

Mindfulness-based cognitive therapy for depression in people with dementia: A qualitative study on participant, carer and facilitator experiences

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Abstract

Background: Depression in dementia is common and associated with negative health outcomes. Mindfulness-based cognitive therapy is a recommended treatment of choice for recurrent depression, but its use for depression in dementia is yet to be assessed.

Objective: This study aimed to investigate the experiences of people with depression and dementia who participated in the mindfulness-based cognitive therapy intervention and those of their carers and facilitators.

Methods: This qualitative study was nested within a randomised controlled feasibility study. Semi-structured interviews were conducted with 18 people (eight people with dementia and depression, six carers and four course facilitators). Thematic analysis was used to analyse the data.

Findings: Several beneficial effects of mindfulness-based cognitive therapy were described. These were a sense of shared suffering among the group, greater present moment focus and awareness, various positive emotional changes, including greater self-compassion, and benefits for carers, such as the reduction of anxiety. Specific aspects of the programme were identified as particularly useful, including facilitator characteristics and certain mindfulness practices. Carer involvement, cognitive difficulties and barriers to home practice influenced engagement with the course. Facilitators described adaptations made to mindfulness-based cognitive therapy and suggested additional modifications for future groups.

Conclusion: Results of this process evaluation suggest that mindfulness-based cognitive therapy is a potentially useful intervention for people with depression in dementia, but that further adaptation of the intervention is required to make the programme suitable for this clinical population.

Keywords

depression, dementia, mindfulness-based cognitive therapy, qualitative, mindfulness

Introduction

Dementia, also known as major neurocognitive disorder in the DSM-V, is a decline in mental ability severe enough to interfere with a person's independence in daily life, affecting functions such as memory and language (American Psychiatric Association, 2013). It is usually diagnosed after the age of 65 and can be caused by various brain diseases, most commonly Alzheimer's disease (AD) (World Health Organization, 2006). Between 20% and 40% of people with dementia (Castilla-Puentes & Habeych, 2010; Karttunen et al., 2011; Lyketsos et al., 2002; Winblad et al., 2004) also experience depression. This comorbidity is associated with several negative outcomes, including poorer quality of life (Shin et al., 2005), functioning (Kales et al., 2005) and cognitive ability (Rapp et al., 2011), as well as increased mortality (Suh et al., 2005), healthcare costs (Kunik et al., 2003) and caregiver stress (González-Salvador et al., 1999).

The efficacy of antidepressants in this group has not consistently been demonstrated (Dudas et al., 2018) and has been found to be often inappropriate (Bhattacharjee et al., 2019). Psychological interventions, such as cognitive behavioural therapy, have been found to be a promising alternative for reducing depression in dementia (Orgeta et al., 2014).

In recent years, mindfulness-based interventions (MBIs) have been investigated as a psychological treatment option for people with dementia. These interventions focus on cultivating the Buddhist concept of mindfulness, which is the 'awareness that emerges through paying attention on purpose, in the present moment, and non-judgmentally to things as they are' (Segal et al., 2007, p. 47). Mindfulness practice has been found to slow cognitive decline in AD (Quintana-Hernández et al., 2016) and improve quality of life in people with mild to moderate dementia (Churcher Clarke et al.,

2017). In addition, participants with progressive cognitive decline, the majority of whom had dementia, reported fewer depressive symptoms after participating in a mindfulness programme (Paller et al., 2015). Although this indicates that MBIs may have a positive effect on depression in people with dementia, research among those with a comorbid diagnosis of both disorders is yet to be conducted.

Mindfulness-based cognitive therapy (MBCT) is a type of mindfulness therapy. It builds principles from cognitive therapy, which address maladaptive thinking patterns, into a mindfulness framework to treat individuals with recurrent depression specifically (Segal et al., 2002).

Mindfulness-based cognitive therapy consists of eight weekly group sessions, which include practices such as meditation, breathing exercises and mindful movement, in combination with home practice exercises (Segal et al., 2002). In-session exercises aim to develop the skill of mindfulness by bringing attention to the present moment experience of thoughts, emotions and physical sensations (Segal et al., 2004). Home practice exercises consolidate this learning, guiding individuals to use mindfulness in their everyday life. As a result, individuals are proposed to be more aware of depressive thinking as it occurs and choose a non-judgemental attitude towards negative thoughts, experiencing them simply as 'passing events in the mind' (Segal et al., 2002, p. 73). Mindfulness-based cognitive therapy is a recommended treatment for depression (National Institute for Clinical Excellence, 2009) and there is consistent evidence that it reduces risk of relapse (Piet & Hougaard, 2011).

