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Peer support for the newly diagnosed: how people with dementia can co-produce meeting centre services

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Abstract

This paper aims to contribute to the knowledge about open, co-produced meeting centres for people with dementia, from their own perspective. Services that support people who are newly diagnosed with dementia are often insufficient. Co-produced services have the potential to address the need of people with dementia to be useful and productive, while reducing the stigma. In this study, we applied a qualitative design. Data were collected at a meeting centre for people with newly diagnosed dementia, and consisted of fieldwork (13 days for about two hours at a time), written materials, and semi-structured interviews (mean length 30 minutes) with five attendees with dementia and two staff persons. The analysis was inspired by situational analysis. The findings showed that the meeting centre provided a place for human encounters, a break from everyday life, and a place to share knowledge and develop new skills. Further, challenges were described. Co-production consisted of the attendees being encouraged to take part in the planning of activities, learning from each other and providing mutual support. The study adds to previous knowledge about co-produced services for people with dementia. Future studies can clarify how co-production can be developed in services for people with newly diagnosed dementia in countries and regions where there is a dearth of this kind of support.

Keywords: Alzheimer's disease; co-production; dementia; mutual support; newly diagnosed; post-diagnostic support; self-help groups

Introduction

Dementia is an umbrella term for conditions that cause progressive brain damage, such as Alzheimer's disease, frontotemporal dementia and vascular dementia. To date, no curative treatment is available (World Health Organization (WHO), 2020). Despite the severity of the condition, support for the newly diagnosed is often poorly developed, and these individuals are often left alone to make sense of and deal with

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their new situation (Bunn *et al.*, 2012; Millenaar *et al.*, 2016; Keogh *et al.*, 2019). There is a risk that newly diagnosed individuals with dementia become inactive and socially isolated (Thomas *et al.*, 2001), which may further increase their symptoms (Lisko *et al.*, 2021). In Sweden, people can apply for assistance from the municipality, such as home help or daytime activities. Before assistance is granted, an assessment is made of whether there is a need for care. In an early phase of dementia, the need for support may not be sufficient to qualify the person for assistance, and instead the person may have to rely on family and friends for support (Szebehely and Trydegård, 2011; Odzakovic *et al.*, 2019).

There is no tradition of working with volunteers to support people with dementia in Sweden. Potentially, volunteer support and co-produced services can be a valuable complement to the existing care, in that they are available earlier in the dementia trajectory, and are built on more equal relationships between the persons who are giving and those who are receiving support, which could strengthen the self-esteem of and empower the person with dementia.

Background

Globally, there is a dearth of support available to people with dementia, especially those who are newly diagnosed (Bunn *et al.*, 2012; Millenaar *et al.*, 2016; Keogh *et al.*, 2019), although there are examples of such services being developed (Kelly and Innes, 2016). People with dementia, because of fear of stigmatisation, may also be reluctant to seek support (Ashworth, 2020). Shortage of post-diagnostic support can contribute to reluctance in people with early signs of cognitive decline to seek medical care (Brooker *et al.*, 2014; Woods *et al.*, 2019), and in physicians to assess and diagnose them (McLaughlin and Laird, 2020).

Dementia is currently affecting around 50 million people worldwide, and the number is expected to rise to 152 million by the year 2050 (WHO, 2020). The WHO estimates that costs for care of people with dementia worldwide will reach US \$2 trillion by 2030 as populations in many European and Asian countries are growing older (WHO, 2017). Age is the most prominent risk factor, however, up to 9 per cent of people with dementia have young-onset dementia (YOD), *i.e.* symptom debut before the age of 65 (WHO, 2020). Dementia affects memory, language, perception, and motor and executive functions (such as planning, organising and abstract thinking) (Smits *et al.*, 2015). Neuropsychiatric symptoms, *e.g.* depression and anxiety, are also common (Van der Linde *et al.*, 2016) and can sometimes be seen as natural reactions to a difficult situation, rather than symptoms of the condition (Keady and Jones, 2010).

The diagnostic process preceding a dementia diagnosis has been described as lengthy, confusing and distressing, and the diagnosis disclosure as often emotional (Samsi *et al.*, 2014). Once diagnosed, people with dementia typically strive for continuity in their everyday life, while they struggle to cope with change, within more- or less-supportive environments (Górska *et al.*, 2018). For some, especially those with YOD, the diagnosis means that they are forced to give up their working life, implying loss of meaningful occupation, professional identity and social roles (McCulloch *et al.*, 2016). Information and post-diagnostic support are often inadequate to meet the persons' and their families' needs and expectations (Innes *et al.*, 2014; Samsi *et al.*, 2014).

