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## Health promotion in early-stage dementia – user experiences from an educative intervention

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### ABSTRACT


Educating and supporting people with early-stage dementia has gained increased focus worldwide as a response to an aging population and limited advancements in the medical treatment of the condition. The aim of this study was to explore the experiences of people with early-stage dementia who were provided with support and information through a 12-week health promotion course and identify elements of the intervention potentially contributing to coping and adjustment to the condition. Data was collected through individual semi-structured interviews with 32 people with dementia after they had attended the course. For each participant, a care partner was also interviewed. The data were analyzed using systematic text condensation. Three main categories emerged from the analysis. These were: (I) bridging the post-diagnostic information gap, (II) facilitating health behavior changes, and (III) new perspectives on living with the condition. The results demonstrated that the intervention was well-received by the participants. Learning about dementia, meeting others in the same situation, and focusing on maintaining a healthy lifestyle was particularly highlighted, as was promoting family communication.

### Background

Worldwide, dementia is a growing healthcare challenge with a huge socio-economic impact (Prince et al., 2014). Despite considerable efforts, there have been no new pharmaceutical treatments available in the last 20 years, and there are no disease-modifying treatments available (Patterson, 2018). Educative approaches like health promotion interventions for people with early-stage dementia have gained an increasing focus over the years to enable people with dementia to stay in their homes for longer (Norwegian Ministry of Health and Care Services, 2015; Prince et al., 2014). Health promotion interventions have the potential to reduce the impact of many avoidable secondary consequences, as well as empower the person affected to take an active role in the situation and take steps themselves to adjust and cope with the condition (Bossen et al., 2009; Buettner & Fitzsimmons, 2009). However, there is limited evaluation and implementation of these types of interventions in clinical practice (Górska et al., 2013). A review by Quinn et al. (2015), exploring literature on group-based interventions for people with early-stage dementia, found that only 5 out of 12 intervention studies included in the review used an educative approach. The remaining were either psychotherapeutic or support groups.

In this study, we focus on the ‘Prevention of hospitalisation and nursing home replacement for persons with dementia’-project’s health promotion intervention (Testad et al., 2020). The intervention consists of a 12-week health promotion course, two-hour group sessions delivered at weekly intervals, for home-

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dwelling individuals over the age of 65 with early-stage dementia. Each group consisted of up to seven participants and was led by two healthcare professionals. During the first session, each participant received a course-specific booklet that covered the following topics: understanding the progression of dementia, physical activity, nutrition, coping strategies, relationships, home- and travel safety, sleep hygiene, medications, and communication with healthcare providers, and planning for the future. The format and content of the intervention were originally based on previous research (Fitzsimmons & Buettner, 2003), and were translated and applied to a Norwegian context by the last author and revised three times by facilitators and participants. The results have been encouraging and demonstrated positive effects on cognition (Buettner & Fitzsimmons, 2009), depression (Buettner & Fitzsimmons, 2009; Testad et al., 2020), self-rated health (Testad et al., 2020), and improved self-efficacy (Richeson et al., 2007). Despite these promising results, there is still a lack of knowledge on how people with dementia experience these interventions, and which elements of the interventions could potentially support coping and adjustment to the condition remains unclear. According to the few studies that included qualitative feedback (Fitzsimmons & Buettner, 2003; Richeson et al., 2007), participants valued the educational aspects of the course, the opportunity to interact with peers, and the opportunity to gain knowledge. Qualitative feedback from similar group-based interventions has found that the intervention positively impacted self-esteem (Martin et al., 2015) and confidence (Quinn et al., 2016; Sprange et al., 2021). Meeting peers and learning from others in the same situation was valued (Skov et al., 2022; Sprange et al., 2021), and the intervention contributed to ease the process of accepting their condition (Øksnebjerg et al., 2020).

In a Norwegian context, the health promotion intervention is an entirely novel program, and further qualitative research is needed in order to optimize future interventions and services for people with dementia. Based on the notion that empowering people with early-stage dementia through increased knowledge and health promotion is a pivotal perspective in informing educational interventions where they themselves are the target group, it is of vital importance to explore their perspectives.

The aim of this study was to explore the experiences of people with early-stage dementia attending a 12-week health promotion course and identify elements of the intervention potentially contributing to coping and adjustment to the condition. The following research questions have guided the study:

- (1) How do people with early-stage dementia experience the provision of support and information through a 12-week health promotion course?
- (2) How can attending a 12-week health promotion course support people with early-stage dementia and their care partner to cope and adjust to their condition?

## Methods

### *Study design*

The present study had a qualitative approach with an explorative design, which is appropriate when the aim is to obtain first-hand knowledge of research participants' experiences of a specific topic (Malterud, 2012).