Participant's subjective experience of participating in MBCT is important, because it can provide an initial indication of potential benefits, understanding of barriers and facilitators to access, highlights potential underlying change mechanisms and can inform treatment adaptations. There is a growing body of qualitative research investigating the experiences of MBCT course participants. A recent meta-synthesis (Cairns & Murray, 2015) found that the intervention is perceived to have several positive effects, such as enabling participants to take control of their difficulties and use mindfulness skills to cope with emotions in everyday life, as well as increased self-care, confidence and a greater sense of identity. Positive effects were also described in studies with older adults included in this meta-synthesis (Smith, 2004; Smith et al., 2007) as well as in a more recent study (Williams et al., 2018).

The current study will build on this work, using qualitative methodology to investigate the perceived effects of MBCT for people with dementia and comorbid depression. In a previous qualitative study, participants reported that their experience of MBCT impacted on their relationships with close others (Bihari & Mullan, 2014). Therefore, we also interviewed carers to determine whether carers experienced any beneficial effects as a result of their relative's participation in MBCT. In addition, interviewing carers allowed us to determine whether participants utilised principles taught on the course outside of weekly sessions, and the level of support required for people with dementia to engage with mindfulness practice at home.

When MBIs have been used for individuals with dementia, adaptations have been required, such as the use of a simple, repeated session format and concrete language (McBee, 2009). A recent qualitative study of MBCT for older adults with depression interviewed course facilitators to obtain information about necessary adaptations (Williams et al., 2018). Facilitators identified differences when using MBCT with older adults compared to younger adults, including how loneliness and inactivity experienced in old age possibly made meditation at home alone more difficult. Therefore, the current study also included facilitators to explore what adaptations are needed to make MBCT suitable for individuals with dementia and depression.

The current study was nested within a randomised controlled feasibility study (Aguirre et al., 2017). It aimed to explore the perspectives of participants, carers and facilitators on an MBCT course for depression in dementia. The following research questions were investigated: (1) How do participants experience the MBCT course? (2) Which aspects of the course are perceived to be

useful? (3) What are the perceived effects of the course amongst participants, their carers and facilitators? (4) How do carers support home practice? and (5) What adaptations are required to make MBCT suitable for this client group?

Methods

Sample

Participants for the randomised controlled feasibility study were recruited from memory services in two National Health Service (NHS) trusts in the UK. People with dementia, who had been randomly allocated to the intervention arm, were invited to attend one of two MBCT groups, which were facilitated by two members of staff each. Carers included in this study were family relatives of participants and had attended an introductory psychoeducation session about MBCT. All MBCT group participants (N = 8), their available carers (N = 6) and the facilitators (N = 4) agreed to take part in qualitative interviews following the completion of the course. Written informed consent to participate in the study was obtained from all participants, carers and facilitators. The demographic details for the three interviewee groups are presented in Table 1.

Inclusion and exclusion criteria. To be included in the randomised controlled feasibility study (Aguirre et al., 2017) and consequently this study people with dementia had to be 60 years or older and met criteria for mild depression, based on a clinical cut-off score of nine and above on the Patient Health Questionnaire (PHQ-9; Kroenke et al., 2001). All included participants had a Mini Mental State

Table 1. Demographics for each interviewee group.

Characteristics		Participant group (n = 8)	Carer group (n = 6)	Facilitator group $(n = 4)$
Age (years)	Mean (SD)	77.30 (8.94)	67.50 (10.04)	Unknown
	Range	62–93	52–83	
Gender	Male (%)	I (I0)	4 (66.6)	I (25)
	Female (%)	7 (90)	2 (33.3)	3 (75)
Ethnicity	White British (%)	7 (87.5)		
	Black Caribbean (%)	I (I2.5)		
MMSE score	Mean (SD)	25.50 (3.17)		
	Range	21–29		
Dementia diagnosis	Alzheimer's disease	5		
	Vascular dementia	1		
	Mixed dementia	1		
	Dementia unspecified	1		
Anti-dementia medication	Prescribed	4		
	Not-prescribed	3		
	Unknown	1		
Relationship to participant	Spouse (%)		4 (66.6)	
	Child (%)		2 (33.3)	
MBCT group	Group one (%)	4 (50)	4 (66.6)	2 (50)
	Group two (%)	4 (50)	2 (33.3)	2 (50)

Notes: SD: standard deviation; MMSE: Mini Mental State Examination; MBCT: mindfulness-based cognitive therapy.

Examination (MMSE; Folstein et al., 1975) score of 18 or above (range 18–29) with no upper score limit, but all needed to have a formal diagnosis of dementia from the referring memory service using DSM-IV criteria. These inclusion criteria were chosen to minimise heterogeneity across the samples after randomisation. Participants were included regardless of their dementia subtype and were not excluded if they had coexisting physical health conditions.

