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Transformative Experiences in Chronic Conditions

Part 1: Literature Review

Transformative experiences in chronic illness: A systematic review of qualitative research.

Part 2: Empirical Paper

"Journeys through depression": Patients' experiences of transformational change through mindfulness based cognitive therapy (MBCT) and antidepressant medication (ADM).

Submitted by Alice Weaver, to the University of Exeter

as a thesis for the degree of Doctor of Clinical Psychology, May 2015

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: …………………………………………………..

Author's Declaration

The literature review was completed independently by the author. In terms of the empirical work, participants were recruited to the main trial (Kuyken et al., 2015) by a team of researchers. Interviews were conducted between January 2013 and June 2014 and were collected jointly by the author and three other trial researchers. A total of 31 interviews were conducted and transcribed by three trial researchers and 11 by the author. All other aspects of the study were completed by the author including analysis of all 42 interviews and write up.

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SCHOOL OF PSYCHOLOGY

DOCTORATE IN CLINICAL PSYCHOLOGY

LITERATURE REVIEW

Transformative experiences in chronic illness: A systematic review of qualitative research.

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Abstract

Background

     Chronic illness is a major health burden which has a significant impact on individuals' quality of life, wellbeing and relationships. Additionally, chronic illness has major financial implications for healthcare providers. Some patients experience transformative changes through chronic illness resulting in positive outcomes to their well-being as well as changes in their relationships with health professionals. Exploration of patients' transformative experiences could identify important factors in how patients can take control of their own healthcare and gain a sense of ownership over their condition, thereby creating an improvement in their well-being.

Objective

     To draw together themes of transformative experiences across chronic illness by way of a systematic qualitative literature review.

Method

     A systematic search of four databases (PubMed, Web of Science, PsycINFO, and the Cumulative Index to Nursing and Allied Health) was carried out with additional hand searches of key journals and examination of reference lists. Papers that met the inclusion criteria were assessed for quality using the Critical Appraisal Skills Programme (CASP; Public Health Resource Unit, 1998).

Results

     Twenty-nine studies were included in a review of the main themes across studies of chronic illness and transformative change experiences. Emergent

themes were: responsibility, balancing life, relationships with the self and others and rebuilding.

Conclusion

The findings suggest that there are some general features of transformative experience across different types of chronic illness. However, these elements are not consistent throughout the studies and it is unclear which are factors and which are outcomes. Future research could establish a clear definition of transformation in order to inform treatments and benefit patients with chronic illness.

Keywords

chronic illness, transformation, change, qualitative, systematic review

Introduction

Chronic illness has been defined as "a long-lasting condition that can be controlled but not cured" (Center for Managing Chronic Disease [CMCD], 2015) and includes conditions such as diabetes, heart disease, cancer and chronic fatigue syndrome. As well as physical health impacts, these conditions also have a major impact on emotional wellbeing, lifestyle, social relationships and self-esteem (Yeo & Sawyer, 2005). Currently, chronic disease is the leading cause of disability and death in the USA, accounting for 70% of all deaths (CMCD, 2015) and it is also responsible for 60% of all deaths worldwide (WHO, 2015). These conditions kill more people each year globally than all other causes combined (WHO, 2010). With populations increasing, people living longer and obesity levels rising, the cost of treating these conditions will continue to rise; the NHS reportedly "cannot cope" with the demand for healthcare from people with (often multiple) long-term conditions (BBC, 2012). One strong correlate of increased healthcare costs is psychosocial adjustment to illness and psychological distress (Browne, Arpin, Corey, Fitch & Gafni, 1990). Browne and colleagues (1990) split patients into "poor", "fair" and "good" adjusters and found that the difference annually in health costs between poor and good adjusters was $14,000, equivalent to approximately $26,500 today. If then, the demand for health services is only weakly linked with type of illness and prognosis and more strongly linked with disability, patient demand and psychosocial factors, it seems important both in economic terms and for patients' well-being to explore elements of "good" adjustment and the psychosocial factors involved in this.

One area of literature in which these ideas feature strongly is in studies exploring the concept of transformative change experiences in chronic illness. Transformation has been identified in the literature as an ongoing process, which entails growth and in which new experiences occur (Paterson, Thorne, Crawford & Tarko, 1999). The process of transformation can often have an impact on one's philosophy of life and individuals can feel more empowered and hopeful (Mulkins & Vernhoef, 2004). However, the exact definition of transformation in the context of chronic illness is debated in the literature with confusion between a variety of interpretations and overlapping of a number of other concepts, including hope and mastery, as well as definitions focusing on outcome rather than component parts (Paterson et al. 1999). Paterson and colleagues (1999) provide a definition based on process as well as outcome and therefore, for the purposes of this study, transformative change was defined as:

> Transformation as an evolving nonlinear process in which the individual learns to restructure the self and the illness experience through the differentiation of the self…transformation as the result of a conscious decision to identify and interpret a challenge and, in so doing, to create a new relationship with the illness and with those who provide health care. (Paterson,1999).

In a systematic review of transformation in chronic disease, Paterson and colleagues (1999), identified two distinct aspects of transformation which emerge from their literature review: the restructuring of the self, including a separation of the self and diseased body, and the restructuring of the illness experience, involving a change of perspective from seeing illness as a threat to

seeing it as a challenge which must be undertaken (Barton, Magilvy & Quinn, 1994). Outcomes of transformation included a more positive outlook on life (Gloersen et al., 1993), acceptance of illness (Folden, 1994) and an increased expertise which allowed patients to challenge health professionals about their routines (Paterson et al., 1999).

Coulter (2012) argues that patients' active participation in medicine is important for three reasons: patient informed preferences, values and attitudes should inform shared decision-making between patients and professionals, if patients with long-term conditions are able to self-manage their conditions this could substantially reduce the financial burden on the NHS and a more clear focus on patients with care centred around their needs would lead to better outcomes including more trust in clinicians (Keating et al., 2002) and better adherence to treatment (Haynes, Ackloo, Sahota, McDonald & Yao, 2008) . Transformative experiences seem to not only result in an increased sense of well-being in patients with chronic illnesses but also allow them to self-manage their condition by taking control of their condition and gaining a sense of expertise in patient-physician interactions. To sustain our current system of healthcare it seems important to consider the factors which are involved in patient descriptions of transformative change and perhaps, a change in their relationship with healthcare systems.

Although previous reviews have explored transformative change in specific conditions, for example, diabetes (Paterson, 1999) and cancer (Arman & Rehnsfeldt, 2003), none have looked at elements of change across a range of chronic illnesses. Consistent themes across studies could have important implications for care, as well as therapeutic treatments for patients with chronic

illness. Accordingly, this systematic review seeks to examine common themes among adults' transformative experiences through chronic illness.

Methods

This literature review was conducted in line with the Preferred Reporting Items for Systematic Reviews and Meta-Analyses (PRISMA) statement (Moher, Liberati, Tetzlaff, & Altman, 2009). Three stages were involved in the review: (1) systematic literature review, (2) critical appraisal and (3) summary of themes across studies.

Search Strategy

The PICOS tool (Centre for Reviews and Disseminations, 2006) was used to help formulate the search terms and initial scoping exercises were done; final search terms are displayed in table one. A systematic search of four key databases was conducted: PubMed, Web of Science (WoS), PsycINFO, and the Cumulative Index to Nursing and Allied Health (CINAHL). The key words listed in table one were combined using Boolean logic terms "or" and "and". The database searches were limited to the period from January 1990 until December 2014. Reference lists of all potential papers were examined to identify other additional relevant papers and/or chapters. Also, key journals in the field, "Journal of Mental Health" and "Qualitative Health Research" were individually searched using the journals' online search engine.

Table 1. Search terms using PICOS (Centre for reviews and disseminations, 2006)

Population	Intervention	Comparison	Outcome	Study design
Chronic illness	Change	Qualitative data	Patient experience	Qualitative data
chronic illness, chronic condition, chronic disease, chronically ill	Transform$, adaptation, self-concept, identity, reconstruction, agency	Qualitative, grounded theory, thematic analysis, ethnograph$, IPA, discourse analysis, narrative analysis, conversation analysis, phenomenol$	patient experiences, patient views, patient attitudes, patients' understanding	

Inclusion and Exclusion Criteria

      The process by which studies were selected is shown in Figure 1 using the PRISMA flow diagram (Moher et al. 2009) including reasons for exclusion. The initial searches resulted in 2531 abstracts, after which duplicates were removed and 1887 abstracts remained. The titles of the studies were then screened and 75 full-text articles were assessed for eligibility. Inclusion and exclusion criteria were applied to the abstracts in order to identify those relevant to the qualitative review (see table 2).

Table 2. Inclusion/exclusion criteria				
	Participants	Intervention	Condition	Outcome	Types of studies
Inclusion	Participants aged 18 or over with a chronic illness	Transformative change experience as defined by Paterson and colleagues (1999)	A chronic illness as defined by the World Health Organisation (WHO, 1994)	Study is about patient experiences	Qualitative studies in peer-reviewed journals reported in English
Exclusion	Participants who are under 18	General illness experience or experiences about a specific aspect of illness e.g.cognitive factors	Illness that is not chronic	Study about a viewpoint other than that of the patient e.g. of carers or staff members	Quantiative methods, editorials or opinion articles, systematic reviews or meta-synthesis

The main reasons for exclusion included articles not being accessible, the full-text not being available in English, or studies were about general or negative illness experiences rather than transformative ones. From the 75 articles screened, 53 were excluded.
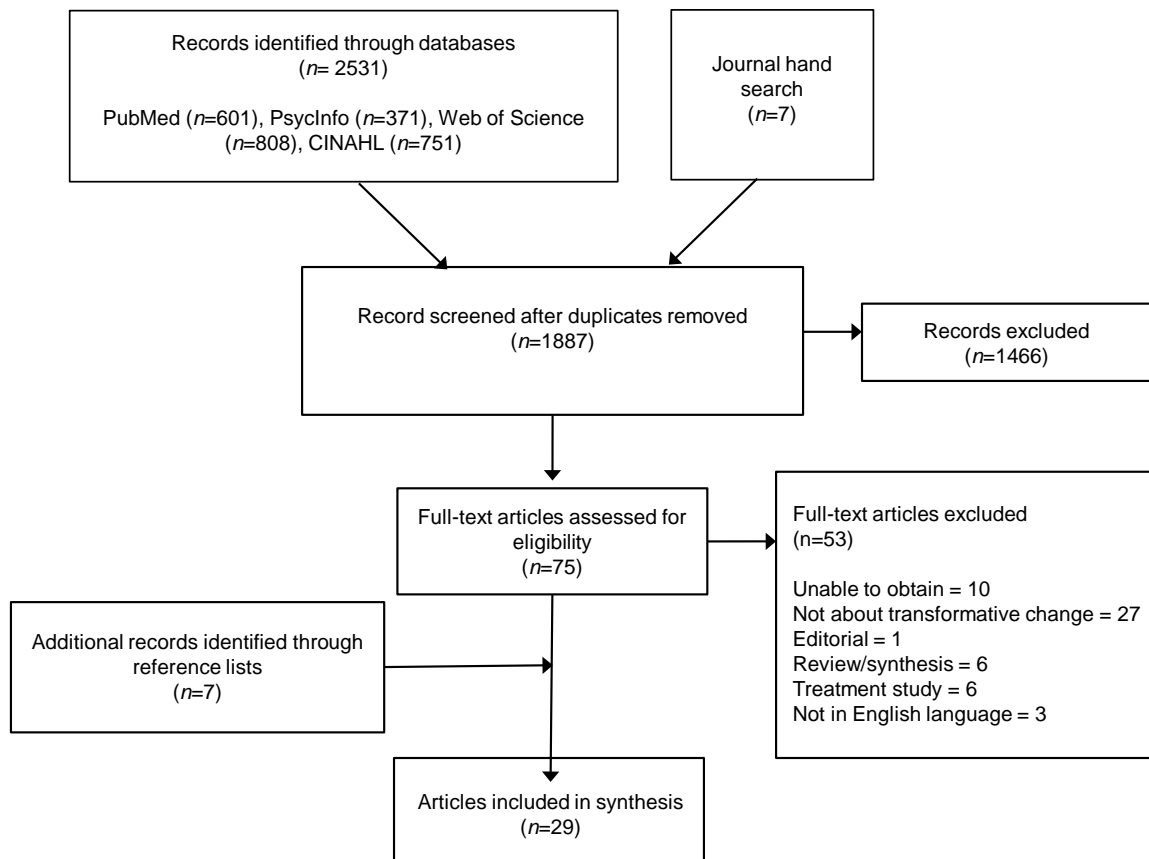

Figure 1. PRISMA flow diagram of inclusion of studies.

Description of Articles Included in Synthesis

Twenty-nine studies representing 21 unique datasets (Baumgartner, 2002 and Baumgartner 2007 use the same dataset) met the inclusion criteria and were included in the synthesis, for their characteristics see table three. All of the articles were published in English between 1993 and 2012 with sample sizes varying from between 1 and 203 with a total of 697 participants.

Evaluation of Quality of Studies

Quality of studies was assessed using the Critical Appraisal Skills Programme (CASP; Public Health Resource Unit, 1998) (see appendix one for full version of the tool). There has been some debate in the literature about tools to assess quality in qualitative systematic reviews (Barbour, 2001). Barbour argues that whilst the creation of checklists for qualitative research has perhaps contributed to the increase in popularity and acceptance of qualitative methods, it is also somewhat reductionist and it is not helpful to uncritically evaluate qualitative research by a range of processes. Nevertheless, checklists, to the inexperienced researcher, new to qualitative work, provide a systematic approach and useful framework to consider quality and rigour in qualitative research, as long as these are used critically (Barbour, 2001). One study comparing three different quality appraisal checklists found that the CASP was a reasonable length and was not too unwieldy and explored a range of content in the research that other checklists did not (Malpass et al., 2009). Accordingly, the CASP was used to evaluate papers in the current review. All studies were appraised and scored with scores ranging from 15-20 (see appendix two for full CASP scoring). Whilst scores varied across studies, no studies were deemed to have significant flaws and all studies were considered valid with clinically

important results (CASP, 2015) and therefore of sufficient quality to remain

included in the review. Some research studies showed areas of methodological

weakness in reporting and these will be discussed later in the critical review. All

29 studies were reviewed (see table three for a brief summary of the studies

and appendix three for a full summary of studies with findings) and are

presented in the following summary of themes.

*Table 3.*Characteristics of studies.

Study	Type of chronic illness	Sample, age and gender	Country	Aim of study	Study design	Theoretical stance and approach to data analysis	CASP score
Asbring (2000)	CFS/Fibromyalgia	*N*=25 females (12 with CFS and 13 with fibromyalgia, 32-65 years)	Sweden	To describe how women with CFS and fibromyalgia create new concepts of identities after onset of illness and how they come to terms with these new identities	Semi-structured interviews	Thematic analysis	17
Baker & Stern (1993)	Diabetes, renal failure, cardiovascular disease, bowel cancer	*N*=12 (4 male, 8 female, 18-65 years)	USA	To investigate how readiness to engage in self-care develops in people with a chronic illness	Open-ended interview schedule	Grounded theory	19
Baumgartner (2002)	HIV/AIDS	*N*=11 (7 male, 4 female, all 31-49 years except 1 male of 61 years)	USA	To explore the nature of learning during the incorporation of HIV/AIDS identity over time.	Semi-structured interviews	Narrative methods	19

Baumgartner (2007)	HIV/AIDS	N=11 (7 male, 4 female, all 31-49 years except 1 male of 61 years)	USA	To examine how people incorporate HIV/AIDS identity into their selves over time	Semi-structured interviews	Narrative methods.	18
Baumgartner (2009)	HIV (not AIDS)	N=14 (9 male, 4 female, 1 transgender, 25-52 years)	USA	To describe the process of incorporation of HIV identity into the self over time	Semi-structured interviews	Grounded theory	17
Brown & Addington-Hall (2008)	Motor neurone disease (MND)	N=13 (9 male, 4 female, 39-85 years)	UK	To explore experiences of living and coping with MND	Narrative interviews	Narrative analysis	19
Charmaz (1994)	Chronic illness (no specific info.)	N=20 males (>21 years)	USA	To examine the impact of chronic illness on identity in men	Semi-structured interviews	Grounded theory	16
Charmaz (1995)	Heart disease, diabetes, cancer, emphysema, CFS, rheumatoid & autoimmune diseases	N=55 (>21 years)	USA	To examine how the body, identity and the self-intersect in illness	Semi-structured interviews	Grounded theory	16

Courtenay et al. (1998)	HIV positive	*N*=18 (10 male, 8 female, 23-45 years)	USA	To understand how meaning constructed in the lives of those who are HIV positive	Semi-structured interviews	Grounded theory	18
Courtenay et al (2000)	HIV positive	*N*=14 (8 male, 6 female, 13 aged 25-47 years, 1 aged 59 years)	USA	To follow up adults from the previous Courtenay et al. (1998) study to see if they had maintained their perspectives and if there were any further transformations	Semi-structured interviews	Grounded theory	19
Curtin et al. (2002)	Kidney failure - on dialysis for 16 years or more	*N*=18 (10 male, 8 female, 38-63 years)	USA	To examine processes involved in some kidney patients' abilities to survive whilst on dialysis	Semi-structured interviews	Thematic analysis	18

Dekkers, Uerz & Wils (2005)	End-stage renal failure - on dialysis for at least 2 years	*N*=7 (2 male, 5 female, 55-82 years)	Netherlands	To examine how people with end-stage renal disease "live well" with chronic illness from a virtue ethics and moral perspective.	Semi-structured interviews	IPA	16
Gibson et al (2005)	Multiple Chemical Sensitivity (MCS).	*N*=203 (average age = 47)	USA	To investigate changes in identity in people with MCS.	Questionnaires	Thematic analysis	18
Hwang, Kim & Jun (2004)	Rheumatoid Arthritis (RA) for between 4-12 years	N=5 females (34-61 years)	Korea	To explore illness experience of Korean women with RA	Semi-structured interviews	Phenomenological method	15
Kalitzkus & Matthiessen (2010)	Fibromyalgia	N=1 female	Germany	To understand the process of one patient's personal growth in chronic illness	Narrative interview	Narrative analysis	17
Kirkpatrick Pinson, Ottens & Fisher (2009)	Progressive MS for at least 8 years	*N*=10 females (46-68 years)	USA	To explore why some women with Multiple Sclerosis (MS) cope	Semi-structured interviews	Thematic analysis	16

				successfully despite progression of condition			
Lindsey (1996)	Chronic illness (no specific info.)	N=8 adults	Canada	To explore the meaning of feeling healthy for people with chronic illness	Conversations with participants, using Carson's (1986) recommendations	IPA	17
Molzahn, Bruce & Sheilds (2008)	Chronic Kidney Disease (CKD)	*N*=100 (62 male, 38 female, 21-88 years)	Canada	To describe patients' experiences of liminality associated with CKD	A secondary analysis of narratives collected for a book produced in order to educate people about CKD	Narrative analysis	15
Paterson et al. (1999)	Type I diabetes which was well managed	*N*=22 (8 male, 14 female, 24-81 years)	Canada	To attempt to explicate the structure and process of transformation in people with chronic illness.	Individual and focus group interviews as well as the "think-aloud" technique where participants record decisions about daily living for a one week period	Grounded theory	18
Price et al. (2012)	Stroke	N=1 male (in his seventies)	USA	To explore resiliency following stroke,	Semi-structured interviews	Narrative analysis	17

				especially its role in supporting continuity of identity			
Prodinger & Stamm (2010)	Rheumatoid Arthritis for at least 10 years	*N*=6 females (no info.)	Austria	To explore taken-for-granted practices in the health care system for women who think of RA as a challenging and enriching experience	A secondary analysis of a subset of women from Stamm et al. (2008) study. Interview material and re-written life stories were revisited by the authors.	Secondary thematic analysis focused on data marginalised in the primary analysis and was influenced by a critical feminist perspective.	18
Räty & Wilde-Larsson (2011)	Epilepsy (out-patients)	*N*=19 (7 male, 12 female, 20-65 years)	Sweden	To describe the perceptions of people with epilepsy and how it is to live with their condition.	Semi-structured interviews	Phenomenographic method	18
Shearer (2007)	Chronic heart disease, chronic respiratory problems, diabetes and stroke	N=14 females (69-94 years)	USA	To understand the experience of empowerment in housebound older women.	Semi-structured interviews	Phenomenological method	17
Sinclair & Blackburn	Rheumatoid arthritis	*N*=19 females (24-	USA	To examine coping patterns	Semi-structured interviews	Thematic analysis	17

(2008)		68 years)		of women with RA.			
Stamm et al. (2008)	Rheumatoid Arthritis	*N*=10 (no info.)	Austria	To explore the narrative life stories of people with rheumatoid arthritis (RA).	Narrative interviews	Narrative biographic method and thematic analysis	20
Thornhill et al. (2008)	Congestive heart failure (13 out-patients, 12 in-patients)	*N*=25 (21 male, 4 female, 35-83 years)	UK	To explore peoples' experiences of congestive heart failure.	Semi-structured interviews	IPA	19
Tsarenko & Polonsky (2011)	HIV (diagnosis >10 years ago)	*N*=15 (8 male, 7 female, 33-60 years)	Australia	To explore the impact of a HIV diagnosis on one's identity and the role that engagement (taking ownership) over this plays.	Semi-structured phenomenological interviews	Hermeneutical perspective.	18
Watts et al. (2010)	Type I diabetes	*N*=4 (2 male, 2 female, 20-67 years)	UK	To explore the experiences of people with type I diabetes and how it is integrated with their lives and identities.	Semi-structured interviews	Data was analysed using thematic decomposition (Stenner, 1993) and presented on a person-by-person (rather than theme-by-theme) basis.	15

Whitehead (2006)	CFS/ME	*N*=17 (6 male, 11 female, 13-63 years)	UK	To examine the reconstruction of identity in people with CFS/ME	Unstructured interviews	Thematic analysis	20

Results

All papers were read multiple times and the main themes relating to transformational change experiences through chronic illness were identified. Themes frequently identified across papers were then grouped to form a broad picture of collective participants' experiences. The review across studies revealed the following themes of responsibility, balancing life, relationships and rebuilding.

