMME

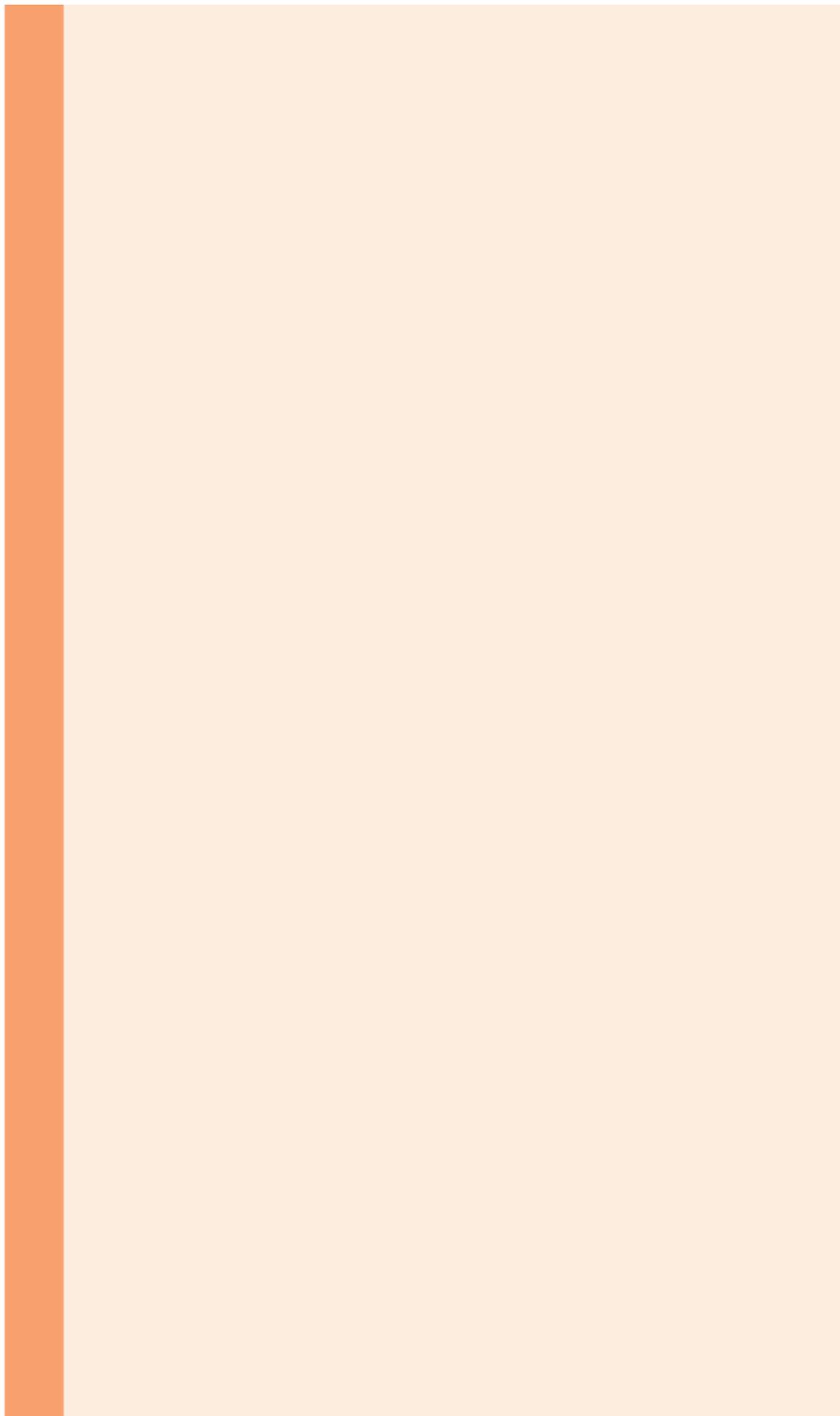


CEDArS
For Carers of Stroke Survivors

Problem Solving

Joanne Woodford, Paul Farrand





PART 1: WHAT IS PROBLEM SOLVING?

Problem solving is an evidence based treatment for low mood or depression. A lot of research has found it to be effective, especially for people who are experiencing stressful life events and difficulties, such as those that can be experienced as a carer of a stroke survivor.

Problem solving helps you to deal with problems you experience in life effectively. These may be significant life events or the day-to-day problems you may encounter.

But what is a problem?

A problem is a situation, task or activity that needs to be sorted out, however it is sometimes difficult to recognise an effective way to do this. There may be barriers getting in the way of being able to sort the problem or you are faced with lots of new tasks and activities that are part of the caring role. Here are a few common problems suggested to us by people caring for someone with stroke:

- The situation or task is a new one, such as caring for someone with a stroke, or taking on things the stroke survivor used to do, such as cooking or DIY.
- Competing demands, such as not having time to do activities for you and also care for someone with a stroke.
- Financial restrictions now you are carer.

If a problem is difficult to solve this can be stressful and impact on how you are feeling emotionally.

A solution is the way you cope with the problem. If a solution is successful this will have a positive effect on how you feel.



When we experience a major life event it often means other difficult life events or problems arise. For example, a loved one experiencing a stroke or becoming a carer is a major life event. Carers we have worked with have spoken to us about a number of other difficulties that may then be experienced:

- Financial difficulties
- Leaving work or education
- Giving up plans for the future or retirement
- Feeling alone
- Own health problems
- Relationship difficulties

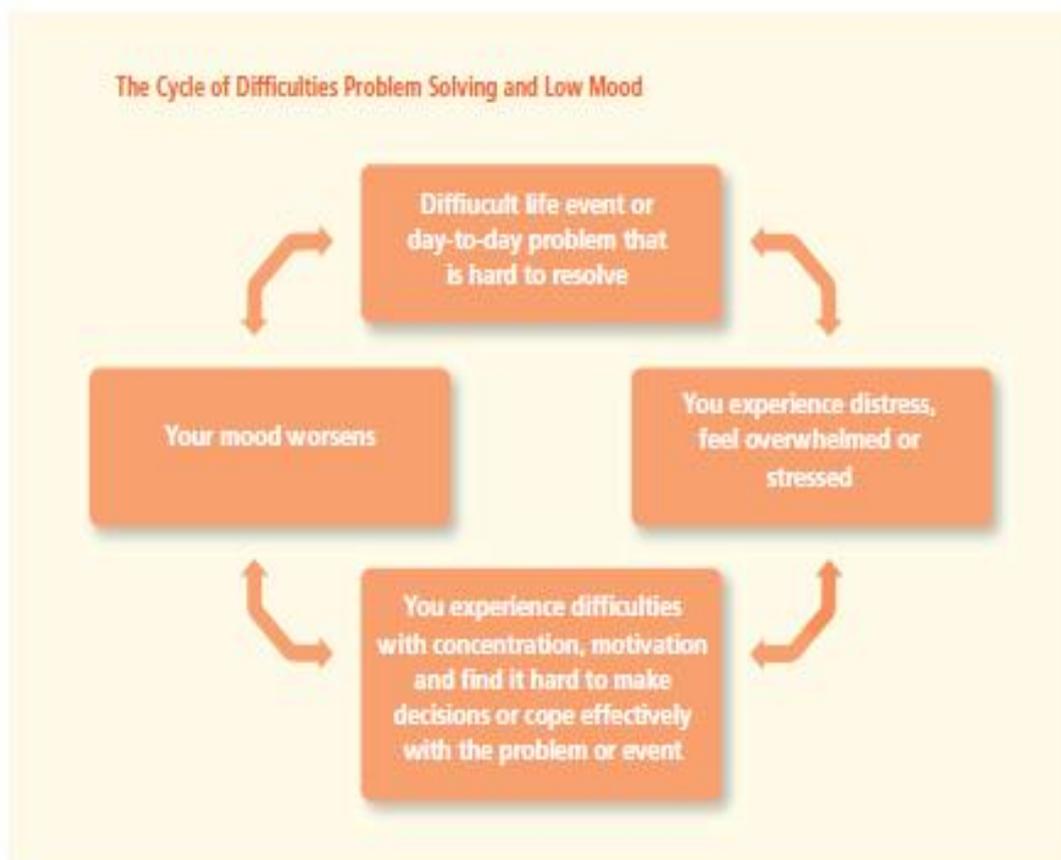
This can make you feel like your problems are increasing which is understandably overwhelming, distressing and can make things seem very difficult to manage. Stressful major life events and day to day problems can cause you to experience emotional difficulties such as low mood, depression or stress. If you then experience difficulties with coping with these problems you will experience increased emotional difficulties and distress.

PART 2: HOW DOES PROBLEM SOLVING WORK?

Difficult life events and day-to-day problems can impact how you feel emotionally. Difficulties managing these can end up resulting in you feeling low or depressed.

The symptoms of low mood or depression can also impact upon your ability to effectively solve these problems, like the 'vicious cycle' or 'downward spiral' mentioned in the 'Introduction' Booklet'.

Therefore both your depression and role as a carer may be impacting on your ability to solve the problems you may currently be experiencing. This can be seen in the diagram on the following page.



With problem solving you can break this vicious cycle by looking at more effective ways of coping with problems in your life. This will put the cycle in reverse and things will start to improve.

You may already feel like you have too many overwhelming problems to solve, or there are no solutions to your problems. This is normal and to be expected, especially as a busy carer of a stroke survivor. However, problem solving helps you identify problems that are important to you and find practical solutions.

Problem solving can also help you to distance yourself from problems that are not important and make things feel less overwhelming.

Your PWP is there to help you too if you find yourself struggling with any of the techniques in this booklet.

PART 3: GETTING STARTED

Step 1: What is really important to me in my life?

The first step is to think about what things in life are really important to you. This can help you prioritise which problems to focus on solving and can make things feel less overwhelming.

It is likely there will be many things of importance to you in your life. Carers we have worked with commonly identified things such as:

Caring for your
loved one

Your children or
grandchildren

Your Partner

Cooking nice meals

Seeing friends

Happiness

Although you may have many things that are important to you, first of all try and think about five or so things that are really important to you right now. This will help you chose which problems to focus on first of all. You can always come back to other things that are important in your life later.

Remember to write down what is important to you, rather than the things you feel you 'should' write down. Use 'Worksheet A: What is really important to me in my life' to record the things you have identified.

Worksheet A: What is really important to me in my life?



List the five most important things in your life right now below:

1	
2	
3	
4	
5	

Helpful Hint: Sometimes people find it helpful to think about the following areas in their life:

- Relationships
- Roles and responsibilities
- Social and leisure activities
- Health
- Finances
- Religious or spiritual life

Step 2: What are my problems?

The next step is to think about your current problems or things you find yourself worrying about, and write them down in 'Worksheet 8: My problems'. It is important to think about the types of things that can make you feel low or depressed no matter how small they might seem.



Worksheet B: My problems



1	
2	
3	
4	
5	
6	
7	
8	
9	
10	
11	
12	

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Step 3: Types of problems, difficulties or worries



Next have a think about what types of problems you are currently experiencing or worrying about.

There are 3 different types of problems:

Not important

These are problems that make you worry but they don't have anything to do with the things in life that are important to you. E.g., 'I was late getting my partner to stroke club' or 'I forgot the bread on my shopping list'. However, you may have problems not related to the things in life you find important but this doesn't necessarily mean they should be classed as unimportant. You can use the list of important things in your life as a guide but make your own judgement about what problems you consider important.

Important and can be solved

These are problems of importance and are relevant to your life that you need to actively work towards solving. Later in the booklet we will talk through ways to help solve these problems or worries. E.g., 'arguing with the person I care for' or 'I don't have many friends anymore who are not carers' or 'What if I forget my partner's medication.'.

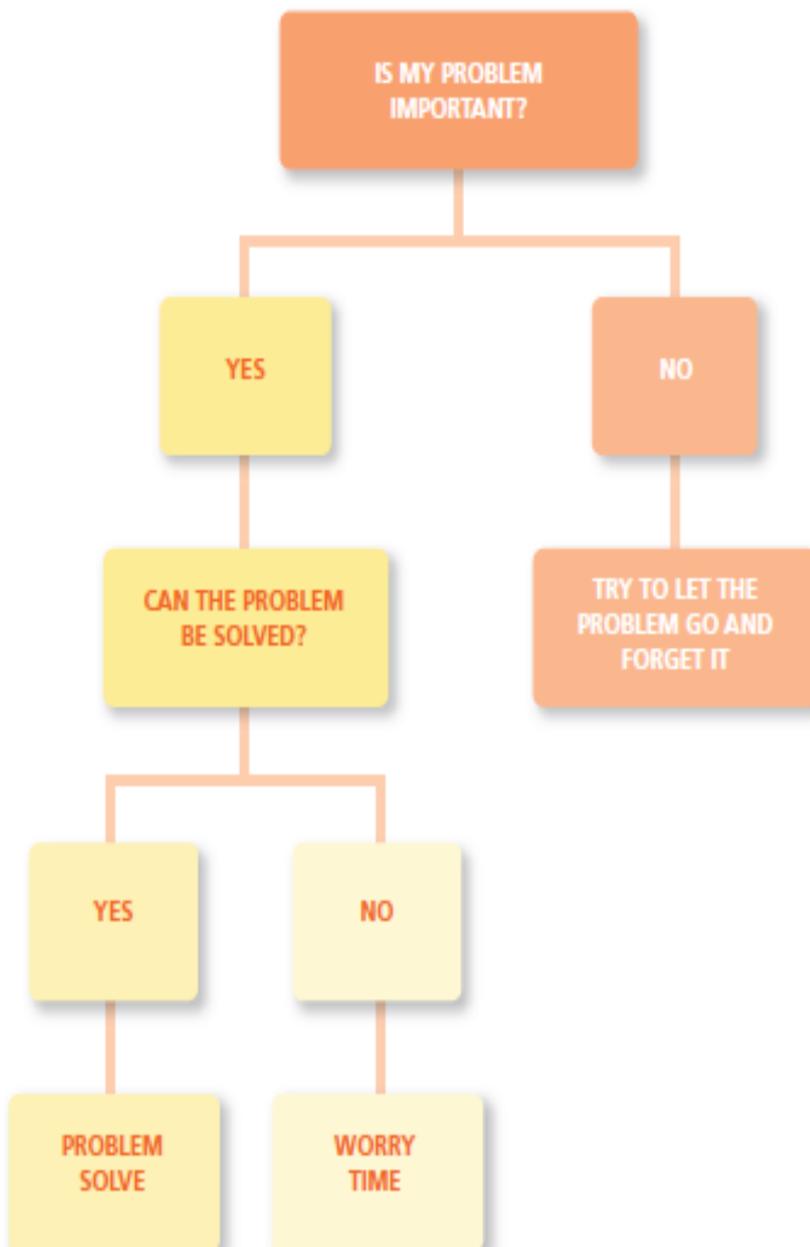
Important but cannot be solved

These are problems that have no way of being solved but they are still important to you. Sometimes these are life events or things that cannot be changed. For example, you cannot change that your partner has had a stroke. E.g., 'my partner has had a stroke' or 'I am now a full time carer and can't work again'.