### *Data collection*

In order to explore the person with dementia's perspectives and experiences with attending the course, data were collected through individual semi-structured interviews with people with dementia after they had completed the 12-week course, and for each participant, a care partner was also interviewed. The interviews were arranged within 1–2 months after the 12-week course, and the participants and care partners were interviewed separately. The care partner interviews provided a complementary perspective in identifying elements of the intervention that could potentially support coping and adjustment to the condition, as they provided information about what they had observed the person with dementia saying or doing between sessions.

Participants were recruited via advertisements or through healthcare personnel who were otherwise not involved in the study. The interviews were recorded by handwritten notes, which were transcribed by the first author. A semi-structured interview guide with open-ended questions was developed as part of the main project (Supplemental online material). The participants and care partners were encouraged to share both positive and negative aspects of the intervention. Three of the authors (MK, MTG, IT) conducted the interviews, which lasted 30 to 60 minutes.

### Sample

The main project ran from 2014 to 2019 and included 108 persons with dementia allocated into 26 groups. In this study, a convenience sample was applied, which meant that all interviews accessible at the time the analysis started were included. The initial analysis, comprising 20 participants and 20 care partner interviews, revealed that the dialogue in the data material was a bit weak. To enhance information power the authors decided to include interviews from two of the project's sub-sites (Malterud et al., 2016). The sub-sites were chosen because they had completed the data collection. This resulted in a sample comprising 32 participants and 32 care partners from health promotion courses held in urban and rural areas throughout Norway's western, eastern, and northern regions. Aside from this intervention, none of these geographical areas offered a comparable healthcare service to people with early-stage dementia. All participants with dementia were home dwelling and had a diagnosis of Alzheimer's disease or vascular dementia. To ensure participants were in the early stages of their condition, the level of dementia were assessed at baseline using the Clinical Dementia Rating Scale (CDR; Morris, 1993). The socio-demographic characteristics of the sample are presented in Table 1. For further details on recruitment, inclusion and exclusion criteria, see, Testad et al. (2020).

### Patient and public involvement

A dedicated user group was formed to ensure patient and public involvement in this PhD project. The user group includes a person with dementia, a care partner, a representative from the Norwegian Health Association, and a retired nurse. The members of the user group attend workshops together with the researchers and contribute to analyzing the data and interpretation of the findings, as well as collaborating with the researchers on disseminating the results.

**Table 1.** Socio-demographic characteristics of sample.

| Selected variables  | Person with dementia<br>(n = 32) | Care partner<br>(n = 32) |
|---|----------------------------------|--------------------------|
| Sex   |                                  |                          |
| Male  | 15 (47%)                         | 14 (44%)                 |
| Female  | 17 (53%)                         | 18 (56%)                 |
| Age, mean (range)   | 77 (66–88)                       | 66 (46–86)               |
| Participant's marital status                              |                                  |                          |
| Married/domestic partner                                  | 21 (66%)                         |                          |
| Widowed   | 7 (22%)                          |                          |
| Divorced/separated  | 4 (12%)                          |                          |
| Living situation  |                                  |                          |
| Living with a spouse/domestic partner                     | 21 (66%)                         |                          |
| Living alone  | 11 (34%)                         |                          |
| Care partner's relationship with the person with dementia |                                  |                          |
| Spouse/domestic partner                                   |                                  | 21 (66%)                 |
| Daughter/son/grandchild                                   |                                  | 11 (34%)                 |
| Clinical Dementia Rating Scale Score                      |                                  |                          |
| 0.5 very mild dementia                                    | 20 (63%)                         |                          |
| 1 mild dementia   | 10 (31%)                         |                          |
| 2 moderate dementia                                       | 2 (6%)                           |                          |

Descriptive variables presented as count and percentages unless specified.

## Preunderstanding

The authors conducting the interviews (MK, MTG, IT), are all female and are registered nurses, experienced in interviewing persons with and without dementia. They are also researchers in health and social sciences. The last author (IT) developed the intervention. The remaining coauthors (VV, MM, ATH) are also all female and registered nurses and have extensive experience within the field of psychiatric nursing and group therapy.

## Analysis

The transcripts from the individual interviews were analyzed using systematic text condensation (Malterud, 2012). The analysis was performed in a four-step analysis, to organize, categorize and interpret the interviews. In the first step, all authors read through the transcripts individually to obtain an overall impression of the data and identify preliminary themes. After reading the transcripts several times, the authors met to discuss their identified themes and agreed on the preliminary main themes. The meaning units were then identified by each author. The meaning units were coded and organized into code groups, which were sorted into subgroups. Condensation and abstraction of the meaning units within each code were then performed. In the fourth and final step, content from the previous steps was re-contextualized into an analytical text, by the first author and presented to the rest of the authors. All authors agreed upon three main categories. A simplified example of the analytic approach is illustrated in Table 2.