People with dementia were excluded if they had a congenital learning disability, presented with severe depression or a high risk of self-harm, experienced bereavement in the past 2 months, were enrolled in other research investigating psychosocial interventions or had a diagnosis of psychosis.

Design

The current study employed a qualitative approach. It was conducted as part of the process evaluation of a randomised controlled feasibility study (Aguirre et al., 2017). This is in line with guidance from the Medical Research Council for the feasibility and piloting stage of intervention development (Medical Research Council, 2006).

Intervention

The MBCT treatment protocol was adapted from MBCT for the prevention of depression relapse (Segal et al., 2002) to be more suitable for people with dementia and depression. The main adaptations were shortening of meditation practices, discussing participants' mood and cognitive symptoms, including distress arising from memory problems, and encouraging participants to use formal as well as informal mindfulness techniques when distressing situations arise during the week. A psychoeducation session was added before the start of the course to introduce the concept of mindfulness and outline the intervention. The introductory session was organised slightly differently across both sites. It was attended together by carers and participants, but at one of the sites, participants only joined for half of the session (until the break) to not overwhelm them. After an initial ice breaker exercise, some psychoeducation about mindfulness was provided, followed by a practical exercise for participants and carers to get an idea of the type of exercise people with dementia would be engaging with. After a break, practicalities of the intervention set-up were discussed, including home practice, how to overcome potential challenges with motivation and how mindfulness might benefit the individual. It was explained that phone calls will be used to support practice, and carers were encouraged to support the process. The adapted MBCT consisted of eight, weekly one and half hour group sessions attended by the people with dementia, which included skills training and in-class practice. Specific in-class mindfulness exercises included (a) 'mindful eating', (b) 'body scan', (c) 'mindful stretching' and (d) sitting 'mindfulness meditation' with varying focus (breath, body, sounds, emotional states and thoughts). All exercises were broadly based on the standard MBCT protocol (Segal et al., 2002); however, they were adapted to meet the ability levels of participants. Several exercises were practised in each session depending on the time available, with their complexity gradually increasing throughout the intervention period. The programme incorporated daily assignments of 'formal' home practice of mindfulness techniques using 15-20 min audio-recordings, as well as 'informal' exercises integrating mindfulness into everyday experiences (e.g. eating, walking and brushing teeth). To make engagement with the home practice element more accessible for people with dementia, expectations for home practice were adapted, reducing the duration of meditation exercises and using simplified home practice sheets to guide and record daily practices. In addition, a weekly telephone call with MCBT participants lasting

approximately 10 min by a member of the team at the half-way point between weekly sessions to further support home practice.

Adherence to the MBCT intervention protocol. Attendance of weekly group sessions was good with 80% of people with dementia attending at least seven sessions. Adherence to the home mindfulness practice was less consistent. Four participants were reported to have practised mindfulness using the recordings and/or home practice sheets between group sessions.

Data collection

Semi-structured topic guides were developed based on the research questions and themes from the recent meta-synthesis of qualitative studies investigating the experiences of MBCT course participants (Cairns & Murray, 2015). Interviews with each participant group covered the similar topics, but guides were tailored as relevant to their role in the intervention. After piloting interviews with the first four interviewees, the topic guides were reviewed by the study team and extended to explore further areas of interest. The final topic guides (Supplementary Appendix 1) covered the utility of the course and specific components, use of MBCT skills outside of sessions and the effects of the course. The participant topic guide also investigated their experience of the sessions and the facilitator guide included questions about adaptations necessary for this client group.

Individual one-off interviews were conducted at NHS sites, participants' homes or over the phone. Interviews with participants from each of the three groups were conducted in the 4 months after the final MBCT session and lasted an average of 40 min each. All interviews were conducted by the same researcher ([researchers initials]), who had not delivered the intervention, but had attended some group sessions as an observer.

Ethics

All procedures contributing to this work comply with the ethical standards of the relevant national and institutional committees on human experimentation and with the Helsinki Declaration of 1975, as revised in 2008. Ethical approval was granted by The Health Research Authority London City and East Research Ethics Committee, ref. number: 16/LO/0578. Written informed consent to participate in the study was obtained for all participants. Participants with dementia included in the study gave consent themselves.

Analysis

Interviews were audio recorded, transcribed and entered into QSR NVivo7 qualitative analysis software. SD used thematic analysis (Braun & Clarke, 2006) to explore the data and develop a framework of themes, with each theme capturing a meaningful aspect of the data. A deductive approach was taken; analysis was guided by actively searching for answers to the research questions (Pope et al., 2000).

