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Title: Starting where I am: a grounded theory exploration of mindfulness as a facilitator of transition in living with a long-term condition

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ABSTRACT

Aim

To explore how practising mindfulness affects people's experiences of living with a long-term condition.

Background

Increasing evidence suggests that mindfulness meditation-based interventions benefit people with long-term conditions, particularly in terms of psychological wellbeing. Most evidence however relates to short-term outcomes, and limited information exists about how people use mindfulness in the longer-term, and how this affects their experience of living with their condition.

Design

A qualitative study using constructivist-informed grounded theory.

Methods

Using interviews, diaries and focus groups, data were collected between 2011 and 2012 from participants and/or trainers of Breathworks' mindfulness intervention. Phased recruitment enabled theoretical sampling, with data analysed concurrently using Charmaz's two-stage coding strategy.

Findings

The final sample comprised 41 adults with diverse physical and/or mental health conditions. Participants reported predominantly positive experiences, almost all identifying significant changes in thinking and behaviour. A core process of 'Starting where I am' was formulated, highlighting how people became more aware and accepting of their condition and thus able to self-care more effectively. The process was encapsulated in five themes: Getting a new perspective; Feeling equipped to cope; Doing life differently; Seeing a change; and Finding mindfulness difficult. Strong resonances were identified between participants' experiences and the process of transition through which people come to terms with challenging life events.

Conclusion

Mindfulness can be conceptualised as a facilitator of transition, enabling people to adapt to living with a long-term condition. Transition is associated with improved, self-

directed self-management, which is significant to both people with long-term conditions and healthcare providers.

KEYWORDS

Mindfulness; meditation; long-term conditions; non-communicable diseases; transition; self-management; nursing; qualitative research; grounded theory

IMPACT STATEMENT

- This paper supports existing evidence that mindfulness mediation-based interventions can positively impact on the lives of people with a diversity of long-term conditions (LTCs).
- It provides new evidence that significant changes in thinking and behaviour can be maintained, sometimes over many years.
- The paper offers a new conceptualisation of mindfulness as a facilitator of transition, enabling people to adapt to living with a LTC.
- It confirms the associations between transition and a more self-directed style of self-management.
- The paper provides new insights into the varying depths and timescales of transition which may occur in individuals' lives. This may enable healthcare practitioners to support people's adaptation to and management of their condition.

SUMMARY STATEMENT

Why is this research or review needed?

- Mindfulness meditation-based interventions have a positive effect on patient outcomes but little is known about their longer term impact.
- Little is known about how mindfulness practice may contribute to people's adaptation to living with a long-term condition, and how this relates to existing research on this topic.

What are the key findings?

- People who had participated in a mindfulness meditation-based intervention identified positive changes in their thinking and behaviour; this was consistent across a range of conditions and often sustained over a number of years.
- The changes described were consistent with the process and experience of transition and were linked with a more self-directed style of self-management.
- Findings provide new insights into the process of transition, highlighting its ongoing and complex nature variation across different aspects of people's lives.

How should the findings be used to influence policy/practice/research/education?

- Mindfulness meditation-based interventions are a potentially valuable self-management tool for people living with long-term conditions, particularly those whose psychological wellbeing has been significantly affected.
- New insights into the varying depth and timescales of transition in different dimensions of individuals' lives can equip health professionals to provide more comprehensive and empathic self-management support.
- The understanding of mindfulness as a facilitator of transition in long-term conditions should be further explored to establish its transferability to a wider population.

INTRODUCTION

Increasing numbers of people globally live with long-term conditions (LTCs), with cases rising most rapidly in middle and low-income countries. Western nations are seeing a particular increase in people with multiple LTC; by 2018 2.9 million people in England will live with at least one LTC (Nolte & McKee 2008, Department of Health 2012, WHO 2014). These statistics are indicative of a significant global disease burden, underlining the need for effective self-management support for people with LTCs.

Living with a LTC presents significant challenges. Healthcare provision often fails to meet the need for long-term integrated care, increasing the risk of other health problems (Nolte & McKee 2008, Department of Health 2012). Daily functioning can be affected, impacting on quality of life and economic status (WHO 2002, Department of Health 2012). Long-term illness can affect people's sense of identity, leading to feelings of loss, anger, anxiety and low self-esteem (Bury 1982, Kralik 2002) . Additionally, conditions such as chronic pain are under-recognised, which can undermine people's sense of having a legitimate illness (Toye *et al.* 2013). Some may not recognise the enduring nature of their condition (Horowitz *et al.* 2004) or feel unable to influence their health (Rijken *et al.* 2008), a belief sometimes reinforced by health professionals uncomfortable with patient-provider partnerships (Paterson 2001, Rijken *et al.* 2008). Such experiences can make it difficult for people to come to terms with their condition, affecting their ability to self-care.

