Developing and Evaluating a Psychological Intervention for use in Palliative Care

Submitted by John Melvin Galfin to the University of Exeter

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I certify that all material in this thesis which is not my own work has been identified and that no material has previously been submitted and approved for the award of a degree by this or any other University.

Signature: ……………………………………………………………..

ABSTRACT

As a GWR research project joint funded by Hospiscare, the main objective of this research was to examine the nature of psychological distress in palliative care, with the specific purpose of developing and evaluating accessible psychological interventions suitable for Hospiscare staff to use with clients.

There is evidence that palliative care patients and their caregivers experience psychological difficulties including (a) studies of depression and anxiety in palliative care; (b) the concerns expressed by palliative care patients and their caregivers. However, the studies are generally qualitative in nature based on interviews of small samples of participants. Therefore, Study 1 and Study 2 adopted a cross-sectional design to examine psychological distress and rumination in samples of palliative care patients, their caregivers and an age-matched control group. The results from Study 1 and Study 2 indicated that psychological distress and rumination on existential concerns were elevated in palliative care patients and their caregivers. Furthermore, findings suggested an association between psychological distress and abstract rumination.

Study 3 reported a case series piloting an intervention developed from concreteness training (CT) designed to address abstract rumination in palliative care. The case series indicated that with some modification to the identification and screening of patients, the treatment could be acceptable and feasible for palliative care patients.

Study 4 examined the effectiveness of the CT guided self-help intervention in a randomized controlled trial. Findings indicated that the intervention could be effective for reducing anxiety, but not depression in palliative care patients. Moreover, Study 5's findings also raised the possibility that abstractness was a partial mediator of the effects of the intervention on self-reported symptoms of anxiety in palliative care patients.

Study 5 utilised a cluster randomized controlled design to evaluate a training programme designed to teach hospice staff how to deliver the CT guided self-help intervention. Results indicated that there was a more positive impact of routine care on patient distress for nurses attending training, when compared to nurses not attending the training. However, the training did not impact on nurses' self-reported confidence or behaviour in addressing patients' distress.

ACKNOWLEDGEMENTS

I am delighted to have completed my thesis, having done so with the support of so many different people. Firstly, I would like to extend my sincere thanks to my supervisor Prof. Ed Watkins for his constant support, patience and guidance. Ed has always been there for me (either in person of via skype and email) and has readily spent much of his valuable time carefully reading over my thesis, making many invaluable suggestions. I also appreciate all the useful advice and insights that have come from the rest of my supervision team. Dr Tim Harlow has helped to keep my focus on the practical objectives of the project, whilst Prof. Michael Hyland has challenged me with his perspectives on psychological treatment. Also thanks go to Prof. David Richards for being my “man on the ground” while Ed was on sabbatical.

In addition, I would like to thank everyone who participated in the research, be they patients, carers, nurses, volunteers, staff’s friends and families, or the wider public. There would have been no research without them. I also appreciate the time that Hospiscare staff found to refer participants to the studies. Specific thanks also go to: Hospiscare's project steering group for their continued help and support; Dr Becky Baines, who was a driving force behind the inception of the research project; Amy Kilburn who helped with promotional materials; Kerry Macnish who helped develop and deliver the training; and Dr Nick Moberly along with the Mood Disorders Centre administrative team for helping with the randomisation of participants.

Last, but definitely not least I would like to thank my family for their undying support and patience in whatever I have chosen to do with my life. Lou, Joseph, Evan and Isaac...I love you and now you get your husband and Daddy back.

STATEMENT OF THE CANDIDATE'S CONTRIBUTION TO CO-AUTHORED PAPERS

There are five studies included in this thesis, four of which have been written up as manuscripts for publication. As detailed below, the substantial contribution to the co-authored papers presented in this thesis was made by the candidate. However, while the candidate is fully responsible for the work presented in this thesis, where the first person is used it is in the plural (i.e., 'we' rather than 'I') as in the original peer-reviewed articles, to reflect the collaborative efforts guiding the research process. All chapters that have been written up as manuscripts are presented in the format requested by the respective journal; since each manuscript is meant to stand alone, some information may be redundant.

Paper 1: Chapter 2

Galfin, J. M., Watkins, E. R., & Harlow, T. (2010). Psychological distress and rumination in palliative care patients and their caregivers. *Journal of Palliative Medicine, 13,* 1345-1348.

The first manuscript, presented in this thesis as Chapter 2, was submitted as a paper to the *Journal of Palliative Medicine* and was accepted in July 2010. The candidate designed the methodology, obtained ethical approval, collected and analysed the data, with supervisory support and statistical advice from Prof. Ed Watkins. The paper was written with supervisory support from Prof. Ed Watkins and Dr Tim Harlow.

Paper 2: Chapter 3

Galfin, J. M. & Watkins, E. R. (in press) Construal level, rumination, and psychological distress in palliative care. *Psycho-oncology.*

The second manuscript, presented in Chapter 3, was accepted for publication in the journal *Psycho-Oncology* in January 2011. The candidate designed the methodology, obtained ethical approval, collected and analysed the data, with supervisory support and statistical advice from Prof. Ed Watkins. The paper was written with supervisory support from Prof. Ed Watkins.

Paper 3: Chapter 5

Galfin, J. M., Watkins, E. R., & Harlow, T. (in press). A brief guided self-help intervention for psychological distress in palliative care patients: a randomized controlled trial. *Palliative Medicine.*

The third manuscript, presented in Chapter 5, was submitted to the journal *Palliative Medicine* and accepted for publication in May 2011. The candidate designed the methodology, obtained ethical approval, collected and analysed the data, with supervisory support and statistical advice from Prof. Ed Watkins. The paper was written by the candidate with supervisory support from Prof. Ed Watkins and Dr. Tim Harlow.

Paper 4, Chapter 6

Galfin, J. M., Watkins, E. R., & Harlow, T. (2011) An evaluation of a training programme to teach a brief guided self-help psychological intervention to hospice staff. *International Journal of Palliative Nursing, 17,* 119-124.

The fourth manuscript, presented in Chapter 6, was accepted for publication in the *International Journal of Palliative Nursing* in March 2011. The candidate designed the methodology, obtained ethical approval, collected and analysed the data, with supervisory support and statistical advice from Prof. Ed Watkins. The paper was written by the candidate with supervisory support from Prof. Ed Watkins and Dr. Tim Harlow.

STATEMENT OF THE SUPERVISORS' CONTRIBUTION TO CO-AUTHORED PAPERS

As outlined in the candidate's statement above, the substantial contribution to the co-authored papers presented in this thesis was made by the candidate. This includes the review of the literature presented in each paper, study design, statistical analyses and interpretation of the data, together with the write-up for publication. The supervisors contributed to the papers by advising on statistical analyses and interpretational issues, relevant literature, and writing style. Moreover, the theoretical framing of the empirical work in this thesis and the arrangement of the papers is a product of a concerted discussion of the thesis content between the candidate and supervisors.

Prof. Ed Watkins (first supervisor)

Dr. Tim Harlow (second supervisor)

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CHAPTER 1: INTRODUCTION

This PhD aims to develop and evaluate a novel psychological intervention that is acceptable and deliverable within the context of palliative care. This first section of the chapter will define palliative care and outline the local and national drivers for the research. These drivers include the current research that indicates elevated levels of anxious and depressive symptoms reported by palliative care patients. The second section will present a critical review of further literature pertinent to the research, with the final section identifying the aims and hypotheses of this research as generated from the review of the literature.

1.1 Definition of palliative care

In their guidance on 'Improving Supportive and Palliative Care for Adults with Cancer' (2004a), the National Institute for Health and Clinical Excellence (NICE) described palliative care as the active holistic care of patients with advanced progressive illness that comprises the management of pain and other symptoms alongside the provision of psychological, social and spiritual/existential support. The goal of palliative care is the achievement of the best quality of life for patients and their families. In order to achieve this goal, palliative care aims to:

a) Affirm life and regard dying as a normal process;
b) Provide relief from pain and other distressing symptoms;
c) Integrate the psychological and spiritual aspects of patient care;
d) Offer a support system to help patients live as actively as possible until death;
e) Offer a support system to help the family cope during the patient's illness and in their own bereavement.

A range of health care professionals provide palliative care across a number of settings including hospitals, hospices, day units and people's own homes (NCPC, 2007). Patients can have a range of diagnoses including cancer, motor neurone disease, end stage heart or renal failure and Chronic Obstructive Pulmonary Disease. Prognoses range from a few days to a few years. According to the National Council for Palliative Care's National Survey of Patient Activity Data for Specialist Palliative Care Services 2006/07, 68% of patient referrals were over the age of 65.

Palliative care patients most commonly face pain, which can interfere with their ability to eat, sleep, think and interact with others. Fatigue and generalised weakness are also common. Furthermore, shortness of breath, delirium, nausea, and vomiting are common symptoms in the last few days of life (Cherny, 2005).

When looking more specifically at psychological support in palliative care, the NICE guidance on improving supportive and palliative care for adults with cancer (2004a) identified that commissioners and providers of cancer services, working through Cancer Networks, should ensure that all patients undergo systematic psychological assessment at key points and have access to appropriate psychological support. A four-level model of professional psychological assessment and intervention was suggested to achieve this (See Figure 1.1). Health care professionals directly responsible for the patient's care provide the professional psychological support at levels one and two, whilst more severe psychological distress at levels three and four is managed by a variety of psychological specialists, including counsellors, mental health nurses, clinical and health psychologists, psychotherapists and liaison psychiatrists. NICE (2004a) also recommended that evaluative research was needed to determine which psychotherapeutic interventions are most effective and cost effective for different groups of patients at different stages of the patient pathway.

←Self help and informal support→	Level	Group	Assessment	Intervention
	1	All social and health care professionals	Recognition of psychological need	Effective information giving, compassionate communication and general psychological support
	2	Health and social care professionals with additional expertise	Screening for psychological distress	Psychological techniques such as problem solving
	3	Trained and accredited professionals	Assessed for psychological distress and diagnosis of some psychopathology	Counselling and specific psychological interventions such as anxiety management and solution-focused therapy, delivered according to an explicit theoretical framework
	4	Mental health specialists	Diagnosis of psychopathology	Specialist psychological and psychiatric interventions such as psychotherapy, including cognitive behavioural therapy

Figure 1.1. Recommended Model of Professional Psychological Assessment and Support (NICE, 2004a, p78)

1.2 Levels of anxious and depressive symptoms in palliative care patients

A key driver for this research is the initial evidence indicating that palliative care patients report elevated levels of anxious and depressive symptoms on a range of validated questionnaires. One of the most commonly used questionnaires is the Hospital Anxiety and Depression Scale (HADS; (Zigmund & Snaith, 1983). The HADS consists of 14 questions in two subscales (anxiety and depression). It can usually be completed in less than 5 minutes, and can be scored easily by non-psychiatric staff. The HADS is especially suitable for the medically ill, since it does not include the somatic symptoms of depression, such as fatigue, pain or insomnia, which may also be caused by the illness or its treatment (Stiefel, Die Trill, Berney, Nunez Olarte, & Razavi, 2001).

As with other questionnaires, there are several problems associated with the use of the HADS in daily clinical practice. First, the sensitivity and specificity of the instrument depends on cut-off points, which may change in different patient populations (e.g., inpatients, outpatients, young and elderly patients, patients differing in stage and type of disease). Second, as with any other instrument, higher sensitivity is associated with lower specificity and higher specificity with lower sensitivity. Third, the HADS is a screening instrument for adjustment disorders with anxious and depressed mood, as well as for major depression or dysthymic and anxiety disorders. Since the types of intervention needed to treat these disorders differ, the HADS lacks a diagnostic component that would determine the appropriate choice of treatment. Fourth, the HADS is an instrument based on self-report: acute stress reactions contribute to relatively high rates of false-positive results and social desirability contributes to false-negative results. Therefore care should be taken when using HADS as a screening instrument for depression in palliative care. Fifth, the HADS does not assess all the symptoms necessary for a diagnosis of major depression, such that it does not provide a comprehensive assessment of depressive symptoms. Sixth, HADS has a wide range of reported positive predictive values from 0.263 to 0.848 in palliative care samples. This reflects a wide range of sensitivity of HADS to correctly diagnose palliative care patients with depression or anxiety (Mitchell, Meader, & Symonds, 2010; Stiefel et al., 2001).

In palliative care, the HADS can be useful for assessing level of depressive and anxious symptoms but it has no single generally acceptable cut-off point to indicate more clinically relevant levels of symptoms (Holtom & Barraclough, 2000). Whilst Zigmund and Snaith (1983) in their original article suggested a cut-off score of 7–8 for possible and 10–11 for probable cases of anxiety and depression in each subscale, results from a number of validation studies have varied. In terminally ill cancer patients, HADS depression cut-off scores ranging from seven (Akechi et al., 2006) to nine have been validated (Le Fevre, Devereux, Smith, Lawrie, & Cornbleet, 1999; Lloyd-Williams, Friedman, & Rudd, 2001), whilst a HADS anxiety cut off score of ten has also been validated (Le Fevre et al., 1999; Lloyd-Williams et al., 2001).

Alternative measures that have been evaluated in palliative care include the Edinburgh Postnatal Depression (EPDS) Scale, which is a 10-item scale that was initially developed to be administered by healthcare workers with no background in psychiatry, to screen for postpartum depression in new mothers. The EPDS scale items correspond to non-somatic symptoms of depression, including subjective sadness, guilt, worthlessness, and hopelessness (Cox, Holden, & Sagovsky, 1987), which are symptoms that may also discriminate between depressed and non-depressed palliative care patients. When compared with a Present State Examination for depression according to International Classification of Diseases (10th edition) criteria in 100 in-patients with metastatic cancer who were receiving palliative care, a cut-off threshold of 13 on the EPDS scale gave the optimum sensitivity (.81) and specificity (.79) (Lloyd-Williams, Friedman, & Rudd, 2000). In a further study of 74 palliative care patients, when compared with a semi structured clinical interview according to DSM-IV criteria, a cut-off threshold of 13 on the EPDS scale was found to have sensitivity of .70 and specificity of .80 (Lloyd-Williams, Dennis, & Taylor, 2004a).

A measure that is widely used and validated across several populations is the Beck Depression Inventory (BDI). The most recent version (BDI-II) has 21 items that have been revised to reflect DSM-IV diagnostic criteria for major depression disorder. The BDI-II contains both affective items (pessimism, past failures, guilty feelings, punishment feelings, self-dislike, self-criticalness, suicidal thoughts or wishes, and worthlessness) and somatic items (sadness, loss of pleasure, crying, agitation, loss of interest, indecisiveness, loss of energy, change in sleep patterns, irritability, change in appetite, concentration difficulties, tiredness and/or fatigue, and loss of interest in sex) (Beck, Steer, & Brown, 1996). The BDI-II has been validated in cancer patients with high sensitivity (.86-.92) and specificity (.90-.95) and good internal consistency (α= .93) (Berard, Boermeester, & Viljoen, 1998; Katz, Kopek, Waldron, Devins, & Tomlinson, 2004).

The BDI-II has been further adapted for use with the medically ill by removing somatic items that may overlap with physical symptoms of chronic illness. The Beck Depression Inventory-Fast Screen (BDI-FS) is a 7-item self-report measure of common symptoms of depression that are distinct from symptoms of physical illness (i.e., sadness, loss of pleasure, suicidal thoughts or wishes, pessimism, past failure, self-dislike, and self-criticism). A study of 50 medical inpatients found that the BDI-FS had reported sensitivity of .82 and specificity of .82 and good internal consistency (α= .86) (Beck, Guth, Steer, & Ball, 1997).

In a review of 216 patients with advanced cancer who had participated in 3 previous clinical studies conducted by their group, Delgado-Guay, Parsons, Li, Palmer, and Bruera (2009) found that 37% of the patients had depressive mood (HADS-D > 7), and 44% had anxiety (HADS-A > 7). In a larger sample of 3025 newly diagnosed cancer patients, Sellick and Edwardson (2007) found that 25.7% of their sample scored either at least 11 on either HADS subscale or had a borderline score (8-10) on both subscales at the same time. Using the same cut off scores, Hopwood and Stephens (2000) found that depression was self-rated in a third of 987 palliative patients undergoing trials before treatment and persisted in more than half of the patients. In a smaller sample, Kramer (1999) found that in 60 community patients with inoperable lung cancer, 50% had borderline depression (HADS score 8-10) at some point during their illness and 37% had scores indicative of depression (HADS score 11-21). Herbaut, Reich, & Horner-Vallet (2003) found that in a sample of 50 hospitalised palliative patients, 58% reported being distressed on the HADS.

Similar results were reported by Lloyd-Williams (2002), who used the EPND Scale, which identified 34% of a sample of 194 palliative patients as being depressed. This study used a cut-off score of 13 because it had been previously validated in patients with advanced metastatic cancer (Lloyd-Williams et al., 2000) and in terminally ill patients (Lloyd-Williams, Dennis, & Taylor, 2004a). Using the same scale and the same cut-off, Reeve, Lloyd-Williams, and Dowrick (2007) found that 22.9% of a sample of patients with advanced metastatic cancer was depressed. However when they then carried out interviews using the revised Clinical Interview Schedule on 11 patients with EPND scores of at least 13, and 8 patients with a score less than 13, they found that the weighted prevalence of depression was 4.1%. Lloyd-Williams and Riddleston (2002) found that depression scores on this scale remained stable during the last few months of life.

In summary, these studies using questionnaires indicate that 23-58% of palliative patients report elevated levels of distress. These findings correspond with a review of 46 studies by Hotopf et al. (2002), which found that the most widely used assessment of depression in palliative care was the HADS, which gave a median prevalence of 'definite depression' (i.e., a score on the depression subscale of >10) of 29%. However, these studies did not use comparison groups to assess if these findings were unique to palliative care patients. Moreover, using questionnaires to ascertain levels of anxious and depressive symptoms in palliative care poses a number of challenges. First, it is difficult to set cut-off points in people experiencing the normal feelings of anxiety and low mood when faced with their death and deteriorating physical health and death. Second, making diagnoses in palliative care is difficult because of the variety of factors that can lead to the physical symptoms of anxiety and depression (e.g., pain, medications and organic issues). These issues will be discussed in more depth in section 2.3.2, as part of the review of the issues pertinent to the assessment of psychological distress in palliative care.

Moreover, in a critical review of studies evaluating psychological therapies in cancer care, Coyne, Lepore and Palmer (2006) argued that the prevalence of psychological distress in cancer patients recruited for trials of psychological interventions does not represent a significant increase compared with what would be expected from the general public. Furthermore it is unclear if the distress is transient and would resolve with routine care.

1.3 Practical drivers for research

Hospiscare is a local charity in Exeter, mid and east Devon that provides palliative care, with the largest proportion of patients cared for through their team of nurse specialists in the community. Although referrals to Hospiscare are based on need rather than diagnosis, the majority of referrals are for people with a cancer diagnosis. In

2006/7 this equated to 94% of new referrals being for people with a diagnosis of cancer (Hospiscare, 2007).

The importance of psychological care in palliative care was endorsed at a local level by Hospiscare's review of their services (2007). The review identified that one of the key priorities of Hospiscare stakeholders was meeting the needs of patients with complex psychological and emotional needs. Recommendations included adopting a generic approach to enhancing psychological support by enabling front-line staff to develop appropriate skills.

The need for more psychological support in palliative care has also been supported in the research literature. Price, Hotopf, Higginson, Monroe, and Henderson (2006) found that of 166 hospices, 45% have no access to a psychiatrist or clinical psychologist. Even though access to specialist palliative care has been shown to positively impact on symptoms such as pain, appetite, nausea, sleep, constipation and overall quality of life (Higginson & Evans, 2010; Strömgren et al., 2006), in a sample of 42 palliative patients, palliative care was shown to have little effect on anxiety and depression (González et al., 2002). Further research into improved means of assessment of psychological symptoms in palliative care (Breitbart, Bruera, Chochinov, & Lynch, 1995; Lloyd-Williams, 2003) along with effective treatments of psychological distress have been argued to be a priority (Hudson, Remedios, & Thomas, 2010; King, Heisel, & Lyness, 2005; Lloyd-Williams, 2001; Lan Ly, Chidgey, Addington-Hall, & Hotopf, 2002).

This project was part funded by Great Western Research (GWR), which funds research with a deliberate applied focus in partnership with businesses or charities outside academia. Hospiscare was the external partner contributing to the funding. Thus, as a GWR research project joint funded by Hospiscare, the main objective of this research is to examine the nature of psychological distress in palliative care. Hospiscare require the project to develop and evaluate accessible psychological interventions suitable for Hospiscare staff to use with clients. Therefore any treatments developed should not be excessively burdensome for palliative care patients to use and should be straightforward enough to learn so that current Hospice staff would require minimal extra training to deliver the intervention as part of their routine practice. In order to achieve this objective, the thesis will begin with an in-depth review of the literature on psychological distress, psychological treatments, and potentially relevant psychological processes that could be addressed in palliative care. The PhD will then examine whether or not those psychological processes are present and associated with psychological distress in palliative care. The PhD will then use those findings to develop and evaluate a psychological intervention for palliative care patients and examine if the intervention can be effectively trained to palliative care staff.

Psychological issues in palliative care

The first part of this review of the literature will critically evaluate published research that palliative care patients and their caregivers experience psychological distress. This will include discussing the prevalence of anxiety and depression and how the types of concerns expressed by patients and their caregivers contribute to their psychological distress. The second part will focus on how the psychological issues impact on the lives of palliative care patients and their caregivers. The review will then move on to discuss issues impacting on the assessment and treatment of psychological distress in palliative care. The final part of the review will then turn to the process of rumination and discuss how it may be relevant to the psychological issues in palliative care from a theoretical standpoint, whilst also evaluating any empirical evidence. As the majority of people who receive palliative care have a diagnosis of cancer, when there is a paucity of research looking specifically at palliative care patients, research that investigates cancer patients will also be discussed.

2.1 Psychological distress in palliative care

There is evidence that both palliative care patients and their caregivers experience psychological difficulties, coming from a range of sources including: (a) studies of depression and anxiety in palliative care; (b) the concerns expressed by palliative care patients and their caregivers.

2.1.1 Definition of depression

Depression refers to a wide range of mental health problems characterised by the absence of a positive affect (a loss of interest and enjoyment in ordinary things and experiences), low mood and a range of associated emotional, cognitive, physical and behavioural symptoms. Depressive symptoms can include tearfulness, irritability, social withdrawal, reduced sleep, an exacerbation of pre-existing pains, and pains secondary to increased muscle tension and other pains, lowered appetite, a lack of libido, fatigue and diminished activity, although agitation is common and marked anxiety frequent. Along with a loss of interest and enjoyment in everyday life, feelings of guilt, worthlessness and deserved punishment are common, as are lowered self-esteem, loss of confidence, feelings of helplessness, suicidal ideation and attempts at self-harm or suicide (NICE, 2004b).

In order to differentiate between these depressive symptoms and a diagnosis of depression, the American Psychiatric Association's Diagnostic and Statistic Manual of Mental Disorders (DSM-IV-TR) provides a definition for the diagnosis of a clinical episode of major depression. According to the DSM-IV-TR (American Psychiatric Association, 2000), the key criteria for a diagnosis of major depression is to have at least five of the following symptoms lasting most of the day, nearly every day for at least two weeks, with at least one of the first two symptoms: persistent depressed mood, anhedonia/loss of interest or pleasure, loss/gain of appetite or weight loss/weight gain, disturbed (increased/decreased) sleep, psychomotor agitation or retardation, fatigue, feelings of worthlessness or intense feelings of guilt, concentration difficulties, and recurrent thoughts of death or suicide ideation. In addition, individuals must also exhibit clinically significant distress or impairment in social, occupational, or other important areas of functioning. Moreover, the symptoms must not be directly caused by a physiological response to medication or physical illness, nor be a response to a bereavement.

Apart from the subjective suffering experienced by people who experience depressive symptoms or are diagnosed as depressed, the impact on social and occupational functioning, physical health, and mortality is substantial. Depression has been shown to have a similar impact on physical health as a number of major chronic and disabling physical illnesses such as diabetes, arthritis and hypertension (Cassano & Fava, 2002). In the World Health Organisation World Health Survey, depression produced the greatest decrement in health compared with the chronic diseases of angina, arthritis, asthma, and diabetes. Depression as a co-morbid disorder was also shown to incrementally worsen health compared to depression alone, any of the chronic diseases alone, and to any combination of chronic diseases without depression (Moussavi et al., 2007). Similar findings for a range of physical illnesses also suggest an increased risk of death when co-morbid depression is present (Cassano & Fava, 2002).

Without appropriate treatment, depression can become a chronic and recurrent condition (Moussavi et al., 2007). Over time, the presence of mental disorders has been associated with higher levels of disability (Brenes, Penninx, Judd, Rockwell, Sewell, & Wetherell, 2008; Scott et al., 2009; Simon, Bauer, Ludman, Operskalski, & Unurtzer, 2007; Ormel, Von Korff, Oldehinkel, Simon, Tiemans, & Ustun, 1999). The cost of disability in terms of loss of productivity along with the costs of treatment produces a significant economic burden. In the UK, at 1990 prices, the direct cost of depression has been calculated at between £222 million (Jönsson & Bebbington, 1994) and £333 million (West, 1992). However, these figures are likely to be underestimates because when including costs for drug treatment, primary healthcare, social services, inpatient stays (including depression, attempted suicide, poisoning and mental illness) and outpatient attendance, the cost has been calculated at £417 million (Kind & Sorensen, 1993). Kind and Sorensen (1993) proceeded to include loss of productivity, which was estimated at 155 million working days lost, a cost of £2.97 billion.

In addition to the negative effects already discussed, depression can also exacerbate the pain and distress associated with physical diseases. Depression has been correlated with increased pain for primary care patients (Means-Christensen, Roy-Byrne, Sherbourne, Craske, & Stein, 2008) and more specifically for patients with lower back pain (Keefe, Wilkins, Cook, Crisson, & Muhlbaier, 1986), early inflammatory arthritis (Schieir et al., 2009), rheumatoid arthritis (Smith & Zautra, 2008) and chronic musculoskeletal pain (Bair, Wu, Damush, Sutherland, & Kroenke, 2007).

Depression is a highly prevalent disorder. In an Office of National Statistics survey of psychiatric morbidity among adults living in private households, Singleton, Bumpstead, O'Brien, Lee, and Meltzer (2000) identified that the symptoms of depression and depressive ideas were reported by about 10% of respondents. In terms of meeting diagnostic criteria, the most prevalent neurotic disorder among the population as a whole was mixed anxiety and depressive disorder (8.8%). The prevalence of mixed anxiety and depression in the general population was reported as 7% for men and 11% for women. These findings are similar to those identified in the National Co-morbidity Survey in the USA, which identified that 10% of the population would experience minor depression during their lifetime, whilst major depressive disorder was shown to be a prevalent (7.5-8.3% of the population in their lifetimes), chronic and recurrent disorder (Blazer, Kessler, McGonagle, & Swartz, 1994; Kessler, Zhao, Blazer, & Swartz, 1997).

More recently, in the Adult Psychiatric Morbidity Survey (2007), prevalence of common mental disorders was assessed using the Clinical Interview Schedule – Revised (CIS-R), which covers non-psychotic symptoms in the past week. Responses to this were used to generate an overall score and to diagnose either Generalised Anxiety Disorder (GAD); Mixed anxiety and depressive disorder; Depressive episode (including mild, moderate and severe); Phobias; Obsessive-compulsive Disorder (OCD); and Panic Disorder. Of the 15.1% of adults presenting with one of these disorders, more than half (9.0%) reported symptoms consistent with mixed anxiety and depressive disorder, whilst 2.3% presented with a depressive episode. When looking more specifically at older adults to reflect the age group of people accessing Hospiscare services, 14.1% of 55-64 year olds and 10.6% of 65-74 year olds reported symptoms consistent with at least one common mental disorder, reflecting rates lower than the results for the adult population as a whole (Deverill & King, 2009).

2.1.2 Definition of anxiety

Depression is often accompanied by anxiety, and in these circumstances one of three diagnoses can be made: (1) depression, (2) anxiety, or (3) mixed depression and anxiety, dependent upon the types of symptoms that are present (NICE, 2004b). When individuals exhibit anxiety as a symptom, they can experience muscle tension, restlessness, panic, or a sense of impending doom. They often also have anxious thoughts, such as fears of dying of a heart attack, fears of embarrassment or humiliation, or fears of something terrible happening. In addition, they often have uncomfortable physical sensations, including heart palpitations, sweating, dizziness, or shortness of breath. Other features of anxiety include irritability, poor sleeping, avoidance and poor concentration. Some people with anxiety disorders perform certain rituals (checking door locks or hand washing) or avoid certain situations (bridges, aeroplanes, or social situations) in order to cope with anxiety. Depression and anxiety have distinct clinical features, in that depression is characterised by loss of interest and enjoyment in everyday life, feelings of guilt, worthlessness and deserved punishment, lowered self-esteem, loss of confidence, and feelings of helplessness, suicidal ideation and attempts at self-harm or suicide, whilst anxiety is characterised by restlessness, panic, a sense of impending doom, anxious thoughts, such as fears of dying of a heart attack, fears of embarrassment or humiliation, or fears of something terrible happening, and/or uncomfortable physical sensations, including heart palpitations, sweating, dizziness, or shortness of breath. While depression and anxiety have distinct clinical features, there is some overlap of symptoms. For example, in both depression and anxiety, irritability, decreased concentration and impaired sleep are common.

There are a number of specific diagnoses of anxiety disorders including Generalised Anxiety Disorder, Panic Disorder (with or without agoraphobia), Post

Traumatic Stress Disorder, Obsessive Compulsive Disorder, Specific Phobia (e.g. of spiders), Social Phobia (social anxiety disorder) and Acute Stress Disorder (American Psychiatric Association, 2000; NICE, 2004c).

A specific anxiety disorder that has been identified in palliative care patients is Generalised Anxiety Disorder (Minagawa, Uchitomi, Yamawaki, & Ishitani, 1996; Wilson et al., 2004; Wilson et al., 2007). Generalised Anxiety Disorder can occur alongside mood disorders such as depression and other anxiety disorders such as panic disorder, social phobia and specific phobias. According to DSM-IV-TR diagnostic criteria, the essential feature of generalised anxiety disorder is excessive and unrealistic anxiety and worry (apprehensive expectation), occurring more days than not for a period of at least 6 months, about a number of events or activities. The individual finds it difficult to control the worry and will experience at least three additional symptoms from a list that includes restlessness, being easily fatigued, difficulty concentrating, irritability, muscle tension and disturbed sleep (American Psychiatric Association, 2000).

The diagnostic criteria further note that although individuals with generalised anxiety disorder may not always identify the worries as excessive, they report subjective distress due to constant worry, have difficulty controlling the worry, or experience related impairment in social, occupational or other important areas of functioning. The intensity, duration or frequency of the anxiety and worry is out of proportion to the actual likelihood or impact of the feared event. With generalised anxiety disorder the individual finds it difficult to keep worrisome thoughts from interfering with attention to tasks being undertaken (American Psychiatric Association, 2000).

In terms of prevalence of symptoms, Singleton et al. (2000) identified that one of the most commonly reported neurotic symptoms among both men and women was worry (not including worry about physical health), with 19% of all adults experiencing this symptom. Anxiety as a symptom was also reported by about 10% of respondents. With regards to meeting diagnostic criteria, generalised anxiety disorder was found in 4.4% of respondents. The rate remained unchanged at 4.4% in the Adult Psychiatric Morbidity Survey (2007) (Deverill & King, 2009). In a sample of 965 primary care patients, Kroenke, Spitzer, Williams, O'Monahan, and Löwe (2007) utilised diagnostic interviews and found that 19.5% had at least one anxiety disorder. In terms of specific diagnoses, 8.6% of the sample met the criteria for posttraumatic stress disorder, 7.6% had generalized anxiety disorder, 6.8% had panic disorder and 6.2% had social anxiety disorder.

2.1.3 Methods of assessing prevalence of depression and anxiety in palliative care patients

Depression and anxiety can be assessed by either using a diagnostic interview to determine if the criteria are met for a diagnosis, or by using a questionnaire to assess the level of symptoms. Whilst diagnostic interviews such as the Structured Clinical Interview for DSM (SCID) offer the gold standard for assessment of diagnostic status, they have the disadvantage of being time-consuming, and therefore expensive to use, as well as being cumbersome for some patients with advanced disease (Hotopf, Chidgey, Addington-Hall, & Lan Ly, 2002). Therefore, the prevalence of anxiety and depression has also been investigated with regards to the severity of symptoms using a number of questionnaires, which indicate severity of symptoms rather than establishing a diagnosis.

In general, interviews as a method of data collection have several advantages, as they enable the researcher to flexibly probe and clarify in order to get rich data that illuminates the topic in greater depth and detail. This also improves validity, as the interviewer checks the data for accuracy and relevance as it is collected. Interviews can also produce data that derives from the participants' priorities and can ultimately be a rewarding experience for the participants, as they get the chance to share their opinions and thoughts with someone who is there to listen and not be judgemental (Burnard & Morrison, 1994; Burns & Grove, 2005; Denscombe, 2003; Hek, Judd, & Moule, 1996; Skodol Wilson, 1993).

Participants' responses in interviews may be influenced by several factors such as the identity and/or the interviewing skills of the researcher, leading to social response bias, whereby they may give answers that fit a 'social norm'. The effects of the researcher and the context also mean that the data collected is specific to the context and individuals involved, potentially reducing reliability. The tape-recording of interviews can have had an inhibitory effect on the participants, as they may be self-conscious of what they were saying. Allowance also has to be made for the time required not only to interview, but also to transcribe and analyse the data collected. However, the interviewer does have an opportunity for more objective assessment by observing behaviour and double-checking, so making interviews less problematic than self-report (Barker, Pistrang, & Elliot, 1994; Burns & Grove, 2005; Denscombe, 2003; Hek et al., 1996; Skodol Wilson, 1993).

In comparison with interviews, questionnaires provide an economical means to collect and analyse data consisting of standardised answers, which have less scope to be affected by the researcher administering them and any bias they may hold (Burnard & Morrison, 1994; Denscombe, 2003; Hek et al., 1996). The disadvantages of questionnaires relate to their rigid structure and the answers they provide, which do not allow for a complete response from the subjects or for the researcher to check or clarify those responses (Denscombe, 2003).

2.1.4 Rates of diagnosis of depression and anxiety in palliative care patients

Compared to questionnaire studies, relatively few studies have utilised diagnostic interviews to determine the prevalence of mood and anxiety disorders in palliative care. Wilson et al. (2007) found that 24.4% of a sample of 381 palliative patients fulfilled the Diagnostic and Statistical Manual of Mental Disorders, fourth edition (DSM-IV) diagnostic criteria for at least one anxiety or depressive disorder, with 20.7% meeting the criteria for depressive disorders and 13.9% having an anxiety disorder. More specifically, 13.1% met the criteria for major depression, 4.7% met the criteria for partial remission of major depression, 2.1% had minor depression, whilst 5.8% met the criteria for generalised anxiety disorder. Using the same criteria, Grabsch et al. (2006) interviewed a sample of 227 women with advanced breast cancer. Results indicated that 42% of the women had a psychiatric disorder: 35.7% of these had depression or anxiety or both. Specific diagnoses included minor depression in 25.6% of women, major depression in 7%, and anxiety disorder in 6.2%.

Durkin, Kearney, and O'Siorain (2003) assessed 224 admissions to a palliative care unit by comparing the findings on clinical assessment with the Mental and Behavioural Disorders of the International Statistical Classification of Diseases and Related Health problems (ICD-10), as laid down by the Diagnostic Criteria for Research (DCR-10). Results indicated that 62% of patients met ICD-10 diagnostic criteria for psychiatric disorder, with 24% having dual diagnoses. The commonest diagnoses were organic disorders (27%) followed by neurotic or stress-related disorders (16%) and depression (16%).

Minagawa, Uchitomi, Yamawaki, and Ishitani (1996) systematically assessed 93 terminally ill cancer patients using the Mini-Mental State Examination (MMSE) and Structured Clinical Interview for DSM-III-R (SCID) within 1 week of admission. Of this sample population, 53.7% met the DSM-III-R criteria for a psychiatric disorder. Delirium was observed in 28%, dementia in 10.7%, amnesic disorder in 3.2% and major depression in 3.2%, and generalized anxiety disorder in 1.1%.

When validating their Structured Interview for Symptoms and Concerns (SISC) that was based on DSM-IV diagnostic criteria, Wilson et al. (2004) reported that in a sample of 69 palliative patients, 23% met the criteria for any anxiety or depressive disorder. Within this group there was some co-morbidity in that 20% of the sample was given a diagnosis of a depressive disorder and 12% had major depression, whilst 10% met the criteria for any anxiety disorder and 3% has generalised anxiety disorder.

In a sample of 33 palliative care patients in a nursing home, Greenberg et al. (2004) compared a psychiatrist's evaluation with a number of questionnaires including a checklist derived from DSM-IV. The psychiatrist diagnosed 36% of the sample with depression and of those 58% had severe depression and 42% had mild depression. Lloyd-Williams, Dennis, and Taylor (2004b) found that when using a clinical interview based on DSM-IV, 27% of palliative patients attending day care fulfilled the criteria for depression. Lichtenthal et al. (2009) also utilised the DSM-IV with 289 palliative patients. Results indicated that shorter patient prognoses were not associated with higher rates of mental disorder. However patients closer to death exhibited more existential distress, physical symptom burden, and were more likely to acknowledge being terminally ill or express a wish to die.

In summary, there appears to be a consensus that within palliative care patients, rates of diagnosable major depression range from 16-36% and of anxiety disorders between 10-20%. Giving more weight to the studies with the most power, that is, the larger studies of palliative patients by Wilson et al. (2007) and Durkin et al. (2003), the range is narrower with 16-21% meeting the diagnostic criteria for depression and 14% for anxiety disorders. These findings correspond with a review of 46 studies by Hotopf et al. (2002), which found studies that used psychiatric interviews indicated a prevalence of major depressive disorder ranging from 5% to 26%. Thus, these suggest that around a fifth to a quarter of palliative care patients experience anxiety or depression at a clinically significant level. When comparing rates of anxiety for palliative care patients compared to rates in the general population, the rates appear similar with 19% of all adults experiencing anxiety, and 4.4% meeting the diagnostic criteria for generalised anxiety disorder. However the findings suggest that the incidence of depression may be higher in palliative patients than in the general population (around 20-25% relative to 10% reported in the general population, Singleton et al., 2000).

A further diagnostic category that has been evaluated in palliative care patients is that of adjustment disorders (AD). Adjustment disorders are defined in DSM-IV-TR as one of the subthreshold disorders that are characterised by the presence of clinically significant emotional or behavioural symptoms in response to an identifiable psychosocial stressor, which could include the diagnosis of terminal cancer. There are six AD subtypes: (1) depressed mood; (2) anxiety; (3) mixed anxiety and depressed mood; (4) disturbance of conduct; (5) mixed disturbance of emotions and conduct; and (6) unspecified. In addition there is an acute form (persistence of symptoms less than 6 months) and a chronic form (persistence of symptoms for more than 6 months) after the termination of the stressor or its consequences. Rates of diagnosed adjustment disorders in palliative care patients range from 7.5% (Minagawa et al., 1996) to 16.3% (Akechi, Okuyama, Sugawara, Nakano, Shima, & Uchitomi, 1996).

2.1.5 Prevalence of depression and anxiety in carers of palliative care patients

Relatively few studies have examined the prevalence of depression or anxiety in carers of patients with terminal illness. Price et al. (2010) found that in a sample of 376 carers of patients with invasive ovarian cancer, 13.7% reported subclinical depressive symptoms (HADS scores 8-10). In a longitudinal study of carers of palliative care patients, Burridge, Barnett, and Clavarino (2009) surveyed the carers (N ranged from 41 to 73) 4 times over the last year of the patient's life. Results indicated that carers' anxiety increased over the last year and depression increased over the last 6 months (as measured on HADS).

Braun, Mikulincer, Rydall, Walsh, and Rodin (2007) recruited a sample of 101 patients with advanced cancer and their spouse caregivers. Braun et al. (2007) found that 38.9% of carers reported significant symptoms of depression (Beck Depression Inventory-II scores greater than 15) compared with 23% of their ill spouses. Increased symptoms of depression were positively correlated with subjective caregiving burden, and caregivers' attachment orientations, and negatively correlated with marital dissatisfaction. Subjective caregiving refers to the experience of caregiving and caregivers' appraisal of their role as caregivers. Caregivers attachment orientations refer to the way people interact and feel in close relationships, along two main dimensions. Anxious attachment reflects the degree to which a person worries that a relationship partner will not be available in times of need. Avoidant attachment reflects the extent to which a person distrusts a relationship partner's goodwill and seeks independence and emotional distance. Individuals scoring low on these dimensions are securely attached and form satisfactory close relationships. Braun et al. (2007) found that higher levels of both caregivers' attachment anxiety and avoidance were associated with more depression.

As with depression, the prevalence of anxiety in pre-bereaved carers is difficult to assess due to the paucity of research. A study of 96 carers found that mean HADS anxiety scores for pre-bereaved men were 7.2 compared with 3.8 in a larger normal sample and for pre-bereaved women 7.9 compared with 4.6 in a non-pre-bereaved sample (Grov, Dahl, Moum, & Fosså, 2005). Results from Price et al. (2010) also indicated elevated levels of anxiety as 23.6 % of 376 carers reported subclinical levels anxious symptoms (HADS scores 8-10) and 18.8% reported clinical levels of anxious symptoms (HADS scores 11-21). These findings suggest that carers of palliative care patients may have elevated levels of depression and anxiety. However, diagnostic interviews have not been used to ascertain if these symptoms are clinically significant.

In summary, the evidence suggests that both palliative care patients and their caregivers report elevated symptoms of anxiety and depression. However a key limitation of all these studies is the lack of an appropriate comparison control group to ascertain if any elevated symptoms are due to living with the palliative diagnosis. These findings suggest the first hypothesis that will be tested in this thesis:

Hypothesis 1. Palliative care patients and their caregivers will report higher levels of psychological distress than matched controls.

2.1.6 Concerns expressed by palliative care patients

The second set of evidence concerning the psychological difficulties experienced by palliative care patients is the reports made by patients of their concerns. A key study by De Faye, Wilson, Chater, Viola, and Hall (2006) grouped these concerns in a way that reflected the key domains of palliative care: concerns about physical symptoms; social concerns; and spiritual/existential issues. In their study of 52 palliative patients, De Faye et al. (2006) conducted semi-structured interviews that inquired about a range of problems within the physical, social, and existential dimensions of stress, as well as the participant's ways of coping with those problems. Each item followed the same pattern: a lead question that asked about the presence of a specific symptom or concern, followed by probing to assist in rating the severity of the problem on a 7-point scale (0=no problem, 1=minimal, 2=mild, 3=moderate, 4=strong, 5=severe, 6=extreme). The probing included an inquiry into the intensity, frequency, and degree of distress associated with each problem. A summary of the concerns and symptoms is in Table 1.1.

Table 1.1. Categories for coding of concerns (Adapted from De Faye et al., 2006)

Social Concerns	Physical Concerns	Existential Concerns
Isolation	Pain	Loss Of Control
Lack Of Information	Drowsiness	Life Dissatisfaction
Lack Of Consultation	Nausea	Hopelessness
Role Loss	Weakness/ Fatigue	Loss Of Dignity
Financial Strain	Shortness Of Breath	Loss Of Meaning
Burden To Others		Concern For The Future

Physical concerns of patients tended to focus on the symptoms they face or are expecting to face. De Faye et al. (2006) found that the physical symptoms they asked about (pain, drowsiness, nausea, weakness and dyspnoea) were reported by over 35% of the participants. The most prevalent symptoms reported by patients were weakness (82.7%) and pain (73.1%). In a sample of 175 palliative care patients who were asked to identify the five symptoms that they found most troublesome, pain was most often chosen as either one of the five most distressing symptoms (71% of participants) or as the single most distressing symptom (44% of participants). Other symptoms that were frequently amongst the top five important symptoms, but not often the single most important were fatigue (57%), poor physical function (39%), reduced appetite (32%) and nausea/vomiting (26%) (Strömgren, Sjogren, Goldschmidt, Petersen, Pedersen, & Groenvold, 2006). In a qualitative study of 10 palliative patients with heart failure, Cortis and Williams (2007) found that all the patients reported experiencing at least one and often several symptoms including breathlessness, falls, anorexia, insomnia, headaches, oedema, palpitations and fatigue. The participants also reported that coping with these symptoms led to fear, anxiety and frustration in many cases.

The social concerns raised by patients in a number of studies frequently focus on how their physical illness and debility leads to them being a burden to others, especially their family. De Faye et al. (2006) reported that this was most prevalent social concern cited by 65.4% of participants. Other social concerns that were frequently reported were role loss (40.4%) and lack of information about their illness or treatment (36.5%). Fitzsimons et al. (2007) conducted a qualitative interview study with 18 palliative patients, who identified their deteriorating health status as a key concern, which led to decreased independence, social isolation and family burden. Social isolation that they experienced as a result of their illness was also a key concern for the patients interviewed by Cortis and Williams (2007). In a phenomenological study of 15 palliative patients, a key concern for patients centred on the physical, emotional and social hardships they created for others (McPherson, Wilson, & Murray, 2007). Turner, Muers, Haward, and Mulley (2007) reported that in a sample of 132 lung cancer patients undergoing radiotherapy, a common concern was about how their illness affects their family.

Existential concerns are focused on the basic concerns of one's own existence and the threats that are posed to one's self-identity (Henoch & Danielson, 2009). The existential concerns reported by palliative care patients can include genuine existential issues centred on meaning or identity, or more general concerns about the future course of their illness. However, care needs to be taken when interpreting these findings as it is unclear whether the existential concerns reported by palliative care patients are pathological or not. These concerns may include genuine existential issues of meaning and identity as well as more problematic existential concerns such as those that involve self-blame, overgeneralization, helplessness, and rumination (This will be discussed in more detail in the discussion of rumination in palliative care in section 2.4).

De Faye et al. (2006) reported that concern for the future was a source of stress for 67.3% of their 52 participants. Concern for the future included concerns about death and dying (e.g., not being ready to die, uncertainty about the time they had left, fear of a painful or prolonged death, being alone, concerns about the afterlife) and concern for the future welfare of family members. Concern for the future and the impact of their death on others was also a key theme in the qualitative findings of McPherson et al. (2007) and Turner et al. (2007). Palliative care patients also reflected back on a number of perceived losses such as loss of independence or control, loss of self esteem and self worth and a diminished sense of self (Cortis & Williams, 2007; Fitzsimons et al., 2007; McPherson et al., 2007).

In summary, the research literature indicates that palliative care patients are most commonly concerned about the physical symptoms of pain and weakness/fatigue, the social concern of how their illness affects their family and existential issues such as concern for the future. Whilst these concerns clearly indicate some psychological distress, it is not clear how much palliative patients think or worry about these concerns and to what extent these concerns lead to psychological distress, i.e., are these thoughts transient or repetitive? Do they interfere with how they lead their lives? Another issue is that these studies have not used comparison groups to ascertain if these concerns are specific to being a palliative care patient or due to common factors found in palliative care patients such as elevated age.

2.1.7 Concerns expressed by carers of palliative care patients

The concerns expressed by carers also reflected the same domains and can be grouped into physical, social, and existential domains. In terms of physical concerns, Maguire, Walsh, Jeacock, and Kingston (1999) utilised an interview design with 48 carers of palliative care patients. Results indicated that 47% of the carers were concerned with the patient's illness including unresolved pain and patient suffering. In a study interviewing 76 hospice patient caregivers, 80% reported seeing the patient in severe pain, 60% saw the patient either choking or unable to eat, 75% saw confusion and 65% identified the "patient had had enough" as major concerns (Prigerson et al., 2003). In an exploratory questionnaire study of 21 carers of palliative care patients, Loke, Faith Liu, and Szeto (2003) found that the physical demands of being in a carer role was a concern for 47.6% of the carers.

