The LivDem 2023 survey: Facilitator views on benefits and the more active involvement of carers in the Living well with Dementia (LivDem) course.

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This is a pre-publication version of the following article:

Cheston R, Reilly F, Topalova N, Woodstoke N and Dodd E (2024) The LivDem 2023 survey: Facilitator views on benefits and the more active involvement of carers in the Living well with Dementia (LivDem) course, *FPOP Bulletin*, 166 (April), pp 48-55, https://doi.org/10.53841/bpsfpop.2024.1.166.48

Abstract

Introduction. The Living Well with Dementia (LivDem) intervention is an eight-week, group based post-diagnostic course for people living with dementia that aims to facilitate adjustment to the diagnosis. We set out to establish the views of course facilitators in two areas: first, the benefits of LivDem for participants, their families and for facilitators; and second whether carers can be more actively involved in the course.

Method. An online survey was distributed to health and social care workers in the UK and overseas who were delivering the LivDem course. The survey explored LivDem facilitators' opinions about the benefits of LivDem and whether families could be involved more actively in the course.

Results. Twenty-eight facilitators completed the survey, with an average course completion rate of 2.43. One participant worked in Italy and another in Ireland, with the remainder working in the UK. All respondents agreed that LivDem was of benefit to participants with dementia (e.g. by enabling them to talk more openly about their dementia) and that it also strengthened participants' relationships with their partner. Many facilitators also felt that they had learnt new skills that they used outside the course. While respondents largely agreed that carers should be more actively involved there were strong concerns that this should not impact on participants' ability to express themselves within sessions.

Discussion. This study is consistent with research elsewhere suggesting that attending the LivDem course facilitates a greater ability to talk openly about dementia. The more active involvement of carers in LivDem needs to be balanced against risks that people with dementia may be inhibited from discussing their

dementia. Accordingly, the study team have begun to explore ways to deliver LivDem directly to family units.

Introduction

The Living well with Dementia (LivDem) course is an eight-week group intervention that aims to support people recently diagnosed with dementia to adjust to their condition (Cheston & Marshall, 2019). Sessions last for 90 minutes and are attended only by people living with dementia. Carers and other family members are invited to attend an introductory session before the course commences and a final session at the end. LivDem courses are led by two facilitators, typically community nurses, occupational therapists or psychology assistants often under the supervision of clinical psychologists in NHS settings. LivDem is currently delivered across over 50 sites in the NHS and voluntary, community, faith and social enterprise (VCFSE) services in the UK, as well as in Ireland, Italy and Japan and is supported by a website (https://www.livdem.co.uk).

In order to help participants to feel safe enough to explore their diagnosis (Cheston, 2022), the course takes a deliberately slow pace, initially focussing on the symptoms of cognitive impairment, then the emotional impact of this and ways in which participants cope with their feelings. Only in the middle sessions, when the group has formed and is ready to discuss more emotionally problematic material, do course facilitators initiate a discussion on how to talk about the diagnosis to others before looking in detail at the diagnosis, its treatment and prognosis. Finally, the LivDem course looks at ways of living well with dementia, including making decisions about the future, and the importance of staying as active as possible (Cheston & Marshall, 2019).

The initial LivDem pilot study (Marshall et al., 2015) showed that there is a significant improvement in self-esteem for LivDem participants, although this became non-significant once differences in baseline levels were accounted for.

Subsequently, two qualitative studies suggested that over the course of the eight weeks, some participants were able to make changes in how they talked about their dementia indicating a potential process of adjusting to their dementia. Thus, in the initial sessions, participants tended to refer to their dementia indirectly, talking about “it” or “that thing that I have”. By the end of the course, however, most participants were able to openly acknowledge their dementia, referred directly to their diagnosis and explored different aspects of their illness (Cheston et al., 2017, 2018). This is supported by informal feedback from course participants who describe three types of benefits: first, attending the course helps participants to feel that they are not alone; second, some attendees feel less frightened about their dementia; and finally, many participants are often more open about their dementia. However, as yet we have made no structured attempt to draw on the opinions of LivDem course facilitators whose experiences of leading groups arguably makes them ideally placed to identify changes in their clients.