Management of LTCs is often complex, requiring greater use of services (Nolte & McKee 2008). In England, treatment for LTCs accounts for approximately 70% of health and social care expenditure (Department of Health/Long Term Conditions 2010). Consequently, effective self-management of LTCs has become a major priority, and programmes have been established to engage patients in their own care (Rijken *et al.* 2008). It is in this context that mindfulness interventions, which focus on teaching skills and attitudes to enable people to cope with challenges such as long-term illness, have received attention.

Background

Mindfulness has been defined as "…the awareness that emerges through paying attention, on purpose, in the present moment, and non-judgementally to the unfolding of experience moment by moment…" (Kabat-Zinn 2003, p.145). Mindfulness meditation has traditionally formed part of Buddhist practices but has more recently been developed to form

the basis of a range of secular interventions, including Mindfulness-Based Stress Reduction (MBSR) (Kabat-Zinn 1990), Mindfulness-Based Cognitive Therapy (MBCT) (Segal *et al.* 2002) and Breathworks (Burch 2008).

Evidence from systematic reviews indicates that mindfulness meditation-based interventions (MMIs) are moderately effective compared to waitlist and some active controls in improving psychological outcomes, particularly depression and anxiety, across a range of clinical populations (Khoury *et al.* 2013, Goyal *et al.* 2014). There is particularly strong evidence for such changes in cancer (Cramer *et al.* 2012, Piet *et al.* 2012) and a range of mental health problems, as well as for relapse prevention in major depression (Piet & Hougaard 2011, Galante *et al.* 2013, Strauss *et al.* 2014). Evidence for improvements in physical symptoms is inconsistent: whilst Bawa *et al.* (2015) found little evidence of improvement in chronic pain populations, Lakhan and Schofield (2013) identified variable degrees of positive change in pain and symptom severity across a range of 'somatization disorders'. However, MMIs do appear to facilitate changes in people's experience of illness such as coping, resilience and perceived pain control (Cramer *et al.* 2012, Bawa *et al.* 2015).

Considering the qualitative evidence, a meta-ethnography of 14 studies of patients' experiences of MMIs concluded that a therapeutic process of transformation took place in people's relationship to both their illness and themselves. This enabled them to view their experience with greater acceptance and from the perspective of an 'observing self' (Malpass *et al.* 2012). Other qualitative studies confirm these findings, some also highlighting improvements in specific symptoms (Chadwick *et al.* 2011, Hawtin & Sullivan 2011, Hertenstein *et al.* 2012, Bermudez *et al.* 2013). Practising mindfulness is frequently identified as challenging, but the benefits gained largely appear to make it worthwhile (Langdon *et al.* 2011).

Existing evidence has a number of limitations however. In addition to frequent methodological weaknesses, most studies have follow-up of less than three months. Little is therefore known about the long-term effects of MMIs, how they might contribute to the process of adaptation to living with a LTC, and how this may relate to existing understandings of living with chronic illness.

THE STUDY

Aim

To explore how practising mindfulness affects people's experiences of living with a LTC.

Design

A qualitative study using grounded theory (GT) was selected as appropriate for exploring the processes of change in relation to a topic whose theoretical understanding remains underdeveloped. Charmaz's constructivist perspective was adopted, as this accorded with the researchers' recognition of the influence of context, including the researchers' own perspectives and the interaction between researcher and participants, on the research process and findings (Charmaz 2006). Data collection and analysis occurred concurrently, enabling development of a theoretical model of how practising mindfulness affected people's experience of living with a LTC.

Sample

Participants were recruited from Breathworks, an organisation delivering manualised MMIs for people with physical or mental health problems across the UK. Breathworks' eight-week, group-based 'Living Well with Pain and Illness' course is MBSR-based, but with greater emphasis on kindness and self-compassion. Breathworks graduates from three centres in the north of England, together with Breathworks trainers and founders, were invited to participate in interviews and/or focus groups.