The social concerns expressed by carers included the difficulty in maintaining their relationship with the patient (Loke et al., 2003) and the life restrictions resulting from adopting a caring role (Payne, Smith, & Dean, 1999), especially those placed on their social life (Loke et al., 2003). The level of support received by carers was also seen as important (Payne et al., 1999), particularly if it was inconsistent and irregular

(Chambers, Ryan, & Connors, 2001). Informational support was also identified as being important, especially relating to basic care, the disease, palliative care, psychosocial issues, spirituality and the social welfare of the patient including financial support (Harding & Higginson, 2003; Lin & Tsao, 2004).

When identifying existential concerns, Maguire, Walsh, Jeacock, and Kingston (1999) found that 33% of carers cited concerns about the future. Furthermore, Murray, Kendall, Boyd, Grant, Highet, and Sheikh (2010) conducted qualitative interviews of 19 carers of patients with lung cancer, which revealed that carers reported psychological and spiritual distress, particularly during the terminal stages of the patient's disease. Carers reported that witnessing suffering triggered personal reflections on the meaning and purpose of life. In another qualitative study, Payne, Smith, and Dean (1999) found that when interviewing 39 carers of palliative care patients, carers were concerned about the emotional demands being put on them as a consequence of their caring role. The emotional demands of the caring role have been reported as a concern for between 23% (Maguire et al., 1999) and 42.9% (Loke et al., 2003) of carers.

In summary, carers of palliative care patients report concerns about the physical wellbeing of the patient they are caring for and about the physical and emotional demands placed on them by their caring role. Their social concerns reflect the impact on their relationship with the patient and how they live their lives as a result of the caring role. Carers also share the existential concern about the future that patients expressed.

2.1.8 Limitations of studies identifying concerns in palliative care

The studies described above examining concerns of palliative care patients and their carers have a number of limitations. First, these studies tend to have small samples (e.g. Maguire et al., 1999, 48 participants; Loke et al., 2003, 21 participants). Second, these studies have not compared the concerns expressed by patients and carers with those of other people of similar age and gender (i.e., a control comparison), to determine if there is a genuine difference between palliative care populations versus other groups or whether the elevated scores may reflect some other characteristic of the sample. Third, they have generally been qualitative studies, which have an emphasis on subjectivity, interpretation, and particularly description and therefore may be prone to the expectations of the researchers, rather than provide an objective test of hypotheses. Qualitative research is often better suited for generating hypotheses than for testing and refuting hypotheses (i.e., falsifying the null hypothesis). A further criticism of qualitative methodology is that it may be difficult to generalise the findings from one study because of the small study size and lack of objectivity, analysis, and measurement. However, in qualitative studies, rigour is associated with openness, strict adherence to a philosophical perspective, thorough data collection and consideration of all the data collected in the analysis phase (Burns & Grove, 2005; Denscombe, 2003).

It is noted that the existential concerns reviewed above involve patterns of thinking associated with psychological distress (e.g., worry about the future; judgements about the past). The evidence reviewed suggests that both palliative care patients and their caregivers report existential concerns. However, an important gap in the evidence is the absence of a comparison of the concerns of palliative care patients and their caregivers versus an appropriate set of matched controls. Thus, one of the principal objectives of the current PhD is to advance knowledge of this field by resolving this absence. Noting the elevated levels of anxiety and depression found in palliative care patients and their caregivers, it is hypothesised that:

Hypothesis 2. Palliative care patients and their caregivers will report more existential concerns than matched controls.

Conclusion for Section 2.1.

This section has demonstrated that there is evidence that palliative care patients and their caregivers experience psychological difficulties from a range of sources. First, studies on depression and anxiety in palliative care indicate that there may be higher levels of diagnosable depression and/or anxiety and elevated symptoms of distress in palliative care patients and caregivers. Second, research investigating the concerns expressed by palliative care patients and their caregivers indicates that both groups report a number of psychological concerns, including physical, social, and existential concerns that would be expected to be linked to increased psychological distress.

2.2 Implications of psychological distress in palliative care

As well as evidence that psychological distress, particularly anxiety and depression, is elevated in palliative care patients, there is evidence that such psychological distress has a clinically significant negative impact on these patients. There is considerable evidence that psychological distress negatively influences the experience of palliative care patients in a number of ways, including exacerbating physical symptoms, increasing emotional distress, reducing quality of life, and increasing desire for hastening death.

2.2.1 Impact of psychological distress on physical symptoms

Depression appears to exacerbate the experience of physical symptoms (Francoeur, 2005). Patients who are depressed perceive their physical symptoms as worse than those who are not depressed (Breitbart, Chochinov, & Passik, 2005; Francoeur, 2006; Hopwood & Stephens, 2000; Levenson, 2005; Lloyd-Williams et al., 2004b). One of the key symptoms associated with depression is pain. Pain limits an individual's physical ability and interferes with their normal work and interpersonal relationships, and therefore contributes to a person's level of anxiety (Mystakidou et al., 2006). Pain also interferes with mood and enjoyment of life and can increase hopelessness (Mystakidou, Tsilika, Parpa, Pathiaki, et al., 2007). Psychological distress has also been found to be a possible cause of sleep disturbance in patients with advanced cancer (Akechi et al., 2007).

Whilst the strength of the relationship between anxiety or depression and physical symptoms was found to be limited in one study of 79 hospitalised palliative patients (Teunissen, de Graeff, Voest, & de Haes, 2007), a recent systematic review of randomized controlled studies concluded that there was strong evidence for the association of physical illness and depression and anxiety, and their effects on outcome in chronic conditions such as cancer (Clarke & Currie, 2009).

2.2.2 Relationship between psychological distress and emotional wellbeing

In patients with life-limiting illness, Chibnall, Videen, Duckro, and Miller (2002) found that higher levels of death distress was associated with living alone and experiencing worse physical symptoms, severe depressive symptoms, and less spiritual well being. Death distress incorporates elements of both death anxiety (death-related fear, obsessiveness, nervousness and arousal) and death depression (death-related feelings of sadness, dread, meaninglessness and lethargy). When linking psychological decline with the events associated with life-limiting illnesses, Murray et al. (2007) found that in cancer patients, psychological well-being decreased at diagnosis, at discharge after treatment, at disease progression and at the terminal stages. In patients with advanced cancer, factors including physical symptoms, role, and social functioning have all been found to be predictors of psychological morbidity (Mystakidou, Tsilika, et al., 2005). Higher levels of depression in patients with advanced cancer have been associated with them being female, unmarried or having limited physical ability (Mystakidou, Tsilika, Parpa, Smyrniotis, et al., 2007). Block (2000) proposed that psychological distress impairs the patient's capacity for pleasure, meaning, and connection, hence reducing the patient's ability to do the emotional work of separating and saying good-bye. This can cause anguish and worry in family members and friends.

2.2.3 Impact of psychological distress on quality of life

Psychological distress has been associated with poorer quality of life. Quality of life is an important issue as elderly patients in particular may prioritise their health related quality of life above a gain in survival (Wedding, Pientkab, & Höffkena, 2007). In non-cancer palliative care patients, deteriorating health status led to reduced independence, and increased social isolation and family burden. This in turn reduced their perceived quality of life (Fitzsimons et al., 2007). Peters and Sellick (2006) also found that physical health and perception of control had a significant effect on quality of life, whilst Smith, Gomm, and Dickens (2003) identified that levels of pain were associated with poor quality of life. Depression and anxiety have also been associated with reduced quality of life in palliative patients (Berlim et al., 2006; Peters & Sellick, 2006; Smith et al., 2003; Wilson et al., 2007).

2.2.4 Impact of psychological distress on desire for hastened death

Psychological distress in palliative care patients has been associated with the desire for hastening their death. Desire for hastened death can act as a key reason for patients experiencing suicidal thoughts and for requesting assisted suicide or euthanasia (Breitbart et al., 2000). In a sample of 92 hospitalised terminally ill cancer patients, Breitbart et al. (2000) found that 17% had a high desire for hastened death. This desire was associated with clinical depression, depressive symptom severity, and hopelessness. As well as depression and hopelessness, physical functioning and social support were also associated with the desire for hastened death. These findings were supported by Kelly, Burnett, Pelusi, Badger, Varghese, and Robertson (2003) in their study of 256 palliative patients. Results indicated that a wish to hasten death was associated with increased depression, being admitted to a hospice, perception of being a burden, lower family cohesion, lower levels of social support, higher anxiety and a greater impact of physical symptoms.

The association between the desire for hastened death and depression, hopelessness, anxiety and sleep quality has also been found in Greek palliative care patients (Mystakidou, Rosenfeld, et al., 2005; Mystakidou, Parpa, et al., 2007), but the link with pain severity has not been replicated (Mystakidou, Rosenfeld, et al., 2005; O'Mahony et al., 2005). In 326 palliative patients with advanced cancer, Rodin et al. (2007) found that desire for hastened death correlated positively with hopelessness, depression and physical distress and negatively with physical functioning, spiritual well-being, social support and self esteem. There are therefore a range of variables linked with desire for hastened death, with a potential range of risk factors (Mishara, 1999). In a small study of 49 palliative patients, valuation of life was found to mediate the relationship between desire for death and quality of life, depression, hopelessness and functional status (Ellwood, 2007).

In summary, for palliative care patients, psychological distress has been shown to be associated with worsening physical symptoms, emotional distress, quality of life, and desire for hastening death. Thus, elevated psychological distress is not a trivial matter in palliative care.

2.2.5 Impact of psychological distress for carers of palliative care patients

There is little research into the effects of psychological distress in carers, although there has been research into the relationship between the distress of the patients and the carer's wellbeing. In a study of 39 matched pairs of palliative care patients and their caregivers, patient mental health and depression positively correlated with caregiver mental health and depression. Patients and carers shared perceptions on health care quality, with caregiver depression correlating with less satisfaction with health care (Fleming et al., 2006). The perceived quality of support received by carers has been found to affect carers' reported levels of anxiety and frustration (Chambers et al., 2001) and contribute to the psychological fatigue resulting from anxiety and caring tasks (Harding & Higginson, 2003). The effects of patient characteristics on carer distress were replicated by Mystakidou, Tsilika, Parpa, Galanos, and Vlahos (2007) who in a sample of 105 palliative patients and 96 carers found that patient characteristics predicted carer hopelessness and patients' depression correlates with carer depression.

In a study of 43 carers of palliative patients, Harding, Higginson, and Donaldson (2003) identified that greater patient distress was associated with carer anxiety, and both patient psychological status and pain were associated with carer psychological morbidity. Carer burden has also been associated with patient psychological distress and pain (Harding et al., 2003). Grov, Fosså, Sørebø, and Dahl (2006) found that in 96 carers, caregiver depression was the main factor associated with caregiver burden.

Another issue that has been associated with carer depression is their awareness of the imminent death of their relative. Whilst interviewing 76 palliative patients and their caregivers, Hinton (1999) found that depression was linked with greater awareness of death in relatives, but not in patients. There is also evidence that a terminal diagnosis can have an impact on the distress encountered by married couples and can result in greater suffering in the last months and weeks of life (McLean & Jones, 2007).

Conclusion for Section 2.2.

In summary there appears to be evidence of an association between psychological distress and the physical, social, and existential issues faced by both patients and their caregivers, with the patient's wellbeing being linked with not only their own distress, but also that of their caregivers. As to date the evidence consists of correlational studies, which are not able to establish a causal relationship, it is hypothesised that:

Hypothesis 3. The psychological distress of palliative care patients and their caregivers will be associated with their perception of their physical, social and existential concerns and with their quality of life.

2.3 Issues in assessment and treatment of psychological distress in palliative care

Previous sections have demonstrated that psychological distress is common in palliative care patients and their caregivers. Furthermore, results from a number of correlational studies highlight an association between psychological distress and a number of clinically significant issues including exacerbating physical symptoms, increasing emotional distress, reducing quality of life, and increasing desire for hastening death. These findings suggest that the development and widespread use of effective interventions for psychological distress in palliative care is important. This section will review the evidence for the efficacy of interventions for psychological distress in palliative care and then consider the accessibility and availability of these treatments. The section will begin by exploring the issues associated with the assessment of psychological distress in palliative care.

2.3.1 Assessment of psychological distress in palliative care

There are a number of assessment factors that can account for the variance in reported rates of psychological distress in palliative care. First, the type of assessment can influence the findings because prevalence estimates based on predefined scores on tools such as the HADS tend to be overestimates, as questionnaires sacrifice specificity for sensitivity (Hotopf et al., 2002). Second, it can be difficult to distinguish between the mood changes associated with major depression and those occurring 'normally'. The key elements used to distinguish clinical depression from normal depressed mood are the persistence and severity of depressed symptoms, the presence of other symptoms, and the degree of functional and social impairment (NICE, 2004b). Making this distinction is particular difficult with palliative care patients because many of their physical symptoms resemble and overlap with the symptoms of depression (e.g., tiredness, poor concentration, poor sleep, and reduced appetite) (Cohen-Cole & Stoudemire, 1987; Endicott, 1984). Also low mood may be overlooked by clinical staff as it is considered "understandable" or the depression may be expressed through physical symptoms such as pain (Twycross & Wilcock, 2001).

Furthermore, the prevalence of depression and anxiety is difficult to estimate as palliative care professionals report reluctance and lack of expertise in assessing depression and anxiety in their patients. Lloyd-Williams and Payne (2002) found that Clinical Nurse Specialists in palliative care have difficulty discussing depression with patients and feel lacking in appropriate skills. Little, Dionne, and Eaton (2005) found that although 98% of an oncology nurse sample reported that they were adequately prepared to assess and treat depression, only 54% indicated that they would mention the patient's depression to a physician or further assess the depression. With regards to palliative care physicians, when asked about how they assessed for depression, 73% routinely assessed for depression, 27% used the HADS, and 10% used the question "are you depressed?" (Lawrie, Lloyd-Williams, & Taylor, 2004). In a review of 55 matched pairs of Palliative Care Outcomes Scale (POS) questionnaires completed by patients and nurses, Horton (2002) found that the assessment of patient anxiety levels differed between patients and nurses, with nurses underestimating the levels of family anxiety. The POS incorporates 10 questions covering the physical, psychological and spiritual domains of life within the remit of palliative care.

There are a number of other barriers to the assessment of psychological distress in palliative care. Patients and health professionals may believe that psychological distress is a normal feature of the dying process. This can lead to a failure to differentiate distress from clinical depression (Block, 2000). Patients can be reluctant to disclose (Lloyd-Williams et al., 2003). Healthcare professionals might avoid exploring extreme distress and low mood because of work pressures and concerns that they will cause further distress (Block, 2000). Stigma might also be associated with psychiatric illness for patients and professional carers (Lloyd-Williams & Payne, 2002).

2.3.2 Psychological interventions for palliative care patients

Only a few studies have specifically investigated psychological interventions in palliative care. Given that the majority of palliative care patients receive a diagnosis of cancer (over 90%), studies of interventions for psychological distress in patients with cancer will also be examined. The review will begin with studies evaluating interventions in palliative care, then move on to studies treating patient with advanced cancer, but who have not entered the palliative care system, and then finish with a review of studies treating patient with early stage cancer.

One approach that has been investigated is the use of Cognitive Behavioural Therapy (CBT). CBT is a psychological treatment that addresses the interactions between thoughts, feelings and behaviour. CBT is usually discrete, time-limited, relatively brief, and focuses on current problems and follows a structured style of intervention. CBT has been widely evaluated as effective for a range of conditions including unipolar depression, generalized anxiety disorder, panic disorder with or without agoraphobia, social phobia, posttraumatic stress disorder, and childhood depressive and anxiety disorders (see review of 16 meta-analyses by Butler, Chapman, Forman, & Beck, 2006).

CBT includes a range of strategies and practices that the therapist can utilise (cognitive, emotional, or behavioural) to address maladaptive cognitions (e.g., distorted beliefs) and/or challenge maladaptive behaviours (e.g., avoidance). In CBT, the therapist may work collaboratively with the patient to identify the types and effects of thoughts, beliefs, and interpretations on current symptoms, feeling states and/or problem areas. The patient then develops skills to identify, monitor and then counteract the problematic thoughts, beliefs, and interpretations related to the target symptoms/problems. Finally, the patient learns a repertoire of coping skills appropriate to the target thoughts, beliefs and/or problem areas. CBT may include the use of behavioural experiments as a means to test negative assumptions and beliefs, whilst also constructing and testing new perspectives (Beck, Rush, Shaw, & Emery, 1979; Bennett-Levy et al., 2004; NICE, 2004b).

CBT for depression has several components including behavioural activation, graded task assignments, behavioural experiments, cognitive restructuring, social skills training, and problem solving. Behavioural activation involves structured attempts at supporting patients to identify pleasurable and meaningful activities and overcome obstacles to perform them. In doing so the patient becomes more active and experiences improvements in thoughts, mood, and overall quality of life. Findings from component analyses of CBT suggest that the behavioural components alone work as well for depression as the full package and may hold greater public health relevance (Jacobson et al., 1996). Specifically, the behavioural activation component alone produced as much change in depressive symptoms as the full CBT condition during acute treatment. Moreover, comparisons of behavioural activation with CBT have indicated that CBT was no more effective than behavioural activation in preventing relapse of depression over a 2-year follow-up (Gortner, Gollan, Dobson, & Jacobson, 1998). Also a more recent study has indicated that among more severely depressed patients, behavioural activation was comparable to antidepressant medication, and both significantly outperformed cognitive therapy (Dimidjian et al., 2006).

Anderson, Watson, and Davidson (2008) carried out a feasibility study with 11 hospice patients on the use of CBT techniques. A short protocol consisting of 3 to 4 sessions was created, with each session lasting between 15-45 minutes. The brief CBT protocol was provided by a Specialist Registrar in palliative care who had attended two short training courses totalling 5 days. The intervention was found to be acceptable for 10 patients and symptoms of anxiety or depression as measured on the HADS were significantly reduced for 9 patients. There was a decrease in anxiety and depression scores for seven patients, one patient had a decrease in depression scores only and one had a decrease in anxiety scores only.

In a controlled study, Mannix et al. (2006) evaluated training 20 palliative care practitioners in CBT Techniques. Palliative care nurses were randomised to the equivalent of 12 days' training plus either 3 months or 9 months skills-building supervision. Supervision was delivered fortnightly in groups of four trainees, for 2 hours, each group working with a supervisor who was both familiar with delivering CBT in a physical health setting and an experienced CBT trainer. CBT skills competency was assessed from audio-recordings of clinical sessions at baseline, after 3 months, and after 9 months. Although the CBT skills of all nurses increased from baseline to final follow-up, the group receiving 9-months supervision showed significantly greater improvement than the group receiving only 3 months supervision. The group receiving 9 months supervision continued to improve over the later 6 months, whereas the group with only 3 months supervision showed a decline in competency over this period.

In a further controlled study, Moorey et al. (2009) evaluated a 10-day training course on CBT techniques (similar to the training used by Mannix et al., 2006). Moorey et al. (2009) randomly allocated eight palliative care nurses to receive CBT training and seven to continue practice as usual. To assess impact on clinical outcomes, 45 palliative care patients treated by the CBT-trained nurses and 35 patients receiving care from the practice as usual group, completed a series of questionnaires at baseline and then at 6, 10 and 16 week intervals. Results indicated that patients receiving care from CBT-trained nurses reported a significantly greater reduction in anxiety as measured on HADS relative to patients treated by nurses who did not receive training, although no effect of the training was found for depression.

In addition to CBT, other treatment approaches have been evaluated in palliative care. Hypnosis has been reported as being effective in improving overall quality of life and reducing reported levels of anxiety and depression in a randomised controlled study of 50 terminally ill patients, when compared with treatment as usual (Liossi & White, 2001). A single music therapy session has also been shown to reduce reported anxiety in a randomised controlled study of 25 terminally ill hospice patients, when compared with a control group receiving a volunteer visit (Horne-Thompson & Grocke, 2008).

Another approach that has been evaluated in palliative care is reminiscence in the form of Short-term life reviews (Ando, Morita, Akechi & Okamoto, 2010). Short-term life reviews involves 2 sessions held over one week. In the first session, the patient reviews his or her life with an interviewer who is trained to conduct the therapy. In the first session, the patients are asked: (1) What is the most important thing in your life and why?; (2) What are the most vivid or impressive memories in your life?; (3) In your life, what event or person affected you most?; (4) What is the most important role you played in your life?; (5) What is the proudest moment in your life?; (6) Is there anything about you that your family needs to know?; (7) Are there things you want to tell them and are there things you want them to remember?; (8) What advice or words of guidance do you have for the important people in your life or for the younger generation?

In preparation for the second session, the therapist makes a simple album that includes key words from the answer to each question that were selected through a discussion between the patient and the therapist. The therapist then pastes photos or drawings from books or magazines that were related to the patient's words or phrases to make the album beautiful and memory-provoking.

In the second session, the patient and therapist view the album together and agree on the contents. The therapist tries to encourage the patient to feel continuity of self from the past to the present, to accept life completion, and to be satisfied with their life. After the second session, the therapist presents the album to the patient. Ando et al. (2010) randomized 68 terminally ill cancer patients to either receive Short-term life reviews and general support (in which the therapist interviewed the patient regarding physical and mental status and mood in a supportive way) or a control group receiving general support alone. All patients received 2 interviews over one week. Results indicated that the patients receiving Short-term life reviews and general support reported significantly greater reductions in distress, as measured by total HADS score, than those patients receiving general support alone.

A number of group-based interventions have also been evaluated in palliative care. Life-Threatening Illness Supportive-Affective Group Experience (LTI-SAGE) involves participation in up to 12 meetings over a 12-month period, which focuses on helping patients assert their needs with their family, friends, and health care providers. These sessions are also aimed at fostering hope and courage. As sessions progress, patients also discuss the importance of intimate, social, and spiritual relationships to help them lead fuller lives. Themes related to meaning, religion, and the use of prayer are also introduced to help patients develop a connection to a divine source, a dimension considered important in helping patients prepare for a peaceful death. Through readings, journaling, discussion of various topics, and sharing of personal experiences, patients gradually move toward greater acceptance and increased awareness of the impact of their illness on their bodies, emotions, relationships, and on their lives. In a randomised controlled trail of LTI-SAGE, Miller, Chibnall, Videen, and Duckro (2005) found that in a total trial sample of 51 palliative patients, those patients allocated to LTI-SAGE reported reduced symptoms of depression as measured on the Beck Depression Inventory when compared with a control group receiving standard care.

Group peer counselling has also been compared with individual counselling in a small study of 18 female palliative cancer patients. It was reported that both types of counselling increased self-esteem, satisfaction, and reduced anxiety and depression, but there was not a control group (Ramsay, Ramsay, & Main, 2007).

There are also a number of studies that have evaluated psychological treatments for patients with advanced cancer who have not accessed specialist palliative care. Ramachandra, Booth, Pieters, Vrotsou, and Huppert (2009) evaluated a simple self-help intervention for patients with advanced cancer. The well-being intervention consisted of 3 items: First, patients were requested to record three positive experiences (no matter how small) each day in a specially designed diary. Second, patients were asked to listen to a recorded mindfulness 'body scan' lasting 10 min twice a day. Third, patients were asked to plan one enjoyable activity each week and record this in the diary. Results indicated that in the 27 patients who completed 6 weeks of the trial, the patients randomly allocated to receive the intervention reported better improvements in quality of life that the waiting-list controls, but improvements in total HADS score did not reach statistical significance.

Breitbart et al. (2010) randomly allocated 90 patients with advanced cancer to one of two types of manualised 8-week group psychotherapy courses: Meaning-centred group psychotherapy (MCGP) or supportive group psychotherapy (SGP). MCGP utilised didactics, discussion, and experiential exercises that focused around themes related to meaning and advanced cancer. Each session addressed specific themes related to an exploration of the concepts and sources of meaning, the relationship and impact of cancer on one's sense of meaning and identity, and placing one's life in a historical and personal context (i.e. understanding one's 'legacy'). In contrast, SGP covered a different topic relating to coping with cancer each week. Through the use of a supportive approach, therapists focused on encouraging patients to share concerns related to the cancer diagnosis and treatment, to describe their experiences and emotions related to these experiences, voice problems that they have in coping with cancer, and offer support and advice to other group members. Results indicated that patients receiving MCGP did not report significantly better improvements in anxiety or depression (as measured on HADS) than the patients receiving SGP.

Savard et al. (2006) randomly assigned 45 women with metastatic breast cancer to either individual cognitive therapy or to a waiting-list control condition. Cognitive therapy was composed of eight weekly sessions of cognitive therapy and three booster sessions administered at 3-week intervals following the end of treatment. Patients treated with cognitive therapy reported significantly lower scores on the Hamilton Depression Rating Scale at post treatment compared to untreated patients. Pooled data from both groups indicated significant reductions of depressive symptoms from pre- to post treatment, as well as reduction of associated symptoms including anxiety, fatigue, and insomnia symptoms. These effects were well sustained at the 3- and 6-month follow-up evaluations.

Another approach that has been evaluated is the use of guided imagery as an intervention. In a group of patients receiving both curative (n=73) and palliative (n=9) radiotherapy, Decker, Cline-Elsen, and Gallagher (1992) found that relaxation training and imagery reduced reported levels of tension, depression, anger and fatigue significantly more than a control condition involving education and counselling. However, the authors did not make it clear whether the groups were matched for contact time.

In a meta-analysis of six randomised controlled studies, Akechi, Okuyama, Onishi, Morita, and Furukawa, 2008 concluded that psychotherapy was associated with a significant reduction in depression scores in advanced cancer patients. Of the six studies, four evaluated supportive psychotherapy, one used CBT and one used Problem Solving Therapy.

In contrast to the studies in palliative care and advanced cancer, the studies of psychological treatments for early stage cancer patients have larger samples and more studies have utilised control groups. In a randomised controlled study of 237 cancer patients, a CBT intervention consisting of 10 sessions over 20 weeks reduced patient depression at 10 weeks, but had no effect at 20 weeks, when compared with conventional care. The intervention was reported as having a greater positive effect on patient depression in those patients with more physical symptoms (Given, Given, Rahbar, Jeon, Mccorkle, & Cimprich, 2004).

In a randomised controlled study of 199 newly treated women with breast cancer, a ten week cognitive behavioural stress management intervention that included anxiety reduction (relaxation training), cognitive restructuring, and coping skills was found to reduce social disruption and increase emotional well-being when compared with a control condition where participants were invited to attend a one day educational seminar. Participants reported less intrusive thoughts, and interviewer ratings of anxiety and emotional distress reduced over a period of 1 year (Antoni et al., 2006). However, these treatments were not matched for length of treatment or therapist contact, so it is not clear whether the CBT component of the treatment or non-specific factors such as duration of treatment or therapist contact were responsible for any changes in symptoms. Andersen et al. (2004) conducted a randomised controlled study comparing a group CBT intervention versus a control condition in 227 women with breast cancer. The control condition involved a baseline assessment and another assessment 4 months later, whilst the intervention involved a weekly small group intervention over 4 months that included relaxation, positive coping, problem-solving and social and health behaviour information. The investigators found that the CBT group treatment significantly reduced reported anxiety and improved health behaviours relative to the control condition.

In a randomised controlled study with 116 newly diagnosed cancer patients, progressive muscle relaxation and guided imagery was reported as having a small, but statistically significant positive improvement on patients’ psychological distress, when compared with a control group receiving standard care. These modest effects were explained by the inclusion of patients with minimal levels of distress in the study who would have reduced the ability to detect significant treatment effects and thereby reduced the effect size (Baider, Peretz, Hadani, & Koch, 2001). In a randomised controlled study of 94 cancer patients, Syrjala, Donaldson, Davis, Kippes, and Carr (1995) compared four groups: treatment as usual control; therapist support; relaxation and imagery training; training in a package of cognitive-behavioural coping skills which included relaxation and imagery. The researchers found that relaxation and imagery training or training in cognitive behavioural coping skills reduced cancer treatment related pain, when compared with treatment as usual.

Another treatment approach that has been evaluated in cancer care is Problem-solving therapy (PST). PST is a cognitive–behavioural intervention geared to improve an individual's ability to cope with stressful life experiences. PST aims to help individuals adopt a realistically optimistic view of coping, understand the role of emotions more effectively, and creatively develop an action plan geared to reduce psychological distress and enhance well-being. Interventions include psycho-education, interactive problem-solving exercises, and motivational homework assignments. Nezu, Nezu, Felgoise, McClure, and Houts (2003) conducted a randomised controlled study comparing three groups of 50 cancer patients (Total N = 150). One group was allocated to PST alone, one group was allocated to PST along with their significant other and the third group was a waiting-list control. Results indicated both the PST alone group and the group who received PST along with their significant other had significantly lower psychological distress and better overall quality of life compared with the waiting-list control group.

In a meta-analysis of 37 published controlled outcome studies, Rehse and Pukrop (2003) concluded that psychosocial interventions could be helpful for improving the quality of life of cancer patients, particularly if the intervention lasted more than 12 weeks.

In summary, a number of psychological approaches have been evaluated in cancer and palliative care, including CBT, group support strategies, hypnosis, music therapy, PST and guided imagery with relaxation. Whilst the results are encouraging, these studies investigating psychological treatments in palliative care have a number of limitations. First, because the studies are generally exploratory in nature, the samples are small, ranging from 9 (Anderson et al., 2008) to 90 (Breitbart et al., 2010). This is an issue because such a small sample is unlikely to be representative of the whole population of palliative care patients (Goodwin, 1995; Haslam & McGarty, 2003; Nation, 1997). Second, a number of the studies (e.g. Anderson et al., 2008; Ramsey et al., 2007) lack a control group, which is necessary to test internal validity regarding the change in symptoms. A control group ensures as far as is practicable that the changes observed in dependent variables (e.g. symptoms of psychological distress) are not due to causes other than the independent variable (e.g. treatment). These may include spontaneous improvement, regression to mean, passage of time, or other life events beyond the control of the researcher (Goodwin, 1995; Haslam & McGarty, 2003; Nation, 1997). Third, a number of the studies did not randomise their participants (e.g.

Anderson et al., 2008; Mannix et al., 2006; Ramsay et al., 2007). The process of randomisation is important as it reduces bias by equalising other factors that have not been explicitly accounted for in the experimental design. This ensures that the differences between the groups to be tested are minimised, so that it is more likely that the independent variable is responsible for any observed effect on the dependent variable (Goodwin, 1995; Haslam & McGarty, 2003; Nation, 1997).

In addition to the methodological issues discussed, in a critical review of studies evaluating psychological therapies in cancer care, Coyne et al (2006) highlighted some additional weaknesses in the evidence. These included confirmatory bias, the omitting of null findings and weak findings made to look stronger, the use of multiple outcome measures and reporting only those that were found to be significantly affected, rather than a primary outcome measure supported by distinct secondary measures, and excluding patients who might be expected to benefit less from the intervention (Coyne et al, 2006). The lack of studies specifically recruiting palliative care patients also highlights the gap in terms of evidence for psychological therapies targeted at palliative care patients, but by extension from cancer patients there may be potential for psychological treatments to be effective.

2.3.3 Psychological interventions for carers of palliative care patients

When compared with palliative care patient studies, there are even fewer that have evaluated psychological interventions for current carers of palliative care patients. In a prospective observational non-randomised study, Harding et al. (2004) compared 37 palliative carers who accepted an intervention involving informal multi-professional teaching and facilitated peer support with 36 carers who declined the intervention. The intervention was delivered over 6 sessions of 90 minutes per week. Questionnaires that measured carer psychological status and patient physical status were administered at baseline, 8 weeks and 20 weeks. However, there was a high attrition rate: at 8 weeks there were 24 carers in the intervention group and 17 in the comparison group; and at 20 weeks there were 15 carers in the intervention group and 11 in the comparison group. The resulting small sample meant that the authors could not demonstrate that the intervention was effective. The authors found from the qualitative interviews that carers were more likely to access the intervention if they did not work, used avoidance as a coping strategy, or their patient had worse physical symptoms.

Hudson, Aranda, and Hayman-White (2005) conducted a randomised controlled trial comparing 52 palliative carers receiving standard home based palliative care with 54 carers receiving standard care plus a psycho-educational programme. The programme was delivered by nurses over two home visits supplemented by a follow up telephone call between the visits. The psycho-education consisted of information on caring for a dying person, promoting self-care, and guidance on how to find meaning and normalise their emotional reactions. Self report questionnaires including HADS were administered at baseline, 5 weeks later and 8 weeks after the patient's death. Whilst no intervention effects were found for psychological distress (as measured by total HADs score), participants who received the intervention reported a more rewarding carer experience than the control group as measured on the rewards of caregiving scale.

In summary, the few studies that have assessed psychological interventions for carers of palliative care patients have found no evidence that the interventions reduce psychological distress. This highlights another gap in the literature with regards to evaluating psychological therapies for carers of palliative care patients.

2.3.4 Pharmaceutical interventions in palliative care

The principal antidepressants suggested for use in palliative care are tricyclic antidepressants (TCAs) and selective serotonin reuptake inhibitors (SSRIs) (Twycross, Wilcock, Charlesworth, & Dickman, 2002). TCAs are the oldest class of antidepressant drugs and block the reuptake of certain neurotransmitters such as dopamine, norepinephrine, and serotonin. They are used less commonly now due to the development of more selective and safer drugs. Side effects include increased heart rate, drowsiness, dry mouth, constipation, urinary retention, blurred vision, dizziness, confusion, and sexual dysfunction (Berney, Stiefel, Mazzocato, & Buclin, 2000; Breitbart et al., 2004; Taylor & Ashelford, 2008; Twycross et al., 2002).

SSRIs are a class of antidepressants considered the current standard of drug treatment. SSRIs prevent the reuptake of serotonin (also known as 5-hydroxytryptamine, or 5-HT) by the presynaptic neuron, thus maintaining higher levels of 5-HT in the synapse. These antidepressants typically have fewer adverse effects than TCAs, although such effects as drowsiness, dry mouth, nervousness, anxiety, insomnia, decreased appetite, long-term weight gain and decreased ability to function sexually may occur. Some side effects may decrease as a person adjusts to the drug, but other side effects may be persistent (Berney et al., 2000; Breitbart et al., 2004; Taylor & Ashelford, 2008; Twycross et al., 2002).

However, the exact mechanism of how antidepressants have a therapeutic effect is still unclear and under debate. Whilst antidepressants were once thought to work by simply increasing neurotransmitters in synaptic clefts, this does not explain the delay between starting medication and any therapeutic benefit occurring some weeks later (Hammen & Watkins, 2008).

Antidepressants have been reported as effective in treating depression in physically healthy populations (Arroll et al., 2009; Cipriani et al., 2009; Moncrieff & Kirsch, 2005). Furthermore, there is evidence that antidepressants are effective in treating depression in physically ill people (Gill & Hatcher, 2000; Rayner et al., 2010). In palliative care, a recent review of 25 clinical studies, concluded that antidepressants were effective in treating depression in palliative care and that their superiority over placebo is apparent within 4–5 weeks and increases with continued use (Rayner et al., 2011).

Whilst the evidence supports the effectiveness of antidepressants in palliative care, research indicates that palliative care clinicians may be unsure about the use of antidepressants in palliative care. Kendrick et al. (2009) conducted a review of 2294 patients' records and found that depressed patients with a concurrent physical illness received fewer antidepressant prescriptions than depressed patients who were physically healthy. In an earlier survey of 1046 consecutive patient admissions to a palliative care unit, Lloyd-Williams, Friedman, and Rudd, (1999) found that terminally ill patients with depression were prescribed antidepressants so late that they often died before the medication had time to take effect.

This therefore highlights the importance of identifying psychological distress in palliative care as early as possible, whilst also giving clinicians a variety of options to address any psychological distress that is identified. This corresponds with the aims of the PhD in terms of Hospiscare's requirement for an intervention that both increases palliative care staff's assessments of psychological distress and can also act as an adjunct to other approaches such as antidepressants.

2.3.5 Accessibility and availability of psychological interventions in palliative care

Despite the need for assessment and interventions for psychological distress, a recent review of palliative care has noted the lack of access to a psychiatrist or clinical psychologist for palliative care patients (Price et al., 2006). One approach to improve access may be to train health care professionals directly responsible for the patient's care to provide professional psychological support at levels one and two of the NICE (2004a) 4 stage model described in section 1.1. Whilst some studies have demonstrated that palliative care staff can be taught psychological techniques such as CBT, the training can last between 5 days (Anderson et al., 2008) and 12 days (Mannix et al., 2006) and require months of ongoing supervision (Mannix et al., 2006). This length of training and ongoing supervision represents a significant investment in terms of time and resources for the charities that provide specialist palliative care. Another issue is the lack of access to training and the potential load on patients, plus the lack of resources for therapists to provide 1 to 1 therapy for individual patients over 6-12 weeks.

Another option that has been proposed to improve access to psychological therapies in mental health is to utilise self-care treatments (Richards, Lovell, & McEvoy, 2003). In palliative care, the NICE guidance also emphasises that health and social care professionals empower and equip patients to recognise and manage their own psychological needs (NICE, 2004a). Self-care involves individuals taking responsibility for their own health and well-being. This includes: staying fit and healthy, both physically and mentally; taking action to prevent illness and accidents; and the better use of medicines and treatment of minor ailments. In contrast, self-management is related specifically to living with a long term condition and has been described in terms of the individual's ability to manage the symptoms, treatment, physical and psychosocial consequences and lifestyle changes inherent in living with a long term disorder (Department of Health, 2006a; Tomkins & Collins, 2006).

In recent years there has been an emphasis placed on supporting self-care in a number of government papers:

- Our health, our care, our say: a new direction for community services (2006b)
- Promoting optimal self care (Tomkins & Collins, 2006)
- Supporting people with long term conditions to self care – A guide to developing local strategies and good practice (2006a)

Hence, the development of an efficacious brief self-management intervention that utilises brief support from palliative care professionals may provide an alternative means to make psychological interventions more accessible within palliative care.

Conclusion for Section 2.3.

In addition to the lack of studies evaluating psychological therapies for palliative care patients and carers, the availability of these therapies is also limited for a number of reasons. First, the patients with psychological distress may not be identified because of the difficulties healthcare professionals have with assessment of distress in this population. Second, there is a lack of access to specialist psychological services. One way to address this lack of availability may be to offer more supported self-help strategies. Supported self-help has the advantage of being straightforward enough to be deliverable by front line palliative care staff in accordance with level 2 of the NICE Recommended Model of Professional Psychological Assessment and Support (See Figure 1.1, NICE, 2004a). Moreover as the intervention is delivered by existing palliative care staff there would be less of a reliance on specialist mental health services.

Thus, in line with the requirements of the funding for the PhD, one of the key aims of this PhD will be to improve access of psychological therapies to Hospiscare patients. This objective will be achieved by first developing and evaluating a self-help psychological treatment that is acceptable to palliative care patients and deliverable by existing Hospiscare staff, whilst also being effective in reducing psychological distress in palliative care.

2.4 Rumination and distress in palliative care

In order to identify a psychological intervention that may be appropriate in palliative care, it is necessary to identify possible treatment targets for a self-help therapy to focus on addressing. These treatment targets could be particular symptoms, cognitive processes, or behaviours. The next section will review evidence that rumination may be a process particularly relevant to distress in palliative care and develop an argument that self-help therapy explicitly targeting this symptom may be beneficial. This section will define rumination and then move on to discuss the theoretical and empirical evidence that supports rumination as a process relevant to palliative care.

2.4.1 Rumination

Cognitive changes associated with depression include poor concentration and reduced attention, pessimistic and recurrent negative thoughts about oneself, one’s past and the future, mental slowing, and rumination (Cassano & Fava, 2002). Repetitive thought has been conceptualised as the “process of thinking attentively, repetitively or frequently about one’s self and one’s world” (Segerstrom, Stanton, Alden, and Shortridge, 2003, p. 909). Rumination was conceptualised by Nolen-Hoeksema (1991) as passively focusing one’s attention on a negative emotional state like depression, its symptoms, and thinking repetitively about the causes, meanings, and consequences of that state. In her Response Styles Theory, Nolen-Hoeksema (1991, 2000, 2004) hypothesized that depressive rumination is a particular response style to depressed mood, which is causally implicated in the onset and maintenance of depression.

In a more general conceptualisation, Martin and Tesser (1996, p. 7) defined rumination as “a class of conscious thoughts that revolve around a common instrumental theme and that recur in the absence of immediate environmental demands requiring the thoughts.” Martin and Tesser (1996) proposed that unresolved personal goals and concerns could lead to rumination. More specifically, repetitive thoughts are instrumental in reducing discrepancy between desired goals and outcomes, whether this occurs in the past, present or future. These repetitive thoughts are argued to have constructive consequences, if they help resolve the discrepancy by either helping progress toward the unattained goal that triggered the rumination, or helping to change the nature of that goal. The repetitive thoughts can also become unconstructive if a person experiences an inability to progress toward reducing the discrepancy and at the same time is unable to give up on the reference value or goal. In such a case, the repetitive thoughts would serve only to focus attention on the discrepancy between the desired goal and the actual situation, making the unresolved discrepancy more salient, perpetuating the unresolved issue, and exacerbating negative affect.

Recent theory and evidence has indicated that there are different styles of rumination with distinct functional effects: a maladaptive form implicated in anxiety and depression characterised by abstract construal (mental representation) focused on general meanings and global implications (“why an event happened”) versus an adaptive form characterised by concrete construal focused on contextual and specific details (“how an event happened”) (Watkins, 2008). Concrete construal is more adaptive during thinking about difficulties because it engenders: (a) better problem solving due to the increased detail available about alternative courses of action and the detail of “how” to proceed (Vallacher & Wegner, 1987); (b) reduced negative overgeneralizations and reduced emotional impact of negative events (Moberly & Watkins, 2006; Watkins et al., 2008). Thus, individuals faced with unresolved goals are more likely to engage in pathological rumination that exacerbates distress if they think abstractly.

Consistent with the Response Styles Theory, the process of rumination has been repeatedly implicated in the onset and maintenance of depression and anxiety, in studies using both prospective longitudinal and experimental designs.

Prospective longitudinal studies

In a longitudinal study, Just and Alloy (1997) found that initially non-depressed undergraduate participants who ruminated were more likely to go on to develop a clinically significant depressive episode in a prospective (18 month) follow up study, even after controlling for other cognitive risk factors. These findings were replicated in a large scale (n = 1109) community study (Nolen-Hoeksema, 2000) in which baseline rumination scores predicted depression onset one year later (for those who were not currently depressed at baseline), controlling for baseline depression. Kuehner and Weber (1999) found that rumination scores post-discharge predicted the diagnostic status of non-remitted patients with unipolar depression three months later. Rumination has also been associated with increased duration of a depressive episode following onset. However, rumination was not found to predict the short-term course of major depressive disorder in a smaller study of 84 college students with a recent-onset major depressive episode (Lara, Klein, & Kasch, 2000).

Moreover, there is evidence that rumination interacts with stressful life events to predict depression onset. Nolen-Hoeksema and Morrow (1991) found that following an earthquake, student's ruminative coping style predicted depression. Students who reported higher levels of rumination prior to the earthquake were more likely to have elevated levels of posttraumatic stress and depression at both ten days and seven weeks following the earthquake. Nolen-Hoeksema, Parker, and Larson (1994) found that ruminative coping mediated the effect of bereavement on subsequent depression, so that participants with a more ruminative response style at one month were more likely to have higher levels of depression at six months than those who did not engage in ruminative coping.

Rumination has also been found to predict increases in anxiety in non clinical populations (Sarin, Abela, & Auerbach, 2005; Segerstrom et al., 2000; Siddique et al., 2006). Furthermore, following traumatic events, rumination about the trauma predicts the persistence of post traumatic stress disorder in prospective longitudinal studies from 6 months to 3 years later, for road accidents (Ehlers, Mayou, & Bryant, 1998, 2003; Holeva, Tarrier, & Wells, 2001; Mayou, Bryant, & Ehlers, 2001; Mayou, Ehlers, & Bryant, 2002; Murray, Ehlers, & Mayou, 2002), assaults (Halligan, Michael, Clark, & Ehlers, 2003; Michael, Ehlers, Halligan, & Clark, 2005), and in ambulance workers (Clohessy & Ehlers, 1999).

Experimental studies

A number of experimental studies have provided evidence that rumination causally contributes to negative mood and negative thinking. These experimental studies have compared a rumination induction versus a control manipulation (distraction) in participants who are already dysphoric. The rumination induction involves participants spending 8 minutes concentrating on a series of sentences that involve rumination about themselves, their current feelings and physical state, and the causes and consequences of their feelings, whilst the distraction involves participants spending 8 minutes concentrating on a series of sentences that involve imagining visual scenes that are unrelated to the self or to current feelings.

Results from experimental studies indicate that relative to distraction, rumination results in more negatively biased explanations for interpersonal problems or distressing experiences (Lyubomirsky & Nolen-Hoeksema, 1995; Lyubomirsky, Tucker, Caldwell, & Berg, 1999), and more negatively biased autobiographical memory recall (Lyubomirsky, Caldwell, & Nolen-Hoeksema, 1998), in participants who are already dysphoric. Experimental studies have also found that for depressed or dysphoric participants, relative to distraction, rumination increased negative thinking about the future (Lavender & Watkins, 2004) and negative global self-judgments such as “I am worthless” (Rimes & Watkins, 2005). Rumination also impaired social problem solving (Donaldson & Lam, 2004), impaired suppression of learned behavioural responses (Watkins & Brown, 2002), impaired performance on academic tasks (Lyubomirsky, Kasri, & Zehm, 2003) and impaired interpersonal problem solving (Lyubomirsky & Nolen-Hoeksema, 1995; Lyubomirsky et al., 1999; Ward, Lyubomirsky, Sousa, & Nolen-Hoeksema, 2003). Together this evidence suggests that rumination plays a causal role in exacerbating negative mood and negative cognition.

A rumination manipulation has also been found to exacerbate pre-existing anxious mood (Blagden & Craske, 1996). When university students were asked to describe a distressing event that occurred in the last 2 years and then were randomly allocated to rumination (prompts like “Why has this event happened to me?”) or distraction (a word generation task), rumination resulted in a greater increase in negative affect and higher levels of intrusive memories than did distraction (Ehring, Szeimies, & Schaffrick, 2007), suggesting a potential causal role for rumination in the development of posttraumatic symptoms.

Rumination has also been associated with individual differences and personality traits such as neuroticism. Roelofs, Hulbers, Peeters, and Arntz (2008) found significant associations between neuroticism and symptoms of anxiety and depression and between neuroticism and rumination in a sample of students. In a study of students, Segerstrom, Tsao, Alden, and Craske (2000) found rumination and worry have correlated highly with negative affectivity or neuroticism. Rumination has been found to be related to neuroticism in depressed people (Cox, Enns, Walker, Kjernisted, & Pidlubny, 2001; Lam, Smith, Checkley, Rijsdijk, & Sham, 2003).

In summary, there is evidence from both prospective longitudinal studies and experimental studies that rumination is an important process in the onset and maintenance of psychological distress. Rumination can predict the course and severity of a depressive and/or anxious episode and may interact with stressful life events to predict the onset of depression. In people who are already dysphoric, rumination causally contributes to negative mood and negative thinking. There is also evidence that rumination has a causal role increasing negatively biased thinking and memory recall. Rumination is also associated with personality traits such as neuroticism.

2.4.2 Theoretical rationale for investigating rumination in palliative care

Given the relatively high levels of anxiety and depression found in palliative care patients, there is good reason to hypothesize that there may also be elevated levels of rumination in palliative care patients, and that this rumination may contribute to the maintenance of psychological distress. Consistent with this hypothesis, there are a number of aspects of the experience of palliative care patients that may make them more prone to rumination.

First, the diagnosis of a life-limiting illness itself constitutes a significant life event that could trigger reactive rumination as people affected may dwell on “Why did this happen to me or my husband/wife?” The difficulties experienced during a life-limiting illness may themselves acts as prompts to consider the causes, meanings, and consequences of these symptoms, including questions about “Why did this happen to me?” It has been hypothesised that rumination can occur in response to stressful events as individuals think repetitively about their experience in order to come to terms with traumatic and upsetting events (Tedeschi & Calhoun, 2004).