Also you may find yourself worrying about things that might happen in the future. For example, 'What if the person I care for has a fall' or 'What if the taxi doesn't turn up to take my partner to stroke club.' These are known as 'hypothetical worries' and although you might dwell on these problems a lot there is no way of solving them.

Is my problem important?

After deciding what types of problems you are currently experiencing follow the diagram below to decide how to best deal with these problems



Next steps

'Try to let the problem go'

Although it can be very difficult to do it is important to try not to worry about problems that are not important. If you find yourself having difficulties with worrying about the problems you have categorised as not important you may want to go to 'Step 4: Problem Solving' if they have a practical solution, or 'Step 5: Worry Time' if they are problems or worries that can't be solved.

'Problem Solving'

If a problem is important and can be solved go to 'Step 4: Problem Solving' on page 12 to start to work towards overcoming these problems.

'Worry Time'

If a problem is important but cannot be solved go to 'Step 5: Worry Time' on page 19 that can help you let go of these problems and worries.



Step 4: Problem solving

Next we will look at ways to tackle the problems that are important to you and solvable.

Most of the problems we experience are solvable. When you are feeling low or depressed, or overwhelmed by the responsibilities of the caring role, it can seem like problems are too difficult to solve. However, there are seven stages that can be followed to help you to work towards practical solutions to your problems.

Stage 1a: Identify the Problem

The first stage is to pick a problem to work towards from your list of problems that can be solved that you identified in 'Worksheet C: The types of problems I am experiencing.'

It is important that the problem you decide to work on is as clear and precise as possible. For example 'problems with the person I care for' is not very precise or clear. A clearer problem may be 'communication difficulties with the person I am caring for due to their aphasia'. However, the problem cannot be too specific, for example 'I had an argument with the person I care for this morning because I didn't understand what they wanted' as this problem is too small to be solved.

Stage 1b: Converting Worries into Problems

You may have written down a number of worries on your list that have practical solutions. It is important to convert these worries into practical problems that you can work towards solving. For example, 'I am worried I am going to forget when to give my wife her medication' could be converted into 'I find it difficult to remember when to give my wife her medication'.

Or 'we're meant to be going out to dinner on Saturday with friends, what if there are problems getting in the restaurant with a wheelchair?' could be converted into 'I don't know if the restaurant we want to go to on Saturday is wheelchair friendly'. Sometimes converting worries into practical problems can be tricky. If you find yourself having difficulties your PWP will be able to help you.

Once you have identified the problem you would like to solve write it down on 'Worksheet D: Problem Solving Record'.

Stage 2: Identify the Solution

Try to identify as many potential solutions as possible. Don't worry if the solution seems ridiculous- at this stage nothing should be rejected.

Stage 3: Analyse Strengths and Weaknesses

Next think about the strengths and weakness of each of the potential solutions you have identified to allow you to think about the main advantages and disadvantages of each solution. You can use 'Worksheet E: Strengths and Weaknesses Analysis' to write these down.

Try to think about the following:

- Is the solution likely to work?
- Are you going to be able to try out the solution?
- Do you have everything you need to try out the solution?

In the final column put a 'yes' for any solutions you would like to try out, a 'maybe' for those you may want to think about more later and 'no' to those solutions you feel you can currently reject.

Stage 4: Select a Solution

On the basis of the strengths and weaknesses analysis of the potential solutions pick a solution you would like to try out. When selecting a solution think carefully about whether you have the resources to try out the solution as if you don't have the necessary resources it will only lead to failure.

Stage 5: Planning Trying out the Solution

Try to think about the steps you need to follow to try out your solution. Some solutions may require careful planning and a number of steps to be achievable. It is important to think about these carefully to increase the likelihood of the solution working. You may want to think about what resources you need to carry out the solution, for example, time, support, financial, equipment etc. Try to think about the steps that you will need to follow in a logical and linked way. It is also really important to write a specific plan. Using the 'Four Ws' – 'what', 'where', 'when' and 'with whom', will help with this. Write down your plan in 'Worksheet D: Problem Solving Record.'

Stage 6: Trying out the Solution

Next you need to put your plan into action! It is really important to write down what you did and how it went. You can use 'Worksheet F: How Trying out my Solution Went' to record this. Try and write down exactly what you did as this can help you highlight things that went well, or things that didn't go so well that you might want to do differently next time.

Stage 7: Review

Now use 'Worksheet F: How Trying out my Solution Went' to review how well your solution worked. Some solutions may have worked, some may have worked a little or some may not have worked at all. Don't worry if your plan didn't work this time. Some problems are very difficult and complex and may need more than one plan to solve. If the solution has worked you may want to think about generating new ones, based on what you learnt here, to apply to other problems. If it did not work, then perhaps go back to Step 4 and consider a new solution to try.

Worksheet D: Problem Solving Record

Stage 1: Identify a Problem

What is the problem I would like to try and solve?

Stage 2: Identify Potential Solutions

What are the potential solutions?

Stage 3: Strengths and Weaknesses Analysis

Use Worksheet E to write these down for each solution considered



Stage 4: Solution Section

What solution am I going to try out?

Stage 5: Planning Trying out the Solution

What steps will I follow to apply my solution?

E.g., What, when, with whom, where? What resources do I need?

What logical steps do I need to follow?

Stage 6: Trying out the Solution

Use Worksheet F to keep a diary of what you did

Stage 7: How did it go?

Use Worksheet F to review how well your solution worked

Worksheet E: Strengths and Weaknesses Analysis

My Problem Write the problem here:

What are the strengths and weakness of each solution? Write these below:

Solution	Strengths
<hr/> <hr/> <hr/>	<hr/> <hr/> <hr/>
<hr/> <hr/> <hr/>	<hr/> <hr/> <hr/>
<hr/> <hr/> <hr/>	<hr/> <hr/> <hr/>
<hr/> <hr/> <hr/>	<hr/> <hr/> <hr/>
<hr/> <hr/> <hr/>	<hr/> <hr/> <hr/>

Worksheet F: How Trying out my Solution Went



Stage 6: Trying out the Solution

What exactly did I do?

Stage 7: How Did it Go?

How did it go? What went well? What didn't go to plan?

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Step 5: Worry time

Even when problems are not solvable it can be really difficult not to worry about them. Worry is something that we all experience on a day-to-day basis however sometimes worrying about things can become a problem and can get in the way of us doing other things.

Sometimes you may worry about a problem that has a practical solution. If you find yourself worrying about a problem that something can be done about it is important to use the 7 stages of problem solving discussed earlier in order to work through problems that are important and solvable.

However, you may find yourself worrying about problems that can't be solved, for example, a hypothetical worry about the future such as 'my partner may have another stroke' or 'what if the person I care for falls whilst I pop up to the shop'.

Although it is important to try and 'let go' of worries that have no practical solution, this is much easier said than done. One solution that some carers told us they find helpful is to schedule something called 'Worry Time'. This allows you to plan time to worry about problems but at a specific time so these worries don't take over your life. You can try following these three steps to help you with these worries:

Step 1: Schedule Worry Time

Think about a period of time each day that you can allow yourself to worry. 20 – 30 minutes should be enough. When you schedule your worry time is completely up to you. Having scheduled worry time can help stop your worries from impacting you during the rest of the day as you know you have this piece of time where you can worry. It is important that you are not disturbed during worry time as far as possible. You might want to let others know not to disturb you, turn your phone on silent and find somewhere quiet for example.

Step 2: Writing your Worries Down

Scheduling worry time won't stop worries from popping into your head during the day. However, as they do write these worries down and set them aside until your scheduled worry time. You can use the 'Worksheet G: Worry Time' on the next page to do this. This can help reduce the impact of the worry as you know you can go back to these worries during your scheduled worry time.

Once you have written the worry down try to focus again on the present. Sometimes it may help to do something different to what you were doing before. Remember you have set aside time later to worry and try to let the worry go for now.

Worksheet G: Worry Time



My scheduled worry time is at:

My Worries

1

2

3

4

5

Step 3: Your Worry Time

When it is your scheduled worry time read through the worries that you have written down during the day. You can use this time to worry about these problems. Sometimes you might find they are no longer a worry for you now it is later in the day. If this is the case put a line through the worry. If the worries you have written down do have a practical solution then go back to the 7 stages of problem solving discussed earlier in order to work through 'Problems that are important and solvable'. Using worry time effectively does take time and practice. However, over time you may find this a useful technique to reduce the impact your worries are having on you on a day-to-day basis.

Next Steps

As you work towards your problems remember to review your list of problems on a regular basis. You should be able to start to tick off unimportant problems that no longer bother you and the important and solvable problems you are starting to work towards. Problems that cannot be solved may stay on the list for longer, but cross these off when you find they no longer bother you as much too.

As you work through your main problems and difficulties you should find yourself having more time to work towards things that are really important in your life – the things you identified in 'Worksheet A: What is really important to me in my life?'

A number of the problems and difficulties you have already started to work on will likely be around these important areas of your life but as you work through solving these problems you should find yourself having more time to concentrate on more areas of life that are important to you.

PART 5: COMMON DIFFICULTIES WITH PROBLEM SOLVING

I am having problems letting go of life events that can't be changed. Sometimes we may find our problems are things that have happened that cannot be changed, for example 'my partner had a stroke' or 'I've had to give up my career'.

The way in which we cope with important events and losses that cannot be changed is very individual. Some people find talking to someone they trust helpful. Others find talking to people who have experienced a similar event helpful.

When coping with such events it is likely that you will experience difficult emotions such as low mood, depression, anger or worry. These emotions are completely normal and to be expected. It is important to accept these difficult emotions as they are part of the acceptance process we go through when experiencing difficult life changing situations or losses.

However, if you identify that accepting these life events or losses is your main difficulty it is important you speak with your PWP as you may need a different type of support.



The problem I am working on seems too big

You may have identified problems that seem too big or overwhelming to solve. This is very normal and to be expected, especially if they are problems you have been looking to solve for some time.

One way of helping with problems that seem too big or overwhelming is to look at breaking them down.

For example, you may have identified that a problem such as 'the house is a mess' and you don't have the time or energy to keep up with the housework. Cleaning the house is actually made up of lots of smaller activities that may be more achievable in the short term. For example, you could break this down into cleaning specific rooms, or performing specific tasks such as hovering or changing the bedding.

Other problems might be very complex, for example difficulties paying the mortgage. When breaking down a difficulty with finance you may want to think about the different components such as how much debt you have, what your income is now you are a carer and what your expenditure is.

If you find yourself struggling with breaking your problems down speak to your PWP who will be able to help.



PART 6: TOM'S RECOVERY STORY

I am 72 years old and my wife Mary had her stroke 2 years ago. Mary suffers from aphasia and also has memory difficulties. When she had her stroke it was like her whole personality had changed, she would get really angry and lose her temper a lot and I found it really difficult to manage. We also had a lot of difficulties communicating with one another which we found frustrating and it put a huge strain on our relationship. I stopped our friends coming over as they didn't really know how to deal with Mary's communication difficulties and never took up offers of support from my grandchildren as I worried they wouldn't be able to understand what she needed, or she might get angry with them. Over time I ended up having to stop doing lots of things I used to enjoy, like playing bowls or watching the local football team play and felt more and more alone. I had to take on a lot of responsibilities around the house too that were totally new to me, like the housework and cooking that I found really tough.

One day when dropping Mary off at the stroke club I broke down to one of the carers. He told me he had experienced similar difficulties and seen someone at his local GP practice that had helped him. I was really unsure. I couldn't see how speaking with someone could help with all my problems. However I decided to speak with my GP and two weeks later I had an appointment with my PWP Charlotte. Charlotte asked me a lot of questions about the things going through my head, how I felt in my body and what things I was doing more or less of. We also spent a lot of time talking about how I was managing becoming a carer and the impact being a carer had on my life. Charlotte explained the vicious cycle of depression to me, and it made sense that what I did, what I was thinking and how I felt physically all impacted on one another and made things worse. We also spent some time talking about how when we experience difficult life events like becoming a carer we may experience lots of other new problems and difficulties that can feel impossible to tackle. Charlotte said that low mood can also make our ability to work on difficulties and problems harder, for example feeling tired and having little energy. Charlotte gave me the 'Introduction Booklet' to read so I could go away and decide on which treatment I wanted to work with.