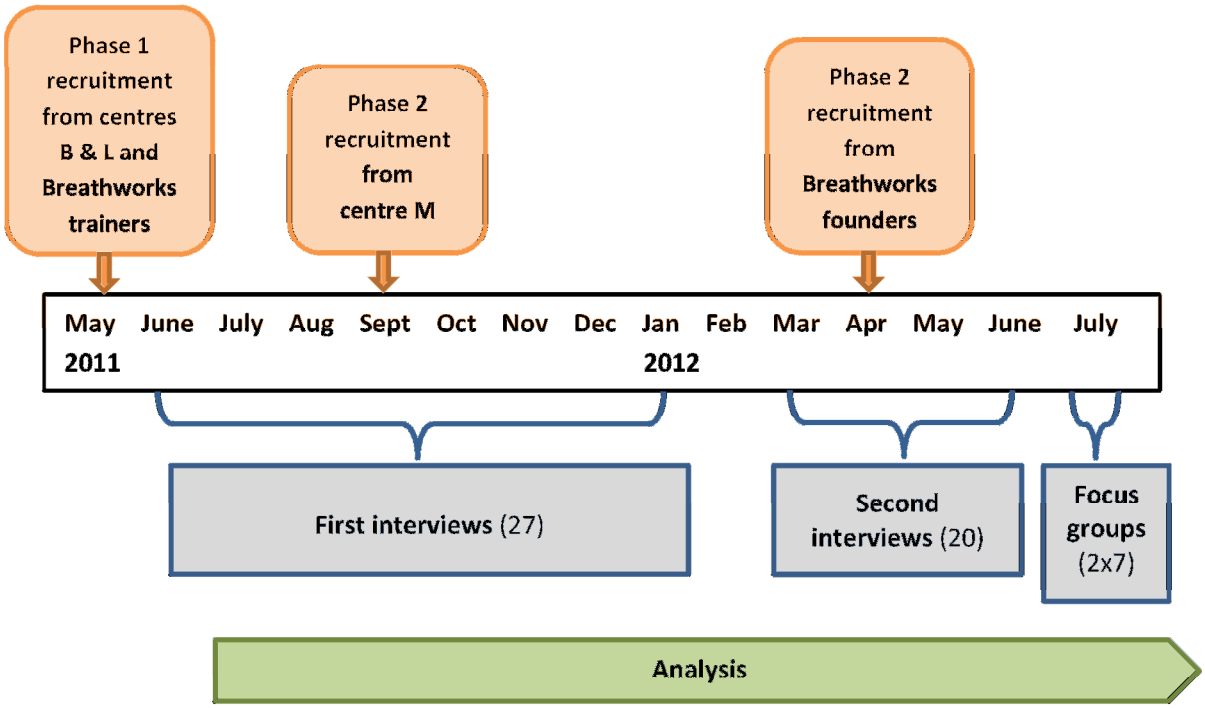
Inclusion criteria for interviews were a) self-report of a LTC; b) started attending Breathworks at least six months prior to study participation; c) attended at least half the course (4/8 sessions); d) tried practising mindfulness since attending; e) over 18; and f) able to speak and understand English. The requirement to have tried practising mindfulness was removed from focus group inclusion criteria to encourage participation by those who had not found mindfulness helpful. Additionally, trainers were not required to have a LTC, the intention being to explore their experience of training others.

An initial purposive sample was drawn from responses to a first recruitment mailing, with eligibility checked on initial contact. Consistent with GT methodology, later sampling was theoretically informed by the themes and concepts emerging from the analysis (Charmaz 2006). Accordingly the second phase of recruitment focused on participants reporting negative experiences of mindfulness, and underrepresented groups e.g. men and those with different LTCs. Sampling ceased when saturation of the themes and categories was deemed to have been achieved (Charmaz 2006).

Data collection

Data collection took place between June 2011 and July 2012 and involved two-stage in-depth interviews, diaries and focus groups. Interviews took place at locations agreed with participants, whilst focus groups were held at a Breathworks' centre. A phased recruitment and data collection process was employed (Figure 1) to manage the level of response and enable theoretical sampling (Charmaz 2006).

Figure 1: Recruitment and data collection process



First interviews (1-2 hours) with Breathworks graduates used a broad topic guide to explore previous health experience, contact with Breathworks and subsequent mindfulness practice. Second interviews (1-1.5 hours) with the same participants, held at least four months later, were informed by a diary completed the week before the interview to facilitate identification of experiences of mindfulness. At the end of the interview, feedback was sought on the emerging model of mindfulness experience. Theoretical sampling and data analysis informed data collection, with interview questions being revised in order to explore and saturate emerging themes (Charmaz 2006). This process continued in the focus groups, with aspects needing further clarification being explored with a group of graduates who had not participated in interviews. Finally, a more theoretically informed perspective was sought from a group of Breathworks' founders and trainers.

All data were collected by the first author and audio-recorded. Recordings were fully transcribed by the first author or an experienced transcriber; in the latter case, transcripts were checked against the audio-recording by the first author.

Ethical considerations

Ethical approval was obtained from the local NHS Research Ethics Committee. Informed consent was obtained prior to interviews and focus groups. To maintain confidentiality, participants were assigned a pseudonym and all identifiers removed from transcripts. No unanticipated ethical issues arose during the study.