Informal feedback from people living with dementia also highlights a second concern about the current LivDem model as many potential participants are reluctant to engage with the group-based nature of the course. Instead, some people living with dementia tell us that they would prefer to discuss their illness within their family, rather than with strangers. However, any more active involvement of carers in the LivDem course would have ramifications for both the process of adjustment that takes place within the course and might also present logistical challenges for services.

In order to explore these issues further, the UWE LivDem team (RC, ED and NW) supported by two undergraduate students (FR and NT), surveyed LivDem facilitators to gauge their opinions around two issues. First, we were interested to learn what benefits course facilitators identified amongst LivDem participants, and second, we wanted to know what they saw as the potential advantages and disadvantages in involving families more actively in the course.

Method

Ethical approval from the University of the West of England Psychology Ethics Committee was obtained on the first of December 2022 (ref: LB2022009).

We used Qualtrics to generate an online survey which was distributed during March and April 2023 to health and social care professionals who had completed the LivDem course facilitator training programme and given their permission to be contacted by the team with research opportunities. The survey addressed two main research questions: first, participants were asked to identify the benefits that they believed could accrue from LivDem for people living with dementia, their carers and for the wider service. Second, facilitators were asked for their opinions as to how families could be more actively involved in LivDem and what potential advantages and disadvantages this might bring. Survey questions allowed a mix of free text replies and ordinal responses (typically across a four-point Likert scale: strongly agree, agree, disagree and strongly disagree).

Twenty-eight participants with a mean age of 43.7 took part in the study with their details being reported in Table 1.

Table 1: Details of Participants.

Demographic variable	**Participants**
Ethnicity	
White British	24 (85.6%)

White Other	2 (7.2%)
Irish	1 (3.6%)
Indian	1 (3/6%)
Gender	
Women	24 (85.7%)
Men	4 (16.7%)
Country in which LivDem was delivered	
England	20
Wales	2
Scotland	1
Republic of Ireland	1
Italy	1
Not given	2
Sector	
State provider of health care (e.g. NHS)	23
Voluntary, Community and Faith Sector organisation	5

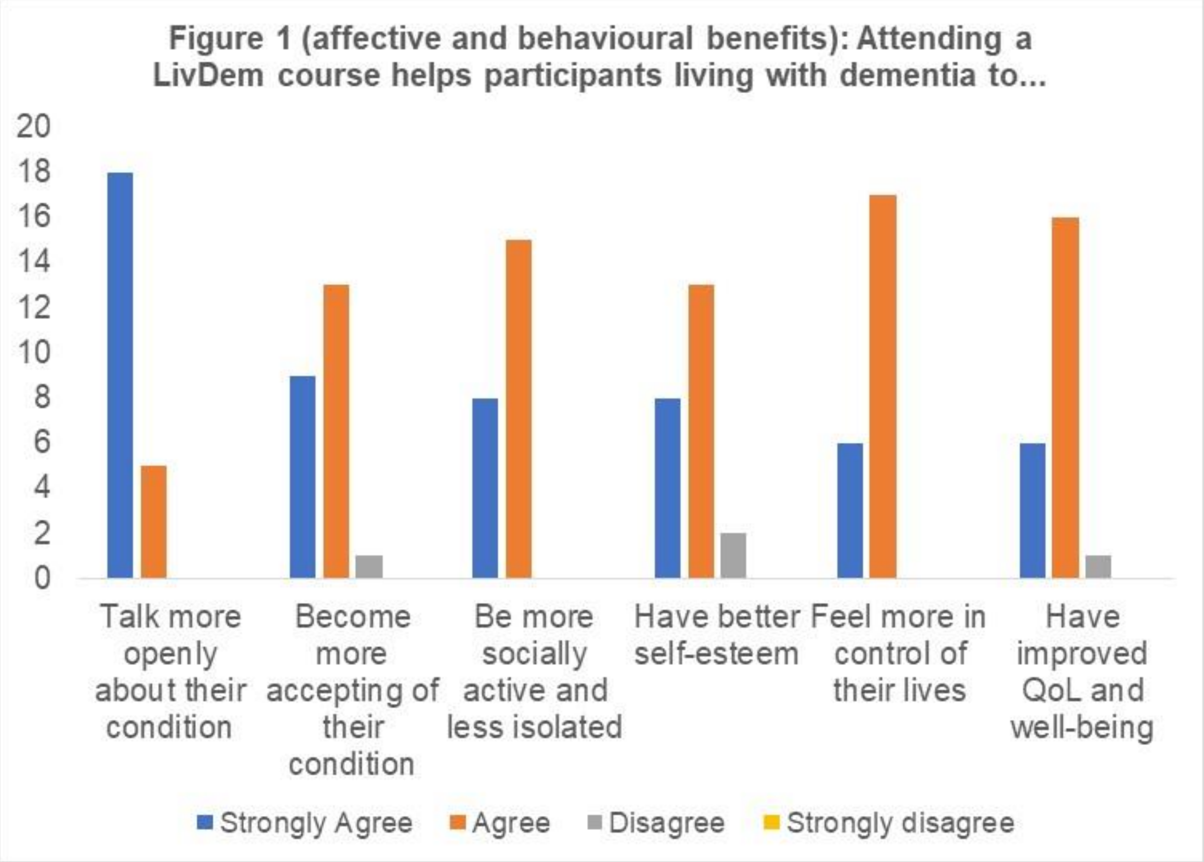
Of the 28 participants, 23 had either facilitated or supervised up to 14 LivDem courses (mean = 2.43 courses). Five participants had not run a LivDem course at the time that they completed the survey (although two stated that they were about to start).