I met with Charlotte the following week and told her that I liked the look of problem solving. It seemed like a practical solution and I could identify with having a lot of problems I felt I couldn't solve.

I started with thinking about the things that were important and of value to me. I found this quite easy and realised that most of the important things were around my relationship with Mary, grandchildren and friends and I noted these down on 'Worksheet A: What is really important to me in my life?'

Worksheet A: What is really important to me in Tom's life?

List the five most important things in your life right now below:

1	My relationship with my wife Mary
2	My relationship with my grandchildren
3	My relationship with my friends
4	Playing bowls
5	Being a good husband and carer for Mary

Next I wrote down all the problems I was currently experiencing into 'Worksheet B: My problems'. Once I got started I realised just how many things there were and it all seemed a bit too much.

Worksheet B: My problems

1	Communicating with Mary
2	I forgot to pick up milk and bread last week and had to go out again
3	Losing my patience with Mary
4	Not being able to play bowls
5	Not seeing my friends at football matches
6	My friends not understanding Mary's difficulties
7	What about if I can't cope and Mary is taken away from me?
8	Not having any time to myself
9	Accepting my grandchildren's offers to help with Mary
10	I am afraid Mary might have another stroke
11	My wife has gone now she has had a stroke
12	I was late getting Mary to stroke club

Charlotte described the three types of problems that we experience: those that were not important; those that were important and could be solved and those that were important but couldn't be solved. Charlotte explained it was important to identify problems that have practical solutions so we could start to work on those difficulties. She explained that sometimes the problems we experience aren't actually that important and that we should try not to worry about these difficulties and focus on those that are important to us. We also spoke about problems that were important but couldn't be solved. Sometimes these are life events that couldn't be changed but I needed to try to come to terms with, however difficult that would be. She also described how we sometimes worry about hypothetical problems, like things that might happen but we can't control. I recognised that I had worries like this, such as 'what if Mary has another stroke'. Charlotte said that we could use something called 'Worry Time' if I found myself having difficulties letting go of these worries.

I then spent some time in the session moving my problems into 'Worksheet C: The types of problems I am experiencing'. I noticed that most of my problems were solvable and many of them were around my relationship with my wife, my grandchildren and friends.



Worksheet C: The types of problems Tom is experiencing

Not important	Important and can be solved	Important but cannot be solved
<p>I forgot the milk when I went to the corner shop and had to go out again</p>	<p>Communicating with Mary</p> <p>Losing my patience with Mary</p>	<p>What about if I can't cope and Mary is taken away from me?</p>
<p>I was late getting Mary to stroke club</p>	<p>Accepting my grandchildren's offer to help look after Mary</p>	<p>What if Mary has another stroke</p>
	<p>Not being able to play bowls</p>	<p>My wife has gone now she has had a stroke</p>
	<p>Not seeing my friends at football matches</p>	
	<p>My friends not understanding Mary's difficulties</p>	
	<p>Not having any time to myself</p>	

I then selected a problem I thought I would like to work on from my 'Important but Solvable' list and to write the problem into Stage 1 on 'Worksheet D: Problem Solving Record.' Initially I wrote down 'Communicating with Mary' as the problem I wanted to work on. But Charlotte pointed out it was important to make sure the problems I work on are as specific as possible. I tried to make the problem more specific but found this really tough. Charlotte helped me by asking me to think carefully about what problems I experienced communicating with Mary, how I wanted to communicate with her and what I wanted as a result. This really helped me think about how I wanted to word the problem and I came up with: 'I find it difficult to communicate with Mary because of her aphasia and we argue and get frustrated with one another'. This was a problem that impacted on myself and Mary and I knew the problems we were having in our relationship were due to us not knowing how to communicate with one another. I felt that this was a really important problem to solve and would have a really big impact on my mood.

I then wrote down all the solutions I could think of to help solve the problem. I found this really difficult but Charlotte told me that at this stage it was important to think about all solutions, even if they seemed silly. After I had managed to come up with a few potential solutions I moved onto Stage 3 and thought about the strengths and weakness for each of the solutions I had identified and wrote these down 'Worksheet E: Strengths and Weaknesses Analysis.'

Charlotte and I started to write these down in the session and I was encouraged to carry on doing this as homework. Charlotte emphasised that if I wanted to I could move onto selecting a solution, planning the solution and trying it out if I felt comfortable doing this before we next met.

Whilst at home I carried on writing down the strengths and weaknesses for each solution. Looking through the strengths and weaknesses I had identified it was clear there were two solutions that looked particularly good: 'speak to the Connect to get some advice about how to communicate with someone with aphasia' and 'speak to some of the carers at the stroke club to get some tips about how they communicate with the person they care for'. Both seemed like really good ideas but I decided to speak with Connect first of all. I remembered reading about them in the 'Introduction Booklet' and it seemed they might be able to provide some really good advice that might be more specific to Mary's difficulties. I wrote down the solution I decided to try out in Stage 4 in 'Worksheet D: Problem Solving Record.'

Next I thought about what steps I would need to follow to try out the solution. Charlotte had explained to me in the last session that I should try to be specific about my plan and the steps I would need to follow, and that it was important to think about the four Ws: What, When, With Whom and where. I realised I would need to call when I had some spare time. Mary often had a nap in the afternoon at about 3pm so I decided that would be a good time to call. I was also a bit worried about asking the wrong questions. So I decided to write down everything I thought they would want to know about Mary's difficulties and also exactly what I wanted to find out so I would hopefully not forget anything important. Breaking down the solution into these different steps was really helpful and calling them didn't seem so overwhelming.

Next I put my plan into action and recorded how it went in 'Worksheet F: How Trying out my Solution Went.' The following week I had my next appointment with Charlotte. It was great telling Charlotte how I had got on. Connect were really helpful and provided me with lots of advice about how to communicate better with Mary. I didn't realise things like having background noise like the TV would be really difficult for Mary.

They also sent me a really good information pack that was helpful for both Mary and I to look through together. In my appointment with Charlotte we spoke about what problem I would start to work through next. I decided that getting the information pack on aphasia might be helpful with some of the other problems I was experiencing. One of my problems was that our friends didn't really understand Mary's difficulties or how to communicate with her. I was also worried about letting our grandchildren help out. I realised that one of my worries was around them not being able to cope with Mary's communication difficulties. However I realised that sharing the information pack with my friends and grandchildren might help with this.

Over the next few weeks things really started to improve. Once I felt comfortable having the grandchildren over and leaving them with Mary I was able to find time to play bowls and I have even managed to see Rutterbridge Rovers with Stan a couple of times at the weekend, blimey I thought I had problems!! Although I still have difficulties being a carer they feel a lot less overwhelming now. It is really useful to have a structured way of breaking my problems down and finding practical solutions to them.



Worksheet D: Tom's Problem Solving Record

Stage 1: Identify a Problem

What is the problem you would like to try and solve?

I find it difficult to communicate with Mary because of her aphasia and we argue and get frustrated with one another'

Stage 2: Identify Potential Solutions

What are the potential solutions?

Leave the room when we have an argument

Use a dictionary

Look for tips online

Speak to Connect to get some advice about how to communicate with someone with aphasia

Speak to some of the carers at the stroke club to get some tips about how they communicate with the person they care for

Stage 3: Strengths and Weaknesses Analysis

Use Worksheet E to write these down for each solution considered

Stage 4: Solution Section

What solution am I going to try out?

Speak to Connect to get some advice about how to communicate with

someone with aphasia

Stage 5: Planning Trying out the Solution

What steps will I follow to apply my solution?

E.g., What, when, with whom, where? What resources do I need?

What logical steps do I need to follow?

Go through Mary's medical notes and make sure I write down everything

Connect might want to know.

Write down the specific difficulties I experience communicating with Mary to

see if they can provide me with specific advice around these problems.

Call Connect on Thursday afternoon at around 3pm when Mary is taking her nap.

Stage 6: Trying out the Solution

Use Worksheet F to keep a diary of what you did

Stage 7: How did it go?

Use Worksheet F to review how well your solution worked

Worksheet E: Tom's Strengths and Weaknesses Analysis

My Problem Write the problem here:

I find it difficult to communicate with Mary because of her aphasia and we argue and get

What are the strengths and weakness of each solution? Write these below:

Solution	Strengths
Leave the room when we have an argument	It gives me a chance to cool down
Use a dictionary	Might help Mary to find what she wants to say to me
Use the internet to look for tips	Should be able to get lots of ideas to try out
Speak to the Charity Connect to get some advice about how to communicate with someone with aphasia	I should be able to get some specific advice to Mary's difficulties. They are a national charity and specialise in aphasia so they are a trusted source
Speak to some of the carers at the stroke club to get some tips about how they communicate with the person they care for	Quite a few people at the stroke club have aphasia so some of the carers will likely have some really good tips. It will make me feel less isolated if I can share my problems with people who understand

Frustrated with one another

Weaknesses	Choice (Yes/ No/ Maybe)
It isn't really going to solve the problem. We will still have arguments which I find distressing	No
Sounds really time consuming and might make us both more frustrated	No
I don't really like searching for tips online because there are so many and I never know where to start or which tips would be best with Mary's problems	Maybe
Need to find the time to call them. I am not sure what questions to ask, what if I ask the wrong thing and sound stupid	Yes
The stroke survivors may have different problems to Mary so the tips might not work for her. I don't want the carers to think I can't cope. I don't normally speak to the carers at stroke club so I feel a bit uncomfortable asking for their advice	Yes

Worksheet F: How Trying out Tom's Solution Went

Stage 6: Trying out the Solution

What exactly did I do?

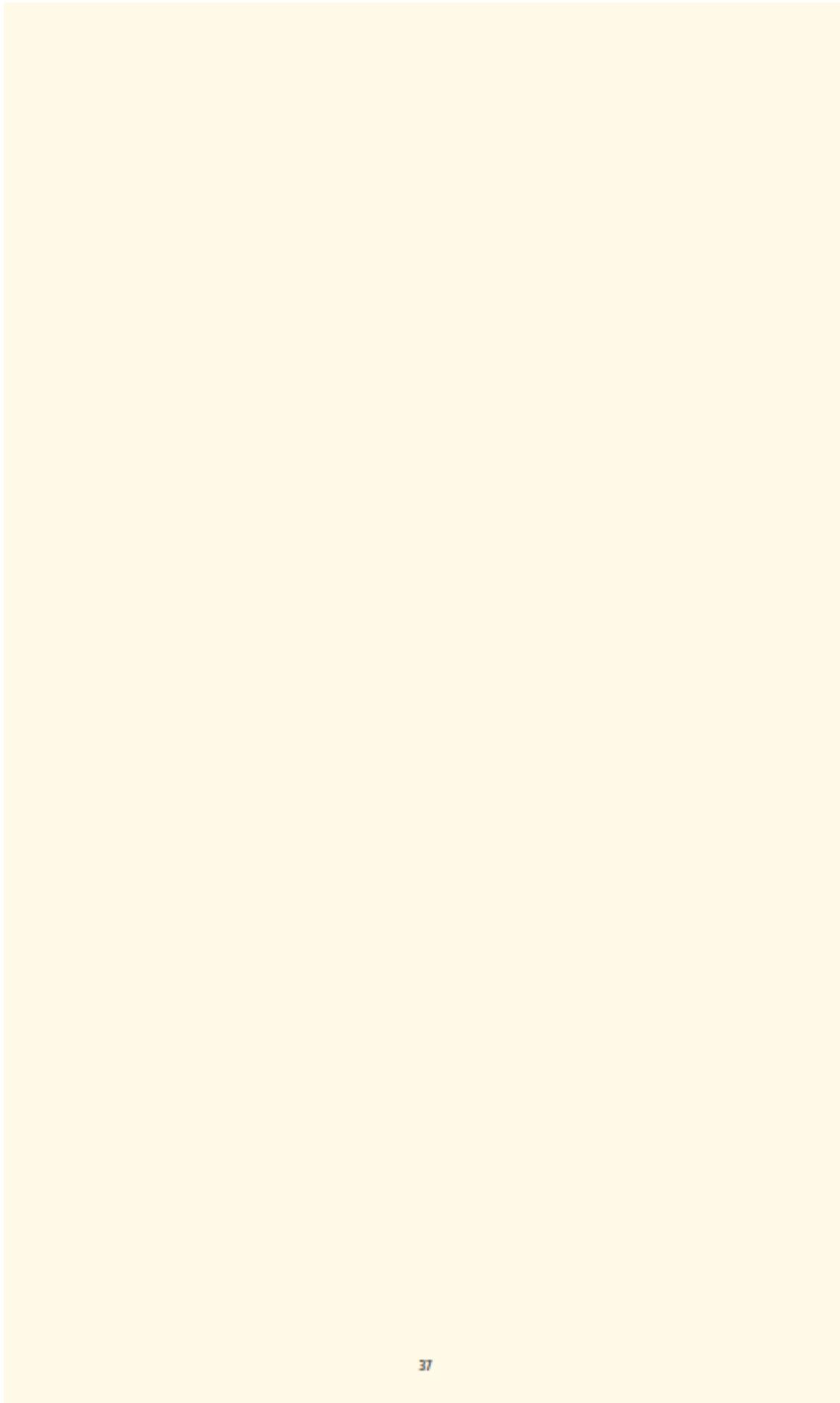
I noted down all of Mary's difficulties when Mary had her afternoon nap on Monday so I was prepared if Connect asked me any questions. I thought about all the communication problems Mary and I had so I could ask about specific advice around dealing with these difficulties. Some of these came to me straight away but I also spent a couple of days jotting down difficulties when they arose to help ensure I didn't leave anything out.

On Thursday afternoon when Mary was having her nap and I made sure I had all the information I needed and a pen and paper and called Connect to speak with one of their advisers.