Second, living with a terminal illness means the re-evaluation of a number of personal current and future goals: There may be difficulties in carrying on previous activities or roles, or future expectations may no longer seem tenable, e.g., “Seeing the grandchildren growing up”. Consistent with Martin and Tesser (1996) conceptualisation of rumination, such unresolved goals and discrepancies between actual situation and desired situation would generate rumination. A diagnosis of a life-limiting illness can be associated with a number of normal life goals becoming unattainable or needing to be re-evaluated. These could include goals such as wanting to see one’s children or grandchildren grow up, or wanting to maintain one’s independence and control over one’s life. As rumination is triggered by unresolved or unattainable goals, this is likely to lead to rumination.

Third, there is evidence that anxiety and depression are elevated in palliative care and rumination has been closely associated with anxiety and depression in other populations. Therefore this constitutes a reason for expecting elevated rumination in palliative care.

In summary, there are a number of reasons for supposing that rumination is a key feature of psychological distress in palliative care. First, rumination may occur in response to the significant life event of being diagnosed with a life-limiting illness. Second, the diagnosis of a life-limiting illness means the re-evaluation of a number of personal goals, which may become unattainable, and, thereby, lead to rumination. Third, as psychological distress is elevated in palliative care and rumination has been associated with anxiety and depression, it is reasonable to postulate that rumination occurs in palliative care.

2.4.3 Empirical evidence of rumination in palliative care

Whilst rumination has not been explicitly studied in studies of palliative care patients and their caregivers, there is indirect evidence suggesting that rumination may be present in palliative care patients and their caregivers.

First, as reported in section 2.1.5, an important area of concerns for palliative patients and their caregivers is centred on existential issues such as the future, and reflecting on a range of losses such as loss of independence or control, loss of self esteem and self worth and a diminished sense of self. The content of these existential concerns, focused on evaluative and analytical thinking about the meanings, implications and consequences of difficulties, matches the phenomenology of depressive rumination as defined by Nolen-Hoeksema' (1991). Thus, focus on such existential concerns is highly likely to involve the focus on negative information coupled with abstract-conceptual thinking (asking "Why?" and thinking about meanings and implications) found to be characteristic of pathological rumination (Watkins, 2008).

Second, there is evidence that rumination involves an avoidant style of coping. From a behavioural standpoint, it has been argued that rumination helps depressed individuals avoid engaging in the aversive environment that surrounds them by preoccupying their attention and time. In this conceptualisation, rumination is more than a method of cognitive avoidance, but instead helps them build a case for justifying avoiding taking action or responsibility for situations and for withdrawing instead. The individual's reduced exposure to the aversive environment then justifies their withdrawal and inactivity (Nolen-Hoeksema, Wisco, & Lyubomirsky, 2008; Martell, Addis, & Jacobson, 2001). This theory has been supported in correlational studies that show rumination is positively related to suppression or avoidance of distressing feelings and thoughts (Moulds, Kandris, Starr, & Wong, 2007; Nolen-Hoeksema & Morrow, 1991; Wenzlaff & Luxton, 2003). Distressing thoughts have also been positively associated with cognitive avoidance mechanisms, and influence the employment of rumination as an avoidant response (Williams & Moulds, 2008). Such an avoidant style of coping would be consistent with the evidence that escape-avoidant coping is reported by palliative care patients and their caregivers (De Faye et al., 2006; McPherson et al., 2007; Riley & Fenton, 2007).

Third, neuroticism was found to have a significant contribution to the dying experience of a sample of 211 patients with end-stage cancer. Neuroticism had a significant positive relationship with end of life sources of distress, including depression, anxiety, low sense of dignity, hopelessness, concentration and outlook on the future and a negative relationship with quality of life (Chochinov et al., 2006). Neuroticism has been shown to be associated with rumination in a number of studies. Conway, Mendelson, Giannopoulos, Csank, and Holm (2000) demonstrated that rumination on sadness positively correlated with neuroticism in undergraduates, whilst

Trapnell and Campbell (1999) found that a rumination scale positively correlated with neuroticism in undergraduates. Given the association between neuroticism and rumination, these findings further suggest the likelihood that rumination may be increased in palliative care patients.

Fourth, Nolen-Hoeksema, McBride, and Larson (1997) found that bereaved men who evidenced more negative ruminative thought in free response interviews showed greater psychological distress both 1 month and 12 months post bereavement. If a similar relationship applies for carers, one would expect a relationship between rumination and depression in carers of palliative care patients.

In summary, there is empirical evidence that supports the theoretical rationale for the role of rumination in palliative care. First, palliative care patients and carers report a number of existential concerns, which by their very nature involve the thinking style and content characteristic of rumination. Second, there is evidence that rumination involves an avoidant style of coping and such an avoidant style of coping would be consistent with the evidence that escape-avoidant coping is reported by palliative care patients and their caregivers. Third, neuroticism is elevated in palliative patients and this too is associated with rumination. Fourth, as rumination has been identified in bereaved carers, it is likely it will be experienced by pre-bereaved carers too. Hence, it is hypothesised that:

Hypothesis 4. Palliative care patients and their caregivers will experience elevated rumination.

Furthermore, given the evidence reviewed earlier that rumination plays a causal role in the development of depression and anxiety in other populations, it is further hypothesised that:

Hypothesis 5. Rumination is a causal process in the development and maintenance of depression and anxiety in palliative care patients and their caregivers.

Aims of Research

The review has highlighted convergent evidence that both palliative care patients and their caregivers experience psychological difficulties including (a) studies of depression and anxiety in palliative care; (b) the concerns expressed by palliative care patients and their caregivers. However, there are a number of limitations with this evidence. First, there is little research that reveals the frequency and nature of psychological distress in carers of palliative care patients. Second, the studies are generally qualitative in nature based on interviews of small samples of participants. Third, the quantitative studies that have used questionnaire designs have not used control groups to establish that elevated distress is specific to the palliative care groups. Fourth, studies have relied very heavily on questionnaire measures such as HADS. HADS has a variety of cut-offs and is not able to have high sensitive and specificity at the same time unlike other measures that have not been utilised.

Therefore, the first objective of the PhD is to explore the nature of psychological distress and rumination in palliative care. The first study adopts a cross-sectional design, comparing samples of palliative care patients, their caregivers and a control group matched for age. This study involves the use of a combination of standardised questionnaires and open-ended interviews. This study aims to test the following hypotheses:

Hypothesis 1. Palliative care patients and their caregivers will report higher levels of psychological distress than matched controls;

Hypothesis 2. Palliative care patients and their caregivers will report more existential concerns than matched controls;

Hypothesis 3. The psychological distress of palliative care patients and their caregivers will be associated with their perception of their physical, social and existential concerns and with their quality of life;

Hypothesis 4. Palliative care patients and their caregivers will experience elevated rumination.

A key gap in the literature is the role of rumination in the experience of palliative care patients and their caregivers. Whilst the review highlighted theoretical and indirect empirical evidence in support of its role, there is no research specifically addressing this question. Therefore another objective of the PhD is to explore the role of rumination in the psychological distress experienced by palliative care patients and their caregivers. The second study utilises the same cross sectional design incorporating samples of palliative care patients, their caregivers and a matched control group, and includes direct measures of rumination as well as indirect measures such as measures of uncertainty and abstractness. This study provides a necessary but not sufficient test for the following hypothesis:

Hypothesis 5. Rumination is a causal process in the development and maintenance of depression and anxiety in palliative care patients and their caregivers.

Whilst a cross-sectional study is not capable of proving a casual relationship between rumination and psychological distress, the causal hypothesis predicts that a cross-sectional study would find a positive significant correlation between rumination and symptoms of depression and anxiety. Failure to find this would rule out a causal relationship, whilst the presence of a correlational relationship only indicates a relationship and not causality. Hence later studies will manipulate rumination to determine its effects on psychological distress.

In order to meet the funding requirements of the PhD, the research programme will use the information from the initial cross sectional studies to develop and evaluate a self-help psychological treatment that is acceptable to palliative care patients and simple enough to be deliverable by existing Hospiscare staff. The intervention will be initially piloted and refined in a case series before being evaluated in a pilot randomised controlled trial to establish its acceptability and effectiveness in experimental trials. The trial of the intervention also represents an opportunity to test the causal relationship between rumination and psychological distress.

In order to facilitate access to the intervention, the PhD will develop a concise teaching programme for palliative care staff to support the use of such interventions with patients. This will incorporate an evaluation of the training programme and its effects on both staff and their patients.

CHAPTER 2: PSYCHOLOGICAL DISTRESS, RUMINATION, AND COPING IN PALLIATIVE CARE

This chapter reports a study investigating psychological distress, rumination and coping in palliative care patients and their caregivers. The key elements of the study are reported in the following article:

Galfin, J. M., Watkins, E. R., & Harlow, T. (2010). Psychological distress and rumination in palliative care patients and their caregivers. *Journal of Palliative Medicine, 13,* 1345-1348.

The article provides the substantive part of the chapter but because of the limited word count of the article, it will be preceded and followed with further discussion of coping and quality of life in palliative care.

This chapter presents the first study of this thesis that tested the following hypotheses:

Hypothesis 1. Palliative care patients and their caregivers will report higher levels of psychological distress than matched controls.

Hypothesis 2. Palliative care patients and their caregivers will report more existential concerns than matched controls.

Hypothesis 3. The psychological distress of palliative care patients and their caregivers will be associated with their perception of their physical, social and existential concerns and with their quality of life.

Hypothesis 4. Palliative care patients and their caregivers will experience more rumination than matched controls.

Additional literature review

In addition to the review of the literature reported in the published paper, a further review of the literature pertaining to coping in palliative care and associated hypotheses is presented below. After the paper, further investigations, results and discussion pertaining to coping and quality of life are presented.

Coping strategies utilised by palliative care patients

A key set of evidence pertinent to examining psychological difficulties in palliative care is the coping strategies utilised by palliative care patients and their effectiveness in mediating levels of psychological distress. When defining coping strategies, the theoretical framework of Lazarus and Folkman's transactional model of stress, appraisal and coping (1984) is an approach frequently utilised in the palliative care setting. Lazarus and Folkman (1984) defined stress as occurring when an individual's personal interpretation is that the demands of the environment exacts or exceeds his/her resources and endangers his/her safety. Coping refers to an individual's attempts at mastering, changing or tolerating the demands of a situation that has been appraised as taxing or surpassing his/her resources.

Lazarus and Folkman (1984) proposed two main dimensions of coping: 'problem-focused coping' whereby the problem that is causing distress is managed, and 'emotion-focused coping' that involves the regulation of the emotions arising from the situation. Thus, if the individual perceives the source of stress as being amenable to change, then he/she would tend towards a problem-focused coping style, where the intention is to deal with the source of the stress. However, if the situation is perceived as being too threatening or it cannot be altered, then the individual will try to mediate the feelings associated with the situation by utilising an emotion-focused coping strategy.

However, in most situations people will use a combination of both approaches to cope with the stressor in the most successful way. The 'goodness-of-fit' hypothesis suggests that the better the fit between the appraisal of the situation and the coping strategy used, the better the individual's adjustment.

Within the dimensions of problem-focused and emotion-focused coping, Lazarus and Folkman (1984) proposed eight different coping strategies. Problem-focused strategies included confrontative coping and planful problem solving. Confrontative coping describes an aggressive approach to coping whereby the individual stands up to the stressor in order to alter the situation (e.g., "I stood my ground and fought for what I wanted"). Planful problem-solving involves the use of deliberate problem-focused efforts to alter the situation, coupled with an analytic approach to solving the problem (e.g., "I changed something so things would turn out right").

Emotion-focused strategies included distancing, self-controlling, accepting responsibility, escape-avoidance, and positive reappraisal. Distancing involves the individual attempting to psychologically detach him/herself from the significance of the situation (e.g., "I went on as if nothing had happened"). The strategy of escape-avoidance involves wishful thinking (e.g., "I hoped a miracle would happen") and behavioural efforts to escape or avoid the problem including drinking or smoking. The strategy of self-controlling involves attempts to regulate one's own feelings and actions (e.g., "I tried to keep my feelings to myself"). In comparison, an individual using positive reappraisal will try to draw positive meaning from a situation by focusing on personal growth, which may have a religious dimension (e.g., "I rediscovered what is important in life"). Accepting responsibility involves acknowledging one's own role in the problem and attempting to put things right (e.g., "I realised I brought the problem on myself”). Seeking social support includes the utilisation of informational support, tangible support, and emotional support and has elements of both a problem-focused strategy and an emotion-focused strategy.

The goodness-of-fit hypothesis has been examined in a small number of studies within healthcare settings. In a longitudinal study of women coping with a medical procedure, in vitro fertilization (IVF), which the researchers categorized as an uncontrollable stressor, Terry and Hynes (1998) found that whilst direct attempts to manage the problem (a problem-focused strategy) were related to poorer adjustment, attempts to manage the emotions arising as a result of the situation (emotion-focused strategy) were related to better adjustment, consistent with the goodness-of-fit hypothesis. However, Terry and Hynes (1998) found that escape, a form of emotion-focused coping, was related to poorer adjustment to IVF. In a study of 862 women undergoing breast cancer screening, Sweet, Savoie, and Lemyre (1999) found evidence in support of Lazarus and Folkman’s model, which proposed that coping and appraisal both act as mediators in response to stress.

In an important study, De Faye et al. (2006) utilised interviews to identify the coping strategies that palliative patients reported using in response to stress. The sources of stress were categorised into physical, social, and existential concerns. De Faye et al. (2006) categorised their coping strategies into problem-focused, emotion-focused approach and emotion-focused avoidance, in line with Lazarus and Folkman’s categorisation. A summary of the coping strategies distinguished is illustrated in Figure 2.1. Overall, the coping strategies that were used most widely across all three dimensions of stress were direct action, seeking instrumental support, perspective-taking, and resignation/acceptance. These strategies were reported by at least half of the participants for all three domains of concern. When looking at which coping strategies were used for which type of stress, De Faye et al. (2006) found that problem-focused strategies were used less for existential concerns and emotion-focused strategies used less for physical stressors. The results are consistent with the goodness-of-fit hypothesis in that the participants used a range of coping strategies depending on the stressor. As participants are likely to feel that they have little control of their existential concerns, they would be less likely to adopt a problem-solving approach. Conversely, participants may feel they can exert more control of physical concerns such as pain, by taking practical steps such as using their analgesia appropriately.

These categories of coping strategies also reflect the themes of coping strategies that McPherson et al. (2007) identified in their phenomenological study of 15 palliative care patients. Palliative care patients with cancer reported attempting to minimise the burden on their caregivers by being active in their care (direct action), concealing their need (emotional control), making preparations (planning), avoidance and acceptance. Puente, Furlong, Gutierrez, and Hernandez (2005) found that palliative patients reported using positive coping strategies including planned problem solving, seeking alternative reward and positive reappraisal. For non-cancer palliative care patients, Fitzsimons et al. (2007) reported that a sample of 18 patients reported using friends and family most for support (emotional support). In interviews of 10 heart failure patients, Cortis and Williams (2007) identified the main coping strategies utilised as stoicism (emotional control), acceptance, self-help and adaptation (direct action), seeking reassurance (emotional support), and generating hope and purpose.

When looking at the five studies reviewed above that investigated how palliative care patients cope with stress, it appears that there is not a consensus on specific coping strategies used. Instead the studies report the use of a range of different problem and emotion focused strategies. The studies all use interview methodologies and have small samples (10-52 participants), which may explain the lack of consistency in results. Another issue is that none of the studies compare the coping strategies used by patients with those used by a matched control group to determine if the strategies reported are specific to palliative care patients (versus strategies that might be used by any individual).

Coping strategies utilised by carers of palliative care patients

There is little research on how carers of palliative care patients cope. Rose, Webb, and Waters (1997) interviewed 21 families of palliative care patients and found that the coping strategies used included denial, normalising (living life in as ordinary way as possible) and togetherness (couples working together through the situation). They reported that carers were not fixed in one particular behaviour pattern, but instead moved within and between strategies. More recently, Riley and Fenton (2007) interviewed 9 carers of palliative care patients and reported that they displayed avoidance strategies such as denial, smoking and/or alcohol use, and keeping busy. The findings of these two studies indicate that carers utilise emotion-focused coping strategies such as distancing, emotional control, diverting attention and emotional support. However, the studies have small samples and report themes arising from qualitative interviews. Moreover, an important gap in the evidence is the absence of a comparison of the coping strategies used by carers of palliative care patients versus an appropriate set of matched controls.

Thus, one of the principal objectives of this PhD research programme is to advance knowledge of this field by resolving this gap in our knowledge. More specifically, given the elevated rates of anxiety and depression in palliative care, and given the often uncontrollable nature of palliative care concerns, it is hypothesised that:

Hypothesis 6. Emotion-focused coping will be more frequent in palliative care patients and their caregivers than in matched controls.

Effectiveness of coping strategies utilised by of palliative care patients and their caregivers

There is relatively little evidence examining how effective the different coping strategies are at reducing distress in palliative care. The research does however indicate a link between patterns of coping and psychological distress.

In a sample of 102 palliative patients, Chen, Jiang, Liu, Liu, and Li (2002) identified that the use of avoidance and support were associated with less psychological distress. In 101 palliative patients with metastatic breast cancer, Classen, Koopman, Angell, and Spiegel (1996) found that fighting spirit and emotional expressiveness were associated with better adjustment. However, perceived informal social support had no relationship with depression in a sample of 100 palliative patients (Lloyd-Williams & Friedman, 2001). In a recent review of eight studies examining coping in advanced cancer, Wattebot, O'Brien and Moorey (2010) found some evidence that active, problem-focused coping appeared to be adaptive, whilst avoidant coping was maladaptive.

For 171 elderly carers, self-sustaining coping strategies such as maintaining interests outside the caring situation predicted a better quality of life, whereas asking for social and practical support predicted worse quality of life (Ekwall, Sivberg, & Hallberg, 2007). In an observational, longitudinal study, Couper et al. (2009) investigated 103 couples facing the diagnosis of either localized (potentially curable) or metastatic (incurable) prostate cancer at baseline and then 6 months later. Results indicated that partners utilising coping patterns of avoidance and self-blame at baseline predicted greater partner psychological distress 6 months later. Furthermore, interviews of 18 carers revealed that distractions and activities were identified as both a form of coping and a source of distress (Harding & Higginson, 2001). The carers' need to escape as a means of coping was tempered by a desire to be ever-present and constantly caring. Whilst carers reported using cognitive avoidance as a means of short term coping, carers also particularly expressed the need for emotional support through sharing their concerns.

In summary, the research suggests that whilst there may be an association between the coping strategy used and psychological distress experienced, there is no clear 'best' coping style for palliative care patients or their caregivers. For palliative patients, avoidance may be adaptive or maladaptive, whilst the use of support may have a positive, negative or no impact on distress or quality of life. For carers, the situation is again unclear as the carer's need for respite conflicts with their desire to fulfil their caring responsibilities. Therefore this study aims to advance knowledge in this field by identifying which coping strategies palliative patients and carers report utilising and whether the choice of coping strategy is associated with psychological distress. Noting the elevated rates of anxiety and depression in palliative care, and given the previous hypothesis that emotion-focused coping will be more frequent in palliative care patients and their caregivers than in matched controls, it is hypothesised that:

Hypothesis 7. Problem-focussed coping will be more adaptive than emotion-focussed coping for palliative care patients and their caregivers.

If this hypothesis was true, then it would predict the following in a cross-sectional study:

Prediction 2.1. The frequency of problem-focussed coping reported by participants will be associated with reduced psychological distress.

This prediction represents a necessary but not sufficient test for the hypothesis, as a cross-sectional study is not able to prove a causal relationship. However, the absence of a correlational relationship would be inconsistent with the hypothesis.

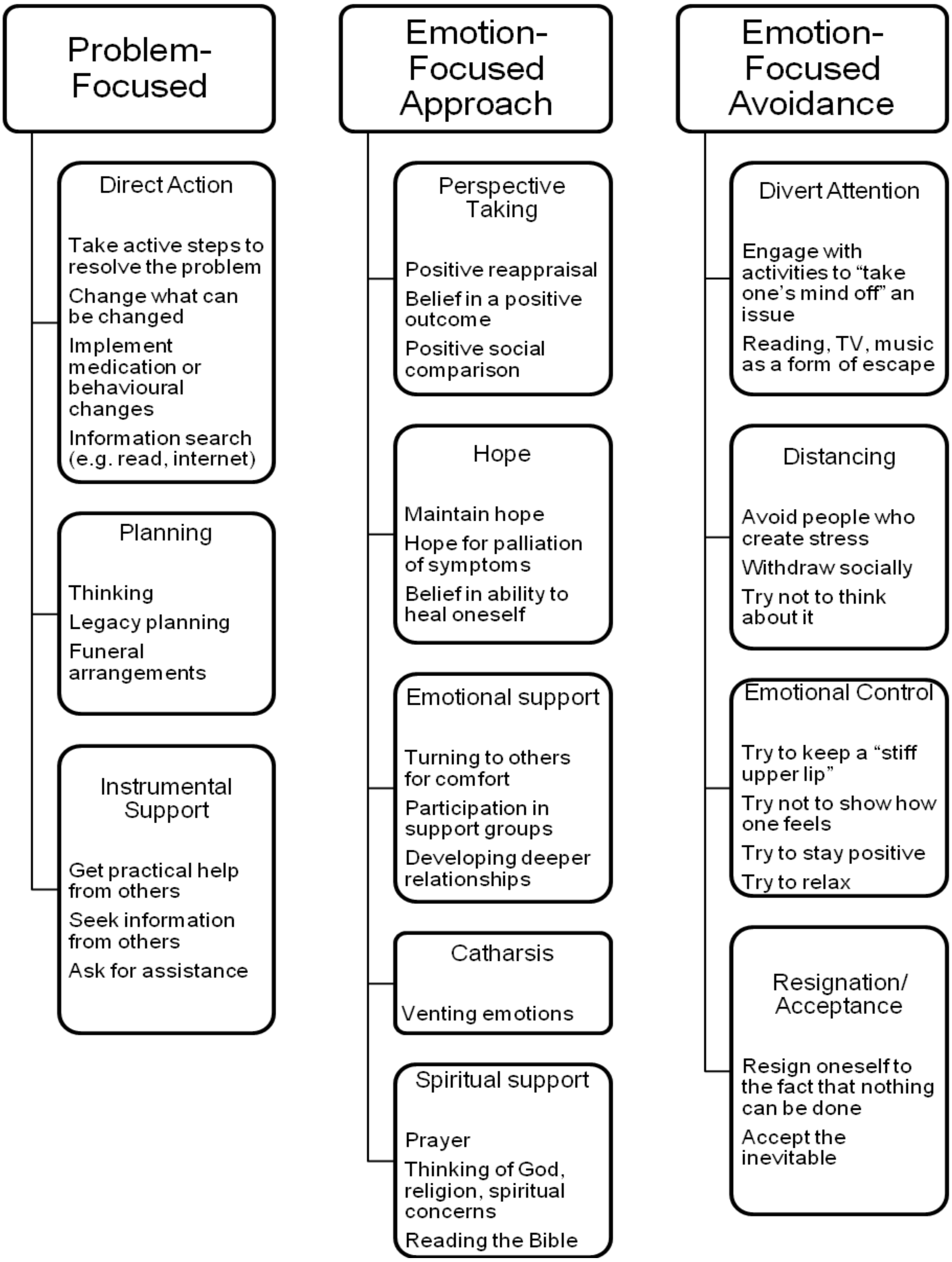

Figure 2.1. Categorisation of coping strategies (Adapted from De Faye et al., 2006, p. 242)

Research Article (Published in Journal of Palliative Medicine):

Galfin, J. M., Watkins, E. R., & Harlow, T. (2010). Psychological distress and rumination in palliative care patients and their caregivers. *Journal of Palliative Medicine, 13,* 1345-1348

Abstract

Background: This study is the first to explore how rumination or recurrent dwelling may contribute to psychological distress in palliative care. We hypothesised that rumination is important in palliative care because a) rumination is triggered by significant life events; b) the diagnosis of a life-limiting illness means the re-evaluation of a number of personal goals, which may become unattainable, and, thereby, lead to rumination; c) palliative care patients and carers report a number of existential concerns, which in their style and content are characteristic of rumination.

Methods: This study adopted a cross-sectional design, comparing samples of palliative care patients (n=36), their caregivers (n=29) and an age-matched control group (n=30). Participants completed a combination of standardised questionnaires to assess their levels of anxiety, depression, and rumination, and open-ended interviews to identify the concerns they were ruminating on and their idiosyncratic experience of rumination.

Results: As predicted, palliative care patients and their caregivers reported significantly more psychological distress than the control group. Palliative care patients and their caregivers also reported significantly more rumination on existential concerns (e.g., about the future) than the control group. The frequency of existential concerns and measures of rumination reported by participants positively correlated with increased psychological distress.

Conclusion: The results support the importance of addressing rumination on existential concerns in palliative care because of its association with psychological distress. Rumination was identified as a mechanism that may be important in addressing psychological distress in palliative care.

Introduction

Diagnosis with a terminal illness is associated with increased psychological distress for patient and carers. In palliative patients, prevalence of major depression is between 16%-36% (Durkin et al., 2002; Greenberg et al., 2004) and of anxiety disorders is between 10%-14% (Wilson et al., 2004; Wilson et al., 2007), with elevated psychological distress reported in 23%-58% (Herbaut et al., 2003; Reeve et al., 2007). Carers also experience elevated psychological distress (Braun et al., 2007; Grov et al., 2005).

De Faye et al. (2006) interviewed 52 palliative patients finding that becoming a burden, pain, weakness/fatigue, and the future were usually the most severe concerns (see Cortis & Williams, 2007; Fitzsimons et al., 2007; McPherson et al., 2007; Turner et al., 2007) for similar findings, and Table 2.1 for examples). Whilst De Faye et al. (2006) found severity of concerns was related to distress, they did not compare palliative patients with matched controls. Other studies show carers of palliative patients are concerned about the patient's physical wellbeing, the demands and impact of their caring role, and the future (Loke et al., 2003; Maguire et al., 1999; Payne et al., 1999; Prigerson et al., 2003).

Table 2.1. Categories for coding of concerns (Adapted from De Faye et al., 2006)

Social Concerns	Physical Concerns	Existential Concerns
Isolation	Pain	Loss of Control
Lack of Information	Drowsiness	Life Dissatisfaction
Lack of Consultation	Nausea	Hopelessness
Role Loss	Weakness/ Fatigue	Loss of Dignity
Financial Strain	Shortness of Breath	Loss of Meaning
Burden to Others	Anorexia / Weight Loss	Concern for the Future
Interpersonal Strain/Friction	Diarrhoea	
Significant Other Wellbeing	Sleep Problems	
Family	Weight / Shape Issues	
Work Related		
Poverty in the World		

Rumination is potentially relevant to psychological distress in palliative care. Rumination involves repetitively focusing on personal difficulties and feelings, and thinking about their causes, meanings, and consequences (Martin & Tesser, 1996; Nolen-Hoeksema, 1991; Watkins, 2008). Rumination focused on depressed symptoms, is implicated in the onset and maintenance of psychological distress (Watkins, 2008; Nolen-Hoeksema, 2000; Just & Alloy, 1997). Rumination is hypothesized to be triggered by unresolved and unattainable goals and in response to discrepancies between actual reality and ideal outcomes and aspirations (Martin & Tesser, 1996).

Therefore, we hypothesized that rumination is associated with psychological distress in palliative care. First, a terminal diagnosis may be a stressful event that triggers rumination. Second, a terminal diagnosis involves re-evaluating personal goals, which may become unattainable, leading to rumination ("I can't do activities I used to do" or "I won't see my grandchildren growing up"). Third, palliative patients and carers report existential concerns, which are characteristic of the thinking about the meaning and implications of difficulties found in rumination. However, rumination has not yet been specifically investigated in palliative care.

This study builds on De Faye et al. (2006) by adding (a) age-matched controls; (b) carers of palliative patients; (c) assessment of rumination; (d) measures of anxiety. This study tests the following hypotheses: (a) palliative patients and carers will report higher levels of psychological distress than age-matched controls; (b) palliative patients and carers will report more rumination on existential concerns than controls.

Methods

Participants

Patients and carers were recruited from a community specialist palliative care service providing home-based advice and support to terminally ill patients (predominantly cancer but also heart, respiratory and neurological conditions). Potentially eligible participants were approached by palliative care nurses; only those willing to participate had their contact details passed to a researcher, who explained the study and sought written consent. The patients had a terminal diagnosis (N = 36, 24 men, 12 women, mean age 68.25 years (10.09), 89% had cancer diagnosis). The carers provided care to a terminally ill family member or friend (N = 29, 7 men, 22 women, mean age of 64.0 years (11.50)). A control group matched for age with the patient and carer groups was recruited from non-clinical hospice staff and a university database.

Controls were neither terminally ill nor caring for a palliative patient (N=30, 9 men, 21 women, mean age of 66.43 years (12.01)).

Procedure

To minimise participant burden, short standardised and well-validated self-report questionnaires were used. The Beck Depression Inventory-Fast Screen (Beck et al., 1997) is a 7-item measure of common symptoms of depression distinct from symptoms of physical illness with reported sensitivity of .82, specificity of .82 and good internal consistency (α= .86). The Generalised Anxiety Disorder GAD-7 (Spitzer et al., 2006) is a 7-item measure of anxiety with sensitivity of 0.89 and specificity of 0.82 (Spitzer et al., 2006; Kroenke et al., 2007). The brooding sub-scale of the Response Style Questionnaire -Ruminative Responses Scale (Nolen-Hoeksema, 1991) is a measure of rumination in response to depressed mood with acceptable internal consistency (Cronbach's α = .77)(Treynor et al., 2003). The brooding sub-scale assesses how passively one compares their present situation with some unachieved standard, when feeling depressed (Full measures are attached in Appendix A).

Participants then participated in a short semi-structured interview, in which open-ended questions identified ruminative concerns (e.g., "Do you have any concerns that you find yourself dwelling on, worrying about, or thinking about repeatedly?"). Further prompts included asking about triggers, contents and consequences of their worrying. For the concern that was self-rated as most bothersome, each participant rated its frequency ("How often do you think about or worry about the problem/concern?") rated from 1 "almost never" to 4 "almost always"; duration ("How long does each bout of dwelling/worry about this concern last?") rated from 1 "only moments" to 4 "for what seems like hours", controllability ("When you think about this problem/concern, do you find it hard to stop thinking about it or to move on to other thoughts/activities?")

rated from 1 “almost never” to 4 “almost always”, and distress (“How much does this problem/concern distress you on a scale from 0 not at all to 10 worst possible distress?”). These questions assessed idiosyncratic rumination on personal concerns.

The interviews were audio-recorded and transcribed verbatim to independently check reliability of coding. The different types of concerns within each category were counted to provide frequency measures of concerns. Reliability in coding was high: for a random 18 transcripts, a second rater blind to condition agreed on categorization of 85.7% of concerns as coded by the interviewer.

Analyses of variance and correlational analyses were performed using the Statistical Package for the Social Sciences (SPSS, version 15.0). A series of one way analyses of variances (ANOVAs) were conducted with group (patients vs. carers vs. control) as the independent variable, and with the relevant questionnaire scores or the reported frequency of each type of concern as the dependent variable. To identify significant differences in the dependent variables between groups, planned *post hoc* Scheffé tests were calculated: to adjust for multiple comparisons, a Bonferroni correction was used to set the significance level at $p = .005$. Correlations were conducted to identify any association between the reported frequencies of concerns and psychological distress (See Table 2.2 for means and standard deviations). Pearson correlation coefficients are reported in Table 2.3.

Results

Psychological Distress

An ANOVA revealed a main effect of group on anxiety ($F(2, 95) = 7.10$, $p = .001$) and depression ($F(2, 95) = 9.31$, $p = .001$). As shown in Table 2.2, patients reported higher levels of anxiety and depression ($p < .001$) than controls.

Table 2.2. Psychological distress, rumination, and concerns across groups (SD in parentheses).

Measure	Sample		
	Patient Mean Score	Carer Mean Score	Control Mean Score
BDI –Fast screen (Scores 0-21)	4.26 (2.93)	3.07 (2.17)	1.67 (1.67)
GAD-7 (Scores 0-21)	5.46 (4.27)	5.45 (5.25)	1.97 (2.37)
RSQ Brooding Scale (Scores 5-20)	8.83 (2.84)	8.34 (2.7)	8.40 (1.98)
Frequency of rumination (Scores 1-4)	2.66 (.97)	2.66 (1.23)	2.27 (1.23)
Duration of rumination (Scores 1-4)	2.34 (1.0)	2.52 (1.30)	1.83 (1.12)
Controllability (Scores 1-4)	1.66 (1.11)	1.79 (1.15)	1.13 (.57)
Distress caused by rumination (Scores 0-10)	6.2 (3.23)	5.79 (3.08)	2.8 (2.76)
Frequency of Social Concerns	.97 (1.0)	1.03 (.68)	.90 (.84)
Frequency of Physical Concerns	.63 (.73)	.17 (.47)	.23 (.50)
Frequency of Existential Concerns	1.26 (.70)	1.03 (.68)	.43 (.57)

Note: BDI-Fast screen = Beck Depression Inventory – Fast screen. GAD-7 = Generalised Anxiety Disorder-7 scale. RSQ Brooding = Brooding subscale from Response Style Questionnaire -Ruminative Responses Scale.

Concerns

There was a main effect of group on the number of existential concerns reported ($F(2, 95) = 13.42, p < .001$), reflecting both patients ($p < .001$) and carers ($p = .003$) reporting more existential concerns than controls. In terms of specific concerns patients reported pain more than carers ($p = .002$) and controls ($p = .002$). Patients reported concerns about the future ($p = .002$) more than controls. Carers reported concern about the wellbeing of their significant other more than controls ($p < .001$).

Rumination

There was a main effect of group on distress caused by rumination ($F\ (2, 95) = 11.63$, $p < .001$) and controllability of rumination ($F(2, 95) = 3.72$, $p < .05$). However no main effect of group was found for the RSQ-Brooding measured rumination, frequency, or duration of rumination. Patients ($p < .001$) and carers ($p = .001$) reported more distress caused by rumination than controls. Carers reported more difficulty in controlling rumination than controls ($p < .05$).

Table 2.3. Correlations between psychological distress, concerns and rumination

	1	2	3	4	5	6	7	8	9	10	11
1. Participants Age	1										
2. GAD-7	-.19	1									
3. BDI-Fast screen	-.07	.62[c]	1								
4. RSQ-Brooding	-.10	.56[c]	.50[c]	1							
5. Frequency of rumination	-.28[b]	.36[c]	.30[b]	.31[b]	1						
6. Duration of rumination	-.21[a]	.45[c]	.37[b]	.33[b]	.56[b]	1					
7. Controllability	-.14	.51[c]	.54[c]	.40[c]	.52[c]	.64[c]	1				
8. Distress caused by rumination	-.17	.53[c]	.51[c]	.27[b]	.43[c]	.55[c]	.49[c]	1			
9. Freq. Social Concerns	-.15	.30[b]	.21[a]	.29[b]	.29[b]	.40[c]	.29[b]	.36[c]	1		
10. Freq. Physical Concerns	-.09	.17	.17	.08	.28[b]	.04	.14	.23[a]	-.04	1	
11. Freq. Existential Concerns	-.05	.39[c]	.33[b]	.27[b]	.28[b]	.21[a]	.28[b]	.43[c]	.06	.15	1

Note: BDI = Beck Depression Inventory – Fast screen. GAD-7 = Generalised Anxiety Disorder-7 scale.

RSQ Brooding = Brooding subscale from Response Style Questionnaire -Ruminative Responses Scale.

[a] $p < .05$, [b] $p < .01$, [c] $p < .001$

Intercorrelations between concerns, rumination, and psychological distress

The frequency of existential concerns correlated positively with anxiety and depression (Table 2.3). Rumination on RSQ brooding subscale and idiosyncratic rumination were positively correlated with anxiety, depression, and frequency of existential concerns.

Discussion

The results are consistent with the prediction that palliative patients and carers have more psychological distress than age-matched controls. This extends the De Faye et al. (2006) findings demonstrating that patients and carers reported more existential concerns than controls. The frequency of existential concerns was correlated with anxiety and depression.

The results are consistent with the prediction that patients and carers ruminate more than age-matched controls. The generic and idiosyncratic measures of rumination were associated with anxiety and depression, consistent with the hypothesis that rumination is involved in psychological distress. The idiosyncratic measures of rumination in terms of distress caused by rumination was elevated in palliative patients suggesting palliative patients have not developed a general tendency towards increased frequency of depressive rumination but rather have elevated rumination in response to their distressing circumstances. The positive association between rumination and psychological distress in palliative patients is worth investigation.

This study has limitations. First, the groups were not gender matched since the carers were most frequently the spouses of the patients in the study. Second, the concerns were analysed by frequency of report, rather than their burden or prevalence. Third, this correlational study could not establish the causal relationship between concerns, rumination, and distress. Fourth, a chronic illness control group would be a useful addition to control for levels of treatment, physical distress, and disability. Fifth, common to all studies involving voluntary participation, there was potential for self-selection of participants, potentially reducing generalizability.

This study has advanced knowledge comparing psychological distress, concerns, and rumination in palliative patients and carers to controls, so extending earlier work.

Notably it confirmed that existential concerns are elevated in patients and carers and indicated these concerns are associated with distressing rumination, and associated with increased anxiety and depression. This study highlights the importance of palliative care research and services addressing existential concerns and associated rumination in holistic palliative care.

Further Investigations and Analysis

In addition to the investigation, analyses, and results presented in the paper, additional measures and coding of the interviews were used to assess the participants' quality of life and coping strategies respectively.

Quality of life measure

To test the prediction that palliative care patients and their caregivers will report worse quality of life than age-matched controls and to test the prediction that worse quality of life will be associated with psychological distress, a quality of life measure was also administered. To minimise burden on participants, the World Health Organisation Quality of Life – Short Version (WHOQOL-BREF) was used (Skevington, Lofty, & O'Connell, 2004). The WHOQOL-BREF is a well-validated and standardised 26-item self-report measure of well-being, with reported internal consistency of α = 0.68-0.82. It consists of two separate questions on overall quality of life and satisfaction with health, with further subscales assessing physical well-being, psychological well-being, social well-being and environmental well-being (Constituents of the four domains are outlined in Table 2.4. For the full measure see Appendix A).

Table 2.4. Constituents of the four domains of the WHOQOL-BREF (Adapted from Skevington et al., 2004)

Physical Wellbeing	Psychological Wellbeing	Social Wellbeing	Environmental Wellbeing
Pain	Positive feelings	Personal relationships	Safety and security
Energy	Cognitions	Social support	Home environment
Sleep	Self-esteem	Sex	Finance
Mobility	Body image		Health/social care
Activities	Negative feelings		Information
Medication	Spirituality		Leisure
Work			Home environment
			Transport

Coping Interview

To test the prediction that palliative care patients and their caregivers use more emotion-focused coping strategies than age-matched controls, transcripts of the interviews described in the paper were also coded for coping strategies (For the full interview schedule see Appendix B). Transcripts were reviewed so that coping was coded according to the categories used by De Faye et al. (2006), with categories added only if the researcher and a second rater blind to group agreed on the need for an additional category (see Figure 2.1). The number of different types of coping strategies reported within each category was counted to provide frequency measures of coping strategies. There was a high level of reliability in coding: for a random selection of 18 transcripts, a second rater blind to condition agreed on categorization of 84.1% of coping strategies as coded by the interviewer.

Supplementary Results

Table 2.5. Quality of life and coping strategies across groups (SD in parentheses)

Measure	Sample Patient Mean Score	 Carer Mean Score	 Control Mean Score
WHOQOL-BREF Q1 Overall QOL (Scores 1-5)	3.24 (.89)	3.76 (.87)	4.43 (.63)
WHOQOL-BREF Q2 Satisfaction with Health (Scores 1-5)	2.24 (1.18)	3.62 (.98)	3.73 (.91)
WHOQOL-BREF Physical Domain	40.35 (20.56)	70.79 (17.08)	73.43 (13.44)
WHOQOL-BREF Psychological Domain	56.88 (13.32)	65.83 (14.73)	71.73 (11.26)
WHOQOL-BREF Social Domain	70.26 (17.21)	74.83 (14.25)	72.50 (15.38)
WHOQOL-BREF Environmental Domain	75.71 (13.80)	77.41 (10.26)	82.47 (8.31)
Frequency of Problem-Focused strategies	.72 (.78)	.72 (0.75)	.77 (.86)
Frequency of Emotion-Focused Approach strategies	.89(.85)	1.21 (.90)	.63 (.76)
Frequency of Emotion-Focused Avoidance strategies	1.06 (.79)	.93 (.75)	.50 (.63)

Note: WHOQOL-BREF = World Health Organisation Quality of Life Brief. All WHOQOL-BREF domain scores are transformed scores from 0-100.

Quality of life

Consistent with the prediction that palliative care patients and their caregivers will report worse quality of life than age-matched controls, an ANOVA with Group (patients vs. carers vs. control) as the independent variable revealed a significant main effect of group on overall quality of life ($F(2, 95) = 16.27, p < .001$), health satisfaction ($F(2, 95) = 19.39, p < .001$), physical quality of life ($F(2, 95) = 36.40, p < .001$), psychological quality of life ($F(2, 95) = 10.31, p < .001$) and environmental quality of life ($F(2, 95) = 3.46, p < .05$). As shown in Table 2.5, palliative care patients reported worse overall quality of life ($p < .001$), physical quality of life ($p < .001$), psychological quality of life ($p < .001$) and less satisfaction with their health ($p < .001$) than the control group. Palliative care patients also reported worse overall quality of life ($p < .05$), physical quality of life ($p < .001$), psychological quality of life ($p < .05$) and less satisfaction with their health ($p < .001$), than carers. Carers reported significantly worse overall quality of life ($p < .01$) than the control group. There was no significant difference for social and environmental quality of life between the three groups.

As shown in Table 2.6, consistent with the prediction that worse quality of life will be associated with psychological distress, reductions in all the measures of quality of life other than the social component were significantly correlated with increased anxiety and depression. Furthermore, elevated rumination as reported on the RSQ was significantly correlated with reduced overall quality of life ($p < .01$), reduced psychological quality of life ($p < .001$) and environmental quality of life ($p < .01$). Reduced psychological quality of life was also significantly correlated with the idiosyncratic measures of rumination; increased frequency ($p < .01$), duration ($p < .001$), difficulty in controllability ($p < .001$) and distress ($p < .001$).

Coping strategies

Consistent with the hypothesis that palliative care patients and their caregivers will use more emotion-focused coping strategies than age-matched controls, an ANOVA revealed a significant main effect of group on the number of emotion-focused approach coping strategies ($F(2,95) = 3.43$, $p < .05$) and the number of emotion-focused avoidance coping strategies reported ($F(2, 95) = 5.03$, $p < .01$) (See Table 2.5). Both palliative care patients and carers reported using more emotion-focused strategies than the control group. Patients reported significantly more emotion-focused avoidance strategies than the control group ($p < .05$), whilst carers reported significantly more emotion-focused approach strategies than controls ($p < .05$).

In terms of individual coping strategies, both palliative care patients and carers reported diverting attention more than the control group (both $p < .05$). Carers also reported catharsis (i.e., venting emotions) more than both patients ($p < .05$) and controls ($p < .05$). The only coping strategy that correlated with measures of psychological distress was the frequency of problem-focused coping strategies, whereby increased problem-focused coping was significantly correlated with reduced depression ($p < .05$). Thus, the results raise the possibility that problem-focused coping may be more successful than emotion-focused strategies in palliative care.

Table 2.6. Correlations between coping strategies, quality of life, psychological distress and rumination.

	1	2	3	4	5	6	7	9	10	11	12	13	14	15	16
1. GAD-7	-	.62***	.56***	-.34**	-.25*	-.30**	-.51***	-.32**	.36***	.45***	.51***	.53***	-.18	.12	.19
2. BDI- Fast screen		-	.49***	-.52***	-.49***	-.46***	-.65***	-.31**	.30**	.37***	.54***	.51***	-.22*	.09	.15
3. RSQ-Brooding			-	-.33**	-.18	-.11	-.43***	-.27**	.31**	.33**	.40***	.27**	-.05	.01	.15
4. WHOQOL-BREF Q1				-	.63***	.49***	.52***	.32**	-.20	-.25*	-.22*	-.36***	.03	-.06	-.19
5. WHOQOL-BREF Q2					-	.74***	.57***	.39***	-.12	-.15	-.19	-.30**	.12	.04	-.15
6. WHOQOL-BREF Physical						-	.54***	.38***	-.10	-.16	-.18	-.30**	.00	.02	-.12
7. WHOQOL-BREF Psychological							-	.43***	-.33**	-.43***	-.42***	-.46***	.07	.01	-.16
9. WHOQOL-BREF Environmental								-	-.16	-.20	-.33**	-.19	-.10	.05	.00
10. Frequency of rumination									-	.56***	.52***	.43***	-.02	.23*	.08
11. Duration of rumination										-	.64***	.55***	.04	.21*	.16
12. Controllability											-	.49***	-.05	.16	.21*
13. Distress caused by rumination												-	-.21*	.27**	.23*
14. Number of problem-focused													-	-.01	-.30**
15. Number of emotion-focused approach														-	-.02
16. Number of emotion-focused avoidance															-

Note: BDI = Beck Depression Inventory – Fast screen. GAD-7 = Generalised Anxiety Disorder-7 scale. WHOQOL-BREF = World Health Organisation Quality of Life Brief. All WHOQOL-BREF domain scores are transformed scores from 0-100. * *p* < .05, ** *p* < .01, *** *p* < .001

Extended discussion

The pattern of results is consistent with the prediction that palliative care patients and their caregivers experience more psychological distress than an age-matched control group. The results also extend the findings of De Faye et al. (2006), by demonstrating that palliative care patients and their caregivers both reported more existential concerns than the control group. Moreover, the frequency of existential concerns was correlated with the extent of anxiety and depression. The pattern of results is also consistent with the prediction that patients with palliative care needs and their caregivers ruminate more than an age-matched control group.

Consistent with the hypothesis that rumination is involved in psychological distress (*Hypothesis 5*), both the generic and idiosyncratic measures of rumination were associated with anxiety and depression. However, only the idiosyncratic measures of rumination in terms of controllability and distress were elevated in palliative care patients. This finding suggests that patients in palliative care have not developed a general tendency towards increased frequency of depressive rumination but rather have elevated rumination in response to their circumstances, such that their concerns revolve around more distressing and difficult-to-address issues related to end-of-life. Moreover, the positive association between rumination and psychological distress suggests a relationship between the experience of distress and rumination in palliative care, worthy of further investigation.

Results were also consistent with the prediction that palliative care patients and their caregivers would use more emotion-focused coping strategies than age-matched controls. In particular, both palliative care patients and carers reported using diverting attention more than the control group. When looking at the effectiveness of coping strategies, the findings were consistent with the prediction that problem-focused coping would be associated with reduced depression. However, the results indicated no association between emotion-focussed coping and psychological distress. This finding corresponds with the general consensus in the literature that emotion focused coping correlates with poor adjustment, and that problem focused coping correlates with less distress (e.g., see Penley, Tomaka, & Wiebe, 2002 meta-analysis). However, it is interesting to note that this seems to be the case in palliative care patients who one might expect would have less scope for problem focused coping due to the lack of perceived control over their condition.

Hence, this raises the possibility that a problem-focused approach may be helpful in palliative care. However, as a cross-sectional study, the results were only correlational so not sufficient to determine a causal relationship between coping style and outcomes.

Furthermore, the results indicate that palliative care patients and their caregivers experience worse overall quality of life and more specifically worse psychological quality of life than an age-matched control group. Moreover, worse quality of life correlated with increased psychological distress and rumination.

In summary, this study has advanced knowledge in the field by comparing psychological distress, concerns, coping and rumination in palliative care patients and carers to age-matched control groups, and as such extends De Faye et al. (2006) findings. In particular, the current findings develop De Faye et al. (2006) work by confirming that existential concerns are elevated in palliative care patients and their caregivers and by indicating that these concerns are associated with distressing and hard-to-control rumination, and associated with increased anxiety and depression. The importance of existential concerns for the palliative care patients in this study support the emphasis placed on spiritual care at the end of life by Dame Cicely Saunders, founder of the modern hospice movement in the United Kingdom. Saunders (1964) proposed that suffering is not only caused by physical symptoms, but also results from psychological, social, and spiritual factors. Saunders' (1988) understanding of "total pain" implied that a person's entire being can be affected by a life-threatening illness, thus suggesting that to treat pain effectively one must treat the whole person. As such, these results highlight the importance of palliative care research and services developing and providing effective means to address existential concerns and associated rumination in the holistic care of palliative care patients.

