

# BMJ Open I need to be who I am: a qualitative interview study exploring the needs of people with dementia in Norway

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## ABSTRACT

**Objective** Many people with dementia receive community services. These services are often based on the needs of informal caregivers and professional caregivers' assessment. User involvement and participation are main objectives in the Norwegian National Dementia Plan 2020. To enhance user involvement and individual tailoring of healthcare services, more information is required about the needs of people with dementia. The aim of this study was to explore the experienced needs of people with dementia in order to facilitate user involvement in provided services.

**Methods** An explorative cross-sectional study design was used. We performed semistructured interviews with people with dementia who were recruited from all regions of Norway. The sample comprised 35 participants diagnosed with dementia. The interviews were audio-recorded and transcribed, and the data material was analysed using a qualitative content analysis.

**Results** Three main categories emerged from the interviews: (1) to stay connected; (2) to be active and participate; and (3) to live for the moment. The overarching theme was: the need to be who I am.

**Conclusions** People with dementia participating in the study were heterogeneous regarding wants and requirements. Most of them expressed the need and wish to hold on to who they are. Close and robust relations with family and friends can give significant support to people with dementia. However, living with dementia might put considerable strain on relations. Services should provide support to enhance relationships, encourage existing networks to remain stable and facilitate participation in meaningful activities for people living with dementia.

## INTRODUCTION

Most people with dementia will receive help from community services such as home services, day-care centres and stays in residential homes and nursing homes during the course of dementia. Traditionally, these services have been offered according to physical disabilities and need for practical help and initiated in line with informal carers' needs and professional care givers' assessments. There is increasing recognition that people with dementia are capable to express their own views, needs and concerns.<sup>1,2</sup> The importance of incorporating the subjective

## Strengths and limitations of this study

- Participants were heterogeneous regarding gender, age, interests, life situation, living arrangements, severity of dementia and function.
- All the interviews were carried out by the same person to ensure continuity.
- People with dementia who had not been in contact with healthcare services were not included and this may be a limitation to generalisation of the results.

experience of people with dementia in research in order to better meet their needs for care has been highlighted.<sup>3–7</sup> Acknowledging and responding to the needs of people with dementia is of great importance as unmet needs may lead to decrease in quality of life, depression, behavioural problems and dissatisfaction with services.<sup>8–10</sup> Previous research reveals that people with dementia have more health needs than the general population.<sup>11,12</sup> Health needs are related to the treatment, control or prevention of a disease, illness, injury or disability and the care or aftercare of a person with these needs.<sup>13</sup> To be sensitive for individual needs is a precondition for person-centred care (PCC), a world-wide care approach of choice to develop high-quality dementia care.<sup>14–16</sup> PCC can be a tool to empower people with dementia to take independent choices in life and to engage in decision making with regard to provision of care and activities.<sup>14–16</sup> Person-centredness is an approach to practice that is established through healthful relationships between care providers, care recipient and significant others in the care recipients' lives. It is underpinned by values of respect for persons, individual right to self-determination, mutual respect and understanding.<sup>17</sup>

Met and unmet needs of people with dementia have been explored earlier; however, often through quantitative studies by the use of questionnaires. According to an American study that used John Hopkins Dementia Care



Needs Assessment, unmet needs of community dwelling people with dementia were most common in domains of personal and home safety, general health and medical care and meaningful activities.<sup>18</sup> A study from the UK used the Camberwell Assessment of Needs for the Elderly (CANE) in a similar community-dwelling population and reported unmet needs in domains of company, meaningful activities and psychological distress.<sup>19</sup> Hancock *et al* investigated met and unmet needs in people with dementia living in residential care. They also used CANE and the results revealed multiple needs, most of which were met by the care home, local services or the person's social network.<sup>20</sup> However, residents still had numerous unmet needs, most commonly for stimulating daytime activities or company. Even though needs in people with dementia are individual and highly influenced by the social situation, living arrangement, care need and severity of the disease, these results show that meaningful activities and company is important to many across heterogeneity.