Dementia is strongly associated with stigma (Batsch *et al.*, 2012). In a recent study, Ashworth (2020) described experiences of stigma in people with YOD and late-onset Alzheimer's disease in mild-moderate stage, and their family supporters. All groups, to various degrees, reported perceived stigma. The people with Alzheimer's disease also expressed self-stigma by describing their cognitive impairment as 'stupidity' (Ashworth, 2020). There is a risk that people with dementia become inactive and socially isolated due to the stigma. Language impairment (Farrell *et al.*, 2014), loss of work (McCulloch *et al.*, 2016), unsupportive (Odzakovic *et al.*, 2020) or overprotective (Fetherstonhaugh *et al.*, 2013) environments, and neuropsychiatric symptoms, *e.g.* apathy (Thomas *et al.*, 2001), add to the risk of social isolation. Remaining active and socially engaged is often described as key to sustaining wellbeing in persons with dementia and their family supporters (Jennings *et al.*, 2017; Giebel and Sutcliffe, 2018) and could possibly delay the progress of symptoms (Lisko *et al.*, 2021). People with dementia have expressed a particular desire to understand more about dementia, specifically how to promote health and manage difficulties associated with the condition (Fitzsimmons and Buettner, 2003).

In a recent overview of the literature, Oyebode and Parveen (2019) found that psychosocial interventions to support people with dementia were often short term, directed to staff or family members, and focused on managing neuropsychological symptoms and enhancing cognitive abilities. The authors concluded that further research should focus on interventions to promote post-diagnostic wellbeing in community-dwelling people with dementia (Oyebode and Parveen, 2019). Despite the general dearth of such interventions, some have been described. For example, Mazurek *et al.* (2019), Szcześniak *et al.* (2018), Söderhamn *et al.* (2014) and Kelly and Innes (2016) have described positive outcomes of support programmes with a mix of individual and group activities. The reported interventions were described as reducing unmet needs (Mazurek *et al.*, 2019), facilitating the pathway to day care (Szcześniak *et al.*, 2018), increasing independence (Kelly and Innes, 2016), and promoting activity and fellowship (Söderhamn *et al.*, 2014). Also, Leung *et al.* (2015), in a systematic review, found that social support groups for people with dementia and mild cognitive impairment showed positive effects on depression, quality of life and self-esteem. Qualitative studies have similarly described positive experiences with social, peer support and self-help groups in the form of strengthened sense of self, agency and communion (Hedman *et al.*, 2014, 2016) and citizenship (Örülv, 2012). Richardson *et al.* (2016), in a review of psychosocial interventions directed specifically to people with YOD and their carers, found only three articles, which were all qualitative and focused on support in worklife. These interventions were found to promote self-esteem, a sense of purpose and wellbeing in the participants with YOD (Richardson *et al.*, 2016). Further, Van Vliet *et al.* (2017) found that attenders of specialised day care services for people with YOD described that these provided opportunities to be useful and engaged. The day care was described as a safe environment where participants felt accepted despite their cognitive impairments.

Theoretical framework for co-production

Previous research has shown that being active, engaged and able to participate is essential to the wellbeing of people with dementia (Jennings *et al.*, 2017; Giebel

and Sutcliffe, 2018). Their ability to do so clearly varies but previous research indicates that abilities are either underestimated or disregarded for convenience when it comes to groups with mental health issues (Arnstein, 2019). This is equally relevant for people with dementia (Kitwood, 1990; Bartlett and O'Connor, 2007). Arnstein (2019) famously ordered levels of participation on a 'ladder' that ranged from illusionary forms of participation to real citizen power. The second 'lowest' form of participation – which Arnstein (2019) argues should perhaps be the lowest – is what she calls therapy, or planning masquerading as participation while actually just teaching the participants to accept their condition. This type of participation therefore means pacifying the person rather than activating them, and Arnstein (2019) uses all types of work with people living with mental health conditions as an example of where it occurs, which can include dementia care. This article considers the participation of people with newly diagnosed dementia as a type of co-production. Although she does not use the term co-production, Arnstein (2019) would place the activity much higher on her ladder, as a type of 'partnership' between the professional and the user. This is, at least, how co-production should be understood, as a co-operation in which power and responsibility to create and maintain a service is shared among users and/or between users and professionals. It is analytically important to study whether participation is meaningful and substantial rather than illusionary, for it to be considered co-production and positive for the wellbeing of people with newly diagnosed dementia.