The following steps were taken as part of analysis, with iterative movement between stages throughout the process. Transcripts were read while noting initial ideas. They were then coded and organised into main themes and subthemes. A second researcher (EA) coded three transcripts and generated themes based on this, which were compared with SD's thematic framework and necessary revisions were made. The results outlined below reflect the finalised thematic framework with illustrative quotes. Interviewee identification numbers are included in brackets following each quote; numbers beginning with 'P' refer to MBCT participants, 'C' to carers and 'F' to facilitators.

Findings

The results were organised into four main themes: the experience of the MBCT programme and components within it, outcomes experienced as a result of the course, influences on the participants' engagement and adaptations that were either used or suggested (Table 2).

I. The experience of taking part in the MBCT group course and important key ingredients of it

The majority of participants mentioned that they enjoyed the course and gained something from taking part in the group programme. Despite this, several participants experienced some negative emotion particularly at the start of the course, such as initially feeling apprehensive. Comments across interviewee groups suggested that participants lacked knowledge of what to expect prior to the course starting or had inaccurate expectations about what it would involve.

'I actually don't know what I expected, some miracle cure, I thought perhaps they'd wave a magic wand and make me feel better, but it didn't happen'. (P01)

In discussing the utility of the MBCT programme, most respondents focused on the course as a whole rather than the value of individual components. However, for two participants, the meditation practice was particularly valuable.

I liked the part where the prayer part came in and the tinging of the bell, that was very soothing because you sat down and you just relaxed and, you know, just meditate on what was being said'. (P05)

A few responses across the interviewee groups also suggested that some participants found the breathing exercises taught in sessions beneficial.

Table 2. Summary of themes and subthemes that emerged from the thematic analysis.

Main themes	Subthemes	
The experience of taking part in the MBCT group course and important key ingredients of it	Valuing the facilitators	
Effects and outcomes of the course	Taking mindfulness home Shared suffering 'I'm thinking now' 'Feeling better' The effect on carers	
Factors influencing engagement Adaptations to the course	Recruitment and assessment Practical adaptations Keeping it simple Mindful facilitators Targeting dementia related distress	

"...the idea of sort of breathing lower in your body, in the abdomen, people seemed to get that and everybody mentioned that as something that helped them feel less distracted and a bit calmer". (F03)

Valuing the facilitators. Almost all of the MBCT participants commented on the value of the course facilitators. Specifically, the responses of some participants and carers indicated that they valued the facilitators' relaxed and understanding nature, and the way in which they guided participants through the course.

'I liked the way that whenever any of us said anything, a nugget was brought out of whatever they said, and that felt heard, that I felt really heard'. (P08)

2. Effects and outcomes of the course

Taking mindfulness home. Some participants engaged with the course beyond weekly sessions. Specifically, three participants used the home practice sheets and two of them stated that they still did this after the end of the course.

"...I just read it and memorise, you know, some of the things that are in the sheets, and I realise that really and truly it's right, and I've got to work on that". (P05)

Half of the participants mentioned using the guided meditation recordings at home and a few continued to do this once the course had ended. For one participant, the recordings were particularly useful as they enabled her to concentrate, which she found challenging in a group setting. In a few cases, interviewee responses suggested that carer involvement positively influenced participant engagement with home practice.

However, several participants also mentioned either a lack of home practice commitment or described barriers to home practice (see below). Most carers and all of the facilitators highlighted similar issues.

Shared suffering. Several participants described being isolated or lonely in their life. Correspondingly, almost all participants reported valuing the social interaction provided by sessions.

'I did look forward to it [the sessions] coming, because I do live alone'. (P07)

Multiple participants, carers and all of the facilitators felt that the group was valuable because it created a feeling among participants that they were not alone in their distress due to being among others experiencing similar difficulties.

'I think the group meeting was the thing that she most looked forward to, talking to the other ladies...and being in the same sort of level of memory loss, you know, they forgot things, [relative] forgets things'. (C03)

Several participants seemed to have become more accepting either of themselves, their situation, their dementia or distress they were experiencing, as a result of the course.

"...I find the group therapy is good because at least it opened the eyes to see what other people are going through. And it's not to say, well, then, you're worse for it, you know, it's just the way things are..." (P05)

One participant explained how the group provided her with a sense of belonging in comparison to the 'outside world', in which she could not belong due to her dementia (P04).

I'm thinking now. Two participants described concentrating more on their actions in the present moment as a result of the course, and how this was useful for dealing with memory difficulties. This change was also noted by one carer.