When exploring the experience of needs, it can be argued that qualitative methods are more appropriate since the participants can express themselves freely and not merely through predetermined alternatives. Qualitative research methodologies also focus more on subtleties in the data and less on metrics and thus enables a more detailed exploration. A few studies have explicitly explored the needs of different groups of people with dementia through qualitative interviews. Barret *et al* outlined the experiences and needs of lesbian, gay, bisexual and transgendered (LBTG) Australians living with dementia.<sup>21</sup> Their participants reported needs of social support and understanding about their situation. The importance of friendships with others in the LBTG community was also communicated. Read *et al* explored the experiences of people diagnosed with dementia and studied their expectations of support needs and how they wished to live their lives.<sup>22</sup> They revealed that people with dementia had limited knowledge of a likely dementia trajectory and found it difficult to identify their future support needs.

Several other studies have indirectly described needs through interviews exploring the experience of living with dementia.<sup>23–25</sup> A review of qualitative studies reported that needs of older people with dementia were less related to instrumental needs and more associated with how they cope with the disease and well-being. The most frequently reported needs of people with dementia were: need to be accepted and respected, the need to find adequate strategies to cope with disabilities and the need to come to terms with their situation.<sup>26</sup> Stephan *et al* studied barriers and facilitators in relation to the access to, and use of, formal healthcare in eight European countries through focus group interviews.<sup>4</sup> People with dementia described a need of information about their condition and about available services, particularly at the point of diagnosis. They also clearly expressed their wish to remain independent and in control for as long as possible and, thus, a wish to be involved in decision-making about their care.

It emerged that formal care was considered a threat to individual independence by people with dementia and that it would only be accepted if it was perceived as absolutely necessary. The same study demonstrated that an appointed key contact person is crucial for the access to and use of dementia care and further reported that a solid social network can postpone the use of formal dementia care.<sup>27</sup> These findings support the results from Beattie *et al* who did in-depth interviews with young people with dementia and emphasised that it is important that health and social care professionals engage with and consult these persons about their experiences and what they want from dementia care services.<sup>28</sup>

The need for help and care increases as the dementia condition progresses, and these needs become extensive in the latter severe stage of dementia. One of the main aims of the Norwegian National Dementia Plan 2020 is to ensure user involvement and participation. To enhance user involvement and individual tailoring of the healthcare services, knowledge concerning the needs of people with dementia is called for. The main objective of this study was to explore the experienced needs of a people living with dementia.

## METHOD

### Design

This was a qualitative descriptive study using semistructured interviews with open-ended questions in line with Kvale and Brinkmann.<sup>29</sup> The participants were people with dementia who may experience problems with expressing specific needs. For this reason, most conversations focused on what the person considers important to him/her. This will advise us on needs in these persons.

### Participants and recruitment procedure

A group of 17 healthcare professionals who provided services for people with dementia received oral and written information about the project and invited participants to take part in the study. These healthcare professionals worked in primary and specialised healthcare in urban and rural areas in all regions of Norway. They contacted eligible candidates among their service users and asked for their permission to let the project leader contact them. The project leader provided further information and asked for their consent to take part in the study. We included people diagnosed with dementia less than 18 months prior to the interview and people who had applied for, or received, residential care during the last 4 months. Initially, 38 participants agreed to take part in the study after the first telephone conversations, but three withdrew their consent prior to the interview. In one instance the participant expressed an unwillingness to talk to the interviewer. The interview was aborted swiftly, and audio file destroyed.

The final sample comprised 35 persons with dementia, 19 women and 16 men, aged between 59 and 92 years. All participants had received a dementia diagnosis

from primary or specialised care. The type of dementia disorder and severity were not recorded as this information was outside the scope of the study, however, the reported need for services can to a certain degree advise us on the severity of dementia condition. About half of the participants (n=16) lived at home and did not use any healthcare services. Most of them were mildly affected by the dementia condition. Fourteen received services such as home-based care, day care or respite stays at nursing homes. The participants who received these services

experienced more severe symptoms from dementia. Five participants who lived in nursing homes were all severely affected by dementia. The participant characteristics are presented with fictive names in [table 1](#).