Responsibility

Self-management, responsibility and control. Long term dialysis survivors conceptualised transformation as comprehensive, active, self-management of life with illness (Curtin et al., 2002). Control was an essential aspect of their transformative experience, both over their treatment and their life. This sense of control and self-management allowed them to come to a state of balance and equilibrium in their lives and to integrate their illness into themselves (Curtin et al., 2002). Patients living with epilepsy (Räty & Wilde-Larsson, 2011) and HIV (Tsarenko & Polonsky, 2011) also had positive experiences of gaining and maintaining control and taking responsibility and ownership of their conditions. One participant found that she had been able to feel in control of her diabetes by sticking to a strict regime, this had been beneficial in other areas of her life and she was a more disciplined, organised, responsible and motivated person because of her condition (Watts et al., 2010). In Brown and Addington-Hall's (2007) study of people with MND, one man described taking control of his life and his choice of treatment which in turn gave him a more positive frame of mind: "I think part of it is that you actually feel 'I am doing something myself to take control of this disease' and I think having

positive thoughts and feeling like you are actually doing something can help, certainly with your frame of mind" (p.205). For womens' chronic illness, the act of choosing to ask for help meant that they felt in control and it reinforced their personal strengths (Shearer, 2007). Women saw RA as a "source of new challenges" (p. 662); they described not just adapting to the illness but mastering it by gaining new skills and knowledge, with many women using these new found skills to actively engage in challenge in their lives, for example by taking on more demanding activities and jobs than pre-RA (Stamm et al., 2008). Additionally, some women described becoming an active agent in the health care system by becoming more aware of what they knew about their illness (in the face of medical authority), resulting in a feeling of increased self-efficacy and empowerment (Prodinger & Stamm, 2010).

Balancing life

Baumgartner (2007) found that people with a diagnosis of HIV valued creating a balance in life and an orientation towards the future by using self-care. Across studies a balanced life seemed to include themes of both transcendence and ascendance to the illness.

Transcendence of illness experience. Women in Asbring's (2000) study of people with CFS/fibromyalgia recognised the transcendence of their illness experience, "another self, outside of the normal self" (p. 315), as a key part of a positive transformation in their identity. For eight adults in Canada with a range of chronic illnesses, transcendence of the self was attained by using visualisation and imagery as a form of escaping the ill self and was a way in which they could continue to feel healthy (Lindsey, 1996).

Assent to illness experience. Participants with a variety of chronic illnesses (Baker & Stern, 1993), and those with chronic kidney disease (Molzhan et al., 2008) found that assenting to their condition allowed them the freedom to re-frame the chronicity of their illness in a positive way and to compare themselves in a favourable way to others. Dekkers and colleagues (2005) also found this; people with kidney failure often compared themselves to others as a way of putting things into perspective.

Struggling *with* illness rather than against it allows people to regain control in their lives and enables them to learn to live with their illness (Charmaz, 1995). People with chronic illness were able to "surrender to their sick body" (p.675), thereby allowing them to newly experience themselves, foster redemption, deeper levels of awareness and courage and transcendence of self (Charmaz, 1995). This study emphasised that these processes were often cyclical rather than linear.

Relationships

With self: increase in self-respect, self-efficacy, awareness and acceptance. Asbring (2000) found that many women with CFS and fibromyalgia interviewed had experienced an increase in self-respect and personal integrity. This offered a fuller understanding of themselves and often led to a more favourable identity than before their illness. Patients with MCS found strength in adversity, becoming emotionally stronger and more confident (Gibson et al., 1995).

For people with diabetes (Paterson et al., 1999) and those with kidney failure (Curtin et al., 2002) elements of transformation included increased self-awareness, and self-control which often resulted in a changed view of the self

with increased self-confidence, self-efficacy and hope. A female with fibromyalgia described a similar process in which her illness forced her to increase her self-care, self-awareness and self-appraisal, and in doing so she was able to feel some control over her illness and gain a positive outlook on life (Kalizkus & Matthiessen, 2010).

With others: emotional/social support and helping/educating others. Participants with a diagnosis of HIV (Baumgartner, 2007) recognise the need, often soon after diagnosis, for emotional support from friends and family (Baumgartner, 2009) but also the need to immerse themselves in a community of people with similar conditions. Additionally, they realised over time the importance of "de-centralising" and acknowledging they are more than their "HIV or AIDS identities". Focus on new relationships and getting back to work (Baumgartner, 2007) or to make meaningful contribution to others (Baumgartner, 2002) was important. For one female with fibromyalgia this was also true as her illness made her determined to improve relationships with family and to look for meaningful ways to engage with others (Kalitzkus & Matthiessen, 2010). Cross-culturally this finding seems consistent; Thai women with RA described the support of family and friends as being important and a 'new life' which incorporates caring for and supporting others (Hwang et al., 2004). One difference in this population of people was the importance of religion in coping with the disease: ''I always go to a Buddhist temple to worship for recovery from the disease." (p. 243), an emphasis not seen in any other paper reviewed.

Patients with renal failure also emphasised the importance of relationships with others and being able to care for others in meaningful

relationships (Dekkers et al., 2005). Gaining meaningful experiences and helping others often enabled patients with HIV (Courtenay et al., 1998) and RA (Sinclair & Blackburn, 2008) to gain a deeper appreciation for life and compassion for other people (Courtenay et al., 1998). Hope and emotional support from family and friends as well as health professionals was important in change in MS (Kirkpatrick Pinson et al., 2009).

Rebuilding

Re-evaluation of life – change in values and priorities, focus on future. Some studies described one factor of transformation being a re-evaluation of life with a change in values and priorities and a focus on the future. Women with RA described the condition as having given them a new perspective on life with a change in values "*I have learned and grown through having arthritis. I think it has made me more compassionate and more patient in some areas*" (p.225), and an increased ability to empathise with others (Sinclair & Blackburn, 2008). This finding was echoed by some people with chronic kidney disease who had experienced an increase in patience (Molzhan et al., 2008). Similarly, Asbring (2000) investigated the change in women's identities after a diagnosis of CFS/fibromyalgia and they often described having a more favourable identity post-illness and that their illness, seen as a positive event, had allowed for "space for thought" (p. 317) and a re-evaluation of life and change in attitude. For one man in Baker and Stern's (1993) study, his illness allowed him to re-evaluate life and he realised he needed to "live" rather than "survive" (p. 31). Eight Canadians with chronic illness (Lindsey, 1996) described illness as a challenge through which they can learn and grow with life now

having a strong sense of purpose and motivation: "It is moving beyond the ordinary, it's saying, 'OK, this is where I am at, but I can do more" (p. 469).

The experience of chronic illness was described as creating more meaningful experiences in people with HIV (Courtenay, 1998), creating a purpose and deeper appreciation of life and other people and becoming more future oriented (Courtenay, 2000). This optimism was shared by those in Baumgartner's study (2002) and by women with RA (Sinclair & Blackburn, 2008), as well as a heightened sensitivity to life and re-evaluation of values. For people with heart failure their illness had initiated positive lifestyle changes and self-improvement (Thornhill et al., 2008). Shearer (2007) found that house-bound women with chronic illness had engaged in making life plans with goals for the near future, for some, life plans including considerations for worsening health.

Rebuilding self: identity with illness incorporated, deeper understanding of self. Some studies named several factors in the process of re-building the self in transformation. For patients with kidney failure (Curtin et al., 2002) and patients with HIV (Courtenay et al., 2000), illness became a part of themselves and their identity which led to a restructuring of themselves (Curtin et al., 2002). In men also, chronic illnesses was viewed as an ally, allowing for integration of it into their identity and lives and using it as an opportunity to reflect and change (Charmaz, 1994). In fact, people with CFS said that their newly constructed self was valued more than their old self (Whitehead, 2006). Baumgartner (2002) found these changes were stable over time in a HIV population. Whilst, Baker and Stern (1993) found that for those

who were unable to accommodate their illness into their identity, they saw themselves as chronically incapacitated and "sick".

People with epilepsy described becoming more tolerant and humble as a result of having the condition and also becoming more understanding and less judgemental towards other's difficulties and hardships in life (Räty & Wilde-Larsson, 2011).

Critical Review

Some studies had methodological issues which should be highlighted. Kirkpatrick Pinson and colleagues (2009) recruited women with MS who were "successfully coping" with MS. Part of the inclusion criteria was no current major depression, measured by the Beck Depression Inventory Fast-Screen (Beck, Steer & Brown, 2000), although there is no information about whether they used a cut-off score or if they excluded anyone because of this. It also could be argued that someone could be well adjusted and successfully coping *and* also be experiencing a depressive episode. This may have limited their breadth of data collection in this group of people. Additionally, Watts and colleagues (2010) gave no information about how participants with diabetes were recruited and therefore it is difficult to know if this is a representative population. Furthermore, the paper mentions that the researcher conducting the interviews has recently been diagnosed with diabetes and the participants were informed of this, however, it does not mention any reflections on how this may have affected analysis of the data.

There are a wide range of time-frames in which data was collected in these studies with some collecting data months after diagnosis and others decades afterwards, often with participants only being interviewed once;

therefore, whilst general themes can be identified, there is not enough information at certain stages of illness to speak to how the themes may develop across time.

The majority of studies used the interview method of data collection, however, there has been much critique of interviews as a method and indeed there is no consensus as to what defines "quality" in interviews (Roulston, 2010). For some, credibility and thoroughness are used as definitions of quality (Rubin & Rubin, 2005) whilst for other researcher's validity is the term deemed to be more applicable (Kvale, 1996). Regardless of definition, it is difficult to judge the quality of the interviews included in this review as the majority of papers did not describe the nature of the interview or specific interview questions used.

Other debates around interviews involve issues of self-reflexivity, in terms of how interviewer characteristics could influence data collection (Pezalla, Pettigrew & Miller-Day, 2012) and the ethical worries around the power imbalance of interviewing vulnerable people such as those with chronic illness who may not have the resources to set their own agenda (Plesner, 2011). Only a handful of papers discussed the relationship between interviewer and participant including considerations of their own role, potential bias or influence and while some detailed using research teams as an aid for reflexivity, none detailed what this entailed, the findings or how this may have influenced future interviews. The issue of power and how it was dealt with was not discussed in any papers and it may have had an impact on ethics around the process of data collection as well as the data itself.

The final criticism of the reviewed body of literature is around the themes and construction of themes. Many papers talk about transformation as a process, whilst others name it as an outcome of living with a chronic illness. This happens across themes however one example is in the theme "rebuilding" in which Curtin and colleagues (2002) identified that one element in the transformation process in patients with kidney failure was that the illness became a part of their identity which led to a restructuring of themselves. Conversely, Whitehead and colleagues (2006) seem to talk about the same concept as an *outcome* of transformation. It is clear, from this review, that the factors involved in transformation are not clearly distinct from the outcomes. Moreover, many studies discuss integration of the illness into their identity as a process which allows participants, for example, to be more engaged with other people and have a greater appreciation for life. However, the idea that people engaging with others and life may *lead* to integration of the illness into the self does not seem to be discussed.

Discussion

A review of the literature exploring transformative experiences in chronic illness was conducted. Themes emerging across studies were: responsibility, balancing life, relationships with the self and others and rebuilding. Patients valued their illness as a positive process and experience which has involved balancing life, sometimes assenting to their illness, living *with* it rather than against it, though sometimes challenging it. The experiences involve gaining more responsibility (both in terms of their illness and life in general), have increased their self-awareness, self-efficacy and self-worth, creating meaningful experiences, has initiated a re-assessment of values and has given them a new

optimism for the future. These themes resonate with other literature on transformation in serious, rather than chronic, illness (Salick & Auerbach, 2006). However, it should be noted that in many of the papers identified, whilst people talked about positive transformation, in the same interview they also talked about feeling hopeless in the face of illness, for example in Asbring and colleague's study (2001) they found that in spite of new insights or changes women still expressed sadness and grief over parts of their identity associated with a healthy life which had been lost.

Some themes were consistent across studies; transformation was described by the majority of studies as an evolving, non-linear process which seems to be prompted by seeing illness as a challenge and included key elements including changes in self-awareness, self-efficacy, control and acceptance. However, there were numerous inconsistencies between papers around whether elements such as a change in life values or engaging with others were part of the process of transformation or an outcome. Moreover, themes were identified but then not discussed in relation to other concepts, for example, if more self-awareness led to increased acceptance or transcendence of the self? These findings indicate that research to identify a more defined characterisation of transformative change is needed before the concept could be used to inform treatments or care of patients with chronic illness.

Often, it seems, in the literature attention is paid to negative experiences of illness. Experiences in the studies reviewed indicate that people do have positive experiences of transformation during chronic illness. It seems important for the future therefore to focus on positive aspects of illness; how people with chronic illness can improve their well-being and how active self-management of

their illness can be facilitated in order to decrease burden on the NHS and other healthcare systems. It is important that clinicians know the elements that are important in peoples' transformative experiences to allow them to identify treatments that may be of therapeutic benefit.

One limitation of this work is the focus on the term "transformational experience". Whilst this broad term captured a large amount of literature, this review shows that there are numerous conceptualisations of this term and there may still be areas of experience which perhaps were not identified by this term. Future work should address which elements are part of the process of transformation and which are outcomes. Additionally, the search for studies included general terms such as "chronic illness" with a view to identifying common themes of transformation across illnesses. Whilst this was useful in gaining a breadth of papers across chronic illness, the exclusion of more specific search terms may have led to an under or over representation of some conditions in the review, for example HIV/AIDS was perhaps over represented. In future reviews more specific illnesses could also be named in search terms such as stroke or breast cancer. Finally, this search did not use a second rater, which would have increased reliability of the findings, and did not review books, editorials, opinion articles or grey literature, which may have widened the findings.

Conclusion

From this review, it is clear that more work is needed to explore what exactly is meant by the concept of transformation; which elements are part of the process and which are an outcome. This review has shown some clear themes across peoples' transformative change experiences in chronic illness, however, it has

not been able to identify the relationship between concepts or which may be contributors to transformation and which are outcomes. Clear identification of the underlying factors and their relationship to one another could promote therapeutic change in patients with chronic illness; this is essential not only for patient well-being but also for the shift that is needed in patients self-management of their illness and the economic and financial benefits that would come with this for the healthcare system.

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Appendices

Appendix A: CASP tool

Critical Appraisal Skills Programme

10 questions to help you make sense of qualitative research

How to use this appraisal tool

Three broad issues need to be considered when appraising the report of a qualitative research:

- **Are the results of the review valid?**
- **What are the results?**
- **Will the results help locally?**

The 10 questions on the following pages are designed to help you think about these issues systematically. The first two questions are screening questions and can be answered quickly. If the answer to both is "yes", it is worth proceeding with the remaining questions.

There is some degree of overlap between the questions, you are asked to record a "yes", "no" or "can't tell" to most of the questions. A number of italicised prompts are given after each question. These are designed to remind you why the question is important. Record your reasons for your answers in the spaces provided.

There will not be time in the small groups to answer them all in detail!

Screening Questions

1. Was there a clear statement of the aims of the research?

☐ Yes ☐ Can't tell ☐ No

HINT: Consider
- What was the goal of the research?
- Why it was thought important?
- Its relevance

2. Is a qualitative methodology appropriate?

☐ Yes ☐ Can't tell ☐ No

HINT: Consider
- If the research seeks to interpret or illuminate the actions and/or subjective experiences of research participants
- Is qualitative research the right methodology for addressing the research goal?

Is it worth continuing?

<u>Detailed questions</u>

3. Was the research design appropriate to address the aims of the research?

☐ Yes   ☐ Can't tell   ☐ No

HINT: Consider
- If the researcher has justified the research design (e.g. have they discussed how they decided which method to use)?