In order to ensure trustworthiness in the analysis and the interpretation of the findings, the authors performed analyst triangulation, and the first author presented an overview of the analysis for the user group (Lincoln & Guba, 1985; Patton, 2015). The user group provided valuable feedback on the interpretation of the findings and highlighted points that needed to be emphasized in the presentation of the results. The results are presented using a proportion scale to indicate the proportion of participants who reported on a specific issue: A few = less than 25%, some = 25%–39%, several = 40%–60%, many = 61–75% and most = >75% (Maxwell, 2010; Neale et al., 2014).

## Ethical aspects

The study has received formal approval from the Regional Committees for Medical and Health Research Ethics, REC North (2013/2266) and was conducted in accordance with the Helsinki Declaration (World Medical Association, 2013). All participants received written and oral information prior to participation and on the day of the interview. Participants willing to take part volunteered written informed consent, with information that they could redraw from the study at any point and without reason. The trial protocol is registered with ClinicalTrials.gov: NCT03741543.

**Table 2.** Example of the analysis.

| Preliminary themes                      | Meaning units  | Subgroups  | Categories                                   |
|---|--|--|--|
| Information and learning about dementia | I believe she has learned more about it, she understands that having dementia entails more than just being forgetful<br>He is still driving, but at the course, he has learned the signs for when to give up his license, and for how long people with dementia can expect continuing to drive | Gaining an understanding   | Bridging the post-diagnostic information gap |
| Using the booklet                       | My mother uses the booklet as a reference – she refers to it. Other family members use it too and learn from it. My mother is proud of the booklet. Have learned and gained insight.<br>I still read the course booklet, the same does my family.  | Increasing care partners knowledge and understanding of dementia |  |

**Table 3.** ain categories and sub-categories

| Categories                                    | Sub-categories   |
|---|--|
| Bridging the post-diagnostic information gap  | Gaining an understanding<br>Increasing care partners knowledge and understanding of dementia                         |
| Facilitating health behavior changes          | Promoting family communication<br>Increased awareness and motivation   |
| New perspectives on living with the condition | Increased engagement with renewed confidence<br>Promoting social participation<br>Coming to terms with the diagnosis |

## Results

Three main categories along with six sub-categories emerged from the analysis (Table 3).

### *Bridging the post-diagnostic information gap*

Most participants reported enjoyment and benefits from attending the course. Learning about dementia and being able to discuss topics relevant to their situation was particularly highlighted. The course booklet served as an important resource for meeting their information needs and was used by several participants and their care partners between and after the sessions. The participants and care partners who read the booklet together reported that it contributed to increased communication within the family and facilitated future planning.

### *Gaining an understanding*

The need for information varied among the participants. Overall, most participants found the course modules and content basic but useful. A few participants reported that they wanted more information about dementia. Some participants and care partners talked about the course bridging the post-diagnostic information gap they were experiencing, as they had not received any information nor support following diagnosis. Most participants found the information provided on the course relevant to their situation, and they were able to familiarize themselves with the examples provided in the booklet:

The course was really useful, providing new insight and information (Person with dementia #1012).

The course gave the participant the opportunity to talk about and reflect upon topics arising from the 12 modules, which in turn contributed to increasing their understanding of dementia not only affecting short-term memory:

She realized that having dementia entails more than just being forgetful (Care partner #2032).

The course discussions concerning driving and dementia were highly appreciated by the carers, and for some participants, as those discussions helped ease coming to terms with eventually losing their driving privileges:

He is still driving, has learned the signs for when to give up his license, and for how long people with dementia can expect to continue to drive (Care partner #2017).

### *Increasing care partners knowledge and understanding of dementia*

The booklet each participant received during the first session was highly appreciated by both participants and care partners, they both found the information about dementia and different symptoms particularly useful, and also that each topic was related to their individual situation. Some reported using the booklet after completing the course, to revisit what they had learned at the 12-week course.

My mother uses the booklet as a reference – she refers to it. Other family members use it too and learn from it. My mother is proud of the booklet. She has learned and gained insight (Care partner #2046).

I still read the course booklet, the same does my family (Person with dementia #1027).

Several of the care partners sized the opportunity to use this resource. Some care partners shared photocopied pages from the booklet about dementia and delirium with friends and family members to increase their knowledge and understanding of dementia.

### ***Promoting family communication***

Many of the care partners also reported on using the booklet together with their family member with dementia and experienced reading the booklet together as a conversation starter, especially concerning difficult subjects. This enabled conversations about important aspects of the condition, addressing future healthcare service needs and how to adapt and cope with the condition, which they otherwise would not have talked about or had difficulties talking about:

The booklet gave us an opportunity to talk about the future, what we anticipate and how we can cope with this (Care partner #2017).