### Data collection

The interviews were supported by a semistructured interview guide (online supplementary appendix A) and carried out by the first author. All of them, except two, took place in the persons' home. The latter two were carried

**Table 1** The participants

Name*	Age group	Marital status	Interview setting	Services
William	75–79	Married	Alone	No services
Sofie	85–89	Married	Alone	No services
Anna	85–89	Married	Next of kin present	No services
Kari	70–74	Cohabiting	Next of kin present	No services
Mia	70–74	Cohabiting	Alone	No services
Jacob	70–74	Lives alone	Alone	No services
Robert	80–84	Lives alone, married	Alone	No services
Billy	80–84	Married	Alone	No services
Liss	80–84	Married	Alone	No services
Ella	65–59	Married	Next of kin present	No services
Julie	75–79	Married	Alone	No services
Jan	65–69	Cohabiting	Together	No services
Olivia	55–59	Married	Alone	No services
Karl	70–74	Cohabiting	Next of kin present	No services
Arthur	75–79	Married	Alone	No services
Marie	65–69	Married	Alone	No services
Hugo	60–64	Married	Alone	Day care centre
Harry	85–89	Married	Alone	Nursing home
Emma	85–89	Widowed	Alone	Home care
Linda	80–84	Married	Alone	Day care centre
Amelia	90–94	Widowed	Alone	Sheltered care
Finn	80–84	Married	Alone	Respite stays
Mona	90–94	Widowed	Next of kin present	Nursing home
Lisa	85–89	Widowed	Alone	Day care centre
Kristian	60–64	Cohabiting	Next of kin present	Sheltered care
Erik	80–84	Married	Alone	Day care centre
Johanne	90–94	Married	Alone	Nursing home 50%
Hannah	85–89	Widowed	Alone	Home care
Greta	90–94	Widowed	Next of kin present	Nursing home.
Thomas	80–84	Married	Alone	Respite care
Alice	85–89	Married	Alone	Nursing home
Victor	75–79	Lives alone	Next of kin present	Home care
Frank	70–74	Married	Next of kin present	Day care centre
Isabella	80–84	Widowed	Next of kin present	Nursing home
Oscar	65–69	Married	Alone	Home care

\*Fictional names to assure anonymity.

out in day care and nursing home during a respite stay. In 12 of the interviews, the person with dementia was interviewed with their partner or a family member present. This was mainly due to communication challenges and efforts to create assurance for the person with dementia. The interviews lasted between 20 and 90 min and were digitally audio recorded with an Olympus VN5500 Dictaphone. Sound files and transcripts were anonymised and stored in a secure database. In order to ensure the quality of the interview guide and make eventual changes, the coauthors read a transcript of the first two interviews before the remaining interviews were performed. No changes were considered necessary. The transcriptions were performed verbatim.

We used the Standards for Reporting Qualitative Research (SRQR) checklist when writing this article.<sup>30</sup>

No additional data available.

### Patient and public involvement

It was not appropriate to involve people with dementia in the design, or conduct, or reporting, or dissemination plans of our research. Hence, no patients were involved.

### Preunderstanding

First author (EWT), who conducted the interviews, is a physiotherapist, concerned with research on physical exercise for people with dementia. The two coauthors (SE and AMMR) are both registered nurses and researchers in health and social sciences. They have extensive experience within the field of dementia care.

### Ethical issues

In most instances (n=31), the first contact was made with next of kin who received information about the project over the phone. In the other instances, first contact was made with the person with dementia. If parties agreed, an appointment was made to meet for an interview. In the beginning of the meeting, before commencing the

**Table 3** Results. Overview categories and subcategories

Theme	The need to be who I am		
Category	To stay connected	To be active and participate	To live in the moment
Subcategories	The importance of close relationships	To experience joy and enthusiasm	
	The vulnerable dependence on others	To experience mastery and meaning in everyday life	
	Dealing with shifting social networks		

interview, the person with dementia were given oral and written information about the project followed by an opportunity to consent or decline participation. The participant was also distinctly informed about his/her possibility to terminate the interview at any time. The participants were considered competent to consent by contact person, next of kin and the interviewer. The transcribed interviews were de-identified and all names in this article are fictional.

### Data analysis

Transcribed interviews were analysed according to qualitative content analysis inspired by Graneheim and Lundman.<sup>31</sup> The data were in part managed by using the software Nvivo V.11.