'I'm stopping, instead of [acting like a] bull in a china shop, I'm thinking now; it's made me stop and think. It has, it must've, that relaxing bit must've come in somewhere...I'm definitely concentrating more...' (P07)

Despite this, at other points in the interview, P07 also described not being present moment focused and continuing to 'live by habit' due to her age and in order to cope on her own. Her daughter also attributed difficulty focusing to her memory difficulties.

Two facilitators felt that participants gained insight, in terms of an increased awareness of negative thoughts or emotions. Two participants also mentioned gaining a sense of self-awareness due to the course.

'I've always tended to tighten up...but I don't do that so much now and if I do I know I'm doing it and I can stop myself'. (P06)

'Feeling better'. Two participants and two carers suggested that the course led to a greater sense of self-kindness. Two facilitators also mentioned this change.

'It [the sessions] stopped me thinking that I was absolutely useless... It made me feel better in myself, it gave me a purpose'. (P01)

Multiple participants stated that the course had lifted their mood in some way, something also mentioned by two carers. Three participants described noticing and appreciating positive aspects of their life as a result of the course.

'Well, yes, because [they] said like, there are all kinds of nice things...I did try that, to think of, you know, something nice that had happened, you know, someone had visit, a friend had visit'. (P02)

For three of the participants, the course seemed to provide them with a sense of purpose. In addition, the comments of two participants suggested that they were able to better cope with difficulties or emotions.

Well, for me, really and truly, sometimes when I'm at home and I get teary eyed I would go out and I'd spend, spend, spend, you know, and then when I went there [to the sessions] I realised that is something that you have to live with, you have to cope with it, and therefore it doesn't have to overwhelm you all the time...' (P05)

One of the facilitators explained how, for one participant, home practice was particularly useful as it provided structure throughout the day, enabling the individual to manage her low mood. Half of the participants mentioned that they were either more relaxed following the course or that they now take time to relax in their daily life. This was also suggested by three carers.

The effect on carers. Some carers reflected on how their relative's participation affected them during the intervention and/or on the resulting effects it had on their relationship. Two carers indicated that they were pleased that their partner enjoyed the course. One of these carers explained how his

partner's attendance at sessions provided him with more time for himself, which he valued. This carer also directly benefitted from the guided meditation home practice, which he did with his wife and found it useful for reducing anxiety. Another carer mentioned that her own worries were reduced due to her mother participating in the course.

'It's [the course] made me a little bit less stressed about her...I think, for me, it's helped because she is less depressed, and she's lighter, so it, kind of, takes something off my shoulders, a little bit, maybe...' (C06)

This carer also felt that she had become more aware of her mother's needs and how to help her. Among the remaining three carers, one felt that the course did not have an effect on him and another explained that it had no effect on her other than giving her and her mother something to discuss. The other carer did not mention whether the course had an effect on him or not.

3. Factors influencing engagement

While factors, such as facilitators' validating nature, positive emotional responses and carer involvement were perceived as positively affecting participants' engagement with the course, interviewees across groups also identified a range of barriers to engagement.

Interviewees described various cognitive difficulties encountered during sessions and/or home practice. The responses of some participants and carers suggested that a lack of concentration was an issue. Several participants became bored and/or struggled to focus their attention during practices.

'I did my best to try and I listened to the CD that I have and I tried to concentrate, it's something that I wanted to be able to help, [but] other things, you know, worries or whatever, start coming in and mixing it up.' (P04)

In addition, all of the facilitators commented on how participants struggled to understand certain parts of the therapy. Two participants stated that they found the home practice sheets challenging due to the literacy skills they required. Memory difficulties were also identified by two interviewees as a barrier to home practice commitment.

"...when you've got someone with memory problems like she's got, by the time she came home from the class she'd forgotten really, what they did there." (C05)

Several carers highlighted technical difficulties that arose when trying to use the recordings at home. Several participants and carers also identified competing commitments, struggling to find time or a lack of motivation as additional barriers to home practice.

IV: So why do you think you found it maybe a little bit harder to do the practices at home?

R8: I think just laziness, I just prefer to watch the television or something like that...' (P05)

4. Adaptations to the course

Facilitators described various modifications they made throughout the MBCT course, in addition to the initial adaptations, and also suggested further potential modifications for future groups of people with dementia and depression.

Recruitment and assessment. Two facilitators mentioned that the introductory session for carers was useful for gaining information about participants, but that more time could have been spent on this to inform further person-specific adaptations. Two facilitators suggested that those participants with more cognitive decline were less suitable for the course and one of them felt that this problem arose because facilitators had not involved in participant selection.

"...there were extremes, to some extent, of people that, kind of, met criteria perfectly and others that, you know, I struggled to see why they would be in the group..." (F04)

One facilitator mentioned that it would have been helpful if more information about how aware participants were of their diagnosis had been included in participant referrals.

