Mindfulness-based cognitive therapy (MBCT) for depression in dementia: a qualitative study on participant, carer and facilitator experiences.

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Abstract

**Background:** Depression in dementia is common and is associated with negative health outcomes. Existing evidence suggests that ‘Mindfulness-Based Interventions’ may be a promising treatment option for people with dementia. Mindfulness-Based Cognitive Therapy (MBCT) is the recommended treatment of choice for recurrent depression, but research investigating its use for depression in dementia is yet to be assessed. This study was part of a randomised feasibility study, which is the first study to examine the use of MBCT among PWD. It aimed to investigate the experiences of people with depression and dementia who participated in the MBCT intervention, and those of their carers and facilitators.

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

**Results:** Several beneficial effects of MBCT were described. These were: the use of mindfulness beyond weekly sessions, 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 the facilitators and certain mindfulness practices. Carer involvement, cognitive difficulties and barriers to home practice influenced engagement with the course. Facilitators described adaptations made to MBCT and suggested additional modifications for future groups.

**Conclusion:** Results of this process evaluation suggest that MBCT 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.

**Key words:** Depression – Dementia – MBCT – Qualitative
Introduction

Dementia is a syndrome involving impairment in cognitive functions such as memory and language, which disrupt the person’s independence in daily life [1]. It is usually diagnosed after the age of 65 and can be caused by various brain diseases including Alzheimer’s disease (AD), which is the most common cause [2]. Between 20-40% of people with dementia (PWD) [3, 4, 5, 6] also suffer from depression. This comorbidity is associated with several negative outcomes, including poorer quality of life [7], functioning [8] and cognitive ability [9], as well as increased mortality [10], healthcare costs [11] and caregiver stress [12]. The efficacy of antidepressants is questionable [13]. Psychological interventions, on the other hand, have been found to be a promising alternative for reducing depression in dementia [14].

In recent years, mindfulness-based interventions (MBIs) have been investigated as a psychological treatment option for people with dementia (PWD). 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” [15, p. 47]. Mindfulness practice has been found to slow cognitive decline in AD [16] and an improvement in quality of life has been reported among people with mild to moderate dementia following a mindfulness programme [17]. It has also been found that after participation in a mindfulness programme, participants with progressive cognitive decline, the majority of whom had dementia, reported fewer depressive symptoms [18]. Although this indicates that mindfulness-based interventions may have a positive effect on depression in PWD, 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 differs from other MBIs because it builds principles from cognitive therapy into a mindfulness framework to treat individuals with recurrent depression specifically [19]. It is the recommended treatment of choice for this population [20] and there is consistent evidence that it reduces the risk of relapse [21]. MBCT is an eight-week programme based on mindfulness-based stress reduction and cognitive therapy. Weekly group sessions include practices such as meditation, breathing exercises and mindful movement [19], which help develop the skill of mindfulness by bringing attention to the present moment experience of thoughts, emotions and physical sensations [22]. Homework exercises consolidate this learning and guide individuals to use mindfulness in their everyday life. It is proposed that by becoming mindful, individuals will be aware of depressive thinking as it occurs and choose a non-judgmental attitude towards negative thoughts, experiencing them simply as “passing events in the mind” [19, p. 73].

There is a growing body of qualitative research investigating the experiences of MBCT course participants. A recent meta-synthesis [23] found that the intervention is perceived by participants to have several positive effects such as enabling them 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 described in the studies of older adults included in this meta-synthesis [24, 25], as well as an additional study of older adults that was not included [26]. The current study will build on this work by using qualitative methodology to investigate the perceived effects of MBCT for people with dementia and comorbid depression.
An additional qualitative study of MBCT found that participants’ intrapersonal experiences of therapeutic change were accompanied by and strongly linked to changes in their relationships with close others [27]. For these reasons, it is important to investigate whether carers also experience benefits as a result of their relative’s participation in MBCT. It will also be useful to interview carers to determine the level of support required for PWD living at home to engage with mindfulness practice outside of therapy. A recently published mindfulness programme for PWD living in care homes involved staff in order to support home practice [28]. The transferral of mindfulness skills beyond weekly sessions is a central aim of MBCT [19]. Thus, it is hoped that carers’ responses will provide an insight into whether participants engage with homework and utilise principles taught on the course outside of weekly sessions.