The analysis was performed in six stages by EWT. The coauthors took part in stage 4–7. Stage 1: preparation phase where all transcripts were read several times to uncover the main themes and provide a sense of the wholeness of each interview. Each transcribed interview was identified as a unit of analysis. Stage 2: the texts were divided into meaning units. Stage 3: the meaning units were condensed into descriptions close to the text. Stage

**Table 2** Examples of the analysis of interviews

Quotes	Codes	Subcategory	Category
In a way, I don't need help, as long as I have my husband and children. (Jane) We make a good match. She gives me just enough room. I think she adjusts. She knows me so well. (Billy)	My partner provides security and stability. He/she understands what I need.	The importance of close relationships	Staying connected
I feel like ... to bother my husband about taking me here and there ... Even though he says he doesn't mind, it takes an effort. Earlier ... I just got in the car and drove anywhere. (Julie) I have always been the one who helps others. To be the one who asks for it; that's a problem. (Robert)	To get things done, I feel I have to rely on other people more than before and it makes me feel sad.	The vulnerable dependence on others	
I have gotten more active after I realized that I am not coping with the things around me. We have gone for walks together for a long time, but now that I walk every single day, I walk fast, and it is absolutely heavenly! (Hugo)	When I am physically active, I feel good	To experience joy and enthusiasm	To be active and participate
I don't want to cultivate this. Still I feel healthy, vigorous and 'with it'. (Jacob)	I feel well and do not want to give attention to the dementia condition		To live in the moment

4: the meaning units were extracted and labelled with codes. Stage 5: codes were compared based on similarities and differences and grouped into subcategories. Stage 6: the subcategories were gathered and abstracted as categories. Stage 7: in the *comprehensive understanding phase*, the categories were summarised and reflected on to reach a presentation of the text as one overall, latent theme. Examples from the analysis process is shown in [table 2](#).

## RESULTS

The main objective of this study was to explore needs of people with dementia. Three main categories emerged from the interview analysis: (1) to stay connected; (2) to be active and participate; and (3) to live in the moment ([table 3](#)).

### To stay connected

The category 'to stay connected' was described by the participants from three perspectives: (1) the importance of close relationships, (2) the vulnerable dependence on others and (3) dealing with shifting social networks.

#### Importance of close relationships

Most of the participants talked about the importance of their close relationships such as partner, children, grandchildren and friends. These relations were described as stable and represented something consistent that they could rely on. Many pointed out that they trusted their next-of-kin's capacity to make sound choices on their behalf in the future.

I'm still doing ok. And I know that Celine (girlfriend) is right here if something happens. In that way, I feel safe. (Jacob)

The participants who lived together with a partner expressed the importance of being a couple and that their situation had been worse if they lived alone. The reassurance of having someone to lean on when challenged with difficult questions or other demanding situations, relieved pressure and reduced concern and uncertainty. The participants talked about the practical help and the facilitating that the partner and family members did, and many were aware of the significance of this help to get through everyday living. The feeling of having their partner or children as a safety net made the participants less worried about the future. The closeness of his relations was pointed out by Hugo who stated that: 'it would have been hell living with this condition without the support from my friends and family'.

The severity of dementia impacted on the participants' sense of identity and roles within their relationship to others. Harry, who had moderate to severe dementia, explained that he felt like he betrayed his family by being inadequate and different from before:

It is aggravating. Just when one is supposed to have strength enough and be funny and joke around ... But it turns out forged because one really must pull

it together to make it happen. Somehow one ends up being hurt. One senses that: I can't do this.

Several of the participants expressed insecurity about how their partner coped with the situation. Many couples had not talked openly about the dementia condition and its implications for the future and their relationship. The participants gave different reasons for this. Some said that it was too emotional and sad to talk about it, while others did not see the point of discussing and dwelling on something that could not be changed.

### Vulnerable dependence on others

The participants described that the notion of being dependent on other people made them feel vulnerable. This could be hard to handle. Linda expressed that she felt like she was kept under surveillance and that, as a direct result from this, she remained passive as not to draw any attention to herself. She did not want to ask for help because that might imply that she was dependent and consequently, had to move to a nursing home. Several participants talked about the burden of care that was placed on their partner. They worried that it might get overwhelming and that the partner no longer would be able to cope with the situation. They often found themselves in a conflict between needing help and feeling compassionate for the partner who had to do 'everything'. This caused feelings of guilt. Johanne stated: 'It gets too much for my husband. I can see that'.