He often revisits the booklet. We have read it together and talked about it. The booklet has been of great help (Care partner #2012).

### ***Facilitating health behavior changes***

Learning about the importance of health promotion contributed to increasing the participants' awareness, motivating them to maintain a healthy lifestyle and reengage in cognitively stimulating activities.

### ***Increased awareness and motivation***

The health promotion aspect of the intervention was well-received by the participants. Many participants gained an increased understanding of the importance of healthy eating habits and regular physical activity. The care partners reported that their family member was taking on a more active role in preparing meals and was more aware of maintaining fluid balance, through drinking enough water during the day and staying physically active:

We have a jug of water available at all times. This was one of the lessons we learned from the 12-week course. Before this, she only drank coffee, rarely any water (Care partner #2026).

He is the one that encourages hiking now, and is the driving force of our hikes (Care partner #2025).

Participants who had already established health routines and engaged in physical activities and eating healthy reported that the course provided validation and made them more motivated to continue staying healthy.

### ***Increased engagement with renewed confidence***

The course appeared to have a stimulating and motivating effect on the participants in engaging them in cognitively stimulating activities, including crossword puzzles, sudoku, reading and dancing. Both participant and care partner interviews reported that several participants found renewed confidence and motivation to reengage in former activities or hobbies. Some participants had starting to knit and solve crossword puzzles after the sessions, instead of resting.

I have started to knit again (Person with dementia #1031).

The care partners had also observed this:

She has been feeling well on Tuesdays after returning from the 12-week course. Instead of settling down and resting, she has started to knit and solve crossword puzzles (Care partner #2014).

The interviews also revealed that some participants had been feeling down before attending the course, and the course had contributed to the participant's well-being and positively impacted their mood:

I was in a bad place and feeling down before attending the 12-week course. Attending the course raised my spirits (Person with dementia #1001).

### ***New perspectives on living with the condition***

Through joint group experience, support and having a place to talk about their condition and meeting others in the same situation contributed to promote social participation, ease the process of coming to terms with the diagnosis and taking control over the situation.

### ***Promoting social participation***

Meeting others in the same situation was a valued aspect of the course. Most participants felt that the other group members were friendly, the course had a social aspect, and they got a chance to talk about their condition without being judged. Two participants said:

Having the opportunity to listen to and meet others in the same situation was good. Listening to what the other group members had to say. It has been very okay. We were able to talk about the condition without feeling the need to hide our challenges (Person with dementia #1204).

We learned to verbalize and discuss what it means to have this condition (Person with dementia #1044).

Many participants mentioned that they were glad there were not too many participants in the group; small groups ensured that everyone got to talk and promoted a good dialogue consisting of both jokes and serious talk.

The fact that the group was small helped the dialogue. The positive attitude of some group members rubbed off on the others (Person with dementia #1031).

Over the duration of the course, most care partners had noticed that the participants enjoyed the social aspects of the course. Having a place to go to every week was important and gave the participants a sense of being part of a community.

Some of the care partners also reported that after the course, the participant was more open and motivated to attend a daycare center and became more aware of the importance of social stimuli:

After attending the 12-week course, she is more motivated to attend the daycare center. She said that it is important to go there and to stay socially active (Care partner #2032).

Despite the fact that most participants felt that meeting others in the same situation was positive, some pointed out that it was difficult to get to know the other participants; it took a while before the group members were comfortable with each other and people opened up about their challenges. Some participants found the composition of the groups to be too mixed in terms of marital status, as the challenges in day-to-day life when living with dementia is different for people living alone compared to people living with their spouse. Furthermore, some of the participants felt that meeting others where the condition had progressed more than for themselves made them worry about how their own condition would progress and created anxiety for the future. One participant said:

Meeting others who were more ill than I was a shock (Person with dementia #1027).

### ***Coming to terms with the diagnosis***

Both care partner and participants' interviews showed that coming to terms with the diagnosis before attending the 12-week course was challenging for the participants. From the care partners' perspective, one of the main challenges resulting from this was the participant's refusal to receive home-based care



or attend a daycare center. Which in turn made the care partner worried about how the participant would manage their everyday life at home as the condition progresses. Over the duration of the course, many of the care partners had observed a positive change in the participant's perceptions of the condition. One care partner stated that the course had played a massive part in helping the participant come to terms with her diagnosis and stop fighting against it:

It has been good for her; it has been tiring to fight against accepting it. I think the 12-week course has contributed big time in that regard (Care partner #2032).

It has been positive to talk about dementia (Person with dementia #1032).

Several care partners also pointed out that they noticed the participant being less ashamed of having dementia after meeting other people with the diagnosis. After attending the course, the participants were more at ease and had started to accept the situation.

He is starting to realize that one day he will have to hand in his driver's license – he doesn't want to hurt anyone (Care partner #2017).