When mindfulness-based interventions have been used for individuals with dementia, adaptations have been required, such as the use of a simple, repeated session format and concrete language [29]. A recent qualitative study of MBCT for older adults with depression interviewed course facilitators to obtain information about necessary adaptations [26]. Facilitators identified differences when using MBCT with this population compared to adults of any age, including how loneliness and inactivity experienced in old age possibly made meditation at home alone more difficult than it was in group sessions. In the current feasibility study, facilitators were interviewed to explore what adaptations are needed to make MBCT suitable for individuals with comorbid dementia and depression.

The current study was nested within a randomised controlled feasibility study, which is the first to examine the use of MBCT among PWD. The aim of the current study is 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 specific effects of the course do participants, their carers and facilitators perceive? 4) How do carers support home practice? and 5) What adaptations are required to make MBCT suitable for this client group?
Methods

Sample
Participants were identified and recruited from memory services in two National Health Service (NHS) trusts in the UK. Consecutive sampling was used: all participants and available carers who were randomised to the intervention group of the randomised controlled feasibility study were invited to take part in the qualitative interviews. The intervention group consisted of two MBCT groups in total. All of the facilitators were also approached by the primary researcher (SD) to ask if they would be willing to be interviewed. Written informed consent to participate in the study was obtained from all participants, carers and facilitators.

Inclusion and exclusion criteria
The following inclusion and exclusion criteria were adopted from the randomised controlled feasibility study. Participants were 65 years or older and met the inclusion criteria for mild depression, based on a clinical cut-off score of 9 and above on The Patient Health Questionnaire (PHQ-9) [30]. Included participants had diagnoses of dementia using DSM-IV criteria and had a Mini Mental State Examination (MMSE) [31] score of 18 or above. Participants were included regardless of their dementia subtype and were not excluded if they had coexisting physical health conditions.

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

Design
This qualitative study was part of the process evaluation conducted alongside a randomised controlled feasibility study, in which quantitative outcome data was also collected [32]. This is in line with guidance from the Medical Research Council for the feasibility and piloting stage of intervention development [33].

Intervention
The intervention used was adapted from the MBCT programme for depressive relapse prevention [19]. Prior to starting the programme, participants and carers (family relatives of participants) attended a psycho-education session about MBCT. Carers did not attend sessions after this. The course consisted of eight, weekly 1.5 hour group sessions, which included mindfulness exercises: mindful eating, the body scan, mindful stretching and seated mindfulness meditation. The programme also included home practice exercises, which were either formal practice using guided meditation recordings or informal mindfulness within daily activities such as mindful walking or eating. Participants were given homework logs to record both types of practice throughout each week.

Data collection
Semi-structured topic guides were developed based on themes from a recent meta-synthesis of qualitative studies [23] and also informed by the research questions. Different topic guides were used for each interviewee group but were similar [see Additional file 1]. A first version of each topic guide was used to interview four participants, two carers and one facilitator. Author JS listened to these interviews and provided suggestions for amendments to the topic guides. The revised topic guides
used for the remaining eleven interviews explored: the utility of the course and specific components within this, 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 also included questions about adaptations necessary for this client group.

Three participants, two carers and one facilitator were interviewed at an NHS site. The remaining five participants and three carers were interviewed in their or their relative’s home. The other three facilitators were interviewed over the phone. Interviews were conducted in the four months after the final MBCT session and lasted an average of approximately 40 minutes each.

**Analysis**

Interviews were audio recorded and transcribed. Transcripts were checked against audio recordings to avoid errors and then entered into QSR NVivo7 qualitative analysis software. Author SD conducted thematic analysis using Braun and Clarke’s guidelines [34] 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 [35]. 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 manually and also using NVivo, and organized into main themes and sub-themes. A second researcher EH 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. These findings were compared with those of the meta-synthesis mentioned above [23] to explore whether themes found in this study confirmed or refuted those previously described in the existing literature.
Results

All eight MBCT participants, six carers and four facilitators invited to interview, were interviewed. The demographic details of these groups are shown in Table 1.