Co-production has been used to describe activities in which citizens or consumers take an active part in the performance of their own and others' social services (Brandsen and Pestoff, 2006; Bovaird and Loeffler, 2012; Vamstad, 2012). Co-production of services for people with dementia could be understood as a cost-effective type of preventive care with the potential to reduce the need for costlier medical care, including institutional care (Loeffler and Bovaird, 2018; Pestoff, 2021). In research and in the care of people with dementia, a co-production approach has previously been used, *e.g.* to increase participant involvement in research (Swarbrick *et al.*, 2019), engage people with dementia as tutors in higher education in dementia (Russell, 2020), develop interventions to improve sleep (Rapaport *et al.*, 2018), conceptualise personhood in dementia care (Bosco *et al.*, 2019) and develop supportive technologies (*e.g.* Davies *et al.*, 2019; O'Connor, 2020). Co-production shares similarities with other concepts that have been applied in research and advocacy concerning people with dementia, such as citizenship (Bartlett and O'Connor, 2007; Bartlett, 2016). Both concepts emphasise the social inclusion, power and rights of people with dementia and other disadvantaged and stigmatised groups. Co-production typically refers more specifically to the context of service provision, while citizenship more broadly guides research on social rights and the creation of dementia-friendly communities (Bartlett, 2016).

Rationale

Support to newly diagnosed people with dementia has often been focused on cognitive training, managing neuropsychological symptoms, supporting the family carers and delaying transition to nursing home care. More recently, there has also been initiatives to actively engage people with dementia in strengthening their

power, social rights, and participation in the forming of support and services (e.g. Bartlett, 2016). Co-produced services may have the potential to reduce the stigma and enable persons to learn about dementia, share their experiences with others, and remain active and engaged in the community (Swarbrick *et al.*, 2019). As the cost of care for people with dementia is expected to rise dramatically in the near future, co-production can be seen as a valuable and cost-effective addition to other forms of care and support for people with dementia. However, research on how participants experience such services is sparse. Learning more about co-produced services that could both benefit the quality of life of people with dementia and make welfare states around the world more socially and economically sustainable is therefore clearly of great importance. Therefore, the aim of this study was to describe an open, co-produced meeting centre for people with dementia.

Methods

Design

This study adopted a qualitative design inspired by situational analysis (Clarke, 2003; Clarke *et al.*, 2015). Situational analysis is an extension of Grounded Theory (Glaser and Strauss, 1967). With its roots in social constructionism, situational analysis has also been influenced by postmodern perspectives that acknowledge the situated and discursive nature of social realities. Therefore, situations rather than social processes are the key focus of analysis (Clarke, 2003; Clarke *et al.*, 2015). Central to situational analysis is the construction of analytical maps. Mapping all possible aspects of a situation allows its complexity to be more fully grasped. Not only what appears in the situation is of interest, but also what is absent and unspoken. Situational analysis is appropriate for mixed datasets, e.g. a combination of interviews and observational data (Clarke *et al.*, 2015).

The meeting centre

The meeting centre in this study was run by a not-for-profit organisation, with partial funding from the municipality. The target group was people newly diagnosed with cognitive impairments who were able to transport themselves and manage independently at the centre. The centre was open to all, provided these conditions were met. No fee was charged, except for a small amount to cover meals. The persons with dementia (hereafter referred to as 'attendees') were required to inform the staff whether they wished to have lunch or not. The staff consisted of two licensed practical nurses (*i.e.* nursing training on secondary school level), one of whom had an overarching responsibility for the centre and one who was present in the daily sessions. There was also an art therapist who led painting sessions once a week. Information about the centre was spread mainly through leaflets distributed via memory clinics, the website and word of mouth. New participants were first invited to visit the centre. This enabled the staff to assess whether they were sufficiently independent, *i.e.* able to manage eating and visiting the toilet independently and finding their way to the centre by themselves. If not, they were instead advised to apply for day care.

The meeting centre was open two days a week between 10 am and about 3 pm. Normally, it was located in a small two-room apartment. However, because of the COVID-19 pandemic, the group had access to a larger locality on one of the weekdays where they were able to receive all attendees (about ten) without breaking the recommendations about physical distancing. In the small apartment, only five attendees were allowed. Therefore, new attendees were invited to attend only once a week, at the larger premises.