Stage 7: How Did it Go?

How did it go? What went well? What didn't go to plan?

I think it went really well. Connect spent a long time on the phone with me and gave me some great information. I felt much more comfortable calling them knowing that I had all the questions I wanted to ask written down. It was good to identify a time when Mary would be asleep so I wouldn't be disturbed whilst on the phone. Connect have also sent me an information pack which I was able to share with Mary. I am also going to use the problem solving technique to speak with our friends about Mary's communication difficulties so they can start to come around again. I think it would be helpful to share this information with my grandchildren and then I might feel more comfortable taking them up on their offers to help out with Mary so I can get a break.



CEDARS LIVING EXPERIENCE GROUP

As well as interviewing a number of carers and relatives of stroke survivors the treatment booklets were also developed closely with the three members of the CEDArS Lived Experience Group.

A little about Celia

I am the sole carer for my partner who had a stroke 2 years ago at the age of 59. By the time he was correctly diagnosed with a stroke (2 weeks later) he had suffered more than one and consequently has damage in different areas. His main problems are weakness down the right hand side and extensive neurological damage. The latter took some time and a lot of research to ascertain exactly what the problems were. Initially it was a huge shock to both of us, but I bore the brunt of it as he seemed immune from worries of the present or the future.

I obtained an MA in Social Care quite late in life, after getting a degree in Politics at 42. I immersed myself in working as a frontline Social Worker with Care Leavers, aged 16-21 and helped develop the team, as the legislation for committing to this age group was new. I also helped write some of Exeter City Councils' policy on Homelessness. When my partner had his stroke I changed to part time work so that I could be his carer but found it hard to fully commit to either task. I left work after 15 months and made his rehabilitation my goal. Initially I channelled myself into basic household tasks for him-later expanding this to the outside world: using a bus pass; ordering and collecting his prescriptions; buying things in a shop etc. I think the trickle of progress has encouraged me and helped me refrain from thinking 'what was', as I cannot change that. Being involved with this project activates my brain, utilises my academic skills and hopefully keeps me at the forefront of stroke advances so that I can continue our long road ahead.

A little about Hilary

For the first fourteen years of our marriage I was a mother of three children, and a housewife, as well as doing the occasional job as for instance, a bar-maid. Our youngest daughter was born profoundly deaf, as a result of which I became interested in education. I helped out at Holiday Playschemes and helped organise and run Toy Libraries for disabled children. This led me to do an English A level when I was 34, then to get a B.Ed degree when I was 38. For a few years I worked as a Care Assistant in a Hostel for people recovering from mental illness, eventually getting a job as an English teacher when I was 44 years of age.

Life with David has obviously been very difficult since his stroke, but my experiences in life have given me a certain amount of patience, something that is greatly needed in our situation. I can communicate in British Sign Language, but David, sadly, can't. He tried to learn over twenty years ago but found it impossible to remember which hand to use, and/or which sign meant what. Anyway, it would be almost impossible to use British Sign Language as he only has the one hand now, so his iPad, with its Grid Player 'qwerty' keyboard, and space for words to be typed, is absolutely invaluable, and has 'saved our lives' nearly every day for over five years now.

A little about David

David studied psychology at University, became a Social Worker, which job he did for many years, ending up as an Assistant Manager, then became a University lecturer in Social Work. He had a severe stroke at the age of 65, caused by a clot, mostly caused by more than 40yrs of smoking even though he had given up 7 years before. The damage was in the left brain which left him with great difficulty in forming and saying words - despite sessions of speech therapy and regular exercises the damage remains very severe. David can't use the telephone, he finds social situations very frustrating (so avoids them a lot of the time!), and gets very miserable when I can't understand what he's trying to say. Another effect of the stroke was to partially paralyse his right hand, particularly the thumb and index finger, making fine movements impossible, such as cutting up food and typing. Again, despite various methods, exercises and devices the damage remains severe. Just to aggravate his disabilities, his hearing, which has been deteriorating over the last twenty years, has got even worse, limiting his social activities even more, especially in public with a lot of background noise.

In David's words: "Unlike some stroke victims, I have been lucky enough to have been nourished and protected by Hilary through our 48 years of marriage. Even so, our lives have been irreversibly damaged by the stroke, compounded by the poor hearing and compensations are hard to find. After five years I routinely get dark moods, depressed, enraged and desperate, and this has put a heavy load on Hilary as my prime carer."

ABOUT THE AUTHORS



Joanne Woodford is an Associate Research Fellow within the Mood Disorders Centre at the University of Exeter with a special interest in developing and improving access to evidence based psychological interventions for people with depression, especially for carers and relatives of people with physical health difficulties, such as stroke. Joanne has previously co-developed an online CBT self-help treatment for postnatal depression and contributed to the development of a treatment for people with chronic physical health conditions. Joanne is also involved in several educational programmes directed at training mental health professionals in the skills required to support patients in the use of CBT self-help materials.



Dr Paul Farrand is a Senior Lecturer within the Mood Disorders Centre and Director of Psychological Wellbeing Practitioner training within Clinical Education, Development and Research (CEDAR) at the University of Exeter. His main clinical and research interests are in the area of low intensity cognitive behavioural therapy (CBT), especially in a self-help format. Based upon his research and clinical practice he has developed a wide range of written self-help treatments for depression and anxiety.





The **Dunhill Medical Trust**

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Appendix 6.5: Staying Well Booklet

HELPING RELATIVES AND CARERS OF STROKE SURVIVORS
OVERCOME DEPRESSION PROGRAMME



CEDArS

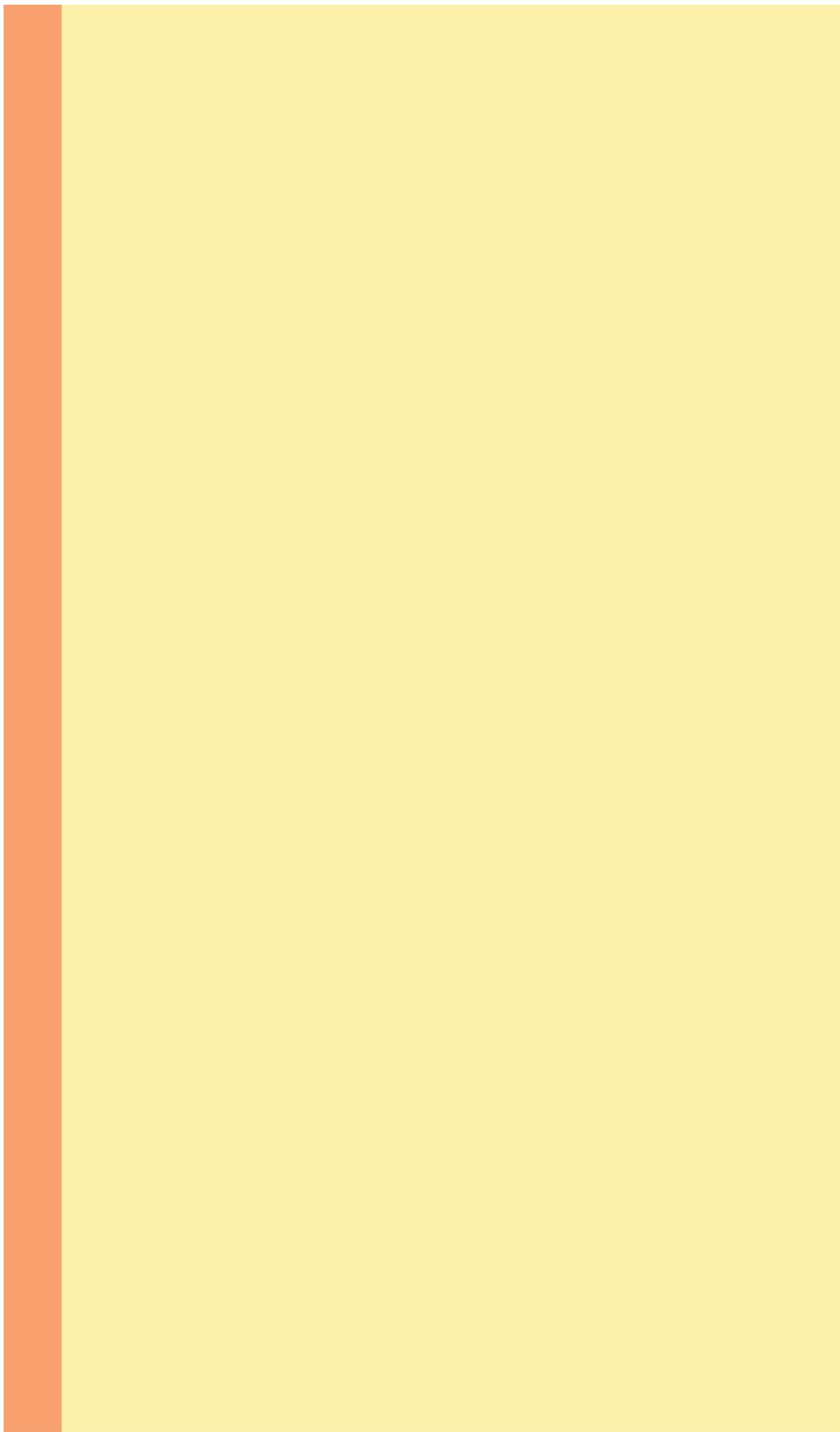
For Carers of Stroke Survivors

Helping You to Stay Well

Joanne Woodford, Paul Farrand



UNIVERSITY OF
EXETER



WELL DONE FOR GETTING THIS FAR

You have now completed all the steps that can help you to feel better and remain well. It is now important to try and make the strategies you have learnt in this programme part of your daily life so you can stay well in the future.

Over the last few weeks you have hopefully noticed your mood improve as you have started to engage in important and meaningful activities that can help bring your life purpose and help you to stay well. You may have started doing activities again that you had stopped doing for a while. You may have started new activities or begun working towards new goals. Hopefully you have started to regain some balance again in your life.

Helping You to Stay Well

It is important to think about what has been helpful for you during this programme so you can stay well in the future. There may be certain strategies you have learnt during the programme that have been helpful - it is really important to make these part of your daily life so that you keep well.

Experiencing setbacks, challenges and difficulties in life is normal. This can especially be the case when we are caring for someone with a stroke. Also, everyone experiences dips in their mood from time-to-time - this is perfectly normal and to be expected. However, it is important to keep an eye on your mood just in case you experience a dip and it doesn't improve on its own.

A good starting place can be to think about the signs and symptoms that may indicate you are not well, or coping as well as normal. These may be signs that you are experiencing low mood or depression again.

MY LOW MOOD WARNING SIGNS

It can be really helpful to write down the warning signs that may indicate you are experiencing low mood or depression. You can refer back to these signs if you feel you are struggling in the future.

It can be useful to think about your warning signs in terms of the 'vicious cycle' or 'downward spiral' we spoke about in the 'Introduction Booklet'. These are the changes in behaviours, thoughts and physical feelings that you experience when feeling depressed or low. Have a think about what your warning signs are and write them down. You may want to look back at the 'vicious cycle' or 'downward spiral' you put together at the beginning of the programme if you struggle with this.

Physical Feelings

Behaviours

Feelings

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MY STAYING WELL TOOL KIT

Next it can be helpful to write down what activities, strategies or techniques you have found helpful in the programme with your low mood. You can then refer back to these in the future if you find your low mood or depression returning.

Remember: Simply experiencing any of these symptoms for a short time will be perfectly normal. However if you find yourself experiencing them for a while and it is beginning to have an impact on your life again then you may need to do something about it.



What activities helped me to feel better the last time I was depressed?

What techniques in this programme were particularly helpful?

What skills have I learnt during this programme?

CHECKING IN WITH YOURSELF

As you finish the programme it can be helpful to find a regular time to check in with yourself to see how you are doing.

You may find this useful to continue for a number of weeks after finishing the programme to help ensure you are keeping up the activities that have helped you to feel better and are making them part of your daily life so that you stay well.

My Check-In

- When will I check in with myself? E.g., every Monday morning
- How many weeks will I check in with myself? E.g., for the next 5 weeks
- What will I do during my check in? You may want to ask yourself the following questions.

What activities slipped?

What activities have I been able to keep up?

What has helped me to keep up these activities?



What has led to these activities slipping?

Am I experiencing any warning signs?

What could I do to help me start doing these activities again?

If so, what might it be helpful to do?

CEDARS LIVING EXPERIENCE GROUP

As well as interviewing a number of carers and relatives of stroke survivors the treatment booklets were also developed closely with the three members of the CEDArS Lived Experience Group.

A little about Celia

I am the sole carer for my partner who had a stroke 2 years ago at the age of 59. By the time he was correctly diagnosed with a stroke (2 weeks later) he had suffered more than one and consequently has damage in different areas. His main problems are weakness down the right hand side and extensive neurological damage. The latter took some time and a lot of research to ascertain exactly what the problems were. Initially it was a huge shock to both of us, but I bore the brunt of it as he seemed immune from worries of the present or the future.

I obtained an MA in Social Care quite late in life, after getting a degree in Politics at 42. I immersed myself in working as a frontline Social Worker with Care Leavers, aged 16-21 and helped develop the team, as the legislation for committing to this age group was new. I also helped write some of Exeter City Councils' policy on Homelessness. When my partner had his stroke I changed to part time work so that I could be his carer but found it hard to fully commit to either task. I left work after 15 months and made his rehabilitation my goal. Initially I channelled myself into basic household tasks for him-later expanding this to the outside world: using a bus pass; ordering and collecting his prescriptions; buying things in a shop etc. I think the trickle of progress has encouraged me and helped me refrain from thinking 'what was', as I cannot change that. Being involved with this project activates my brain, utilises my academic skills and hopefully keeps me at the forefront of stroke advances so that I can continue our long road ahead.