Table 1. Participant demographics

<table>
<thead>
<tr>
<th>Characteristics</th>
<th>PWD group (n=8)</th>
<th>Carer group (n=6)</th>
<th>Facilitator group (n=4)</th>
</tr>
</thead>
<tbody>
<tr>
<td>Age (years)</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Mean (SD)</td>
<td>77.30 (8.94)</td>
<td>67.50 (10.04)</td>
<td>Unknown</td>
</tr>
<tr>
<td>Range</td>
<td>62-93</td>
<td>52-83</td>
<td></td>
</tr>
<tr>
<td>Gender</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Male (%)</td>
<td>1 (10)</td>
<td>4 (66.6)</td>
<td>1 (25)</td>
</tr>
<tr>
<td>Female (%)</td>
<td>7 (90)</td>
<td>2 (33.3)</td>
<td>3 (75)</td>
</tr>
<tr>
<td>MMSE score</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Mean (SD)</td>
<td>25.50 (3.17)</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Range</td>
<td>21-29</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Dementia diagnosis</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Alzheimer’s Disease</td>
<td>5</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Vascular Dementia</td>
<td>1</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Mixed Dementia</td>
<td>1</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Dementia unspecified type</td>
<td>1</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Anti-dementia medication</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Prescribed</td>
<td>4</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Not-prescribed</td>
<td>3</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Unknown</td>
<td>1</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Relationship to PWD</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Spouse (%)</td>
<td>4 (66.6)</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Child (%)</td>
<td>2 (33.3)</td>
<td></td>
<td></td>
</tr>
<tr>
<td>MBCT group</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Group one (%)</td>
<td>4 (50)</td>
<td>4 (66.6)</td>
<td>2 (50)</td>
</tr>
<tr>
<td>Group two (%)</td>
<td>4 (50)</td>
<td>2 (33.3)</td>
<td>2 (50)</td>
</tr>
</tbody>
</table>

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 (see Table 2). Quotations are included in the text to illustrate these themes. 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.
Table 2. Summary of themes and subthemes that emerged from thematic analysis

<table>
<thead>
<tr>
<th>Main themes</th>
<th>Subthemes</th>
</tr>
</thead>
<tbody>
<tr>
<td>The experience of the MBCT course and components within it</td>
<td>Valuing the facilitators</td>
</tr>
<tr>
<td>Effects and outcomes of the course</td>
<td>Taking mindfulness home</td>
</tr>
<tr>
<td></td>
<td>Shared suffering</td>
</tr>
<tr>
<td></td>
<td>“I’m thinking now”</td>
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<tr>
<td></td>
<td>“Feeling better”</td>
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<tr>
<td></td>
<td>The effect on carers</td>
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<tr>
<td>Factors influencing engagement</td>
<td>The role of carers</td>
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<td></td>
<td>Cognitive difficulties and barriers to home practice</td>
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<tr>
<td>Adaptations to the course</td>
<td>Recruitment and assessment</td>
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<td></td>
<td>Practical adaptations</td>
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<td></td>
<td>Keeping it simple</td>
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<td></td>
<td>Mindful facilitators</td>
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<td></td>
<td>Targeting dementia related distress</td>
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</tbody>
</table>

1) **The experience of the MBCT course and components within it**

The majority of participants mentioned that they enjoyed the course and gained something from taking part in the 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 also 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, several respondents focused on the course as a whole rather than the value of individual components.

“IV: I was wondering what aspects of the therapy you found particularly useful?  
P06: I don’t really know anything anymore particular than, you know, I just, everything that went on there...I just used to enjoy it whatever they were doing.” (P06)

Nevertheless, other comments highlighted the utility of specific course components. 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)

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

“...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
Several 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. However, the majority of 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 also highlighted this issue.

Shared suffering
Several participants described being isolated or lonely in their life. Correspondingly, all but one participant valued the social interaction provided by sessions. Multiple participants, carers and all facilitators suggested that this social aspect of the course was useful for preventing isolation.

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

One facilitator explained that she felt that any potential benefits of the course would be related to the group environment itself. Similarly, the comments of one carer suggested that her relative did not value the course for its content, but simply due to the social interaction it provided.

“…I feel that a lot of the benefits may have just come from having a group that’s quite relaxing and chatting to people.” (F02)

Multiple participants and carers 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 the same or similar difficulties. All of the facilitators also mentioned the value of this sense of shared suffering. 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)

In addition, four participants described noticing how other group members were ‘worse off’ in some way and for two of them, this made them feel more positive about their own situation. 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 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)

“You know, a group is a group is a group. It’s different from trying to struggle on your own with things.” (F01)

“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 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. Memory difficulties were also identified by her daughter as an additional reason for this.

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, and this was also mentioned by two carers. One of the facilitators also explained how, for one participant, the home practice was particularly useful as it provided structure throughout the day that enabled the individual to manage her low mood. 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 would visit, a friend would visit.” (P02)

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

“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)

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 the comments of three carers.