4. Was the recruitment strategy appropriate to the aims of the research?

☐ Yes   ☐ Can't tell   ☐ No

HINT:Consider
- If the researcher has explained how the participants were selected
- If they explained why the participants they selected were the most appropriate to provide access to the type of knowledge sought by the study
- If there are any discussions around recruitment (e.g. why some people chose not to take part)

5. Was the data collected in a way that addressed the research issue?   ☐ Yes   ☐ Can't tell   ☐ No

HINT: Consider
- If the setting for data collection was justified
- If it is clear how data were collected (e.g. focus group, semi-structured interview etc.)
- If the researcher has justified the methods chosen
- If the researcher has made the methods explicit (e.g. for interview method, is there an indication of how interviews were conducted, or did they use a topic guide)?
- If methods were modified during the study. If so, has the researcher explained how and why?
- If the form of data is clear (e.g. tape recordings, video material, notes etc)
- If the researcher has discussed saturation of data

6. Has the relationship between researcher and participants been adequately considered?   ☐ Yes   ☐ Can't tell   ☐ No

HINT: Consider
- If the researcher critically examined their own role, potential bias and influence during
  (a) Formulation of the research questions
  (b) Data collection, including sample recruitment and choice of location
- How the researcher responded to events during the study and whether they considered the implications of any changes in the research design

7. Have ethical issues been taken into consideration?   ☐ Yes   ☐ Can't tell   ☐ No

HINT: Consider

- If there are sufficient details of how the research was explained to participants for the reader to assess whether ethical standards were maintained
- If the researcher has discussed issues raised by the study (e.g. issues around informed consent or confidentiality or how they have handled the effects of the study on the participants during and after the study)
- If approval has been sought from the ethics committee

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8. Was the data analysis sufficiently rigorous?   ☐ Yes   ☐ Can't tell   ☐ No

HINT: Consider

- If there is an in-depth description of the analysis process
- If thematic analysis is used. If so, is it clear how the categories/themes were derived from the data?
- Whether the researcher explains how the data presented were selected from the original sample to demonstrate the analysis process
- If sufficient data are presented to support the findings
- To what extent contradictory data are taken into account
- Whether the researcher critically examined their own role, potential bias and influence during analysis and selection of data for presentation

9. Is there a clear statement of findings?

☐ Yes   ☐ Can't tell   ☐ No

HINT: Consider

- If the findings are explicit
- If there is adequate discussion of the evidence both for and against the researchers arguments
- If the researcher has discussed the credibility of their findings (e.g. triangulation, respondent validation, more than one analyst)
- If the findings are discussed in relation to the original research question

10. How valuable is the research?

HINT: Consider

- If the researcher discusses the contribution the study makes to existing knowledge or understanding e.g. do they consider the findings in relation to current practice or policy?, or relevant research-based literature?
- If they identify new areas where research is necessary
- If the researchers have discussed whether or how the findings can be transferred to other populations or considered other ways the research may be used

Appendix B: CASP scoring

Study	1. Aims	2. Qual appropriate	3. Design appropriate?	4. Recruitment appropriate?	5. Data collection	6. Relationship - research and ps	7. Ethical issues	8. Data analysis	9. Clear findings	10. How valuable?	Total
Asbring (2000)	2	2	2	2	2	1	2	2	1	1	17
Baker & Stern (1993)	2	2	2	2	2	1	2	2	2	2	19
Baumgartner (2002)	2	2	2	1	2	2	2	2	2	2	19
Baumgartner (2007)	2	2	2	2	2	1	2	1	2	2	18
Baumgartner (2009)	2	2	2	1	2	1	2	2	2	1	17
Brown & Addington-Hall (2008)	2	2	2	2	2	1	2	2	2	2	19
Charmaz (1994)	2	2	2	1	2	1	1	2	2	1	16
Charmaz (1995)	2	2	2	1	2	1	1	2	2	0	15
Courtenay et al. (1998)	2	2	2	2	2	1	1	2	2	2	18
Courtenay et al (2000)	2	2	2	2	2	2	1	2	2	2	19
Curtin et al. (2002)	2	2	2	1	2	1	2	2	2	2	18
Dekkers, Uerz & Wils (2005)	2	2	2	1	2	1	1	2	2	1	16
Gibson et al (2005)	2	2	2	2	1	1	2	2	2	2	18
Hwang, Kim & Jun (2004)	2	2	2	1	1	0	1	2	2	2	15
Kirkpatrick Pinson, Ottens & Fisher (2009)	2	2	2	1	1	1	2	1	2	2	16
Kalitzkus & Matthiessen (2010)	2	2	2	1	2	1	2	2	1	2	17
Lindsey (1996)	2	2	2	1	2	1	1	2	2	2	17
Molzahn, Bruce & Sheilds (2008)	2	2	1	1	2	0	2	1	2	2	15
Paterson et al. (1999)	2	2	2	2	2	1	1	2	2	2	18
Price et al. (2012)	2	2	2	1	2	1	1	2	2	2	17
Prodinger & Stamm (2010)	2	2	2	1	2	2	2	1	2	2	18
Räty & Wilde-Larsson (2011)	2	2	2	1	2	2	2	1	2	2	18
Shearer (2007)	2	2	2	1	2	1	2	1	2	2	17
Sinclair & Blackburn (2008)	2	2	2	1	2	1	2	1	2	2	17
Stamm et al. (2008)	2	2	2	2	2	2	2	2	2	2	20
Thornhill et al. (2008)	2	2	2	2	2	2	1	2	2	2	19
Tsarenko & Polonsky (2011)	2	2	2	2	2	1	2	2	2	1	18
Watts et al. (2010)	2	2	2	1	2	2	1	2	0	1	15
Whitehead (2006)	2	2	2	2	2	2	2	2	2	2	20
0= no, 1=can't tell, 2=yes											

Appendix C: Full summary table with findings

Study	Type of chronic illness	Sample, age and gender	Country	Aim of study	Study Design	Theoretical stance and approach to data analysis	Findings
Asbring (2000)	CFS/ Fibromyalgia	N=25 females (12 with CFS and 13 with fibromyalgia, 32-65 years)	Sweden	To describe how women with CFS and fibromyalgia create new concepts of identities after onset of illness and how they come to terms with these new identities	Semi-structured interviews about experience of illness, consequences and coping.	Thematic analysis	Biographical disruption caused by illness leads to transformation of identity. Illness creates 'space for thought' and a re-evaluation of life. Positive gains of illness included increased self-respect/personal integrity. Transcendence of illness experience and created more favourable identity than previous.

| Baker & Stern (1993) | Diabetes, renal failure, cardiovascular disease, bowel cancer | *N*=12 (4 male, 8 female, 18-65 years) | USA | To investigate how readiness to engage in self-care develops in people with a chronic illness | An open-ended interview schedule covering topics about the illness and its history, social life and self-care attitudes and behaviours. Data was triangulated through interviews with patients' nurses and also other nurses working in other areas of chronic illness (e.g. diabetes clinics). | Grounded theory | Those who were able to self-manage their illness perceived chronicity in a positive way. Finding meaning in chronic illness was achieved by assenting to it and by reframing its meaning in their life. Some participants talked about illness forcing them to re-evaluate their life and the need to "live" rather than to "survive". Taking control of their illness and actively managing their own self-care resulted in them feeling "normal". |

Baumgartner (2002)	HIV/AIDS	N=11 (7 male, 4 female, all 31-49 years except 1 male of 61 years)	USA	To explore the nature of learning during the incorporation of HIV/AIDS identity over time.	Semi-structured interviews about the nature of learning over time in incorporating their HIV/AIDS into their identity.	Narrative methods	Transformative experiences and change in perspective remained stable over time. Participants also described their condition resulting in an increased appreciation for the human condition, increased acceptance and an expanded view of intimacy.
Baumgartner (2007)	HIV/AIDS	N=11 (7 male, 4 female, all 31-49 years except 1 male of 61 years)	USA	To examine how people incorporate HIV/AIDS identity into their selves over time	Semi-structured interviews were conducted three times over four years about a range of topics; meaning-making, feelings pre and post diagnosis, process of identity incorporation and learning from that, faith development	Narrative methods.	Following diagnosis participants immersed themselves in the HIV/AIDS community whereby their HIV identity became most salient for them. Part of incorporation of identity involved a move away from immersion over time towards "de-centralising"; realising they were more than their HIV/AIDS identities. Also participants balanced their lives - focused on the future in terms of new

					and coping.		relationships/returning to work. Disclosure about diagnosis to others was another important part of identity incorporation.
Baumgartner (2009)	HIV (not AIDS)	*N*=14 (9 male, 4 female, 1 transgender, 25-52 years)	USA	To describe the process of incorporation of HIV identity into the self over time	Semi-structured interviews including main topics of learning about HIV and identity incorporation of HIV.	Grounded theory	Participants experienced "turning points" post-diagnosis which jarred them out of their negative emotional reaction and were integral to the identity incorporation process. Turning points involved emotional support, education about HIV and medical intervention. Integration involved support from inside and outside HIV

							community, educating others and a re-evaluation/change in salience of other identities e.g. work, spiritual etc.
Brown & Addington-Hall (2008)	Motor neurone disease (MND)	*N*=13 (9 male, 4 female, 39-85 years)	UK	To explore experiences of living and coping with MND	Three narrative interviews over an 18 month period exploring experiences of living and coping with MND	Narrative analysis	Four narrative storylines were identified: sustaining, preserving, enduring and fracturing. Sustaining and preserving narrative in particular emphasised coping with illness by maintaining a positive outlook on life, taking control and seeking sources of hope.

Charmaz (1994)	Chronic illness (no specific info.)	N=20 males (>21 years)	USA	To examine the impact of chronic illness on identity in men	Semi-structured interviews gaining insight into the situations and perspectives of men with chronic illness and a collection of personal accounts.	Grounded theory	Findings indicated that some men experienced their illness as a positive experience and through which their life has changed for the better. Illness was seen by some as an "ally" which can be used as an opportunity to reflect and change.
Charmaz (1995)	Heart disease, diabetes, cancer, emphysema, CFS, rheumatoid & autoimmune diseases	N=55 (>21 years)	USA	To examine how the body, identity and the self intersect in illness	Interviews about experiences of chronic illness, then further, more focused, interviews about body in illness.	Grounded theory	Struggling with illness rather than against it allowed people to regain control over their bodies and lives, thereby learning to live with their illness. "Surrendering to the sick body" allows people to experience themselves anew, fosters redemption and transcendence of self. They noticed a deeper level of awareness and courage. Often these experiences are cyclical and not a one-off

							process.
Courtenay et al. (1998)	HIV positive	*N*=18 (10 male, 8 female, 23-45 years)	USA	To understand how meaning constructed in the lives of those who are HIV positive	Semi-structured interviews included topics of coping, psychosocial development and meaning making.	Grounded theory	The meaning - making process involved five stages: initial reaction, catalytic experience, exploration and experimentation, consolidation of new meaning and a new perspective. Transformative experiences included gaining more meaningful experiences in life through helping others and creating a purpose for life and a deeper appreciation for life and other people.

Courtenay et al (2000)	HIV positive	*N*=14 (8 male, 6 female, 13 aged 25-47 years, 1 aged 59 years)	USA	To follow up adults from the previous Courtenay et al. (1998) study to see if they had maintained their perspectives and if there were any further transformati ons	Semi-structured interviews enquired about how participants made sense of their lives currently, current physical and emotional health and the activities they are involved in.	Grounded theory	The two main findings were that transformative experiences and perspectives had remained over time and that additionally participants had become more future-oriented, had increased self-care and had more fully integrated their diagnosis into their sense of self.
Curtin et al. (2002)	Kidney failure - on dialysis for 16 years or more	*N*=18 (10 male, 8 female, 38-63 years)	USA	To examine processes involved in some kidney patients' abilities to survive whilst on dialysis	Topical semi-structured interviews covered a broad range of categories, including, family and peer roles, major life events, daily life experiences and	Thematic analysis	Transformation was conceptualised as comprehensive, active, self-management of life with illness. It involves restructuring of both the self and the illness. Themes around self-identified included self-preservation, self-identity, self-worth and self-efficacy. Restructuring

					turning points.		illness experiences included coming to terms with death, life constraints, intrusiveness of illness and repeated setbacks.
Dekkers, Uerz & Wils (2005)	End-stage renal failure - on dialysis for at least 2 years	*N*=7 (2 male, 5 female, 55-82 years)	Netherlands	To examine how people with end-stage renal disease "live well" with chronic illness from a virtue ethics and moral perspective.	Semi-structured in-depth interviews were conducted with the patients' narrative leading the structure of the interview but with the focus "living well with a chronic illness".	IPA	Key themes in living well with a chronic illness included having a sense of reality and putting things in perspective, self-control, balancing life, importance of relationships with other people and vitality - being active, being able to enjoy and be happy, acceptance and one's own responsibility.

Gibson et al (2005)	Multiple Chemical Sensitivity (MCS).	N=203 (average age = 47)	USA	To investigate changes in identity in people with MCS.	Questionnaires with four open-ended questions about how MCS has affected their sense of self and how they deal with this.	Thematic analysis	Overarching themes included "forced growth" - forms of personal growth forced on people by their illness, the importance of social and spiritual support and identity reconsolidation. Participants described finding strength in adversity, becoming emotionally stronger and more confident.
Hwang, Kim & Jun (2004)	Rheumatoid Arthritis (RA) for between 4-12 years	N=5 females (34-61 years)	Korea	To explore illness experience of Korean women with RA	Semi-structured interviews to explore participants' experience of RA	Phenomenological method (Colaizzi, 1978)	Findings suggested that the women were able to cope with their illness through acceptance and support of family and friends. Many had created a "new life" in which they lived only for themselves, they have gained new interests and have a new desire to engage in activities for public benefit.

Kalitzkus & Matthiessen (2010)	Fibromyalgia	N=1 female	Germany	To understand the process of one patient's personal growth in chronic illness	Narrative biographical interview to explore experience of living with fibromyalgia	Narrative analysis	Elements of personal growth through chronic illness included improved relationships, creating meaningful ways of engaging with others, the re-evaluation of priorities in life and further development of aspects of her personality which had been neglected in life pre-illness.
Kirkpatrick Pinson, Ottens & Fisher (2009)	Progressive MS for at least 8 years	*N*=10 females (46-68 years)	USA	To explore why some women with Multiple Sclerosis (MS) cope successfully despite progression of condition	Semi-structured interviews in which participants were asked open ended questions about seven precursors to change (Hanna, 2002).	Thematic analysis	Findings indicated that the pre-cursors important in adapting to and coping with MS were willingness to experience anxiety/difficulty, awareness, confronting the problem, effort to change, hope and support from friends/family and health professionals.

Lindsey (1996)	Chronic illness (no specific info.)	N=8 adults	Canada	To explore the meaning of feeling healthy for people with chronic illness	Three conversations with participants, using Carson's (1986) recommendations, exploring the meaning of being healthy.	IPA	Themes about elements of health experiences included: honouring the self, seeking and connecting with others, creating opportunities, celebrating life, transcending the self and acquiring a state of grace.
Molzahn, Bruce & Sheilds (2008)	Chronic Kidney Disease (CKD)	N=100 (62 male, 38 female, 21-88 years)	Canada	To describe patients' experiences of liminality associated with CKD	A secondary analysis of narratives collected for a book produced in order to educate people about CKD	Narrative analysis	Participants described a range of liminal spaces in illness experience, for example, living/not living, worse off/better off and alone/connected. Some participants identified being better off because they had developed closer relationships, changed in themselves, for example become more patient, and developed the ability to adapt.

Paterson et al. (1999)	Type I diabetes which was well managed	*N*=22 (8 male, 14 female, 24-81 years)	Canada	To attempt to explicate the structure and process of transformation in people with chronic illness.	Individual and focus group interviews as well as the "think-aloud" technique where participants record decisions about daily living (e.g. diet, exercise, insulin) in an ongoing way for one week periods.	Grounded theory	The experience of transformation involved a change in self-awareness, self-efficacy and self-control. It was described as an ongoing process often initiated by a challenge and involving a differentiation of the self. The process of transformation was found to be key to healthy outcomes in diabetes for these participants.
Price et al. (2012)	Stroke	N=1 male (in his seventies)	USA	To explore resiliency following stroke, especially its role in supporting continuity of identity	Two semi-structured, open-ended interviews about significant events helping to form the participant's identity and how he experienced and responded	Narrative analysis	Elements contributing to resilience and change post-stroke were identified as seeing the stroke as a challenge and being resourceful in tackling it, taking control and a change in perspective on life in terms of "making the most of things".

					to the consequences of the stroke.		
Prodinger & Stamm (2010)	Rheumatoid Arthritis for at least 10 years	*N*=6 females (no info.)	Austria	To explore taken-for-granted practices in the health care system for women who think of RA as a challenging and enriching experience	A secondary analysis of a subset of women from Stamm et al. (2008) study. Interview material and re-written life stories were revisited by the authors.	Secondary thematic analysis focused on data marginalised in the primary analysis and was influenced by a critical feminist perspective.	Women who previously thought of RA as a "source of new challenges" described their becoming an active agent in the health care system. They did this by challenging cognitive authority, becoming more conscious of their own knowing (over health care professional's authority) and using self-reflection to take control of their own health care. Sub-themes included empowerment, increased self-efficacy, increased awareness, and personal transformation through an increasing consciousness about cultural values.

| Räty & Wilde-Larsson (2011) | Epilepsy (out-patients) | *N*=19 (7 male, 12 female, 20-65 years) | Sweden | To describe the perceptions of people with epilepsy and how it is to live with their condition. | Semi-structured interviews about experiences of epilepsy and the effect on daily life. | Phenomenographic method (Alexandersson, 1994) | Findings indicate that positive experiences of living with epilepsy involved a focus on life (rather than the condition), gaining and maintaining control, acceptance, humility, courage and taking responsibility. Participants described becoming more tolerant and humble as a result of having the condition and it has led to a change in values for themselves and their families including becoming more understanding and less judgemental towards other's difficulties and hardships in life. |

Shearer (2007)	Chronic heart disease, chronic respiratory problems, diabetes and stroke	N=14 females (69-94 years)	USA	To understand the experience of empowerment in housebound older women.	Semi-structured interviews explored women's experiences of change, improvement and participation in their health.	Phenomenological method (Colaizzi, 1978)	Elements of change through illness were described as approaching illness as a challenge and finding inner strength, using problem solving to purposefully participate in their own healthcare, maintaining a positive attitude allowing new personal discoveries and engaging in life and finding new ways of connecting with others as well as having a focus on the future and a life plan.
Sinclair & Blackburn (2008)	Rheumatoid arthritis	N=19 females (24-68 years)	USA	To examine coping patterns of women with RA.	Semi-structured interviews focusing on stress and coping with it.	Thematic analysis	Findings indicated that for some women RA had meant a re-prioritisation of values, personal growth, acquiring optimism, increased patience, compassion for others and wanting to help them.

Stamm et al. (2008)	Rheumatoid Arthritis	*N*=10 (no info.)	Austria	To explore the narrative life stories of people with rheumatoid arthritis (RA).	Three narrative interviews explored participants' life stories.	Narrative biographic method and thematic analysis	Some of the people with RA described it as a "source of new challenges". They tried to master their health condition by engaging in challenge and meaningful activity in their lives as well as helping others. Some felt that they had been given the opportunity to experience their body in a new way and also gaining new perspectives on life.
Thornhill et al. (2008)	Congestive heart failure (13 out-patients, 12 in-patients)	*N*=25 (21 male, 4 female, 35-83 years)	UK	To explore peoples' experiences of congestive heart failure.	Semi-structured interviews explored peoples' illness experiences and its impact on their everyday life.	IPA	Heart failure was viewed by some participants as an event by which their life could be improved. It was seen as a positive life-change; a trigger for initiating positive lifestyle changes and self-improvement.

Tsarenko & Polonsky (2011)	HIV (diagnosis >10 years ago)	*N*=15 (8 male, 7 female, 33-60 years)	Australia	To explore the impact of a HIV diagnosis on one's identity and the role that engagement (taking ownership) over this plays.	Semi-structured phenomenological interviews with an interest in transition of identity from pre to post diagnosis.	Hermeneutical perspective.	Key themes included acceptance and control, acquiring knowledge, rebuilding the self and gaining ownership of the condition. Support mechanisms were found to be key to individuals reworking and transforming their roles, actions and behaviours.
Watts et al. (2010)	Type I diabetes	*N*=4 (2 male, 2 female, 20-67 years)	UK	To explore the experiences of people with type I diabetes and how it is integrated with their lives and identities.	Semi-structured interviews focused on four main topics: diagnosis, impact, feelings and reflection.	Data was analysed using thematic decomposition (Stenner, 1993) and presented on a person-by-person	One participant found that she had been able to feel in control of her diabetes by sticking to a strict regime, this had been beneficial in other areas of her life and she was a more disciplined, organised, responsible and motivated person because of her condition.