A little about Hilary

For the first fourteen years of our marriage I was a mother of three children, and a housewife, as well as doing the occasional job as for instance, a bar-maid. Our youngest daughter was born profoundly deaf, as a result of which I became interested in education. I helped out at Holiday Playschemes and helped organise and run Toy Libraries for disabled children. This led me to do an English A level when I was 34, then to get a B.Ed degree when I was 38. For a few years I worked as a Care Assistant in a Hostel for people recovering from mental illness, eventually getting a job as an English teacher when I was 44 years of age.

Life with David has obviously been very difficult since his stroke, but my experiences in life have given me a certain amount of patience, something that is greatly needed in our situation. I can communicate in British Sign Language, but David, sadly, can't. He tried to learn over twenty years ago but found it impossible to remember which hand to use, and/or which sign meant what. Anyway, it would be almost impossible to use British Sign Language as he only has the one hand now, so his iPad, with its Grid Player 'qwerty' keyboard, and space for words to be typed, is absolutely invaluable, and has 'saved our lives' nearly every day for over five years now.

A little about David

David studied psychology at University, became a Social Worker, which job he did for many years, ending up as an Assistant Manager, then became a University lecturer in Social Work. He had a severe stroke at the age of 65, caused by a clot, mostly caused by more than 40yrs of smoking even though he had given up 7 years before. The damage was in the left brain which left him with great difficulty in forming and saying words - despite sessions of speech therapy and regular exercises the damage remains very severe.

David can't use the telephone, he finds social situations very frustrating (so avoids them a lot of the time!), and gets very miserable when I can't understand what he's trying to say. Another effect of the stroke was to partially paralyse his right hand, particularly the thumb and index finger, making fine movements impossible, such as cutting up food and typing. Again, despite various methods, exercises and devices the damage remains severe. Just to aggravate his disabilities, his hearing, which has been deteriorating over the last twenty years, has got even worse, limiting his social activities even more, especially in public with a lot of background noise.

In David's words: "Unlike some stroke victims, I have been lucky enough to have been nourished and protected by Hilary through our 48 years of marriage. Even so, our lives have been irreversibly damaged by the stroke, compounded by the poor hearing and compensations are hard to find. After five years I routinely get dark moods, depressed, enraged and desperate, and this has put a heavy load on Hilary as my prime carer."

ABOUT THE AUTHORS



Joanne Woodford is an Associate Research Fellow within the Mood Disorders Centre at the University of Exeter with a special interest in developing and improving access to evidence based psychological interventions for people with depression, especially for carers and relatives of people with physical health difficulties, such as stroke. Joanne has previously co-developed an online CBT self-help treatment for postnatal depression and contributed to the development of a treatment for people with chronic physical health conditions. Joanne is also involved in several educational programmes directed at training mental health professionals in the skills required to support patients in the use of CBT self-help materials.



Dr Paul Farrand is a Senior Lecturer within the Mood Disorders Centre and Director of Psychological Wellbeing Practitioner training within Clinical Education, Development and Research (CEDAR) at the University of Exeter. His main clinical and research interests are in the area of low intensity cognitive behavioural therapy (CBT), especially in a self-help format. Based upon his research and clinical practice he has developed a wide range of written self-help treatments for depression and anxiety.



CBT SELF-HELP: INFORMAL CARERS OF STROKE SURVIVORS



The **Dunhill Medical Trust**

This trial is funded by The Dunhill Medical Trust, a member of the Association of Medical Research Charities (AMRC) and a National Institute for Health Research (NIHR) recognised non-commercial partner.

Acknowledgement:

The 'Behavioural Activation' booklet is based on the behavioural activation model included within 'Reach Out: National Programme Educator Materials to Support the Delivery of Training for Psychological Wellbeing Practitioners Delivering Low Intensity Interventions' by Professor David Richards and Dr Mark Whyte.

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Research Statement:

This booklet has been developed as part of a research grant awarded by The Dunhill Medical Trust in the form of a doctoral research training fellowship awarded to the first author (JW).

Appendix 6.6: PWP PowerPoint training slides



CEDArS Training

For Carers and Relatives of Stroke Survivors

Woodford, J., Farrand, P., Bouquet, C., & Jeffreys, J; Rayson, K



Outline of the Day

- › 10:00-10:30: Introduction to the Study (Joanne Woodford)
- › 10:30-11:30: The Experience of Caring for a Stroke Survivor (Celia Bouquet)
- › 11:30-12:00: Break
- › 12:00-13:00: Stroke: Causes; treatment; signs / symptoms and effects (Jules Jeffreys)
- › 13:00-13:45: Lunch
- › 13:45-16:30: Intervention Training (Joanne Woodford & Kathryn Rason)



Aims

- › Background to trial and general procedures
- › Gain an appreciation of common difficulties experienced by carers and relatives
- › Understand common physical difficulties experienced by stroke survivors and impact on carers
- › Develop skills in how to treat and support carers and relatives with depression



Objectives

- › To understand general trial procedures
- › To be able to define common difficulties experienced by carers
- › To be able to define common physical difficulties experienced by stroke survivor
- › To adapt practice to treat and support carers
- › To understand the key adaptations to the low intensity clinical method for carers



Introduction to the Study

- Currently no psychological treatments specifically for carers of stroke survivors who are struggling with depression.
- Self-help cognitive behavioural therapy (CBTsh) may represent a solution.
- However, it is vital materials presented and method of delivery is tailored to the patient group.



Study Aims

- 1. To develop an acceptable CBTsh intervention tailored to the specific needs of carers of stroke survivors
- 2. To carry out a pilot randomised controlled trial comparing the new CBTsh intervention with treatment-as-usual (TAU) within an NHS setting.



CBT SELF-HELP: INFORMAL CARERS OF STROKE SURVIVORS



The Trial

- 60 patients randomised to CBTsh or TAU (30 per arm)
- 15 patients treated by Dorset, 15 treated by Cornwall
- Patients recruited from GP practices, Stroke Rehabilitation teams, stroke units, stroke rehabilitation units and community organisations

IMPORTANT: Only patients recruited through these avenues eligible. Routine patients who are carers seen by service cannot be part of the study

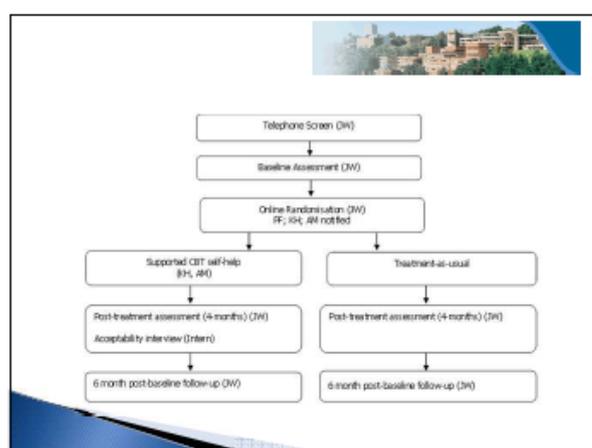
CEDARS
The Centre for Evidence-Based Systems

Inclusion / Exclusion

- Inclusion:** Age 16 or over; carer/relative of stroke survivor minimum 2 months home discharge; meet diagnostic criteria for major depression; PHQ-9 10-23; stable anti-depressant medication for 1 month
- Exclusion:** GAD-7 >21; PTSD; Psychosis; Type 1 & 2 Bipolar; Personality Disorder; Alcohol abuse; Substance abuse; PHQ-9 Qu 9=3 or determined acutely suicidal; persistent self-injury; receiving formal psychotherapy; reading impairment

IMPORTANT: Determined by research team initially however if status changes during treatment to inform Kathryn Rayson or Ed Watkins as per Trial Handbook

CEDARS
The Centre for Evidence-Based Systems



Trial Procedure Post-Consent

- JW randomises patients online (<https://penctu.pcmd.ac.uk/cedars/>)
- Unblinded email to the PWP; EW and unblinded researcher (Sarah Harris, SH)
- SH contacts PWP with patient contact details
- PWP contacts patient and arranges assessment
- Patient treated by PWP

IMPORTANT: JW must remain blind – Names of patients treated must never be given to or discussed with JW.

CEDARS
The Centre for Evidence-Based Systems

Treatment Procedure

- 1 x Assessment Session (35 mins max)
- Up to 12 treatment sessions (35 mins max)
- Single strand treatment, patient choice of:
 - Behavioural Activation
 - Goal Setting
 - Problem Solving
- Last support session – Relapse Prevention
- Patients can move onto another treatment if not recovered and still within maximum treatment sessions and deemed appropriate in case management supervision.
- All sessions recorded if patient consents (see Trial Handbook for Protocol regarding Recording Treatment Sessions and Transfer of Recordings to the University of Exeter)

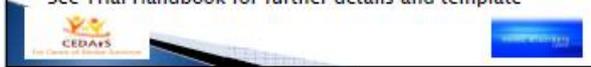
CEDARS
The Centre for Evidence-Based Systems



Data Collected by PWPs During Treatment

- ▶ Minimum data set (PHQ-9; GAD-7; WASAS)
- ▶ Number of sessions
- ▶ Duration of each session
- ▶ DNAs
- ▶ Risk
- ▶ Intervention used (including any changes to treatment)
- ▶ Session discharged
- ▶ Reason for discharge

See Trial Handbook for further details and template



Supervision

- Trial patients taken as normal to case management supervision
- KR to provide 45 minutes of clinical supervision per month of the trial over the telephone/video-conference/skype as discussed.

Risk

- Normal service policies to be followed
- Actively suicidal patients deemed not suitable via service policies will no longer be eligible to remain in trial. In event contact JW as per Trial Handbook.



The Experience of Caring for a Stroke Survivor

Celia Bouquet



Stroke: causes; treatment; signs/symptoms and effects

Jules Jeffreys



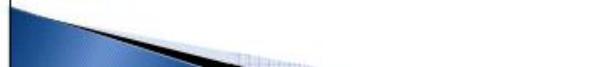
Intervention Training

Joanne Woodford & Kathryn Rayson



Outline of Session

- ▶ Adaptations to Assessment
- ▶ Adaptations to Behavioural Activation
- ▶ Adaptations to Goal Setting
- ▶ Adaptations to Problem Solving
- ▶ Relapse Prevention
- ▶ Risk





Assessment

- ▶ Patient already determined eligible
- ▶ Use A1 Informal Carer / Relative Patient-centred assessment (Informal Carers/Relatives of Stroke Survivors)
- ▶ **Introduction**
 - Include research trial when explaining role
 - Collaborative care made clear
 - Potential for depression to co-exist when caring for a stroke survivor made explicit



▶ Information Gathering

- Gather clear information around difficulties experienced in the caring role
- Behavioural problems – focus on activities of value and importance stopped doing
- Balance between caring and mental health difficulties
- Thorough assessment of risk **to others** (return to later)
- Impact of problem must include:
 - Relationship with stroke survivor (e.g., communication)
 - Role changes (e.g., work, retirement plans, education)
- Detailed information around support from others
- Ask explicitly about transition
 - E.g., how managed transition to caring role, loss, acceptance
- Goal revision – how have they adapted their life goals



▶ Information Giving and Shared Decision Making

- Problem statement to include details about the caring role:

*My main problem is feeling low and down since **becoming a carer** for my husband, I am tearful, tired and have problems sleeping, I have stopped doing activities **outside the caring role** and I no longer see my friends, I feel overwhelmed and I think I am **failing my husband as a carer**. As a consequence my relationship with my husband is strained and I am isolated from my friends.*



▶ Information Giving and Shared Decision Making

- Information giving linked to caring role
- Ideally:
 - Provided with "Introduction Booklet"
 - CBT model explained (with own examples)
 - Aims for treatment (for homework if no time in session)
 - Homework: Read the recovery stories to decide on treatment
- Next steps:
 - Explicit discussion about how to provide support e.g., recognition of barriers experienced (time; finance; guilt; stigma)
 - Emphasis on flexibility of support



▶ Control, Confidence and Connection

Three elements important in psychotherapy to initiate and maintain behavioural change (Ryan & Deci, 2008):

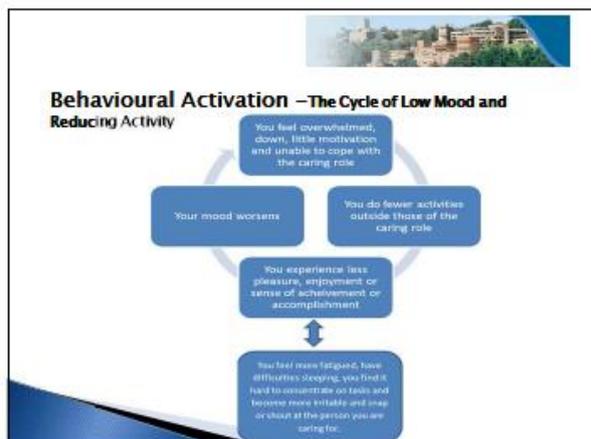
- **Control:** Understands individuals opinions, validate their experience, provide patient choice and rationales for treatment.
- **Confidence:** Need to feel goals of activities are achievable. Confidence can be increased by a structure to work within, to enable people work towards their goals.
- **Connection:** Patients need to feel they are being cared for and are connected with others. PWP's can provide this via common factors skills such as empathy. Also important (dependent on patient choice) activities and goals involve others. As well as being connected to people, for many connection can also be felt with the environment.