Some of the participants mentioned that it was difficult to ask for help because it conflicted with the person they used to be—and still wanted to be. Robert used to help neighbours with practical things. He found it very difficult to be the recipient of help and could not bring himself to ask for it, so his daughter had to ask on his behalf. Early in the course of dementia, many participants were happy to accept help from the family or partner, but as the disease progressed, some found professional help relieving. They recognised that the professional help alleviated the pressure on their informal carer.

For some, the dependence on others was very concrete. The confiscation of driving license was a common example of this. Persons who had always been able to travel around independently were suddenly dependent on someone else to take them where they wanted to go. The participants said that even though they knew that their partner was happy to drive them, they hesitated to ask in fear of being bothersome. Julie explained that because of this she often cancelled small and 'unnecessary' errands and activities.

Even though they were dependent on help from others, the participants expressed a wish to contribute and not be reduced to passive bystanders. Several described situations when they felt they were in the way and that their contribution slowed things down instead of being of help. These experiences were hurtful and damaging to their self-esteem. Johanne explained that when she tried to help out in the house, her husband would say: 'I can do

it quicker'. Consequently, she would retire to the chair. Hugo had similar experiences:

She gets annoyed when I ask: Can I help you with that? because I obviously can't. But if I don't ask, I think to myself that I should ask ... But it is no good. (Hugo)

### Dealing with shifting social networks

Several participants told about a shrinking social network. They mainly explained this by their advancing age and said that when you are old it is normal that friends get ill or die. Another reason for change in social networks was relocation to another accommodation; most often to a smaller and easier to keep apartment, or to assisted living or a nursing home. Participants who had experienced this said that they missed their friends and family who used live close by, and they regretted not being able to maintain the relationships. Amelia explained that friends from her old neighbourhood did not come to see her after she moved to assisted housing. She did not expect them to visit because it was too far for them to travel.

Persons who used services such as day care centres, attended dementia group meetings or moved to nursing home experienced an *expansion* of the social network, but this was not always a positive experience. The participants explained that being together with people who were further along the course of dementia than themselves was demanding. A common diagnosis did not automatically create a feeling of fellowship. Some said that they felt lonely in these social situations due to difficulties with communication. Being reminded of the severity and seriousness of the disease, and in that way their own future, was perceived as challenging:

A couple of the others (at day care) are much more ill than me, and it is painful to watch .... I am not afraid of being stupid now, but it is burdensome to be together when you fear those things for yourself. (Hugo)

The participants said that they preferred spending time with people of similar age and gender. They pointed out that there was great heterogeneity at the day care centres regarding activity preferences. One man said that he stopped going to the day care centre because he felt that he had nothing in common with the other attendees, and that the activities they offered were uninteresting to him:

There were only old women ... When you have sung the same songs ... and bingo ... and the same food every week, reading the papers to find out who died last week ... It is pathetic. (Kristian)

As the disease progressed, many participants had to discontinue activities and hobbies. Subsequently they had to give up activities that they appreciated *and* lost contact with the people associated with that activity. Some mourned these losses and were pushed towards isolation and withdrawal. Others said that they kept in touch with

the network through supported and facilitated participation. This was done in different ways, for instance, that the person with dementia kept partaking in the music group but played an instrument that was easier to manage, or the network facilitated transport and allowed for fluctuation in function or mood. For this to be attainable, openness about the diagnosis was a prerequisite. Some of the participants talked about their choice not to tell 'everybody' about the diagnosis. In these situations, the network was not able to adapt and the person with dementia felt inadequate and excluded. Julie, who had chosen not to be open about her dementia diagnosis, experienced criticism while playing bridge and decided to withdraw from this activity. She explained that she was hurt by the comments from a fellow bridge player but regretted not to be part of that social group anymore.

### To be active and participate

The category 'to be active and participate' was described by the participants from three perspectives: (1) to experience joy and enthusiasm and (2) to experience mastery and meaning in everyday life.