							(rather than theme-by-theme) basis.	
Whitehead (2006)	CFS/ME	*N*=17 (6 male, 11 female, 13-63 years)	UK	To examine the reconstruction of identity in people with CFS/ME	Unstructured interviews were used starting with one open question "can you describe the onset of symptoms?" and minimal probes throughout.	Thematic analysis		Reconstruction of identity involves three stages at different time trajectories of the illness: the acute stage when identity is disrupted, the medium term when there is an attempt to return to aspects of former self and a long term stage when a newly constructed self-emerged which is valued more than the previous self. Themes of the new self - included transcending the illness, gaining a deeper understanding of themselves, others and life in general.

Appendix D: Instructions to Authors

CLINICAL PSYCHOLOGY REVIEW

ELSEVIER

AUTHOR INFORMATION PACK

TABLE OF CONTENTS

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EMPIRICAL PAPER

"Journeys through depression": Patients' experiences of transformational change through mindfulness based cognitive therapy (MBCT) and antidepressant medication (ADM).

Trainee Name:	**Alice Weaver**
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Submitted in partial fulfilment of requirements for the Doctorate Degree in Clinical Psychology, University of Exeter

Abstract

Background

Mindfulness-based cognitive therapy (MBCT) is a promising new alternative to anti-depressant medication (Kuyken et al., 2015) and whilst some qualitative studies have explored participants' experiences of MBCT, none yet have explored experiences of participants who are considering coming off their antidepressant medication alongside MBCT or how patients experience change in relationships with self, others and illness.

Aim

To examine MBCT participants' experience of change across 24 months, particularly in relation to change in views of their self and their illness over time.

Method

Thematic analysis of in-depth retrospective interviews with 42 participants, two years after attending an 8 week MBCT group with an invitation to taper their antidepressant medication (ADM). Each participant took part in one retrospective interview which was semi-structured and focused on experiences of MBCT and ADM over the previous two years since attending an MBCT group and how these have impacted on a change in self and experience of illness.

Findings and conclusion

Four over-arching themes were found: taking control, relationships (with self, other and illness), rebuilding the self and shifts in perspective. The findings in the current study are very similar to those found in transformation in the

physical chronic illness literature (e.g. Paterson et al., 1999). Perhaps MBCT could be the challenge which lead patients suffering from chronic depression towards change and creates a context in which patients can consider self and identity.

Keywords

Depression, MBCT, antidepressant medication, transformation, qualitative

Introduction

Depression is a major public health burden. The World Health

Organisation (WHO) predicts that by 2020 depression will be the second

leading cause of disability worldwide (Murray & Lopez, 1997). Depression is

associated with high levels of distress and psychosocial disability (Judd, 2000).

The risk of a worsening course of the disease increases with each new episode

of depression (Kessing, Hansen, Andersen, & Angst, 2004). Around 20% of

cases develop into chronic depression lasting for two years or more (Keller &

Boland, 1998). In this way, depression is akin to other chronic health conditions

in that it is recurrent in its course (Judd, 1997) with over half of patients

experiencing two or more episodes and relapse rates amongst this group of up

to 80% (Frank et al., 1990). Chronic illness can be defined as a slow

progressing condition that has a long lasting course (WHO, 2013). Whilst WHO

does not formally categorise depression as a chronic condition, often it is seen

in these terms with many people suffering numerous depressive episodes with

little recovery between episodes (Klein, 2010). Chronic depression negatively

impacts on peoples' quality of life (Wells, Burnam, Rogers, & Hays, 1992),

results in more hospitalisations and suicide attempts (Arnow & Constantino,

2003), results in more service use (Howland, 1993) and economically incurs

higher costs (Smit et al., 2006).

Depression is more likely to follow a chronic course if left untreated

(Keller & Boland, 1998). Currently the National Institute of Clinical Excellence

(NICE) recommends two main treatments for chronic depression:

antidepressant medication (ADM) and psychological interventions (NICE, 2009).

Antidepressants are the most common treatment with prescriptions rising by 25

million in England between 1998 and 2012, an increase of 165% (Spence, Roberts, Ariti, & Bardsley, 2014). Many people have very positive experiences of ADM (e.g. Karp, 1993), however, some patients can experience adverse side-effects and many state a preference for psychosocial interventions (NICE, 2009; van Schaik et al., 2004). One such psychological intervention recommended by NICE to treat recurrent depression is mindfulness based cognitive therapy (MBCT). MBCT is an 8 week group treatment which blends mindfulness techniques and cognitive therapy and aims to teach participants skills to prevent depressive relapse (Segal, Williams, & Teasdale, 2002). It has been found to be an efficacious treatment for various conditions including anxiety and depression (Khoury et al., 2013).

The proposed study is informed by two recent separate ethnographical studies of participants' experiences of MBCT and ADM (Malpass et al., 2009; 2012). Malpass and colleagues (2009) conducted a meta-ethnography of patients' experiences of antidepressant medication. They found that patients' experiences of antidepressant use could be characterised by two related processes – a decision-making process which they term 'medication career', a treatment focused approach, and a meaning-making process which they call 'moral career' which focuses around identity in relation to the illness and changes in self-concept, sometimes called 'transformation' in the literature. However, the constructs should be interpreted with caution as there were some limitations to the range of data the review was based on. The review took into account 16 papers, however, these papers were only from 11 studies. This may mean that the data the constructs identified were based on may have been over-represented. Additionally, there are limitations with the principles of meta-

analysis in that some argue that it is both epistemologically and ethically

inappropriate to summarize findings from studies involving human experiences

of health and illness (Sandelowski, Docherty & Emden, 1997); the nature of

studies of idiographic knowledge mean that qualitative studies resist summing

up data (Light & Pillemer, 1984).

More recently, the other meta-ethnography has focused on patients'

experiences of MBCT (Malpass et al, 2012). Their synthesis found that there

were four pairs of therapeutic processes which occurred during mindfulness

courses which created a shift in peoples' sense of self and their illness; sense of

control and self-regulation, acceptance and kindness, embodiment and sense of

command over the body, and taking action and flexible response. These

processes come together to create a transformative experience for patients, of

the illness and of themselves. However, this meta-ethnography included studies

which collected qualitative data about MBCT at various time points, ranging

from straight after the MBCT had finished to over a year afterwards. This should

be taken into account as this will have influenced the quality of data and the

issues that were identified; some concepts may have been more relevant

straight after the course and not one year later yet this is not clear in this review.

These two studies consider ADM and MBCT separately but both suggest

the importance of change in self-concept, a sense of agency, self-control, and

change in the way they think about their illness. Transformation during illness is

a concept which has been discussed within the chronic illness literature.

Chronic illness has often been seen as a burden; however, some authors have

proposed that illness can lead to a change in the self and as something which

can enhance meaning in life (Coward, 1990; Finfgeld, 1995; Yoshida, 1993). The construct of transformation associated with those living with chronic illness, has created controversy in the literature and is an ill-defined term. Often it has been defined according to its outcomes rather than its constituent parts with many studies interpreting transformation as, or overlapping it with, other concepts such as hope, meaning and mastery (Paterson, Thorne, Crawford, & Tarko, 1999). In a systematic review of chronic disease, Paterson and colleagues (1999), identified two distinct aspects of transformation which emerge from their literature review: the restructuring of the self and the restructuring of the illness experience.

Restructuring an illness experience involves a philosophical and cognitive shift in how illness is perceived by the ill person (Barton, Magilvy, & Quinn, 1994). Key themes identified in this restructuring of the illness experiences are gaining a sense of control or mastery over the illness and its impact on a persons' life, and accepting oneself as a person with the illness. This has been found to lead to a more positive outlook on life (Gloersen et al., 1993) an appreciation of what is important (Brodsky, 1995), more collaborative relationships with health professionals (Ferrans, 1994), acceptance of illness (Folden, 1994) and self-empowerment (Morse & Johnson, 1991). Restructuring of some aspects of the self has been described by many researchers as an outcome following a threat to self-integrity from the illness experience (Dildy, 1996). This prompts a need to maintain self-integrity, to maintain health and balance in life (Carpenter, 1994; Kawaga-Singer, 1993; Morse, 1997). However, others maintain that the motivation for restructuring the self is to transcend the body (Corbin & Strauss, 1988); a separation of the self

and the diseased body. Transformation is proposed as a change in self-identity; that the self is restructured in order to integrate limitations imposed by the illness which allows acceptance of the illness through separating the person of the past with the person in the present.

With many inconsistent findings about transformation in chronic illness, Paterson et al. (1999) attempted to clarify the definition by studying transformation in patients living with diabetes. They found that transformation was seen as a way to deal with challenges associated with the illness and threats to self-integrity, as well as a way to mediate the impact of their illness. A key theme was the 'differentiation of the self'; patients accepting their illness and creating a different relationship with it by recognising that they are able to control it and are no longer "at the mercy of it". The transformation of self-allowed patients a new appreciation of their own expertise, allowed them to engage with and challenge, where necessary, health professionals about their routines.

There are parallels between chronic physical conditions like diabetes and chronic mental health problems like recurrent depression, for example, the relapsing and remitting course, as well as the high degree of impairment they can cause. There are of course some key differences, for example, the increased stigma around mental health conditions. Whilst illness as a transformation experience has been identified in various physical health conditions including diabetes and breast cancer, it has been investigated to a much lesser degree in people suffering from chronic mental health conditions (Malpass, 2009).

Current Study

Many studies have investigated peoples' experiences of MBCT and ADM separately. However, as MBCT becomes more widely available in the health service it is likely that many people with recurrent depression will try to find ways to stay well using either MBCT and ADM or MBCT as a way of discontinuing maintenance anti-depressant medication (m-ADM). The current study is unique in that it is the first to investigate how people at risk for depressive relapse experience both MBCT and ADM treatments and the interaction between these as they seek to stay well. Additionally, with Malpass et al. (2009; 2012) finding transformation as a theme for both those who have received MBCT as well as those who have used ADM, it seems pertinent for this study to examine if people describe their experience of MBCT and/or ADM as transformative. Lastly, previous qualitative studies have only studied participants' experiences soon after MBCT and it is not clear which concepts may be more relevant over a longer time period.

The current study is embedded within a large randomised controlled trial which compares two strategies to help people with recurrent depression stay well over two years; MBCT (with an invitation to taper ADM) and maintenance anti-depressants. It aims to understand in more depth patients' experiences and choices around using MBCT and ADM and their combination over a two year period. It investigates how participants who participate in MBCT and are invited to discontinue their ADM experience both MBCT and ADM in a journey of staying well. The qualitative data, having been gathered after a long follow-up

period, is well-placed to allow the investigation of depression over a lengthy time course, akin to the chronic illnesses mentioned above.

Aims and Research Questions

Aims. The aim of this study is to investigate how people describe their experiences of change retrospectively 24 months after participation in MBCT and encouragement to taper m-ADM, with a particular focus on how experiences of MBCT and ADM contribute to a restructuring of the self and illness experience.

Research questions.

1. What are people's experiences of MBCT and ADM which contribute to their descriptions of change across the 24 month trial period?

2. How do people talk about change in terms of restructuring their self and experience of illness?

Method

Study Context

This study was embedded within a randomised controlled trial which compared MBCT plus an invitation to discontinue ADM (N=212) with maintenance antidepressant medication (N=212) in preventing depressive relapse for people with a history of recurrent depression in primary care

settings; the study design is described fully in (Kuyken et al., 2010; 2015). The trial's primary outcome found MBCT therapy with invitation to taper was not superior to maintenance ADM in preventing depressive relapse over two years in patients with recurrent depression. Both treatments were found to have lasting positive outcomes in terms of depressive relapse, residual depressive symptoms and quality of life. The embedded process study is a qualitative study using a retrospective interview to investigate participants' experiences of MBCT and ADM across a two year period. The study gained ethical approval from the NHS South West Research Ethics Committee and University of Exeter, School of Psychology ethics committee (REC ref: 09/H0206/43 approved on 15th January 2010).

MBCT and Antidepressant Tapering/Discontinuation

Participants completed an 8 week course of MBCT (attending at least 4 out of 8 sessions) and they were asked during the course to reduce and then stop their ADM; this was requested approximately six weeks into the MBCT course.

Participants

Forty-six participants who were enrolled on the trial were approached and asked to take part in the interview. Forty-two agreed to take part, of the four who declined, two had moved away from the area, one was not interested in participating and one participant had changed their contact details and could not be reached. Qualitative data was therefore collected from a sample of 42 participants who enrolled in the trial. Study participants were people aged 18 or over, with a history of three or more episodes of depression (with depression as primary disorder and not secondary to substance abuse or bereavement),as defined by the Diagnostic and Statistical Manual IV (American Psychiatric

Association, 2000) in full or partial remission at the time of entry to the trial, on a therapeutic dose of antidepressant medication (according to the British National Formulary) (British Medical Association & Royal Pharmaceutical Society of Great Britain., 2006) who were open to taking part in MBCT and discontinuing their ADM. Exclusion criteria were: participants who were currently depressed, had co-morbid diagnoses of current substance abuse, organic brain damage, current/past psychosis, bi-polar disorder, persistent anti-social behaviour or self-injury (requiring clinical management) and formal concurrent psychotherapy. Of the 212 participants allocated to receive MBCT, 42 were interviewed. To ensure as wide sample as possible, participants were purposively sampled equally according to whether they experienced a depressive relapse or not during trial and also across four categories according to their use of ADM across the 24 month follow-up period:

1. **Stopped ADM and stayed stopped**: From the point they stopped medication, they did not start taking ADM again during the follow-up period.

2. **Stopped ADM and then resumed**: Had stopped at some point during the trial and then resumed medication for at least a portion of the follow-up period, (this group captures participants whose ADM use was quite variable across the follow-up period).

3. **Reduced but never stopped**: Have reduced their ADM dose at some point during the trial but never stopped completely by the end of the follow-up period.

4**.**   **Never stopped or reduced**: throughout the follow-up period has

maintained the same (or higher) level of ADM dose.

The demographic, psychiatric, and treatment characteristics of participants is

shown in table one. Participants had all suffered from recurrent depression,

being treated in primary care services, on a therapeutic dose of antidepressant

medication, who had expressed an interest in MBCT as a treatment approach

and were open to reducing/discontinuing their ADM. Participants had varying

experiences of MBCT groups, they showed a wide variation in ADM use across

the course of the trial as well as variations in occurrence of depressive relapse.

Service User Involvement

The interview schedule was reviewed by and piloted on two people who

have suffered from recurrent depression and have received MBCT therapy.

Based on this feedback the interview schedule was adapted accordingly, for

example, removing questions which were too similar and restructuring and

rephrasing of interview questions in order that they more specifically explored

experiences of change.

Recruitment

Participants were recruited from 95 primary care general practices in

urban and rural settings across Devon and Bristol. The study was also

advertised locally and interested patients could self-refer. Patients who

expressed an interest in the trial were screened using the Structured Clinical

Interview for DSM disorders (First et al., 1997) to establish potential eligibility.

Participants then gave informed, written consent to take part in the interviews as

part of the main trial. Of the 46 participants approached to take part, 42 agreed

to participate. Additionally, before the interviews commenced, interviewees were reminded of the purpose of the interview, and their verbal consent was sought in order to carry out the interview. Participants were free to withdraw at any time without giving a reason. Participants were advised that if they found the interview upsetting that they should speak to their GP. For full recruitment protocol and CONSORT diagram please refer to the main trial paper by Kuyken and colleagues (2015).

Table 1. Participant demographics and depression related variables

Participant ID	Gender	Age	Ethnicity	Number of previous episodes of depression	Relapsed (Y/N)	ADM category
1031	Female	51	White	3	Yes	Reduced/Never stopped
1069	Male	61	White	3	No	Stopped
1072	Female	46	White	12	Yes	Stopped
1075	Female	49	White	Too many to remember	Yes	Stopped
1087	Female	54	White	4	No	Reduced/Never stopped
1108	Female	62	White	Too many to remember	Yes	Never Stopped
1123	Female	69	White	4	No	Reduced/Never stopped
1139	Male	48	White	Too many to remember	Yes	Never Stopped
1146	Female	59	White	Too many to remember	No	Reduced/Never stopped
1154	Male	64	White	3	No	Stopped/Resumed
1159	Female	45	White	4	Yes	Stopped
1177	Female	42	White	4	No	Stopped/Resumed
1185	Male	59	White	5	No	Stopped
1203	Male	55	White	5	No	Stopped
1206	Female	72	White	3	No	Stopped/Resumed
1212	Female	55	White	10	No	Stopped
1222	Female	68	White	4	Yes	Stopped
1228	Female	50	White	4	Yes	Never Stopped
2016	Female	49	White	4	Yes	Stopped
2089	Female	25	White	3	Yes	Never Stopped
2090	Female	56	White	4	Yes	Stopped
2102	Female	47	White	4	No	Never Stopped
2103	Female	60	White	5	Yes	Stopped
2114	Male	67	White	3	No	Stopped/Resumed
2123	Female	40	White	Too many to remember	Yes	Reduced/Never stopped
2131	Male	52	White	Too many to remember	Yes	Reduced/Never stopped
2140	Female	48	White	5	Yes	Stopped/Resumed
2161	Female	60	White	Too many to remember	No	Stopped
2168	Male	37	White	10	Yes	Stopped
2170	Female	54	White	12	No	Stopped
2176	Female	65	White	5	Yes	Stopped
2200	Female	47	White	5	Yes	Reduced/Never stopped
3071	Male	57	White	3	No	Stopped
3081	Female	57	White	10	No	Stopped
3090	Female	49	White	3	Yes	Stopped/Resumed
3103	Female	48	White	4	No	Stopped/Resumed
3105	Male	54	White	5	Yes	Never Stopped
3109	Male	38	White	6	Yes	Never Stopped
4007	Female	39	White	10	No	Never Stopped
4016	Female	37	White	10	No	Never Stopped
4044	Female	55	White	5	Yes	Never Stopped
4057	Female	29	White	13	Yes	Stopped

Data Collection

Data was collected over a ten month period by the first author of this study as well as three other members of the research trial team. Participants were interviewed face-to-face, either in their home or at the University of Exeter, using a collaborative, semi-structured interview which explored participants' experiences of MBCT and ADM use retrospectively over the 24 month trial follow-up period. To aid this, researchers prepared a 'time-line' which had details of the participants' use of ADM during the trial as well as any known periods of depression and wellness. Participants were given the opportunity, at the beginning of the interview, to check this and make any alterations or add further information that may be relevant. The interview was developed by the author, along with other members of the research team. The author contributed to development of all interview questions and had sole responsibility for questions focusing on sense of self. The interview (see Appendix A for interview schedule) covered the following topics:

- MBCT practice and ADM use during periods of wellness, feeling low (but not depressed) and depression
- their sense of self
- thoughts about the causes and consequences of depression.

This interview method retained some structure with specific open questions and prompts to guide interviewers and to increase consistency across interviews, whilst also allowing interviewees to give in-depth answers. Interviews drafts had input from, and were piloted on, people with a lived experience of depression. Based on this process, feedback was used to make

adaptations to the interview. Interviews using the final interview schedule were recorded using a digital voice recorder and lasted for between 20 and 100 minutes in length.