Behavioural Activation

Activity in the Caring Role

- Days full of routine and necessary activities around caring role – may be doing **too much**
- Likely to have stopped a number of activities as the caring role takes over –activities are likely ones previously of **value** and **importance** to the carer (e.g., social activities, work, own health care needs)
- Guilt experienced if do activities outside the caring role
- **IMPORTANT:** Both low mood and role of carer will impact on activity
- Key focus: **STRIKING A BALANCE**



Behavioural Activation

My Starting Diary

- ▶ Important to get a baseline diary of activities the carer is currently doing – help identify whether doing **too much**.
- ▶ Type of activity recorded- this will help identify **lack of balance** in diary.

Behavioural Activation

What Is Important In Life?

- ▶ Important to identify activities of importance and value to optimise recovery.
- ▶ Patients need to identify 5 areas of life and write these down.
- ▶ These will be used to identify activities to start again, or new activities carers would like to start.

Behavioural Activation

Identifying Activities

- ▶ Identify activities of **importance** and **value** to the carer that they have stopped doing, or would like to start doing. **Use important areas of life to guide.**
- ▶ Explicitly identify R, N and P activities that will help give their life **purpose or meaning**.
 - E.g., activities that will bring pleasure, sense of achievement, accomplishment, satisfaction
- ▶ Carers may feel starting certain activities again will be impossible – normalise, but still get them to write them down as can problem solve around these difficulties.

Behavioural Activation

Common Difficulty – Guilt

Scenario: You are working with a patient and she tells you that she feels guilty even thinking about doing activities for herself outside of the caring role. She feels that the most important thing is to care for her husband and finds the idea of trying to do activities of value and importance to herself hard to understand. She would also feel really guilty doing things that her husband can no longer do because of the stroke.

What would you do in this situation?

Behavioural Activation

Hierarchy

- ▶ As usual note certain tasks may need to be broken down into more steps
 - Certain activities will be difficult if the carer can't look after the stroke survivor whilst doing them.
 - Getting support may be an important step for many activities.
 - Steps to overcoming barriers may need to be incorporated



Behavioural Activation

Planning

- ▶ Focus on trying to identify **time** to do activities of **importance** and value to **strike a balance**.

Scenario: You are working with a patient who has identified that their days are filled with caring or doing things around the home, like cooking, cleaning, washing etc. They would really like to be able to start going swimming again once a week but see no way of being able to find any time in their diary and also the stroke survivor can't be left alone.

What could you do in this situation?



Behavioural Activation

Overcoming Difficulties Around Finding Time:

- ▶ Problem solving around **time** may be needed – finding space is a common problem
 - Support – family, friends, social services (collaborative care)
 - How important / what priority level are activities currently doing. May be doing a lot of tasks that aren't important – distraction from low mood, difficult feelings or situations (procrastination)
 - E.g., Doing the ironing for an hour to avoid argument with person care for
 - Rate priority level of all activities currently doing as an extra step to help identify potential movement in diary
- ▶ Emphasise rationale and importance of striking a balance and positive feedback from environment
 - E.g., pleasure, enjoyment, satisfaction, achievement

Caveat: If the carer has difficulties with problem solving you may want to use this as an intervention instead.



Behavioural Activation: Common Difficulties

New Overwhelming Tasks

- ▶ Many carers find themselves doing a lot of new overwhelming tasks
 - E.g., never cooked before, never had to be in control of financial arrangement, never had to look after the garden (activities the stroke survivor used to do)
- ▶ May need to spend time breaking these overwhelming new tasks down to make them more achievable and manageable.

Caveat: Again, if a significant problem may want to use Problem Solving as a treatment



Behavioural Activation: Common Difficulties

Adapting Activities

- ▶ May have given up activities of importance and value that are **no longer achievable** now a carer
 - E.g., work, holidays, going out with friends

Scenario: You are working with a carer who has given up work early to care for her mother. She had a really good career that was very important to her and she is really struggling no longer working. She knows that she can't work again but is finding it hard to come up with new activities she could do instead.

What could you do in this situation?



Behavioural Activation: Common Difficulties

Adapting Activities

- ▶ May have given up activities of importance and value that are **no longer achievable** now a carer
 - E.g., work, holidays, going out with friends
- ▶ May be able to overcome some barriers (try and problem solve)
- ▶ If not, may need to think of new activities which are similar to ones given up (adapting activities)
 - Ask what was **important / of value** of previous activity
 - E.g., "Work got me out of the house and speaking to other people"
 - Brainstorm what other, more achievable activities, would have a **similar value or meaning**:
 - E.g., "Joining a carers group could get me out of the house and speaking with new people".



Goal Setting

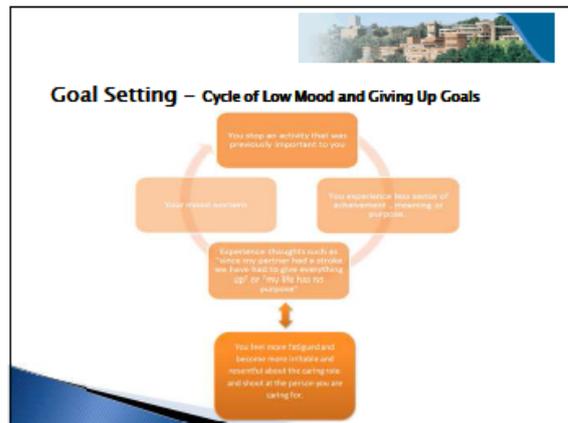
Goals and Caring

- ▶ Becoming a carer: major life change / role transition
- ▶ Often give up goals
 - E.g., job, education, plans for retirement, friends, interests
- ▶ Sense of hopelessness and helplessness
- ▶ Resentment of new restrictions on life, leads to feelings of guilt
- ▶ Guilt also around pursuing things for self



Goal Setting

- ▶ Both low mood and difficulties experienced as carer make people feel unable to work towards things of value and importance (goals)
- ▶ Goals important to wellbeing – provide life with sense of purpose and meaning
- ▶ Emphasise can still work towards goals
 - Think about different ways to achieve goals
 - Adapt old goals
 - Set new goals
 - Important: Continuing to work towards unobtainable goals causes distress. Giving up some goals will cause less distress in long-term




Goal Setting

Step 1: Three Rules of Goal Setting

Rule 1: Set *three* goals

Rule 2: Focus upon *short-term* goals

Rule 3: Set *positive* goals

Step 2: Important areas of life (as per BA)



Goal Setting

Step 2: What are my Goals

- ▶ Brainstorm goals
- ▶ Write down any, even if feel not achievable
- ▶ Break into long, medium and short-term
- ▶ If struggle, what is of value and importance? (Use Step 2 to guide)
 - Relationships
 - Social activities
 - Health
 - Roles and responsibilities



Goal Setting

Step 3: Setting S.M.A.R.T Goals

- ▶ **S** is for **Specific**
- ▶ **M** is for **Measurable**
- ▶ **A** is for **Achievable**
- ▶ **R** is for **Relevant**
- ▶ **T** is for **Time Specific**



Goal Setting

Step 4: Starting to Work Towards Your Goals

- ▶ Start with 3 short-term goals

Step 5: Reviewing Progress

- ▶ Encourage patient to record how well they have worked towards their goals and write comments on the worksheet to discuss in the next support session.



Goal Setting – Common Difficulties

Selecting New Goals of Importance

Scenario: You are working with a carer who used to go travelling regularly with his wife before she had a stroke. His wife is now in a wheelchair and going abroad is really tough. Also the carer had to give up work and they no longer have enough money to go away. The carer has identified not being able to travel anymore as a really big difficulty.

What could you do in this situation?



Goal Setting – Common Difficulties

Selecting New Goals of Importance

- › What was of importance and value to the goals they have given up? Funnel around this.
 - E.g., "I have had to give up my career but I miss the sense of achievement I got from my job and being able to get out of the house".
 - E.g., "We can no longer travel abroad, but I miss seeing new places, meeting new people and getting out of the house".
- › Brainstorm what other activities could bring the same value to come up with new goals



Goal Setting – Common Difficulties

Adapting Way Work Towards Goals

- › When become a carer experience change in resources
 - E.g., time, financial, less energy
- › Funnel around changes in resources / barriers
- › Brainstorm problem solving around changes in resources / barriers
 - E.g., finding and allocating time
 - E.g., support and help from other
 - E.g., similar activity that costs less



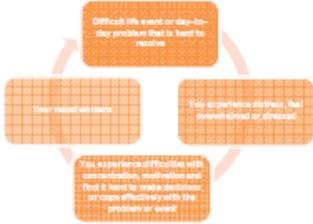
Problem Solving

- › Becoming a carer = significant life event
- › Other difficulties as a result:
 - **Financial**
 - **Giving up work / education / plans for future**
 - **Social Isolation**
 - **Own health difficulties**
 - **New tasks and activities**
 - Caring role
 - Housework, gardening, DIY, responsible for finances
- › Problems feel overwhelming and ever increasing.



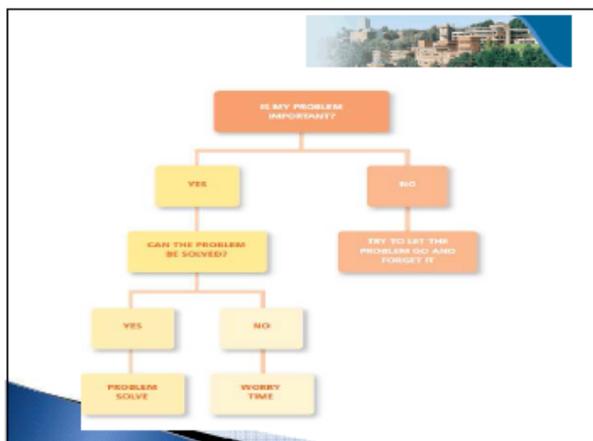
Problem Solving

The Cycle of Difficulties Problem Solving and Low Mood




Problem Solving

- › **Step 1: What things in life are important to you?**
 - **Exercise:** How might you support a patient finding it difficult to identify areas of life that are important to them?
- › **Step 2: What are my problems, difficulties and worries?**
- › **Step 3: Types of problems, difficulties or worries:**
 - Not important
 - Important and cannot be solved (including "Hypothetical Worries"
 - Important and can be solved
 - **Exercise:** Brainstorms examples for each type of problem.



Problem Solving

- ▶ **Step 4: Tackling Important and Solvable Problems**
 - Stage 1: Identify the Problem
 - (convert worry into problem if necessary)
 - Stage 2: Identify the Solutions
 - Stage 3: Analyse Strengths and Weaknesses
 - Stage 4: Select a Solution
 - Stage 5: Planning Trying out the Solution
 - Stage 6: Trying out the Solution

Next Steps: Regularly review list of problems and tick them off when solved or no longer bother patient.

Problem Solving

- ▶ **Step 5: Tackling Important and Unsolvable Problems**
- ▶ **Schedule Worry Time:** 20-30 minutes each day; no distractions
- ▶ **Writing Worries Down:** as they come to them in the day. Once a worry is written down it is important they focus again on the present – task switching can sometimes help this.
- ▶ **Worry Time:** Read through the worries written down during the day. They may find the worry is no longer important. They may find that the worry actually does have a practical solution and should therefore use Problem Solving.

Worry time does take time and practice.

Problem Solving – Common Difficulties

Converting Worries into Problems

- ▶ May need to convert worry into a problem.
- ▶ **Exercise:** How would you convert the following worries into problems?
 - “We’re meant to be going out to dinner on Saturday with friends, what if there are problems getting in the restaurant with a wheelchair?”
 - “Our friends are visiting Sunday, what if they don’t know how to talk to my husband because of his aphasia?”
 - “I am worried I am going to forget when to give my wife her medication”

Problem Solving – Common Difficulties

- ▶ **Letting go of life events that cannot be changed**
- ▶ Carers may be having difficulty coming to terms with life events, such as becoming a carer and their loved one having a stroke.
- ▶ How people cope with major life events and losses is individual.
- ▶ They may find it helpful to talk to some they trust or to people who have experienced a similar life event (e.g., stroke or carers club).
- ▶ Depression, anger and worry are very normal and part of the acceptance process.
- ▶ If during treatment the carer is having major difficulties with acceptance another treatment such as counselling maybe more appropriate.

Problem Solving – Common Difficulties

The problem I am working on seems too big

- ▶ **Scenario:** You are working with a carer who has had to give up work, they don’t qualify for carers allowance and are now struggling to pay the mortgage. Understandably this is a big worry and difficulty for them.

How might you break this problem down?

CBT SELF-HELP: INFORMAL CARERS OF STROKE SURVIVORS



Relapse Prevention

Step 1: Warning Signs (ABC model)
 Step 2: Activities, techniques and skills learnt
 Step 3: Check-in

- Activities kept up
- What has helped keep up these activities
- What activities have slipped?
- What has led to activities slipping?
- How could start doing these activities again?
- Warning signs?
- If yes, what might it be helpful to do?



Risk

- › Normal service protocol to be followed
- › If actively suicidal or persistent self-injury need to be excluded from trial.
- › In these cases make an initial decision as to exclude and contact JW.
- › **NB: You will not be contacting JW to manage risk. This will be done as per normal service protocol.**
- › Must have a focus when risk assessing on:
 - Harm from others (including explicitly person care for)
 - Harm to others (including explicitly person care for)
 - Neglect of others (including explicitly person care for)
- › Any form of high level risk to be reported to EW or KR for decision to be made re remaining in trial



Assessing Abuse and Neglect of Others

Exercise: What types of activity may indicate the following types of abuse/neglect?