CHAPTER 3: CONSTRUAL LEVEL, RUMINATION, AND PSYCHOLOGICAL DISTRESS IN PALLIATIVE CARE

This chapter reports a study investigating construal level, rumination, and psychological distress in palliative care patients and their caregivers. The key elements of the study are reported in the following article:

Galfin, J. M. & Watkins, E. R. (in press) Construal level, rumination, and psychological distress in palliative care. *Psycho-oncology.*

The article provides the substantive part of the chapter but because of the limited word count of the article, it will be preceded with an expanded literature review and introduction and followed with an expanded discussion of construal level and elaborated control theory in palliative care. This chapter presents the second study of this thesis that tested the following hypotheses (see expanded introduction below for full rationale):

Hypothesis 8. Palliative care patients and their caregivers will experience more uncertainty and be more abstract in their construal than matched controls;

Hypothesis 9. The uncertainty experienced by palliative care patients and their caregivers will be associated with abstractness, and this abstractness will lead to rumination.

Furthermore, the hypothesis that rumination is a causal process in the development and maintenance of depression and anxiety in palliative care patients and their caregivers (*Hypothesis 5*) has been elaborated to:

Hypothesis 10. Abstract rumination is a causal process in the development and maintenance of depression and anxiety in palliative care patients and their caregivers.

If Hypotheses 9 and 10 are correct, then they would predict the following within the constraints of a cross-sectional study:

Prediction 3.1. Uncertainty will be associated with abstractness in patients with palliative care needs and their caregivers;

Prediction 3.2. Abstractness will be associated with elevated rumination in palliative care patients and their caregivers;

Prediction 3.3. Both abstractness and rumination will be associated with symptoms of depression and anxiety in patients with palliative care needs and their caregivers.

These predictions represent necessary but not sufficient evidence for the hypotheses, as a cross-sectional study is not able to prove a causal relationship. However, the absence of a correlational relationship can disprove the hypotheses.

Expanded literature review

This study examines whether two specific psychological processes – pathological rumination and increased abstractness– may be involved in psychological distress in palliative care. More specifically, this study examines uncertainty, abstractness, and rumination in patients undergoing palliative care and their caregivers as a means to: (a) better understand the mechanisms underpinning psychological distress in palliative care; (b) test whether predictions arising from (i) Construal Level Theory (CLT; Trope & Liberman, 2003) and (ii) a recent extension of principles within control theory that relate level of abstraction to psychopathology (Watkins, 2008) apply within real world settings. Therefore, an expanded literature review pertaining to both CLT and elaborated control theory is presented below.

Construal level theory

CLT (Liberman & Trope, 1998, Liberman, Trope, & Stephan, 2007; Trope & Liberman, 2003) proposes that the more psychologically distant an event is, the more it will be represented at higher levels of abstraction. As individuals become removed from the direct experience of an event, detailed information about the event becomes less available or less reliable. Consequently, CLT proposes that individuals tend to represent psychologically distant events by their essential, abstract, and global features (high-level or abstract construals) and psychologically near events by their peripheral, concrete, and local features (low-level or concrete construals). Within this analysis, an abstract construal involves general, superordinate, and decontextualized mental representations that convey the essential meaning of events and actions and that denote the "*why*" aspects of an action including the ends that are consequential to it (e.g., why can't I do the things that I used to be able to do?). In contrast, a concrete construal involves subordinate, contextual, and specific details of events and actions that denote the feasibility, mechanics, and means of "*how*" to do the action (e.g., how could I get out to see my friends?). This association between distance and construal level is proposed to become overgeneralized such that construal of a given event is more abstract when it is psychologically distant versus when it is psychologically near, even if the information known about the event is equivalent (Liberman et al., 2007; Trope, Liberman & Wakslak, 2007).

Events may be psychologically distant in a number of ways. An event may be temporally distant, in that it occurs further into the future or past; spatially distant in that it occurs in a location further away; it may be hypothetically distant in that it is unlikely or uncertain to occur, or the event may be socially distant where it happens to people who are dissimilar or unconnected to the individual. Consistent with CLT, there is a growing body of experimental evidence demonstrating that construal of events and actions becomes more abstract as psychological distance increases, whether it be temporal distance (Liberman, Sagristano, & Trope, 2002; Peetz, Wilson & Strahan, 2009), spatial distance (Fujita, Henderson, Eng, Trope, & Liberman, 2006), or social distance (Liviatan, Trope, & Liberman, 2008). Likewise, increased hypotheticality of events (or reduced likelihood or certainty of the event occurring) leads to those events being viewed more abstractly (Wakslak, Trope, Liberman, & Alony, 2006).

This CLT analysis is relevant to palliative care patients because they experience elevated psychological distance in the form of increased hypotheticality as a function of their condition. Thus, palliative care patients and their caregivers experience significant day-to-day uncertainty, including uncertainty about the future course of their illness (e.g., ranging from "How will I feel tomorrow?" to "How long have I got to live?"), possible symptoms (e.g., pain), levels of functioning, ability to implement future plans, and concern about what will happen to the family they leave behind. CLT predicts that this uncertainty and increased hypotheticality about the occurrence of future events is a form of psychological distance, and thus, should lead to more abstract construal of events and behaviours within palliative care patients relative to controls. Thus, the comparison of palliative care patients with a matched control group provides a natural experiment to test whether psychological distance (hypotheticality) influences level of abstraction.

Such a natural experiment is of value because, whilst the causal relationship between psychological distance and construal level has been established with experimental manipulations in the laboratory, it has yet to be reliably established if it co-occurs naturally in ecologically valid settings and non-student populations, i.e., do these relationships continue to occur in everyday experience? Demonstrating that psychological distance is associated with construal level under real world conditions is therefore important convergent evidence for CLT.

Elaborated control theory

More critically for understanding psychological distress in palliative care, recent theoretical and empirical work (Watkins, 2008) has proposed that when thinking about negative material, abstract construal will be maladaptive relative to more concrete construal. In particular, this elaborated control theory approach proposed that (a) rumination is triggered as a consequence of unresolved, unattained goals and discrepancies between actual situation and desired situation, consistent with Martin and Tesser's (1996) account of rumination; (b) pathological rumination that contributes to distress occurs when these unresolved goals are represented more abstractly. Within this control theory account, goals are organized in a hierarchy of levels, with superordinate levels providing a more abstract description of the ends why the subordinate goal is enacted, and with subordinate levels providing a more concrete description of the means how the superordinate goal is enacted (Carver & Scheier, 1982). Within this hierarchical organization, pursuit towards abstract goals occurs by specifying reference values at the next lower level of abstraction, all the way down to the concrete representations required to specify the actual behaviours needed to progress towards the goal. For example, one classification of levels within control theory approaches (Carver & Scheier, 1990) proposes that the reference values at the most abstract levels may represent a global sense of idealized self (i.e., a decontextualized, superordinate meaning capturing the essence of the self), which in turn sets the broad principles that organize goals and behavioural standards across multiple situations (e.g., to be an honest person), whereas the reference values at the more concrete levels represent the specific actions and behavioural programs and sequences necessary to implement the principles in a particular situation (e.g., telling the truth to a friend, i.e., more contextualized, specific details of how to do the action).Within this control theory analysis, at any moment, a goal and/or action can be represented more abstractly (reflecting why it is enacted) or concretely (how it is enacted), depending on which level of the hierarchy is functionally prepotent.

Watkins (2008) proposed that a more concrete level of construal would be more adaptive during thinking about difficulties and problems because concrete construal would engender: (a) better problem solving due to the increased detail available about alternative potential courses of action and the detail of "how" to proceed (Vallacher & Wegner, 1987); (b) reduced negative overgeneralizations and reduced emotional impact of negative events because a concrete construal of an event will have less bearing on central elements of the self than an abstract construal (Carver & Scheier, 1990).

Consistent with these hypotheses, a series of studies that manipulated processing style during rumination focused on self, feelings, and symptoms, found that, relative to abstract ruminative self-focus, concrete ruminative self-focus resulted in better social problem solving, more specific autobiographical memory, less global negative self-judgments (Rimes & Watkins, 2005; Watkins & Baracaia, 2002; Watkins & Moulds, 2005; Watkins & Teasdale, 2001, 2004), and better emotional recovery from prior failure (Watkins, 2004) and upsetting images (Ehring, Szeimies, & Schaffrick, 2007). Moreover, adopting a concrete style of processing reduced emotional vulnerability to subsequent failure relative to adopting an abstract style of processing (Moberly & Watkins, 2006; Watkins, Moberly, & Moulds, 2008).

Also consistent with this account, the phenomenology and clinical presentation of depressive rumination is characterized by the repeated use of abstract "Why" questions, which also form a substantial component of the principal self-report measure of rumination (e.g., thinking "Why do I always react this way?"; "thinking "Why do I have problems other people don't have?"; thinking "Why can't I handle things better?").

Thus, the elaborated control theory (Watkins, 2008) hypothesizes that rumination will be associated with distress when it is characterized by more abstract construal when focusing on unresolved goals. Thus, since CLT predicts that palliative care patients will tend to adopt more abstract construals because of increased uncertainty, we hypothesize that palliative care patients are more likely to adopt the pathological form of rumination that is associated with increased distress. Whilst the maladaptive implications of abstract construals in terms of rumination and psychological distress have been established through experimental manipulations and examinations of clinically depressed populations, this has not been explored in palliative care.

Research Article (Accepted for publication in Psycho-oncology):

"Construal level, rumination, and psychological distress in palliative care."

Abstract

Background. Patients with a life-limiting illness, such as cancer, and their caregivers experience elevated psychological distress. However, the psychological mechanisms underpinning distress in palliative care have been little studied. Recent theories predict that individuals who experience increased uncertainty in the context of ongoing difficulties, such as palliative patients and their caregivers, will (a) think more abstractly; (b) ruminate more; (c) be more distressed.

Methods. Palliative patients (n=36, 89% with cancer), their caregivers (n=29) and age-matched controls (n=30) completed standardized questionnaires to assess anxiety, depression, and rumination, and open-ended interviews to identify their concerns and idiosyncratic levels of rumination. Concerns were analyzed linguistically for level of abstraction.

Results. As predicted, (i) palliative patients and carers reported significantly more uncertainty, rumination, and abstract thinking than controls; (ii) uncertainty, abstractness, and rumination were associated with psychological distress.

Conclusions. Abstraction and rumination are psychological mechanism potentially involved in increased psychological distress in palliative care.

Introduction

Being diagnosed with a life-threatening illness such as cancer is associated with elevated psychological distress for both patients and their caregivers (Wilson et al., 2007; Reeve et al., 2007; Braun et al., 2007; Grov et al., 2005). However, the mechanisms underpinning this distress have been little studied. This study examines whether two specific psychological processes – pathological rumination and increased abstractness–are involved in psychological distress in palliative care.

Rumination involves repetitively focusing on personal difficulties and feelings, and thinking about their causes, meanings, and consequences (Martin & Tesser, 1996; Nolen-Hoeksema, 1991; Watkins, 2008). Rumination is empirically implicated in the onset and maintenance of anxiety and depression (Watkins, 2008). Empirically-supported theoretical accounts propose that unresolved goals trigger rumination (Watkins, 2008; Martin & Tesser, 1996). Since living with a life-limiting illness can result in current and future goals becoming unattainable or requiring re-evaluation, it is hypothesized that palliative patients and their caregivers experience elevated rumination. Recent theory and evidence has indicated that there are different styles of rumination with distinct functional effects: a maladaptive form implicated in anxiety and depression characterised by abstract construal (mental representation) focused on general meanings and global implications ("why an event happened") versus an adaptive form characterised by concrete construal focused on contextual and specific details ("how an event happened") (Watkins, 2008). Concrete construal is more adaptive during thinking about difficulties because it engenders: (a) better problem solving due to the increased detail available about alternative courses of action and the detail of "how" to proceed (Vallacher & Wegner, 1987); (b) reduced negative overgeneralizations and reduced emotional impact of negative events (Moberly &

Watkins, 2006; Watkins et al., 2008). Thus, individuals faced with unresolved goals are more likely to engage in pathological rumination that exacerbates distress if they think abstractly.

In parallel, Construal Level Theory (CLT) (Trope & Liberman, 2003) proposes that individuals are more likely to think abstractly about events that are psychologically distant. An event may be psychologically distant because it is temporally distant (further into future or past), spatially distant (a location further away), or hypothetically distant (unlikely or uncertain to occur). CLT proposes that as individuals become removed from the direct experience of an event, detailed information about the event becomes less available or less reliable, such that distant events are represented by their abstract and general features and meaning rather than by concrete details (Trope et al., 2007). Consistent with CLT, there is evidence that construal of events becomes more abstract as psychological distance increases (Liberman et al., 2002; Peetz et al., 2009; Fujita et al., 2006), e.g., increased hypotheticality of events leads to those events being viewed more abstractly (Wakslak et al., 2006).

This analysis is relevant to palliative patients because they experience significant day-to-day uncertainty about the future course of their illness, daily symptoms and functioning and about their family after their death. Therefore, since palliative patients and their caregivers experience (a) ongoing unresolved goals and (b) greater psychological distance in the form of elevated uncertainty, we hypothesize that relative to age-matched controls, palliative patients and carers will a) be more abstract; b) have more pathological rumination, and therefore (c) experience greater distress. Thus, we examined uncertainty, abstractness, and rumination in palliative patients and their caregivers to: (a) better understand the mechanisms underpinning psychological distress in palliative care; (b) test whether recent theoretical predictions (Watkins, 2008; Trope & Liberman, 2003) apply within real world settings.

Method

Participants

Patients with a life-limiting illness (24 men, 12 women; mean age 68.3 years, *SD* = 10.09, 89% with diagnosis of cancer) and their caregivers (7 men, 22 women, mean age 64 years, *SD* = 11.50) were recruited from a community palliative care team. Potential participants were approached by their palliative care nurse, and those who expressed interest were contacted by the researcher, who briefed them about the study, and sought written informed consent. An age-matched control group was recruited from non-clinical hospice staff, volunteers, and a university participant database (9 men, 21 women, mean age 66.4 years, *SD* = 12.01).

Procedure

The study was approved by the local Research Ethics Committee. To minimize burden, short standardized questionnaires were administered. Participants completed the questionnaires and participated in a short interview in which open-ended questions identified ruminative concerns (e.g., “Do you have any concerns that you find yourself dwelling on, worrying about, or thinking about repeatedly?”). Further prompts asked about triggers, contents and consequences of their worrying.

Measures

The Beck Depression Inventory-Fast Screen is a well-validated 7-item measure of common symptoms of depression distinct from symptoms of physical illness with reported sensitivity of .82, specificity of .82 and good internal consistency (α= .86) (Beck et al., 1997). The Generalised Anxiety Disorder GAD-7 is a well-validated 7-item measure of anxiety with sensitivity of .89 and specificity of .82 (Spitzer et al., 2006). The Brooding subscale of the Ruminative Reponses Scale (RSQ) is a well-validated 5-item measure of the extent an individual passively compares their present situation with some unachieved standard (Nolen-Hoeksema, 1991), with reasonable internal consistency and reliability (Cronbach's α = .77) (Treynor et al., 2003).

Rumination Interview.

For the concern that was the most bothersome, participants rated their idiosyncratic rumination about the personal concern for: frequency (1 *almost never* to 4 *almost always*); duration (1 o*nly moments* to 4 *for what seems like hours*), controllability (find it hard to stop thinking about it: 1 *almost never* to 4 *almost always*), and distress (0 *not at all* to 10 *worst possible distress*). The interviews were audio-recorded and transcribed verbatim.

The transcripts were coded for uncertainty and abstractness. The participants' uncertainty about the future was rated from 1*(completely certain)* to 4 (*neither certain or uncertain*) to 7*(completely uncertain).* For 16 transcripts randomly selected, inter-rater reliability between an independent blind rater and the original interviewer was high ($r = .98, p < .001$).

A scheme based on the Linguistic Categorization Model was used to code transcripts for abstractness (Fujita et al., 2006). Two judges blind to group analyzed the transcripts and coded each predicate as belonging to one of four linguistic categories that range along a continuum from most concrete (scored 1) to most abstract (scored 4) (Semin & Smith, 1999): descriptive action verb (DAV: an action with at least one physically invariant feature. e.g., hold, lift, say); interpretive action verb (IAV: general class of behaviours that can be manifested in multiple physical ways, e.g., help, save, harm); state verb (SV: verb reflecting emotional or mental states, e.g., think, feel); or adjective (e.g., tired, angry, stupid). To control for transcript length, total score was divided by number of predicates, giving an abstractness index score. The index scores calculated by the judges were highly correlated, $r = .89$, $p < .001$.

Results

Analyses of variance (ANOVA) and correlational analyses were calculated using the Statistical Package for the Social Sciences (SPSS, version 15.0). A series of ANOVAs were conducted with group (patients vs. carers vs. control) as the independent variable, and with measures of distress, rumination, uncertainty, or abstractness as the dependent variable. Planned *post hoc* Scheffé criteria compared between groups.

Table 3.1. Means for measures across groups (SD in parentheses)

	Sample		
Measure	Patient	Carer	Control
BDI	4.26 (2.93)	3.07 (2.17)	1.67 (1.67)
GAD-7	5.26 (4.18)	5.45 (5.25)	1.97 (2.37)
Brooding	8.83 (.84)	8.34 (2.7)	8.40 (1.98)
Frequency of rumination	2.69 (.98)	2.66 (1.23)	2.27 (1.23)
Duration of rumination	2.31 (1.01)	2.52 (1.30)	1.83 (1.12)
Controllability of rumination	1.64 (1.10)	1.79 (1.15)	1.13 (.57)
Distress caused by rumination	6.17 (3.12)	5.79 (3.08)	2.80 (2.76)
Uncertainty score	4.31 (2.0)	4.93 (1.60)	3.17 (1.70)
Abstractness Index	2.44 (.31)	2.47 (.45)	2.17 (.43)

Note: BDI = Beck Depression Inventory – Fast screen (Scores 0-21). GAD-7 = Generalised Anxiety Disorder-7 scale (Scores 0-21). Brooding = Brooding sub-scale of Response Styles Questionnaire (Scores 5-20).

There was a main group effect on uncertainty (F (2,95) = 7.60, $p < .005$, $\eta^2 = .14$), abstractness (F(2,91) = 4.88, $p < .05$, $\eta^2 = .10$), controllability of rumination (F(2, 95) = 3.72, $p < .05$, $\eta^2 = .08$), distress caused by rumination (F(2, 95) = 11.63, $p < .001$, $\eta^2 = .20$), anxiety ($F_{(2, 95)} = 7.10$, $p < .01$, $\eta^2 = .13$), and depression ($F_{(2, 95)} = 9.31$, $p < .001$, $\eta^2 = .17$). Consistent with hypotheses, as reported in Table 3.1, these effects reflected palliative patients and carers being more uncertain ($p < .005$, $p < .05$ respectively), abstract (both $p < .05$), reporting more distress caused by rumination ($p < .001$, $p < .005$ respectively) and more depression ($p < .001$, $p < .01$ respectively) than controls. Carers reported more difficulty in controlling rumination than controls ($p <$

.05). Palliative patients reported higher levels of anxiety ($p < .01$) than controls. No significant main effect of group was found for Brooding ($F(2,91) = .35, p > .05, \eta^2 = .008$), frequency ($F(2, 95) = 1.33, p > .05, \eta^2 = .028$) and duration ($F(2, 95) = 2.3, p > .05, \eta^2 = .058$) of idiosyncratic rumination.

Table 3.2. Correlations between abstractness, rumination, and symptoms.

		1.	2.	3.	4.	5.	6.	7.	8.	9.	10.	11.
1.	Gender	-	-.26 *	.19	.04	.30 **	.07	.09	.07	-.01	.23 *	.23 *
2.	Age		-	-.19	-.07	-.10	-.28 **	-.21 *	-.14	-.17	-.22 *	-.08
3.	GAD-7			-	.62 ***	.56 ***	.36 ***	.45 ***	.51 ***	.53 ***	.23 *	.33 **
4.	BDI				-	.49 ***	.30 **	.37 ***	.54 ***	.51 ***	.05	.21 *
5.	Brooding					-	.31 **	.33 **	.40 ***	.27 **	.09	.12
6.	Frequency of rumination						-	.56 ***	.52 ***	.43 ***	.28 **	.31 **
7.	Duration of rumination							-	.64 ***	.55 ***	.16	.38 ***
8.	Controllability								-	.49 ***	.16	.32 **
9.	Distress caused by rumination									-	.42 ***	.38 ***
10.	Uncertainty score										-	.32 **
11.	Abstractness Index											-

Note: BDI = Beck Depression Inventory – Fast screen. GAD-7 = Generalised Anxiety Disorder-7 scale. Brooding = Brooding sub-scale of Responses Styles Questionnaire * $p < .05$, ** $p < .01$, *** $p < .001$

As predicted (see Table 3.2), abstractness was significantly positively correlated with uncertainty ($p < .01$), anxiety ($p < .01$), depression ($p < .05$), and frequency ($p < .01$), duration ($p < .001$), controllability ($p < .01$) and distress of idiosyncratic rumination ($p < .001$). The RSQ brooding subscale and the idiosyncratic measures of rumination were significantly positively correlated with anxiety and depression (all $p < .01$).

Discussion

The results are consistent with the predictions that palliative patients and their caregivers would report more abstract thinking, uncertainty, and rumination than controls. Consistent with CLT, increased abstractness was associated with increased uncertainty (i.e., hypotheticality). Furthermore, consistent with Watkins (2008), increased abstractness was associated with increased pathological rumination and psychological distress. Thus, the results provide both further ecological validity and convergent evidence alongside previous experimental manipulations in support of the relationship between psychological distance and abstractness (Trope & Liberman, 2003) and of the maladaptive consequences of abstract construals (Watkins, 2008). These results provide preliminary evidence that rumination and abstraction are elevated in palliative patients and that rumination and abstraction are associated with psychological distress. Although the current findings are correlational and leave unresolved the causal relationship between rumination and psychological distress, the extensive evidence that rumination causally contributes to anxiety and depression (Watkins, 2008) and that abstraction influences emotional vulnerability (Moberly & Watkins, 2006; Watkins et al., 2008) makes it a plausible hypothesis that these variables causally increase distress in palliative care. Since the idiosyncratic measures of rumination were elevated in the patient and carer group relative to controls, but brooding was not, it appears that in palliative care, rumination about idiosyncratic concerns and difficulties, rather than rumination about depressed symptoms is elevated.

This study has limitations. First, the groups were not gender-matched, since the carers were most frequently the spouses of the patient group. Second, there would be merit in having a control group with chronic but not life-threatening illness to control for distress, disability, and treatment effects.

In summary, this study indicates that both rumination and increased abstraction are psychological processes elevated in palliative patients and associated with distress, suggesting that they may be mechanisms underpinning distress in palliative care. Future experimental manipulations or prospective longitudinal studies are necessary to determine whether these psychological processes cause distress in palliative care.

Further details on methods and expanded discussion

Uncertainty

The participants' perception of uncertainty about the future, whether it be their own or others' future, was judged on a 7-point scale from 1(*completely certain)* to 7(*completely uncertain),* with a midpoint 4 (*neither certain or uncertain*). The following is an example of a transcript coded as completely certain, e.g., "We've had a bit of a rough time, the computer's gone down, a puncture on the car...oh what else...the strimmer packed up...it's just you go through phases every so often. Everybody does and we seem to be going through it". The following is an example of a transcript coded as completely uncertain, e.g., "I suppose it's sort of well not knowing at all how the children are going to handle it, it's you know, it's one of those things you don't know until it happens isn't it? You kind of think of all these different kinds of scenarios". For a random selection of 16 transcripts, the scores of an independent rater blind to group were significantly correlated with those of the original interviewer ($r = .98$, $p < .001$).

Abstractness

In order to code for abstractness, the transcripts were coded using a scheme based on the Linguistic Categorization Model (Semin & Fiedler, 1988) and adapted from a method used by Fujita et al. (2006). Two judges blind to group analyzed the transcripts generated from the interviews and coded each predicate as belonging to one of four linguistic categories (See Table 3.3 for examples of predicates and Appendix C for further details of the coding): descriptive action verb (DAV; e.g., *call,*), interpretive action verb (IAV; e.g., *help,*), state verb (SV; e.g., *hope,*), or adjective (e.g., *lethargic*). Semin and Fiedler (1988) demonstrated that these four linguistic categories were organized along a dimension of concreteness to abstractness, with DAVs being the most concrete and adjectives the most abstract. To reflect the different levels of abstraction, a simple weighting schema based on 1, 2, 3, and 4 was used to weight DAVs, IAVs, SVs, and adjectives, respectively (Semin & Smith, 1999). To control for the length of the transcript, the total score was divided by the number of predicates in the description. The resulting abstractness index score is an ordinal scale that reflects degree of abstraction and ranges from 1 to 4. The index scores calculated from the two judges' ratings were highly correlated, $r = .89$, $p < .001$. Discrepancies in codes were resolved through discussion to form a single index.

Table 3.3. Examples of linguistic categories

Descriptive Action Verb	Interpretive Action Verb	State Verb	Adjective
call	help	think	sad
hold	trouble	feel	tired
visit	thank	worry	angry
lift	bother	cope	disappointed
say	try	like	alone
hear	harm	hope	worried
see	save	dwell	ill

More extensive discussion of findings

The pattern of results is consistent with the prediction that palliative care patients and their caregivers would report more abstract thinking, uncertainty, and rumination than the control group. Furthermore the levels of abstractness in this sample (2.17-2.47) appear to be higher than those reported in other samples (e.g., 1.55-1.78 in a sample of university students, Fujita et al., 2006). Consistent with the predictions of CLT concerning psychological distance being associated with increased abstraction, the results indicated that increased abstractness is associated with increased uncertainty (i.e., hypotheticality). Furthermore, consistent with the hypothesis derived from Watkins (2008), increased abstractness is also associated with increased pathological rumination and increased psychological distress.

These findings contribute to our understanding of psychological distress in palliative care in a number of ways. First, the results provide initial evidence that ruminative thought is elevated in palliative care patients and that such rumination is associated with levels of psychological distress. Although the current findings are only correlational and thus the causal relationship between rumination and psychological distress cannot be determined, given the extensive evidence that rumination causally contributes to symptoms in other samples (Watkins, 2008), it is a plausible hypothesis that rumination may contribute to distress in palliative care. Future research will need to examine this causal role through experimental manipulations or prospective longitudinal studies. Interestingly, whilst the idiosyncratic measures of rumination were elevated in the patient and carer group and were associated with abstractness, rumination as measured by the brooding items of the RSQ was not. This pattern of findings suggests that for palliative care patients, it is not rumination about depressed symptoms that is elevated but rather rumination about their own idiosyncratic concerns and difficulties, i.e., rumination is elevated about their difficult circumstances.

Second, the results indicate that increased abstractness of thinking may be a psychological variable involved in psychological distress in palliative care. The current findings indicate that palliative care patients and their caregivers tend to be more abstract when thinking about their personal concerns than controls. Given the experimental evidence indicating that abstract thinking about negative events can lead to worse social problem solving (Watkins & Baracaia, 2002; Watkins & Moulds, 2005), slower emotional recovery (Watkins, 2004) and increased emotional reactivity (Moberly & Watkins, 2006; Watkins et al., 2008), these results suggest that the abstract thinking found in palliative care could contribute to increased psychological distress.

Thus, the results raise the possibility that developing a treatment that addresses the unhelpful rumination and/or the abstract construals arising from the uncertainty inherent in palliative care may be helpful in reducing the psychological distress experienced by patients and their caregivers. One approach that has been developed to train participants to adopt more concrete construals rather than abstract construals is cognitive bias modification (CBM). In a recent proof-of-principle study, Watkins, Baeyens, and Read (2009) examined whether repeated daily training to adopt more concrete construals ("think about how events happen" and "imagine the details of what is happening") reduces naturally occurring depressive symptoms in a dysphoric sample. Participants in the concreteness training condition experienced significantly greater decreases in depressive symptoms and significantly greater increases in concrete thinking than participants in either a waiting list control condition or a bogus training control condition, and significantly greater decreases in rumination than the waiting-list control condition. Thus an investigation of this training approach in palliative care would examine the potential benefit of this intervention and provide a test of the hypothesis that abstraction and rumination causally influence distress since this intervention would directly manipulate rumination and abstraction.

The need for psychological support in palliative care is also emphasised in the NICE guidance on improving supportive and palliative care for adults with cancer (2004). The guidance recommended that all patients undergo systematic psychological assessment at key points and have access to appropriate psychological support. Furthermore, whilst access to specialist palliative care has been shown to positively impact on symptoms such as pain, appetite, nausea, sleep, constipation and overall quality of life (Strömgren et al., 2006), the impact of palliative care on anxiety and depression may be limited (González et al., 2002). Thus treatments that help patients think more concretely about their difficulties and/or reduce unhelpful rumination could potentially be helpful as part of holistic palliative care.

Moreover, the results confirm the principle within CLT that increased psychological distance is associated with more abstract construals. Providing convergent evidence with the causal relationship established in experimental studies, palliative care patients and carers reported more uncertainty about the future (i.e., hypotheticality), which was associated with increased levels of abstractness. Thus, the results provide ecological validity for the relationship between uncertainty and abstractness demonstrated through experimental manipulations, and suggest that this relationship can be found outside of the laboratory and may be pertinent to aspects of everyday experience.

Furthermore, consistent with the proposal that abstract thinking is less helpful than concrete thinking in the context of unattained goals that can trigger repetitive thought about difficulties, the results indicate a correlational relationship in palliative care between abstractness, increased rumination, and psychological distress. Thus, the results provide both further ecological validity and convergent evidence alongside previous experimental manipulations in support of the maladaptive consequences of abstract construals as set out by Watkins (2008).

However, there are a number of limitations in this data. First, the groups were not matched for gender since the patient group was predominantly male, whilst the carer and control groups were predominantly female, reflecting the fact that the carers were most frequently the spouses of the patients that participated in the study. Second, as a correlational study, the causal nature of the relationship between abstractness, uncertainty, rumination, and distress has not been established. Third, there would be merit in having an illness control group that was matched for age and gender and that was experiencing a chronic but not life-threatening illness, to control for levels of treatment, physical distress, and disability and to separate out the specific effects of having a terminal illness. Fourth, it is worth noting that whilst uncertainty was significantly correlated with abstractness, uncertainty was not significantly associated with depressive symptoms, controllability, or duration of rumination. As both uncertainty and abstractness were rated from the same interviews, a possible reason for this could be that there was a closer relationship between problematic rumination and abstractness than there was between generalised uncertainty and abstractness.

In summary, this study has examined the potential role of rumination and increased abstraction as psychological processes involved in distress in palliative care. The results indicate that abstractness is associated with elevated rumination and psychological distress in palliative care. Thus the findings contribute to a better understanding of the mechanisms underpinning psychological distress in palliative care and raise the possibility that an intervention that addresses the issue of abstract rumination may be helpful in reducing the experience of psychological distress in palliative care. Furthermore, the study examined the concept of CLT in palliative care patients and their caregivers, and in doing so has provided evidence in support of the CLT prediction that uncertainty about the future or hypotheticality is associated with increased abstractness in this population.

CHAPTER 4: CASE SERIES

This chapter presents the pilot of the guided self-help intervention in a case series of palliative care patients. The study used a case series with questionnaire and interview–based methodologies to refine an existing guided self–help package (Watkins et al., 2009) and make it acceptable, feasible, and viable for palliative care patients.

Introduction

As reported in Chapter 2, palliative care patients reported higher levels of psychological distress and rumination than an age-matched control group. Furthermore, in Chapter 3, the results indicated a correlational relationship in palliative care between abstractness, increased rumination, and psychological distress, which was consistent with the hypothesis that abstract thinking is less helpful than concrete thinking in the context of unattained goals that can trigger repetitive thought about difficulties (Watkins, 2008). Thus, the results provided both further ecological validity and convergent evidence alongside previous experimental manipulations in support of the maladaptive consequences of abstract construals as set out by Watkins (2008). Hence, an intervention that addresses the issue of abstract rumination may be helpful in reducing the experience of psychological distress in palliative care. Moreover, developing and testing such an intervention provides a proof-of-principle test of the hypothesis that abstract rumination causally influences distress.

One approach that has been developed to train participants to adopt more concrete construals rather than abstract construals is cognitive bias modification (CBM). Consistent with the hypothesis that concrete construals may be more helpful than abstract construals, voluntarily recalling an emotional event in specific detail produces less emotional response than recalling it at a more general level (Philippot, Baeyens, &

Douilliez, 2006; Philippot, Schaefer, & Herbette, 2003), and practising recall of specific autobiographical memories reduces the negative response to a later stressful task relative to recall of general autobiographical memories (Raes, Hermans, Williams, & Eelen, 2006). Moreover, the CBM method has recently been used to investigate whether abstract processing causally influences emotional reactivity. In one study, after a failure experience, higher levels of trait rumination were associated with lower levels of positive affect, but only for participants who previously practised abstract processing of emotional scenarios ("think about the causes, meanings, and implications of each situation") and not for participants who had practised more concrete processing ("focus on how the event happened"; Moberly & Watkins, 2006). In three replications, participants who practised focusing on imagined emotional scenarios in a more concrete way demonstrated smaller increases in negative affect following a subsequent failure compared with participants who practised more abstract processing when focusing on the same emotional scenarios (Watkins, Moberly, & Moulds, 2008). These studies provided initial evidence that the extent of abstract processing could be successfully modified (e.g., assessed via blind ratings of the concreteness of problem descriptions) and that this bias causally influences emotional reactivity. However, these studies only involved a mild failure induction and nonclinical participants, raising the questions of the generalisability of these findings to real-world settings, naturally occurring negative affect, and more depressed samples. However, recent work has suggested that repeated sessions of CBM training can be beneficial in reducing real-world anxiety (Mathews & MacLeod, 2002; Mathews, Ridgeway, Cook, & Yiend, 2007).

In order to test the generalisability of these findings to real-world settings, Watkins, Baeyens and Read (2009) examined whether repeated concreteness training of this type would reduce naturally occurring depressive symptoms in a dysphoric sample.

Following a 10-min guided relaxation procedure, participants spent the remaining 60–80 min of the initial training session practising the key elements of concrete processing via direct instructions, guiding questions, and using mental imagery: (a) focusing on sensory details in the moment (e.g., questions asking participants to focus on and describe what they could see, hear, feel); (b) noticing what is specific and distinctive about the context of the event; (c) noticing the process of how events and behaviours unfold (e.g., "imagine a movie of how events unfolded"); (d) generating detailed step-by step plans of how to proceed from here. As part of the training, participants practised all these elements of concrete processing for three personally relevant, self-generated, specific autobiographic memories (defined as memories that took place at a particular place and time and lasted less than 1 day; one negative, one positive, and one memory of an occasion when the participant was highly immersed and absorbed in the process of an activity). Watkins et al. (2009) found that a week of repeated daily concreteness training resulted in significantly greater decreases in depressive symptoms and significantly greater increases in concrete thinking than a waiting-list control condition and a bogus training control condition, and significantly greater decreases in rumination than the waiting-list control condition. Following this "proof of principle" study, Watkins et al. (submitted) further developed the concreteness training into a facilitated self-help intervention that consisted of an initial 1.5-hr face-to-face session, followed by 15-30 min practice every day for 4-8 weeks using an audio-recording of the concreteness exercises, as a means to make concrete thinking a habit. In a randomized controlled trial of 121 currently depressed participants in primary care, Watkins et al. (submitted) found that concreteness training had a significant additional benefit to treatment as usual in reducing symptoms of depression.

One element of concreteness training used in Watkins et al. (2009) and Watkins et al. (submitted) is the induction of an absorbed state by vividly recalling and imagining previous memories of being completely absorbed and immersed in an activity. During a period of absorption, the individual is completely engaged and directly connected with the experience in the moment, with no other concerns or evaluations running through his or her mind. Being absorbed requires the individual to be focused on the specific sensory details of the scene and/or the process of how he or she is undertaking the activity (e.g., if an individual is absorbed in a sunset he/she is witnessing, his/her attention may be on the pattern of colours and lights of the sunset; or if an individual is absorbed in playing golf, his/her attention may be on how he/she is holding the club, how he/she will swing the club and he/she will be looking at the ball). This element of concreteness training is designed to ensure that participants are actively engaging in generating concrete construals, as being absorbed involves a focus on the concrete details of an event, on what makes each event unique. Furthermore a state of flow or being highly immersed and absorbed in the process of an activity is characterised by concrete processing focussed on the specific details of the task (Csikszentmihalyi, 2002). To make the training more applicable to daily life and more personally relevant, concreteness training included repeated practice on self-selected personal autobiographical memories of times when the individual had been absorbed.

A sense of flow in an activity is typically associated with a number of factors including: a) the activity has clear goals; b) a person engaged in the activity will have the opportunity to focus and to delve deeply into it; c) when in a sense of flow, the individual may lose his/her feeling of self-consciousness; d) the individual's sense of time may be altered; e) the activity includes direct and immediate feedback; f) there is a balance between ability levels of the individual and the challenge of the task; g) the individual has a sense of personal control over the situation or activity; h) the activity is intrinsically rewarding; i) the individual is not aware of their bodily needs, so he/she may not realise he/she is getting tired or hungry; j) the individual's awareness narrows to the here-and-now to and is focused on the activity rather than any other concerns (Csikszentmihalyi, 2002). As such, the experience of being in a state of flow involves a concrete level of construal and is antithetical to ruminative thinking.

This study has adapted this absorption technique to make it acceptable to palliative care patients. The absorption technique was chosen because the focus of the technique was on a positive absorbing memory and not on current difficulties. Furthermore, the absorption technique involved following a set script with few decision points unlike other therapies, so this approach also fulfilled the other key criteria for the intervention to be relatively straightforward to learn, both for the patient and for palliative care staff who were to be trained how to deliver the intervention. Due to high levels of co-morbidity, frailty and fatigue, a key consideration was the length of the training, both in terms of the initial face to face session and the length of daily practice required to make concrete thinking a habit. Watkins et al. (2009) original training involved an initial 1.5- to 2-hr session with an experimenter to explain and practise the training method, followed by a 30-min practice daily. The current study focussed on the specific aspect of the training involving visualisation and mental imagery of an absorbing memory, thus shortening the face-to-face session to 30-min (1-hr including questionnaires and consent) and the daily practice to 10-min.

This approach also builds on the preliminary evidence that other guided self-help interventions that involving imagery can be efficacious for palliative care and cancer patients. These included reminiscence in the form of Short-term life reviews (Ando et al., 2010); well-being self-help including mindfulness (Ramachandra et al., 2009); guided imagery and relaxation (Decker et al., 1992; Syrjala et al., 1995; Baider et al., 2001) (See Chapter 1, section 2.3.2 for further discussion).

The aims of the case series study are to: a) examine the acceptability of this approach and refine who it may be suitable for; b) check that the intervention does not have iatrogenic or harmful effects; c) check to see if there is preliminary evidence that this approach may be helpful; d) pilot and refine elements of the treatment to make it more appropriate for a palliative care sample.

Method

Design

As well as an overall statistical examination of average treatment effect of the guided self-help on symptom measures across patients from pre-treatment to post-treatment, we also used a case series design, whereby the effects on individual participants is reported. A measure of depressive symptoms (BDI -Fast screen) and a measure of anxious symptoms (GAD-7) were administered each week of the course of therapy.

Participants

Palliative care patients were recruited from the caseload of a community specialist palliative care team. The 6 participants (1 male and 5 female) who met the inclusion criteria (see Table 4.1) had a mean age of 59.5 years (*SD* = 12.91). Four participants had a diagnosis of cancer, whilst 1 had a diagnosis of myalgic encephalomyelitis (M.E.) and 1 had a diagnosis of asbestosis and ischemic heart disease.

Table 4.1. Inclusion and exclusion criteria for case series

Inclusion Criteria	Exclusion Criteria
Aged over 18	Learning disability or organic brain damage
On caseload of Hospiscare Community Palliative Care Nurse Specialist	Currently receiving formal psychotherapy or counselling
BDI-FS score at least 4 and/or GAD-7 score at least 5, reflecting a clinically meaningful level of psychological distress, suitable to be addressed by the self–help therapy.	Unable to engage for physical, practical or other reasons (e.g., very disabling physical or mental health; concentration impaired by strong drug regimens)
	Unable to comprehend materials
	Commencing, stopping or changing dosage of antidepressant within previous month

Training intervention

The training involved an initial 30-min face-to-face session with the researcher to explain and practise the training, followed by a 10-min practice daily for 4 weeks. The session began with the researcher giving a clear explanation of the rationale for the training in terms of reducing unhelpful rumination and worry. Next, the participants worked through a guided visualisation of a specific memory in which they had been completely absorbed and immersed. The visualisation consisted of 5 stages (See script in Appendix D for further details). Stage 1 involved the researcher introducing the rationale for the intervention. Stage 2 was concerned with identifying an appropriate memory for the visualisation that was detailed, absorbing, and specific in terms of person, place, and time. Stage 3 involved the researcher asking questions to ascertain if the participant was absorbed in the memory. The researcher asked questions to check for detail of the memory, check the patient's attention and focus was on the scene and/or activity, rather than them being evaluative or having a running commentary on the event, and to check for signs of absorption (e.g., sense of flow, loss of sense of time, feeling absorbed, calm, and positive). Stage 4 was where the researcher gave feedback to the participant that identified the aspects of the memory that the participant had found absorbing and highlighted the positive response that the participant had reported. Finally, Stage 5 involved the researcher and participant making a detailed concrete action plan for how the participant would use the visualisation as part of their daily routine. This included planning how participants would identify and undertake more activities that they found interesting, enjoyable, and absorbing, building on the example of being absorbed already practised.

At the end of the session, the participants were given a digital recording of the exercise to listen to and practise with daily and a booklet explaining the training (See Appendix E for booklet). The researcher contacted the participants by telephone at weekly intervals (See Appendix F for details). The telephone follow up sessions were an opportunity for the researcher to provide support and guidance for the participants, to address any issues the participants had experienced with the training, and to complete measures of anxiety and depression. At the end of 4 weeks of training, the participants were interviewed about their experiences with the training.

Materials

In order to minimise burden, each participant was asked to complete short standardised questionnaires of symptoms and well-being, taking about 10 minutes. These included the Beck Depression Inventory – Fast screen (BDI -Fast screen), the Generalised Anxiety Disorder questionnaire (GAD-7) and the World Health

Organisation Quality of Life – Short Version questionnaire (WHOQOL-BREF). These measures have already been described in Chapter 2.

Procedure

Patients were initially approached by their palliative care nurse to identify if they were interested in taking part in the study. Interested individuals were given an information sheet and completed a return slip that was sent to the researcher. On receipt of the return slip, the researcher contacted the potential participant to arrange the screening interview. At this meeting, participants were briefed in more detail about the study, given an opportunity to ask questions, and assessed as to whether they met the inclusion criteria of the study. Following successful screening, participants were provided with the opportunity to give written informed consent. Measures of anxiety, depression, and quality of life were completed prior to training and after 4 weeks of training. Measures of anxiety and depression were also completed at weekly intervals as part of the telephone follow up sessions. The study was approved by the local Research Ethics Committee.

Results

Group results

A series of t-tests revealed no significant change to participant's symptoms before and after treatment (See Table 4.2). However, this analysis was conducted on only 4 sets of data, as this represented the participants that had completed both pre and post treatment questionnaires (i.e., Participants 1, 4, 5, 6).

Table 4.2. Means for psychological distress and quality of life measures pre and post training (SD in parentheses)

Measure	Pre training	Post training
BDI	9.00 (7.87)	6.00 (6.38)
GAD-7	12.25 (6.02)	11.25 (10.81)
Overall QOL	2.50 (1.29)	2.75 (1.23)
Health satisfaction	2.00 (1.41)	2.00 (1.41)
Physical QOL	34.75 (25.20)	33.00 (27.36)
Psychological QOL	36.00 (28.72)	51.75 (23.60)
Social QOL	72.00 (20.70)	71.75 (27.85)
Environmental QOL	68.75 (10.21)	73.75 (18.19)

Note: Data taken from Participants 1, 4, 5, 6. BDI = Beck Depression Inventory – Fast screen (Scores 0-21). GAD-7 = Generalised Anxiety Disorder-7 scale (Scores 0-21). Overall QOL = WHOQOL-BREF Question 1 (Scores 1-5). Health satisfaction = WHOQOL-BREF Question 2 (Scores 1-5). Physical QOL = WHOQOL-BREF Transformed Physical Domain (Scores 0-100). Psychological QOL = WHOQOL-BREF Transformed Psychological Domain (Scores 0-100).Social QOL = WHOQOL-BREF Transformed Social Domain (Scores 0-100). Environmental QOL = WHOQOL-BREF Transformed Environmental Domain (Scores 0-100).

Individual Cases

For each of the participants, the results presented include their self-reported symptoms of anxiety and depression over the 4 weeks of practice and quality of life pre and post treatment. The frequency of practice and the factors that affected their ability to practise are also reported. A summary of the changes in depressive and anxious symptoms for all the participants is displayed in Figures 4.1 and 4.2. These charts also include details on how often the participants managed to practise the intervention (see key on next page).