Analysis Strategy and Procedure

Interviews were recorded and transcribed verbatim in a basic 'playscript' format; paying attention to basic features of speech e.g. pauses and emphasis and non-verbal communication, e.g. crying, and a transcription protocol was used to ensure consistency. At the point of transcription all identifying information was removed including names of people and places.

Data was analysed using thematic analysis (Braun & Clarke, 2006). Thematic analysis is independent of theory and epistemology making it a very flexible form of analysis which is often used within the field of psychology as well as other health disciplines (Braun & Clark, 2006; Braun & Clarke, 2014). The lack of subscription to any particular pre-existing theoretical framework lends itself to large datasets such as those embedded in a trial and therefore constrained by certain analytical and epistemological constraints. Additionally, conducting thematic analysis with such a large dataset allows core similarities and differences to be identified within and across the dataset. Thematic analysis focuses not only on the explicit content of data but also data in which themes are implicitly inferred (Joffe & Yardley, 2003). Analysis was driven by the research questions and explored themes that emerged inductively from the data as well as integrating other relevant theory and research. Deductive coding from theoretically derived themes allows for comparison to prior research in order to replicate, extend, or refute previous findings (Boyatzis, 1998). The main theories which were used to inform this analysis included those found in the

literature review; theories of transformation during illness (e.g. Paterson et al., 1999) and knowledge about mechanisms of MBCT (Van der Velden et al., 2015). Key elements of these theories, for example, control and acceptance were highlighted in analysis as deductive codes. Codes that are important to the analysis, yet only occur once or twice may be included if they are important for the research topic, which can be determined by saliency analysis (Buetow, 2010).

An alternative qualitative approach could have been used, for example, grounded theory (Glaser & Strauss, 1967), however, the constraints of conducting a study within a RCT with specific time frames meant that some aspects of grounded theory, such as, the iterative process of data collection, analysis and theoretical sampling based on preliminary analyses of ongoing data was not feasible.

The analysis employed a method underpinned by a social-constructivist paradigm (Braun & Clarke, 2006) which takes into account both the way in which people make meaning from experiences as well as the social contexts that impact on those experiences. A constructivist, interpretive approach (Krauss, 2005) sought to establish the understanding of personal meanings associated with experiences of MBCT and ADM.

Data analysis followed Braun and Clarke's six phase model of thematic analysis (Braun and Clarke, 2006). All interview transcripts were read multiple times and broad patterns noted. Data was then coded for primary features of interest relating to the research questions i.e. elements of change, descriptions of transformative experience. More general themes not related to the research questions e.g. "barriers to MBCT" were discarded. This process was aided by

the computer software package NVivo, for an example of coding please see Appendix B. The analysis then broadened to look at themes and sub-themes across codes relevant to the research questions. Themes were compared and contrasted with similar themes and sub-themes grouped together whilst for seemingly different concepts new themes or sub-themes were created. These themes were then reviewed and refined and coherent patterns were identified across the data. Themes were then considered in terms of their importance and relevance for the dataset as a whole. Throughout the process original transcripts were consulted for every participant to ensure themes were true to the source and to re-define and check themes, sub-themes and the relationships between them. Pertinent excerpts of raw data were identified and used to re-check themes were accurate to participants' original descriptions. The themes were then named and a description around each theme written with clear ideas about how these fit together to create the overall "story" of the data and additionally how the themes fit with relevant theory and research.

Results

This study explored elements of participants' experiences of MBCT and ADM which contributed to their descriptions of change, paying particular attention to the restructuring of the self and experience of illness. Participants had a range of experiences of MBCT groups, ADM use and of depressive relapse and periods of wellness. However, for the majority of people MBCT was described as a key element of a transformative change process. For some, this process was also benefited by use of antidepressant medication. This analysis focuses on descriptions of key elements of change in participants, especially in

terms of restructuring themselves and their illness experience across a two year time period after taking part in MBCT. Four over-arching themes illustrated key features of participants transformative change processes: "taking control", "relationships", "rebuilding the self" and "shift in perspective". Descriptions of themes and sub-themes are described below including illustrative data excerpts. Additionally, Appendix C shows a proposed graphic representation of all themes in more detail.

Taking Control

For many participants, MBCT allowed them to feel in control of their illness representing a change for some after years of feeling controlled by depression. Participants spoke about an increase in awareness, as well as specific tools taught through MBCT allowing them to have control and leading to a feeling of empowerment and wellness.

Many participants made a link between having increased awareness of their thoughts and feelings and being able to control them. Having techniques to employ, such as, stepping back from their thoughts, has meant that people feel less overwhelmed and more empowered.

"They're [depressive thoughts and feelings] something I can recognise and know I can do something about ..whereas before it was something, it was like a train hitting you, it was coming, you could see it coming, but there was nothing you could do ..whereas this time you could see it coming, you could recognise it, okay I can either stand here and let it hit me or I can do something about it so I felt more empowered, more in control of things.. it was the mindful- based stuff, the, yeah the being in control of my own thoughts rather than just letting them overwhelm me or sort of wash you away." (4044)

Many participants described depression as having controlled their life for many years, however, after engaging in MBCT they felt much more able to take control over not only their depression, but also the rest of their life, leading to a feeling of empowerment.

"yeah it's changed my perspective of it- it's-it's um it's given me control back I think which I think is the most important thing that before I think that I felt very much the depression was controlling me." (3081)

Other areas of life in which a sense of control had impacted were dieting and exercise for several people.

"I think I'm-I'm more in control now. Um in-in-in some respects I think I can use the um the mindfulness stuff to help me with-with my diet, help me to stick to um what I'm needing to do. Although I still have a weight problem and I-I still sort of go backwards and forwards I'm-I'm more in control of it now." (2090)

"Remaining in control has- has- um has emphasised to me, I think, the um, the role that self- discipline- the positive role that self-discipline can have in- in one's life. Um, and so I now exercise more" (1072)

Some participants talked about the combination of ADM and MBCT as being very useful in their sense of control over their depression. Whilst acknowledging the usefulness of medication when in the middle of a depressive episode, one participant talked about MBCT being useful in dealing with the "*double whammy*" of ADM. Before taking the medication she already felt out of control and her ADM reinforced this yet MBCT proved to be a useful counter.

"Because, there are side effects, you know, one does feel less- less in control with antidepressant medication and that's a um, uh, a real, it's a- it's a double whammy really, because you know, one wasn't feeling particularly in control in the first place and to-, and to have the medication that- that- that removes you a little bit more from reality is, you know, it's not great… it's de-skilling and de-powering and, you know the opposite is true of the mindfulness practice. None the less, if you haven't um had any experience of mindfulness and you're stuck in the middle of a period of depression-I think those pills are jolly useful." (1072)

However, others felt that mindfulness on its own would not be enough, especially when trying to reduce ADM but that having MBCT skills available made her feel more in control of reducing her ADM.

"if you are coming off them it's important to have them both [MBCT and ADM] there…but also to probably you- if you've got the skills, um, so you're not literally just reaching for a stronger version [of ADM]…but, to take them away completely and then expect you to manage on just the course…would be too much I think" (1075)

For some people, MBCT seemed to have increased confidence to allow people to be more in control of their own medication career both with themselves and their GPs.

"The mindfulness gave me the opportunity to come off of the medication … it took the fear away in a way because I- if I did have to go back again it-it would just be for a short time. There's-there's more of a control over it, I understood more" (2090)

"there was a cer-certain element I think of-of pretty well immediately after I started the course, I made- made a decision that I would stop taking the medication…So I went along to the doctors because I was polite to-to ask him if I could stop taking it. And he said, "Well yeah maybe in a few months time you can taper it- ease it off a bit." But really I had decided I was- I was going to stop. So-so I was just there out of politeness really. (laughs)" (1203)

However, others felt that mindfulness did not give them the power or control to feel able to come off of their ADM.

"I didn't feel I had any sort of power to change how I was feeling…I felt very reluctant even with the mindfulness, umm, very reluctant to come off it again 'cause I <u>knew</u> how bad I got, umm so that's why I haven't felt <u>able</u> to come off them I think, even with the mindfulness" (2102)

Relationships

All participants described some change in their relationships over the two years. For many this involved a change in their relationship with themselves or with other people. Additionally, many described a change in their relationship with their illness and/or medication. Accordingly this theme contains three sub-themes: relationships with self, others and illness.

With Self. Many participants described MBCT as having changed their understanding of themselves especially their thought processes and bodily feelings. This understanding was enhanced by increased awareness of their thoughts, emotions and bodily feelings.

"I understood better, what my mind was doing. Um, and understood the- some of the things it was doing- some of the- things that were happening, were not useful..I know that continuously all the time I'm using the tools that it- it provided me with, not in terms on meditation but in terms on monitoring how I am.. and as I say it's the linkage between how I'm thinking and how my body's reacting and use my body reaction to tell me uh- how I'm thinking about things" (1069)

Additionally, a number of people had noticed a change in their self in terms of objectivity. Some described this as another self, transcending the self or being able to take a step back, which allowed them to make different decisions about situations and to not be as reactive as they had been in the past.

"Umm, it, it's given me this tool to, well, take a step back from the situation and review the situation without becoming in a circle of chasing one's tail. It's taken me outside of the circle, broken the circle and allowed me to look at the situation and then go back into it and progress as opposed to going round in circles. So, yes that's definitely changed mentally" (1154)

The majority of participants talked about having an increase in self-compassion and also being less judgemental both of themselves and of others. An increase in self-compassion seemed to allow some participants to become more accepting of themselves.

"Not to be umm hard myself that is what I've learnt as well. I'm very quick to be my own worst critic ' you're useless, you're rubbish' … I try to say that to myself to sort of lessen the sort of impact you know. I kind of like myself like that now,

whereas before I didn't like myself at all. So I kind of sometimes now think, I don't mind myself whereas before I used to hate myself. so it's quite nice to actually think, hey you know you're alright." (3103)

With others. For some participants, acceptance and openness to themselves seemed to have had an impact on their relationships with other people. One participant talked about how she is now able to be open and honest with friends about depression.

"so it's actually opened up with friendships and much more open and I don't have to pretend anymore" (1087)

With illness. Many participants highlighted the importance of MBCT in changing their relationship will their illness and in turn their antidepressant medication.

Some had used MBCT to discontinue their ADM, however, acknowledged that there may be times in which they may need to go back onto medication and that MBCT has given them the tools or determination not to do that.

"it's given me the courage to not resume anti-depressant medication because it's given me the tools and the knowledge that I have a battery of tools" (1072)

For others, who had remained on their medication, MBCT had allowed them to not only be more accepting of depression but also to have self-compassion around taking ADM as a form of treatment for it and for some this was very empowering.

"Yeah I think again it doesn't- I don't feel anymore when I take my pill every morning um that there's something wrong with me or that I'm trying to escape something or you know medicating myself away from problems because I know that um I have done everything in my power to help myself" (1177)

Participants had a range of views about the combination of MBCT and ADM.

For some people, ADM had helped them to be in a place where they could engage with the MBCT and use the tools they had been taught.

"if I came off the antidepressants, I think I would have been all over the place, so I'm not sure I would have been in the right headspace to appreciate the MBCT" (1228)

Whilst for some participants, the combination of ADM and mindfulness together led to increased confidence and a feeling of being able to cope.

"My take on it was, well, there's the pills, there's the, um, meditation and the processes I've learnt. So, it- it gave me confidence I think..That I had, um, I had a way of dealing with it…not just come off the pills… but it gave me confidence that I could cope." (1069)

Conversely, a few participants related how in very low periods MBCT was not enough and ADM was the only thing that they felt could help.

"they did help me actually a lot, the antidepressants…and I don't think mindfulness would have helped me at that stage to be honest because all I could see was blackness." (1222)

MBCT and ADM were separately talked about as stabilising influences.

Some participants described MBCT as a constant which underpinned their feelings of wellness and allowed them to maintain their medication dose rather than increase it.

"Mindfulness was my cushion, that was my safety belt, because that was stopping me taking more tablets." (2016)

However, for others ADM was seen as a stabilising influence, a "chemical hammock" (2103).

"at the moment I'm still feeling that it's a bit of a comfort blanket for me just to sort of keep taking the medication really." (1146)

One person described the delicate balance of treatments, using both ADM and MBCT to stay well.

"The antidepressants did bring me back up from the brink. The easiest way to explain it is to say I was hovering before I was unwell, I was hovering above the table, but as soon as I started getting ill and getting depressed I was under the table…So the tablets near enough gave me a boost or a little boost that lifted me back up to the same level as the table and having the mindfulness as well brought me back hovering" (2016)

Rebuilding the Self

Many participants described MBCT changing themselves over the course of the two years resulting in new or re-built selves.

Gaining increased control over their condition resulted for many in a change in their sense of self; they became more accepting of depression and had integrated it as a part of themselves.

"I think it's made myself much more accepting of myself, umm, and much more, much gentler on myself, umm, much less, you know, judgemental and (..) actually much more positive about umm, and much more realistic I spose about, yeah, OK, this is just a little bit, a little part, it's not who you are it's just what is happening at that time. (1159)

Many associated self-acceptance with an increase in openness and honestly in their relationships with themselves as well as others.

"I think I'm more honest- I'm more honest now with myself. I'm realising who I am more... I'm sort of more honest with my emotions now. And I can accept that whereas I think before I sort of deviated from there and sort of played the fool and you know this, that and the other, diversionary tactics. So I'm now more comfortable in myself and um feel that I've grown up a bit actually." (1228)

Others described self-acceptance as being a key element of a shift in how they see themselves.

"I think there is this thing about liking yourself more. I think a lot of the time- I think I was struggling to be the person I thought I ought to be and um rather than just accepting myself and liking the person I am." (1203)

For a few participants, a sense of being more relaxed and accepting of their condition came from their continued use of ADM.

"Now on the antidepressants, I am slightly more chilled than I was" (1222)

Shifts in Perspective

For many MBCT has meant a completely different outlook or perspective on life. Many participants talked about an increased appreciation for life, especially nature.

"Well I suppose it helps you to see the world in a different light, umm, to appreciate things in a different light, not just from a depressed sense, to appreciate what's around you and, and enjoy that…" (1108)

For some, this change in outlook had resulted in changes in lifestyle and pace of life.

"I like quiet now and birds, I love birdsong and I just notice it more now, I probably always did love birdsong but I just find it so relaxing sitting in the garden and whereas before I didn't take the time to do those sort of things." (1228)

For many MBCT had meant a radical shift in their perspective on life and their view of others, becoming less judgemental.

"I think it's made me see life and people in a different way. Through different eyes really. Um, I think you probably look at someone more as a whole and sort of think 'Oh gosh you know what's happening to them and thinking well that's why they're like that because this is happening in their lives' or whatever so it's (1) and maybe you almost sort of see a mirror of yourself in them sometimes." (2170)

Many participants talked about changing their lifestyles to make more time for themselves and being more content and happy.

"I think just generally on the whole I'm more laidback and happy." (2123)

Discussion

Participants described a range of ways in which they had changed across the two year period, with MBCT identified as a key element in a transformative change process for many. The analysis resulted in four over-arching themes which illustrated key features of participants transformative change processes: "taking control", "relationships", "rebuilding the self" and "shifts in perspective". These themes will now be discussed in relation to other relevant literature.

Taking Control

Participants talked about MBCT skills allowing them an increase in control over their depression. For some though, ADM was a stabiliser which led them to feel more relaxed and in control. As in previous studies (Allen, Bromley, Kuyken, Sonnenberg, 2009; Malpass et al., 2012), MBCT skills allowed participants to increase their awareness and take control by using techniques, for example, stepping back from their thoughts, resulting in feelings of empowerment. This sense of control not only impacted on the way in which they thought about their depression, that it is controllable, but it also had an impact on how in-control they felt in their lives. Previous studies (Benassi, Sweeney, & Dufour, 1988) have found that depression can be less severe when one's internal sense of self control is greater. Thereby, in this context, an increase in self-awareness as well as using MBCT skills to notice and cope with strong emotions lead to a higher sense of internal control over depression. This active approach may go some way to overcome the passivity often accompanying depression.

Additionally, this concept of self-control relates to restructuring of aspects of the self-identified in previous studies of physical chronic illness such as diabetes (Gloersen et al., 1993; Paterson et al., 1999). Findings in the current study support previous findings by Johnson and Morse (1990) that regaining control is an integral part of adapting to illness.

Many studies have documented the relationship between lower socio-economic status and increase in prevalence of both mental illness (e.g. Murali & Oyebode, 2004) and chronic illness (WHO, 2014). Lachman and Weaver (1998) compared social class differences and sense of control between two groups of adults, one with lower incomes and the other with higher incomes. They found that higher levels of perceived control were related to better health, quality of life and lower depressive symptoms. Overall, the group with lower incomes had a lower sense of control and poorer health, however, those with low incomes and a high sense of mastery or control showed levels of well-being comparable with those people in high income groups. In this context, the current findings are important as sense of mastery could have wider impacts on wellbeing across social class.

One new finding from this study is the relationship between MBCT and control over treatment for depression. For some people, increased control through MBCT allowed greater control of their treatment of depression, including making decisions about ADM use, both with and without health professionals. Illness often results in a loss of control for people with increased reliance on family, friends and professionals. MBCT skills could offer people an opportunity to take more control over their illness, including medication choices,

and also could increase their sense of power in their interactions with health professionals.

Relationships

With Self. Participants described changes in ways of relating to themselves as well as others. Themes of increased awareness, transcendence of self and increased acceptance and self-compassion found in this study mirror findings from previous studies about MBCT (Mason & Hargreaves, 2001; Allen et al., 2009) and in chronic illness (Paterson et al., 1999).

The findings in the current study focusing on depression, reflect similar themes to those in chronic illness (Lindsey, 1996). Paterson and colleagues (1999) found that enhanced awareness of the self, and 'differentiation of the self' – a separation of the self from the diseased body. In this study it seems that acceptance and self-awareness were linked with differentiating the self and the illness as was found in the diabetes literature (Paterson et al., 1999). It seems that increased self-awareness allows the participants to know their body better and in so doing it is possible to consider the 'diseased body' in a more objective manner.

With illness. This is the first paper to explore participant's experience of the combination of MBCT and ADM together in treating depression and clearly, there are a diverse range of interactions between MBCT and ADM. For many participants, MBCT skills (especially an increase in self-control and self-awareness) were described as a key element to maintaining or reducing/discontinuing ADM and for some MBCT had given them the courage not to go back onto ADM in the future. However, for others MBCT was "not enough" when they were depressed and they needed ADM to help them stay

well. The combination of the two was important for some people, for example,

one person said that ADM allowed them to be in the right "headspace for MBCT

and another said that whilst MBCT had not enabled them to come off of ADM, it

had increased their quality of life. Many participants described MBCT as

increasing their acceptance of both their condition as well as their need to take

ADM (or not). Malpass and colleagues (2009) in a review of literature found that

transformation could occur through medication (not illness) experience and

Karp postulates that medication prescription can trigger transformation process

(Karp, 1993). However, this was not found in the current study, perhaps

because the group of participants were a set of people who had expressed an

interest in coming off of their medication.