- Financial
- Psychological
- Physical
- Sexual
- Neglect



Assessing Abuse and Neglect of Others

Types of abuse and neglect (O'Keefe et al., 2007)

Type of Abuse/Neglect	Operational Definition
Financial abuse	Stolen money, possessions or property Attempted to steal money, possessions or property Made you give money, possessions or property Tried to make you give money, possessions or property Used fraud to take money, possessions or property Tried to use fraud to take money, possessions or property Taken or kept power of attorney Tried to take or keep power of attorney
Psychological abuse	Insulted you, called you names or sworn at you Threatened you Undermined or belittled what you do Excluded you or repeatedly ignored you Threatened to harm others that you care about Prevented you from seeing others that you care about



Assessing Abuse and Neglect of Others

Physical abuse	Slapped you Grabbed, pushed or shoved you Kicked, bit or hit you with a fist Burned or scalded you Threatened you with a knife, gun or other weapon Used a knife, gun or other weapon Any other violence Tied you down Locked you in your room Gave you drugs or too much medicine in order to control you/ to make you dole Restrained you in any other way
Sexual harassment / abuse	Talked to you in a sexual way that made you feel uncomfortable Touched you in a sexual way against your will Tried to touch you in a sexual way against your will Made you watch pornography against your will Tried to make you watch pornography against your will Had sexual intercourse with you against your will Tried to have sexual intercourse with you against your will
Neglect	Respondent must have stated that they need and receive help with an activity, and that they have difficulty carrying out the activity by themselves. Neglect grouped into three categories: Day to day activities (shopping for groceries or clothes, preparing meals, doing routine housework, travel or transport) Personal care (getting in and out of bed, washing or bathing, dressing or undressing, eating including cutting up food, getting to and using toilet) Help with correct dose and timing of medication



Assessing Abuse and Neglect of Others

- › When assessing abuse / neglect of others important to consider:
 - Context
 - Type
 - Frequency
 - Duration
 - Differences between intent, plans and actions
- › Not “one strike and you’re out”
- › Follow normal service safeguarding policies

Appendix 6.7: Adapted low intensity assessment protocol

A1 Informal Carer / Relative Information Gathering WEIGHTING 40%

	<u>Clear evidence demonstrated</u>	<u>Some evidence demonstrated</u>	<u>Not demonstrated</u>
<p>Uses 4 W's to structure questions:</p> <p>What is the problem Where does the problem occur With whom is the problem better or worse When does the problem happen</p>	(At least first 3 evident)	(2 evident)	(0 or 1 evident)
<p>Clearly asks about the caring role and follows up where necessary</p>	(Clearly asks question and where appropriate follows up answers to gain understanding about extent to which psychological and difficulties experienced within the caring role may be linked)	(Asks vaguely or fails to follow cues where difficulties due to being a carer are evident)	(Does not obtain information)
<p>Elicits autonomic aspects of the problem e.g. physiological aspects of problem</p>	(Asks specific questions and follows answers up to gain thorough understanding)	(Asks vaguely and fails to follow cues/or asks specifically but fails to obtain thorough info)	(Does not obtain information)
<p>Elicits behavioural aspects of the problem e.g. what is the patient doing or not doing; what activities of value and importance to them has the carer given up</p>	(Asks specific questions and follows answers up to gain thorough understanding)	(Asks vaguely and fails to follow cues/or asks specifically but fails to obtain thorough info)	(Does not obtain information)
<p>Elicits cognitive aspects of the problem e.g. what is the patient thinking – as internal mental scripts or images</p>	(Asks specific questions and follows through answers to gain thorough understanding)	(Asks vaguely and fails to follow cues/or asks specifically but fails to obtain thorough info)	(Does not obtain information)
<p>Enquires about 'triggers' e.g. current trigger specific examples of past trigger</p> <p>NOT THE PRESUMED HISTORICAL CAUSE</p>	(Specifically asks about triggers)	(Vague in enquiry or does not follow up cues)	(No enquiry made)

A1 Informal Carer / Relative Patient-centred assessment (Informal Carers/Relatives of Stroke Survivors)

How to use this assessment sheet

This assessment sheet is divided into four sections:

1. Introduction
2. Interpersonal skills
3. Information gathering
4. Information giving and shared decision making

This assessment sheet is divided into four sections: introduction; interpersonal skills; information gathering; information giving and shared decision making. Each section includes a number of competences which are specific and central to these four aspects of an initial patient-centred interview, including where caring for a stroke survivor is potentially impacting on the mental health of the patient.

Each component of the rating sheet is divided into three columns. Assessors should rate each competence according to observations made of the student's interview. The right-hand column represents an aspect of the interview which was not conducted sufficiently well to be regarded as competent. The middle column should be ticked when students displayed the behaviours necessary but could have done more. The left-hand column is reserved for students who are fully competent in the relevant skill. Guidelines are given in each cell of the rating sheet to assist assessors make an objective judgement of competence.

The four sections are weighted: 10% for the introduction section, 30% for

interpersonal skills, 40% for information gathering and 20% for information giving and shared decision making. Each section is rated from 0 – 10 and multiplied by the relevant weighting to give a final score. The assessment is marked as an overall pass/fail exercise. The middle two sections **MUST** be passed independently – students cannot fail the interpersonal skills section and make up marks on the other three sections. The same applies to the information gathering section. A missing risk assessment leads to an automatic fail. The section ratings given should reflect the amalgamated ticks given in each cell, the majority of which would need to be in the left-hand or middle columns to constitute a pass. Because competence ratings are dependent on multiple criteria, the overall percentage ratings are indicative only and used to give students feedback rather than indicate concrete competence performance differences between students.

It is best to use this assessment sheet on filmed clinical simulation interviews using actors with clear instructions on how to role play patients. This allows the scenarios being assessed to be consistent between students. Filming also allows double blind marking, external examiner scrutiny and an audit trail. Finally, filming allows students to observe their interview in order to write a reflective commentary on their own performance. The reflective commentary is subject to the examination regulations of the awarding body and is assessed accordingly.

**A1 Informal Carer / Relative Patient-centred assessment
(Informal Carers/Relatives of Stroke Survivors)**

Participant Number: _____

Date: _____

Introduction to the Session - WEIGHTING 10%

	<u>Clear evidence demonstrated</u> (The worker fully demonstrated the criteria)	<u>Some evidence demonstrated</u> (The worker demonstrates part of the skill or limited skill)	<u>Not demonstrated</u> (Not demonstrated)
Introduces self by name	(Clearly states own full name)	(States first name only)	(Does not introduce or just uses role e.g. "I am a case manager")
Elicits patient's full name	(Finds out patient's full name/preferred name)	(Finds out part of name e.g. first name)	(Fails to discover name or ascertains later during interview)
Role of the worker made clear	("I am a mental health worker, my job is....")	(Vague, e.g. "I work here")	(Does not state role)
Collaborative care made clear	("I work collaboratively as part of a larger team....")	(Vague, e.g. "I work with others")	(Does not state collaborative working)
Potential for anxiety/depression to co-exist caring for a stroke survivor mentioned	(Potential for depression/anxiety co-existing with caring for a stroke survivor explicitly stated e.g., "Low mood and depression are very common emotional difficulties experienced by carers and relatives of stroke survivors. Around 1 in 3 carers are likely to experience such difficulties")	(Mentioned as an aside or vaguely)	(Does not state)
Describes purpose/agenda of interview	(Purpose stated e.g. "I will be asking you to tell me what your main difficulties are then we will look at what we can do about this")	(Vague statements e.g. "I am going to interview you")	(No purpose stated)
Defines time scale for the interview	(Explicitly states time) e.g. "we have thirty five minutes")	(Vague statement about time scale e.g. "we only have a short time")	(Time not mentioned)

0 1 2 3 4 5 6 7 8 9 10

A1 Informal Carer / Relative Interpersonal Skills - WEIGHTING 30%

	<u>Clearly demonstrated</u>	<u>Some evidence demonstrated</u>	<u>Not demonstrated</u>
<p>Displays empathy by verbal communication skills e.g.</p> <p>"I realise that this is very distressing for you"; "It must be distressing feeling resentment towards the person you care for"</p>	(More than 1 occasion)	(One occasion only)	(Not demonstrated)
<p>Displays engagement by non verbal cues e.g. eye contact, posture, nods, facial expression</p>	(Displays all/most of the time)	Displays some/part of the time)	(Not demonstrated)
<p>Acknowledges the problem by reflection e.g.</p> <p>"so you felt that you were having a heart attack"; "so you felt really anxious"; "so you think people will judge you if they knew you were struggling with the caring role;"</p>	(More than one occasion)	(One occasion)	(Not demonstrated)
<p>Acknowledges the problem by summarising e.g.</p> <p>"you have told me your difficulties are..... is that correct?"</p>	(Two or more occasions)	(One occasion only)	(Not at all)
<p>Uses patient centred interviewing and clear information gathering</p> <p>Uses a funnelling process to elicit patient centred problem identification by:</p> <ul style="list-style-type: none"> • General open questions • Specific open questions • Closed questions • Summarising and clarification 	(Full elements of process demonstrated appropriately)	(Some evidence/not all appropriate use, e.g. general open questions leading too quickly to closed questions without intervening stage)	(Not demonstrated, e.g. mainly closed questioning or interrogative style)

0 1 2 3 4 5 6 7 8 9 10

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Determines the Impact of the problem on lifestyle, roles and responsibilities and relationship with care recipient	(Clearly enquires including relationship with the stroke survivor (e.g., impact of communication difficulties); domestic role changes (e.g., work, retirement, education), social leisure, private leisure and family relationships)	(Vaguely or incompletely enquires)	(No enquiry made)
Maintains the correct balance between information gathering around the mental health difficulty and around the caring role.	(Appropriate balance maintained at all times)	(Some emphasis upon mental health difficulty although too much placed upon the difficulties experienced being a carer)	Emphasis far too much on the difficulties experienced as a carer with little or none directed at the mental health difficulty.
Includes assessment of risk <u>Intent</u> : suicidal thoughts <u>Plans</u> : specific action plans <u>Actions</u> : current/past; access to the means <u>Prevention</u> : social network, services	(Comprehensive risk assessment appropriate to risk level articulated by patient)	(Risk investigated but limited in depth) We teach PWP's to gather info on impact before risk so although it's this way round on the generic initial assessment, perhaps it would be a could opportunity to change the order	(No risk assessment undertaken) AUTOMATIC FAIL
Includes assessment of risk of abuse or neglect of care recipient: <u>Financial</u> <u>Psychological</u> <u>Physical</u> <u>Sexual</u> <u>Neglect</u>	(Comprehensive risk assessment appropriate to risk level articulated by patient)	(Risk investigated but limited in depth)	(No risk assessment undertaken) AUTOMATIC FAIL
Use of routine outcome measures	(Uses at least one clinical outcome measure from the minimum dataset (or for physical health) and feeds back result)	(Uses a Likert scale or other means to assess problem severity or does not feed back result)	(Does not use any measures)
Asks about other important issues such as modifying factors, onset and maintenance , why do they want help now , patient expectations and goals , past episodes and treatments , drugs & alcohol , current medication and attitude to this , other	(Clearly enquires including follow up of important leads from patient)	(Vaguely or incompletely enquires)	(No enquiry made)

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<p>treatments, anything else that has not been covered in the assessment that is relevant from both perspectives</p>			
<p><i>Also ask about the following unless addressed above:</i> support from others (who and with what), transition (how successfully they feel their transition has been; issues around loss and acceptance), goal revision (how have they adapted their short, medium and long term life goals)</p>			

0 1 2 3 4 5 6 7 8 9 10

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A1 Informal Carer / Relative Information Giving & Shared Decision Making - WEIGHTING 20%

	<u>Clear evidence demonstrated</u>	<u>Some evidence demonstrated</u>	<u>Not demonstrated</u>
Summarises and defines problem (including the caring role where appropriate) Using the framework 4 W's ABC Triggers Impact and in patient's own words	(All used with appropriate language in patient's words)	(Some demonstrated and/or in appropriate language)	(Vague/absent/poorly demonstrated)
Seeks patient's affirmation of problem statement	(Gives opportunity to revise statement)	(Presents statement but limited opportunity to revise)	(Does not seek patient view)
Information giving (linked to the caring role where appropriate) and the presentation of options for the appropriate step, including explicit mention of collaborative care.	- Information given - Next steps discussed - Collaborative care discussed	(Brief and incomplete information giving)	(None described)
Explicit discussion required of how support can be provided e.g., recognition of the barriers carers experience accessing support and how these barriers can be worked around through flexible working (e.g., time; financial; stigma; guilt).	- Explicit discussion of barriers to receiving support	(Brief and incomplete discussion of barriers)	(None described)
Provided with the "Introduction Booklet" and the CBT model explained. Homework to include: - Treatment Aims - Recovery Stories	- CBT model explained - Homework agreed collaboratively with patient	(Brief, incomplete or non-collaborative)	(None described)
Next steps agreed collaboratively taking into account any barriers and brief summary of the session and patient's agreement sought.	- Session summarised - All next steps agreed collaboratively with patient	(Brief and incomplete ending with no collaborative action plan)	(None described)

0 1 2 3 4 5 6 7 8 9 10

Appendix 6.8: Adapted standard low-intensity support protocol

A3 Informal Carer / Relative Clinical simulation assessment (Informal Carers/Relatives of Stroke Survivors)

How to use this assessment sheet

This assessment sheet is divided into six sections:

1. Introduction
2. Interpersonal skills
3. Information gathering
4. Information giving
5. Shared decision making
6. Ending

Each section includes a number of competences which are specific and central to these six aspects of a patient-centred interview which is focussed on planning and implementing a low-intensity treatment programme, including where caring for a stroke survivor is potentially impacting on the mental health of the patient.

Each component of the rating sheet is divided into three columns. Assessors should rate each competence according to observations made of the student's interview. The right-hand column represents an aspect of the interview which was not conducted sufficiently well to be regarded as competent. The middle column should be ticked when students displayed the behaviours necessary but could have done more. The left-hand column is reserved for students who are fully competent in the relevant skill. Guidelines are given in each cell of the rating sheet to assist assessors make an objective judgement of competence.