Results

We asked participants to respond to statements about the potential benefits from LivDem for people living with dementia, their families and for the facilitators themselves.

What benefits do LivDem participants living with dementia gain?

Reassuringly, all respondents agreed that LivDem helped participants to talk more openly about their dementia, to be more in control of their lives and to be less socially isolated. Most respondents also agreed or strongly agreed that LivDem helped people to be more accepting of the illness, to have better self-esteem and quality of life (Figure 1).

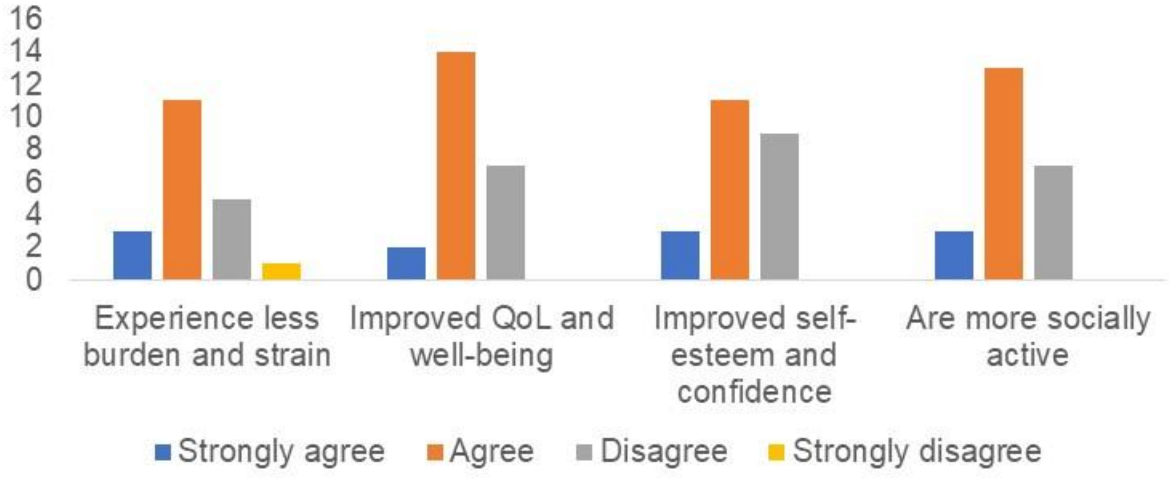


In addition to these affective and behavioural outcomes, most facilitators agreed that LivDem helped participants to improve their self-care (two strongly agreed, 15 agreed and five disagreed) and cognitive functioning (two strongly agreed, 12 agreed and eight disagreed). More respondents disagreed (12) than agreed (10) that attending a LivDem course improved long-term memory.

What benefits do family carers gain from LivDem?