I feel more content now, the condition is less intimidating (Person with dementia #1046).

Accepting the situation contributed to the participants being more open, and it was now possible to have a conversation about dementia:

My mother has started to accept the diagnosis. She is open about it, and she no longer blames the stroke for her situation (Care partner #2023).

Feeling less intimidated by the condition, many had also found the strength and courage to tell their family and friends about having dementia. Several participants had also been observed talking openly to others around them about the positive aspects of attending the course and learning about dementia. One participant said:

I started talking about the condition after the 12-week course. It felt good to say it (Person with dementia #1044).

The care partners talked about how acceptance of the diagnosis had empowered the participants and enabled them to take more control over their situation, taking measures to sort out and address future challenges:

He has started to realize what the condition might mean to him. He has delegated some of his economic responsibilities to his grandchildren. Thinking of how short life really is. As a result of attending the 12-week course, he has now started to come to terms with the diagnosis (Care partner #2033).

However, some participants did not come to terms with their diagnosis after completing the 12-week course and care partners reported challenges around denial and taking in the information provided on the course.

'She has not accepted the diagnosis and continues to deny that she has any problems. It was necessary to inform the neighbours that she would no longer be able to help them look after their cat' (Care partner #2019).

## Discussion

The aim of this study was to explore the experiences of people with early-stage dementia attending a 12-week health promotion course, and identify elements of the intervention potentially contributing to coping and adjustment to the condition. The findings demonstrate that the intervention was well-received by the participants and that they enjoyed various aspects of attending the course, including learning about the condition, focusing on health-promoting activities, and meeting others in the same situation. However, some aspects were described as challenging, which is important to take into consideration and can affect coping and adjustment to the condition. These included group members being in different stages of the condition and different stages of processing the diagnosis, and it took

a while before the group members developed trust in one another and opened up about their challenges. The health promotion intervention's most apparent benefits were educating and supporting people with dementia. In line with previous research (Frost et al., 2020; Wheatley et al., 2021), our findings describe a post-diagnostic information gap, and the majority of participants did not receive any healthcare services (Testad et al., 2020). Following diagnosis, many people do not have an immediate need for healthcare services. However, they still need information and support in order to cope with the diagnosis and adjust to and manage the changes in day-to-day life (Górska et al., 2018; Norwegian Ministry of Health and Care Services, 2015).

Another promising feature of the 12-week course was the information and a discussion about how the condition over time will affect people with dementia's driving skills and how eventually, they will have to give up driving. This topic was highly appreciated by the care partners, and some reported that the participant started to come to terms with eventually losing their driving privileges. Discussions concerning whether to stop driving or not after being diagnosed with dementia can cause a lot of distress for both the person with dementia and their care partner (Holden & Pusey, 2020). For many people, driving provides a sense of independence and flexibility; thus, giving it up can create stress and sadness. Receiving information and being involved in the decision to give up driving can empower the person with dementia and ease the process of coping and adjusting to this loss (Holden & Pusey, 2020).

A key finding from this study was the importance of the booklet. Talking about how the condition will affect day-to-day life and the future can be difficult within the family. The person with dementia may be reluctant to think too far ahead while still adapting to the diagnosis, or the family may feel uncomfortable themselves, and are afraid to upset the person they are caring for (Kelly & Innes, 2016). This way, the participants in the health promotion course received the information first-hand and were the ones to bring the resource back to the care partner (Testad et al., 2020). The participants were also encouraged, at the end of each session, to write down a goal of what is important to them related to the session's topic. These aspects may have played a significant role in empowering the participants to take control of their situation and opening up conversations around topics of importance for the participant. Reading through the booklet together as a family was reported to be a conversation starter and enabled conversations about important aspects of the condition and planning for the future. Some care partners used the information in the booklet to educate the rest of the family. Being able to talk openly about the process and future challenges with family members in the early stages of the condition can be empowering for everyone involved (Kelly & Innes, 2016).

The health promotion aspect of the course was well-received by the participants. The findings demonstrate that the participants' perception of health-related behavior, belief in their own abilities to engage in a healthy lifestyle and health-related behavior changed as a result of attending the course. In line with previous research (Kelly & Innes, 2016; Sprange et al., 2021), the participants also found renewed confidence and motivation to reengage in cognitive activities. Increased belief in one's own abilities resonates with Bandura's (1997) theory on self-efficacy. Self-efficacy has been identified as an important component in educational programs in order to engage participants in health-promoting behavior, managing and adjusting to life with a chronic condition (Bandura, 1997; Holloway & Watson, 2002). Most people with dementia have coexisting conditions, and improving health-related behaviors is therefore especially beneficial and has the potential to contribute to better physical function and overall health, as well as preventing unnecessary hospitalization (Livingston et al., 2020).