**The effect on carers**
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, as a result of the course. 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**

**The role of carers**
Carers interviewed were family relatives of participants and they attended an introductory psycho-education session about MBCT prior to the course starting. In a few cases, interviewee responses suggested that carer involvement positively influenced participant engagement with home practice.

“IV: And why do you think you found it particularly useful to do it together as opposed to being on your own?
P06: I don’t really know. I suppose I can do it, I could get on with it but if there’s someone else doing it with you, you do seem to find you relax more I think if you do it together than if you’re on your own you tend to keep having to remind yourself to relax.” (P06)
Cognitive difficulties and barriers to home practice
Interviewees described various cognitive difficulties encountered during the course. The responses of some participants and carers suggested that a lack of concentration was an issue. Certain 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. Specifically, 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, or the session, she’d forgotten really, what they did there.” (C05)

It was clear from the comments of several carers, that technical difficulties arose when trying to use the recordings at home. Several participants and carers also suggested that competing commitments or struggling to find time were additional barriers to home practice. A few carers identified a lack of motivation or interest as also preventing home practice being done.

“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 adaptations that were made to the MBCT course and also suggested potential modifications for future groups of people with dementia and depression.

Recruitment and assessment
One facilitator mentioned that the carers’ attendance at the introductory session was useful for gaining information about participants, but that more time could have been spent on this. Similarly, another facilitator explained that a meeting with the carer and participant would have been beneficial to obtain additional information about the participants’ difficulties to inform what adaptations are required. Two facilitators suggested that some participants were not suitable for the course and one of them felt that this problem arose because facilitators were 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 also suggested that there was a lack of information about how aware participants were of their diagnosis and mentioned that this could be included in participant assessment.

“...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), facilitate independent practice at home or assess participants’ continued use of mindfulness. One facilitator thought that sessions could have been lengthened to enable her to present course content to this client group, as this was particularly time consuming. 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 were lengthened 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. Phone call ‘check ins’ were used to support home practice and 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 practices was more beneficial for participants and three facilitators mentioned participants experiencing difficulties with abstract parts of the course. Instead, their comments suggested that more concrete aspects, including mindful listening, physical demonstrations by facilitators and the use of visual aids, were 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 emphasized 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**

The comments of three facilitators suggested 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 that 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. These findings have been reported in previous qualitative studies investigating MBCT for older adults with depression [24, 25, 26]. The results also reflect the central intended mechanism of MBCT; by cultivating present moment focus, an awareness of mental state occurs. Once conscious in this way, individuals can choose an attitude of acceptance and compassion [19].

The present study also found that interviewees identified specific aspects of the MBCT course as particularly useful. Participants valued components within both weekly sessions and home practice, which is consistent with the MBCT developers’ emphasis on the importance of both parts of the therapy [19]. The value of the facilitators’ attitude reported by course participants in this study has been commented on previously [26]. Similarly, the utility of the group setting has also frequently been highlighted across qualitative studies of MBCT, including those investigating older participants specifically. In particular, the value of exchanging difficulties commonly experienced by group members has been described previously, as in this study [23, 26]. This finding conflicts with evidence suggesting that individual interventions are more effective for older adults [36]. The discrepancy may be explained by a greater likelihood of loneliness among participants in this study due to their dementia [37], which could make social interaction provided by the group particularly valuable.

A few participants continued to use the home practice resources and multiple participants described effects of the course in the context of their daily life, suggesting that mindfulness skills were transferred outside of weekly sessions, which is a specified aim of MBCT [19]. While struggling to find time and a lack of motivation are common barriers to practice among MBCT participants [19], 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 [1]. Although problematic, these barriers do not preclude the use of MBCT for PWD but suggest instead that adaptations are required to overcome them.

Implications for practice
Comments from facilitators in this study suggested several potential adaptations to MBCT for people with depression in dementia. Firstly, facilitators’ responses 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 mindfulness-based interventions [16]. In addition, one facilitator in the current study 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 [38]. 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 PWD, found
improvements in depression among carers [18]. This is a particularly potentially useful adaptation given the negative effect of depression in dementia on carers [12].

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 ten sessions rather than eight [24]. Additionally, in an existing study of a mindfulness programme for dementia, half of the participants were still attending reunions two years post intervention, suggesting that follow ups may prove beneficial [17]. A need for the course to remain simple through the use of shorter practices, repetition of practices, a focus on informal mindfulness and making the course as ‘concrete’ as possible was also suggested by the facilitators’ comments. This need for simplicity may reflect learning impairments that are symptomatic of dementia [1]. 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.