"...the downside of, or the danger of naming something [the dementia diagnosis] was, do people in the group, are they aware of it, have they been told, how have they been told, what do they understand..." (F03)

Practical adaptations. Three facilitators suggested that the course ought to be longer or that follow-up sessions were required to 'embed' practice (F01) and facilitate participants' continued use of mindfulness. One facilitator thought that sessions could have been lengthened, as presenting the course content was particularly time consuming with this client group. Three facilitators mentioned the tea break included in sessions, used to 'contain' discussion (F03). Facilitators felt that this took up time and, in one group, sessions extra time was added to allow for this. Adaptations made to accommodate sensory and physical difficulties were also described by facilitators: participants with hearing difficulties sat closer to the facilitator and mindful walking was replaced with seated mindful movement.

The facilitators' responses also indicated that the home practice component of the course required adaptation.

The use of phone call 'check-ins' to support home practice varied between the two intervention groups. For one group, the facilitators did not feel the weekly support calls led to greater adherence to the home mindfulness practice and they were discontinued. In the other group, all except one participant were contacted each week. Facilitator feedback for this group indicated that the support calls managed anxieties associated with attending the group and built rapport with the group facilitators to minimise dropouts. They also found that the support calls helped to remind participants to practice the home mindfulness exercises. One facilitator suggested that a video to watch at home could also help with this. She also created sheets for participants to place around their home to remind them of informal techniques, such as mindfully doing the dishes.

In addition, comments from facilitators indicated that it might be useful to increase carer involvement in the course, either to enable carers to support home practice or to include them in weekly sessions.

"...running those sessions on a one to one with a carer present might have been equally beneficial ... you'd have the time and the sole attention, no distractions ... my hunch is you'll probably get potentially better outcomes'. (F04)

Keeping it simple. Two facilitators felt that using shorter exercises was more beneficial for participants and three facilitators mentioned participants experiencing difficulties with abstract parts of the course. Instead, more concrete aspects, including mindful listening, physical demonstrations by facilitators

and the use of visual aids, were perceived as particularly valuable. For example, one facilitator described how a picture of an hourglass was referred to during the meditation, which helped to communicate the idea of moving through the body from top to bottom. All facilitators also emphasised the importance of informal mindfulness for this client population, rather than formal practices.

"...we steered the group conversation...to just tease out moments of mindfulness that they had engaged with that they hadn't realized were moments of mindfulness so that they could get an idea of 'oh look, oh so that's what it is, oh I see, right yes, so when I'm always looking out of the window and listening to the birds, just watching the sky and all of that kind of thing, that could have been mindfulness'...' (F01)

Familiarity also seemed to be important for this client group. Two facilitators mentioned that repeating the same practices was useful; particularly how starting each session in the same way was valuable because participants knew what to expect and could get 'in the zone' (F02). Similarly, two facilitators also felt that focusing on the same home practice each week was beneficial.

Mindful facilitators. Three facilitators emphasised the importance of being mindful while leading the course. One facilitator mentioned how she felt an 'ethical responsibility' to adapt the course to the specific needs of the participants rather than 'blindly' follow the protocol (F03). She explained that time constraints prevented her from remaining mindful and to counteract this, she had to be aware of the 'pressure to get through the content' and focus instead on 'slowing it down and getting across the basic concepts that we needed to get across'. Similarly, another facilitator described how she was 'less mindful' at times due to becoming preoccupied with teaching concepts that participants were struggling with (F04). She felt that the need to be flexible in order to make adaptations as the weeks progressed meant that her experience of facilitating was itself 'present-focused'.

Targeting dementia related distress. Two facilitators made a distinction between distress caused by having dementia, in comparison to depression as an illness in itself which MBCT is designed to treat.

"...I'm using the word distress, because we did abandon the use of the word depression, because that wasn't something that felt appropriate for the whole group...what we had was a group of people that were presented with a really tricky life situation where their depression or their mood difficulties could have been a reaction to the diagnosis that they had'. (F04)

This facilitator explained that the distinction created problems when delivering MBCT and suggested an alternative for how mindfulness could be used for this clinical population, which was also mentioned by one other facilitator.