The six sections are weighted: 10% for the introduction section, 20% for interpersonal skills, 20% for information

gathering, 20% for information giving, 20% for shared decision making and 10% for the ending. Each section is rated from 0 – 10 and multiplied by the relevant weighting to give a final score. The assessment is marked as an overall pass/fail exercise.

The middle four sections **MUST** be passed independently – students cannot fail **ANY** of the sections on interpersonal skills, information gathering, information giving or shared decision making. A missing risk assessment leads to an automatic fail. The section ratings given should reflect the amalgamated ticks given in each cell, the majority of which would need to be in the left-hand or middle columns to constitute a pass. Because competence ratings are dependent on multiple criteria, the overall percentage ratings are indicative only and used to give students feedback rather than indicate concrete competence performance differences between students.

It is best to use this assessment sheet on filmed clinical simulation interviews using actors with clear instructions on how to role play patients. This allows the scenarios being assessed to be consistent between students. Filming also allows double blind marking, external examiner scrutiny and an audit trail. Finally, filming allows students to observe their interview in order to write a reflective commentary on their own performance. The reflective commentary is subject to the examination regulations of the awarding body and is assessed accordingly.

A3 Informal Carer / Relative Clinical simulation assessment (Informal Carers/Relatives of Stroke Survivors)

Participant Number:

Date:

Introduction to the Session - WEIGHTING 10%

	<u>Clear evidence demonstrated</u> (The worker fully demonstrated the criteria)	<u>Some evidence demonstrated</u> (The worker demonstrates part of the skill or limited skill)	<u>Not demonstrated</u> (Not demonstrated)
Introduces self by name	(Clearly states own full name)	(States first name only)	(Does not introduce self or just uses role e.g. "I am a mental health worker")
Checks patient's full name	(Ensures the worker is speaking to the right person by checking patient's full name)	(Uses patient's name without checking to whom they are speaking)	(Fails to use or check name or ascertains later during interview)
Role of the worker reiterated	("As we discussed last time, I am a mental health worker, my job is....")	(Vague, e.g. "as you know, I work here")	(Does not state role)
Collaborative care made clear	("I work collaboratively as part of a larger team....")	(Vague, e.g. "I work with others")	(Does not state collaborative working)
Potential for anxiety/depression to co-exist caring for a stroke survivor mentioned	(Potential for depression/anxiety co-existing with caring for a stroke survivor explicitly stated e.g., "Low mood and depression are very common emotional difficulties experienced by carers and relatives of stroke survivors. Around 1 in 3 carers are likely to experience such difficulties")	(Mentioned as an aside or vaguely)	(Does not state)
Describes purpose/agenda of interview	(Purpose stated e.g. "I will be reviewing what you told me the last time we met and then we will look in more detail at what you can do to help you overcome your difficulties")	(Vague statements e.g. "I am going to interview you again today")	(No purpose stated)

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Defines time scale for the interview	(Explicitly states time e.g. "we have twenty five minutes")	(Vague statement about time scale e.g. "we have some time today")	(Time not mentioned)
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0 1 2 3 4 5 6 7 8 9 10

A3 Informal Carer / Relative Clinical simulation assessment
(Informal Carers/Relatives of Stroke Survivors)

Interpersonal Skills - WEIGHTING 20%

	<u>Clearly demonstrated</u>	<u>Some evidence demonstrated</u>	<u>Not demonstrated</u>
Displays empathy by verbal communication skills e.g. "I realise that this is very distressing for you"; "It must be distressing feeling resentment towards the person you care for"	(More than 1 occasion)	(One occasion only)	(Not demonstrated)
Displays engagement by non verbal cues e.g. eye contact, posture, nods, facial expression	(Displays all/most of the time)	Displays some/part of the time)	(Not demonstrated)
Acknowledges the problem by reflection e.g. "so you felt that you were having a heart attack"; "so you felt really anxious"; "so you think people will judge you if they knew you were struggling with the caring role?" This includes reflections that link caring to the psychological difficulties when appropriate.	(More than one occasion)	(One occasion)	(Not demonstrated)
Acknowledges the information given by summarising e.g. "you have told me your problem has remained constant with its main focus as.... is that correct?"	(Two or more occasions)	(One occasion only)	(Not at all)
Uses patient centred interviewing and clear information gathering Uses a funnelling process to elicit patient centred information by: <ul style="list-style-type: none"> • General open questions • Specific open questions • Closed questions • Summarising and clarification 	(Full elements of process demonstrated appropriately)	(Some evidence/not all appropriate use, e.g. imposition of worker understanding without check-back with patient)	(Not demonstrated, e.g. dismissal of patient perspective)

0 1 2 3 4 5 6 7 8 9 10

A3 Informal Carer / Relative Clinical simulation assessment
(Informal Carers/Relatives of Stroke Survivors)

Information Gathering WEIGHTING 20%

	<u>Clear evidence demonstrated</u>	<u>Some evidence demonstrated</u>	<u>Not demonstrated</u>
Reminds the patient: a) about the main problem statement agreed at the last contact and b) ascertains whether there has been any change in the problem and its impact since the last contact. c) Ascertain whether any change in relationship between caring role, ABCs and impact.	(All evident in depth)	(Two evident or all superficially)	(One or none evident)
Includes assessment of risk, related to information gathered at the last contact and any new information <u>Intent</u> : suicidal thoughts <u>Plans</u> : specific action plans <u>Actions</u> : current/past; access to the means <u>Prevention</u> : social network, services	(Comprehensive risk assessment appropriate to risk level articulated by patient)	(Risk investigated but limited in depth)	(No risk assessment undertaken) AUTOMATIC FAIL
Includes assessment of risk of abuse or neglect of care recipient: <u>Financial</u> <u>Psychological</u> <u>Physical</u> <u>Sexual</u> <u>Neglect</u>	(Comprehensive risk assessment appropriate to risk level articulated by patient)	(Risk investigated but limited in depth)	(No risk assessment undertaken) AUTOMATIC FAIL
Use of routine outcome measures	(Uses at least one clinical outcome measure from the minimum dataset and feeds back result related to this and previous scores)	(Uses a Likert scale or other means to assess problem severity or does not feed back result)	(Does not use any measures)

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Reviews patient's use of other treatments for depression/anxiety, including the effects and unwanted effects of medication	(Clearly enquires including follow up of important leads from patient)	(Vaguely or incompletely enquires)	(No enquiry made)
Reviews patients use of, and any changes, to support received as a carer (e.g., carer/ stroke support groups, GP, social services etc).	(Clearly enquires including follow up of important leads from patient)	(Vaguely or incompletely enquires)	(No enquiry made)
Review any new understanding about extent to which psychological and difficulties experienced within the caring role may be linked.	(Clearly enquires including follow up of important leads from patient)	(Vaguely or incompletely enquires)	(No enquiry made)
Reviews patient's use of psychological treatment agreed at previous contact	(Clearly enquires of use, including depth of understanding, attitudes to treatment, activities undertaken and diaries completed)	(Vaguely or incompletely enquires; does not use material completed by patient between contacts such as diaries)	(No enquiry made)

0 1 2 3 4 5 6 7 8 9 10

A3 Informal Carer / Relative Clinical simulation assessment
(Informal Carers/Relatives of Stroke Survivors)

Information Giving - WEIGHTING 20%

	<u>Clear evidence demonstrated</u>	<u>Some evidence demonstrated</u>	<u>Not demonstrated</u>
Discussion of intervention options with methods of delivery where appropriate	(More than one option discussed or rationale for previous intervention reiterated and understanding checked with patient)	(Only one option discussed or previously selected intervention re-introduced without checking understanding)	(No discussion of options or previously selected intervention)
Clearly addresses patients use of each part of the intervention to help to identify and address any potential misunderstandings.	(Clearly discusses patient use of each part of the intervention with difficulties/ misunderstandings addressed)	(Little discussion of patients use of the intervention, or focus on difficulties/ misunderstandings incorrect)	(No discussion of intervention use)
Identifies and addresses appropriate aspect(s) of the intervention leading to difficulty.	(Clearly identifies and addresses the main patient difficulty(s))	(Identifies the patient difficulty(s) in part, or identifies the correct difficulty(s) but addresses a different one.	(Fails to identify and/or address the correct difficulty)
Identifies and addresses barriers associated with the caring role that may have led to difficulties where appropriate (e.g., time, travel, finance, stroke survivor, lack of support), with appropriate support around problem solving these difficulties	(Identifies and addresses barriers associated with the caring role with patient reaching own understanding in order to problem solve around barriers).	(Identifies the patient barrier(s) in part, or small amount of interaction around the information with patient struggling to reach their own understanding around problem solving barriers)	(Fails to identify patient barriers or patient predominantly given information only around how to problem solve barriers).
Interactive discussion with difficulties addressed collaboratively	All material is discussed interactively to support the patient reach their own understanding)	(Small amount of interaction around the information with patient struggling to reach their own understanding)	(No interactive discussion of material; or patient predominantly being given information only)

0 1 2 3 4 5 6 7 8 9 10

A3 Informal Carer / Relative Clinical simulation assessment
(Informal Carers/Relatives of Stroke Survivors)

Shared Decision Making - WEIGHTING 20%

	<u>Clear evidence demonstrated</u>	<u>Some evidence demonstrated</u>	<u>Not demonstrated</u>
Action plans, including collaborative care where appropriate	(Collaborative action plan arrived at, including where appropriate the plan for collaborative care liaison. The patient's understanding and attitude towards the plan is checked)	(Action plan agreed but no understanding or attitude checked and/or the plan for collaborative care liaison is missing)	(Either no action plan or plan imposed by worker without collaboration)
Method of implementation and recording of action plan: e.g. diaries or record sheets	(Diaries or record sheets discussed interactively with patient. Plan includes a schedule of inter-sessional activity by patient and/or worker)	(Diaries or record sheets given to patient without planning any scheduled activity)	(No diaries or record sheets used)

0 1 2 3 4 5 6 7 8 9 10

Ending - WEIGHTING 10%

	<u>Clear evidence demonstrated</u>	<u>Some evidence demonstrated</u>	<u>Not demonstrated</u>
Summary of session	(Worker summarises the whole session and seeks agreement from patient)	(Brief summary and/or no agreement from patient sought)	(No summary)
Next steps agreed collaboratively taking into account any barriers (e.g., time, financial) to attending support sessions.	(Collaborative agreement of next step with feedback from patient to check understanding)	(Next steps agreed with no check of understanding)	(No next steps or very vague decision for the future)

0 1 2 3 4 5 6 7 8 9 10

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Appendix 8.1: Detailed reasons for study exclusion and study citations (updated review)

No.	Authors, year	Reason for exclusion
1	Gonyea, López, & Velásquez, 2014	Inappropriate comparator
2	Moore et al., 2013	Inappropriate comparator
3	Pfeiffer et al., 2014	Inappropriate comparator
4	Ostwald et al., 2014	Inappropriate comparator
5	Hou et al., 2014	Inappropriate comparator
6	Phung et al., 2013	Inappropriate comparator, follow-up of Waldorff et al., 2012
7	Vazquez Gonzalez et al., 2013	Aim to prevent depression. Those meeting diagnosis for depression excluded.
8	Kajiyama et al., 2013	Depression and / or anxiety are not the primary target of the intervention. Depressive symptoms are measured as a distal outcome.
9	Kuo et al., 2013	Depression and / or anxiety are not the primary target of the intervention. Depressive symptoms are measured as a distal outcome. Aims to improve carer health-related quality of life and reduce the risk for depression.
10	Okai et al., 2013	Depression and / or anxiety are not the primary target of the intervention or measured
11	Bevans et al., 2014	Depression and / or anxiety are not the primary target of the intervention or measured. Not a randomised controlled trial.
12	Martín-Carrasco et al., 2014	Depression and / or anxiety are not the primary target of the intervention. Psychological distress, including symptoms of depression and anxiety are secondary targets of the intervention.
13	Rodriguez-Sanchez et al., 2013	Depression and / or anxiety are not the primary target of the intervention or measured.
14	Kwok et al., 2013	Depression and / or anxiety are not the primary target of the intervention or measured.
15	Passoni et al., 2014	Inadequate randomisation
16	Dubenske et al., 2013	Depression and / or anxiety are not the primary target of the intervention or measured
17	Keeping-Burke et al., 2013	Not a psychological or psychosocial intervention.

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18	Löfvenmark, Saboonchi, Edner, Billing, & Mattiasson, 2013	Not a psychological or psychosocial intervention.
19	Leone et al., 2014	Not a randomised controlled trial
20	Scott & Beatty, 2013	Not a randomised controlled trial.
21	Boele et al., 2013	Symptoms of depression or anxiety are not targeted or measured.
22	Collins et al., 2013	Not a randomised controlled trial. The primary aim was to examine the acceptability and feasibility of the intervention.
23	Eames, Hoffman, Worrall, Read & Wong, 2013	Treatment primarily focused on the patient rather than the carer.
24	Jha, Jan, Gale, & Newman, 2013	Treatment primarily focused on the patient rather than the carer.
25	Dowling et al., 2014	Intervention target unclear, authors not contactable
26	Czaja, Loewenstein, Schulz, Nair, & Perdomo, 2013	Intervention target unclear, authors not contactable
27	Shum, Lui, Law, & Fong, 2014	Missing data, authors did not respond to request
28	Whitebird et al., 2013	Inappropriate comparator
29	Judge, Yarry, Looman, & Bass, 2013	The treatment is focused on how to manage the behavioural and psychological symptoms of Dementia

Note. Please see references for full citations