Data analysis

Data were initially analysed by the first author using NVivo 8 (QSR 2008). Analysis was guided by Charmaz's two-stage coding approach (2006). During open coding, codes were assigned to all relevant text to break it into 'units of meaning'. In the second stage of focused coding, key themes and associated categories and sub-categories with greater "carrying capacity" (Charmaz 2006, p.139) were identified. A metaphor for participants' experience - an unwanted journey to an unfamiliar place - was identified and used as a tool to further integrate the analysis (Birks & Mills 2011). The authors collaborated through regular meetings to develop a coding frame and agree final themes. Finally, Charmaz's (2006) insights into theoretical coding informed the identification of relationships between the themes, integrating the analysis around one core theme.

Rigour

Meyrick's (2006) criteria of transparency and systematicity were adopted to ensure credibility of the findings. These provided a framework for ensuring all research procedures were clearly reported, and that specific processes of data collection and analysis were employed. Wider aspects of quality were addressed using Charmaz's (2006) criteria of originality, resonance and usefulness. Two early transcripts were coded independently by three researchers and discussed to identify emerging themes and categories. Discussion of the analysis continued throughout data collection. To ensure findings were grounded in the data, provisional findings were shared with participants and verbatim quotes used to illustrate themes. Field notes and memos were used to record thoughts on data collection and analysis, and to develop the themes and categories. A reflective journal kept by the first author was used to support reflexivity.

FINDINGS

Twenty six first interviews were conducted with Breathworks graduates, and additional limited data obtained from another participant unable to complete an interview due to health problems. Twenty of this sample participated in second interviews conducted between 4.5 and 9.5 months later. Most (42/47, 89%) interviews took place in participants' homes. Two focus groups were run, one for graduates, the other for trainers and founders; each had seven participants. Total sample size was 41 (sample characteristics in Table 1).

Table 1: Participant characteristics

Characteristic		**n (%)**
Gender	Male	8 (20)
	Female	33 (80)
Ethnicity	White British	38 (93)
	White Other	2 (5)
	Mixed White/Black African	1 (2)
Age	Under 35	1 (2)
	36-45	6 (15)
	46-55	8 (20)
	56+	26 (63)
Religion	Buddhist	13 (32) ϕ
	Christian	10 (24)
	Jewish	2 (5)
	None	10 (24)
	Other/Not stated	6 (15)
*Education level**	GCSE/Level 2	1 (4)
	A level/Level 3	4 (15)
	Higher post-A level vocational qualification	5 (19)
	Undergraduate degree	4 (15)
	Postgraduate degree/qualification	13 (48)
*Employment status**	Working full-time	4 (15)
	Working part-time or not working due to ill-health	21 (78)
	Retired	2 (7)
*Years since attending Breathworks**	6 months-1 year	4 (15)
	1-2 years	11 (41)
	2-5 years	9 (33)
	>5 years	3 (11)

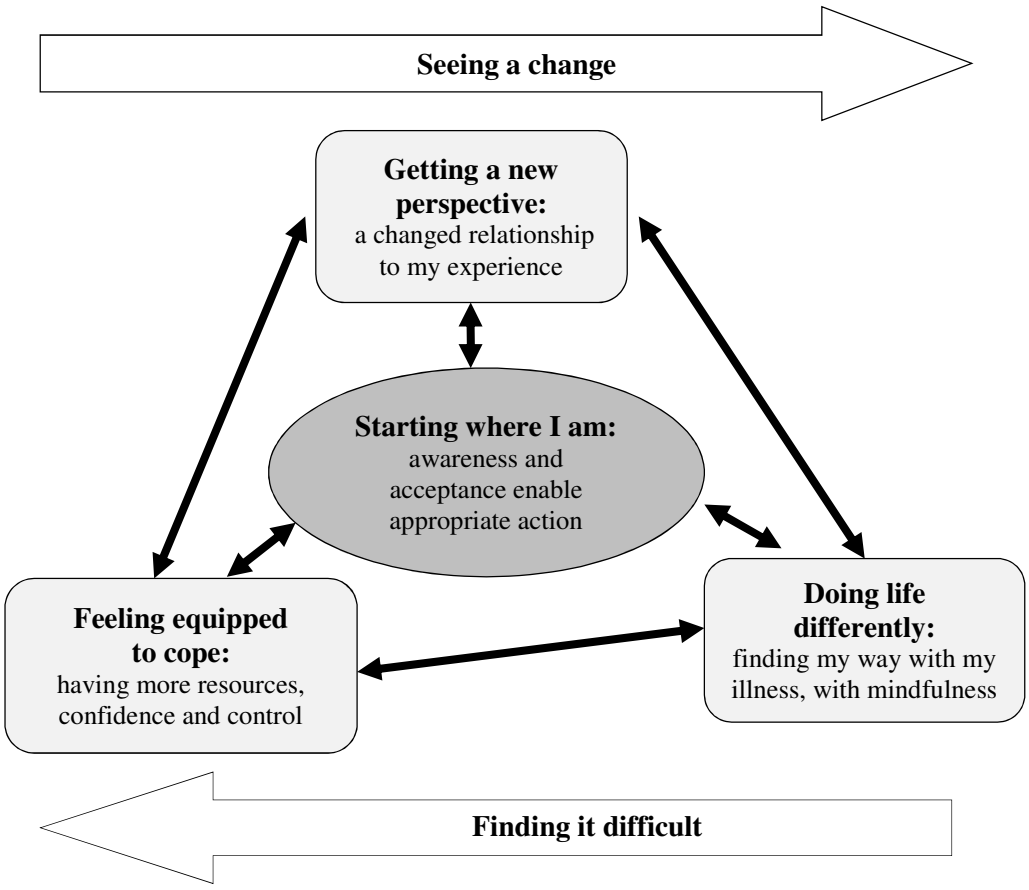
ϕ The high number of Buddhist participants partly reflects Breathworks' association with Buddhism, with six of the seven trainers identifying as Buddhist.