Key to frequency of practicing exercise

5-7 days practice per week ━━━━━━━━━━━━

3-4 days practice per week ═ ═ ═ ═ ═ ═

1-2 days practice per week ▬ ▬ ▬ ▬ ▬ ▬ ▬ ▬ ▬ ▬ ▬ ▬

0 days practice per week -

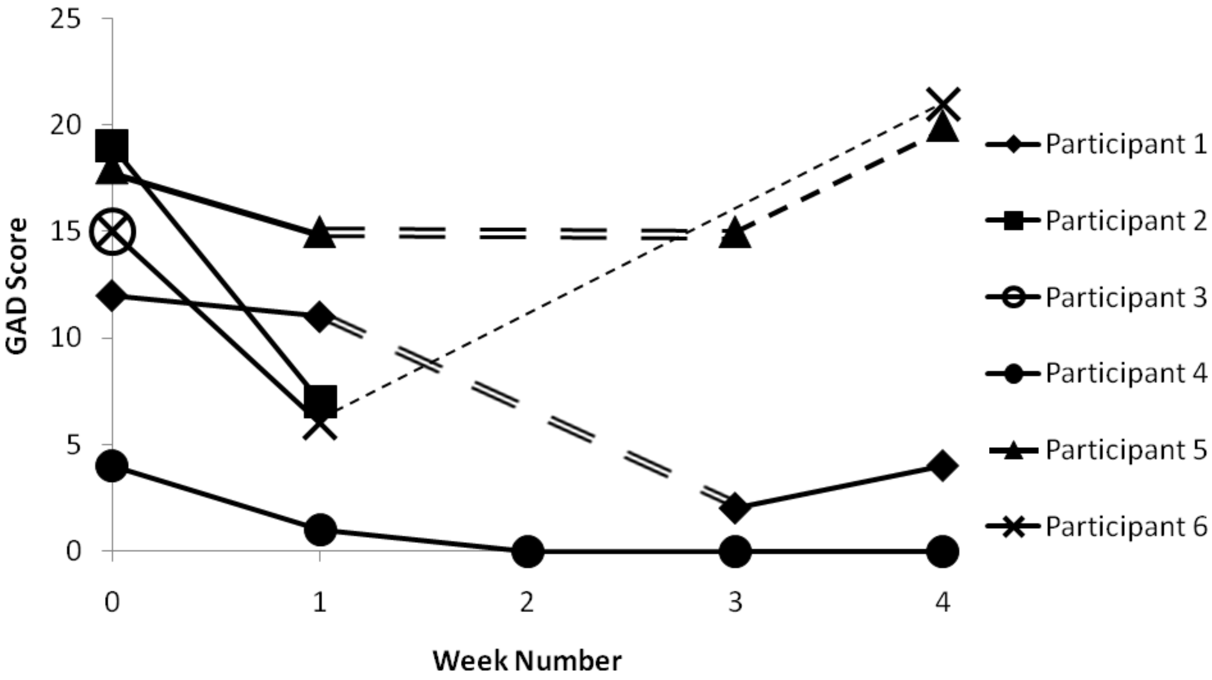

Figure 4.1. Participants' anxious symtomology at each assesment

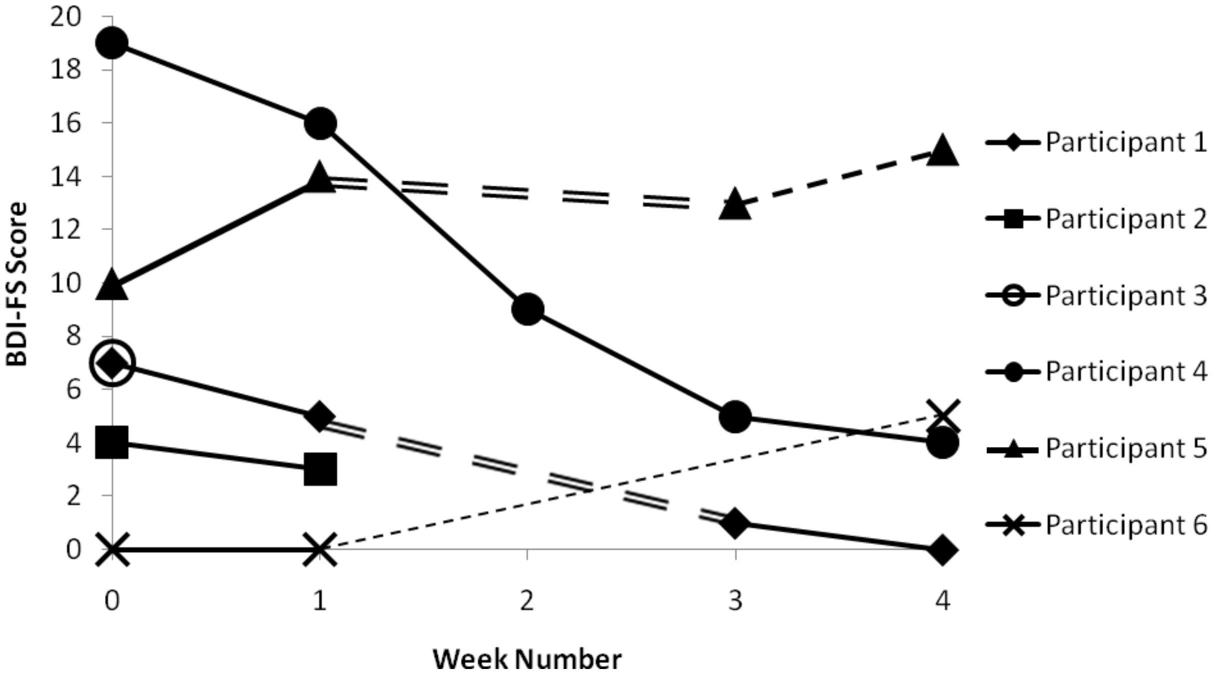

Figure 4.2. Participants' depressive symtomology at each assesment

Participant 1

Participant 1 was a 55 year old women diagnosed with bowel cancer that had spread to her liver. She lived with her husband and was concerned about the limiting effect the cancer was having on her ability to get out and undertake her normal activities. She completed all four weeks of training but missed one telephone follow up and approximately 7-10 days of practice primarily due to a fall and subsequent concussion in week 2. She had utilised a number of different memories such as flower arranging, dog walking, and attending to her allotment, and had used the exercise each morning to motivate her to concretely plan activities for the day, which were then completed. Her planned activities corresponded with the visualisations, i.e., flower arranging, dog walking, and attending to allotment. She felt she had successfully made concrete thinking into a habit as a means to improve motivation. Over the 4 weeks of training, Participant 1 reported a reduction in symptoms of anxiety (see Figure 4.1) and depression (see Figure 4.2) and improvements in all the measures of quality of life (see Table 4.3).

Table 4.3. Participant 1's quality of life before and after training

QOL Measure	Pre training	Post training
Overall QOL	3	4
Health Satisfaction	2	4
Physical QOL	38	69
Psychological QOL	50	69
Social QOL	69	94
Environmental QOL	81	88

Note: Overall QOL = WHOQOL-BREF Question 1 (Scores 1-5). Health satisfaction = WHOQOL-BREF Question 2 (Scores 1-5). Physical QOL = WHOQOL-BREF Transformed Physical Domain (Scores 0-100). Psychological QOL = WHOQOL-BREF Transformed Psychological Domain (Scores 0-100).Social QOL = WHOQOL-BREF Transformed Social Domain (Scores 0-100). Environmental QOL = WHOQOL-BREF Transformed Environmental Domain (Scores 0-100).

Participant 2

Participant 2 was a 75 year old women diagnosed with pancreatic cancer. She lived with her husband. She was concerned primarily about the cancer and her diabetes, especially uncertainty about what she should be eating. She withdrew from the study following the first face-to-face session and one telephone follow-up. She had initial difficulty getting absorbed because during her chosen memory of undertaking cross-stitch, she reported having a running mental commentary focused on the need to complete that particular project before an upcoming event (i.e., she was not fully absorbed in the activity). This was resolved at the first telephone follow-up by visualising a different occurrence of the same activity, but due to technical problems with her CD player and feeling generally less well she decided to withdraw from the study. Participant 2 initially reported a reduction in her depressive and anxious symptoms and reported that she had missed only one day's practice before she withdrew from the study due to increased fatigue and frailty (see Figures 4.1 and 4.2). Participant 2's initial self reported quality of life scores are in Table 4.4.

Table 4.4. Participant 2's quality of life before training

QOL Measure	Pre training
Overall QOL	3
Health Satisfaction	2
Physical QOL	38
Psychological QOL	25
Social QOL	81
Environmental QOL	63

Note: Overall QOL = WHOQOL-BREF Question 1 (Scores 1-5). Health satisfaction = WHOQOL-BREF Question 2 (Scores 1-5). Physical QOL = WHOQOL-BREF Transformed Physical Domain (Scores 0-100). Psychological QOL = WHOQOL-BREF Transformed Psychological Domain (Scores 0-100).Social QOL = WHOQOL-BREF Transformed Social Domain (Scores 0-100). Environmental QOL = WHOQOL-BREF Transformed Environmental Domain (Scores 0-100).

Participant 3

Participant 3 was a 72 year old man diagnosed with asbestosis and ischemic heart disease. He lived with his wife. His primary concerns were his chronic breathlessness and the ways in which it was hindering him undertaking activities he had done previously. He completed the first face-to face session and then withdrew from the study after one week, prior to the first telephone session. His baseline symptoms of anxiety and depression were reflected in a BDI-Fast screen score of 7 and a GAD score of 15. His physical condition was very frail in that he was taking constant oxygen via a face mask and the low levels of oxygen in his blood stream meant he was fatigued and found it difficult to talk or concentrate even for a few minutes at a time. This physical difficulty had meant that he was unable to concentrate enough to engage fully with the exercise and get absorbed. His general debility was also reflected in his initial quality of life measures in that his physical quality of life was 19 out of 100 (see Table 4.5).

Table 4.5. Participant 3's quality of life before training

QOL Measure	Pre training
Overall QOL	2
Health Satisfaction	2
Physical QOL	19
Psychological QOL	38
Social QOL	50
Environmental QOL	56

Note: Overall QOL = WHOQOL-BREF Question 1 (Scores 1-5). Health satisfaction = WHOQOL-BREF Question 2 (Scores 1-5). Physical QOL = WHOQOL-BREF Transformed Physical Domain (Scores 0-100). Psychological QOL = WHOQOL-BREF Transformed Psychological Domain (Scores 0-100).Social QOL = WHOQOL-BREF Transformed Social Domain (Scores 0-100). Environmental QOL = WHOQOL-BREF Transformed Environmental Domain (Scores 0-100).

Participant 4

Participant 4 was a 64 year old women diagnosed with scleroderma that resulted in her requiring a permanent tracheotomy. She lived with her husband and was primarily concerned about falling. She completed the 4 weeks of training and all 3 telephone follow ups, whilst she only missed 5 days practice over the 4 weeks. She used memories of knitting initially and then playing golf for the last 2 weeks. Overall, she felt that the training had helped her to be able to enjoy positive memories again. This was reflected in her reporting a reduction of anxious and depressive symptoms over the 4 weeks of training (see Figures 4.1 and 4.2). She also reported improvements in overall quality of life, physical, psychological and social quality of life (see Table 4.6).

Table 4.6. Participant 4's quality of life before and after training

QOL Measure	Pre training	Post training
Overall QOL	2	3
Health Satisfaction	1	1
Physical QOL	19	38
Psychological QOL	19	50
Social QOL	69	81
Environmental QOL	69	69

Note: Overall QOL = WHOQOL-BREF Question 1 (Scores 1-5). Health satisfaction = WHOQOL-BREF Question 2 (Scores 1-5). Physical QOL = WHOQOL-BREF Transformed Physical Domain (Scores 0-100). Psychological QOL = WHOQOL-BREF Transformed Psychological Domain (Scores 0-100).Social QOL = WHOQOL-BREF Transformed Social Domain (Scores 0-100). Environmental QOL = WHOQOL-BREF Transformed Environmental Domain (Scores 0-100).

Participant 5

Participant 5 was a 47 year old women diagnosed with M.E. She lived with her husband and was initially concerned about her family and what other people thought about her. She completed four weeks of training, but missed one telephone follow up and 11 days practice due to elevated pain associated with her illness, primarily during the last 2 weeks of practice. She visualised a memory of knitting on holiday, but struggled to find other memories from her past that were both specific and not associated with her feeling unwell. This was because she had lived with M.E. for many years and had suffered symptoms of fatigue, pain, weakness, reduced mobility and lack of concentration throughout that time. Despite reporting that she found the intervention helpful and her concerns changing over the 4 weeks to more concrete ones about physical pain, weakness, and finances, this was not reflected in any of her outcome measures apart from psychological quality of life (see Figures 4.1 and 4.2 and Table 4.7).

Table 4.7. Participant 5's quality of life before and after training

QOL Measure	Pre training	Post training
Overall QOL	1	1
Health Satisfaction	1	1
Physical QOL	13	6
Psychological QOL	6	19
Social QOL	50	31
Environmental QOL	56	50

Note: Overall QOL = WHOQOL-BREF Question 1 (Scores 1-5). Health satisfaction = WHOQOL-BREF Question 2 (Scores 1-5). Physical QOL = WHOQOL-BREF Transformed Physical Domain (Scores 0-100). Psychological QOL = WHOQOL-BREF Transformed Psychological Domain (Scores 0-100).Social QOL = WHOQOL-BREF Transformed Social Domain (Scores 0-100). Environmental QOL = WHOQOL-BREF Transformed Environmental Domain (Scores 0-100).

Participant 6

Participant 6 was a 44 year old woman diagnosed with breast cancer. She lived with her husband and her main concern was about anxiety brought on by witnessing events beyond her control. She completed the first face-to-face session, six days of practice and one telephone follow-up before withdrawing from the training due to her condition deteriorating. During the first week of training she had developed severe migraines that made it difficult for her to concentrate on the memory of sitting by a river she had visualised as part of the practice. Initially she reported a reduction of anxiety, but this was short-lived and her anxiety and depression then increased once she had ceased practising (see Figures 4.1 and 4.2). Also there was a reduction in overall quality of life, health satisfaction, physical and social quality of life over the study period (see Table 4.8).

Table 4.8. Participant 6's quality of life before and after training

QOL Measure	Pre training	Post training
Overall QOL	4	3
Health Satisfaction	4	2
Physical QOL	69	19
Psychological QOL	69	69
Social QOL	100	81
Environmental QOL	69	88

Note: Overall QOL = WHOQOL-BREF Question 1 (Scores 1-5). Health satisfaction = WHOQOL-BREF Question 2 (Scores 1-5). Physical QOL = WHOQOL-BREF Transformed Physical Domain (Scores 0-100). Psychological QOL = WHOQOL-BREF Transformed Psychological Domain (Scores 0-100).Social QOL = WHOQOL-BREF Transformed Social Domain (Scores 0-100). Environmental QOL = WHOQOL-BREF Transformed Environmental Domain (Scores 0-100).

Discussion

There was mixed evidence that the participants in this case series gained some benefit whilst they were engaged with the treatment. Participants 1 and 4 reported improvements in anxiety, depression, overall quality of life, physical and psychological quality of life over the 4 weeks in which they participated. Participants 2 and 6 reported reductions in anxiety during the first week in which they practised prior to withdrawal from the treatment. Participant 5 reported an initial improvement in anxiety, but over the 4 weeks she reported increased depression and anxiety, but an improvement in psychological quality of life. Participant 3 withdrew from the study before follow-up data was obtained because his chronic breathlessness and fatigue made it difficult for him to concentrate. Moreover, there were a number of drop-outs reflecting deteriorating health, increased pain, and poor concentration. Participant 2 withdrew after 1 week because of her deteriorating health and increased frailty, Participant 3 was unable to concentrate due to his severe and chronic breathlessness and withdrew before the first follow-up telephone call, and Participant 6 stopped practising after a week due to severe migraines.

Nonetheless, the data raises the possibility that for participants who were able to practise the treatment (both motivated and physically able to do so) the treatment was of benefit (i.e., Participants 1 and 4 throughout the four weeks; Participants 2, 5 and 6 during the weeks they practised). This is consistent with the theoretical rationale for the treatment that repeated practice at entering an absorbed mindset through visualising and recreating past absorbing experiences would a) increase the likelihood of adopting a more concrete style of processing; b) increase the likelihood of being absorbed in other activities. However, like all CBM approaches, this intervention requires repeated practice to instil a habit of being more concrete in place of the previous tendency to be abstract.

The case series results also suggest that the absorption intervention is acceptable to patients. First, there was no evidence that the interventions exacerbated the course of the participants' illnesses or had any negative side effects. Second, participants who completed the intervention commented favourably on their experiences. Participant 1 felt she had successfully made concrete thinking into a habit as a means to improve her levels of motivation. Furthermore, Participant 4 felt that the training had enabled her to be able to enjoy positive memories again, rather than be fearful that the positive memories would lead to negative memories associated with her illness.

Despite some participants reporting reductions in anxiety and depression during the brief intervention, the case series also indicated that the treatment package needed refining and improving, and suggested a number of ways that it could be improved.

First, as noted with participant 3, it was observed that the underlining frailty of palliative patients could make it difficult for them to concentrate enough on their autobiographical memory to get fully engaged and absorbed. It therefore seemed that the treatment package was not appropriate for those palliative care patients whose physical condition was seriously interfering with their abilities to concentrate. In the light of this, to improve the relevance and efficacy of future interventions, it was deemed sensible to screen participants and to determine whether they were able to concentrate sufficiently to become absorbed. As a result an extra question was added to the screening procedure that asked participants to give a detailed description of a positive memory that occurred at a specific time and place and lasted no longer than a day (See Appendix H).

Second, the importance of ensuring that the participant was fully absorbed in an appropriate memory was highlighted as part of the researcher's reflections on delivering the intervention. With particular reference to Participant 2, a key issue identified was the need for the researcher to ensure that participants were engaged with appropriate memories and fully absorbed in those memories during the initial training session. The researcher utilised practice and role-play to refine his skills in identifying appropriate memories and assessing whether participants were fully absorbed in those memories. Furthermore, it was noted that the selection of appropriate memories and recognising if participants were absorbed in those memories would be a key message when training other palliative care staff to deliver the intervention.

Third, the physical deterioration of the participants as measured by their self-rated physical quality of life (see participant 5) appears to be a potentially important factor affecting their outcomes with the intervention, although it cannot be tested in such a small sample. In practice, assessing participants for physical frailty may be of value as a covariate in subsequent analyses. In particular, given the trajectory of increasing physical difficulties in palliative care patients, maintaining the same level of psychological distress, rather than it worsening over time, may indicate treatment benefit. Also the increasing physical frailty suggest that in order to increase the likelihood that the treatment may be helpful, patients should be selected for the treatment at an appropriate time in their disease course – i.e., relatively early, when they are physically less frail.

The case series does however have a number of limitations, including a small sample size and the lack of a control group or randomisation. Therefore, without a control group, the observed results cannot be attributed to the intervention, rather than to another factor such as regression to mean, spontaneous recovery or as a function of repeated measurement. Also any improvement in self-reported symptoms may have been due to nonspecific factors, such as positive expectations arising from the training rationale, or support and empathy from the researcher administering the training. However, the findings of this study indicate with some modification to the identification and screening of patients that the treatment could be acceptable and feasible for palliative care patients because no participants found the treatment unacceptable or considered that it made them worse. Given the brevity of the intervention, this indicates that there is value in examining the efficacy of the intervention further in a randomised controlled study that has refined the intervention in the light of lessons learnt here.

CHAPTER 5: A PILOT RANDOMIZED CONTROLLED TRIAL OF GUIDED SELF-HELP INTERVENTION.

This chapter reports a pilot randomized controlled study evaluating a brief guided self-help intervention developed for use with palliative care patients. The key elements of the study are reported in the following article:

Galfin, J. M., Watkins, E. R., & Harlow, T. (in press). A brief guided self-help intervention for psychological distress in palliative care patients: a randomized controlled trial. *Palliative* Medicine.

The article provides the substantive part of the chapter but because of the limited word count of the article, it will be followed with a further discussion of the concept of abstractness.

The results of Study 2 as described in Chapter 3 indicated that palliative care patients reported more rumination on abstract concerns than an age-matched control group and that there was an association between abstract rumination and psychological distress in palliative care. Hence, an intervention that targets abstract rumination may reduce psychological distress in palliative care. However, to date, our evidence is only correlational and there is not direct evidence that abstract rumination causally contributes to psychological distress in palliative care. Testing such an intervention against a control condition provides a proof-of-principle test of the hypothesis that abstract rumination causally influences distress in palliative care patients. Thus, this study tests the following hypothesis identified in Chapter 3:

Hypothesis 10. Abstract rumination is a causal process in the development and maintenance of depression and anxiety in palliative care patients.

Within the confines of the trial's design and sample, this hypothesis translates into the following predictions:

Prediction 5.1. A brief guided self-help intervention based on concreteness training will make palliative care patients think more concretely than a waiting-list control group.

Prediction 5.2. Increased concrete thinking will mediate the effects of the intervention on self-reported symptoms of psychological distress in palliative care patients.

Furthermore, the study also builds on the results of the case series in Chapter 4 as a means to evaluate the efficacy of the brief CT guided self-help intervention for palliative care patients and therefore tested the following hypothesis:

Hypothesis 11. A brief CT guided self-help intervention will reduce symptoms of anxiety and depression and improve quality of life in palliative patients compared with waiting-list controls.

Research Article (Accepted for publication in Palliative Medicine):

"A brief guided self-help intervention for psychological distress in palliative care patients: a randomized controlled trial."

Abstract

Background: Previous findings implicated rumination (recurrent dwelling on abstract concerns) in elevated psychological distress in palliative patients. We hypothesised that reducing rumination may be important in addressing psychological distress in palliative care.

Aim: This study tested the prediction that a brief guided self-help technique targeting abstract rumination would reduce psychological distress in palliative patients.

Design: A randomized controlled trial evaluated 4 weeks of guided self-help that involved patients practising thinking more concretely by recalling specific and vivid memories of when they were completely absorbed in an activity or scene. Participants completed a combination of standardised questionnaires to assess anxiety, depression, and quality of life.

Setting/participants: Palliative care patients who were reporting clinically significant psychological distress, whilst also physically well enough to take part in the trial were recruited from hospices in Devon and Somerset and randomised to either a treatment condition (n = 19) receiving 4 weeks of guided self-help, or a waiting-list control condition (n=15) receiving treatment as usual.

Results: As predicted, the palliative patients receiving the intervention reported significantly greater reductions in anxiety than the waiting-list controls ($F(1,23) = 20.55$, $p < 0.001$, *partial* $\eta^2 = 0.47$). However, no significant effect was found on depression or quality of life.

Conclusion: The findings suggest that a brief guided self-help intervention based on concreteness training can be effective in addressing anxiety in palliative care.

Introduction

Psychological interventions are required in palliative care for a number of reasons. First, palliative patients experience more depression (Durkin et al., 2002; Greenberg et al., 2004) and anxiety disorders (Wilson et al., 2004; Wilson et al., 2007) than the general population and also report elevated psychological distress (Herbaut et al., 2003; Reeve et al., 2007; Galfin, Watkins, & Harlow, 2010). Second, there is a lack of access to psychologists and psychiatrists in UK hospices (Price et al., 2006). Third, whilst access to specialist palliative care can positively impact on physical symptoms and quality of life (Strömgren et al., 2006), the direct effect of palliative care on psychological symptoms has yet to be confirmed (González et al., 2002). Moreover, psychological interventions in palliative care need to be brief and simple to learn for palliative patients who can experience a range of symptoms including pain, lack of concentration, and fatigue/weakness (Cherny, 2005). Ideally, psychological interventions should also be suitable for delivery by existing palliative care staff, to overcome the lack of access to specialist psychological services, to optimise current resources, and to take advantage of existing therapeutic relationships.

A number of psychological approaches have been investigated in palliative care including cognitive behavioural therapy (Anderson et al., 2008; Moorey et al., 2009), hypnosis (Liossi & White, 2001), group support (Miller et al., 2005; Ramsay et al., 2007), and music therapy (Horne-Thompson & Grocke, 2008). These studies have limitations, as some studies (Anderson et al., 2008; Miller et al., 2005) lacked a control group and some studies did not randomize their participants (Anderson et al., 2008, Moorey et al., 2009; Ramsay et al., 2007). The absence of control group comparisons and randomization means that findings lack internal validity regarding the change in symptoms. Moreover randomization would minimise allocation bias, balancing both known and unknown prognostic factors in the assignment of treatments.

The current paper describes the evaluation of an intervention for psychological distress in palliative care that focuses on ameliorating worry and rumination. Rumination is the process of repetitively focusing on personal difficulties, symptoms, and feelings, and thinking about their causes, meanings, and consequences (Martin & Tesser, 1996; Nolen-Hoeksema, 1991; Watkins, 2008). There is evidence that pathological rumination and worry is characterized by abstract thinking about unattained goals, whereas more concrete repetitive thought has more constructive consequences (Watkins, 2008). Here, abstract thinking is focused on evaluating the causes, meanings, consequences, and implications of self-experience, whereas concrete thinking is focused on the specific, contextual, and concrete moment-by-moment details of how self-experience unfolds (Watkins, 2008).

An intervention targeting abstract rumination may reduce psychological distress in palliative care because a) palliative patients report more rumination on abstract concerns than age-matched controls (Galfin et al., 2010 [Chapter 2]; b) abstract rumination is associated with psychological distress in palliative care (Galfin & Watkins, in press) [Chapter 3]; c) both experimental and longitudinal prospective studies implicate rumination in the onset and maintenance of anxiety and depression (Watkins, 2008). Palliative patients experience more abstract rumination in several ways. First, a terminal diagnosis may be a stressful event that triggers rumination. Second, a terminal diagnosis involves re-evaluating personal goals, which may become unattainable (“I can’t do activities I used to do” or “I won’t see my grandchildren growing up”), leading to abstract rumination about the causes and implications of these changes (“Why can’t I do this anymore? What will it mean for my family?”). Third, palliative patients report existential concerns, which are characteristic of the thinking about the meaning and implications of difficulties found in rumination (Galfin et al., 2010[Chapter 2]; De Faye et al., 2006).

One approach to address the negative effects of abstract rumination is by directly training participants to think more concretely. Such training involves repeated practice at thinking in a more concrete way (i.e., focus on the specific details and process of a scenario) rather than in an abstract way (i.e., think about the causes, meanings, and implications of a situation). In experimental studies, training individuals to be more concrete has been shown to reduce the negative effect of upsetting events on subsequent emotional response (Philippot et al., 2006; Philippot et al., 2003; Raes et al., 2006; Moberly & Watkins, 2006; Watkins et al., 2008).

These experimental manipulations have been developed into a treatment package for depression and dysphoria, called concreteness training (Watkins et al., 2009) (CT). CT utilises face-to-face and telephone interactions and audio-recorded instructions to facilitate repeated practice of mental imagery exercises to encourage concrete thinking about emotional events. One exercise involves the induction of an absorbed state by vividly imagining previous memories of being completely absorbed in an activity. Whilst absorbed, the individual is completely engaged and directly connected with the experience in the moment, with no other concerns or evaluations running through their mind. This requires the individual to be focused on the specific sensory details of the scene and/or the process of how they are undertaking the activity (e.g., whilst absorbed in witnessing a sunset, an individual’s attention may be on the pattern of colours and lights of the sunset; or whilst absorbed in playing golf, an individual's attention may be on how he/she is holding and swinging the club). This element of CT is designed to ensure participants are actively engaging in generating concrete thoughts, as being absorbed involves focusing on the concrete details of an event. Furthermore a state of flow or being highly absorbed in the process of an activity is characterised by concrete thinking focussed on the specific details of the task (Csikszentmihalyi, 2002). To make the training applicable to daily life and more personally relevant, CT includes repeated practice on self-selected personal autobiographical memories of absorbing situations (Watkins et al., 2009).

Watkins et al. (2009) found that a week of repeated daily CT resulted in significantly greater decreases in depressive symptoms and significantly greater increases in concrete thinking than a waiting-list control condition and a bogus training control condition, and significantly greater decreases in rumination than the waiting-list control condition. Thus, repeated practice at entering a concrete mindset was shown to increase the likelihood of adopting a more concrete style of processing. Following this "proof of principle" study, Watkins et al. (submitted) further developed CT into a facilitated self-help intervention.

This study has adapted the facilitated self-help intervention to make it acceptable to palliative patients. As palliative patients experience high levels of co-morbidity, frailty, and fatigue, we could not use all of the facilitated self-help intervention (1.5- to 2-hr initial face-to-face coaching, followed by 30-min daily practice). We chose to use the absorption element alone because a) it kept the treatment brief; b) it was considered the easiest element to explain and practise daily; c) its focus was on a positive absorbing memory, not current difficulties.

This study tests the following hypothesis: a brief CT guided self-help intervention will reduce symptoms of anxiety and depression and improve quality of life in palliative patients compared with waiting-list controls.

Methods

Procedure

Patients were recruited from hospices in Devon and Somerset. Potential participants were approached by clinical staff and those interested in taking part met the researcher (See Appendix G for strategies and materials used to facilitate recruitment). The researcher screened them against the inclusion and exclusion criteria to ascertain if the patient was physically well enough to take part, whilst also reporting clinically significant psychological distress (see Table 5.1). A member of university staff unconnected with the study and blind to participants prepared randomly ordered envelopes for treatment assignment using a computer-based randomization programme, and informed the researcher of treatment randomization once each participant consented. The participants then either commenced the intervention immediately (treatment) or commenced the intervention after 4 weeks of receiving their usual hospice support (waiting-list control).

Table 5.1. Inclusion and exclusion criteria for the RCT.

Inclusion Criteria	Exclusion Criteria
Aged over 18	Learning disability or organic brain damage
In receipt of specialist palliative care from hospice.	Currently receiving formal psychotherapy or counselling
BDI-FS score at least 4 and/or GAD-7 score at least 5, reflecting a clinically meaningful level of psychological distress, suitable to be addressed by the self−help therapy.	Unable to engage for physical, practical or other reasons (e.g., very disabling physical or mental health; concentration impaired by strong drug regimens)
Must be able to generate detailed memory	Unable to comprehend materials
	Commencing, stopping or changing dosage of antidepressant within previous month

Note: See Appendix H for screening questions.

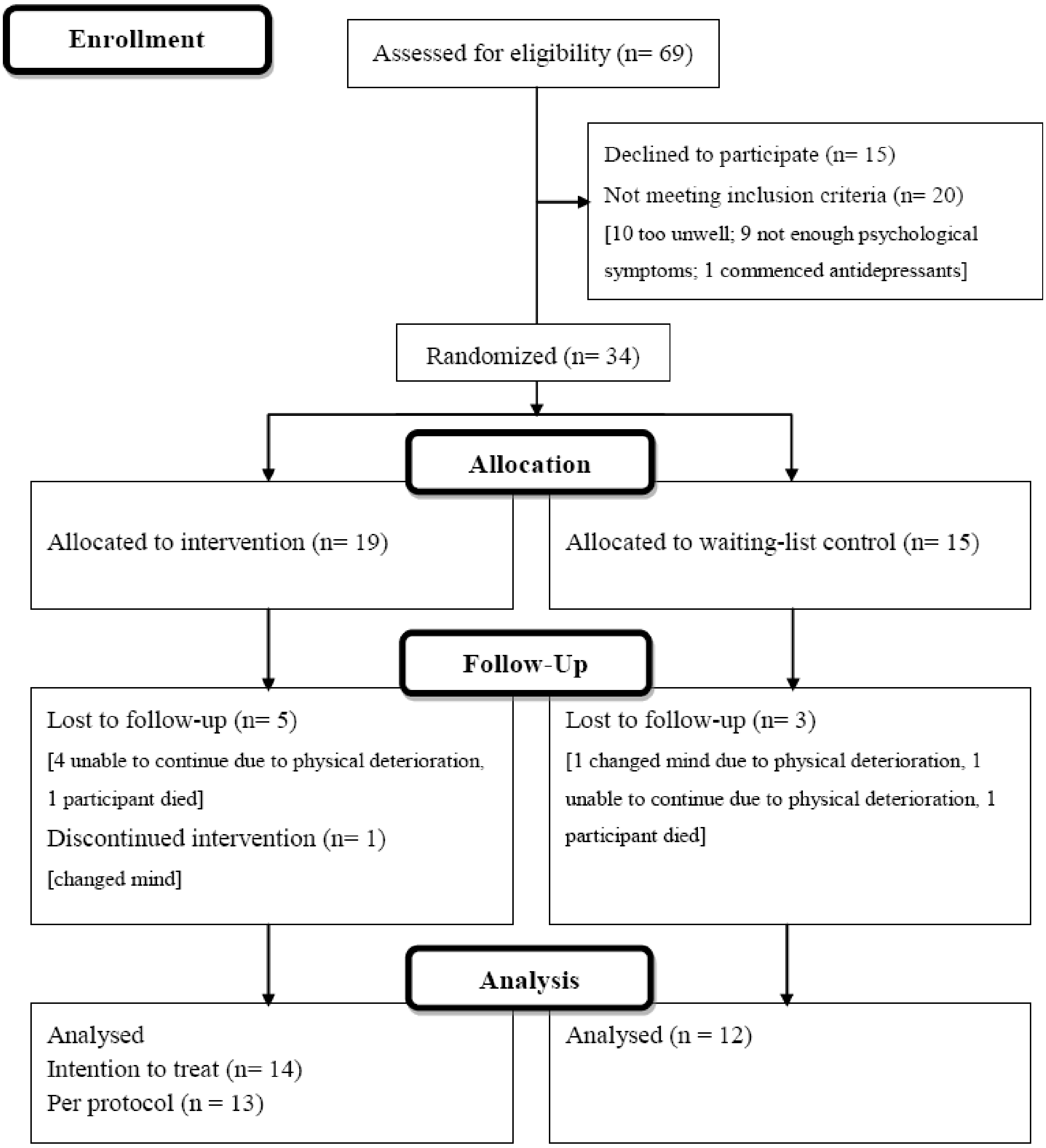

Figure 5.1. Participant flow chart following Consolidated Standards of Reporting Trials guidelines.

Participants

As reported in Figure 5.1, from July 2009 to August 2010, 69 potential participants were referred to the study. Fifteen people declined to take part and 20 were ineligible to take part due to physical frailty or lack of psychological symptoms. Of the 34 participants successfully screened, 19 were randomized to the treatment group and 15 to the control group (see Table 5.2 for characteristics of each group). There was no significant difference in baseline characteristics between the treatment and control groups. 76.5% (n = 26) of participants met the inclusion criteria for both anxiety and depression, 20.6 % (n = 7) met the inclusion criteria for anxiety only, and 2.9% (n = 1) met the inclusion criteria for depression only. During the trial, 5 of the treatment group and 3 controls were lost to follow-up and did not complete the 4 week period of intervention/waiting. The only significant difference between completers and non-completers was that non-completers reported significantly lower baseline anxious symptoms (as measured on GAD) than completers, $F(1,32) = 4.79$, $p = .036$. Of the 8 participants lost to follow up, 5 withdrew because they were physically unable to continue, 2 died and one changed her mind and withdrew because she felt less well.

Table 5.2. Characteristics of participants randomized to treatment and waiting-list control conditions

Characteristic	Treatment[a]		Control[b]	
Mean age	67.32 years (SD = 11.60, Range 49-87)		62.67 years (*SD* = 11. 86, Range 49-86)	
Gender	9 men	10 women	6 men	9 women
Cancer diagnosis	18		13	
Non-cancer diagnosis	1 MND		1 MND	1 COPD
Current antidepressants	5		4	
Living alone	4		3	
Educated to at least Further/Higher education	9		7	

Note: [a]*n = 19,* [b]*n = 15. MND = Motor Neurone Disease; COPD = Chronic Obstructive Pulmonary Disease.*

Interventions

CT guided self-help

The intervention involved an initial 30-min face-to-face session with the researcher to explain and practise the training, followed by 10-min practice daily for 4 weeks. The researcher followed a set intervention script that took participants through a guided visualisation of a specific memory in which they had been completely absorbed. Participants used a range of memories including dancing, decorating, boat trips, and cross-stitch (See Chapter 4 for full description of guided self-help intervention).

The intervention had 5 stages (See Appendix D for intervention script). In Stage 1, the researcher introduced the intervention's rationale in terms of reducing worry and rumination. In Stage 2, participants identified an appropriate memory for the visualisation that was detailed, absorbing, and specific in terms of person, place, and time. In Stage 3, the researcher ascertained if participants were absorbed in the memory. The researcher asked questions checking that a) the memory was detailed; b) participants' attention and focus were directly in the scene and/or activity; c) the memory did not involve evaluative thinking or having a running commentary; d) participants were absorbed (e.g., sense of flow, loss of sense of time, feeling absorbed, calm, and positive). In Stage 4, the researcher gave feedback to participants identifying aspects of the memory that participants found absorbing and highlighted the positive response participants had reported. In Stage 5, the researcher and participants made action plans detailing how participants would use the visualisation as part of their daily routine. This included planning how participants would identify and undertake more absorbing activities, building on the practised example.

At the end of the session, participants received a digital recording of the exercise to practise each day and a booklet explaining the training. The researcher telephoned participants at weekly intervals. The telephone sessions were an opportunity for the researcher to address any issues participants had experienced with the training. At the end of 4 weeks of training, participants were interviewed about their experiences with the intervention.

Materials

To minimise participant burden, short standardised and well-validated self-report questionnaires were administered at the initial meeting with the researcher (Time 1) and again 4 weeks later corresponding to the intended treatment duration (Time 2).

The Beck Depression Inventory-Fast Screen (Beck et al., 1997) is a 7-item measure of common symptoms of depression distinct from symptoms of physical illness with sensitivity of .82, specificity of .82 and good internal consistency (α= .86). The Generalised Anxiety Disorder-7 (GAD-7; Spitzer et al., 2006) is a 7-item measure of anxiety with sensitivity of .89 and specificity of .82 (Spitzer et al., 2006; Kroenke et al., 2007). The GAD-7 has 2 items specifically focussed on worry (Not being able to stop or control worrying; Worrying too much about different things) and 5 items reflecting general anxiety (Spitzer et al., 2006). The World Health Organisation Quality of Life – Short Version (WHOQOL-BREF) (Skevington, Lofty, & O'Connell, 2004) is a well-validated and standardised 26-item self-report measure of well-being, with internal consistency of α = .68-.82. It consists of two separate questions on overall quality of life and satisfaction with health, with further subscales assessing physical, psychological, social and environmental well-being.

Analysis

Since there were no previous studies examining CT guided self-help in palliative care, we estimated treatment effects from trials of CT guided self-help for dysphoria (Watkins et al., 2009; Watkins et al., submitted) which found a Cohen's d =1.3 between CT and waiting list control. Assuming a reduced effect size of d =1 in palliative care, 18 participants per condition are required for a power of 0.9 at $p < .05$. In this preliminary exploration of the efficacy of CT in palliative care we therefore sought to recruit 36 participants. Analyses of covariance (ANCOVA) were performed using the Statistical Package for the Social Sciences (SPSS, version 15.0). A series of one way ANCOVAs were conducted to examine any effect of the treatment condition on self-reported symptoms of psychological distress and quality of life. Measures of psychological distress and quality of life at Time 2 were the dependent variables, treatment condition was the between-subject independent variable, and measures of psychological distress and quality of life at Time 1 were covariates. To examine if the intervention reduced unhelpful worry, the sub-scores for GAD-7 'worry' and 'anxious' items were also analysed (See Table 5.4 for means, standard deviations and 95% confidence intervals). Analyses were performed according to the principle of intention to treat (ITT, i.e., all patients randomized). A secondary 'per protocol treatment' (PP) analysis was conducted for all patients who completed the intervention as set out in the protocol: a minimum of at least 4 days practice of the intervention for 2 of the 4 weeks and at least one telephone follow-up session over the four weeks. One participant who changed their mind after being randomized to the treatment condition and didn't practise at all was removed for the PP analysis.

As data was missing from 8 patient withdrawals, disregarding those patients without data could potentially bias the results and effect trial conclusions. To address this, we calculated both a case completer analysis and a last observation carried forward (LOCF) analysis, in which participants' initial questionnaire data at Time 1 was carried forward to Time 2. LOCF assumes no change in symptoms over time, which given that palliative patients are likely to deteriorate over time, provides a conservative estimate of change i.e., it assumes that the waiting-list control group (or treatment as usual) has a positive impact on psychological symptoms. There was no difference in results between the complete case and LOCF analyses, and, thus, we only report the former.

Results

Anxiety

ANCOVAs revealed that after controlling for Time 1 anxiety, there was a significant effect of treatment condition on Time 2 anxiety for both ITT, $F(1,23) = 20.55, p < .001$, *partial* $\eta^2 = .47$, and PP analyses, $F(1,22) = 28.72, p < .001$, *partial* $\eta^2 =$

.57, indicating that patients receiving the treatment reported lower anxious symptoms than patients in the waiting-list control condition (see Table 5.3). The significant effect was found for both the GAD-7 ‘worry’ items (ITT, $F(1,23) = 6.86$, $p = .015$, *partial* $\eta^2 = .23$; PP, $F(1,22) = 8.27$, $p = 0.009$, *partial* $\eta^2 = .27$), providing a successful manipulation check that the self-help treatment reduced unhelpful repetitive thought, and for the GAD-7 ‘anxious’ items (ITT, $F(1,23) = 23.55$, $p < .001$, *partial* $\eta^2 = .51$; PP, $F(1,22) = 31.23$, $p < .001$, *partial* $\eta^2 = .59$).

Depression

ANCOVAs revealed that after controlling for Time 1 depression, there was no significant effect of training condition on Time 2 depression, for both ITT and PP analyses, all Fs ≤ 2.91, all $p \geq .10$, *partial* $\eta^2 \leq .12$.

Quality of Life

ANCOVAs revealed that after controlling for Time 1 quality of life, there was no significant effect of training condition on Time 2 quality of life for any of the WHOQOL-BREF subscales, for both ITT and PP analyses, all Fs ≤ 2.49, all $p \geq .10$, *partial* $\eta^2 \leq .10$.

Table 5.3. Means [and 95% Confidence Intervals] for psychological distress and quality of life measures in treatment and control conditions at Time 1 and Time 2 (SD in parentheses)

	Treatment[a]		Control[b]	
Measure	M(SD)	95% CI	M(SD)	95% CI
T1 GAD-7	13.50(4.77)	[10.80, 16.20]	10.00(5.03)	[7.09, 12.91]
T2 GAD-7	6.07(3.87)	[3.43, 8.71]	11.25(5.68)	[8.40, 14.10]
T1 BDI	7.29(4.23)	[5.32, 9.25]	5.83(2.55)	[3.71, 7.96]
T2 BDI	5.00(4.06)	[3.09, 6.91]	5.25(2.60)	[3.19, 7.32]
T1 Overall QOL	3.21(1.05)	[2.59, 3.84]	3.00(1.21)	[2.33, 3.67]
T2 Overall QOL	3.14(1.17)	[2.54, 3.74]	3.33(.99)	[2.69, 3.98]
T1 Health satisfaction	2.00(.88)	[1.38, 2.62]	2.33(1.37)	[1.66, 3.01]
T2 Health satisfaction	2.36(1.15)	[1.76, 2.95]	2.08(1.00)	[1.44, 2.73]
T1 Physical QOL	44.29(20.42)	[33.46, 55.12]	42.17(18.66)	[30.47, 53.87]
T2 Physical QOL	45.36(21.97)	[33.40, 57.32]	40.83(21.35)	[27.91, 53.75]
T1 Psychological QOL	46.86(18.56)	[36.50, 57.22]	53.67(19.03)	[42.48, 64.86]
T2 Psychological QOL	52.29(22.43)	[41.33, 63.24]	52.17(16.31)	[40.34, 64.00]
T1 Social QOL	58.93(22.66)	[47.86, 69.99]	68.83(16.46)	[56.88, 80.78]
T2 Social QOL	67.36(17.23)	[56.86, 77.85]	70.83(20.95)	[59.50, 82.17]
T1 Environmental QOL	72.00(12.18)	[65.18, 78.83]	76.75(12.59)	[69.38, 84.12]
T2 Environmental QOL	78.71(10.19)	[72.78, 84.65]	78.33(11.40)	[71.92, 84.75]

Note: [a]n = 14, [b]n = 12. *BDI = Beck Depression Inventory – Fast screen (Scores 0-21). GAD-7 = Generalised Anxiety Disorder-7 scale (Scores 0-21). Overall QOL = WHOQOL-BREF Question 1 (Scores 1-5). Health = WHOQOL-BREF Question 2 (Scores 1-5). Physical QOL = WHOQOL-BREF Transformed Physical Domain (Scores 0-100). Psychological QOL = WHOQOL-BREF Transformed Psychological Domain (Scores 0-100).Social QOL = WHOQOL-BREF Transformed Social Domain (Scores 0-100). Environmental QOL = WHOQOL-BREF Transformed Environmental Domain (Scores 0-100)*

Discussion

The results are consistent with the prediction that a CT guided self-help intervention will reduce anxious symptoms in palliative patients compared with waiting-list controls. However the findings were not consistent with the prediction that the intervention would significantly reduce depressive symptoms or improve quality of life relative to waiting-list controls. Thus, results indicate that CT guided self-help has efficacy in reducing one major dimension of psychological distress (anxiety) but not another (depression).

These preliminary findings suggest that CT guided self-help may be a feasible intervention in palliative care that was acceptable to patients and efficacious for reducing anxiety. Thus, brief self-help interventions involving practising a simple cognitive strategy may have scope to increase accessibility of psychological help into palliative care settings.

There are a number of possible explanations for the finding that CT guided self-help reduced anxiety but not depression relative to waiting-list controls. First, the intervention may be more effective for anxiety than depression. Second, the measure of anxiety (GAD-7) may have been more sensitive to treatment change than the measure of depression (BDI-FS). Related to this, elevated anxiety was more prevalent than elevated depression in the current sample, such that there may be more scope to detect reductions in anxiety. Moreover, the significant reduction in GAD-7 ‘worry’ items indicated the intervention reduced unhelpful repetitive thought, but the effect was also maintained for the ‘anxious’ items alone so the main effect was not simply due to the ‘worry’ items alone. Third, paralleling other results (Moorey et al., 2009), depression reduced across both conditions indicating that any improvement may have been due to beneficial effects of palliative care support or regression to the mean. Fourth, any potential impact of the intervention on quality of life may have been masked by worsening of physical symptoms and/or ongoing patient frailty. Fifth, the sample may have been too small to detect an effect on depression or quality of life. Importantly, this pattern is consistent with other palliative care research, which found that patients receiving care from CBT-trained nurses reported lower anxiety over time, but no effect of the training was found for depression or other symptom measures (Moorey et al., 2009).

The current study demonstrated that it is possible to conduct a RCT, albeit over a brief treatment period, in palliative care, although it also indicated the difficulties of recruiting and retaining palliative patients in trials. The deteriorating physical health and fatigue of patients can prevent them from entering a trial and contribute to attrition from the trial. Hospice staff may have also been concerned about burdening patients with the research. In addition, there may be particular difficulties in recruiting palliative patients experiencing psychological distress. First, palliative care professionals report reluctance and lack of expertise in assessing patient psychological distress (Lloyd-Williams & Payne, 2002; Little et al., 2005). Second, patients and health professionals may believe that psychological distress is a normal feature of the dying process. This can lead to a failure to differentiate distress from clinical depression (Block, 2000). Third, due to stigma associated with psychiatric illness (Lloyd-Williams & Payne, 2002), patients can be reluctant to disclose (Lloyd-Williams, Spiller, & Ward, 2003). Fourth, healthcare professionals might avoid exploring psychological distress because of work pressures and concerns that they will cause further distress (Block, 2000).

This study has limitations. First, the sample size was relatively small, reflecting the difficult nature of recruiting and retaining palliative patients into research studies for any length of time. Second, a significant proportion of referred patients (15/69) declined to enter the study and a significant proportion of referred patients were ineligible

(20/69) because of either insufficient psychological distress or increased physical frailty. We therefore cannot generalize the findings of the intervention to all palliative care patients but can only apply the findings to this particular subset, raising questions as to the wider applicability and clinical utility of the intervention. Third, there was a relatively high level of drop-out from the CT self-help group (26%), which has implications for the feasibility of the intervention, although this attrition reflects deteriorating physical health and fatigue of patients since a similar rate was found in the treatment-as-usual condition. Moreover, recruitment and retention was comparable to other palliative care research in that a) 50.7% of referrals to the study either declined or were ineligible to take part compared with 42% (Anderson et al., 2008) and 64% (Moorey et al., 2009); b) 23.5% of participants were lost to follow up primarily due to deterioration of their condition, which is similar to other studies (21%, Anderson et al., 2008; 42%, Moorey et al., 2009; 26%, Miller et al., 2005). Fourth, common to all studies involving voluntary participation, there was potential for self-selection of participants, potentially reducing generalisability. Fifth, in the absence of an attention control condition, the study was not able to test the construct validity of the intervention to ascertain if the observed effect of the intervention was due to the absorption intervention specifically or to non-specific therapeutic factors such as contact with a supportive therapist during the guided self-help. The goal of the study was to test the internal validity of the intervention (i.e., does CT have better outcomes than waiting list?), for which an attention control condition is not necessary. Future studies would usefully determine the mechanism underpinning treatment benefit by comparing the CT guided self-help with an attention control condition to determine if treatment gains were due to the specific content of the CT or due to non-specific effects such as contact with a caring therapist.

This study has advanced knowledge by developing and evaluating a brief guided self-help intervention in palliative care. These preliminary findings suggest that a brief guided self-help intervention is acceptable, feasible, and effective in addressing anxiety in palliative patients. Implications for research include replicating the study with a larger sample and multiple researchers delivering the intervention to further validate the findings. Furthermore an investigation into the mechanism of such interventions (e.g., does it make participants think more concretely?) and into the longer terms effects of such treatments would be helpful. The intervention could also be evaluated for caregivers of palliative patients who also experience elevated rumination on abstract concerns (Galfin et al., 2010; Galfin & Watkins, in press). A further step in evaluating the effectiveness of this approach is the development and evaluation of a training programme to teach palliative care staff to deliver the intervention. Such training could facilitate implementation of the intervention in clinical practice and examine its potential for being widely used in palliative care. These results have considerable implications for clinical practice, assuming that the beneficial effect is replicated. CT guided self-help potentially provides a widely accessible and easily disseminated brief intervention to help palliative care patients manage their distress.