### To experience joy and enthusiasm

The participants talked about many different activities that brought them joy and feelings of well-being. Examples of appreciated experiences were visits, listening to music, reading books and being physically active. Many of the participants talked about the joy of visits. Visits are all about the social encounter, and the participants' need to socialise was made apparent in many of the interviews. The participants explained that social visits and spending time together with friends and family was something they anticipated and enjoyed. When asked 'what is important for you to feel good?', Amelia stated: 'to have visitors—absolutely!'. Walks were an important arena for socialising that several participants talked about. Olivia said that the best part of going for walks was gossiping with her friend. Other activities also had important social aspects. The participants talked about singing together with others at the day care centre or going to a concert with friends or family. Religious meetings were also mentioned as enjoyable social activities.

Different cultural experiences were also appreciated by the participants. Many attended concerts locally or in the nursing home and enjoyed sharing the music experience with others. Others preferred to listen to music alone. Julie said that she loved jazz music and when she was home alone, she enjoyed turning up the volume 'the higher, the better'. Music was considered a source of entertainment, pleasant feelings and provided an opportunity to reminiscence:

We sang many old songs. I closed my eyes and had a wonderful time. (Hugo)

Reading or listening to books were also popular activities among the participants. One participant said that he

often forgot about what he had heard, but he still enjoyed the feeling he got when listening to an audiobook.

Exercise and physical activity were also sources of well-being and positive experiences:

It feels good to torment the body a little bit because it feels so damn good afterwards ... when you have had a shower. It gives me pleasure before, during and after. (Jacob)

The participants appreciated outdoor activities, and the fresh air and sunlight were part of this experience. The joy of being around animals was also mentioned by several. They spoke of day care-services located on farms with farm animals and about the significance of the family pet. The animals often represented an activity they enjoyed—like riding a horse, feeding the cows or walking, as well as petting, the dog.

#### To experience mastery and meaning in everyday life

The participants described their experience with mastery in different ways. This theme surfaced when they talked about measuring themselves to others and expressed contentment about still being able to ‘keep up’.

I really appreciate the ability to walk and be independent. And I am happy that I can still keep up with my husband. Naturally, he is fitter than me, but we can go for walks without him having to wait too much for me. (Mia)

It was important to the participants to master practical everyday chores and activities. The routines gave rhythm, meaning and content to the day. Examples of routines were household chores, mealtime habits, watching the news or taking walks around the neighbourhood. Arthur explained that he was grateful that he could still manage his daily routine: get up in the morning, dress himself and go for a walk while listening to the radio.

The participants differed greatly regarding the experience of mastering in everyday life. Some were satisfied with what they accomplished, while others frequently experienced let-downs that damaged their self-esteem. Several of the participants talked about actions they took to improve their health; generally, or in relation to the dementia condition. The most common examples were healthy diet and physical exercise. Most of the persons who talked about exercising led an active life before the diagnosis, but some explained that they started to engage in regular exercise after the diagnosis. Through making healthy choices, they tried to influence their health and to some extent the progression of the disease.

I run every day. They told me at the hospital, that it can be good for my head. (William)

Several younger participants considered everyday life to be boring and uneventful. This was more pronounced when the partner was still working. Jan said he felt like everyday life was ‘like a bus route’ and that ‘nothing much happens’. Among the older participants, a quieter

life was considered ‘normal’, and the need for activities and outings seemed to be reduced. They did not talk about being bored, but mentioned specific activities that they missed, such as having visitors or going to the shops.

#### To live in the moment

The conversations revealed that the persons coped with life with dementia in different ways and their needs differed. Their thoughts about the future were diverse and were very much influenced by the severity of dementia symptoms, age and social situation. Nevertheless, most of them expressed a wish to live in the moment and not worry about the future. Jacob was definite when he expressed that he did not want to give attention to the dementia condition. He felt healthy and was reluctant to talk about the future as there was no point in worrying about what may come.

The participants were very interested in the research that went on concerning medications, and several of them had been involved in clinical trials. They remained hopeful that drug treatment was conceivable, and that they may benefit from this in the future. Some pointed out that everybody goes through their own progression of the condition, and no two cases are the same. The older participants pointed out that they were happy that they were ‘otherwise’ healthy and were comforted by the thought that ‘most people get *something* at my age’.