"...although we set out to treat the depressive symptoms through the use of mindfulness and particularly the CT [cognitive therapy] bit, I'm not sure we got there with that...if we broaden it to encompass distress, and then to say, actually, it's about learning, using mindfulness to learn to live with this devastating diagnosis and all of its components, which might be depression, that opens up a whole new world of opportunity for, you know, for change and wellbeing'. (F04)

Discussion

The present study explored participants, carers and facilitators' experiences and perspectives on MBCT for depression in dementia. Across interviewee groups, several beneficial effects were

described. Interviewees mentioned that the course led to various positive emotional changes. They described an increased ability to focus on and be aware of the present moment, and a greater sense of acceptance and self-compassion. Similar findings have been reported in previous qualitative studies investigating the specific MBCT benefits for older adults with depression (Smith 2004; Smith et al., 2007; Williams et al., 2018). The results also reflect the central intended mechanism for change of MBCT, which proposes that cultivating present moment focus activates participants' cognitive awareness. Once conscious in this way, individuals have the opportunity to choose an attitude of acceptance and compassion (Segal et al., 2002).

Participants valued specific aspects of the MBCT course within both weekly sessions and home practice, which is consistent with the MBCT developers' emphasis on the importance of both parts of the therapy (Segal et al., 2002), although the current study suggests that the home practice element might be more challenging for this client group. The value of the facilitators' attitude reported by course participants in this study has been commented on previously (Williams et al., 2018). Across themes there is a sense that part of the beneficial effect might stem from socialising with other group members, although one participant also commented that she could concentrate better at the task on hand when alone at home, and relationship enhancement between the person with dementia and their carer. The utility of the group setting and value of discussing shared difficulties has also frequently been highlighted across qualitative studies of MBCT, including those investigating older participants specifically (Cairns & Murray, 2015; Williams et al., 2018). This finding somewhat conflicts with evidence suggesting that individual interventions are more effective for older adults (Pinquart et al., 2007). The discrepancy may be explained by a greater likelihood of loneliness among participants in this study due to their dementia (Moyle et al., 2011), which could make social interaction provided by the group particularly valuable. The role of socialisation should be evaluated in future research, for example, by comparing different modalities of treatment delivery or through further qualitative research with targeted questioning about social aspects of the course, for example, specifically about the role of relationships with other participants, facilitators and carers.

While struggling to find time and a lack of motivation are common barriers to practice among MBCT participants (Segal et al., 2002), the other difficulties described by interviewees may be unique to or more pronounced among this client population. Problems with understanding, memory and sustained attention may be related to cognitive impairments caused by dementia (American Psychiatric Association, 2013). Although problematic, these barriers do not preclude the use of MBCT for depression in dementia, but suggest instead that adaptations are required to overcome them. Future work implementing mindfulness practices in this population could benefit from reevaluating the overall goal of mindfulness practice and underlying mechanisms that could lead to improvement for this population. At least for some people with dementia, it seems to be more difficult to implement regular practice at the levels required for a more profound shift in attitude, and experience and relationship to distress. Nonetheless, present moment awareness exercises might support these people to feel more 'settled in the moment and sharing that peace with others', which in turn might impact on their mood. Considering this, it might even be of value to investigate adaptations of this intervention for people with more advanced memory and cognitive issues.

Implications for practice

The interview findings suggest several potential adaptations to MBCT for people with depression in dementia.

When starting the intervention, some participants seemed to lack knowledge of what the course would entail. It might be helpful to provide all the introductory information to participants as well as

carers, although some of the participants who attended the introductory session together with their carers might have not been able to take in all information provided on that day. This could be addressed by spreading out the introductory information over two sessions to give them time to process the information. This could also be an opportunity for facilitators to learn more about participants to inform individualised adaptations. It might also be helpful to provide some psychoeducational material for them to engage with at home prior to starting the intervention. Facilitators should ensure to remind participants of the purpose and to set expectations at the start of each session.

Participants' adherence rates and qualitative responses suggest that home practice might be a particularly challenging element of the intervention for some people in this population and further adaptation might be required to enable more participants with dementia to benefit from it. Facilitator's feedback suggests that the purpose of the weekly phone call could be more specific to ensure they are effectively supporting home practice. Facilitators made suggestions of additional materials, which could be incorporated into the protocol, such as video demonstrations for home use and notes for participants to place around their house to remind them of informal mindfulness techniques. Facilitators' responses also highlighted the possibility of increasing carer involvement in home practice. In line with this suggestion, carer involvement was found to positively impact participant engagement with home practice, and carers have previously been actively involved in the home practice component of MBIs (Quintana-Hernández et al., 2016). Home practice elements, remote support and involving live-in relatives might be of particular import in situations when possibility for in-person and group sessions are limited, for example, during a pandemic, such as COVID-19, which has occurred since this study had been conducted. It could even be possible to deliver these groups online, although digital poverty and age-based factors might influence ability and willingness to participate. Further studies will need to develop and evaluate MCBT interventions delivered via different modalities for this population.