* *Data for these characteristics only collected from interview participants.*

Interview participants reported a range of LTCs, including chronic fatigue syndrome (CFS), musculoskeletal and neurological conditions, chronic pain, cancer, depression and anxiety; most (24, 89%) reported multi-morbidity. Over 40% had been practising mindfulness for more than two years. Many focus group participants volunteered information suggesting a similar range of both health conditions and mindfulness practice, with only a minority of trainers not having LTCs.

Almost all participants described strongly positive experiences of how practising mindfulness affected living with their health conditions. A number of interacting dimensions of this experience were identified in five themes, each containing a number of categories and sub-categories. These were encapsulated in a core theme of 'Starting where I am', which identified how mindfulness allowed people to become aware and accepting of their illness and to respond to it appropriately. This process was supported by and expressed in three key themes: 'Getting a new perspective'; 'Feeling equipped to cope'; and 'Doing life differently'. Two further supporting themes, 'Finding mindfulness difficult' and 'Seeing a change', identified ways that this process could be negatively or positively impacted (Figure 2).

Figure 2:Model of mindfulness experience in long-term conditions



1. Getting a new perspective: a changed relationship to my experience

Practising mindfulness brought about changes in how participants viewed their situation. This had two main aspects: moving towards their difficulty, and stepping back to see the bigger picture. In the first, they learnt through non-judgemental awareness to acknowledge and accept the sometimes distressing reality of their condition. Alongside this however, mindfulness enabled them to gain a wider perspective on their situation and appreciate pleasant aspects of their experience. They learnt to hold the whole of their experience in a 'bigger container', neither denying nor being overwhelmed by their health condition and its impact.

> "It's really like having a balloon really… it gives you the chance to float around and see the nicer things in life, and stop worrying about everything and it's a nice feeling, like floating off, and it's a coping mechanism isn't it…. to see things as they are, because you have got to be able to live with what you've got, but accepting and being able to live within it, rather than blocking it all out." (Tania)

Mindfulness also prompted participants to focus more on the present moment and become clearer about the reality of their current experience, rather than becoming distressed by catastrophising about future scenarios or ruminating about the past. This focus also enabled them to recognise the changing nature of their symptoms and accompanying negative thought patterns, and to realise that "there's a me that isn't all this stuff that's going on in my head" (Helen). These shifts in perspective contributed to a changed sense of identity, recognising that their illness was "a part of who you are, but it's not the whole of who you are" (Jeannette).

2. Feeling equipped to cope: having more resources, confidence and control

Learning mindfulness provided participants with skills and insights which enabled them both to develop greater awareness of their experience, and to respond effectively to it. Practical tools helped them manage their symptoms more positively, whilst new concepts and language offered a means to make sense of and talk about their experience. In addition, the course group had validated people's experience and reduced isolation, offering inspiration and support which was often sustained afterwards. Having these resources meant that participants felt more confident in managing their condition and able to meet any future challenges:

> "I'm just so happy I'm doing it cos I know it's going to help me with whatever next happens …. it would be very upsetting if I had something like Alzheimer's….but it's how to deal with it, how to look oneself and other people because of it. So it's there for me." (Shirley)

Learning to observe their experience non-judgementally had enabled people to respond to both illness-related and other situations in a more considered way, "to really evaluate what's going on" (John), which increased their sense of control and choice. Having new self-care strategies also enhanced their sense of competence and autonomy, including when liaising with health professionals.