A further necessary adaptation, suggested by the responses of two facilitators, is a need to re-examine the target of MBCT when used for people with depression and 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 [39, 40, 41], future use of the therapy for depression in dementia requires further theoretical conceptualisation. This is consistent with warnings from Teasdale et al. [42, p. 157] who emphasize 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”.

The facilitators also emphasized the need to remain ‘mindful’ in order to run the groups and make necessary adaptations to accommodate participants’ difficulties. Thus, although certain pre-planned adaptations may be required for this population, it will also be beneficial for facilitators to remain constantly mindfully aware of specific challenges faced by participants and flexible in adapting the course progressively to take these into account. Interestingly, taking this approach made one facilitator feel particularly grounded in the present (F04). 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” [19, p. 79].

Limitations

There are several limitations of the study. Firstly, SD attended some of the MBCT sessions of one group meaning that she had previously met four participants and two facilitators, which may have influenced their responses. To reduce the likelihood of interviewer bias, SD emphasized the importance of hearing interviewees’ honest opinions throughout each interview. Secondly, as interviews were conducted within the four 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 [1]. Future research could conduct interviews during and immediately after the course in addition to later interviews to reduce bias. Finally, 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. This was the case for some of the subthemes within the ‘effects and outcomes of the course’ theme. Quantitative results from the feasibility study will be examined to further elucidate the effect of the intervention across all participants. In addition, the
MBCT participants included in the study were predominantly white females, which reduces the transferability of findings to the wider dementia population. Although saturation can often be reached even with a small sample [43], a larger sample could be used in a future study to ensure that a broad range of interviewee experiences are captured.

**Conclusion**

This is the first 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 and aspects of the course are perceived to be particularly useful. Certain factors were found to influence participant engagement with the course: while carers had a positive influence, cognitive difficulties and barriers to home practice were identified as problems interfering with engagement. In addition, responses from facilitators indicated the need for a range of adaptations required to make MBCT an acceptable intervention 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 comorbid depression and dementia.

**Abbreviations**

MBCT: Mindfulness-based cognitive therapy  
AD: Alzheimer’s disease  
PWD: People with dementia  
PHQ-9: Patient Health Questionnaire  
MMSE: Mini Mental State Examination  
NHS: National Health Service  
CT: Cognitive therapy
Declarations

Ethics approval and consent to participate
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.

Consent for publication
Not applicable.

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

Competing interests
The authors declare that they have no competing interests.

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Authors’ contributions
SD collected and analysed the data, and wrote the manuscript. JS revised the topic guides and the manuscript. EA, AS and JS conceived and designed the study. EA gained funding for the study from the Oxford Mindfulness Centre, supervised the entire process of conducting the study, and also reviewed and approved the final manuscript. EA, DN, EH and MP were involved in the adaptation of the MBCT intervention. All authors commented on the manuscript and took part in the design and delivery of the study.

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Topic guides

The order of the questions outlined will not necessarily be followed. Probe/follow up questions are written in italics – they will be used if deemed to be relevant and useful within a given interview.

Topic guide for MBCT participants

1. Could you describe your experience of the MBCT sessions?
   - Could you describe what it was like to be in the sessions at the start of the 8 weeks? Could you describe what it was like to be in the sessions in the middle of the 8 weeks? Could you describe what it was like to be in the sessions at the end of the 8 weeks?

2. What aspects of MBCT did you find to be useful?
   - Can you describe some examples of the aspects of MBCT you found to be useful?
   - Why do you think that particular aspect was useful? What do you think MBCT helped you with? Can you describe some examples of what MBCT helped you with?

3. What aspects of MBCT did you find to not be useful?
   - Can you describe some examples of the aspects of MBCT you found to not be useful?
   - Why do you think that particular aspect was not useful? What do you think MBCT did not help you with? Can you describe some examples of what MBCT did not help you with?

4. How did you find being in a group for the MBCT sessions?
   - Why was this useful or not useful?
   - In what way was this useful or not useful?

5. Did you take any of the skills or techniques you learned in the MBCT sessions into your daily life?
   - Which skills were you able to take into everyday life?
   - In what way did you include these skills in everyday life?
   - Which skills were you not able to take into everyday life?

6. Did MBCT change your feelings towards yourself?
   - In what way did MBCT change your feelings towards yourself?
   - Why did MBCT change your feelings towards yourself?