With regard to carer involvement, one facilitator felt that including carers in sessions themselves could be useful, and existing qualitative findings suggest that attending MBCT sessions with a partner does facilitate home practice (Smith et al., 2015). Future research is required to investigate whether this is also the case for people with comorbid depression and dementia. The fact that MBCT was found to have a positive impact on some carers also indicates that it may be beneficial to increase their involvement in the course. A previous study, which included carers in mindfulness training alongside people with dementia, found improvements in depression among carers (Paller et al., 2015). This might be particularly useful given the negative effect of depression in dementia on carers (González-Salvador et al., 1999).

The facilitators' comments also suggested that the course ought to be longer and/or that follow-up sessions are needed. MBCT for older adults has already been extended in this way; previously it has been delivered over 10 sessions rather than eight (Smith 2004). Additionally, in a previous study of a mindfulness programme for dementia, half of the participants still attended reunions 2 years post intervention, suggesting that follow-ups may prove beneficial (Churcher Clarke et al., 2017).

A need for the course to remain simple through using shorter practices, repetition of practices and focus on informal mindfulness was also suggested by the facilitators. This need for simplicity may reflect learning impairments that are symptomatic of dementia (American Psychiatric Association, 2013). It would be useful for future research to include these suggestions within MBCT and investigate whether they enhance the participants' ability to benefit from the therapy.

Facilitators also indicated a need to re-examine the target of MBCT when used for people with depression in dementia. A distinction was made between recurrent depression and a 'secondary' dementia related distress experienced by participants. Although existing evidence does suggest that MBCT is useful for people suffering from distress in relation to a separate primary condition

(Malpass et al., 2015; Moore & Martin, 2015; Schoultz et al., 2016), future use of the therapy for depression in dementia requires further theoretical conceptualisation. This is consistent with warnings from Teasdale et al. (2003, p.157) who emphasise the importance of 'adequately formulated views of the kind of disorders they [practitioners] seek to treat and of the ways that mindfulness training can be helpful to clients with those disorders'.

Finally, the facilitators emphasised the need to remain 'mindful' in order to run the groups and make necessary adaptations to accommodate participants' difficulties. Thus, although certain preplanned adaptations may be required for this population, it will also be beneficial for facilitators to remain flexible in adapting the course progressively to take into account any specific challenges faced by individual participants. This is useful in itself given that the developers of MBCT stress the importance of the 'teachers' ability to embody "from the inside" the attitudes they invite participants to cultivate and adopt' (Segal et al., 2002, p. 79).

Limitations

There are several limitations of the study. Firstly, [researchers initials] attended some of the MBCT sessions and thus had previously met four participants and two facilitators. To reduce the likelihood of interviewer bias, [researchers initials] emphasised the importance of hearing interviewees' honest opinions throughout the interviews. Secondly, as interviews were conducted within the 4 months after course completion, recall bias is a potential issue particularly as participants in this study may struggle to remember accurately due to memory impairment associated with their dementia (American Psychiatric Association, 2013). Future research should conduct interviews during and immediately after the course in addition to later interviews to reduce bias. Thirdly, as this was a pilot study, there was a small sample of interviewees, meaning that there was a lack of thematic saturation for certain themes. Although saturation can often be reached even with a small sample (Guest et al., 2006), a larger sample could be used in a future study to ensure that a broad range of interviewee experiences are captured, facilitating a more in-depth evaluation of different aspects of the intervention and which elements and adaptations might work for different individuals. In the case of the current study, quantitative results from the feasibility study will be able to further elucidate the effect of the intervention across all participants (Aguirre et al., 2017). In addition, the MBCT participants included in the study were predominantly white females and some of them had particularly high scores on the MMSE. Therefore, the transferability of findings to the wider dementia population might be reduced.

Conclusion

This is the first qualitative study to investigate the use of MBCT for depression in dementia. The findings suggest that the intervention has several perceived beneficial effects for some participants. However, additional evidence is needed to further investigate its effectiveness for this clinical population. Specific components of the course, such as the shared experience within the group, were perceived to be particularly useful. While carers had a positive influence, cognitive difficulties and barriers to home practice were identified as problems interfering with engagement. In line with these results, carer involvement could be considered as an essential part for future trials to increase engagement with home practice component of mindfulness-based intervention. Responses from facilitators indicated the need for a range of additional adaptations to make MBCT more acceptable for this client population. Further research will be needed to explore whether these adaptations enhance the participants' ability to benefit from the course and whether, once modified, MBCT can facilitate therapeutic change for individuals with depression in dementia.

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Data availability

The data generated and analysed during the current study are not available as individual privacy could be compromised.

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Supplementary material

Supplemental material for this article is available online.

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