Facilitators also identified benefits from attending the LivDem course for participants' relationships with their partner and wider family (Figure 2). LivDem was believed to help families to talk more openly about dementia (five strongly agreed, 17 agreed and one disagreed) and that it also improved the relationship (two strongly agreed, 18 agreed and three disagreed) and as a result helped families to connect more effectively (two strongly agreed, 16 agreed and five disagreed). Some facilitators also identified that carers received a number of indirect benefits from their partners attending the course (see Figure 2).

Figure 2: Benefits to family carers from the LivDem course.



Are there benefits for facilitators from delivering LivDem?

All the facilitators who responded to the survey agreed that they had benefitted from the experience. This included agreeing that they were more aware of how dementia affects people (13 strongly agreed and 10 agreed), that they had learned new skills (11 strongly agreed and 12 agreed) which they could carry over into other areas of their working lives (eight strongly agreed and 15 agreed).

Should carers be more actively involved in LivDem?

Currently carers of people living with dementia do not attend the eight-week LivDem course but are instead invited to sessions that take place before and at the end of course. Our team is often asked if it is possible for families and carers to attend the LivDem course itself. We therefore asked course facilitators for their thoughts about whether a more inclusive approach would be possible.

Respondents agreed or strongly agreed (21) that carers should be more actively involved although seven disagreed or strongly disagreed with this statement and that carers would benefit from this (22 agreed, six disagreed). However, a majority of facilitators expressed concerns at the impact of this on participants with dementia: thus, more facilitators disagreed or strongly disagreed (15) with the statement that involving carers would improve engagement than agreed with it (12). Similarly, facilitators were equivocal as to whether having carers more actively involved might improve the adjustment of participants with dementia, with 17 being unsure what the effect would be, six believing it might help adjustment and five being concerned that it might make adjustment harder.

We explored facilitators' concerns around the impact of involving carers might be through a series of questions allowing open text responses. The response to these suggested that facilitators were worried that participants with dementia might be over-shadowed by having their carers present:

> *Having the people with dementia attend on their own has certainly allowed space for honest conversations about the changes and challenges within relationships, which has seemed to be supportive. We have also found that in the sessions where the carer attends, they can sometimes tend to speak for the person with dementia. In the sessions where the carer isn't there, given time and space, the person with dementia has almost always found their own way of expressing what they're trying to say, and this has felt really important.*
>
> 52-year-old female working in a VCFSE

> *I feel that participants may feel unable to share their true thoughts with carers at every session and I often find that carers will speak on behalf of the participant. I believe there is a place for carer support and attendance within the sessions but not at the detriment of the positive effect the course has on the confidence of the participant.*
>
> 49-year-old female working in NHS

We asked facilitators to rank four different service responses that might allow carers to be more actively involved. Facilitators' preferred option was for a parallel group for carers running alongside the LivDem course (average rating 1.12, where 1 = best and 5 = worst). A female facilitator working in the NHS wrote: "*We have now set up a carers support group in the same building at the same time which Alzheimer's Society facilitate and this is working REALLY well".* The other options that facilitators were asked to rank were for carers to join in with more of the current sessions (2.92), to have a shorter course for both the person with dementia and their carer (3.0) and to have a longer course with additional sessions included for carers (3.76). Respondents told us:

> *I do not think this needs changing at all. Carers feel involved due to handouts and invitation to the first and last sessions. Carers generally like that their loved ones have their own space to discuss diagnosis.*
>
> *48-year-old female working in NHS*

> *A new course could provide something a bit different, enabling people to learn together about the diagnosis and consider how they approach this together. Maybe some of the ideas from the current course could be included. We would still like to offer separate groups for people living with dementia and for carers but do see benefits in a more systemic approach.*
>
> *48-year-old female working in NHS*

While the clear preference of facilitators is for parallel groups for carers, the labour-intensive nature of this means that it is not a realistic option for many services. Importantly, there is a risk that involving carers as well as the person living with dementia in the LivDem course might interfere with the core feature of the course:

> *I believe that the current LivDem model offers a vital forum for the person with the dementia to be heard and to have their voice respected. It also provides a 'safe' space for them to share their thoughts and feelings and have these validated by their peers.*
>
> 55-year-old male working in the NHS

A number of NHS respondents frequently identified service priorities as a likely stumbling block to greater carer involvement. Thus a 41-year-old female working in the NHS old us: "*I believe that my managers would ultimately wish to prioritise the needs of the person with dementia and therefore be less keen on a mixed course*". Another participant described a "*lack of understanding of [the] positive impact to person and family*" and stated that "*managers don't see family as warranting a service only the person*" (52-year-old female working in Ireland). Respondents suggested that the ability to run a course for carers would be dependent on whether services are commissioned to provide services for carers. Issues with funding were also discussed by respondents outside of the NHS.