Patients' concepts of depression and mental illness often involve

'perceived stigma' and they can feel responsible for their illness and unable to

cope (Knudsen, Hansen, Traulsen, & Eskildsen, 2002; Knudsen, Hansen, &

Traulsen, 2002). It seems from this study that patients are able, through MBCT,

to take back responsibility for their illness and feel they are able to cope. This

has important implications both clinically and financially; Coulter (2012) argues

that if patients are actively participating in their treatment then not only will

patients' values and attitudes inform shared decision-making with professionals

but if patients with long-term conditions are able to self-manage their conditions

this could substantially reduce the financial burden on the NHS.

Rebuilding the Self

Participants in the current study related how MBCT has impacted on their

sense of self and in relation to their illness this included, for many, an increase

in acceptance of depression as part of themselves. An increase in acceptance

prompted a shift in people being more open with others, an increase in self-confidence. This is supported by other literature in chronic illness (Courtenay et al., 1998; Curtin et al., 2002).

One in three people do not complete ADM treatment (Pampallona, Bollini, Tibaldi, Kupelnick, & Munizza, 2002) and these findings indicate that inability or reluctance to accept an illness as part of the self may be a key element to non-compliance. This echoes previous research from other illnesses, for example, in asthma, use of medication has been found to be related to identity and illness (Adams, Pill, & Jones 1997) Deniers often rejected the role of asthmatic as part of their self-image and therefore, did not take medication associated with it. Conversely accepters had completely accepted their condition both into their lives and self-image and were taking their medications, with a clear understanding of what they were for and why they were taking them. Some participants in the current study linked acceptance of depression and self with having integrated their illness into their identity resulting in a gain in self-confidence and sel-worth. This again echoes findings in the chronic health literature (Courtenay et al., 2000; Gibson et al., 2005). Although, some people did not have such a shift in acceptance and they were still critical of themselves and their illness.

Shifts in Perspective

People related MBCT to a shift in perspective on life with participants commenting on becoming less judgemental, having a change in values and with a greater appreciation for life. These findings resonate with findings in the chronic illness literature (Räty & Wilde-Larsson, 2011; Tsarenko & Polonsky, 2011) and are stronger in this study than in previous studies exploring

experiences of MBCT (Allen et al., 2009). Additionally, participants in this study talked more about "me time"; ensuring quality time to do something they enjoy, which was not a dominant theme in the chronic health literature. This could perhaps link to the previous 'rebuilding of self' theme; acceptance of self and illness perhaps allows participants time to carry on working at keeping themselves well.

Limitations

One way of both establishing quality within qualitative research, as well as ensuring findings represent the meanings of its participants is by establishing trustworthiness in analysis (Johnson & Waterfield, 2004). Researchers in the current study met as a reflective group (Mauther & Doucet, 2003) after conducting interviews to engage in this reflexive process throughout the data collection process. Additionally, the data collection and analysis process was supervised by research supervisors with expertise in psychological therapies, thematic analysis and experiences as MBCT therapists. This ongoing peer debriefing helped to minimise effects of reactivity and bias as themes were fed back to supervisors and discussed (Leitz, Langer, & Furman, 2006). Other ways in which trustworthiness could have been established would have been through triangulation by observation (Leitz, Langer & Furman, 2006) in which a researcher outside of the study team conducts a brief analysis of data and compares this to the initial results (Russell & Kelly, 2002). Ideally, participants would have been invited to comment on the accuracy of the analysis (Johnson & Waterfield, 2004), however, due to the time constraints of this project this was not feasible.

Another limitation of this study is the use of a semi-structured interview as the method of data collection. There has been much debate in the literature about the quality of interviews as well as issues around reflexivity and power (Pezalla, Pettigrew, & Miller-Day, 2012; Plesner, 2011). In this study, interviewers were part of the main trial (Kuyken et al., 2015) team and often participants knew this association and had met with them numerous times over the two years. This bias may have limited the responses from participants and may have biased them to talk in a positive way about MBCT. However, it was made clear at the beginning of the interview that the study was interested in their views both positive and negative.

Future Directions

Patients who have experienced and benefited from MBCT may do so for a variety of reasons, due to linear and non-linear processes and including specific and non-specific factors (Van der Velden et al., 2015). Van der Velden and colleagues concludes from their meta-analysis that it is important to explore specific and non-specific factors relevant to change. The current study has made an attempt to study these factors. But more replicable studies are needed to detail the complex mechanisms underpinning change through MBCT.

This study uses qualitative data from a large RCT to investigate individual differences in journeys through depression and MBCT in a way that quantitative data cannot. The main trial found no differences between groups in terms of primary and secondary outcomes (Kuyken et al., 2015), however, the findings in this study go some way to highlighting the diversity of participants journeys that quantitative results often do not uncover. Whilst going some way to characterising participants' change experiences the findings do not answer

the question of *why* some experience transformation and others do not? Nor are they able to answer questions relating to the relationship between transformation and social context. These would be interesting directions for future research.

Clinical Implications

Paterson and colleagues (1999) postulate that transformation during chronic illness can occur as a response to challenges in illness as well as a conscious decision to take on a challenge. They state that key aims for care professionals working in health settings should be creating a context in which individuals can approach questions of self and identity. The findings in the current study are very similar to those found in physical chronic health literature (e.g. Paterson et al., 1999) and therefore demonstrate that elements of MBCT can prompt or challenge in ways that lead to transformative change experiences, which are likely to lead to better health care outcomes (Paterson et al., 1999). Perhaps MBCT could be the prompt or challenge which could lead patients suffering from chronic depression to transformation and create a context in which patients can consider self and identity.

Conclusion

Participants have described key elements over a two year period of change in self and perception of illness through participation in an MBCT group. These include taking control, a change in relationships with self and illness as well as rebuilding the self and shifting perspective in life. These themes echo those in the literature on transformation in chronic illness in terms of restructuring the self and experience of illness. However, they also offer new insights into relationships with self and illness, including decisions about

treatment for depression. There are a range of implications for this study both clinical and methodological. Firstly, MBCT could provide a prompt for transformation and a context in which patients could consider self and identity. Secondly, by using qualitative methodology this study sheds light on participants experiences in a trial in which found no differences in primary and secondary outcomes. This data shows that participants' experiences were diverse, however, many had positive experiences of MBCT which changed their sense of self and experience of depression.

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Appendices

A. Interview schedule

PREVENT: End of Trial Interviews
Final Draft 10: 21st of August 2013
Guidance for Interviewers

<u>**Conducting the Interview**</u>

The interview is semi-structured. In each section questions and follow-up questions are suggested. However, researchers should use their judgment in drawing out participants in relation to the research topic. Interviewers ask open-ended questions and follow participants' "leads" while keeping in mind the research question. The aim is to enable participants to give their "story" around the main topics of investigation.

Researchers should be strategic in use of time in the interview to ensure the topic guide/respondent covers material that answers the research questions; especially in Section 1 it is important to keep the interview focused. If the interviewer feels respondents are being unclear or opaque help the respondent unpack what they mean or agree with the participant that the issue is unclear. Interviewers should ensure *that all the interview questions that are relevant to the participants' particular profile are covered.*

→ Consider a temporal order to do the interview allocating/planning pre-set time windows for each consecutive episode/junction so as not to exceed a **maximum of 60 minutes** for the overall interview.

Participants may feel the need to please researchers or give the "right" answers. This is particularly likely around ADM tapering where the trial has consistently communicated that we want participants to taper and discontinue their ADM. It is important that researchers communicate explicitly and non-verbally that there are no right and wrong answers to any of the questions and we want to know people's experiences in relation to MBCT and ADM.

Use of particular terms (e.g., "wobble," "relapse") can be adapted in the light of language used by participants. Follow-up questions should be asked for clarification and elaboration, *and this should be driven by the research aim for each section of the interview*. As far as possible interviewers should cover all the suggested topics and questions and behave with the minimum of variation between interviews. Instructions to interviewers and suggested wordings for introductions to each section are given in italics below. The key issues for each question are in bold.

<u>**Interview Opening / Introduction**</u>

Open the interview with something like:

"Thank you for agreeing to do this interview with me. The interview is about hearing from you how things have been in the trial and checking that we have got your story right. It will be collaborative and semi-structured which means I have some topics I'd like to cover, but the

questions will be quite open so as to give you, as an expert of your own lived experience, a chance to express your own views and tell me about your experiences and what seems important to you.   Everyone will have had different experiences and we are interested in hearing about these from your point of view – both the good and the not-so-good experiences – so that we can learn about and develop our treatments further. Please tell us exactly how you feel!

Just to let you know that I am un-blinded and know that you have participated in the MBCT group, so it is ok to talk freely about this. I would like to record this interview, and the recording will be transcribed word for word and analysed as part of the research for the PREVENT trial. All identifying information will be removed at this point. Your name will never appear on the transcription or any other documents or files that result from this interview (such as the audio file).

Do you have any questions before we begin?"

Section 1: Overview of the follow-up period using the timeline

The aim of this section is to obtain a brief overview of how the participant has experienced the follow-up period in terms of 3 areas: 1. Periods of wellness and depression; 2. Antidepressant medication; 3. Life events. Subsequent interview sections follow up on each of these in more detail and the profile of experiences here can be used to tailor subsequent interview questions. Information on the first two areas should be available in advance and summarised on the prepared timeline. Information on life events might be found in the research files and database but will need to be obtained here. Preparation by thoroughly reading the file, and possibly even some of the audio recordings, in advance will help a lot here.

Use the timeline in whatever way feels most comfortable and guided by the respondent's preference. The participant can add life events him/herself; or the researcher can do this; or it can simply be used as a guide. Show the timeline and say something like:

"I'd like to start with a brief overview of how life has been for you in the trial. In preparing for our meeting today, we have put together this timeline. It summarises the information you've given us as part of the research study about any periods of depression or wobbles, and your use of antidepressant medication during the trial.   It also includes the date of your most recent episode of depression before taking part in the trial as well as information on your previous ADM use, based upon what you told us during your first assessment. I've also looked through your comments in the Feedback Booklets you completed one month after the end of the mindfulness course and again recently. These were very helpful and I'll use some of what you wrote there to guide what we talk about today."

Interview Question	Probes/Examples/Directions
1.1. Do you think the information we've got here on the timeline looks about right? Is there anything you would like to change?	If we know from previous assessments that the person has had a significant life event ensure this is acknowledged here. Mark – or get the respondent to mark – any life events on the time-line / graph.

1.2. Have there been any important events in your life during your time in the trial that have affected you either positively or negatively that we can add to the timeline?	Keep the discussion focused and brief to allow as much time for later sections as possible.
1.3. Can we check that I have your use of antidepressant medication right these last two years?	Work through timeline for any tapering/discontinuation, dosage, resumption etc.
1.4. How have things been between the last time we spoke and today?	Informally extend timeline with relevant depressive episodes/ADM use/life events up until current interview date; Where necessary, establish current symptomatic status (informally) and make sure they are ok to continue.

"The remaining questions in this interview will focus upon your experiences with the aid of this timeline."

Keep the time-line / graph in view to refer back to / use further in later parts of the interview. Use the timeline to keep the interview contained with regard to the different episodes/junctures identified prior to interview. Allow and encourage the participant to use a pen to put down details in their copy of the timeline.

Section 2: Questions on wellness (for all)

Comment on Section 2-4: Particularly in the wobbles section it is important to go for depth rather than breadth with regards to potential issues around these time points (e.g. what happened in days before, relationships, sleep etc.). As a general principle, interviewers should encourage interviewees to focus on prototypical or most memorable junctures in timeline. In order to keep interview contained, agree on a timeframe for each episode/juncture and keep questions focused on this.

"I'd like to ask about any times when you were well during the trial – when you weren't feeling low or experiencing an episode of depression"

Interview Question	Probes/Examples/Directions
2.1. How did these experiences of wellness compare to previous experiences of wellness before you took part in this trial?	Probe: before/after trial
2.2. Has anything from the mindfulness course played a part in staying well during the trial? If so, can you describe how?	Examples: any techniques, ideas; response plan Prompts: How / why / why not?; Therapist/Group/Researcher Role
2.3. Did your use of antidepressants play a part in staying well during the trial? If so, can you describe how?	Prompts: How / why / why not? ; GP Role
2.4. What about the combination of xxx from the mindfulness course and use of antidepressants in periods of wellness?	Check answers to booklet questions 1.2.G/2.23., quote if relevant for interaction between MBCT and ADM; [ask qn if both MBCT and ADM relevant in qns 2.2/2.3., otherwise skip];

Section 3: Question on wobbles/early signs of depression (for all, ask even if no wobbles recorded and include recent wobbles after end of trial)

"I'd like to ask about any times when you were well, but you felt yourself starting to 'wobble' or feel low. So any times when you might have felt that your mood was dipping or you were starting to have more of the negative thoughts that were around when you were depressed"

Interview Question	Probes/Examples/Directions
3.1. How did these experiences of 'wobbles' or starting to feel low compare to previous experiences of wobbles (if no relapse skip section 4 and compare wobble to previous depressive episodes here)?	Use timeline to go right into the situation shortly before, during and directly after episode. Probe: What happened, how was it different? What did you do? How did you get out of it?
3.2. Was anything from the mindfulness course useful at the time of wobbling or when starting to feel low during the trial? If so, can you describe how?	Probe: before/during/after wobble Examples: any techniques, ideas; response plan, self-compassion etc. Prompts: How / why / why not?
3.3 Did your use of antidepressants during the trial play a part in wobbling or starting to feel low during the trial? If so, can you describe how (if stopped still ask whether any thoughts about ADM at the time)?	Prompts: How / why / why not?
3.4 What about the combination of xxx from the mindfulness course and use of antidepressants in periods of wobbling or when starting to feel low (How did any thoughts related to ADM interact with MBCT if at all)?	[ask this additional qn if respondent says that both MBCT and ADM have had some value, otherwise skip as appropriate]

Section 4: Experiences of depressive relapse (for those who've relapsed, if no relapse compare wobble to previous depressive episodes, see 3.1.)

Use the timeline to guide question choices in relation to experiences of relapse.

Say: "I'd like to ask you about your experiences this / these episode of depression..."

Interview Question	Probes/Examples/Directions
4.1. How did this episode of depression compare to previous episodes of depression?	Use timeline to take them right into the situation shortly before, during and directly after episode. Probe: What happened, how was it different? What did you do? How did you get out of it?
4.2. Was anything from the mindfulness course useful at the time of depression? If so, can you describe how? [If not practising:] ***Do you think depression would have been different had you been practising?***	Examples: any techniques, ideas; response plan Prompts: How / why / why not?
4.3. Did your use of antidepressants during the trial play a part in this episode of depression? If so, can you describe how?	Prompts: How / why / why not?
4.4 What about the combination of xxx from the mindfulness course and use of antidepressants in periods of depression?	[ask this additional qn if respondent says that both MBCT and ADM have had some value, otherwise skip as appropriate]

Section 5: MBCT and ADMs combined

"I'd like to end with some open questions about your experiences of taking part in this study."

For sakes of time-keeping and for keeping this section contained it is critical how the questions are set up. Encourage people to step back from and reflect critically on their own experience rather than letting them share their raw experience. Use formulations like the following: *'I am sure that this was an intensive time for you. If you took yourself away from the experience today and were to reflect on this, what may I ask are the key elements/thoughts that you would have with regards to staying well etc.'*

Interview Question	Probes/Examples
5.1. Has taking part in the trial changed the way you think about depression? If so, could you tell me how?	Probe: How; why / why not? Probe : Has it changed the way you think about the causes/consequences of depression? Role of GP.
5.2. Has taking part in the trial changed how you think about yourself? If so, could you tell me how?	Probe: how identity was before the trial if person describes a sense of change. Examples: Role of group, immediate and wider social environment
5.3. Now that you've had experiences of both mindfulness and antidepressants, what do you think of each of them as treatments for depression?	Probes: do you favour one over the other? In combination? At different points e.g. in wellness, wobbles and depressive episodes? For prevention? For recovery?
5.4. Apart from depression, has taking part in the trial had any impact on other psychological or physical health problems you may have?	Examples: Anxieties/phobias, Chronic health conditions like pain, diabetes etc.

Section 6: Ending

"I've covered all the questions we have, but before we end, is there anything you would like to add…":

Interview Question	Directions
6.1. …about any of the topics we have discussed?	
6.2. …about any of your experiences of depression, mindfulness or antidepressant medication that we haven't talked about?	
6.3. …about anything else you think is relevant to this project on MBCT, antidepressants, and depression?	

End by thanking the respondent for their time and for sharing their views and experiences. Reiterate how valuable this is for research trying to develop treatments for depression. Inform them about further dissemination of PREVENT findings and discuss their potential involvement in future activities of MDC.

B: Example of thematic coding

1)   I – **How would you say these experiences of feeling well compare to previous experiences of wellness before you took part in the trial?**

2)   R1 – Well I think I became more aware of the, the happy time

	Increased

3)   I – Uhum

4)   R1 – they were, sort of, enlightened more and I appreciated them more

	Greater

5)   I – Uhum

6)   R1 – Umm, I've always felt very grateful and I've always enjoyed the blue sky, the birds, the sea and the garden and the little things in life, I've always umm, aesthetically appreciated beauty but I spose instead of just taking one moment I've ended up taking ten moments to enjoy it

	Taking more time

7)   I – Hmm

8)   R1 – so I've spent longer appreciating the things that I've always appreciated (..) and I suppose I've, I've not (..) beaten myself up quite so much. I mean *therapist's name* used to say that I, I did, I gave sort of compassion to friends and family but not to myself and I'm always aware of that, not to be so hard on myself and I've learnt to say "that's how it is"

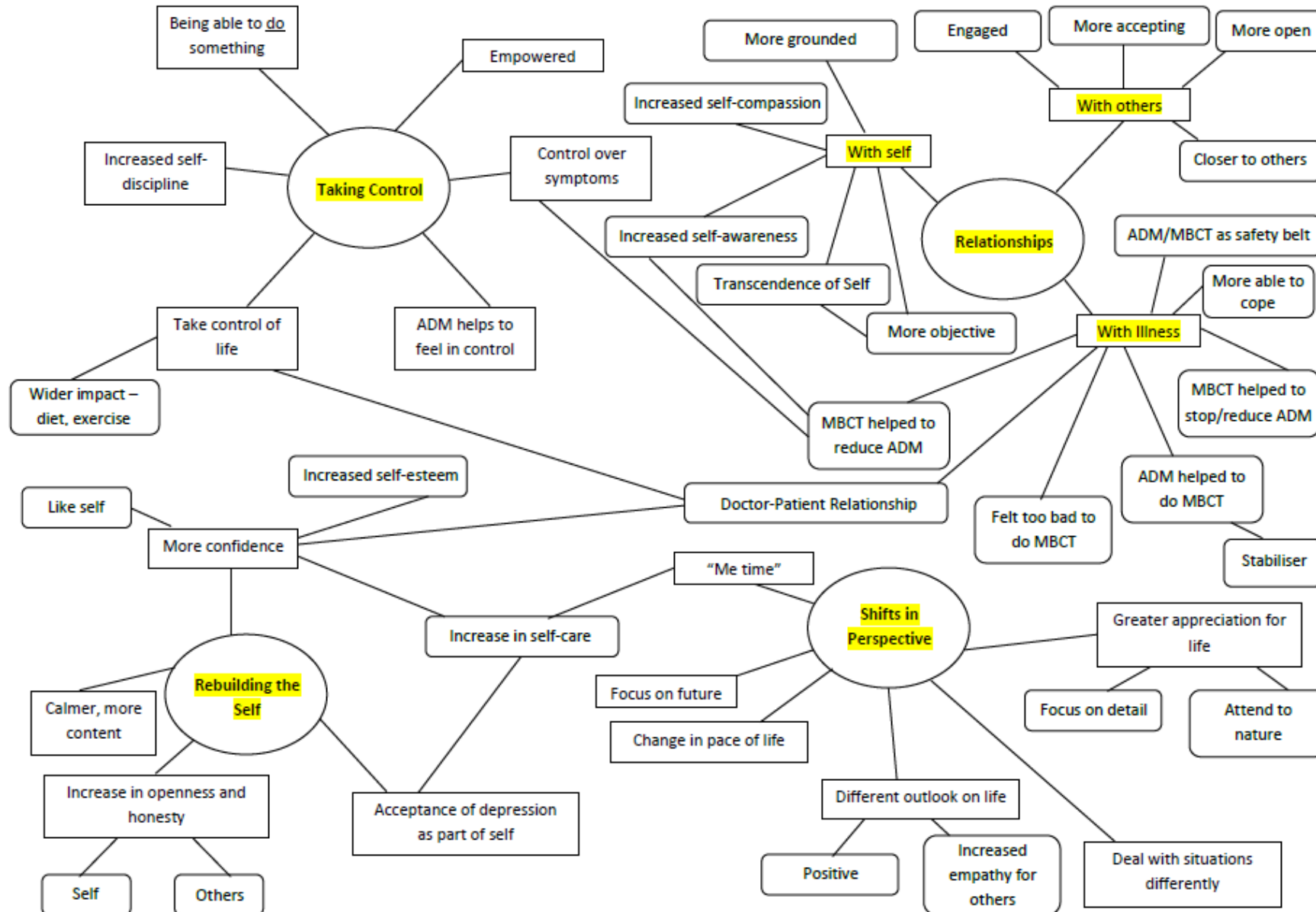|	
	Greater
	Increased
	More accepting of