The days started with coffee or tea and a sandwich while the attendees arrived. One staff member welcomed attendees as they arrived and assisted with the serving. During the first hour, the group all sat together and talked about everyday topics and what was relevant to them at the moment. This was followed by an hour when the attendees had the opportunity to paint under the lead of the art therapist (one day per week). This took place in another room where the attendees were undisturbed and calm music was played. Attendees who did not want to paint could sit and talk or do something else like going for a walk or make bracelets of beads. Meanwhile, the staff prepared lunch and set the table. After lunch, the group had coffee or tea and the staff collected the payment for the meals. Thereafter, some attendees left while others continued talking until it was time to leave. Occasionally, some of the attendees went for a walk. It also occurred that the group visited museums, exhibitions and concerts.

Research participants

Initially all attendees at the meeting centre were invited to participate in the study. When new attendees arrived, they were also informed about the study and asked to participate. Three women declined to participate. During the data collection periods, a total of 11 attendees were included, five women and six men. Five of the included participants stopped visiting the meeting centre during the data collection as their condition deteriorated and they were in need of more extensive support. They were therefore only included in the observations, but not interviewed. Further, one of the included attendees did not wish to be interviewed. The remaining five of the included attendees were interviewed. The three staff persons agreed to participate in the study; however, because of the pandemic, only two of them were able to participate in the interviews (see [Table 1](#)).

Data collection

Because of the COVID-19 pandemic and consequent temporary closure of the centre, the data were collected in two time periods, from the beginning of February until the middle of March and from the end of September to the beginning of November 2020.

Fieldwork

Two of the researchers (MS, RH) took turns being present at the meeting centre on a total of 13 days for about two hours at a time. The researchers had coffee and talked with the attendees of the centre and listened to their conversations. On most occasions, the researchers were asked who they were and had to present

Table 1. Demography of participants in the interviews (self-reported)

Person with dementia	Sex	Age	Living arrangements	Profession	Dementia diagnosis	Years since diagnosis	Length of participation in the group (months)	Frequency of participation in the group (days per week)
1	Female	55	Single	Office and sales employee	Alzheimer's	4	24	2
2	Female	76	Single	Secretary	Lewy body	1.5	18	2
3	Male	68	Married	Lawyer	Alzheimer's	2	8	1
4	Female	56	Married	Manufacturing employee	Frontotemporal	Not sure, about 2	12	2
5	Female	59	Single	Site manager	Not sure, mixed	Not sure, about 4	1.5	1
Staff	Sex	Age	Profession/training			Experience in dementia care (years)	Experience in the study setting (years)	
A	Female	57	Licensed practical nurse. One-year specialisation in dementia care			26	13	
B	Female	56	Licensed practical nurse. Short, Web-based course in dementia care			25	1.5	

themselves. When the group heard about the research, they wanted to know if there were any new results about dementia and dementia treatment. After each visit to the centre, field notes were made and read by both researchers before the next visit.

Interviews

Five attendees and two staff were individually interviewed. Semi-structured interview guides were used. Follow-up questions were asked based on participants' responses in order to learn more about their experiences. Each interview was listened to in its entirety before the next one was conducted. The interviews lasted between 20 and 35 minutes (mean 30 minutes).

The five attendees' interviews took place in an undisturbed, quiet room during the day either before or after lunch. The interviews started with the question 'Can you please tell me how you like being at the meeting centre?', followed by questions about how the attendees had received information about the centre, the content and activities at the centre, and the significance of the centre for them and their everyday life. At the end of each interview some demographic questions were asked regarding their dementia diagnosis, age, living arrangements, vocational background and how long the interviewee had attended the centre.

One staff person was interviewed after the attendees had left for the day and the other was interviewed by phone (because of the COVID-19 lockdown). The interviews started with the question 'Please tell me about the meeting centre', followed by questions about the significance the meeting centre has for attendees, and what challenges and difficulties there are. Demographic questions were posed at the end of the interview concerning the staff's age, profession, length of time working at the centre and years of experience of working with people with dementia.

Written materials

The meeting centre was advertised on the organisation's website and in flyers. The information that was presented on the website/in flyers was also included in the data analysis.

Data analysis

Throughout the data collection, the researchers who performed the fieldwork (MS, RH) continuously discussed possible patterns and themes in the data that could be further explored in the ongoing data collection. A situational map was constructed at the beginning of the data collection and revised repeatedly during the process, as described by Clarke *et al.* (2015). At the beginning of the data collection, all possible aspects of the situation, including non-human aspects, were noted in a 'messy map' which then was sorted into an 'ordered map'. The written materials were the main source of content for the situational map in this phase of the analysis. During the data collection all data (transcribed interviews, field notes from observations and documents) were read several times and constantly searched for aspects to include in the situational map (open coding) and clues on how aspects might be related (relational mapping) (Clarke *et al.*, 2015). Preliminary themes and