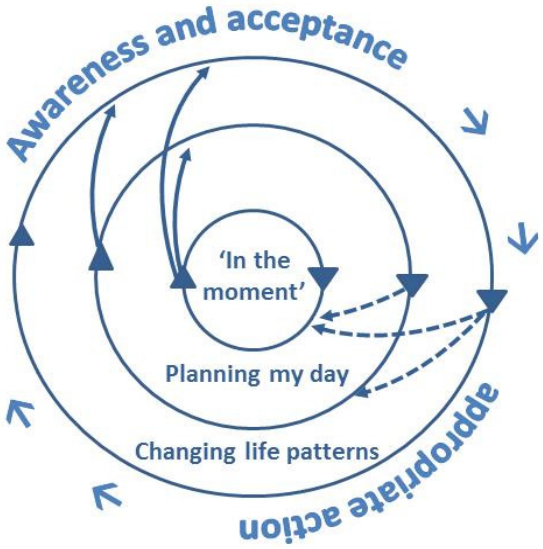
3. Doing life differently: finding my way with my illness with mindfulness

For many participants, their changed perspective and new resources had translated into new ways of 'doing life', both in terms of mindfulness practice and living with their condition. They described adapting mindfulness practice to suit their particular situation, and over time this had often led to mindfulness becoming 'second nature'.

> "… I use the breathing for anything that might cause me any kind of stress…. um, actually I don't think it's conscious any more I think it's just, it's automatic." (Christine)

Greater knowledge, understanding and acceptance of themselves had enabled people to make significant changes in managing their illness or, in some instances, to accept having a LTC at all. They described being able to 'start where they were': to make an accurate assessment of their health and needs, and to respond based on this awareness rather than on how they might prefer things to be. This process of awareness, acceptance and appropriate action operated over three interacting timescales: responding to immediate need; day-to-day planning of activity; and long-term patterns of living (Figure 3).

Figure 3: Doing life differently: patterns of awareness and response



Participants recounted numerous instances of how these cycles of awareness and response improved their health and wellbeing. Through being more "tuned-in to how I feel" (Holly) they learnt to act differently. This often meant not pushing themselves so hard, being more aware of their limits. This, for some, led to a stabilising or even improvement in their symptoms. A contrasting pattern was also noted, with some suggestion of a condition-related dimension to this experience. Whilst reducing activity was the predominant direction of change, particularly for those with conditions aggravated by overexertion such as CFS, two participants with neurological conditions emphasised learning not to unnecessarily over-limit themselves. More generally, participants described pushing their limits more consciously, using the processes of prior planning and ongoing monitoring which mindfulness facilitated.

> "….the whole thing is about awareness, and it's to be really aware of what's going on… If I can see things coming up ahead of me… for two days before I will rest, two days afterwards… physically I will be in the best condition I can be to do it, and yes if we go out and I do get very, very tired, I don't get frustrated with meself for doing that." (John)

Many emphasised how changes in their behaviour were supported by learning to be kinder to themselves, a shift in attitude they linked with attending Breathworks and learning mindfulness. Greater self-acceptance helped to counteract the low self-esteem many associated with having a LTC and this, combined with kindness, increased people's motivation to give their own needs greater priority. It also enabled them to communicate

more openly about their condition and ask for help. These changes had a significant impact on people's improved self-care.

A further change identified by some was a move from focusing on the outcome of activities to valuing the process of undertaking them: "not getting [it] right … but yes, doing it right" (Clive). This change integrated two apparently contradictory themes in the data: of 'letting go' and 'gaining control'. Mindfulness gave people the awareness to recognise what was within their control, and the acceptance to let go of struggling with things that were not. In the context of their illness, this often involved letting go of the outcome of a cure or fixed timescale for improvement. What participants gained control of however was the process of choosing how they responded to and lived with their illness. Letting go of specific illness-related outcomes may also have been instrumental in enabling an appreciation of the wider benefits of mindfulness.

4. Seeing a change

Participants highlighted a range of benefits from practising mindfulness. Some experienced direct improvements in symptoms such as pain, energy and sleep, although these were often short-lived. Improvements in depression and anxiety were reported, sometimes to a significant degree. Better management of their condition enabled them to avoid illness-related problems, and to achieve and contribute more. Participants reported that these changes helped to improve confidence, self-esteem and optimism.

Many identified how the benefits of mindfulness extended to wider aspects of life. They coped better with other stresses, experienced greater calm and relaxation, and found more clarity and focus in their thinking. Improvements in relationships were highlighted, with participants describing more kindness and acceptance towards others as well as themselves, and a greater sense of connection. Improved communication enabled family and friends to understand and help more effectively, reducing their helplessness and frustration. Their improved coping had also sometimes reduced others' anxiety about them and made them easier to live with.