9)   I- Hmm

10)   I've, I've learnt to be more comfortable with myself and I think that was the one thing that I wasn't. I wasn't comfy in my own skin

C: Thematic Analysis Framework

D: Participant pack

    a.   Information sheet

Preventing Recurrent Depression in NHS Settings
Comparing Antidepressants with Mindfulness-Based Cognitive Therapy (MBCT)
PREVENT

As you know, we are carrying out research to develop effective ways of helping people who have experienced depression. I would like to thank you for all of your help so far. With your support we have recruited 424 people and without your participation we would never have been able to do this. You may remember that Mindfulness-based Cognitive Therapy (shortened to MBCT) is a new treatment for depression that helps people develop skills that may prevent them from becoming depressed again in the future. We are interested in finding out more about whether MBCT works in real-world NHS settings and also how it works in the long-term. We have now come to the end of our planned follow-ups but we would like to know how people do in both groups over a longer period of time. We would like to invite you to take part in an additional 2 year follow-up which would involve two more assessments just like the ones you have done before, one in a years time and another in two years time. However, before you decide whether or not you would like to take part, please read this information sheet carefully. You may also like to discuss taking part in this extension with your family, friends or GP. If you have any questions after reading this, please feel free to contact me directly (contact details are given below). Thank you for taking the time to read this.

Patient Information Sheet—v3.2 21-03-12   South West Rec 09/H0206/43

UNIVERSITY OF EXETER   telephone: 01392 726102 email: prevent@exeter.ac.uk web: www.prevent-southwest.org.uk
ISRCTN26666654 EudraCT number 2009-012428-10
In collaboration with The University of Bristol, King's College London and the Medical Research Council Cognition and Brain Sciences Unit. Funded by National Institute for Health Research HTA   **NHS**

What is the purpose of the study?

Depression is an extremely common mental health problem that is most commonly treated with antidepressant drugs. Antidepressant drugs can help people with depression get better, but it is still very common for people to suffer from depression again in the future. It is also attractive for some people to find a therapy that means they do not have to take any medication. We are interested in comparing two different treatments that aim to help people recover from depression and also stay well in the long term. Mindfulness-based Cognitive Therapy (shortened to MBCT) is an 8 week group programme for people with recurring depression. In several studies it has been shown to halve rates of depression recurring compared to usual NHS care. In order for MBCT to potentially be offered to more people we need to know how it works in the long term compared to antidepressant medication and also how much it costs over a long period of time.

This study is an extension of the PREVENT trial that you have been involved in for the last two years. In the PREVENT study we are following the progress of 424 people for 24 months. We asked half of these people to continue with their antidepressant medication throughout the 24 months and we asked half to attend an MBCT group and slowly reduced the medication they were taking (although we know for some people this was difficult and not everyone has done the same thing). We are still monitoring the progress of people and this will be important information that informs future treatment of depression.

We now feel it's important to see how people are doing in the longer term and if the effects last longer than 24 months. We are asking you to consider taking part in 2 more future follow up assessments. This extension of PREVENT will last for 2 years, however, we will not be asking people to do anything with their medication—it is called a 'naturalistic' follow up, so we just want to see how you do in terms of your mood and quality of life but we won't be asking you to do anything different in terms of how you choose to manage your well-being.

2

What happens if I'm in the group who were offered MBCT and were asked to reduce their medication?

We would like you to carry on doing what you usually do, whether that means practising the mindfulness or not, and we would like to meet with you two more times to see how you are doing in the long term. Unlike during the last two years will not be asking you to do anything with your medication and you, with the advice of your GP, can choose to increase, reduce or come off your medication, it will be totally up to you. We would just ask that we could meet with you twice more for an hour or so each time to see how you're doing.

What happens if I'm in the group who were asked to stay on their medication?

Unlike during the last two years we will not be asking you to do anything with your medication and you, with the advice of your GP, can choose to increase, reduce or come off your medication, it will be totally up to you. You are free to have any other treatment you would like during the two years. We would just ask that we could meet with you twice more for an hour or so each time to see how you're doing.

Why have I been chosen?

You are one of the 424 people already involved in PREVENT and we would like to follow-up as many people as possible over another two years.

Do I have to take part?

No; it is up to you to decide whether or not to take part. If you do decide to take part you will be given this information sheet to keep and be asked to sign a new consent form which you can also keep. The consent form, like the last one that you filled in at the beginning of the trial, simply gives us permission to look at some parts of your medical records, gather and store information and sets out how we plan to go about running the research project. If you decide to take part you are still free to withdraw at any time and without giving a

reason. The study doctor may also withdraw you from the study if they feel it would be in your best interests. A decision to withdraw at any time, or a decision not to take part, will not affect the standard of care you receive.

What will happen if I take part? What will I have to do?

Taking part in this study involves two more assessments like the one you've just had, one assessment in a year and one in two years time. It will involve the same questionnaire booklets and a face-to-face interview with a researcher which will ask about how you've been feeling over the year, how you've been feeling recently and your use of hospitals and other services over the past year. In addition, we are interested at 24 months in three questionnaires that you completed at your first follow-up assessment to see how you are dong in terms of your levels of mindfulness and compassion. Each time you come in for one of these meetings you will be given £10 to help cover the cost of your travel and any other expenses, should your journey cost more than this, then we will arrange for the full amount to be reimbursed to you.

Questions you might have:

What information do you want to know about me?

With your permission, we would like to audiotape the meeting to make sure that the researchers are doing a good job. These audiotapes will also be stored securely in a locked cabinet in the Mood Disorders Centre and will be accessible only to members of the research team. You can however opt out of this part if you wish to.

What about my DNA?

As you may remember we previously acquired a sample of your saliva to carry out a DNA analysis to look at one particular gene which we think may be important in understanding depression (a part of the gene SLC6A4 called the Polymorphic variant in the Serotonin Transporter promoter gene or SERT). Because of

scientific advances in our understanding of genetics and depression we would like to seek your consent to look at other genes that may also be important. *We would **not** need to take an additional saliva sample to do this.* We can use the sample that you have already kindly provided. We simply seek your consent to do these additional investigations. As before, we would never store the information about your DNA with your name, only your trial number. It would not be possible to ever match the sample we are asking for with any other DNA sample that may be in existence. *You could never be identified from this sample.*

How will you check to see how I'm getting on?

You will be given a set of questionnaires and asked some questions about how you are doing over the next two years, we will do this in 12 and 24 months.

Will I have to do the mood experiment again or the computer task?

No, we are grateful for those of you who were asked to do these tasks and completed them and we will not be asking you to do them again.

What are the possible disadvantages and risks of taking part?

Your health, welfare and wellbeing are the first priority for all the members of the research team and we will do our very best to minimise any disadvantages and risks. Taking part in this research will involve you taking some time to complete the questionnaires and discuss with the researchers how you are doing. These questionnaires are about you and some of the questions are personal, sometimes people can find it upsetting to discuss these issues. You don't have to discuss anything you don't want to and the research team members are trained to make sure that they are sensitive to your feelings and concerns.

We would ask you to just carry on as normal and we would like to see how you are doing.

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At all points during the study, you and your GP will make all decisions about the best approach to your antidepressant medication. All that we will ask is that you remember to tell us about any medication you have been taking and we will check with you at regular intervals (12 and 24 months).

What are the possible benefits of taking part?

We hope that either the antidepressant drug or MBCT treatments will help you by preventing depression reoccurring in the long term. Both treatments are recommended by NICE (The National Institute for Clinical Excellence) as helpful treatments for recurrent depression. However, we cannot guarantee that these treatments will help you. The information we get from this study may help us to treat future people with depression better. We will keep an eye on everyone in the study to see how they are doing. If anyone shows signs of suffering a relapse of depression we will help ensure they have access to appropriate help.

What happens when the research study stops?

At the end of the study you should discuss with your GP the best continuation of your treatment plan to promote your recovery from depression.

What if new information becomes available?

Sometimes during the course of a research study, new information becomes available about the treatment that is being studied. If this happens, we will tell you about it and discuss with you whether you want to continue in the study. If you decide to withdraw, we will make arrangements for your care to continue. If you decide to continue in the study, you will be asked to sign an updated consent form. On receiving new information, we might consider it to be in your best interests to withdraw you from the study. If this happens, we will explain the reasons and arrange for your care to continue.

What if something goes wrong?

If you are experiencing problems or you feel that something is going wrong please bring it to our attention immediately. We will do our very best to deal with the issue properly. You can talk to your MBCT therapist if you are in the MBCT group and whichever group you are in you can always contact me, Willem Kuyken, the trial's Chief Investigator (contact details below). If you wish to complain about any aspect of the research team's work you can also raise this with me. The normal National Health Service complaints mechanism is also available to you (Patient Advice & Liaison Service FREEPHONE 0800 073 0741 or dpn-tr.pals@nhs.net).

Will my taking part in this study be kept confidential?

All information collected about you during the course of the research will be kept strictly confidential. Your personal details are stored in a separate locked cabinet from all the information we collect and we never put your name on any of the questionnaires that we ask you to fill out. The only exception would be if the interview revealed a significant risk of harm to yourself or others, in which case information may be fed back to your doctor but normally only after discussion with you.

What will happen to the results of the research study?

The researchers aim to publish the work in an academic journal. We will also provide all those who take part with regular newsletters and an information sheet at the end of the study detailing the results we have found. Your identity will never be revealed in any report or publication. Generally our research is reported on the Mood Disorders Centre website at: http://www.centres.ex.ac.uk/mood/.

Who is organising and funding the research? Who has reviewed the study?

This research is funded by the National Institute for Health

Research Health Technology Assessment Programme and is sponsored by the University of Exeter. The research has been approved by the South West Research Committee (ref number 09/ H0206/43) and has the support of the University of Exeter, School of Psychology Ethics Committee.

What happens next?

Your appointment with a researcher has been arranged and at that you will have the chance to ask any questions you have. If you are still happy to take part in the extension to the PREVENT study we will ask you to sign a form to say so and we will be in contact in one years time.

What if I have any questions or concerns either now or in the future?

If you do have any questions or concerns please feel free to talk to Willem Kuyken, the study's Chief Investigator.

Prof Willem Kuyken
Professor of Clinical Psychology
Co-director Mood Disorders Centre
Mood Disorders Centre
School of Psychology
University of Exeter
Exeter EX4 4QG

01392 724659
w.kuyken@exeter.ac.uk

Thank you for taking the time to read this information

For more information you can also contact
Dr Rachel Hayes
Trial Manager
01392 724669
rahayes@exeter.ac.uk

www.prevent-southwest.org.uk
prevent@exeter.ac.uk

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b Consent form

PART 2: To be completed by **ELIGIBLE** patients only

		Please initial the box
7.	I agree to take part in the above study	
8.	I give my permission for responsible individuals from the PREVENT study team (which includes researchers based at the University of Bristol and the University of Exeter), to have access to any of my medical records	
9.	I understand that my participation is voluntary and that I am free to withdraw at any time, without giving any reason, without my medical care or legal rights being affected	
10	I agree to have a sample of my DNA tested to determine what version of the SERT gene I have	
11.	I understand that I may be contacted by a member of the PREVENT research team to discuss my views and experiences of taking part in the trial	
12.	I agree to my interviews and treatment (if I am offered MBCT) being audio / video-taped for **research** purposes	
13.	I agree to my interviews and treatment (if I am offered MBCT) being audio / video-taped for **teaching** purposes	
14.	I agree to my GP being informed of my participation in this study and being updated with information relevant to my medical care	
15.	I agree to my contact details being added to the Mood Disorders Centre's database so that I might be invited in the future to take part in other depression research	

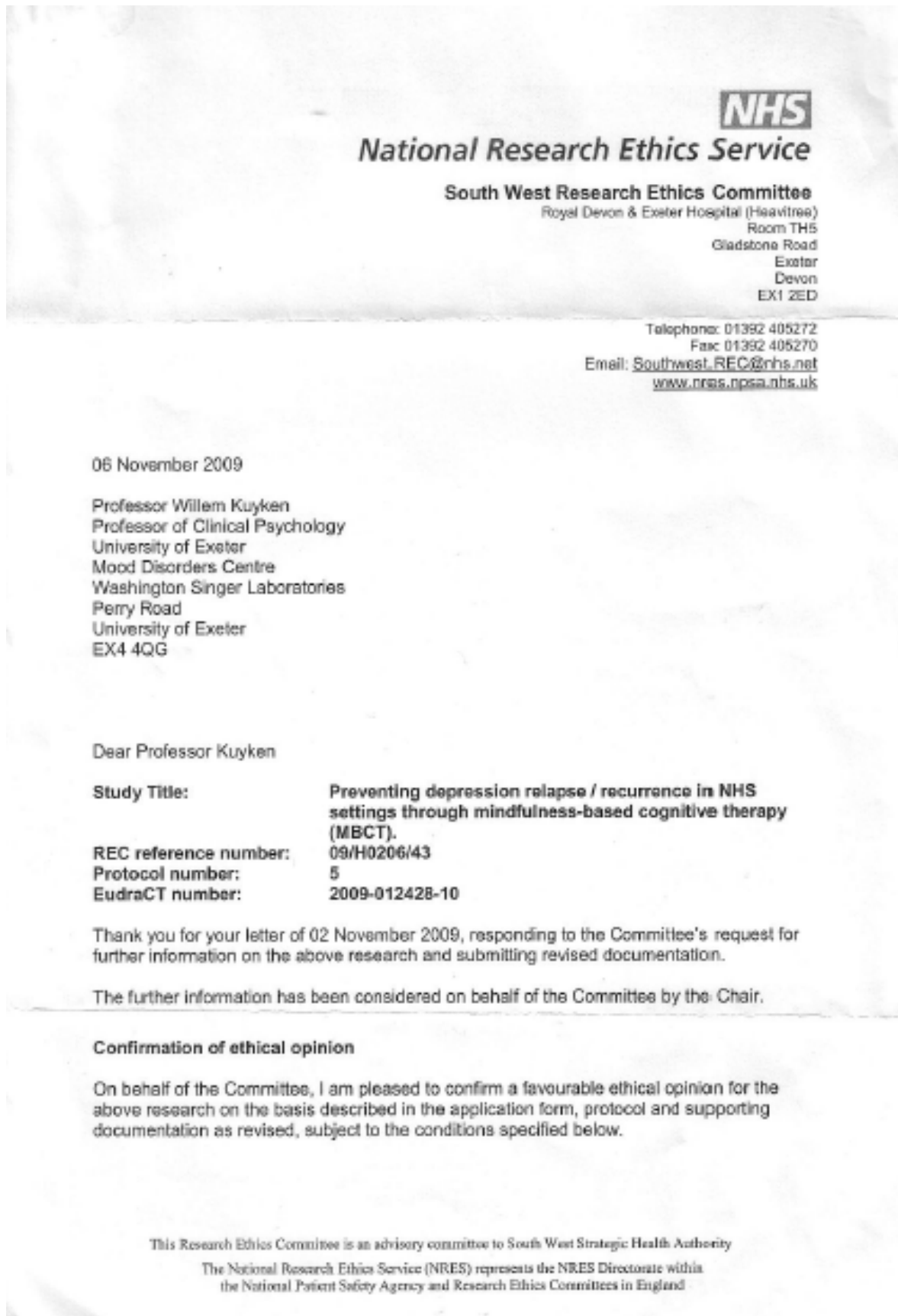When you have initialled all the boxes above, please complete below including the date yourself.

_____   _____   _____
Name of Patient   Date   Signature
(BLOCK CAPITALS)

I have explained the study to the above patient and he/she has indicated his/her willingness to take part in the study.

_____   _____   _____
Name of Researcher   Date   Signature
(BLOCK CAPITALS)

E. Ethics documentation
  a. NHS ethical approval (agreed and substantive amendment)

NHS

National Research Ethics Service

South West Research Ethics Committee
Royal Devon & Exeter Hospital (Heavitree)
Room TH5
Gladstone Road
Exeter
Devon
EX1 2ED

Telephone: 01392 405272
Fax: 01392 405270
Email: Southwest.REC@nhs.net
www.nres.npsa.nhs.uk

06 November 2009

Professor Willem Kuyken
Professor of Clinical Psychology
University of Exeter
Mood Disorders Centre
Washington Singer Laboratories
Perry Road
University of Exeter
EX4 4QG

Dear Professor Kuyken

Study Title:	Preventing depression relapse / recurrence in NHS settings through mindfulness-based cognitive therapy (MBCT).
REC reference number:	09/H0206/43
Protocol number:	5
EudraCT number:	2009-012428-10

Thank you for your letter of 02 November 2009, responding to the Committee's request for further information on the above research and submitting revised documentation.

The further information has been considered on behalf of the Committee by the Chair.

Confirmation of ethical opinion

On behalf of the Committee, I am pleased to confirm a favourable ethical opinion for the above research on the basis described in the application form, protocol and supporting documentation as revised, subject to the conditions specified below.

This Research Ethics Committee is an advisory committee to South West Strategic Health Authority

The National Research Ethics Service (NRES) represents the NRES Directorate within the National Patient Safety Agency and Research Ethics Committees in England

NHS

Ethical review of research sites

The favourable opinion applies to all NHS sites taking part in the study, subject to management permission being obtained from the NHS/HSC R&D office prior to the start of the study (see "Conditions of the favourable opinion" below).

The Committee has not yet been notified of the outcome of any site-specific assessment (SSA) for the non-NHS research site(s) taking part in this study. The favourable opinion does not therefore apply to any non-NHS site at present. I will write to you again as soon as one Research Ethics Committee has notified the outcome of a SSA. In the meantime no study procedures should be initiated at non-NHS sites.

Conditions of the favourable opinion

The favourable opinion is subject to the following conditions being met prior to the start of the study.