The social aspect of the course and the opportunity to meet others in the same situation was valued by the participants. In line with the findings of Skov et al. (2022), our findings indicate that being a part of a group and socializing may have a carry-over effect in terms of participants being more positive about attending other services that provide social contact. National strategies for dementia emphasize the importance of creating a meeting arena for people with dementia (Norwegian Ministry of Health and Care Services, 2015). Having a place to meet peers can reduce both isolation and condition burden (Skov et al., 2022). However, it is critical to remember that people with dementia are not a homogeneous group and may only have their diagnosis in common, which can impact how much they benefit from meeting

other group members, and, as the findings demonstrate, living alone versus living with a spouse significantly alters the experience of living with dementia. Furthermore, the findings revealed that grouping participants at different stages of the condition might lead to increased anxiety. Skov et al. (2022) reported that meeting peers who were perceived to be in better health provided a sense of optimism for the participants. Meeting peers in worse physical or cognitive health than themselves, on the other hand, served as a reminder of their condition's inevitable progression (Skov et al., 2022).

Many of the care partners reported that their family member was experiencing difficulties accepting their diagnosis before attending the course, and the care partners found this particularly difficult. Challenges related to accepting the diagnosis can cause anxiety and tension within the family (Sims & McCrum, 2012), thus making it more challenging to adjust to the condition and manage their daily lives and the future. Denial can be related to the organic changes that have occurred in the brain as a result of their condition, but it can also be a coping mechanism. Denial, according to Lazarus and Folkman (1984), is an emotion-focused coping mechanism that people adopt to alleviate the discomfort of the situation, and it can be a helpful short-term response in order to adjust to a new situation. Learning about the condition and meeting others in the same situation can ease the process of coming to terms with the diagnosis and change one's perception of how to cope with the situation (Górska et al., 2018; Taylor, 2006). For some participants in this study, attending the 12-week course appeared to ease the process of accepting the diagnosis. Consistent with the findings from Øksnebjerg et al. (2020) study, the participants found the condition less intimidating and were able to verbalize their diagnosis, thus making the lives of both the participants and the care partner easier in terms of accepting help and support.

This study suggests important elements for future group interventions. As the findings indicate, the composition of the group must be considered. While it is impossible to match group members exactly, we suggest selecting group members based on shared interests and marital status, if possible, to ensure that the group consists of more than one person living alone. Given the time required for group members to develop trust in one another and for individuals to open up about their challenges, we recommend that these types of group interventions be offered for a certain period of time.

### **Trustworthiness**

To enhance trustworthiness, we followed the guidelines outlined by Lincoln and Guba (1985). Credibility was achieved by increasing the number of interviews, ensuring a heterogeneous demographic sample, and the triangulation of participant and care partner interviews. To reduce researcher bias and ensure confirmability, analyst triangulation was applied, and all authors were involved in analyzing the data, and the final step and interpretation of the findings were also discussed with a user group. The paper provides a description of the study context, selection of participants, socio-demographic characteristics of the sample, the data collection procedure, and the data analysis, which allows other researchers to assess the transferability to similar contexts.

### **Strengths and limitations**

There are some limitations to this study that should be taken into consideration. The interviews were recorded by handwritten notes, which can affect the accuracy of the data collected, as it is impossible to write everything down and the researcher is bound to make selections on what is relevant or not (Sandelowski, 1994). However, the interviewers were instructed to prioritize verbatim quotes and to write a summary of the interview afterward, without any selection or interpretation. Including the care partner's perspective was a strength of this study, as the care partner and person with dementia form a dyadic relationship in which they mutually influence and strengthen each other (Lyons & Lee, 2018), although the care partners were not involved in the intervention. As a result, the care partner interviews provided valuable information on how the intervention can aid in coping and adjustment to living with early-stage dementia. The participants in this study were in the mild to moderate stages of dementia (Testad et al., 2020) and as the nature of the condition

involves memory difficulties, some participants had difficulty elaborating on their experiences, hence the participant quotes in the results section are at times brief. Despite the limitations, this study comprises first-hand experiences of people with dementia, participants from both rural and urban areas in three different parts of Norway, and provides new and valuable insight into participants' experiences of attending a health promotion intervention for people with dementia that warrants further investigation.

Many aspects of the present study require further exploration to gain more knowledge on how to best support people with dementia and their care partners to cope with the condition. Direct observations of the groups could be a valuable method for gaining a better understanding of the group process and changes over the duration of the course.

## Conclusion

The health promotion intervention was well-received by the participants, and learning about the condition first-hand enabled participants to take more control over their new situation. Based on our findings, we argue that the 12-week course can help close a vital service gap, meet the needs of people in the early stages of dementia, contribute to adjustment and coping with the condition by easing the process of accepting the diagnosis and promoting healthy behaviors. Dementia is a life-changing and disabling condition and unless we find a cure or effective treatment, it is of utmost importance to find ways to educate and support people with early-stage dementia in order to improve their adjustment to and coping with the condition.