When talking about the need for help in the future, most of the participants were hesitant to think or talk about it. They said that it will be figured out when it happens and that they will ask the partner or children for help, or the general practitioner. All the participants had been in contact with the dementia liaison team; however, most of the participants did not think of this team, or representatives from the team, as a possible source of help/support.

#### Overall interpretation: the need to be who I am

The conversations demonstrated that the experiences of needs described by the participants are diverse. An overall synthesis of the categories generated from the data material reveals a comprehensive understanding that the persons wish to keep their identity. The overall latent theme was therefore summarised in the concept: *the need to be who I am*.

#### DISCUSSION

The main aim of this study was to explore the experienced needs of a people living with dementia. The results formed the overarching theme: ‘the need to be who I am’. This coincides with the content and implications brought forward in PCC; to strengthen the identity of the person, promote user involvement and enable the service user to stay independent as long as possible. According to Kitwood, psychological needs in all people, but heightened in persons with dementia, are comfort, attachment, inclusion, occupation and identity.<sup>3</sup>



The participants in this study talked a lot about the importance of the close relationships with family members and friends. The relationships confirm and maintain the identity through being long-standing 'life witnesses'. By tying together past, present and future, they are of special importance to persons with dementia when the memory function is declining and the ability to express themselves is reduced. Identity is also confirmed by being part of a bigger unit; the 'family'. The relations may provide emotional support and practical help and are important sources of attachment and comfort in line with the work of Kitwood concerning PCC.<sup>3 32</sup> Social support is often referred to in the literature and there is consensus about the role it can play in providing assurance and attachment in the elderly.<sup>33 34</sup> Social support can reduce risk for depression, isolation and loneliness and provide access to information and resources and maintain identity and self-esteem,<sup>35</sup> however the lack of social support impairs quality of life and predict a faster progression of chronic disease and mortality.<sup>36 37</sup>

As people with dementia suffers from decline of cognitive functions that, among other things, creates communication challenges, this can complicate social participation and thereby also reduce access to social support.<sup>38</sup> In addition, living with a serious chronic disease puts an enormous strain on relations and people may drift away due to uncertainty or because they cannot cope.<sup>39</sup> It can become a great struggle to keep up a good relation, and in some cases, the relation was not even that robust before the diagnosis. The quality of the relationship between the person with dementia and the partner and family members is associated with different factors such as loss of cognitive or physical function, quality of life and hospital admittances.<sup>40–42</sup> Therefore, it is of great importance to offer psychosocial interventions that can improve and support the relation between person with dementia and family and friends. It is reasonable to believe that families who access resources that can teach them about coping strategies and communication will be better equipped to tackle the forthcoming challenges. This could potentially have great consequences for the person with dementia and the perceived social support. It would also be beneficial to facilitate a meeting point for the social resources early in the course of the dementia condition. It is possible that these kinds of initiatives can delay institutionalisation, but this needs to be investigated further.<sup>43</sup>

The participants talked about activities they wanted to carry forward, and these occupations were important to experience mastery, meaning and content to the day. Continuing with activities also means keeping in contact with existing networks. The importance of usual activities and social engagement was also pointed out in a review of qualitative research on the experience of life with dementia.<sup>44</sup> The ability to remain active and engaged was considered essential for maintaining continuity and well-being. The link between activity, participation and health has been repeatedly reported on in the literature<sup>45 46</sup>

and the WHO recognise social engagement to be within the concept of health.<sup>47</sup> This is in line with Kitwood who states that occupation is one of the five psychological needs.<sup>3</sup> The participants talked about the pleasure activities bring and that they enjoy the feeling of mastery. The importance of meaningful activities has also been pointed out by Roach and Drummond,<sup>48</sup> who interviewed young persons with dementia. Their results suggested that purposeful activities, such as work, or volunteering may help to preserve the person with dementia's dignity and sense of self.