Management permission or approval must be obtained from each host organisation prior to the start of the study at the site concerned.

For NHS research sites only, management permission for research ("R&D approval") should be obtained from the relevant care organisation(s) in accordance with NHS research governance arrangements. Guidance on applying for NHS permission for research is available in the Integrated Research Application System or at http://www.rdforum.nhs.uk. *Where the only involvement of the NHS organisation is as a Participant Identification Centre, management permission for research is not required but the R&D office should be notified of the study. Guidance should be sought from the R&D office where necessary.*

Sponsors are not required to notify the Committee of approvals from host organisations.

Clinical trial authorisation must be obtained from the Medicines and Healthcare products Regulatory Agency (MHRA).

The sponsor is asked to provide the Committee with a copy of the notice from the MHRA, either confirming clinical trial authorisation or giving grounds for non-acceptance, as soon as this is available.

It is the responsibility of the sponsor to ensure that all the conditions are complied with before the start of the study or its initiation at a particular site (as applicable).

Approved documents

The final list of documents reviewed and approved by the Committee is as follows:

Document	Version	Date
Questionnaire: Structured Interview Guide for the Hamilton Psychiatric Rating Scale for Depression (HSRD)		
Questionnaire: LIFE SCID		
REC application	2.2	17 August 2009
Investigator CV		
Application Checklist	2.2	
Patient Summary Pamphlet	2.0	20 August 2009

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Patient Reply Form	2.0	20 August 2009
Letter as from GP		20 August 2009
Letter to confirm baseline		16 June 2009
Poster		
Protocol	5	20 August 2009
Letter from Sponsor		17 August 2009
Insurance Certificate		24 July 2009
Mood Induction Task	1	20 August 2009
Questionnaire: Medical Symptom Checklist (MSCL)		
Questionnaire: Health (EQ-5D)		
Questionnaire: WHO-Qol-BREF		
Questionnaire: Beck Depression Inventory-II (BDI-II)		
Questionnaire: 5-FACET M		
Questionnaire: Self-Compassion Scale (SCS)		
Questionnaire: The General Self-efficacy Scale (GSS)		
Questionnaire: Measure of Parental Style (MOPS)		
Questionnaire: The Snaith-Hamilton Pleasure Scale (SHAP)		
Questionnaire: DAS-A		
Questionnaire: DAS-B		
Questionnaire: VAS		
Questionnaire: AD-SUS		
Questionnaire: CERTS		
Interview questions at end of Trial		
Structured Interview Guide for the Hamilton Psychiatric Rating Scale for Depression		
Response to Request for Further Information		02 November 2009
Participant Information Sheet: Patient Information Sheet	3	28 October 2009
Participant Consent Form	3	28 October 2009

Statement of compliance

This Committee is recognised by the United Kingdom Ethics Committee Authority under the Medicines for Human Use (Clinical Trials) Regulations 2004, and is authorised to carry out the ethical review of clinical trials of investigational medicinal products.

The Committee is fully compliant with the Regulations as they relate to ethics committees and the conditions and principles of good clinical practice.

The Committee is constituted in accordance with the Governance Arrangements for Research Ethics Committees (July 2001) and complies fully with the Standard Operating Procedures for Research Ethics Committees in the UK.

After ethical review

Now that you have completed the application process please visit the National Research Ethics Service website > After Review

NHS

You are invited to give your view of the service that you have received from the National Research Ethics Service and the application procedure. If you wish to make your views known please use the feedback form available on the website.

The attached document "*After ethical review – guidance for researchers*" gives detailed guidance on reporting requirements for studies with a favourable opinion, including:

- Notifying substantial amendments
- Adding new sites and investigators
- Progress and safety reports
- Notifying the end of the study

The NRES website also provides guidance on these topics, which is updated in the light of changes in reporting requirements or procedures.

We would also like to inform you that we consult regularly with stakeholders to improve our service. If you would like to join our Reference Group please email referencegroup@nres.npsa.nhs.uk.

RERC ref: 09/H0206/43	Please quote this number on all correspondence

Yours sincerely

PP **Mr Chris Foy**
Chair

Email: Southwest.REC@nhs.net

Enclosures: "After ethical review – guidance for researchers" SL-AR1 for CTIMPs

Copy to: Helen Loughlin, University of Exeter

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b. School ethics

Your application for ethical approval (2014/606) has been accepted

REPLYREPLY ALLFORWARD

Mark as unread

apache@exeter.ac.uk

 on behalf of

Ethics Approval System <D.M.Salway@exeter.ac.uk>

Thu 29/05/2014 09:07

Inbox

To:

Weaver, Alice;

Ethical Approval system

Your application (2014/606) entitled "Journeys through depression": Patients' experiences of transformational change through mindfulness based cognitive therapy (MBCT) and antidepressant medication (ADM). has been accepted

Please visit http://www.exeter.ac.uk/staff/ethicalapproval/

Please click on the link above and select the relevant application from the list.

F. Dissemination statement

The results of this study will be disseminated to interested parties through feedback, journal publication and presentation.

Dissemination to participants and NHS services.

As stated on the participant information sheet participants will be informed of the results of the study. Participants will be provided with details of who to contact, should they require further information. Additionally the MBCT therapists and research team from the main RCT will be provided with a summary of the findings. The NHS research ethics committee at Exeter and the Research and Development team will be sent a summary of the findings of the study and will be informed that the study is now complete.

Journal Publication

It is expected that the study will be submitted for publication with the journal Social Science and Medicine (Impact factor 2.56).

Presentation

On 8th June 2015, my research findings were presented to an academic audience, for peer review, as part of the Doctorate in Clinical Psychology at the University of Exeter.

E: Author's instructions

Manuscript Submission Guidelines: *Qualitative Health Research* (QHR)

Qualitative Health Research (QHR) is an international, interdisciplinary, refereed journal for the enhancement of health care and furthering the development and understanding of qualitative research methods in health care settings. We welcome manuscripts in the following areas: the description and analysis of the illness experience, health and health-seeking behaviors, the experiences of caregivers, the sociocultural organization of health care, health care policy, and related topics. We also consider critical reviews; articles addressing qualitative methods; and commentaries on conceptual, theoretical, methodological, and ethical issues pertaining to qualitative inquiry.

QHR is a member of the Committee on Publication Ethics.

This Journal recommends that authors follow the Uniform Requirements for Manuscripts Submitted to Biomedical Journals formulated by the International Committee of Medical Journal Editors (ICMJE)

Please read the guidelines below then visit the Journal's submission site http://mc.manuscriptcentral.com/qhr to upload your manuscript. Please note that manuscripts not conforming to these guidelines may be returned.

Only manuscripts of sufficient quality that meet the aims and scope of QHR will be reviewed.

As part of the submission process you will be required to warrant that you are submitting your original work, that you have the rights in the work, that you are submitting the work for first publication in the Journal and that it is not being considered for publication elsewhere and has not already been published elsewhere, and that you have obtained and can supply all necessary permissions for the reproduction of any copyright works not owned by you.

1. Article types

1. Article types

Each issue of QHR provides readers with a wealth of information - book reviews, commentaries on conceptual, theoretical, methodological and ethical issues pertaining to qualitative inquiry as well as articles covering research, theory and methods in the following areas:

Description and analysis of the illness experience
Experiences of caregivers
Health and health-seeking behaviors
Health care policy
Sociocultural organization of health care

A Variety of Perspectives

QHR addresses qualitative research from variety of perspectives including: cross-cultural health, family medicine, health psychology, health social work, medical anthropology, medical sociology, nursing, pediatric health, physical education, public health, and rehabilitation.

In-Depth Timely Coverage

Articles in QHR provide an array of timely topics such as: experiencing illness, giving care, institutionalization, substance abuse, food, feeding and nutrition, living with disabilities, milestones and maturation, monitoring health, and children's perspectives on health and illness.

Look Out for These Regular Special Features

Pearls, Pith and Provocation: This section fosters debate about significant issues, enhances communication of methodological advances and encourages the discussion of provocative ideas.

Computer Monitor: These are articles related to computers and qualitative research.

Book Review Section: *Qualitative Health Research* includes a book review section helping readers determine which publications will be most useful to them in practice, teaching and research.

Mixed Methods: This section includes qualitatively-driven mixed-methods research, and qualitative contributions to quantitative research.

Advancing Qualitative Methods: Here, qualitative inquiry that has used qualitative methods in an innovative way is described.

Evidence of Practice: Theoretical or empirical articles addressing research integration and the translation of qualitatively derived insights into clinical decision-making and health service policy planning.

Ethics: Quandaries or issues that are particular rot qualitative inquiry are discussed.

Teaching Matters: Articles that promote and discuss issues related to the teaching of qualitative methods and methodology.

2. Editorial policies

2.1 Peer review policy

QHR strongly endorses the value and importance of peer review in scholarly journals publishing. All papers submitted to the journal will be subject to comment and external review. All manuscripts are reviewed initially by the Editors and only those papers that meet the scientific and editorial standards of the journal, and fit within the aims and scope of the journal, will be sent for outside review.

QHR adheres to a rigorous double-blind reviewing policy in which the identity of both the reviewer and author are always concealed from both parties. Please refer to the editorial on blinding found in the Nov 2014 issue: http://qhr.sagepub.com/content/24/11/1467.full.

2.2 Authorship

Papers should only be submitted for consideration once consent is given by all contributing authors. Those submitting papers should carefully check that all those whose work contributed to the paper are acknowledged as contributing authors.
The list of authors should include all those who can legitimately claim authorship. This is all those who:

- (i)   Made a substantial contribution to the concept and design, acquisition of data or analysis and interpretation of data,
- (ii) Drafted the article or revised it critically for important intellectual content,
- (iii) Approved the version to be published.

Authors should meet the conditions of all of the points above. Each author should have participated sufficiently in the work to take public responsibility for appropriate portions of the content.

When a large, multicentre group has conducted the work, the group should identify the individuals who accept direct responsibility for the manuscript. These individuals should fully meet the criteria for authorship.

Acquisition of funding, collection of data, or general supervision of the research group alone does not constitute authorship, although all contributors who do not meet the criteria for authorship should be listed in the Acknowledgments section.
Please refer to the International Committee of Medical Journal Editors (ICMJE) authorship guidelines for more information on authorship.

2.3 Acknowledgements

All contributors who do not meet the criteria for authorship should be listed in an Acknowledgements section. Examples of those who might be acknowledged include a person who provided purely technical help, or a department chair who provided only general support.

2.3.1 Writing assistance

Individuals who provided writing assistance, e.g. from a specialist communications company, do not qualify as authors and so should be included in the Acknowledgements section. Authors must disclose any writing assistance – including the individual's name, company and level of input – and identify the entity that paid for this assistance").
It is not necessary to disclose use of language polishing services.

Please supply any personal acknowledgements separately to the main text to facilitate anonymous peer review.

2.4 Funding

QHR requires all authors to acknowledge their funding in a consistent fashion under a separate heading. Please visit the Funding Acknowledgements page on the SAGE Journal Author Gateway to confirm the format of the acknowledgment text in the event of funding, or state that: This research received no specific grant from any funding agency in the public, commercial, or not-for-profit sectors.

2.5 Declaration of conflicting interests

It is the policy of QHR to require a declaration of conflicting interests from all authors enabling a statement to be carried within the paginated pages of all published articles. Please ensure that a 'Declaration of Conflicting Interests' statement is included at the end of your manuscript, after any acknowledgements and prior to the references. If no conflict exists, please state that 'The Author(s) declare(s) that there is no conflict of interest'.

For guidance on conflict of interest statements, please see the ICMJE recommendations here

2.6 Research ethics and patient consent

Medical research involving human subjects must be conducted according to the World Medical Association Declaration of Helsinki.

Submitted manuscripts should conform to the ICMJE Recommendations for the Conduct, Reporting, Editing, and Publication of Scholarly Work in Medical Journals, and all papers reporting animal and/or human studies must state in the methods section that the relevant Ethics Committee or Institutional Review Board provided (or waived) approval. Please ensure that you have provided the full name and institution of the review committee, in addition to the approval number.

For research articles, authors are also required to state in the methods section whether participants provided informed consent and whether the consent was written or verbal.

In terms of patient privacy, authors are required to follow the ICMJE Recommendations for the Protection of Research Participants. Patients have a right to privacy that should not be infringed without informed consent. Identifying information, including patients' names, initials, or hospital numbers, should not be published in written descriptions, photographs, and pedigrees unless the information is essential for scientific purposes and the patient (or parent or guardian) gives written informed consent for publication. Informed consent for this purpose requires that a patient who is identifiable be shown the manuscript to be published. Participant descriptors should not be listed individually. Because qualitative research is descriptive, it is recommended that participant quotations not be linked to identifiers in the manuscript.

2.7 Clinical trials

QHR conforms to the ICMJE requirement that clinical trials are registered in a WHO-approved public trials registry at or before the time of first patient enrolment as a condition of consideration for publication. The trial registry name and URL, and registration number must be included at the end of the abstract.

2.8 Reporting guidelines

The relevant EQUATOR Network reporting guidelines should be followed depending on the type of study. For example, all randomized controlled trials submitted for publication should include a completed Consolidated Standards of Reporting Trials (CONSORT) flow chart as a cited figure, and a completed CONSORT checklist as a supplementary file.

Other resources can be found at NLM's Research Reporting Guidelines and Initiatives.

2.9 Data

SAGE acknowledges the importance of research data availability as an integral part of the research and verification process for academic journal articles.

QHR requests all authors submitting any primary data used in their research articles alongside their article submissions to be published in the online version of the journal, or provide detailed information in their articles on how the data can be obtained. This information should include links to third-party data repositories or detailed contact information for third-party data sources. Data available only on an author-maintained website will need to be loaded onto either the journal's platform or a third-party platform to ensure continuing accessibility. Examples of data types include but are not limited to statistical data files, replication code, text files, audio files, images, videos, appendices, and additional charts and graphs necessary to understand the original research. [The editor(s) may consider limited embargoes on proprietary data.] The editor(s) [can/will] also grant exceptions for data that cannot legally or ethically be released. All data submitted should comply with Institutional or Ethical Review Board requirements and applicable government regulations. For further information, please contact the editorial office at vshannonqhr@gmail.com.

3. Publishing Policies

3.1 Publication ethics

SAGE is committed to upholding the integrity of the academic record. We encourage authors to refer to the Committee on Publication Ethics' International Standards for Authors and view the Publication Ethics page on the SAGE Author Gateway

3.1.1 Plagiarism

QHR and SAGE take issues of copyright infringement, plagiarism or other breaches of best practice in publication very seriously. We seek to protect the rights of our authors and we always investigate claims of plagiarism or misuse of articles published in the journal. Equally, we seek to protect the reputation of the journal against malpractice. Submitted articles may be checked using duplication-checking software. Where an article is found to have plagiarised other work or included third-party copyright material without permission or with insufficient acknowledgement, or where authorship of the article is contested, we reserve the right to take action including, but not limited to: publishing an erratum or corrigendum (correction); retracting the article (removing it from the journal); taking up the matter with the head of department or dean of the author's institution and/or relevant academic bodies or societies; banning the author from publication in the journal or all SAGE journals, or appropriate legal action.

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3.3 Open access and author archiving

QHR offers optional open access publishing via the SAGE Choice programme. For more information please visit the SAGE Choice website. For information on funding body compliance, and depositing your article in repositories, please visit SAGE Publishing Policies on our Journal Author Gateway.

3.4 Permissions

Authors are responsible for obtaining permission from copyright holders for reproducing any illustrations, tables, figures or lengthy quotations previously published elsewhere. For further information including guidance on fair dealing for criticism and review, please visit our Frequently Asked Questions on the SAGE Journal Author Gateway

4. Preparing your manuscript

4.1 Word processing formats

Preferred formats for the text and tables of your manuscript are Word DOC, RTF, XLS. LaTeX files are also accepted. The text should be double-spaced throughout and with a minimum of 3cm for left and right hand margins and 5cm at head and foot. Text should be standard 10 or 12 point. Word and LaTex templates are available on the Manuscript Submission Guidelines page of our Author Gateway.

4.2 Artwork, figures and other graphics

For guidance on the preparation of illustrations, pictures and graphs in electronic format, please visit SAGE's Manuscript Submission Guidelines. Please refer to clause 4.5 for information on SAGE Language Services.

Figures supplied in color will appear in color online regardless of whether or not these illustrations are reproduced in colour in the printed version. For specifically requested color reproduction in print, you will receive information regarding the costs from SAGE after receipt of your accepted article.

4.3 Supplementary material

This journal is able to host additional materials online (e.g. datasets, podcasts, videos, images etc) alongside the full-text of the article. These will be subjected to peer-review alongside the article. For more information please refer to our guidelines on submitting supplementary files, which can be found within our Manuscript Submission Guidelines page.

4.4 Journal layout

In general, QHR adheres to the guidelines contained in the Publication Manual of the American Psychological Association ["APA"], 6th edition (ISBN 10:1-4338-0561-8, softcover; ISBN 10:1-4338-0559-6, hardcover; 10:1-4338-0562, spiral bound), withregard to manuscript preparation and formatting. These guidelines are referred to as the APA Publication Manual, or just APA. Additional help may be found online at http://www.apa.org/, or search the Internet for "APA format."

4.5 Reference style

QHR adheres to the APA reference style. Click here to review the guidelines on APA to ensure your manuscript conforms to this reference style.

4.6 English language editing services

Authors seeking assistance with English language editing, translation, or figure and manuscript formatting to fit the journal's specifications should consider using SAGE Language Services. Visit SAGE Language Services on our Journal Author Gateway for further information.

5. Submitting your manuscript

5.1 How to submit your manuscript

QHR is hosted on SAGE Track, a web based online submission and peer review system powered by ScholarOne™ Manuscripts. Visit http://mc.manuscriptcentral.com/qhr to login and submit your article online.

IMPORTANT: Please check whether you already have an account in the system before trying to create a new one. If you have reviewed or authored for the journal in the past year it is likely that you will have had an account created. For further guidance on submitting your manuscript online please visit ScholarOne.

5.2 Title, keywords and abstracts

Please supply a title, short title, an abstract and keywords to accompany your article. The title, keywords and abstract are key to ensuring readers find your article online through online search engines such as Google. Please refer to the information and guidance on how best to title your article, write your abstract and select your keywords by visiting the SAGE Journal Author Gateway for guidelines on How to Help Readers Find Your Article Online

5.3 Corresponding author contact details

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7. Further information

Any correspondence, queries or additional requests for information on the manuscript submission process should be sent to the QHR editorial office as follows:

Vanessa Shannon, Managing Editor, vshannonqhr@gmail.com.

Appendix F: Dissemination statement

The results of this study will be disseminated to interested parties through feedback, journal publication and presentation.

Dissemination to participants and NHS services.

As stated on the participant information sheet participants will be informed of the results of the study. Participants will be provided with details of who to contact, should they require further information. Additionally the cardiac staff involved in the research will be provided with a summary of the findings. The NHS research ethics committee at Exeter and RD&E Research and Development team will be sent a summary of the findings of the study and will be informed that the study is now complete.

Journal Publication

It is expected that the study will be submitted for publication with the Journal of Psychosomatic Research (Impact factor 3.37).

Presentation

On 9th June 2014, my research findings were presented to an academic audience, for peer review, as part of the Doctorate in Clinical Psychology at the University of Exeter.

The findings will also be orally presented to the Lifetime service in Bath, a specialist paediatric service which work closely with children and young people with complex cardiac conditions.