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## Data availability statement

The data analysed during this study are available from the corresponding author upon reasonable request.

## References

- Bandura, A. (1997). *Self-efficacy: The exercise of control*. Freeman.
- Bossen, A. L., Specht, J. K. P., & McKenzie, S. E. (2009). Needs of people with early-stage Alzheimer's disease: Reviewing the evidence. *Journal of Gerontological Nursing*, 35(3), 8–15. <https://doi.org/10.3928/00989134-20090301-01>

- Buettner, L., & Fitzsimmons, S. (2009). Promoting health in Alzheimer's disease: Evaluation of a 12-week college course for individuals with a new diagnosis. *Journal of Gerontological Nursing*, 35(3), 39–49. <https://doi.org/10.3928/00989134-20090301-02>
- Fitzsimmons, S., & Buettner, L. L. (2003). Health promotion for the mind, body, and spirit: A college course for older adults with dementia. *American Journal of Alzheimer's Disease & Other Dementias*, 18(5), 282–290. <https://doi.org/10.1177/153331750301800504>
- Frost, R., Walters, K., Wilcock, J., Robinson, L., Denning, K. H., Knapp, M., Allan, L., & Rait, G. (2020). Mapping post-diagnostic dementia care in England: An e-survey. *Journal of Integrated Care*, 29(1), 22–36. <https://doi.org/10.1108/JICA-02-2020-0005>
- Górska, S., Forsyth, K., Irvine, L., Maciver, D., Prior, S., Whitehead, J., Flockhart, J., Fairnie, J., & Reid, J. (2013). Service-related needs of older people with dementia: Perspectives of service users and their unpaid carers. *International Psychogeriatrics*, 25(7), 1107–1114. <https://doi.org/10.1017/S1041610213000343>
- Górska, S., Forsyth, K., & Maciver, D. (2018). Living with dementia: A meta-synthesis of qualitative research on the lived experience. *The Gerontologist*, 58(3), e180–e196. <https://doi.org/10.1093/geront/gnw195>
- Holden, A., & Pusey, H. (2020). The impact of driving cessation for people with dementia—An integrative review. *Dementia* 20(3), 1105–1123. <https://doi.org/10.1177/1471301220919862>
- Holloway, A., & Watson, H. E. (2002). Role of self-efficacy and behaviour change. *International Journal of Nursing Practice*, 8(2), 106–115. <https://doi.org/10.1046/j.1440-172x.2002.00352.x>
- Kelly, F., & Innes, A. (2016). Facilitating Independence: The benefits of a post-diagnostic support project for people with dementia. *Dementia*, 15(2), 162–180. <https://doi.org/10.1177/1471301214520780>
- Lazarus, R. S., & Folkman, S. (1984). *Stress, appraisal and coping*. Springer Publishing Company.
- Lincoln, Y. S., & Guba, E. G. (1985). *Naturalistic inquiry*. Sage.
- Livingston, G., Huntley, J., Sommerlad, A., Ames, D., Ballard, C., Banerjee, S., Brayne, C., Burns, A., Cohen-Mansfield, J., Cooper, C., & Costafreda, S. G. (2020). Dementia prevention, intervention, and care: 2020 report of the Lancet Commission. *The Lancet*, 396(10248), 413–446. [https://doi.org/10.1016/S0140-6736\(20\)30367-6](https://doi.org/10.1016/S0140-6736(20)30367-6)
- Lyons, K. S., & Lee, C. S. (2018). The theory of dyadic illness management. *Journal of Family Nursing*, 24(1), 8–28. <https://doi.org/10.1177/1074840717745669>
- Malterud, K. (2012). Systematic text condensation: A strategy for qualitative analysis. *Scandinavian Journal of Public Health*, 40(8), 795–805. <https://doi.org/10.1177/1403494812465030>
- Malterud, K., Siersma, V. D., & Guassora, A. D. (2016). Sample size in qualitative interview studies: Guided by information power. *Qualitative Health Research*, 26(13), 1753–1760. <https://doi.org/10.1177/1049732315617444>
- Martin, F., Turner, A., Wallace, L. M., Stanley, D., Jesuthasan, J., & Bradbury, N. (2015). Qualitative evaluation of a self-management intervention for people in the early stage of dementia. *Dementia*, 14(4), 418–435. <https://doi.org/10.1177/1471301213498387>
- Maxwell, J. A. (2010). Using numbers in qualitative research. *Qualitative Inquiry*, 16(6), 475–482. <https://doi.org/10.1177/1077800410364740>
- Morris, J. C. (1993). The Clinical Dementia Rating (CDR): Current version and scoring rules. *Neurology*, 43(11), 2412–2414. <https://doi.org/10.1212/WNL.43.11.2412-a>
- Neale, J., Miller, P., & West, R. (2014). Reporting quantitative information in qualitative research: Guidance for authors and reviewers. *Addiction*, 109(2), 175–176. <https://doi.org/10.1111/add.12408>
- Norwegian Ministry of Health and Care Services. (2015). *National dementia plan 2020: A more dementia friendly society*. <https://www.regjeringen.no/en/dokumenter/dementia-plan-2020/id2465117/>
- Øksnebjerg, L., Woods, B., Vilsen, C. R., Ruth, K., Gustafsson, M., Ringkøbing, S. P., & Waldemar, G. (2020). Self-management and cognitive rehabilitation in early stage dementia—merging methods to promote coping and adoption of assistive technology. A pilot study. *Aging & mental health*, 24(11), 1894–1903. <https://doi.org/10.1080/13607863.2019.1625302>
- Patterson, C. (2018). *World Alzheimer Report 2018: The state of the art of dementia research: New frontiers*. Alzheimer's Disease International (ADI).
- Patton, M. Q. (2015). *Qualitative research & evaluation methods: Integrating theory and practice* (4th ed.). Sage.
- Prince, M., Albanese, E., Guerchet, M., & Prina, M. (2014). *World Alzheimer Report 2014: Dementia and risk reduction: An analysis of protective and modifiable risk factors*. Alzheimer's Disease International (ADI).
- Quinn, C., Toms, G., Anderson, D., & Clare, L. (2015). A review of self-management interventions for people with dementia and mild cognitive impairment. *Journal of Applied Gerontology*, 35(11), 1154–1188. <https://doi.org/10.1177/0733464814566852>
- Quinn, C., Toms, G., Jones, C., Brand, A., Edwards, R. T., Sanders, F., & Clare, L. (2016). A pilot randomized controlled trial of a self-management group intervention for people with early-stage dementia (The SMART study). *International Psychogeriatrics*, 28(5), 787–800. <https://doi.org/10.1017/S1041610215002094>
- Richeson, N. E., Boyne, S., & Brady, E. M. (2007). Education for older adults with early-stage dementia: Health promotion for the mind, body, and spirit. *Educational Gerontology*, 33(9), 723–736. <https://doi.org/10.1080/03601270701364438>