It was important to the participants to be met as individuals and not a diagnosis, however it can be challenging for the services to provide meaningful activities in a group context. This became apparent when the participants talked about being placed in groups with other people with dementia without any considerations made regarding interests, background or level of functioning. Many of the services that are provided for this group, such as day care, are designed for people at the later stages of the dementia condition. It can be difficult to find support in the earlier stages because the person, or their next of kin, feel they are too well to partake in activities that they consider uninteresting and unsuitable. Especially the younger participants talked about age appropriate care, and they were reluctant to go to day activities that were localised at nursing homes. This is in line with the results from Beattie *et al* who performed in-depth interviews with young persons with dementia living in England.<sup>28</sup> Participants in the current study reported that negative experiences, for instance lack of age, or function appropriate day care, had caused them to withdraw from using the services. Nevertheless, several of the participants talked about enjoyable experiences with other people with dementia—in support groups or at day care. These are arenas where one can talk about worries and share thoughts with people in the same situations. It can be a place where they can 'be themselves' and not worry about being 'stupid' or inappropriate. Social group participation has shown to increase quality of life and reduce risk for depression in earlier stages of dementia disease.<sup>38 49</sup>

The participants were asked about thoughts about the future. Most of the participants stated that they wish to live for the moment and not think about, or plan for, the future. They expressed great trust in their partner and family to make good decisions on their behalf for the future because they know them so well. The persons talked about hope. They were comforted by the thought that 'dementia progression is individual' and commonly articulated: 'nobody knows what the future brings, no need to worry in advance'. According to Wolverson *et al*, hope is an active process that is important in the adjustment to life with dementia when the person tries to maintain normality and develop strategies to increase self-confidence.<sup>50</sup> An association between higher levels of hope and greater self-worth have been demonstrated in a group of people with dementia.<sup>51</sup> Maintaining hope, participating in activities and receiving social support are

likely to be factors that positively influence adaptation to daily living with dementia.<sup>52</sup> They will facilitate the preservation of own identity and, in line with the results from this study, support the persons' need to 'be who they are'.

### Implications for policy, practice and research

People with dementia express a need to continue to be themselves when the dementia condition progresses and they describe important elements like staying connected, being active and participate and to live in the moment. Several initiatives are being taken to meet the need of people with dementia. On policy level, social inclusion, dementia friendly cities and advance care planning facilitate the need to contribute according to capacity and talent. The need for independence and mastering can be enabled through support groups, acknowledgement of need of assistance when it arises, initiatives that support the strengths and capacities of the person with dementia and access to meaningful activities that are stimulating and provide positive experiences. In practice, PCC is central in this endeavour; the actions to support people with dementia must be tailored for individual needs, focus on positive experience and facilitate good and meaningful social relations.<sup>53</sup>

Even though advance care planning can be a useful tool for user participation regarding future services for persons with dementia, the results from this study give the message that not everybody wishes to consider these options in the early stages of a dementia condition. Many clearly state that they do not wish to plan and think about the future. Consequently, it is very important that the person gets to decide when, or if, advance care planning should be carried out.

Future research should explore how we can ensure user involvement in services for people with dementia. Social support and relations are important to this group, and efficiency of interventions that support these resources are also important in future research.

### Strengths and limitations

The group of persons who have been interviewed in this study is heterogeneous regarding gender, age, interests, life situation, living arrangements, severity of dementia and function. All these factors shape the conversations and the interview setting. Most interviews were carried out in the persons home. Hopefully this contributed to the participants feeling assured and comfortable. The type of dementia disorder and severity were not recorded. Due to communication difficulties mostly caused by severity of dementia disease and/or hearing difficulties, the answers at times were short and it was difficult to have the participant elaborate on relevant topics. Several persons sought confirmation or help from partner or would ask the interviewer to check with partner afterwards to make sure it was the 'correct answer'. Twenty-three interviews were performed with the person with dementia alone and 12 with a partner or son/daughter present. When the interviews were performed with another person present, eager

partners and daughters/sons sometimes interrupted or cut the person short. The interviewer tried to control this, but it was challenging. The partners wanted to speak on behalf of the person and often the person with dementia was happy to let them do that. The participants gave the impressions that they were comfortable in the interview situation, and in most situations, there was a positive atmosphere. The participants expressed appreciation for the opportunity to contribute to the project. They expressed satisfaction in being 'handpicked' for this assignment and was interested to hear about the project. The restricted interview experience of the first author is a limitation, however the coauthors had extensive interview experience with this patient group. The active participation of all authors in the data analysis process is a strength.

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