Supplementary Material: Further details, investigations and analyses

Recruitment

To address the difficulties associated with recruiting palliative care patients for the trial, a number of strategies were utilised (See Appendix G). First, to try to raise and maintain awareness of the research, the researcher held regular meetings with hospice staff, sent out monthly email updates, and wrote an article for the hospice newsletter. Second, to clarify the process of recruitment for staff, a flowchart of the recruitment process was prepared and circulated to staff in a variety of formats including colour posters and laminated bookmarks for their work diaries. The researcher also spent a substantial amount of time shadowing hospice staff, so that the recruitment process and criteria could be directly related to patients that were seen by the staff member and researcher together. Third, to expand the population from which patients could be referred, the study was extended to Somerset and another hospice. Fourth, a competition was launched for the staff member referring the most patients to the study.

Abstractness interview

In this study, the hypothesis that abstract rumination will lead to psychological distress in palliative care patients and their caregivers (*Hypothesis 10*), translated into the prediction that the CT guided self-help intervention will make palliative care patients think more concretely than a waiting-list control group. To test this prediction, participants' abstractness was coded from interviews with the researcher. Participants were asked open-ended questions to assess the key concerns about which they ruminated at the initial meeting with the researcher (Time 1) and again 4 weeks later corresponding to the intended treatment duration (Time 2). In order to code for abstractness, transcripts were coded using the same methodology described in Chapter

3. The index scores calculated from the two judges' ratings were highly correlated, $r = .88$, $p < .05$.

Supplementary Results

Abstractness

Consistent with the hypothesis that abstract rumination will lead to psychological distress in palliative care patients, as predicted, ANCOVAs revealed that after controlling for Time 1 abstractness, there was a significant effect of treatment condition on Time 2 abstractness, $F(1,21) = 5.22$, $p = .033$, *partial* $\eta^2 = 0.20$. This pattern of results (See Table 5.4) reflected the patients receiving the self-help treatment becoming less abstract in their description of their concerns than patients in the waiting-list control condition.

Table 5.4. Means [and 95% Confidence Intervals] for abstractness measures in treatment and control conditions at Time 1 and Time 2 (SD in parentheses)

	Treatment[a]		Control[b]	
Measure	M(SD)	95% CI	M(SD)	95% CI
T1 abstractness	2.47(.21)	[2.36,2.59]	2.40(.19)	[2.28,2.52]
T2 abstractness	2.13(.27)	[1.94,2.30]	2.41(.34)	[2.22,2.61]

Note: [a]n = 13, [b]n = 11.

Mediational analysis

The rationale for the CT guided self-help intervention predicts that reduced abstractness (or increased concreteness) mediates the effects of treatment condition on the psychological distress reported by participants. In accordance with the steps set out by Baron and Kenny (1986), separate regression equations were used to test the criteria for mediation. First, change in abstractness was regressed to treatment condition; second, change in anxiety was regressed to treatment condition; and third, change in anxiety was regressed to both treatment condition and change in abstractness. These three regression equations provide the tests of the linkages of the mediational model. To establish mediation, the following conditions must hold: First, the independent variable (treatment condition) must affect the mediator (change in abstractness) in the first equation; second, the independent variable (treatment condition) must be shown to affect the dependent variable (change in anxiety) in the second equation; and third, the mediator (change in abstractness) must affect the dependent variable (change in anxiety) in the third equation. If these conditions all hold in the predicted direction, then the effect of the independent variable (treatment condition) on the dependent variable (change in anxiety) must be less in the third equation than in the second. Perfect mediation holds if the independent variable has no effect when the mediator is controlled.

The standardized residual or change scores of abstractness and anxiety (as the aspect of psychological distress that improved with use of the intervention) were calculated by regressing Time 1 abstractness/anxiety to Time 2 abstractness/anxiety. Since a residual is the difference between an observed value and its fitted value, residuals represent any variation in the dependent variable that is not explained by the independent variables in the model. Change in abstractness was significantly associated with change in self-reported anxiety on GAD-7 (adj $R^2 = .32$, $\beta =.51$, $t = 2.96$, $p = .007$), but did not remain so when treatment condition was entered into the regression equation (adj $R^2 = .61$, $\beta =.22$, $t = 1.46$, $p = .16$).

To further explore the potentially mediating effect of abstractness on the therapeutic benefit of the intervention, the analyses were repeated with the separate subscales of the GAD-7, i.e., GAD-worry and GAD-anxiety. Changes in abstractness were significantly associated with both changes in GAD-worry (adj $R^2 = .16$, $\beta = .45$, $t = 2.35$, $p = .028$) ($r = .46$, $p = .025$) and changes in GAD-anxiety (adj $R^2 = .34$, $\beta = .51$, $t = 3.04$, $p = .006$) ($r = .55$, $p = .005$). When treatment condition was entered into the regression equation, changes in abstractness did not remain significantly associated with changes in GAD-worry (adj $R^2 = .27$, $\beta = .25$, $t = 1.21$, $p = .24$), or GAD-anxiety (adj $R^2 = .64$, $\beta = .23$, $t = 1.64$, $p = .12$). When change in abstractness was entered into the regression equation, treatment condition remained a significant predictor of GAD-anxiety ($\beta = -.66$, $t = -4.30$, $p < .001$), but was no longer a significant predictor of GAD-worry ($\beta = -.44$, $t = -2.07$, $p = .052$). Thus, these analyses indicate that a change in abstractness may partially mediate changes in worry, but not changes in anxiety generally.

Further discussion on mechanism of the treatment effect

The results were consistent with the prediction that a CT guided self-help intervention would make participants more concrete in their construal than waiting-list controls. Hence the results support the hypothesis that abstract rumination causally influences anxiety in palliative care patients. Moreover, using Baron and Kenny's (1986) criteria for mediation, change in abstractness was found to be a partial mediator of the effects of treatment condition on reduction in worry. This finding is consistent with the proposed mechanism of action of the CT guided self-help intervention. However, more recent criteria propose that one also needs to demonstrate that there is change in the mediator before there is change in the outcome variable (Kraemer, Wilson, Fairburn, and Agras, 2002). Without this, one cannot rule out the possibility of backward causality in which change in the mediator (abstractness) is a consequence of treatment outcome (reduced anxiety) rather than a contributor to that outcome. The current study assessed abstractness and worry concurrently, so we cannot rule out the possibility that change in worry led to change in abstractness. Nonetheless, the current finding is a necessary step in determining whether change in abstractness mediates the effect of the CT guided self-help intervention – a failure to satisfy Baron and Kenny's (1986) criteria would clearly have argued against this.

In summary, the study has advanced knowledge by developing and evaluating a brief guided self-help intervention in palliative care. These preliminary findings suggest that a brief guided self-help intervention is acceptable, feasible, and effective in addressing anxiety in palliative patients. Furthermore, the findings raise the possibility that the intervention makes palliative care patients more concrete in their construal and that more concrete construal are associated with reduced worry and problematic repetitive thought.

CHAPTER 6: AN EVALUATION OF A TRAINING PROGRAMME TO TEACH A BRIEF GUIDED SELF-HELP INTERVENTION TO HOSPICE STAFF.

This chapter reports a cluster randomized controlled study evaluating a training programme designed to teach hospice staff how to deliver a brief guided self-help intervention developed for use with palliative care patients. The key elements of the study are reported in the following article:

Galfin, J. M., Watkins, E. R., & Harlow, T. (2011) An evaluation of a training programme to teach a brief guided self-help psychological intervention to hospice staff. *International Journal of Palliative Nursing, 17,* 119-124.

The article provides the substantive part of the chapter but because of the limited word count of the article, it will be preceded and followed with further discussion of the training programme and the implications of the study.

As a GWR research project joint funded by Hospiscare, one of the key objectives of this research is to develop and evaluate accessible psychological interventions suitable for Hospiscare staff to use with clients. Therefore any treatments should be straightforward enough to learn so that current Hospice staff would require minimal extra training to deliver the intervention as part of their routine practice.

In preparing to design the training intervention required to teach Hospice staff how to deliver the CT guided self-help, it was important to review the literature pertinent to training psychological therapies. More specifically, the review includes research evaluating different types of training (Brief workshops and extended programmes), different outcomes of training (impact on trainees and/or trainees' patient outcomes), and evaluating training that had been specifically provided to palliative care staff. In addition, although the focus of the review is on guided self-help training, much of the limited literature on brief training of therapeutic approaches has been concentrated within CBT.

Expanded literature review

There is a growing body of research evaluating brief training programmes, particularly those that are focussed on methods associated with Cognitive Behavioural Therapy (CBT). Training methods examined include brief workshops (½ to 3 days), extended courses, and the presence or absence of ongoing supervision of casework. The outcome of training has been assessed using self-report of confidence and competence, tests of therapeutic knowledge, evaluation of therapy skills from direct observation or role-plays, and examining patient outcomes.

Brief workshop-based training

Research suggests that providing brief workshops alone has limited value in disseminating a complex therapy like CBT. King et al. (2002) randomly allocated 84 general practitioners into clusters to either attend four weekly half-day workshops on cognitive behavioural therapy or to a control condition where they were offered the training at the end of the trial. King et al. (2002) found doctors' knowledge of depression and attitudes towards its treatment showed no major difference between the intervention and control groups after 6 months. Furthermore, the training had no discernible impact on patients' outcomes as measured by the Beck Depression Inventory and the State Trait Anxiety Inventory over the 6 months of the trial.

In a review of 17 studies evaluating workshop training for substance abuse, Walters, Matson, Baer, and Ziedonis (2005) found that in general, training improved attendees' knowledge, attitudes, and confidence in working with clients who have substance abuse problems. Some skill improvements, when measured, were seen immediately after training, but were less often maintained over a longer time. Extended contact, through follow-up consultation, supervision, or feedback, appeared necessary for the long-term adoption of skills.

Extended training programmes

The evidence regarding the effect of longer training programmes on trainees is limited because it largely consists of uncontrolled or non-randomized designs. In one of the few controlled studies evaluating the effect of longer training on trainees, Sholomskas et al. (2005) assigned 78 community-based clinicians to 1 of 3 training conditions: review of a CBT manual only, review of the manual plus access to a CBT training Web site, or review of the manual plus a didactic seminar followed by supervised casework. The primary outcome measure was the clinicians' ability to demonstrate key CBT interventions, as assessed by independent ratings of structured role plays. Assessments were completed at baseline, 4 weeks after baseline (e.g., after exposure to the Web site or didactic training for clinicians assigned to those conditions), and 3 months after post-training assessment (i.e., after completion of supervision for clinicians assigned to the seminar plus supervision condition). Statistically significant differences favouring the seminar plus supervision over the manual only condition were found for adherence and skill ratings for 2 of the 3 role plays, with intermediate scores for the Web condition. This study had a number of limitations. First it was not possible to randomize all clinicians because several of the participants could not attend the scheduled training seminars and others had limited computer skills or inadequate computer access. Second although little change appeared to be associated with the manual only condition, the study did not include a no-manual control condition. Third these findings reflect effects of training on clinicians who volunteered to participate in an evaluation of training strategies, and it is not known whether these findings generalize to other, possibly less motivated, groups of clinicians or to other types of treatment.

In an uncontrolled evaluation of six days of training in basic cognitive-behavioural formulation and intervention techniques delivered to 30 homelessness workers (15 of whom received six months of fortnightly clinical supervision), the only significant effect of the training and supervision was on reducing burnout as measured on Maslach's burnout inventory (Maguire, Grellier, & Clayton, in press). An uncontrolled longitudinal evaluation of 40 one-hour sessions of CBT training for psychiatric nurses, occupational therapists, psychiatric trainees and social workers by Newton and Yardley (2007), also found significantly improved participant's self-reported knowledge and confidence in implementing CBT for symptoms of psychosis, depression, and anxiety. However, due to lack of a control comparison, it is unclear if this result was due to expectancy and demand effects. Milne, Baker, Blackburn, James, and Reichelt (1999) evaluated a 40-day training programme in cognitive therapy (CT) delivered to 20 mental health professionals. The evaluation focussed on changes in the professionals' competence and its generalization to their patients' coping strategies, utilising direct observations and self-report instruments before, during and after training (for the CT trainees) and therapy (for the patients). Results indicated that a 40-day training programme led to significantly higher post-training competence scores and to improved patient coping.

There is also some evidence that therapist competence can affect patient outcome. A small number of studies have examined the direct effect of training on trainees' patient outcomes using a variety of methods. In a small uncontrolled study, Westbrook, Sedgwick-Taylor, Bennett-Levy, Butler, and McManus (2008) evaluated a

CBT training course consisting of 10 weekly sessions for 24 primary care staff with no prior experience of CBT. Each of the weekly sessions included both formal training in CBT and clinical supervision. Audio recordings of clinical sessions carried out within the 4 weeks after the end of the course (post-training) were compared with audiotapes of sessions carried out in the first 2 weeks of training (pre-training) to assess clinical skills. Results indicated that post-training recordings were rated significantly higher than pre-training recordings on both trainee- and assessor-rated measures of CBT skills (Cognitive Therapy Self-Rating Scale and Cognitive Therapy Scale CTS respectively). Clinical outcomes were evaluated by obtaining patient assessments from electronic clinical records. Pre- and post-treatment assessments of 23 patients who had completed treatment before the first day of the course were compared with 78 assessments of patients who commenced treatment after the last day of the course. Results indicated that patients treated after training reported significantly greater reductions in their symptoms than patients treated before training. This pattern of results suggests that the training influenced clinician skills and their effectiveness in routine clinical practice. However, there are a number of limitations to this study. First, there was not a non-trained control group, which is necessary to rule out potential threats to the internal validity of the training (e.g., observer effect, passage of time, or cohort effects). Second, the first tape submission for CTS ratings was often up delayed by up to 4 weeks into the course, rather than being rated at the start of the course. Third, raters of the therapy tapes were not blind as to whether the tapes were from the pre or post training time period.

Training palliative care staff

In a controlled study, Mannix et al., (2006) evaluated training CBT techniques to 20 palliative care practitioners. Palliative care nurses were randomised to the equivalent of 12 days training plus either 3 months or 9 months skills-building supervision. CBT skills competency was assessed from audio-recordings of clinical sessions at baseline, after 3 months and after 9 months. Although the CBT skills of all nurses increased from baseline to final follow-up, the group receiving 9-months supervision showed significantly greater improvement than the group receiving 3 months, continuing to improve over the later 6 months, whereas the group with only 3 months supervision showed a decline in competency over this period.

In a further controlled study, Moorey et al., (2009) evaluated a 10-day training course on CBT techniques (similar to the training used by Mannix et al., 2006). Moorey et al (2009) randomly allocated eight palliative care nurses to receive CBT training and seven to continue practice as usual. To assess impact on clinical outcomes, 45 palliative care patients treated by the CBT-trained nurses and 35 patients receiving care from the practice as usual group, completed a series of questionnaires at baseline and then at 6, 10 and 16 week intervals. Results indicated that patients receiving care from CBT-trained nurses reported a significantly greater reduction in anxiety as measured on HADS relative to patients treated by nurses who did not receive training, although no effect of the training was found for depression. However, there were a number of potential methodological limitations. First, the researchers were unable to randomize the patients to either receive CBT or treatment as usual, so there was potential for nurses to be biased in their selection of which treatment patients received. Second, there was potential for contamination of knowledge and skills as CBT-trained nurses were working in the same teams alongside nurses allocated to the no-training control condition. This would mean that non-trained nurses may learn through working with trained nurses. Moreover, whilst nurses had their own caseloads, their patients may have been visited by other nurses during their leave or out of hours. Third it is unclear how much CBT the patients received from the CBT-trained nurses as part of their care.

Therefore there is a range of evidence that training practitioners in brief CBT techniques may have an impact on the practitioners' skills, confidence, competence, and patient outcomes. However, the evidence does vary in quality with many studies having methodological limitations, e.g., a lack of control group or randomisation. In palliative care, findings indicate that a brief workshop based training programme on CBT can have a positive effect on not only trainees' confidence and competence, but also on patient outcomes in the form of self-reported anxiety.

There is also evidence that non-specialists can be trained to deliver psychological therapy in mental health. For example, Behavioural Activation has been demonstrated as being effective when delivered by generic mental health workers without previous experience as therapists in a phase 2 randomised controlled trial (Ekers, Richards, McMillan, Bland, & Gilbody, 2011). Generic mental health workers received 12 1-hour sessions of training over a 3 month period. There is also evidence that when compared with high intensity CBT (characterised by considerable therapist input, akin to traditional therapy models), low intensity CBT (emphasis on patient self management with less contact time between mental health workers and patients e.g., using guided self-help) can have a similar impact on depression (Gellaty, Bower, Hennessey, Richards, Gilbody, & Lovell, 2007), though low-intensity CBT is generally less effective and more variably effective for anxiety disorders (Hirai & Clum, 2006). Moreover, there is evidence that the delivery of low-intensity self-help programmes can be trained in a much briefer workshop format (Westbrook et al, 2008).

Given the evidence that a brief workshop-based training programme (lasting 10 days) can be effective for training CBT skills to palliative care staff, and the wider evidence that generic health workers can be effectively trained to deliver CBT and behavioural activation, a brief workshop-based training programme was designed to train hospice staff how to deliver the CT guided self-help intervention. Moreover, in accordance with Hospiscare's aim to develop an intervention that could be disseminated to clinical staff within current resources, the training needed to be as brief as practicable. Furthermore, CT guided self-help was explicitly designed to require minimal training to deliver, and is relatively simple and straightforward requiring clinicians to follow a set script with few decision points (unlike CBT). In consultation with a palliative care lecturer and the originator of concreteness training, a brief workshop-based training programme lasting one and a half days was developed that reflected the researcher's training in delivering the intervention for the case series and trial.

This chapter presents the fifth study of this thesis that tested the following hypothesis:

Hypothesis 12. A brief workshop-based training programme teaching palliative care staff how to deliver CT guided self-help will have a beneficial influence on trainees' confidence and competence and their patient outcomes.

Within the confines of this cluster randomized controlled design, this hypothesis translates into the following predictions:

Prediction 6.1. Patients of nurses attending a brief workshop-based training programme (training team) will report greater reductions in psychological distress, as assessed on routine clinical instruments, when compared with patients of nurses awaiting training (waiting-list control team);

Prediction 6.2. The training team will report increased confidence and competence in addressing patient dwelling and rumination, compared to the waiting-list control team.

Research Article (Published in International Journal of Palliative Nursing):

Galfin, J. M., Watkins, E. R., & Harlow, T. (2011) An evaluation of a training programme to teach a brief guided self-help psychological intervention to hospice staff. *International Journal of Palliative Nursing, 17,* 119-124.

Abstract

Background: A recent trial demonstrated that a brief guided self-help technique reduces anxiety in palliative care patients. This study investigated whether training palliative care nurses in this intervention would improve their routine management of psychological distress.

Methods: A randomized controlled cluster trial compared a team of nurses attending a training programme (n = 5) with a team allocated to a no-training waiting-list control condition (n = 5), on self-reported behaviour and confidence in addressing psychological distress. Ratings of psychological distress at routine clinical assessments from all patients assessed twice at least 28 days apart were examined pre-training and post-training to assess the impact of training on patient distress.

Results: As predicted, the trained team demonstrated significantly reduced patient distress post-training, relative to the untrained team. There was no significant difference in self-reported behaviour, and confidence.

Conclusion: These findings suggest that a brief workshop-based training programme improves clinical outcomes on psychological distress, and may be a means to increase the accessibility of effective psychological interventions in palliative care.

Introduction

Whilst palliative patients experience elevated psychological distress (Durkin et al., 2002; Greenberg et al., 2004; Wilson et al., 2004; Wilson et al., 2007; Herbaut et al., 2003; Reeve et al., 2007; Galfin et al., 2010), there is a lack of access to psychologists and psychiatrists in hospices (Price et al., 2006). Moreover, even though palliative care can positively impact on physical symptoms and quality of life (Strömgren et al., 2006), its direct effect on psychological symptoms has yet to be confirmed (González et al., 2002). Thus, efficacious psychological interventions that can be disseminated to and effectively delivered by existing palliative care staff are a priority. Whilst research has evaluated the efficacy of psychological interventions in palliative care (Anderson et al., 2008; Moorey et al., 2009; Liossi & White, 2001; Miller et al., 2005; Ramsay et al., 2007; Horne-Thompson & Grocke, 2008; Galfin, Watkins & Harlow, in press), few controlled studies have evaluated the effectiveness of training palliative care staff to deliver psychological treatments (Moorey et al., 2009, Mannix et al., 2006). Therefore, there is a need to know whether such training can be effective and in what forms (Westbrook et al., 2008).

Several studies have evaluated the effect of training programmes, particularly for Cognitive Behavioural Therapy (CBT). Training methods examined include brief workshops (King et al., 2002; Walters et al., 2005), extended courses (Newton & Yardley, 2007; Milne et al., 1999), and ongoing supervision of casework (Maguire et al., in press; Sholomskas et al., 2005). The outcome of training has been assessed using self-reported confidence and competence (Westbrook et al., 2008), tests of therapeutic knowledge (King et al., 2002), evaluation of therapy skills from direct observation or role-plays (Sholomskas et al., 2005), and examining patient outcomes (Westbrook et al., 2008). In general, research suggests that providing brief workshops alone has limited value in disseminating a complex therapy like CBT, with little long-term maintenance of skills (Westbrook et al., 2008; Walters et al., 2005), and that adding ongoing supervision may produce better clinical skills and patient outcomes. However, the research is mainly limited to uncontrolled or non-randomized designs.

Two controlled studies have explicitly examined CBT training in palliative care. After attending an initial training programme equivalent to 12 days' teaching, Mannix et al. (2006) randomised 20 palliative care nurses to 3 months versus 9 months skills-building supervision. CBT skills competency was assessed from audio-recordings of clinical sessions at baseline, after 3 months and after 9 months. Although the CBT skills of all nurses increased from baseline to final follow-up, the group receiving 9-months supervision showed significantly greater improvement than the group receiving 3 months, continuing to improve over the later 6 months, whereas the group with only 3 months supervision showed a decline in competency over this period.

Moorey et al. (2009) evaluated the impact of nurses receiving a 10-day training course on CBT techniques on the clinical outcomes of their palliative patients. Patients receiving care from CBT-trained nurses reported a significantly greater reduction in anxiety relative to patients treated by nurses who did not receive training, although no effect of the training was found for depression. However, the researchers were unable to randomize the patients to either receive CBT or treatment as usual, so there was potential for nurses to be biased in their treatment allocation. Further, there was potential for treatment contamination as CBT-trained nurses worked in the same teams alongside nurses allocated to the no-training control condition. Finally, it is unclear how much CBT the patients received from the CBT-trained nurses as part of their care. Nonetheless, these studies suggest that palliative care nurses can be trained to utilise

CBT techniques, with this training leading to improvements in psychological distress in palliative patients.

These training programmes have focused on palliative care staff learning to deliver a complex therapy like CBT. An alternative method to disseminate psychological interventions in palliative care is to teach nurses simpler, specific techniques to foster their awareness and repertoire in dealing with psychological distress. A recent pilot randomized controlled trial (Galfin et al., in press) indicated that a brief guided self-help intervention focusing on increasing absorption in positive events reduced anxiety in palliative patients relative to a waiting-list control condition. Training in such an intervention could enhance palliative care nurses skills and repertoire for dealing with psychological distress. Therefore, this study examined whether training nurses in the guided self-help strategy would reduce patient psychological distress. A workshop format was chosen because: (a) the intervention was explicitly designed to require minimal training to deliver, and is relatively simple and straightforward requiring clinicians to follow a set script with few decision points (unlike CBT); (b) brief training would be deliverable within the resources available in palliative care.

This study tested the following hypotheses: (a) patients of nurses attending a brief workshop-based training programme (trained team) will report greater reductions in psychological distress, assessed on routine clinical instruments, relative to patients of nurses awaiting training (waiting-list control team); (b) the trained team will report increased confidence in addressing psychological distress compared to the waiting-list control team.

Methods

Design

A cluster randomised controlled study design compared two palliative care nursing teams within a community palliative care service consisting of 10 teams organized into 5 geographical clusters. Both teams had a team-level approach to patient care, where nurses visited and assessed each other's patients, rather than an individual case worker approach. Therefore, the impact of training on team-level clinical outcomes, rather than on individual outcomes, was assessed. To reduce the likelihood of contamination of learning from the trained team to the waiting-list control team, the selected teams were geographically separate and did not visit each other's patients, whilst also being matched for palliative care experience and caseload.

Procedure

The teams were independently randomized using a computer programme to the trained condition or to the waiting list control condition. To identify if the training programme influenced the teams' impact on their patients' psychological distress, relevant data was assembled from 'Crosscare' electronic clinical records (Advanced Heath & Care) twice (*baseline, post-routine-care*) during 2 separate 8-week time periods occurring *pre-training* and *post-training* respectively. To assess the impact of training on self-reported behaviour and confidence a series of face valid questions were administered at the start of the first day of training (Time 1), immediately after the half-day follow up (Time 2) and 2 months after training (Time 3).

Nurse Teams

The trained team consisted of 5 women and the waiting-list control team consisted of 4 women and 1 man. The teams had equivalent palliative care experience and similar caseloads (trained team, mean experience of 12.80 years, SD = 4.3, 158 patients; waiting-list control team, mean experience of 14.20 years, SD = 5.02, 152 patients).

Absorption Guided Self-help Intervention

The intervention involves patients learning to engage in a guided visualisation of a specific positive absorbing memory. In doing so, the intervention trains patients to think more concretely about their concerns, instead of ruminating on them, a known risk factor for psychological distress (Watkins, 2008). The intervention involves asking patients about personal concerns that are worrying them. The intervention consists of an initial face-to-face session, after which patients are given a digital recording of the exercise to practise daily and a booklet explaining the intervention.

The face-to-face session involves the nurse taking the patient through a guided visualisation of a specific absorbing memory. Having introduced the intervention’s rationale in terms of reducing rumination and worry, the nurse helps the patient identify an appropriate memory for the visualisation that is detailed, absorbing, and specific. During the visualisation, the nurse checks the patient is absorbed in the memory. After the visualisation, the nurse provides feedback to the patient identifying the absorbing aspects of the memory and highlighting the positive response that the patient has reported. Finally, the nurse helps the patient make a detailed concrete action plan for how the patient will use the visualisation as part of their daily routine and engage in absorbing activities (Galfin et al., in press). Thus, the intervention engages the nurse in identifying and discussing psychological distress with the patient, focusing on positive experiences, closely attending to the content of thoughts, and planning useful behaviours, which could benefit patients both in the context of the delivery of the intervention and through nurses using these skills more generically.

Training Programme

The training programme consisted of one full-day workshop followed by a half-day workshop 4 weeks later. The initial workshop consisted of (a) a session explaining the rationale and the stages of the intervention through a didactic lecture; (b) an interactive role-play demonstration of the intervention; (c) the nurses practising the intervention in repeated role-plays both as nurse and as patient. The role-plays were observed by the researcher, who completed a checklist assessing participants' proficiency at each of the five stages of the intervention: (i) introducing the rationale; (ii) identifying an appropriate memory; (iii) ascertaining if the patient is absorbed; (iv) giving feedback; (v) formulating an action plan (See Appendix I for checklist). The follow-up half-day was intended to provide nurses the opportunity to reflect on and discuss their experience of practising the intervention in the 4 weeks since the initial workshop (See Appendix J for full programme).

Materials

A series of face valid questions assessed nurses' behaviours and attitudes with regards to psychological care (See Appendix K for full set of questions). Behaviour was assessed by questions that asked nurses about the patient visits they had conducted in the previous week. Of the patients seen in the previous week, nurses were asked how many had been assessed for psychological distress, and the frequency of different strategies used to improve psychological wellbeing (including advising on medication, supportive listening, teaching a coping strategy and/or referral to GP or other therapy). Nurse's confidence in assessing and managing patient psychological distress was assessed by summing ratings scored 1 (not at all) to 5 (completely) on two items (e.g., "How confident are you in your initial management of the psychological concerns of your patients?").

Psychological Outcomes: caseload

As part of routine clinical assessments, nurses rate each patient on four psychological symptoms (low mood, anxiety, fear, anger) at each contact on a scale of 0 = none; 1 = mild; 2 = moderate and 3 = severe. We summed these scores to generate a total personal distress score for each patient at each assessment (range 0 to 12). To assess the impact of routine clinical care on patient distress, within each time period, data was assembled for all patients clinically assessed at least twice in an 8-week period, where the assessments were at least 28 days apart, and the total personal distress score ≥2 at the first assessment (first assessment labelled baseline, second assessment labelled post-routine-care). This search strategy yielded the following eligible patients from the relevant caseloads: pre-training, trained team, n = 20, waiting-list control team, n = 50; post-training, trained team, n = 18, waiting-list control team, n = 59. This data compilation strategy ensured that we only examined the effect of routine care on patients with a meaningful level of psychological distress and enabled us to examine change in psychological symptoms across the caseload at both pre-training and post-training periods, and thereby examine the impact of each team's routine care on patient improvement pre and post-training. Twenty-eight days was selected as the minimum time frame between assessments because this is a reasonable time for any intervention initiated by the nursing team to influence psychological distress. This strategy means that we assessed the impact of the team's care on psychological distress across their caseload for all participants within each time period. Importantly, it was not necessarily the same patients assembled in the pre-training and post-training periods.

Analysis

Repeated measures Analyses of Variance (ANOVAs) were conducted separately pre-training and post-training to examine the effect of the training condition (Trained team vs. Waiting-list control team) and time of testing (baseline vs. post-routine-care) on personal distress reported within each teams' caseload (see Table 6.1). Repeated measures ANOVAs examined the effect of condition and time (Time 1, Time 2, Time 3) on nurses' self-reported behaviour and confidence (see Table 6.2). All analyses were performed using the Statistical Package for the Social Sciences (SPSS, version 15.0).

Results

Psychological Outcomes: caseload

Pre-training distress: In the pre-training time period, there was no difference between conditions in baseline personal distress, $F(1,68) = .09, p = .76, r = .04$. The repeated measures ANOVA found a significant main effect of time on personal distress, reflecting a reduction in distress over time for both conditions, $F(1,68) = 9.43, p = .003, r = .35$. Importantly, there was no significant interaction of training condition with time, $F(1,68) = 1.87, p = .18, r = .16$, indicating that there was no difference in the clinical impact on distress of routine care between the conditions at pre-training.

Post-training distress: In the post-training time period, there was no difference between conditions in baseline personal distress, $F(1, 75) = .14, p = .71, r = .04$. The repeated measures ANOVA found a significant main effect of time on personal distress, $F(1,75) = 23.98, p < .001, r = .49$, which was secondary to a significant interaction of training condition by time, $F(1,75) = 4.76, p = .032, r = .24$. As predicted, this interaction reflected a greater reduction in distress from baseline to post-routine-care for the caseload of the trained team relative to the waiting list control team.

Table 6.1. Means [and 95% Confidence Intervals] for personal distress of patients receiving care from trained and waiting-list control teams pre- and post-training (SD in parentheses)

	Pre-training		Post-training	
Measure	Trained [a]	Control [b]	Trained [c]	Control [d]
Baseline personal distress	3.55(1.47)	3.42(1.66)	3.33(1.46)	3.49(1.61)
	[2.89,4.21]	[2.96,3.88]	[2.63,4.03]	[3.07,3.91]
Post-routine care distress	2.30(2.08)	2.94(1.68)	1.39(2.12)	2.75(1.93)
	[1.35,3.25]	[2.43,3.45]	[0.39,2.39]	[2.28,3.22]

Note: [a] *n = 20,* [b] *n = 50,* [c] *n =18,* [d] *n = 59. Personal distress = anxiety (scored 0-3) + low mood (scored 0-3) + fear (scored 0-3) + anger (scored 0-3).*

Participant behaviour and confidence

There was no significant difference in self-reported behaviour and confidence across the teams at Time 1, although there were trends for the trained team to report addressing more physical concerns ($F(1, 8) = 4.98, p = .06$) and having more confidence than the control team ($F(1, 8) = 4.90$, $p = .06$) (all other $F \leq .88$, all $p \geq .38$). Both teams reported relatively high levels of confidence at Time 1 (all ≥ 6.20 out of 10).

The repeated measures ANOVA found that there were no significant main effects or interactions on self-reported behaviour and confidence. There were trends for an interaction of condition by time on percentage of visits addressing physical concerns, $F(2, 16) = 3.27$, $p = .07$, and teaching coping strategies, $F(2, 16) = 2.67$, $p = .10$, reflecting the trained team addressing fewer physical concerns and teaching more coping strategies over time relative to the waiting-list control team (all other $F \leq 1.00$, all $p \geq .39$). Only one of the trained team reported using the guided self-help with a patient.

Table 6.2. Proportion of cases where self-reported behaviour is used and confidence measures in trained and waiting-list control teams at each assessment (SD in parentheses)

Question	Pre-training (Time 1)		Post-training (Time 2)		2 months post-training (Time 3)	
	Trained [a]	Control [b]	Trained	Control	Trained	Control
% ask psy.	79.3(21.7)	76.2(25.0)	68.9(29.2)	69.2(25.3)	71.9(31.0)	67.5(26.3)
% physical	100(0.0)	84.3(15.7)	87.3(25.0)	96.5(7.8)	91.4(19.2)	89.2(11.8)
% social	46.9(28.8)	55.1(27.1)	59.1(31.4)	64.4(22.4)	43.2(24.3)	53.2(20.7)
% exist.	51.9(31.5)	46.5(25.0)	41.7(47.1)	68.0(28.0)	43.8(27.9)	46.9(14.9)
% med. adv.	27.7(32.8)	45.0(42.4)	23.5(17.8)	50.0(43.0)	33.0(21.6)	53.3(31.1)
% ref. GP	20.2(13.8)	13.9(11.7)	23.5(13.3)	15.2(18.2)	24.4(20.7)	18.0(12.4)
% ref. ther.	11.5(11.40)	7.8(6.3)	8.2(7.9)	6.4(7.3)	10.7(3.7)	15.1(15.8)
% listening	89.3(15.4)	84.0(35.8)	90.0(22.4)	100(0.0)	88.4(20.2)	90.1(10.8)
% strategy	11.4(11.9)	20.1(16.9)	7.4(7.8)	16.0(25.5)	13.5(10.2)	6.9(8.9)
Confidence	7.6 (0.9)	6.2(1.1)	7.6(0.9)	6.6(0.6)	8.0(0.0)	6.8(1.1)

Note: [a] *n = 5,* [b] *n = 5. % ask psy. = % of patients visited in last week asked about psychological wellbeing; % physical = % of patients visited in last week nurse addressed physical concerns; % social = % of patients visited in last week nurse addressed social concerns; % exist. = % of patients visited in last week nurse addressed existential concerns; % med. adv. = % of patients visited in last week nurse advised changes in their medication; % ref. GP = % of patients visited in last week nurse referred to GP; % ref. ther.= % of patients visited in last week nurse referred to specific therapy;% listening = % of patients visited in last week nurse used supportive listening; % strategy = % of patients visited in last week nurse taught coping strategy; Confidence = nurse confidence in assessing and managing psychological distress.*

Discussion

The findings are consistent with the hypothesis that a brief workshop-based training programme in guided self-help will improve the impact of routine clinical care on psychological distress within a palliative care team's caseload, relative to no training. However, findings were not consistent with the prediction that nurses attending the training will report increased confidence in addressing patients' distress relative to waiting-list controls. These preliminary findings raise the possibility that a brief workshop-based training programme has scope to enhance palliative care nurses' ability to reduce psychological distress within their caseload.

Several hypotheses could account for the greater impact of routine care on psychological distress for the trained team relative to the control team post-training. Hypothesis One proposes that training increased nurse's confidence in addressing psychological distress. Hypothesis Two proposes that the trained nurses successfully used the guided self-help intervention with their patients. Hypothesis Three proposes that training increased nurses' awareness and recognition of the psychological issues faced by their patients. Hypothesis Four proposes that training led the nurses to use more psychological coping strategies with their patients. Hypothesis Five proposes that training improved nurse's generic skills when addressing psychological issues, such as the ability to elicit and explore concerns, or to encourage a focus on positive experiences. The evidence is inconsistent with Hypothesis One: the trained nurses did not report an increase in confidence relative to the control nurses. However, it is possible that the assessment of confidence was not sensitive to detect change, especially given the high pre-training levels of confidence. The evidence is also inconsistent with Hypothesis Two: the analyses did not include patients who received the self-help intervention. This is important because it means that participating in the training programme was not a proxy for increased delivery of the intervention. There was a trend to suggest that training in coping strategies increased in the trained team, consistent with Hypothesis Four. However, proper evaluation of Hypotheses Three, Four and Five requires direct observation of nurses' clinical practice (e.g., listening to audio-recordings of interactions with patients).

An alternative explanation for the positive impact of training is that attending the training increased nurses' expectations of having a positive impact on their patients' distress, and thereby, influenced their ratings of patient's distress. However, ratings were made on different patients by different nurses at different times making it unlikely that there could have been a systematic rating bias. Moreover any such bias should influence both baseline and post-routine care ratings, especially as nurses were unaware of the procedure for assembling study data and thus could not have pre-guessed which assessments would be relevant.

The absence of a significant impact on nurses' self-reported behaviour and confidence may be due to a number of reasons. First, the sample size was small requiring a large effect size to find a significant difference. Second, the nurses were all experienced nurse specialists who reported themselves as confident in addressing psychological issues prior to training, such that there may be a ceiling effect for these ratings. Third, only one of the trained team delivered the intervention in practice. The lack of implementation of the intervention may have reflected the random allocation of teams to the training programme. As the nurses were not self-selected for training there were different degrees of engagement and motivation towards the training. Furthermore, the training programme coincided with major changes in working practice in the hospice and therefore may have been a low priority for nurses. The lack of implementation of the intervention may also reflect the need to further refine the training programme. Refinements to improve motivation and engagement with the training could include more direct supervision (Sholomskas et al., 2005) to increase implementation of the technique into practice. Furthermore the time period between the full day and half-day could be extended to allow more time for nurses to practise the intervention.

The study has limitations. First, it had a small sample size with only 5 nurses in each team, although this translated into a reasonable sample size for case-load. Second, the questions used to assess behaviour and confidence may have lacked sensitivity to detect changes. An alternative approach would have been to assess therapy skills through observation.

In summary, the findings indicate that brief training can potentially influence the impact of routine nurse contacts on psychological distress in palliative care. Thus, these findings indicate the potential value of brief workshop-based training as a cost-effective means to disseminate useful psychological treatment approaches into palliative care.

Further analyses

As the sample sizes for distress data were different at each time point and the distress data was not normally distributed at each of the 4 assessment points according to the Shapiro-Wilk test (all $W < .92$, all $p < .01$), there was a possibility that the sample would not meet assumptions necessary for ANOVA. Therefore two alternative approaches were used to check the robustness of the reported findings of this study. First, ANOVAs for repeated measurements were completed using equivalent sample sizes across conditions, by selecting patients from the waiting-list control team caseload that matched the patients from the training team caseload for pre- and post-training baseline personal distress, age, diagnosis, gender and time between assessments (see Table 6.3.). Second, non parametric analyses were used: the Mann-Whitney test was used to compare personal distress across the training conditions (training versus waiting-list control) at each assessment point.

Matched samples.

In the pre-training period, the 20 patients seen by the trained team, consisted of 12 women and 8 men, with 18 of them having a diagnosis of cancer. The 20 matched patients from the caseload of the control team consisted of 10 men and 10 women, with 16 of them having a diagnosis of cancer. In the post training period, the 18 patients seen by the trained team, consisted of 14 women and 4 men, with 16 of them having a diagnosis of cancer. The 18 matched patients from the caseload of the control team consisted of 4 men and 14 women, with 17 of them having a diagnosis of cancer (See Table 6.3 for further information).

Table 6.3. Means [and 95% Confidence Intervals] for baseline characteristics and psychological distress in training and control conditions pre- and post-training used for matched sample parametric analysis (SD in parentheses)

	Pre-training [a]		Post-training [b]	
Measure	Training	Control	Training	Control
Patient age	73.55(13.13) [68.22,78.88]	71.50(10.24) [66.17,76.83]	70.67(13.77) [65.17,76.16]	70.83(8.56) [65.34,76.33]
Days between assessments	35.10(5.59) [32.42,37.78]	34.75(6.22) [32.07,37.43]	33.67(4.68) [31.32,36.01]	33.11(5.10) [30.77,35.46]
Baseline personal distress	3.55(1.47) [2.89,4.21]	3.60(1.57) [2.91,4.23]	3.33(1.46) [2.63,4.03]	3.33(1.46) [2.63,4.03]
Post-treatment personal distress	2.30(2.08) [1.47,3.13]	2.45(1.54) [1.62,3.28]	1.39(2.12) [0.38,2.40]	3.06(2.10) [2.05,4.07]

Note: [a] *Training and control n's = 20,* [b] *Training and control n's =18. Personal distress = anxiety (scored 0-3) + low mood (scored 0-3) + fear (scored 0-3) + anger (scored 0-3).*

Pre-training period. In the pre-training time period, a repeated measures ANOVA revealed no significant effect of training condition on the baseline personal distress reported by the respective patient sample, $F(1,38) = .05$, $p = .82$, $r = .04$ (See Table 6.3). Across both conditions, there was a significant effect of time on personal distress, indicating that patients on both teams' caseloads were reporting less distress over time, $F(1,38) = 16.30$, $p < .001$, $r = .55$. However, there was no significant interaction of training condition with time $F(1,38) = .03$, $p = .87$, $r = .03$, indicating that whilst patients appeared to be reporting less distress across both conditions over time, there was no difference in that reduction between the conditions pre-training.

Post-training period. In the time period after training, repeated measures ANOVA revealed no significant effect of training condition on personal distress at baseline, indicating that patients' personal distress did not differ across conditions, $F(1, 34) = 2.71$, $p = .11$, $r = .27$. Across both conditions, there was a significant effect of time on personal distress, reflecting that patients on both teams' caseloads were reporting less distress over time, $F(1,34) = 11.4$, $p = .002$, $r = .50$. Furthermore there was also a significant interaction of training condition with time, indicating that patients on the caseload of the training team reported a greater reduction in distress over time after training, than patients on the caseload of the waiting-list control team, $F(1,34) = 6.41$, $p = .016$, $r = .40$.

Non-parametric analysis

Pre-training period. During the pre-training period, personal distress did not differ significantly between the training team and waiting-list controls either at baseline, U = 459, $z = -.55$, $p = .58$, r = -.066, or following at least 4 weeks treatment from the nurse team (post-treatment), U = 406, $z = -1.25$, $p = .21$, r = -.15 (see Table 6.4). Across both conditions, personal distress was significantly lower at post-treatment (*Mdn* = 2) than at baseline (*Mdn* = 3), $z = -2.57$, $p = .01$, r = -.22, suggesting that contact with the teams was beneficial for patients. However, whilst there was not a significant reduction in personal distress from baseline to post-treatment across the caseload in the waiting-list control team, z = -1.29, $p = .20$, r = -.13, there was a significant reduction in the training team, $z = -2.67$, $p = .008$, r = -.42.

Table 6.4. Median psychological distress in training and control conditions pre- and post-training used for non-parametric analysis

	Pre-training		Post-training	
Measure	Training [a]	Control [b]	Training [c]	Control [d]
Baseline personal distress	3.5	3.0	3.0	3.0
Post-treatment personal distress	2.0	2.5	1.0	2.0

Note: [a] *n = 20,* [b] *n = 50,* [c] *n =18,* [d] *n = 59. Personal distress = anxiety (scored 0-3) + low mood (scored 0-3) + fear (scored 0-3) + anger (scored 0-3).*

Post-training period. During the post-training period, there was not a significant difference in personal distress at baseline between the training team and waiting-list controls, U = 515, $z = -.20$, $p = .84$, r = -.023. However, at post-treatment, personal distress was significantly lower in the training team relative to waiting-list controls, U = 273.5, $z = -3.15$, $p = .002$, r = -.36. Across both conditions, personal distress was significantly lower post-treatment (*Mdn* = 2) than at baseline (*Mdn* = 3), $z = -3.87$, $p < .001$, r = -.31. There was a significant reduction in personal distress from baseline to post-treatment across the caseload in both the training team $z = -2.81$, $p = .005$, r = -.47, and the waiting-list control team, $z = -2.57$, $p = .01$, r = -.24.

In summary the findings from both the matched sample parametric and non-parametric analyses are consistent with the results of the ANOVA analysis of the raw data. Hence it would appear that the findings of the study are robust to the different sample sizes used in this study.

Further discussion

Further limitations of the study

A further limitation of the study was that the nurses' own assessments of patient distress were used as an outcome measure, rather than an independent assessment, such as a validated observer scored measure of anxiety or depression for example. Furthermore, there was potential for bias in the way in which assessments of patient psychological distress were gathered. If one sample contained mostly the same patients in the pre and post training time periods, whilst the other sample contained mostly different patients in each time period then this difference could account for some of the differences in outcomes reported. However, when reviewing the samples, most of the patients in both teams' samples were unique to each time period, i.e., training team: 18 patients only appeared in the pre training time period, 16 patients only appeared in the post training time period, and 2 patients appeared in both time periods; control team: 36 patients only appeared in the pre training time period, 45 patients only appeared in the post training time period, and 14 patients appeared in both time periods.

Treatment effect

Given the lack of implementation of the CT guided self-help intervention, the most beneficial effects of the training on patient outcomes are unlikely to be due to the intervention. Instead, it is hypothesized that the means by which the training improved patient outcomes is by increasing the awareness of the nurses attending the training in a number of ways. First, the training may have raised nurses' awareness of the signs and symptoms of psychological distress, and hence led to increased recognition of the psychological issues faced by their patients. Second, the training improved nurse's generic skills when addressing psychological issues. This may have been through identifying appropriate questions to use to elicit and explore concerns, or as is the case with the CT guided self-help, to encourage a focus on positive experiences.

Lack of implementation of the intervention

There are a number of hypotheses that could explain why the nurses attending the training did not use the intervention in their daily practice. First, the nursing teams were matched for experience and caseload. However, the teams were not matched for referrals they had made to the previous trial of the CT guided self-help (trained team 9 referrals, waiting-list control team 16 referrals), which may have reflected different levels of engagement with the research. Second, as recruitment for the trial was continuing at the time of the training, the findings of the research were not yet available. The lack of evidence of efficacy of the intervention from either the trial or through seeing many of their patients experience the intervention may have also led to the trained team's lack of implementation of the intervention in practice. Third, the nurses were preoccupied with a number of service redevelopments at the time of the training including changes in how they worked as palliative care nurse specialists. Fourth, due to the selection of teams that were geographically separate, we may have recruited the more confident teams of nurses such that they didn't need feel a need to extend their skills in this area. Fifth, Hospiscare's review of services indicated a lack of staff confidence in addressing psychological issues, but the review was based in part on anonymous feedback. However, the training involved such small groups of nurses that the questionnaires may not have been perceived as anonymous, so leading to systematic differences in how confident the nurses reported themselves to be. Finally, the lack of implementation may have been associated with a lack of formal supervision as part of the training, which has been highlighted in other studies as an important factor in improving skills and adherence (Mannix et al., 2006; Sholomskas et al., 2005).

There are a number of strategies that could be employed to increase implementation of the intervention in future training. First, nurses could discover the need for the intervention by asking their patients about worry and rumination in advance of the training. In doing so the nurses would also identify potential patients to practise with after the training. Second, nurses could be shown the benefits of the intervention, through providing final results of the trial and asking the nurses to practise the CT guided self-help themselves. Third, nurses could be self-selected for the training, ensuring that the nurses attending want to learn about the intervention. Fourth, more formal supervision could be added to the training to support the nurses develop their skills and confidence in delivering the intervention.

CHAPTER 7: GENERAL DISCUSSION

Overview

As reviewed in Chapter 1, there is convergent evidence that both palliative care patients and their caregivers experience psychological difficulties including (a) studies of depression and anxiety in palliative care; (b) the concerns expressed by palliative care patients and their caregivers. However, there are a number of limitations with this evidence. First, there is a little research that reveals the frequency and nature of psychological distress in carers of palliative care patients. Second, the studies are generally qualitative in nature based on interviews of small samples of participants. Third, the quantitative studies that have used questionnaire designs have not used control groups to establish that elevated distress is specific to the palliative care groups. Therefore, the first objective of the thesis was to explore the nature of psychological distress in palliative care.