7. I’d like to ask you about how you found practicing the skills and techniques you learnt in the MBCT sessions outside of the sessions. What did you do?
   - Why did you do this?
   - What skills or techniques did you avoid? What skills or techniques did you find hard to do? Why did you find this skills or techniques harder?
8. Thank you for your time. Do you have any questions that you would like to ask me? Is there anything else you would like to add about your experience of MBCT?

**Topic guide for carers**

1. Overall, do you think MBCT was useful for your relative?

2. Which aspects of MBCT do you think were useful for your relative?
   - Can you describe some examples of the aspects of MBCT you think were useful?
   - Why do you think that particular aspect was useful? What do you think MBCT helped your relative with? Can you describe some examples of what MBCT helped your relative with?

3. Which aspects of MBCT do you think were not useful for your relative?
   - Can you describe some examples of the aspects of MBCT you found to not be useful?
   - Why do you think that particular aspect was not useful? What do you think MBCT did not help your relative with? Can you describe some examples of what MBCT did not help your relative with?

4. How do you think your relative found being in a group?
   - Why was this useful or not useful?
   - In what way was this useful or not useful?

5. From what you’ve noticed, do you think your relative has been able to take any of the MBCT skills into everyday life?
   - Which skills were they able to take into everyday life?
   - In what way did your relative include these skills in everyday life?
   - Which skills was your relative not able to take into everyday life?

6. Do you think MBCT changed your relative’s feelings towards themself?
   - In what way did MBCT change your relative’s feelings towards themself?
   - Why did MBCT change your relative’s feelings towards themself?

7. Has your relative doing the MBCT course made any differences to you as their main carer?
   - In what way did it impact you?
   - Can you give some examples of the ways in which your relative’s experience impacted you?

8. Was your relative’s experience of MBCT useful for you or not?
   - In what way was your relative’s experience of MBCT useful for you?
   - Were there any ‘downsides’ to your relative doing the MBCT course?
   - Can you give some examples of the ways in which your relative’s experience of MBCT was useful or not useful for you?

9. Did your relative’s experience of MBCT impact your relationship with each other?
- In what way did your relative’s experience of MBCT impact your relationship with each other?
- Can you give some examples of the ways in which your relative’s experience of MBCT impacted your relationship with each other?

10. Thank you for your time. Do you have any questions that you would like to ask me? Is there anything else you would like to add about your own or your relatives’ experience of MBCT?

Topic guide for facilitators

1. What previous experience of delivering MBCT or other mindfulness-based interventions have you had?
   - Which client groups have you previously delivered MBCT or other mindfulness-based interventions to?
   - How did this client groups’ response to MBCT differ from other clients’ responses?
   - Did these sessions differ to those you have previously delivered?

2. Did you make any adaptations to MBCT for this client group?
   - What adaptations did you make?
   - Do you think these adaptations were successful? If you were to deliver the sessions again, would you make the same adaptations, which adaptations would you keep, which would you not use, which would you add etc.

3. Do you think participants were selected in an appropriate way for the MBCT sessions?
   - Would you have done this differently?

4. Overall, do you think MBCT was useful for participants?

5. What aspects of MBCT do you think were useful for participants?
   - If the individual is struggling or is providing a vague answer: Can you describe some examples of the aspects of MBCT you think were useful?
   - Why do you think that particular aspect was useful?

6. What aspects of MBCT do you think were not useful for participants?
   - If the individual is struggling or is providing a vague answer: Can you describe some examples of the aspects of MBCT you think were not useful for participants?
   - To gain further detail: Why do you think that particular aspect was not useful?

7. What do you think MBCT helped participants with?
   - If the individual is struggling or is providing a vague answer: Can you describe some examples of what you think MBCT helped participants with?

8. What do you think MBCT did not help participants with?
   - If the individual is struggling or is providing a vague answer: Can you describe some examples of what you think MBCT did not help participants with?
9. Do you think that the group setting of MBCT sessions was useful or not?
   - Why was the group setting useful or not useful?
   - In what way was the group setting useful or not useful?

10. Do you think participants were able to take the MBCT skills into everyday life or not?
    - Which skills do you think participants were you able to take into everyday life?
    - In what way do you think participants included these skills in everyday life?
    - Which skills do you think participants were not able to take into everyday life?

11. Do you think MBCT changed participants feelings towards themselves?
    - In what way do you think MBCT changed participants’ feelings towards themselves?
    - Why did MBCT change participants’ feelings towards themselves?

12. Thank you for your time. Do you have any questions that you would like to ask me? Is there anything else you would like to add about your own or your participants’ experience of MBCT?