> "I think because I live with pain,… instead of when I feel pain, sort of stressing on the pain and taking it out on others, I'm able to take a deep breath, and realise it's not their fault." (Lydia)

Despite continuing to live with the challenges of their illness, many participants considered their overall quality of life had improved.

> "…it's just made me happy, …it's made me want to live, and like, I think I've embraced life….I've realised wallowing doesn't help, but I don't think I'd have got there without the meditation." (Gloria)

Whilst the degree and pace of change varied between participants, seeing the benefits gained from mindfulness provided important motivation to continue practising.

5. Finding mindfulness difficult

Participants highlighted a number of challenges presented by engaging with mindfulness. Becoming more aware of and accepting of their health condition could be distressing and difficult, particularly for those who had previously ignored their condition or were experiencing intensely challenging symptoms. For one participant this prevented engagement with mindfulness practice; others reflected on negotiating a complex balance of acceptance and change, and of using mindfulness and kindness to choose when not to be mindful.

Paying more attention to their own needs presented a challenge for many whose self-esteem had been affected by their illness experience. It also raised particular issues for some women, challenging traditional beliefs about 'putting other people first' held both by them and those around them.

> "…it's been hard for my family as well because everybody always expects me to, I've always offered to do it… and now I'm having to say 'no' and I find that hard, and they don't like it either you know." (Leah)

Many described the difficulties of finding time for mindfulness practice, and the continuing and often variable changes in their attitudes and behaviour. Whilst these challenges were common, they were however mostly balanced by significant gains which motivated participants to continue their journey with mindfulness.

DISCUSSION

This study has identified how mindfulness enabled participants to become more aware and accepting of their illness and respond appropriately, whilst retaining a broader sense of perspective on themselves and their lives. New ways of thinking and a range of tools and strategies facilitated changes in behaviour which led to improved self-care, echoing a previous study of healthy participants (Matchim *et al.* 2008). The often significant changes identified by participants in coming to terms with and managing their condition are consistent

with existing research, and cohere with Malpass *et al.*'s (2012) model of transformation, extending it to show longer-term patterns of change. The findings strengthen suggestions that the process of change is not condition-specific, whilst strong similarities between this study of Breathworks and others of MBSR and MBCT confirm a common core of experiences across MMIs.

In relation to existing models of living with long-term illness, the findings of this study have strong resonance with the concept of transition (Chick & Meleis 1986, Meleis *et al.* 2000). Transition is defined by Kralik *et al.* as "a process of convoluted passage during which people redefine their sense of self and redevelop self-agency in response to disruptive life events" (2006, p.321), and has been explored in relation to a range of conditions (Kralik 2002, Mengshoel 2008, Baumgartner & David 2009, Wilson *et al.* 2011, Halding & Heggdal 2012, Adili *et al.* 2013). The transition experience is characterised by a number of key properties and indicators (Meleis *et al.* 2000), and these were clearly evident (italicised below) in almost all study participants' accounts.

Learning mindfulness had been a *critical point* in participants' experience of their illness, triggering a *change* in their response. It had significantly enhanced their *awareness*, as evidenced by their descriptions of greater knowledge of their needs and limits. Greater *engagement* with the realities of their situation was facilitated by the tools and concepts of mindfulness, and was demonstrated in participants' changed responses to their illness. This led to more effective self-care, which resulted in feelings of *coping, confidence* and *mastery* in managing the challenges of their condition and other stressful situations.

The new perspective engendered through mindfulness facilitated significant shifts in people's *identity*, enabling them to integrate their LTC into their lives. Acknowledging the end of an earlier reality and acceptance of the new situation have been identified as key to this process (Kralik 2002, Kralik *et al.* 2006), and these attitudes were strongly evident in study participants' accounts of letting go of their old self and valuing who they were now.

Through developing greater awareness, acceptance and kindness, mindfulness increased participants' *sense of connection* to others. This was apparent in their improved *interaction* and communication with family and friends, which enabled them to negotiate a more shared meaning and understanding of their situation. These accounts of improvements in relationships add to other recent work highlighting this as a significant outcome of mindfulness (Bihari & Mullan 2014), whilst indirect benefits to others around them were also

uniquely identified by participants. Improved connection and interaction was also evidenced in participants' greater confidence regarding disclosure of their condition, a change identified as associated with transition and a reduced need to preserve a former sense of self (Charmaz 1995, Baumgartner 2007, Baumgartner & David 2009).