A key gap in the evidence concerns the role of rumination in the experience of palliative care patients and their caregivers. Whilst the review highlighted theoretical rationales and indirect empirical evidence in support of its role, there was no research specifically addressing this question. Therefore another objective of the thesis was to explore the role of rumination in the psychological distress experienced by palliative care patients and their caregivers.

As a GWR research project joint funded by Hospiscare, the main objective of this research was to examine the nature of psychological distress in palliative care, with the specific purpose of developing and evaluating accessible psychological interventions suitable for Hospiscare staff to use with clients. Therefore the intervention was required to not be excessively burdensome for palliative care patients to use, whilst also being straightforward enough to learn so that current Hospice staff would require minimal extra training to deliver the intervention as part of their routine practice. In order to achieve this objective, the PhD examined whether or not rumination was present and associated with psychological distress in palliative care. The PhD research programme then used those findings to develop and evaluate a self-help psychological treatment that was acceptable to palliative care patients and simple enough to be deliverable by existing Hospiscare staff. In order to facilitate access to the intervention, the PhD also developed and evaluated a concise teaching programme for palliative care staff to support the use of such interventions with patients.

Study 1 (Chapter 2) examined psychological distress and rumination using a cross-sectional design, comparing samples of palliative care patients, their caregivers and an age-matched control group. Study 2 (Chapter 3) utilised the same design and samples to further examine the relationship between uncertainty, abstractness and rumination in palliative care. The results from Study 1 and Study 2 provided an opportunity to clarify the potential role of rumination in psychological distress in palliative care. Study 3 (Chapter 4) reported a case series piloting an intervention developed from concreteness training designed to address abstract rumination in palliative care. The case series indicated that with some modification to the identification and screening of patients, the treatment could be acceptable and feasible for palliative care patients because no participants found the treatment unacceptable or considered that it made them worse. Study 4 (Chapter 5) examined the effectiveness of the CT guided self-help intervention in a randomized controlled trial. Moreover, Study 4 also examined the potential role of abstractness as a mediator of the effects of the intervention on self-reported symptoms of psychological distress in palliative care patients. Study 5 (Chapter 6) utilised a cluster randomized controlled design to evaluate a training programme designed to teach hospice staff how to deliver this brief guided self-help intervention developed for use with palliative care patients. More specifically, Study 5 examined the effects of the training on trainees' confidence and competence and their patient outcomes. Table 7.1 summarises the findings of the studies in relation to each of the hypotheses generated by the thesis.

Table 7.1. Summary of hypotheses and findings

Prediction/Hypothesis	Findings
Hypothesis 1. Palliative care patients and their caregivers will report higher levels of psychological distress than matched controls.	*Study 1.* Palliative care patients and their caregivers reported significantly more psychological distress than age-matched controls.
Hypothesis 2. Palliative care patients and their caregivers will report more existential concerns than matched controls.	*Study 1.* Palliative care patients and their caregivers reported significantly more rumination on existential concerns (e.g., about the future) than age-matched controls.
Hypothesis 3. The psychological distress of palliative care patients and their caregivers will be associated with their perception of their physical, social and existential concerns and with their quality of life.	*Study 1.* The frequency of existential concerns and measures of rumination reported by participants were associated with increased anxiety and depression. *Study 1.* Palliative care patients and carers reported worse quality of life than age-matched controls. Reduced quality of life was associated with anxiety, depression and rumination.

Hypothesis 4. Palliative care patients and their caregivers will experience more rumination than matched controls.	*Study 1.* Palliative care patients and carers reported more distress caused by rumination than age-matched controls. Carers reported more hard to control rumination than controls. However, no main effect of group was found for the RSQ-Brooding measured rumination, frequency, or duration of rumination.
Hypothesis 5. Rumination is a causal process in the development and maintenance of depression and anxiety in palliative care patients and their caregivers.	*Study 1.* Both generic and idiosyncratic measures of rumination were associated with elevated anxiety and depression [such correlational evidence is consistent with the hypothesis but is not sufficient to confirm it]. *Note: See Hypothesis 10 for evidence of causal relationship from Study 4.*
Hypothesis 6. Emotion-focused coping will be more frequent in palliative care patients and their caregivers than in matched controls.	*Study 1.* Palliative care patients and carers reported using more emotion-focused strategies than age-matched controls.
Hypothesis 7. Problem-focussed coping will be more adaptive than emotion-focussed coping for palliative care patients and their caregivers.	*Study 1.* Increased problem-focused coping was associated with reduced depression [such correlational evidence is consistent with the hypothesis but is not sufficient to confirm it].
Hypothesis 8. Palliative care patients and their caregivers will experience more uncertainty and be more abstract in their construal than matched controls.	*Study 2.* Palliative patients and their caregivers reported more abstract thinking and uncertainty than age-matched controls.

Hypothesis 9. The uncertainty experienced by palliative care patients and their caregivers will be associated with abstractness, and this abstractness will lead to rumination.	*Study 2.* Increased uncertainty was associated with increased abstractness, and increased abstractness was associated with increased rumination.
Hypothesis 10. Abstract rumination is a causal process in the development and maintenance of depression and anxiety in palliative care patients and their caregivers.	*Study 2.*Increased abstractness and rumination were associated with increased anxiety and depression. *Study 4.*Palliative care patients receiving CT guided self-help reported less abstractness and anxiety than waiting-list controls. Change in abstractness was found to be a partial mediator of the effects of the treatment condition on reduction in worry.
Hypothesis 11. A brief CT guided self-help intervention will reduce symptoms of anxiety and depression and improve quality of life in palliative patients compared with waiting-list controls.	*Study 4.* Palliative care patients receiving CT guided self-help reported less anxiety than waiting-list controls. However no significant effect of the intervention was found for depression or psychological quality of life.
Hypothesis 12. A brief workshop-based training programme teaching palliative care staff how to deliver CT guided self-help will have a beneficial influence on trainees' confidence and competence and their patient outcomes.	*Study 5.* There was a more positive impact of routine care on patient distress for nurses attending training, when compared to nurses not attending the training. However, nurses attending the training did not report increased confidence or changed behaviour in addressing patients' distress relative to waiting-list controls.

Summary and implications of main findings

This PhD made an attempt to build on the existing research in understanding psychological distress in palliative care and to also examine whether rumination was a potentially relevant psychological process that could be addressed in palliative care. The main findings will be presented in a way that broadly reflects the section headings in the Chapter 1 review: a) Understanding psychological distress in palliative care; b) Assessment and treatment of psychological distress in palliative care; c) Rumination and psychological distress in palliative care. Furthermore, a final section will explore the implications arising from the limitations of this research.

Understanding psychological distress in palliative care

Building on a range of studies using questionnaires in palliative care patients and their caregivers, this research programme compared the levels of psychological distress reported by palliative care patients and carers with a control comparison group. However, the research programme did not evaluate the levels of adjustments disorders in the palliative care sample, which may have accounted for some of the distress reported. The elevated anxiety and depression reported in Study 1 were consistent with other findings indicating elevated symptoms of anxiety and depression in palliative care patients and carers (See Chapter 1, sections 2.1.2 and 2.2.3 for review).

Study 1 also extended the findings of De Faye et al. (2006), who examined the concerns and coping strategies reported by palliative care patients and how those concerns and coping strategies related to depression (as measured on BDI – Fast screen). More specifically, Study 1 built on De Faye et al. (2006) by comparing palliative care patients with age-matched controls and carers of palliative patients. Study 1 also added assessments of rumination and measures of anxiety. Consistent with De

Faye et al. (2006) and others (See Chapter 1 sections 2.1.5 and 2.1.6; and Chapter 2 additional literature review) the findings indicated that palliative care patients and their caregivers reported elevated existential concerns (particular focussed on the uncertainty associated with their future) and used more emotion-focussed coping strategies. This is consistent with Lazarus and Folkman (1984) 'goodness-of-fit' hypothesis, such that when a situation is perceived as being too threatening or it cannot be altered (as is the case with a terminal diagnosis), then the individual will try to mediate the feelings associated with the situation by utilising an emotion-focused coping strategy. The results of Study 1 also highlighted the potential importance of addressing existential concerns (as previously proposed by Saunders, 1988), as the frequency of existential concerns was associated with increased psychological distress. Furthermore, the results raised the possibility that a problem-focused approach may be helpful in palliative care, as problem-focused coping was associated with reduced depression.

Study 1 also built on other research indicating an association between psychological distress and reduced quality of life in palliative patients (Berlim et al., 2006; Peters & Sellick, 2006; Smith et al., 2003; Wilson et al., 2007), by adding samples of carers and matched controls. Consistent with other findings, Study 1 found that palliative care patients and their caregivers experience worse overall quality of life and more specifically psychological quality of life than an age-matched control group. Moreover, worse quality of life correlated with increased psychological distress.

Assessment and treatment of psychological distress in palliative care

This research fulfilled a key aim of developing and evaluating a psychological intervention for use with palliative care patients, in line with the requirements of the funding for the PhD. A key issue raised in the initial review of the literature was the importance of assessment of psychological distress in palliative care. Not only was the need for improved assessment highlighted in Hospiscare's review of their services (2007), but the research also revealed a number of barriers to assessment of psychological distress in palliative care (See Chapter 1, section 2.3.1). First, patients and health professionals may believe that psychological distress is a normal feature of the dying process. This can lead to a failure to differentiate distress from clinical depression (Block, 2000). Second, patients can be reluctant to disclose (Lloyd-Williams et al., 2003). Third, healthcare professionals might avoid exploring extreme distress and low mood because of work pressures and concerns that they will cause further distress (Block, 2000). Fourth, stigma might also be associated with psychiatric illness for patients and professional carers (Lloyd-Williams & Payne, 2002). Moreover, early identification of psychological distress in palliative care gives clinicians a variety of options to address any psychological distress that is identified including both pharmaceutical and non-pharmaceutical means (See Chapter 1 section 2.3.4). The intervention developed as part of this PhD was specifically designed to facilitate discussions between clinical staff and patients about the patients' psychological concerns. These discussions would enable palliative care patients to have their psychological concerns assessed more frequently, to aid early identification and treatment of anxiety and depression.

A specific issue raised in Study 3 in relation to patient assessment was the potential effect that the physical deterioration of the participants could have on their outcomes with the psychological intervention. Specifically, it was hypothesized that physical deterioration would interfere with the benefits of the psychological intervention. However, this hypothesis was not specifically tested in this research programme. A key issue in identifying the potential effect of physical deterioration on psychological outcomes would be to identify an appropriate measure for the assessment of the physical status of palliative care patients (e.g., Karnofsky performance status; Glare & Christakis, 2005). The physical quality of life scores obtained in Study 4 did not support this hypothesis as there was no significant change of physical quality of life either across the whole sample or in the individual conditions. Furthermore, there was no significant interaction between treatment condition and change in physical quality of life. However, this measure may not have been the most appropriate one to assess the participants' physical status.

In conducting a randomised controlled study, this research has specifically addressed limitations of previous studies evaluating psychological therapies in palliative care. First, Study 4 utilised a waiting-list control group to test internal validity regarding the change in symptoms, unlike some other studies (e.g. Anderson et al., 2008; Ramsey et al., 2007). Second, Study 4 randomised participants to either the treatment or waiting list control condition, unlike some other studies (e.g. Anderson et al., 2008; Mannix et al., 2006; Ramsay et al., 2007). In doing so, this PhD has added to the developing body of research that has evaluated psychological therapies for use in palliative care (See Chapter 1 section 2.3.3 for review). However, in spite of a number of strategies used to facilitate recruitment (see Appendix G for details) the sample for study 4 was small (19 randomised to treatment and 15 randomised to control condition) consistent with other research evaluating psychological interventions in palliative care, ranging from 9 (Anderson et al., 2008) to 90 (Breitbart et al., 2010).

Although the results of Study 3 and Study 4 were encouraging, findings suggested that the CT guided self-help reduced anxiety but not depression, relative to the waiting-list control condition. There are a number of possible explanations for the finding that CT guided self-help reduced anxiety but not depression relative to the waiting-list control condition. The first reason is that elevated anxiety was more prevalent than elevated depression in the trial's sample (20.6 % did not meet the inclusion criteria for minimum levels of depressive symptoms), such that there may be more scope to detect reductions in anxiety. However, a post hoc analysis of data from Study 4 only including patients who meet inclusion criteria for elevated depression, found that after controlling for Time 1 depression, there was still no significant effect of treatment condition on Time 2 depression, $F(1,17) = 1.52$, $p = .23$, $partial\ \eta^2 = 0.08$, although this analysis involves a diminished sample size. Another potential explanation is that consistent with other results (e.g., Moorey et al., 2009), depression reduced across both conditions potentially because of the beneficial effects of palliative care support or regression to the mean.

A further area for development is the evaluation of CT guided self-help with other populations. First, carers of palliative care patients also reported elevated distress, existential concerns, abstractness and rumination in Study 1 and Study 2, indicating that they may also potentially benefit from the intervention for similar reasons to palliative care patients. However due to the difficulty experienced recruiting palliative caregivers in those studies, it was decided to focus on recruiting palliative care patients for the case series and RCT. Second, the potential of the intervention could be explored for palliative care staff as part of their routine self-care.

A further aim of the research was to develop an intervention that could be delivered by existing hospice staff with minimal training. Study 5 examined a brief workshop-based training programme designed to teach hospice staff how to deliver the CT guided self-help intervention developed for use with palliative care patients. A key issue arising from the findings of this study was how patients of the trained nurses reported greater reductions in psychological distress, as assessed on routine clinical instruments, when compared with patients of nurses not receiving training.

There are a number of hypotheses that could account for the patients of the trained team reporting greater reductions in psychological distress, relative to patients of the waiting-list control team. First, whilst the training was designed to teach staff how to deliver the intervention, it also included content on the importance of recognition and assessment of patient concerns, anxiety, and depression in palliative care. As very few of the staff trained used the intervention in practice, it is unlikely that the intervention was responsible for improvements in patients psychological outcomes. Instead it could be hypothesised that the training increased the nurses' awareness of the signs and symptoms of psychological distress, and hence led to increased recognition of the psychological issues faced by their patients. Moreover, the training may have improved nurse's generic skills when addressing psychological issues. This may have been through identifying appropriate questions to use to elicit and explore concerns, or as is the case with the CT guided self-help, to encourage a focus on positive experiences.

To test the hypothesis that the training improved patient outcomes through increasing trainees' awareness and generic skills rather than by the specific content and techniques within the CT guided self-help intervention, training staff to use the CT guided self-help (as described in Study 5) could be compared with a control condition consisting of training designed to increased awareness of psychological issues and generic skills when addressing psychological issues (e.g., the ability to elicit and explore concerns, or to encourage a focus on positive experiences) but without including a specific self-help component to provide to patients. Both sets of training would involve identical teaching methods and contact time with trainers. This study would test the predictions that if the effect of the training is on training generic skills, rather than specific skills associated with CT guided self-help: a) matched generic skills training would have the same positive impact on the trainees' patients' psychological outcomes as the patients of the staff receiving CT guided self-help training; b) trainees receiving both training programmes would demonstrate the same improvements in generic skills when addressing psychological issues.

The impact of the training programmes on the patient outcomes of routine care could be compared using the same methodology as Study 5 (i.e., by retrieving routine assessments of patient psychological distress from clinical records pre and post training). However, the impact of training on trainees' behaviour would also need to be assessed. One of the limitations of Study 5 was that the face valid questions used to assess changes in staff competence and behaviour may not have been sensitive enough to detect any change as the staff being trained were already experienced and reported themselves to be confident and competent in dealing with patient psychological distress prior to training. Therefore, an alternative approach that may be more sensitive to changes in competence and behaviour and has been adopted by other studies (e.g., Westbrook et al., 2008) would involve the researcher observing and evaluating trainees' competence and behaviour. Such an approach would involve the researcher assessing trainees' competence and behaviour pre and post training by observing trainees' role plays and listening to and coding recordings of staff-patient interactions. If the effects of CT guided self-help training on improved patient outcomes are due to trained staff learning generic skills, then if Study 5 was repeated, we would expect to see the observed skills for the trained group to be better than for the untrained group post-training. Likewise, to test the prediction that generic skills are improved by both sets of training (CT self-help versus generic), the researcher would assess trainees' competence and behaviour pre and post training by observing trainees' role plays and listening to recordings of staff-patient interactions. The researcher would code specific skills that have been demonstrated by the trainees such as active listening, appropriate use of probing questions, and encouraging a focus on positive experiences.

Rumination and psychological distress in palliative care

This thesis reports the first studies exploring rumination in palliative care. More specifically, this research conducted preliminary tests of hypotheses regarding the role of rumination as a causal process in the development of psychological distress in palliative care. The preliminary findings of the PhD research programme (Study 1, Study 2, and Study 4) are consistent with an association between uncertainty, abstractness, rumination and psychological distress. This association may be the result of a two stage process by which palliative care patients' uncertainty about their future initially contributes to more abstract construals. Ruminating or dwelling on those abstract concerns then leads to psychological distress. However, this two stage process has not been explicitly tested by the PhD.

The first stage of the process is consistent with Construal Level Theory (CLT; Liberman & Trope, 1998, Liberman, et al., 2007; Trope & Liberman, 2003), which proposes that the more psychologically distant an event is, the more it will be represented at higher levels of abstraction. For palliative care patients, it is hypothesised that events may be psychologically distant in a number of ways. The PhD research programme specifically examined the association between increased hypotheticality (or uncertainty) of events and increased psychological distance (Wakslak et al., 2006) because palliative care patients and their caregivers experience significant day-to-day uncertainty. Uncertainty can include uncertainty about the future course of their illness (e.g., ranging from “How will I feel tomorrow?” to “How long have I got to live?”), possible symptoms (e.g., pain), levels of functioning, ability to implement future plans, and concern about what will happen to the family they leave behind.

Palliative care patients may also experience increased psychological distance between themselves and the future due to increased subjective temporal distance between the present and the future. Varying subjective temporal distance can occur because how far away future events are perceived to be can change. For example, if an event 6 months away is thought of in the context of the next year, it may be perceived as further away than if the 6 months is considered in the context of the next 10 years. Moreover, if that event is perceived as being further away in time from the present, this can lead to the event being viewed more abstractly (Peetz et al., 2009). For palliative care patients, the diagnosis of a terminal illness is likely to shorten their life expectancy. Thus, their perception of time may be altered such that future events may be considered against a shorter time period and therefore be perceived as more temporally distant relative to individuals without a terminal illness. For example, an upcoming event such as a family birthday in 2 months may be experienced as relatively further away in subjective time for an individual with a prognosis of less than one year to live relative to a healthy individual with expectations of normal life-expectancy. This hypothesis was not explicitly examined in the PhD research programme.

To examine the effect of a palliative diagnosis on subjective temporal distance, a sample of palliative care patients could be compared with a matched control group. Both groups would be asked to place a series of events (1 day, 1 week, 1 month, 1 year in the future) on a time line running from today at one end to the limit of their foreseeable future at the other end. The study would test the prediction that the limited life expectancy (and therefore shortened foreseeable future) of the palliative care patients would lead to them placing these events further along the timeline than the control group. Both groups would also be asked to describe those events, so that those descriptions could be analysed linguistically for abstractness (as in Study 2 and Study 4). This study would test the predictions that: a) palliative care patients would place the events further away along the timeline than matched controls; b) palliative care patients will describe the events more abstractly than a matched control group.

The association between abstract rumination and anxiety is consistent with elaborated control theory (Watkins, 2008),which has proposed that when thinking about negative material, abstract construal will be maladaptive relative to more concrete construal. Watkins (2008) proposed that a more concrete level of construal would be more adaptive during thinking about difficulties and problems because concrete construal would engender: (a) better problem solving due to the increased detail available about alternative potential courses of action and the detail of "how" to proceed (Vallacher & Wegner, 1987); (b) reduced negative overgeneralizations and reduced emotional impact of negative events because a concrete construal of an event will have less bearing on central elements of the self than an abstract construal (Carver & Scheier, 1990). Whilst the maladaptive implications of abstract construals in terms of rumination and psychological distress have been established through experimental manipulations and examinations of clinically depressed populations, this PhD was the first to explore these implications in palliative care.

Addressing limitations of the research

The first limitation that could be addressed is the small samples recruited for Study 4. On reflection, the most effective strategies that were utilised to address these difficulties with recruitment were to raise and maintain awareness of the research and extending recruitment to a second hospice in Somerset. Therefore, to enable recruitment of larger samples one option would be to recruit across multiple centres. Furthermore, to increase local awareness and engagement with the research, any future trials could include hospice staff as ‘research champions’ who could act as local advocates for the research and facilitate and support recruitment in their area.

A further limitation, in common with other studies in palliative care, was that because Studies 1 and 2 were correlational, the causal nature of the relationships between psychological distress, concerns, coping, abstractness, uncertainty, and rumination could not be established. Thus, Study 4 acted as a proof of principle test that the CT guided self-help designed to reduce abstractness would reduce psychological distress. When considering alternative studies, the nature of palliative care patients as a sample limits options. First, Study 4 represented a unidirectional test that reducing abstractness would reduce distress, rather than a bidirectional manipulation whereby one tests whether increasing or decreasing abstractness would increase or decrease psychological distress. However, a unidirectional test represented the best option in a palliative care sample, as it would not be appropriate to increase abstract thinking or rumination in a sample of palliative care patients. Moreover, it is difficult to ethically justify testing manipulations that make people feel more distressed in a vulnerable population who are already experiencing elevated distress and have a limited life expectancy. Second, prospective longitudinal studies are impractical in palliative care samples due to the unpredictable nature of the course and severity of palliative care patients’ symptoms and general frailty.

A range of studies have evaluated the effect of manipulating processing style during rumination in other samples, such as healthy undergraduates who may be a different from an older, more experienced, less physically well sample found in palliative care (e.g., Ehring et al., 2007; Moberly & Watkins, 2006; Watkins, 2004;

Watkins et al., 2008). Instead, prospective longitudinal studies and studies comparing a rumination induction versus a control manipulation (distraction) could be conducted with a sample of people not requiring palliative care. This analogous sample would match as closely as possible with palliative care patients on a range of other important characteristics e.g., age, marital status, physical disability, and prevalence of psychological distress. These samples might include people with chronic, but not life threatening disabilities, such as people living with limited mobility due to injury.

A limitation of Study 4 was that it was not able to test the construct validity of the intervention to ascertain if the observed effect of the intervention was due to the absorption intervention specifically or to non-specific factors such as the interaction with the researcher. In order to test this, Study 4 could be repeated comparing CT guided self-help with a placebo attention control condition that is matched for non-specific factors (e.g., time talking with the researcher and time practising the absorption exercise), but does not contain the hypothesised ‘active ingredients’ of the intervention such as practising absorption and concrete thinking. Moreover, any placebo control condition would need to have a rationale that is plausible to participants and is unlikely to cause them any further distress. The placebo control condition would involve the researcher meeting with potential participants in exactly the same way as with CT guided self-help, but instead of practising an absorption exercise, participants could listen to a CD containing a recording of natural sounds such as waves hitting the shore for example. Having asked participants about their concerns, the control condition would then differ from CT guided self-help, in that the researcher would give a rationale for the control condition in terms of promoting calmness and distraction from day-to-day concerns. To check that the control condition has a plausible rationale and was acceptable and did no harm to palliative care patients, it would need to be piloted in a case series similar to Study 3. The subsequent trial (if sufficiently powered) would then test the prediction that if the beneficial effects of CT guided self-help were due to specific elements of the intervention rather than non-specific factors, the patients receiving CT-guided self-help would have better psychological outcomes than a matched attention control group.

Final conclusions

In summary, the findings of this PhD have contributed to knowledge in a number of ways. First, this research was the first to explicitly examine the potential role of rumination in the distress encountered by palliative care patients and their caregivers. The preliminary findings (Study 1, Study 2, and Study 4) are consistent with an association between uncertainty, abstractness, rumination and psychological distress.

Overall, the findings of the PhD provide convergent evidence from both cross sectional studies (Study 1 and Study 2) and a manipulation study in the form of the randomised controlled study of the CT guided self-help intervention (Study 4) that abstract rumination may have a causal relationship with worry. Whilst the cross-sectional studies were not capable alone of proving a casual relationship between abstract rumination and psychological distress, the causal hypothesis predicts that the cross-sectional studies would find a positive significant correlation between uncertainty, abstractness, rumination and anxious symptoms. Failure to find this would have ruled out any relationship between these variables, whilst the presence of a correlational relationship only indicates a relationship and not causality. The addition of proof of principle manipulation in Study 4 indicated that abstractness partially mediated the effect of the intervention on worry.

Second, the PhD research programme piloted a brief guided self-help intervention based on an absorption exercise and found preliminary evidence that the intervention could reduce abstractness and symptoms of anxiety in palliative care patients. Third, this research explicitly evaluated if the intervention could be trained to hospice staff and preliminary findings indicated that the training had a positive impact by reducing distress in the patients of those nurses being trained.

The next step in evaluating the efficacy of the CT-guided self-help would be to conduct a definitive Phase III trial. A Phase III trial would be a randomized controlled multicenter trial on a large sample of palliative care patients (at least 300). The trial would test how effective the intervention is, in comparison with a current 'gold standard' treatment (e.g., antidepressants or CBT). However, due to the difficulties involved in the recruitment of palliative care patients in this and other research programmes, a Phase III trial is likely to be expensive and time-consuming.

Once fully evaluated, the intervention has the potential to improve access to psychological treatment for palliative care patients. More specifically as an intervention explicitly designed to be trained to current palliative care staff, the intervention would be particularly aimed at palliative care staff working at level 2 of NICE’s four-level model of professional psychological assessment and intervention (NICE, 2004a). On a local level, the intervention also fulfils the requirements of Hospiscare, who funded the research as a means of identifying and developing a psychological intervention that could be delivered by their staff within existing resources.

Appendix A

Psychological Measures

Generalised Anxiety Disorder GAD-7 (Spitzer et al., 2006)

Over the last 2 weeks, how often have you been bothered by the following problems? *(Use "✔" to indicate your answer)*	Not at all	Several days	More than half the days	Nearly every day
1. Feeling nervous, anxious or on edge	0	1	2	3
2. Not being able to stop or control worrying	0	1	2	3
3. Worrying too much about different things	0	1	2	3
4. Trouble relaxing	0	1	2	3
5. Being so restless that it is hard to sit still	0	1	2	3
6. Becoming easily annoyed or irritable	0	1	2	3
7. Feeling afraid as if something awful might happen	0	1	2	3

Beck Depression Inventory-Fast Screen (Beck et al., 1997)

Please read each group of statements carefully, then pick out the **one statement** in each group which best describes the way you have been feeling during the **past 2 weeks, including today.** Circle the number beside the statement you have picked.

If several statements in the group seem to apply equally well, simply circle the statement which has the largest number.

1 Sadness
0 I do not feel sad.
1 I feel sad much of the time.
2 I am sad all the time.
3 I am so sad or unhappy that I can't stand it.

2 Pessimism
0 I am not discouraged about my future.
1 I feel more discouraged about my future than I used to be.
2 I do not expect things to work out for me.
3 I feel my future is hopeless and will only get worse.

3 Past Failure
0 I do not feel like a failure.
1 I have failed more than I should have.
2 As I look back, I see a lot of failures.
3 I feel I am a total failure as a person.

4 Loss of Pleasure
0 I get as much pleasure as I ever did from the things I enjoy.
1 I don't enjoy things as much as I used to.
2 I get very little pleasure from the things I used to enjoy.
3 I can’t get any pleasure from the things I used to enjoy.

5 Self Dislike
0 I feel the same about myself as ever.
1 I have lost confidence in myself.
2 I am disappointed in myself.
3 I dislike myself.

6 Self Criticalness
0 I don't criticize or blame myself more than usual.
1 I am more critical of myself than I used to be.
2 I criticize myself for all of my faults.
3 I blame myself for everything bad that happens.

7 Suicidal Thoughts or Wishes
0 I don't have any thoughts of killing myself.
1 I have thoughts of killing myself, but I would not carry them out.
2 I would like to kill myself.
3 I would kill myself if I had the chance.

The brooding sub-scale of the Response Style Questionnaire -Ruminative Responses Scale (Nolen-Hoeksema, 2000)

People think and do many different things when they feel down, sad or depressed. Please read each of the items below and indicate whether you never, sometimes, often, or always think or do each one when you feel down, sad or depressed. Please indicate what you *generally* do, not what you think you should do.

Almost Never	Sometimes	Often	Almost Always	
☐	☐	☐	☐	1. Think about how passive and unmotivated you feel
☐	☐	☐	☐	2. Think “Why do I always react this way?”
☐	☐	☐	☐	3. Think about a recent situation, wishing it would have gone better
☐	☐	☐	☐	4. Think “Why do I have problems other people don’t have?”
☐	☐	☐	☐	5. Think “Why can’t I handle things better?”

The World Health Organisation Quality of Life – Short Version (WHOQOL-BREF)

(Skevington et al., 2004)

This assessment asks how you feel about your quality of life, health, or other areas of your life. Please answer all the questions. If you are unsure about which response to give to a question, please choose the one that appears most appropriate. This can often be your first response. Please keep in mind your standards, hopes, pleasures and concerns. We ask that you think about your life in the last two weeks.

Please read each question, assess your feelings, and circle the number on the scale for each question that gives the best answer for you.

		Very poor	Poor	Neither poor nor good	Good	Very good
1 (G1)	How would you rate your quality of life?	1	2	3	4	5

		Very dissatisfied	Dissatisfied	Neither satisfied nor dissatisfied	Satisfied	Very satisfied
2 (G4)	How satisfied are you with your health?	1	2	3	4	5

The following questions ask about **how much** you have experienced certain things in the last two weeks.

		Not at all	A little	A moderate amount	Very much	An extreme amount
3 (F1.4)	To what extent do you feel that (physical) pain prevents you from doing what you need to do?	1	2	3	4	5
4 (F11.3)	How much do you need any medical treatment to function in your daily life?	1	2	3	4	5
5 (F4.1)	How much do you enjoy life?	1	2	3	4	5
6 (F24.2)	To what extent do you feel your life to be meaningful?	1	2	3	4	5
7 (F5.3)	How well are you able to concentrate?	1	2	3	4	5
8 (F16.1)	How safe do you feel in your daily life?	1	2	3	4	5
9 (F22.1)	How healthy is your physical environment?	1	2	3	4	5

The following questions ask about **how completely** you experience or were able to do certain things in the last two weeks.

		Not at all	A little	A moderate amount	Mostly	Completely
10 (F2.1)	Do you have enough energy for everyday life?	1	2	3	4	5
11 (F7.1)	Are you able to accept your bodily appearance?	1	2	3	4	5
12 (F18.1)	Have you enough money to meet your needs?	1	2	3	4	5
13 (F20.2)	How available to you is the information that you need in your day-to-day life?	1	2	3	4	5
14 (F21.3)	To what extent do you have the opportunity for leisure activities?	1	2	3	4	5

		Very poor	Poor	Neither poor nor good	Good	Very good
15 (F9.1)	How well are you able to get around?	1	2	3	4	5

The following questions ask you to say how good or satisfied you have felt about various aspects of your life over the last two weeks.

		Very dissatisfied	Dissatisfied	Neither satisfied nor dissatisfied	Satisfied	Very satisfied
16 (F3.3)	How satisfied are you with your sleep?	1	2	3	4	5
17 (F10.3)	How satisfied are you with your ability to perform your daily living activities?	1	2	3	4	5
18 (F12.4)	How satisfied are you with your capacity for work?	1	2	3	4	5
19 (F6.3)	How satisfied are you with yourself?	1	2	3	4	5
20 (13.3)	How satisfied are you with your personal relationships?	1	2	3	4	5
21 (F15.3)	How satisfied are you with your sex life?	1	2	3	4	5
22 (F14.4)	How satisfied are you with the support you get from your friends?	1	2	3	4	5
23 (F17.3)	How satisfied are you with the conditions of your living place?	1	2	3	4	5
24 (F19.3)	How satisfied are you with your access to health services?	1	2	3	4	5
25 (F23.3)	How satisfied are you with your transport?	1	2	3	4	5

The following question refers to **how often** you have felt or experienced certain things in the last two weeks.

		Never	Seldom	Quite often	Very often	Always
26 (F8.1)	How often do you have negative feelings such as blue mood, despair, anxiety, depression?	1	2	3	4	5

THANK YOU FOR YOUR HELP

Appendix B

Interview schedule for studies 1 and 2

Do you have any concerns or problems that you find yourself dwelling on, worrying about, or thinking about repeatedly?

[If no, check “Have any of the following (from the table below) bothered you recently?”]

If yes, tell me briefly what you have been dwelling on/worrying about.

Which of these bothers you the most?

[Tell me about a recent example when you worried/dwelled/ruminate about that]

[Prompts include:
What was happening before you worried? What set it off? When/where?
What were you thinking?
What were the effects / consequences of this worry/rumination?]

Categories for coding relate to either patient or carer (De Faye et al., 2006)		
Social Concerns: Isolation; lack of information; lack of consultation; role loss; financial strain; burden to others.	Physical Concerns: Pain; drowsiness; nausea; weakness; dyspnoea.	Existential Concerns: Loss of control; Life dissatisfaction; hopelessness; loss of dignity; loss of meaning; Concern for the future.

For the problem or concern that bothers you most:

How often do you think about or worry about the problem/concern? How many times a day?

Frequency per day = ….	Almost never	Sometimes	Often	Almost always

How long does each bout of dwelling/worry about this concern last?

Only moments	For a few minutes	For many minutes	For what seems like hours

When you think about this problem/concern, do you find it hard to stop thinking about it or to move on to other thoughts/activities?

Almost never	Sometimes	Often	Almost always

How much does this problem/concern distress you on a scale from zero not at all to 10 worst possible distress?

0	1	2	3	4	5	6	7	8	9	10

What do you do to cope with the problem/concern?

[Is this the only way that you try and cope?

How well does this work? How does it help?]

Categories for coding relate to either patient or carer (De Faye et al., 2006)		
Problem-Focused: Direct action Planning Instrumental support	Emotion-Focused Approach: Perspective taking Hope Emotional support Catharsis Spiritual Support	Emotion-Focussed Avoidance: Divert attention Distancing Emotional Control Resignation/ Acceptance

What help or support do you already find useful to cope with this?

What further help or support would you find useful to cope with the problem/concern?

How would that help?

Family	Primary care	Specialist Palliative Care	Other:
Friends	Social Services	Psychology	Other:

Which of the following types of help would you find most useful?

Help for problem-solving	Help in accepting things	Help for relaxing	Help for being kinder to yourself

Appendix C

Identification of predicates

A predicate must have had a subject (I, (s) he, they, it, the *x*) that it modified and included a verb or adjective, as in Jane opened the door or Jane is very sleepy. A sentence may have comprised of more than one predicate, but each predicate MUST have had a subject that it modified, as in: I am tired and that is why I can't go out. The predicates could be linked by words such as 'because'. A predicate may also be a question as long it had a subject that it modifies e.g., how serious is it really? However in the case when the predicates were long and contained a number of verbs or adjectives, the verb or adjective most relevant to the subject was coded as in: I want to go out with my family, the subject is "wanting" to go out, rather than actually going out, so want was the key verb to code. The same applied for liking to do something where like was the key verb, or thinking/worrying about doing something where like/worry is the key verb, or feeling something where feel was coded because that was what the subject is doing. Therefore predicates relating to the SUBJECT rather than the OBJECT were coded. For example 'I (subject) think (Coded state verb) that the nurses (Object) are nice (not coded)'.

Another important aspect of identifying predicates to code was identifying linguistic fillers that participants use when speaking quite automatically. These fillers were not coded e.g. 'there you are', 'you know', 'you know what I mean', 'I mean', 'isn't it'

Identification of Linguistic category:

1. Descriptive Action Verbs (DAV): Refer to one particular activity and to at least one physically invariant feature of the action. Action has a clear beginning and an end and usually does not have a positive or negative connotation.

2. Interpretive Action Verbs (IAV): Refer to general class of behaviours with a defined beginning and end, but have a positive or negative semantic connotation.
3. State Verbs (SV): Refer to emotional or mental states with no clear definition of beginning or end.
4. Adjectives (ADJ): Describe the subject, which could be a person, object or an intangible “it”. *I have included “it’s” because if someone is very abstract they may refer to their general situation as “it is horrendous” and I think this should be coded as a predicate.* Note that adjectives are not coded when paired with a noun as they are now describing the object e.g. I am a poor sleeper, the adjective ‘poor’ refers to the object ‘sleeper’ rather than the subject ‘I’. Also if an adjective follows a state verb, then the state verb is coded e.g., “I <u>feel</u> ill”.
5. Context Dependent Words: these could fit in more than one category depending on their context. The common ones from the transcripts include:
    a. Get/got: I get up in the morning (code as DAV); My friends are getting at me (code as IAV); I’ve got a good strong faith or He’s got no quality of life (code as SV); I get tired (code as ADJ).
    b. Make: My wife makes the bed (Code as DAV); The diagnosis made me unhappy (Code as IAV); I made my mind up (Code as SV).
    c. Change: The nurses changed my sheets (code as DAV); The Doctor changed my mind about it (code as IAV); My worries about cancer change all the time (code as SV)
    d. Give/take: The Doctor gave me the bad news (code as IAV); The nurse gave me my tablets (code as DAV); I took my time (code as IAV); I took my pills (code as DAV).

The difference here is the presence of a physically invariant action when being given or taking a physical object versus being given or taking an intangible such as time, news etc.

   e. Deal(t): In the case of the data this is a SV as in I deal with my prognosis, but it could be coded as DAV in the case of dealing cards or IAV in the case of dealing with someone.

6. Non Coded Verbs: The main category of verbs that fall outside of the main 4 categories are possessive verbs such as have and has, which are not coded as anything. Also am, is, be, was and can are not coded, but if an adjective follows that refers to the subject that is coded. The other verb that does not clearly fall into any category is do/does/don’t, happens which therefore should not be coded.

Appendix D

Script for Guided Self-Help Intervention

Introduction

Acknowledge that individual is experiencing some distress – anxiety/depression and some concerns/worry.

Explain that we are attempting to use some mental strategies to get the most out of each moment rather than getting caught up in concerns and worries, about the future or about not being able to do the things you used to do.

Connecting with and getting the most out of what you are doing day to day is important because it is easy to lose connection with what you are doing and not get the most out of it if your mind is preoccupied with concerns, worries about the future, uncertainty

Check with participant… "Can you see how such dwelling on concerns might get in the way of you getting the most out of the moment and lead to more anxiety/stress?"

When you are dwelling on things, you move away from the direct experience of what is happening around you and begin to think in a more abstract way about meanings and implications, and less about what is actually happening with you here and now.

One of the ways to connect again with direct experience is to directly attend to what you are doing and to the world around you. A good way to practice doing that is to focus your attention onto an activity that you find interesting and absorbing…something that you can get completely immersed in.

What we're going to do is to help you think in a more...concrete way by focusing on … reliving the experience … the memory … of a time when you are completely absorbed, immersed or caught up in the process and details of what you are doing. I will explain more about this as we go along. The idea is this concrete thinking can help to reduce rumination and worry and this reduces stress and anxiety …. There is more detail about this idea in the handbook.

Before starting with the exercise, could you tell me about any concerns or problems that you find yourself worrying about/dwelling on repeatedly?

What was happening before you worried? What set it off? When/where?

What were you thinking?

What were the effects / consequences of this worry/rumination?

Please tell me how much this concern [use their term] is bothering you right now from 0- not at all to 10 as much as possible?

Tell me how stressed you are feeling right now on a scale from 0- not at all stressed to 10 as stressed as could be?

Identifying an Absorbing Memory

Let’s try the ‘absorption’ exercise now. As best you can, focus on an experience in which you were totally absorbed and immersed in what you were doing. In this state, you lose all sense of self and time and experience things coming together naturally without much conscious thought, being completely focused in the present moment…

Absorbing activities can be anything and they vary from person to person. They can include doing something creative, musical, or artistic, focusing on the natural world, participating in sport or dance, challenging physical activities and activities that involve intellectual stimulation and learning, or it could be any activity that you lost yourself in, in a good way. Focus on a memory of doing an activity that occurred at a specific … particular place and time that lasted no longer than a day. … There is no right or wrong way to become absorbed … imagine being absorbed in the activity that feels right for you …

In a few words, briefly describe to me the event, the memory you choose to focus on	*Get feedback. Note event in Participant Response Sheet*
To check, ask “When, where , what, who?”, although this should be brief	*Checks located at a specific, particular place and time*
Was this a time when you were completely focused on what you were doing? Did you lose sense of yourself and of time? Were you directly in the present moment? Was there any running commentary in your mind?	*Checks that the memory is likely to involve absorption*
Could you tell me what it is about the activity that makes you find it so enjoyable and immersive?	*Identify what the individual values about the activity.*

If the patients is struggling to come up with a memory use the following prompts:

Reminders of what absorption feels like

- A state of complete absorption,
- one thing flowing naturally after another
- of "feeling" what to do next naturally, without thinking about it
- concentration on the process of what you are doing
- totally focused on what you are doing, without any running commentary in your mind, without your thoughts wandering off
- totally absorbed in the details of the present moment, focused on the here and now, on how you are doing things and not on the future or the past …

Examples of absorbing activities

- the beauty of the natural world – looking at the sky, scenery, landscape, sea, patterns of light and dark, differences in colour and texture, the sensory experience … the aesthetic experience of the world around them
- Creative activities – writing, cooking, painting, playing music, listening to music
- Physical activities – physical exertions, risk, rock climbing, scuba diving, sky-diving, where next to put your hands when rock climbing
- Shape ideas, make new links between thoughts, look at things a different way, create structure and order from what was disorganized and messy
- Working with hands involving craft and skill, wood-working, pottery, making things, fixing things, working out how machinery works
- the grace and fluidity of movement, rhythm, dancing, exercising, an action completed with economy, elegance and beauty

If necessary, can prompt the kind of processes involved in absorption

- Deep & effortless involvement in activity;
- Merging of action & awareness;
- Balanced ratio between challenge (opportunities) & skills;
- Focused attention on the task at hand;
- Narrow temporal focus – immediate, present-moment;
- Clear goals, rules & immediate feedback;
- Loss of self-consciousness;
- Changed perception of time;
- Connection with environment
- self-guiding; Sense of possibility of control;

The Absorption Exercise

Ok, now, as best you can, just concentrate on following my instructions – keep focusing on what I am saying and on what you are imagining– until I ask you to tell me what you are experiencing. Some of these instructions may be more relevant to you than others for you, so just focus and concentrate on the ones that make most sense for you. It might help to close your eyes or focus on a spot on the wall, so you can concentrate fully on the exercise

This instruction is useful in the training as some participants keep interrupting to explain what they are doing halfway through instructions

Ok, that's great, now imagine this absorbing situation as vividly and as concretely as you can … and as best you can, imagine yourself doing this absorbing activity of ***x*** in ***place y*** at ***time t*** *(i.e., more detailed specification from memory already described)*.. … Go ahead and take a few moments to have a vivid, concrete, detailed image of becoming positively absorbed ... imagine that you are there right now, looking out onto the scene, seeing through your own eyes …experiencing the sensations of being in your own body…. hearing … feeling … using all of your senses to become fully aware of your experience in the moment. … And as you imagine this scene, fill it with rich and vivid details that make it more and more real and deep for you …

As you continue to visualize this event vividly … focus your attention on any details, any information, anything that was specific and particular ... to this time when you are absorbed in the activity. … Focus your attention on these vivid, specific and concrete details as you recapture the sense of being deeply … positively immersed and absorbed in what you are doing. …[5]

Briefly tell me what you are noticing.

looking for highly detailed description

Describe to me what you are seeing, hearing and experiencing

Check whether completely focused on what doing/sensory experience or whether any comparisons, evaluations, running commentary

Check concrete details of sights, smells, sounds, check that getting some of the important elements of being in an absorbed state:

- sense of flow,
- lose of sense of time,
- absorbed,
- calm,
- positive

Key elements include:

- *Deep & effortless involvement in activity;*
- *Merging of action & awareness;*
- *Balanced ratio between challenge (opportunities) & skills;*
- *Focused attention on the task at hand;*
- *Narrow temporal focus – immediate, present-moment;*
- *Clear goals, rules & immediate feedback;*
- *Loss of self-consciousness;*
- *Changed perception of time;*
- *Connection with environment*
- *self-guiding; Sense of possibility of control;*
- *Activity intrinsically rewarding – valued as an end in itself (autotelic);*
- *Focus on discovery, learning, growth – build self-potential.*

Focus on the details of what you can see and hear – ... [5] ... focus your attention on the world around you, concentrating in a deep and relaxed way on the pattern of light … colours … movements … sounds…you experience … becoming more and more absorbed. ... [5] ....

Focus on the sensations in your body …concentrate on how your movements naturally follow each other, how they feel right and effortless .. [5] ... . Notice how you feel inside. ... [2] ...

Notice how you are attending to the situation - notice if your attention is narrowly focused on a specific detail or if your attention is loose … flexible … shifting easily from one thing to another.... [5] ...

Notice what you are paying attention to as you become more absorbed in this experience … Focus your attention on the details of the scene that help you become absorbed ... [5] ...

Observe how you can sense what to do next … whether this is an instinct or gut feeling or a feeling of what fits, what feels right. ... [5] ...

Concentrate on your experience of curiosity … of creativity … of playfulness … of exploring … of learning …of connection….. of enthusiasm…… of warmth……of growth… of closeness…of communing with nature…of peace…of absorption…as you imagine doing this activity… let those feelings grow and expand ... [5] ...

Select the values that seem most appropriate to the participant and the situation from the answers given earlier

Focus your attention on the process of how you are doing the activity … notice what your mind is focusing on … little by little, each moment … Notice what is important to you … what motivates you … what draws your attention … as you become more and more absorbed … [5] ...

Focus on how the activity expresses your own personal values. …how it reflects what is important and meaningful to you ... [5] ...

Initial Feedback

What is your experience as you are absorbed in reliving this experience and back in that situation in your mind?

What did you notice as you were absorbed back in the scene?

What did you value about this activity?

check for some experience of benefit, e.g., calm, relaxed, better mood, more motivated, pick up and correct any confusion, uncertainty, misunderstanding. Check for thoughts of what they might do differently

Now please tell me how much your main concern [use their term] is bothering you right now from 0- not at all to 10 as much as possible?

Tell me how stressed you are feeling right now on a scale from 0- not at all stressed to 10 as stressed as could be?

Feedback if results positive or go back over exercise if negative to assess what parts were most problematic. Do not dwell on scores if they are having difficulty…important not to move into evaluative thinking. If they are quickly switching to more abstract thinking, take them back into scenario and move on to facilitate them generating a concrete plan.

If report that positive effect fading off and going back into making comparisons, evaluations about how now is different from past event, very briefly acknowledge that this indicates how abstract thinking is coming back and ask to step back into experience of absorption. E.g. "When you report thoughts like x, that is another illustration of how quickly the habit of being more abstract can reassert itself and how it can make you feel down again. The concrete self-help is about learning to shift away from that habit. So, as best you can, get back in touch with your experience of doing x in place y at time t. Step back into that experience, focusing on what you find absorbing" if necessary, prompt further

This can be repeated several times if necessary to help patient to see how briefly stepping into absorbed mind-set can shift mental gears and help feel temporarily better.

If person refers to how it makes sad because of activities no longer doing then can note this is not surprising as would be sadder if missing activities value and note importance of building these activities up, linking to point 3 below. Here can use other aspects re concreteness to break down into steps and put into perspective re finding time to do activity if saying can’t find time to do it or focus on what is valued to find alternative activity

Planning Ahead

As I mentioned before, times when we are completely absorbed in an activity involve very concrete thinking – focused on the details of the task and our sensory experience, concentrating on the process and sequence of what is happening. Furthermore, these experiences are very powerful at improving our mood as they get us directly in touch with positive experiences and are a strong antidote to rumination and worry, and dwelling on concerns. Moreover, being absorbed tends to increase motivation and is a frame of mind that helps to get as active as one can.