Alongside the issues related to funding alternative formats for the group, participants also raised the challenges of alternative formats for facilitators:

> *If the vision is to attempt to develop a single 'combined course' that would satisfy both carer and the person with dementia, then I think that the facilitator's task would become exceedingly difficult (a little like a teacher trying to educate two markedly different groups of students mixed together in one classroom). The workload involved in running a second carer-focused group alongside the original LivDem course would likely be a step too far in terms of staff capacity*.
>
> 41-year-old female working in the NHS

Discussion

The views of course facilitators extend our previous research in this area (Cheston et al., 2017, 2018). Not only are LivDem participants believed to be less frightened about their dementia, able to talk more openly about it and more accepting of their condition but LivDem participants were also reported to be more socially active and less socially isolated. Facilitators also agreed that participants were more in control of their lives, had increased self-esteem and had an improved quality of life and well-being. Taken together, these results suggest that facilitators see LivDem as an effective intervention with significant benefits to attendees. Moreover, some facilitators also identified improvements in self-care and cognition from attending the group. Whilst these are not primary aims of the course, they may reflect the associated benefits from being part of a stimulating, socially inclusive group.

This survey went beyond previous research to explore potential benefits of LivDem to the family carers of those attending the course. It is well established that being a family carer of a person living with dementia can be an emotionally and physically demanding experience, with a recent large survey finding that 95% of respondents experienced clinically significant levels of burden (Gilsenan et al., 2023). Indeed, the Alzheimer's Association (2015) recognised that the wellbeing of unpaid carers is a public health concern. Whilst facilitators were not in full agreement about the benefits of LivDem to family carers, a majority agreed that LivDem may reduce strain on carers, enhance communication and improve relationships. Overall, there was broad agreement for increased carer involvement as long as this did not impact negatively on the experiences of people living with dementia. There was a preference for a parallel, complementary carer group and indeed one respondent reported that they had already set such a group up. However, this is a time and resource heavy option that might be difficult to implement if services are not commissioned to provide caregiver support.

Facilitators were clear that the core features of LivDem should not be changed. This highlights the challenges for services in meeting the needs of both people living with dementia and their families in the current funding context. However, at the same time both the person living with dementia and their families would benefit from having the time and space to talk about and adjust to a condition which can impact on every aspect of their daily lives. Accordingly, we propose to explore whether LivDem can be adapted into a format that can be used with separate families (Alexander et al., 2023; Edwards et al., 2018).

Finally, in this study LivDem facilitators also reported a number of benefits to their own clinical practice from taking part in the training and delivering the sessions. These changes included having an increased awareness of how dementia affects people and developing new skills which they were then able to use in other areas of their work. This suggests that facilitators are often able to use the knowledge that they gain from LivDem to improve the way that they work with people living with dementia in other contexts.

We are aware that a response bias may well have affected responses to this survey: it is likely that health and social care professionals who did not have good experiences of LivDem would not have taken part. Consequently, our conclusions are necessarily limited. However, the feedback is consistent with the opinions expressed to the research team in many of our other interactions with people delivering LivDem. We strongly believe that for many people living with dementia and their families being more able to talk more openly about what is happening is a fundamental part of adjustment and helps people to “Live well”. Indeed, we would go so far as to suggest that supporting people to adjust to their condition should be at the heart of all dementia services.

If you are interested in learning more about LivDem or in taking part in the online training programme, then do contact us via LivDem@uwe.ac.uk.

Acknowledgements.

We are very grateful to everyone who completed the survey.

This research was partially funded by a Research Capacity Funding grant from Avon and Wiltshire Mental Health Partnership Trust. Dr Natasha Woodstoke’s work is also funded by the NIHR Building Capacity in Dementia Research Programme. The views expressed in this paper are those of the authors and not necessarily those of the NIHR or the Department of Health and Social Care.

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