Confirming previous understandings of transition as a complex, multi-directional process (Kralik 2002, Adili *et al.* 2013), participants described an ongoing process of adjustment to living with long-term illness. Additionally, they offered detailed and unique insights into the transition process, suggesting that transition not only took place over the longer term, but was often part of people's daily experience, enabling them to negotiate the complex demands in their lives. In particular, different 'timescales' of awareness and response were identified, suggesting that a number of different trajectories of adjustment may be taking place in different aspects of an individual's life, and that these may occur repeatedly and to varying degrees.

The shared experience across study participants, including those living with mental health problems, potentially significantly extends the application of the transition model, which has previously only been applied to chronic physical illness. It also resonates with the concept of 'recovery' in mental health, which suggests that people can come to live well with mental illness and find a new sense of value and purpose (Anthony 1993). This supports the view that whilst some aspects of experience may differ, living with any LTC has many similar dimensions which can be positively impacted.

The findings corroborate existing work exploring the relationship between transition and self-care, which suggest that "the process of self-management is central to the experience of transition" (Kralik *et al.* 2004, p.260). Mindfulness practice had provided study participants with a sophisticated understanding of their condition, which provided confidence and clarity regarding what was needed to live well with it. Whilst willing to engage with health professionals, they considered themselves experts in their condition, and their self-care was directed by this knowledge. This reflects the 'Self-Agency Model' of self-management identified by Koch *et al*. (2004), characterised by individuals giving greater authority to their own experience of illness rather than relying on the medical perspective. The study's identification of participants' movement towards this 'self-agency' approach through mindfulness thus provides confirmation of self-directed self-care as an aspect of the transition process.

This new conceptualisation of mindfulness, and the insights it provides into the transition process, may be valuable to health professionals in a number of ways. Health professionals have an important role in helping people come to terms with diagnosis of a LTC (Toye *et al.* 2013), and the study provides qualitative evidence of the potential benefits of MMIs in equipping patients to accept and manage LTCs more effectively. The findings suggest that the skills and attitudes engendered by mindfulness may be particularly valuable for people struggling to adjust to their condition, whilst the emphasis on kindness may make these interventions especially helpful to those whose low self-esteem impacts on their ability to self-care.

Provision of individualised, empathic care is central to the role of the nurse, helping patients develop knowledge, skills and confidence to optimise their health and well-being. The new insights this study offers into the multi-faceted nature of transition may enable this role to be undertaken more effectively. By recognising this complexity and identifying areas of life where patients are struggling to adapt, health professionals can provide more comprehensive and individualised self-management support targeted at these areas of need.

The introduction of MMIs into healthcare settings may also however precipitate unexpected challenges. Mindfulness encourages a holistic approach to illness, locating it within the wider context of people's lives and needs. It also supports a high level of self-directedness in people's management of their condition. These qualities can present challenges for health professionals, whose focus is often on disease-specific aspects of illness and who may be uncomfortable with the reality of empowered patients (Paterson 2001). These tensions, such as being considered 'non-compliant' with treatment, have been described by others with self-management expertise (Kralik 2002, Thorne *et al.* 2003, Kralik *et al.* 2004). From a person-centred nursing perspective however, people's awareness and understanding of their condition developed through mindfulness may make them engaged and informed partners in the management of their care.

Limitations

Sample characteristics do not reflect national statistics for people with LTCs, with those from lower socio-economic groups, minority ethnic communities and in the 65+ age group particularly underrepresented. Sample size also precluded significant consideration of condition-specific aspects of mindfulness experience. The sample included very few participants with negative or indifferent experiences, and it is likely the findings are based on

the experiences of those who found mindfulness particularly beneficial. As a result, certain perspectives are missing from the data and the transferability of the findings requires further exploration. Finally, findings are based on participants' retrospective view since learning mindfulness. This was an inevitable outcome of the study intentionally targeting people with longer-term experiences of mindfulness in order to explore this under-researched area.

CONCLUSION

This study provides a unique and original account of the mechanisms by which MMIs can impact on the way in which people with LTCs manage their daily life. It highlights how practising mindfulness enabled participants to make a profound change in their relationship to their LTCs in both their thinking and behaviour. Greater awareness and acceptance of their condition enabled people to become skilled and responsive in managing their health condition.

The experiences and processes described resonate strongly with the concept of transition, suggesting mindfulness can be understood as an effective facilitator of transition for people with LTCs. This is a new understanding of mindfulness which locates it within the existing chronic illness literature. The findings confirm the relationship between transition and self-care, and indicate that MMIs may offer a valuable self-management intervention. The study provides new insights into the transition process, illuminating its complex and ongoing nature, which may enable health professionals to support patients more effectively on their journey towards adjusting to life with a LTC.

Conflicts of interest:

No conflict of interest has been declared by the authors.

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