You can use this exercise in a number of different ways. First, we suggest that you use this exercise as a regular daily exercise to help promote feeling better and more relaxed, by setting a regular time aside to practice the exercise using the CD. Second, you can use this exercise as a useful response when you notice that you are worried or stressed – you can use this approach as a first aid strategy to change mental gear when you become stressed to get back in touch with your direct experience, and, thereby, feel better.

Third, this exercise can help us to identify day-to-day activities that you could do more of to feel better.

How much are you doing any of the activities that you could find absorbing?

Why are they difficult to do?

Are there any alternative activities that capture your key values, which you could find absorbing?

Practical issues, physical limitations, lack of access, lack of motivation/concentration

Important to translate visualisation into action

For participants who are concerned that they no longer do things because they no longer find them enjoyable – the following may be helpful – a) The absorbing activities are the most enjoyable and interesting activities that participants can do – this might make it easier; b) the mental exercise is designed to help put them in right frame of mind to do it; c) to get better they need to experience rewarding activities that can recharge their batteries – what is the balance between doing chores & duties versus interesting absorbing activities – perhaps more energy needs to be devoted to activities that can make someone feel better; d) activities can be built up gradually & doing more leads to having more energy – as they have done less and less, have they become more or less tired.

What activities does the absorption exercise suggest that you can do more of in order to feel better?

Can you make a plan to start doing any of these activities this next week? How would you start?

If you want more information or a reminder about this, there is more detail in the handout.

Generate a reasonable list – get a sense of what activities interesting e.g., creative, etc what values do they support?

Look at thinking concretely about starting

We recommend that for the next week, you try to practice the absorption exercise using the example we just went through every day. The more you practice the exercise the more benefit you will get.

Let’s note down **WHEN AND WHERE** you will do the training.

Setting aside a regular time and place to listen to the CD will help to get you into the *habit* of doing the training, and so make it easier to remember to do it each day. It is helpful to select a time and place that is likely to be free, that is quiet, private and relaxing, where you will not be interrupted, where you can minimise external distractions and where you will be alert and awake to get the most out of the practice.

Do these with the patient as speak– need to do the same with respect to making times and places for phone calls- making sure have contact details

What room will be best for you to ensure space, quiet, and privacy?

What time of day is most likely to ensure that you have time available to do the training?

What time of day will give you the most benefit?

How can you best fit the training into your daily schedule?

Discuss these questions to build the daily plan for practise. e.g. some people prefer to do in morning, some people may find it useful to do it to help sleep. ***Have participant write in HANDBOOK***

Often people find that making a **WRITTEN COMMITMENT** increases the likelihood that they will do something. Are you happy to complete the form in your folder?

Encourage participant to write in the handbook

Can you think of any **PROBLEMS** or hurdles that might interfere with your plans to practise the self-help exercises?

Can you think of anything else that might come up?

If any of these problems come up next week you can contact me by email or phone.

These problems can be "practical", like not having enough time, forgetting to practice, or more physical or psychological, like feeling unmotivated, tired or anxious …

To help you get the most out of the practice, I will talk to you again in a week and see how you found the exercise - this will be an opportunity for you to ask any questions, and for us to practise the exercise again and fine-tune it. When would be a convenient time to call you in a week?

Arrange time for next follow-up telephone call. Make this explicit

OK, so we have the following plans *(summarise activity plans and times to practice the exercise)* for the next week, and I will be calling you at *TIME* to see how you are getting on and check on the practice. Good luck.

Appendix E

Information booklet to accompany guided self-help intervention

Engaging With Life – helping you to become absorbed and get the most out of positive experiences.

Introduction

Palliative care involves the physical, social, spiritual and psychological care of people with life-limiting illnesses. People with palliative care needs can experience increased levels of psychological distress, such as anxiety, stress and depressed mood. Our previous research suggests that this distress is often linked to worry about concerns, such as uncertainty about the future or no longer being able to do the things what you once could do. We also found that people with palliative care needs thought in a more abstract way, that is, they described events in terms of general meanings and implications rather than in terms of specific details and actions. The distress and the abstract thinking or worrying about these concerns can make it difficult for people to connect directly and fully engage with life, and make it hard to get the most of each moment. When we are not connected to our experience this can leave us feeling lower in mood because we can miss out on feeling the benefits of doing something enjoyable.

This self-help training programme aims to use mental exercises and imagery to help reconnect you directly with the here and now rather than dwelling on the meanings and implications of what is happening. This should help to reduce this abstract thinking and therefore reduce your psychological distress and stress.

Content of the Self-Help Training Programme

- An initial face-to-face training session lasting 30 minutes to an hour in which you practise the mental exercise, focusing on an experience when you were totally absorbed and immersed in what you were doing.
- Three telephone sessions lasting no more than 15 minutes each at weekly intervals. We'll call you for these sessions and we'll use them to check on how you're getting on and to help you improve your practice.
- Between the telephone sessions, you will practise on your own with the CD. You will have this handout to guide you and the opportunity to call John Galfin if you have any questions. Your daily practice is the most important part of the self-help therapy!

Choosing Events for the Engaging with Life Exercise

Each time you do the Engaging with Life exercises on the CD, you will be asked to focus on an experience when you were totally absorbed and immersed in what you were doing.

It is very important that the absorbing events you choose must have occurred at a specific place and time, and lasted no longer than 1 day.

You can use the same event each time you practise the Engaging with Life exercise, or you can use different ones. It's up to you.

Examples of Absorbing Events

Absorbing activities include doing something creative, musical, or artistic (e.g., playing guitar or flower arranging), or focusing on the natural world (a walk in your favourite park), participating in sport or dance, challenging physical activities (like running or rock climbing), and activities that involve intellectual stimulation and learning (e.g., reading a good book). In this state, you lose all sense of self and time and experience things coming together naturally, without much conscious thought, being completely focused in the present moment. There is no right or wrong way to become absorbed. Try and think of memories of when you have been completely absorbed in an activity.

Your Examples of Absorbing Activities Are an Important Starting Point

There is no right or wrong way to become absorbed. Try and think of memories of when you have been completely absorbed in an activity. Use the lines below to write down several examples of times when you have been fully absorbed in what you are doing. Try to be as specific and detailed (concrete) as possible:

1)____

2)____

3)____

4)____

As you look at these different examples, you might find that there are some elements in common between them. Positive absorption is more likely to occur under particular conditions, many of which are under your control:

- There is a balance between the challenge (difficulties and opportunities) of the task & your skills – if the task is too difficult it is hard to get absorbed but if it is too easy it will be boring. Ideally, you need to try tasks that are within the reach of your skills whilst slightly stretching you.

- Your attention is focused on the task at hand – the more you attend directly to what you are doing, the more absorbed and connected you become.

- The activity involves you focusing your attention on the immediate, present moment, on what is happening in the moment right now, rather than on the past and the future.

- There are clear goals, rules & immediate feedback - it is easier to get absorbed when you know what you are trying to do and for every action you take there is an immediate and direct response – for example, when playing a musical instrument, you immediately hear what note was played; when painting you can directly see the effect of the brush on the canvas.

- The activity is rewarding in itself – what you are doing is **valued as an end in itself because the process of doing it is interesting**, rather than because of what you might achieve as a result of doing the activity. For example, playing sport might feel good as you are doing it because of the feeling in your body, whether you win or lose.

- There is a focus on discovery, learning, growth – you are doing the activity out of curiosity, to see what happens or to learn and improve.

- The activity is consistent with your values – it reflects what is important and meaningful to you – for example, if you appreciate the natural world, then you might find walking in the countryside, paying attention to nature, absorbing. If you value learning and curiosity, you will be find activities that involve learning more absorbing, for example, learning to play a musical instrument.

The examples you thought of provide memories for you to use when you practise the mental exercise of imagining and recreating absorbing activities, using the CD. During these mental self-help exercises, you will imagine one of these absorbing situations as vividly and as concretely as you can. You imagine that you are there right now, looking out onto the scene, seeing through your own eyes, experiencing the sensations of being in your own body, using all of your senses to become fully aware of your experience in the moment.

You can use this exercise to get you into a frame of mind where you are more directly connected to experience, in order to practise this skill and as a means to fully experience what you are doing. In addition, the state of mind you have when absorbed makes you more motivated to do things and makes it easier to fully experience what you are doing and get more enjoyment from it. It can therefore be helpful to practise the absorption exercise to get yourself into the right frame of mind before starting an activity – to increase your chance of getting started and to increase your enjoyment of what you are doing.

Your examples give you clues as to activities that you can find absorbing and beneficial. Think about the examples you chose. How many of these activities have you stopped doing or are you doing less frequently? Are there any other alternative activities that you would be able to do now that would give you the same feelings? If you have any ideas about activities that you could do, write them below.

1)____

2)____

3)____

4)____

Planning the exercise:

Where will you practise? ____

When will you practise? ____

What problems have you found with the exercise? ____________________

What has got in the way of your practice? ____________________________

Appendix F

Pro forma for telephone follow up sessions

GUIDED SELF-HELP TELEPHONE FOLLOW UP SESSIONS

ID number						
Date	d	D	m	m	y	y

Starting Time		**Finishing Time**	
Session	☐ TF 1	☐ TF 2	
Researcher			

ASSESSMENT OF SELF-HELP TRAINING USE

FREQUENCY: How often have you been practising the self-help exercises by listening to the CD?

Number of days in last week ____________ days

(If relevant, ask) What problems (if any) have prevented you from practising every day?

____

____

[Attempt to address problems preventing practice, where appropriate]

DURATION: For how long have you been practising the CD each time?

[Are you listening to the full CD?] [check if any sections being skipped or missed]

____

INVOLVEMENT/EFFORT: How much are you able to concentrate and get fully involved in the exercises? Rate on a 0-100 scale:

0 10 20 30 40 50 60 70 80 90 100

no involvement completely involved

can't concentrate highly focused

If necessary, Ask – "What makes it hard to get involved/concentrate?

____

____

[Attempt to address problems preventing involvement, where appropriate]

DAILY APPLICATION: Do you find that you are changing your thinking/relaxing (delete as appropriate) on a day to day basis even when you aren't listening to the CD?

Is it becoming more of a habit? ☐ Yes ☐ No ☐ Unsure

Can you give me an example?

____

____

[Use to provide positive Feedback and encouragement]

USEFULNESS: Is the self-help training proving helpful? How useful would you describe it on a 0-100 scale:

0 10 20 30 40 50 60 70 80 90 100

not at all extremely useful

In what ways is it useful? Note down examples:

____

____

[Use to provide encouragement and further guidance]

<u>GENERAL ATTITUDE TO TRAINING</u>: How do you feel about the self-help training?

1	2	3	4	5	6	7
Extremely negative			Neither negative nor positive			Extremely positive

CHECK CHANGES IN TREATMENT AS USUAL

☐ Nothing

Have you done something to deal with your feelings ☐ Yes ☐ No in the last week?

If yes, specify: ______________________________

☐ Support from Hospiscare

Have you discussed your concerns with your Hospiscare nurse ☐ Yes ☐ No during the last week?

How many times : ____________ For how long : ______________

Did you find that helpful? ☐ Yes ☐ No

Have you started something else to deal with your feelings ☐ Yes ☐ No during the last week?

If yes, specify: ______________________________

☐ Support from GP

Have you discussed your concerns with your GP ☐ Yes ☐ No during the last week?

How many times : ____________ For how long : ______________

Did you find that helpful? ☐ Yes ☐ No

Have you started something else to deal with your feelings ☐ Yes ☐ No

during the last week?

If yes, specify: ____

☐ Medication

Have you changed the type or dose of your medication ☐ Yes ☐ No

during the last week?

If yes, specify: ____

☐Other: ____________ Specify: ____

Any change in last week? ☐ Yes ☐ No

ENGAGING WITH LIFE

RECORD MEMORY:

RECORD FUTURE ACTIVITIES:

PRE-EXERCISE. NOTE CONCERN____

RATING OF HOW MUCH BOTHER /10 RATING OF STRESS /10

POST-EXERCISE.

RATING OF HOW MUCH BOTHER /10 RATING OF STRESS /10

FURTHER NOTES:

--

PHONE CALLS RECEIVED BETWEEN THE TF SESSIONS

Date: ______________________ **Object:** __________________________

Description:____

____

____

Action Taken:

____

____

Date: ______________________ **Object:** __________________________

Description:____

____

____

Action Taken:

____

____

Appendix G

Strategies and materials used to facilitate recruitment to randomized controlled study

Table 7.1. Strategies used to facilitate recruitment

Month	Number of referrals	Strategies used to increase recruitment
Jul-09	1	Met community teams in Devon to explain recruitment
Aug-09	4	Met with Day Care team in Devon
Sep-09	6	Developed flow chart poster and bookmark to aid recruitment
Oct-09	3	Attended monthly meeting of whole Devon community team
Nov-09	4	Shadowed individual community nurses
Dec-09	3	Shadowed individual community nurses
Jan-10	3	Ethics and Hospice permission granted to recruit in Somerset
Feb-10	3	Met community teams and Day Care in Somerset to explain recruitment
Mar-10	10	Launched referral competition in Devon and new flyer
Apr-10	10	Started monthly email update to Devon teams
May-10	6	Submitted article for Hospice newsletter
Jun-10	6	
Jul-10	6	
Aug-10	4	

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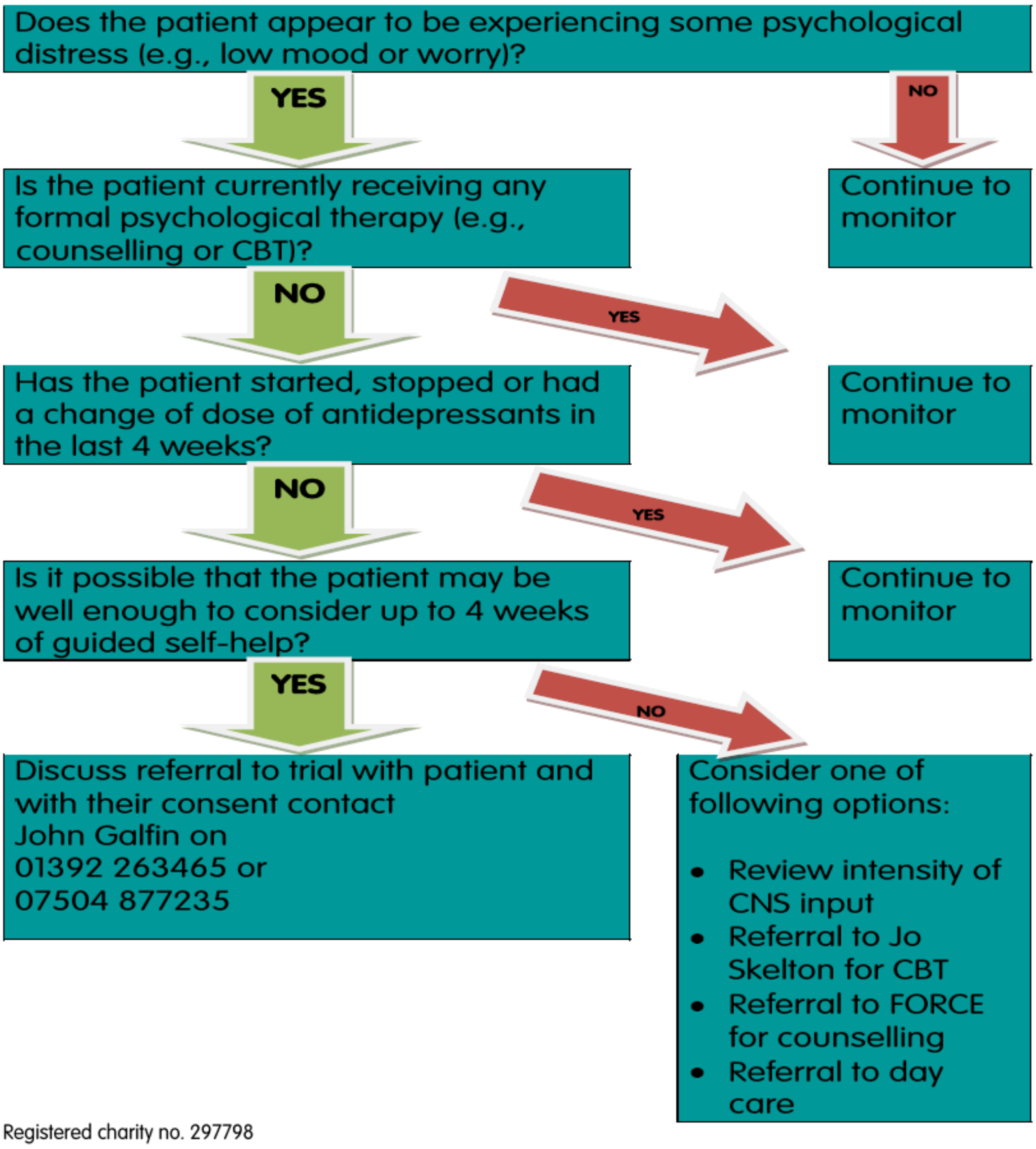
Psychological Care

Referral Flowchart



Does the patient appear to be experiencing some psychological distress (e.g., low mood or worry)?

YES

Is the patient currently receiving any formal psychological therapy (e.g., counselling or CBT)?

NO

Has the patient started, stopped or had a change of dose of antidepressants in the last 4 weeks?

NO

Is it possible that the patient may be well enough to consider up to 4 weeks of guided self-help?

YES

Discuss referral to trial with patient and with their consent contact
John Galfin on
01392 263465 or
07504 877235

Consider one of following options:

- Review intensity of CNS input
- Referral to Jo Skelton for CBT
- Referral to FORCE for counselling
- Referral to day care

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Psychological Care

Research Update & Competition

Thank you all so much for your help and support over the last 2 years. However, as we enter the last 6 months of the trial, we need your help for the final push.

The therapy appears to be very helpful for the patients we have used it with so far, but we need to recruit as many patients as possible, so that we can prove it!

Participants have said:

"I can feel that wind in my face when I play the CD. It takes me back to a very happy place"
"For a while I forgot about being and feeling ill. I can remember better times"
"This has put me back in control of my life"

A nurse who has referred a number of patients to the study has said:

"It's something you can actively make a difference with"
"It's empowering for the patients. The patients feel they can help themselves"

Now approaching patients for the study is even easier as you can now give the attached flyer to patients who you think may benefit from the treatment. Then they can get more information from yourself or contact John directly.

Also we now want to reward you for your support by announcing our new competition. We have a prize of lunch for 2 at Michael Caines' restaurant at Abode in Exeter to be won!
The prize will go to the Hospiscare nurse who refers the most patients to the study between 1st March and the end of August this year,
so Good Luck !!

Remember if you have any questions, issues or referrals please contact John Galfin on 01393 263465, 07504 877235 or by email jmg211@exeter.ac.uk

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See yourself happier

New therapy could help you

- Are you finding yourself dwelling on thoughts or concerns repeatedly?
- Does this leave you feeling worried or low?
- Does this interfere with your sleep?
- Would you like to reduce this repetitive thinking and worry?

If Yes, then our new guided self-help therapy may be for you!
Hospiscare are currently trialling a new therapy based on visualising and mental imagery, which has been designed to reduce dwelling, worry and low mood.

If you would like to find out more, then feel free to discuss this with your Hospiscare nurse, or contact our researcher, John Galfin directly and he will be happy to explain how the therapy works and how you can take part.

John is available by phone on 01392 263465 or email at jmg211@exeter.ac.uk

Appendix H

Transcript of Screening questions for RCT of guided self-help intervention:

"In order to check whether the training may benefit you, I would like you to complete 2 short questionnaires that assess how your mood has been over the last 2 weeks [*administer BDI –FS and GAD-7*]"

"So that we can be sure that it is the training that is helping you rather than something else, could you clarify if you are taking any medication for your mood (if so how long have you been on this dose?) and if you are currently receiving any psychological therapy such as counselling or cognitive behavioural therapy?"

"A key part of the training involves you visualising a specific memory of when you were doing an activity that you were immersed or absorbed in. To see if this is something you are able to do, I'd like you to recall a memory of an enjoyable and positive event. The memory can be of anything and can be recent or from a long time ago – the key thing is that the memory is personal and specific. By specific, I mean that it is a memory of a particular event that occurred at a particular place and time that lasted less than a day. For example, when I went for a walk by the sea at Exmouth last Wednesday afternoon and it was hot and sunny is an example of a specific memory. Please tell me what specific positive memory comes to mind [*Check for clear memory of location, environment, sensory information, time, how it made them feel, what were they thinking –check that can describe where, when, what, with whom it occurred – may need to prompt and check further re memory.*]"

Appendix I

Checklist used to assess nurses' competence in guided self-help

Engaging With Life Training Competencies Checklist

COMPETENCY	YES	NO	COMMENTS
Trainee understands the rationale for the guided self-help therapy and is able to explain this to patients			
Trainee is able to identify an appropriate memory with a patient			
Trainee is able to check if the patient is absorbed			
Trainee is able to give appropriate feedback to patient			
Trainee is able to work with patient to formulate a concrete action plan			

Assessor	
Trainee	
Date	

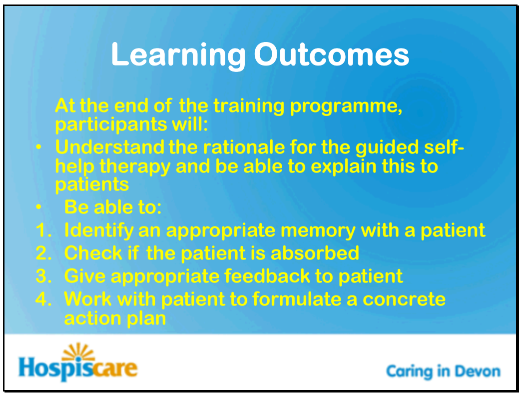
Appendix J

Training programme presentation

DAY 1 (full day)

<u>Introduction</u> (1 hour approx)

- Discussion of rationale for guided self-help treatment
- Outline of what guided self-help entails i.e. face to face practice followed by practice supported by CD and written materials
- Discussion of assessment of the signs and symptoms of anxiety and depression in palliative care patients (draw on knowledge/experience of attendees)



Learning Outcomes

At the end of the training programme, participants will:

- Understand the rationale for the guided self-help therapy and be able to explain this to patients
- Be able to:

1. Identify an appropriate memory with a patient
2. Check if the patient is absorbed
3. Give appropriate feedback to patient
4. Work with patient to formulate a concrete action plan

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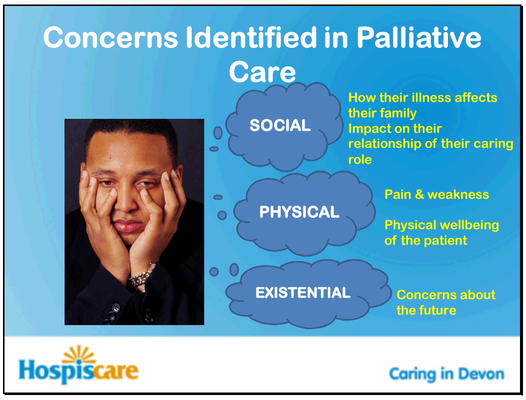

Concerns Identified in Palliative Care

SOCIAL

How their illness affects their family
Impact on their relationship of their caring role

PHYSICAL

Pain & weakness

Physical wellbeing of the patient

EXISTENTIAL

Concerns about the future

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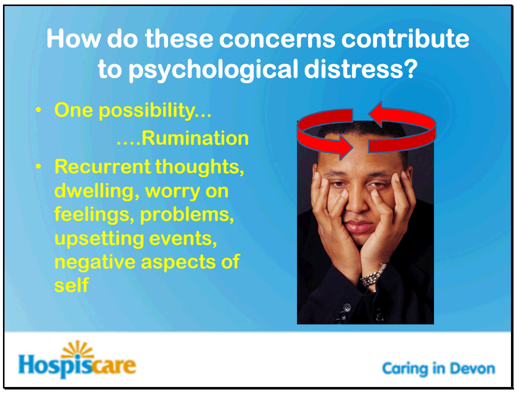
Slide identifies most common concerns for patients and carers in each category



How do these concerns contribute to psychological distress?

- One possibility…
  ….Rumination
- Recurrent thoughts, dwelling, worry on feelings, problems, upsetting events, negative aspects of self

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Why did this happen to me?

Will I see my daughter get married?

What happens if my disease comes back?

Implicated in the onset and maintenance of psychological distress
(see review by Watkins, 2008)

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Slide indicates why rumination may be important in palliative care

The problem with abstract thinking…

Abstract thinking:
focussed on meanings and implications of concerns…why?

For example: Fear of falling
Abstract:
Why can't I get about like I used to do?
What will happen if I fall over?
Will I break my hip?
Will anyone find me?
Will I end up in hospital?

Concrete thinking:
focussed on the process and details…how?

Concrete:
How can I move around without falling?
How can I break down what I need to do into manageable steps?

Abstract + Rumination = Distress

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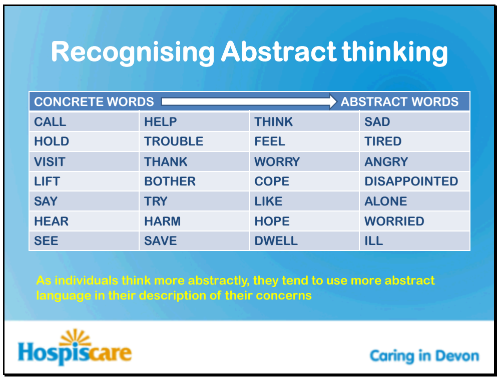

Recognising Abstract thinking

CONCRETE WORDS → ABSTRACT WORDS

CALL	HELP	THINK	SAD
HOLD	TROUBLE	FEEL	TIRED
VISIT	THANK	WORRY	ANGRY
LIFT	BOTHER	COPE	DISAPPOINTED
SAY	TRY	LIKE	ALONE
HEAR	HARM	HOPE	WORRIED
SEE	SAVE	DWELL	ILL

As individuals think more abstractly, they tend to use more abstract language in their description of their concerns

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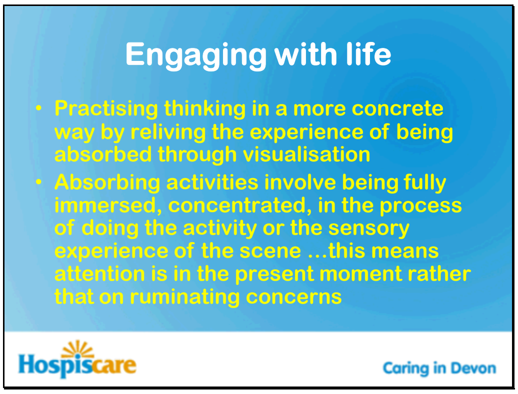
On left words describe discrete actions (i.e. How to do it).

As you move right, words have more interpretation i.e., There are more than one way to help

Third column, words relate to internal emotions and are completely subjective

Fourth column words are much broader and can apply to many things disappointed



Engaging with life

- Practising thinking in a more concrete way by reliving the experience of being absorbed through visualisation
- Absorbing activities involve being fully immersed, concentrated, in the process of doing the activity or the sensory experience of the scene …this means attention is in the present moment rather that on ruminating concerns

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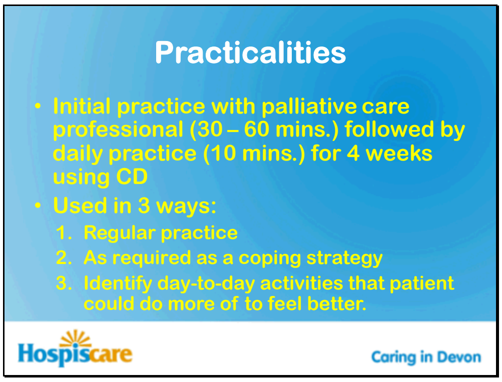
They include:

-being creative (e.g. Painting, knitting, playing instruments)

-being physical (e.g. Dance, playing golf)

-focusing on the natural world (e.g. day at the beach, steamer across Lake Windermere)

-intellectual stimulation and learning



Practicalities

- Initial practice with palliative care professional (30 – 60 mins.) followed by daily practice (10 mins.) for 4 weeks using CD
- Used in 3 ways:
  1. Regular practice
  2. As required as a coping strategy
  3. Identify day-to-day activities that patient could do more of to feel better.

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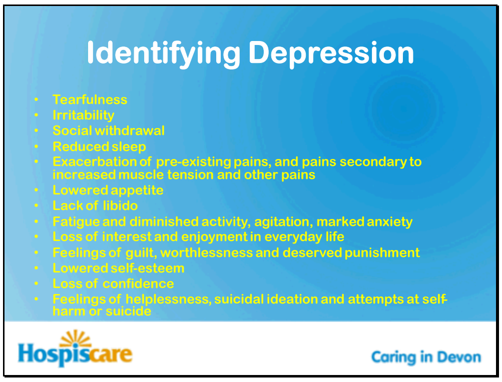

Identifying Depression

- Tearfulness
- Irritability
- Social withdrawal
- Reduced sleep
- Exacerbation of pre-existing pains, and pains secondary to increased muscle tension and other pains
- Lowered appetite
- Lack of libido
- Fatigue and diminished activity, agitation, marked anxiety
- Loss of interest and enjoyment in everyday life
- Feelings of guilt, worthlessness and deserved punishment
- Lowered self-esteem
- Loss of confidence
- Feelings of helplessness, suicidal ideation and attempts at self-harm or suicide

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Identifying Anxiety

- Muscle tension
- Restlessness
- Panic
- Sense of impending doom
- Irritability
- Poor sleeping
- Avoidance
- Poor concentration
- Anxious thoughts, such as fears of dying of a heart attack
- Fears of embarrassment or humiliation, or fears of something terrible happening
- Uncomfortable physical sensations, including heart palpitations, sweating, dizziness, or shortness of breath

(NICE, 2004).

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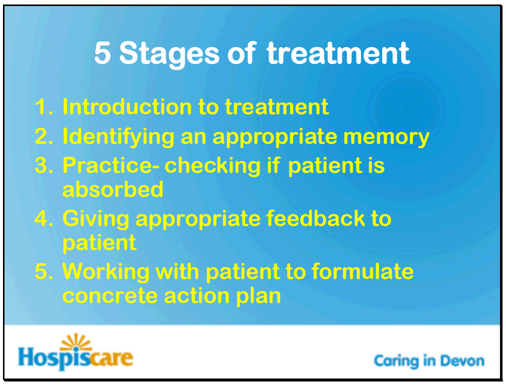
Demonstration (2 hours approx)

- Live demonstration of role-playing the guided self-help (Video recorded)
- Work through specific examples to discuss pertinent points for each stage:
    - Introduction – link to rationale discussed earlier
    - Indentifying appropriate memory
    - Practice- checking if patient is absorbed
    - Giving appropriate feedback to patient
    - Working with patient to formulate concrete action plan



5 Stages of treatment

1. Introduction to treatment
2. Identifying an appropriate memory
3. Practice- checking if patient is absorbed
4. Giving appropriate feedback to patient
5. Working with patient to formulate concrete action plan

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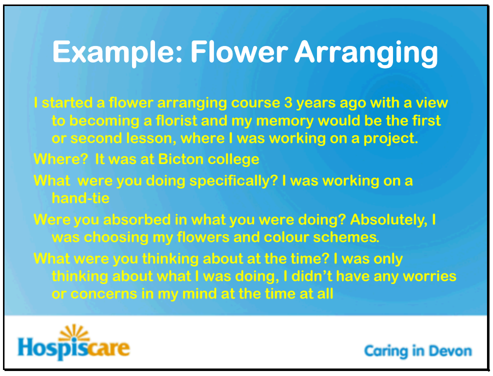
Identifying an appropriate memory

- Specific: Person, place, time
- Awareness of sensory details – seeing place, people, objects – colours, shapes, movements; hearing sounds; noticing feelings etc
- Focus of attention: here and now, task at hand
- Lose sense of self and of time
- No running commentary in head
- Enjoyment of activity for the sake of it…not evaluative
- Feel free to prompt and suggest…
- Consider props (pictures, music)



Example: Flower Arranging

I started a flower arranging course 3 years ago with a view to becoming a florist and my memory would be the first or second lesson, where I was working on a project.

Where? It was at Bicton college

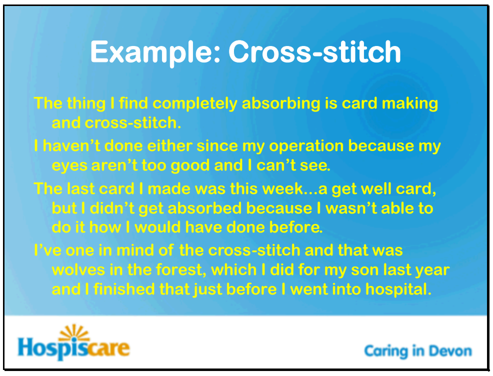
What were you doing specifically? I was working on a hand-tie

Were you absorbed in what you were doing? Absolutely, I was choosing my flowers and colour schemes.

What were you thinking about at the time? I was only thinking about what I was doing, I didn't have any worries or concerns in my mind at the time at all

Ask participants...

Is there anything else you'd want to ask? At each bullet point.



Example: Cross-stitch

The thing I find completely absorbing is card making and cross-stitch.

I haven't done either since my operation because my eyes aren't too good and I can't see.

The last card I made was this week…a get well card, but I didn't get absorbed because I wasn't able to do it how I would have done before.

I've one in mind of the cross-stitch and that was wolves in the forest, which I did for my son last year and I finished that just before I went into hospital.

Ask participants...

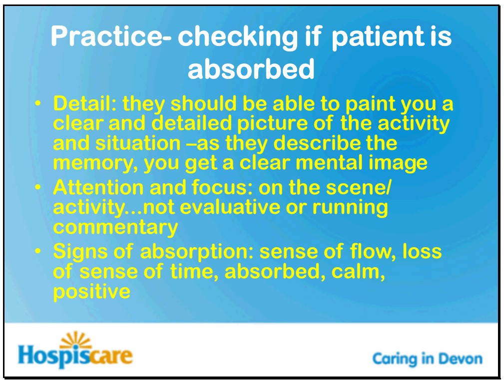
Is there anything else you'd want to ask? At each bullet point.

What's missing?

Running commentary?

Focus of attention?

Is she being evaluative?



Practice- checking if patient is absorbed

- Detail: they should be able to paint you a clear and detailed picture of the activity and situation –as they describe the memory, you get a clear mental image
- Attention and focus: on the scene/ activity…not evaluative or running commentary
- Signs of absorption: sense of flow, loss of sense of time, absorbed, calm, positive

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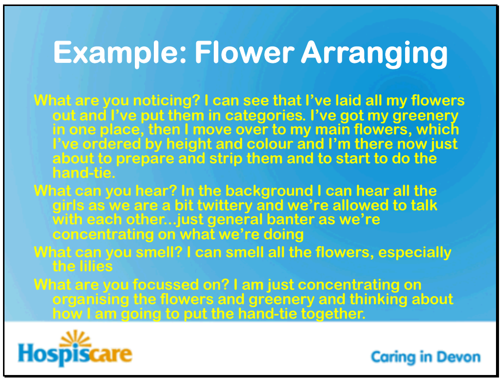

Example: Flower Arranging

What are you noticing? I can see that I've laid all my flowers out and I've put them in categories. I've got my greenery in one place, then I move over to my main flowers, which I've ordered by height and colour and I'm there now just about to prepare and strip them and to start to do the hand-tie.

What can you hear? In the background I can hear all the girls as we are a bit twittery and we're allowed to talk with each other…just general banter as we're concentrating on what we're doing

What can you smell? I can smell all the flowers, especially the lilies

What are you focussed on? I am just concentrating on organising the flowers and greenery and thinking about how I am going to put the hand-tie together.

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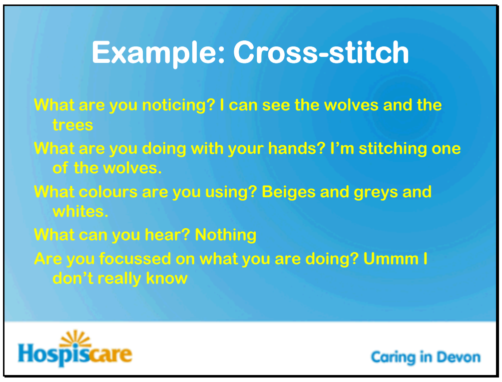
Ask participants...

Is there anything else you'd want to ask? At each bullet point.



Example: Cross-stitch

What are you noticing? I can see the wolves and the trees

What are you doing with your hands? I'm stitching one of the wolves.

What colours are you using? Beiges and greys and whites.

What can you hear? Nothing

Are you focussed on what you are doing? Ummm I don't really know

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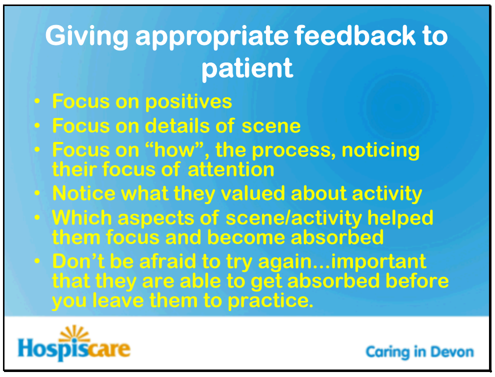
Ask participants...

Is there anything else you'd want to ask? At each bullet point.

What's missing?

Is she really absorbed?

Running commentary?



Giving appropriate feedback to patient

- Focus on positives
- Focus on details of scene
- Focus on "how", the process, noticing their focus of attention
- Notice what they valued about activity
- Which aspects of scene/activity helped them focus and become absorbed
- Don't be afraid to try again…important that they are able to get absorbed before you leave them to practice.

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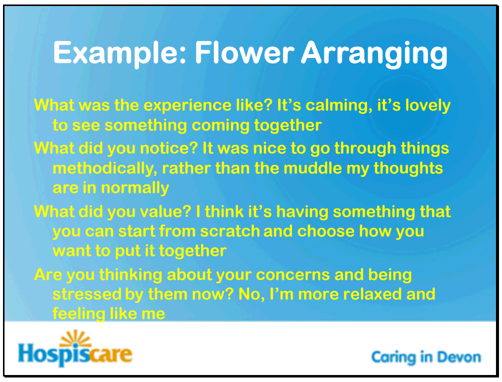

Example: Flower Arranging

What was the experience like? It's calming, it's lovely to see something coming together

What did you notice? It was nice to go through things methodically, rather than the muddle my thoughts are in normally

What did you value? I think it's having something that you can start from scratch and choose how you want to put it together

Are you thinking about your concerns and being stressed by them now? No, I'm more relaxed and feeling like me

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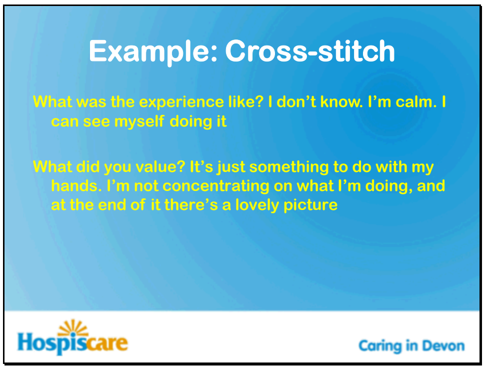
Ask participants...

Is there anything else you'd want to ask? At each bullet point.



Example: Cross-stitch

What was the experience like? I don't know. I'm calm. I can see myself doing it

What did you value? It's just something to do with my hands. I'm not concentrating on what I'm doing, and at the end of it there's a lovely picture

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Ask participants...

Is there anything else you'd want to ask? At each bullet point.

What's missing?

What did you notice?

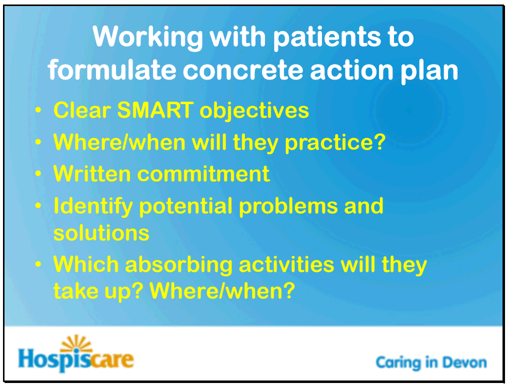
Are you thinking about your concerns and being stressed by them now?

Is she being evaluative?

Is she really absorbed?

What else could I have done?

Try another memory?



Working with patients to formulate concrete action plan

- Clear SMART objectives
- Where/when will they practice?
- Written commitment
- Identify potential problems and solutions
- Which absorbing activities will they take up? Where/when?

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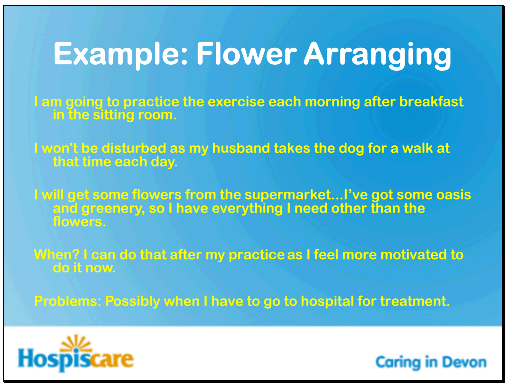
Useful hint: advise patient to use the memory you practiced together for the first week before trying other ones.



Example: Flower Arranging

I am going to practice the exercise each morning after breakfast in the sitting room.

I won't be disturbed as my husband takes the dog for a walk at that time each day.

I will get some flowers from the supermarket…I've got some oasis and greenery, so I have everything I need other than the flowers.

When? I can do that after my practice as I feel more motivated to do it now.

Problems: Possibly when I have to go to hospital for treatment.

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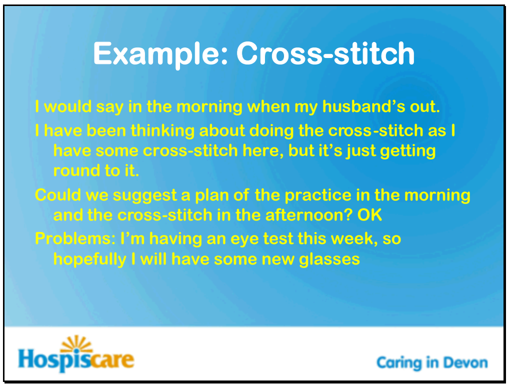
Ask participants...

Is there anything else you'd want to ask? At each bullet point.

Solution to problem. Think about the type of arrangement you want to make and the flowers you will need.



Example: Cross-stitch

I would say in the morning when my husband's out.

I have been thinking about doing the cross-stitch as I have some cross-stitch here, but it's just getting round to it.

Could we suggest a plan of the practice in the morning and the cross-stitch in the afternoon? OK

Problems: I'm having an eye test this week, so hopefully I will have some new glasses

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Ask participants...

Is there anything else you'd want to ask? At each bullet point.

What's missing?

Is it concrete enough?

Specific where and when

Written commitment

Which cross-stitch?

Practice (2 hours approx)

- Attendees work in pairs taking turns in role of patient and professional.
- When in patient role encouraged to use genuine memories to see if they can get absorbed

Feedback (1 hour approx)

- Attendees feedback from practice issues including:
    - Problems and how they addressed them
    - What went well…any phrases or techniques that are worth sharing
    - What did it feel like
- Planning ahead: Attendees formulate concrete action plan for how they will identify and approach patients about guided self-help; what will they do to prepare for practice?

Feedback from practice

- What problems did you have and how did you address them
- What went well? Were there any phrases or techniques that are worth sharing?
- What did it feel like for you…as a patient & as a therapist?

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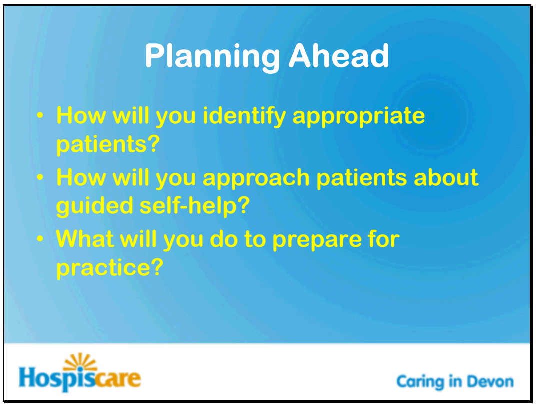

Planning Ahead

- How will you identify appropriate patients?
- How will you approach patients about guided self-help?
- What will you do to prepare for practice?

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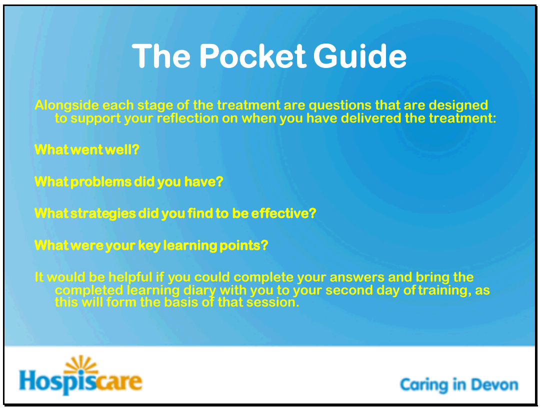

The Pocket Guide

Alongside each stage of the treatment are questions that are designed to support your reflection on when you have delivered the treatment:

What went well?

What problems did you have?

What strategies did you find to be effective?

What were your key learning points?

It would be helpful if you could complete your answers and bring the completed learning diary with you to your second day of training, as this will form the basis of that session.

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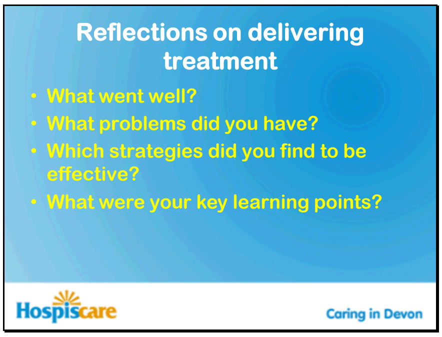
This guide is designed to be used as a quick reference after you have attended the first day of the training programme. The guide covers each stage of the treatment, from identifying appropriate patients, through the treatment itself and then onto formulating a concrete plan with the patient.

DAY 2 (half day)

With reference to their learning diaries, attendees will reflect on their experience with the guided self help treatment. Aim to encourage shared learning and mutual support.



Reflections on delivering treatment

- What went well?
- What problems did you have?
- Which strategies did you find to be effective?
- What were your key learning points?

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Appendix K

Face-valid questions assessing nurses' behaviour, competence and confidence

PSYCHOLOGICAL INTERVENTIONS IN PALLIATIVE CARE RESEARCH SURVEY

When answering the following questions, please think about your clinical practice and patient visits over the last week. The results of this survey will be completely anonymous and used for research purposes only.

1	How many patients have you visited in the last week?	

2	How many of these patients did you ask about their psychological wellbeing?	
3	How many patients did you consider asking, but not ask about their psychological wellbeing?	
4	Why did you not ask them?	

	For the following concerns, please indicate how many patients you spent any time addressing them in the last week:	
5	Physical Concerns (e.g. Pain, drowsiness, nausea, weakness, dyspnoea.)	
6	Social Concerns (e.g. Isolation, lack of information, lack of consultation, role loss, financial strain, burden to others.)	
7	Existential Concerns (e.g. Loss of control, Life dissatisfaction, hopelessness, loss of dignity, loss of meaning, Concern for the future.)	

	How many of the patients you visited did you use the following strategies when addressing their psychological wellbeing:	
8	Advise changes in their medication	
9	Refer them back to their GP	
10	Refer them onto a specific therapy (e.g. CBT, counselling, complementary therapies)	
11	Use supportive listening skills	
12	Teach the patient how to use a different coping strategy (e.g. relaxation, absorption)	

		Not at all	A little	A moderate amount	Very much	Completely
13	How confident are you in assessing the psychological wellbeing of your patients?	1	2	3	4	5
14	How confident are you in your initial management of the psychological concerns of your patients?	1	2	3	4	5
15	How much are your patients dwelling on their concerns, rather than engaging in, and getting the most out of, life?	1	2	3	4	5
16	How effective are you helping your patients engage with life, rather than dwelling on their concerns?	1	2	3	4	5
17	To what extent do you think that your patients have unmet psychological needs?	1	2	3	4	5
18	What are those unmet needs?					

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