- Sandelowski, M. (1994). Focus on qualitative methods. Notes on transcription. *Research in Nursing & Health*, 17(4), 311–314. <https://doi.org/10.1002/nur.4770170410>
- Sims, D., & McCrum, T. (2012). Measuring the benefits. *Journal of Dementia Care*, 20(4), 20–22. <http://scholar.google.com/scholar?hl=en&q=SimsD.%2C+McCrumT.+%282012%29.+Measuring+the+benefits.+Journal+of+Dementia+Care%2C+20%2C+20%E2%80%9322>
- Skov, S. S., Nielsen, M. B. D., Krølner, R. F., Øksnebjerg, L., & Rønbo Lauridsen, S. M. (2022). A multicomponent psychosocial intervention among people with early-stage dementia involving physical exercise, cognitive stimulation therapy, psychoeducation and counselling: Results from a mixed-methods study. *Dementia*, 21(1), 316–334. <https://doi.org/10.1177/14713012211040683>
- Sprange, K., Beresford-Dent, J., Mountain, G., Thomas, B., Wright, J., Mason, C., & Cooper, C. L. (2021). Journeying through dementia randomised controlled trial of a psychosocial intervention for people living with early dementia: Embedded qualitative study with participants, Carers and interventionists. *Clinical Interventions in Aging*, 4(16), 231–244. <https://doi.org/10.2147/CIA.S293921>
- Taylor, S. E. (2006). *Health psychology* (6th ed.). McGraw-Hill.
- Testad, I., Kajander, M., Gjesten, M. T., & Dalen, I. (2020). Health promotion intervention for people with early-stage dementia: A quasi-experimental study. *Brain and Behaviour*, 10(12), e01888. <https://doi.org/10.1002/brb3.1888>
- Wheatley, A., Bamford, C., Brunskill, G., Booi, L., Denning, K. H., & Robinson, L. (2021). Implementing post-diagnostic support for people living with dementia in England: A qualitative study of barriers and strategies used to address these in practice. *Age and Ageing*, 50(6), 2230–2237. <https://doi.org/10.1093/ageing/afab114>
- World Medical Association. (2013). World Medical Association Declaration of Helsinki: Ethical principles for medical research involving human subjects. *JAMA*, 310(20), 2191–2194. <https://doi.org/10.1001/jama.2013.281053>