Table 2. Themes and subthemes

Themes	Subthemes
A place for human encounters	<ul style="list-style-type: none"> • To be acknowledged as a person • To share enjoyment • To share experiences and support each other • To have easy access to support
A break from everyday life	<ul style="list-style-type: none"> • To be involved and have an influence • A distraction from negative thoughts • A change of environment • A relaxing moment
To share knowledge and develop new skills	<ul style="list-style-type: none"> • To learn from each other • To develop skills
Challenges for the meeting centre	<ul style="list-style-type: none"> • To ensure adequate localities, staff and financing • To reach out with information about the meeting centre • To find an appropriate mix of activities • To reject or being rejected from participation

subthemes were constructed in a process of constant comparison and discussion among the researchers (MS, RH) until consensus was reached. To ensure trustworthiness, two authors (MS, RH) worked independently on the analysis and the result was continuously critically discussed between all authors. The data from the interviews, fieldwork and written materials were consistent and gave an insight into the significance, for newly diagnosed people with dementia, of having a meeting centre to go to.

Ethical considerations

Ethical approval was obtained from the Swedish Ethical Review Authority. The participants were given oral and written information about the purpose and procedure of the study, and were informed that all participation was voluntary, that they were entitled to withdraw their consent at any time during the data collection, that data and personal information would be handled with confidentiality, and that the presentation of findings would be anonymised. The information was repeated on request and when participants appeared to have forgotten. All participants with dementia were considered able to provide informed consent autonomously. Written consent to participate in the study was collected.

Findings

The themes and subthemes are presented in [Table 2](#). The findings are presented in the four themes: ‘A place for human encounters’, ‘A break from everyday life’, ‘To share knowledge and develop new skills’ and ‘Challenges for the meeting centre’.

A place for human encounters

The not-for-profit organisation that ran the meeting centre had a long tradition of providing support to people in vulnerable life situations. On the internet, the

meeting centre was described as a place for those who wished to get in contact with others in similar situations and exchange experiences. In the interviews, attendees similarly described the meeting centre as a place for human encounters in a relaxing environment where they could meet people in the same situation. Everyone was treated with respect and dignity, and invited to participate in the group conversation irrespective of any shortcomings, which also was noted in observations during fieldwork. The attendees welcomed each other, and shared experiences and the joy of getting together during their meetings. If someone had difficulty expressing themselves, the others showed support by trying to help or comfort the person by saying that the words would come back.

The attendees said that they felt relaxed and that they could be themselves. One of the attendees said:

...it's pretty nice to chat and then you're relaxed here, since you know that everyone is in the same boat; here you don't need to think about having said something multiple times, here you can, like, just be. That is indeed what is so lovely. (Interviewee 4)

In other contexts, they said that people could pretend not to notice that they, for example, were saying the same thing several times, and treat them with indulgence; or making remarks about their shortcomings which they were aware of but unable to correct. At the meeting centre, it was okay not to find words or to lose the thread and forget what to say. They supported and encouraged each other as they shared enjoyment and difficulties in everyday life. The attendees appreciated that the meeting centre existed. They said that they would miss it if it ceased to exist, for example:

...it would be very sad if I wasn't able to come here, yeah, no, it's ... it's actually brilliant, so it ... it helps, like, to sit here and chat with one another, and so on. So it would be ... sad if we didn't have it, actually. (Interviewee 1)

It was also appreciated by the attendees that they did not have to apply and get permission from the municipality to participate, and that the service was free of charge.

The staff described that it was very important for people with dementia to meet others who are experiencing similar things as oneself and that exchanging experiences is worth its weight in gold. The staff described that they could never understand the attendees in the same way that the attendees could understand each other. It was therefore extremely important for them to meet others who had the same experiences, who understood each other, and talk and joke about their situation. For example, the attendees might say, 'Don't you remember? Have you also got Alzheimer's?' and then laugh together. Such a comment could also be directed at the staff. This illustrates how the attendees are also co-producers of the care situation and its special qualities, adding value that could not be provided by the staff.

The conversations were not only about dementia. Also, current events in society and politics were discussed. When a new person was introduced to the group, everyone introduced themselves and this was appreciated by all, including those who had been in the group for a long time. It was suggested that they should all have a name tag to make it easier to remember everyone's name. However, this

remained a proposal and was not implemented. When one of the researchers suggested at the beginning of the fieldwork that the researchers might wear name tags, the staff responded that this would imply an 'us and them' perspective, which is not desirable in co-production. On the other hand, the researchers were invited to use the staff's cloakroom, instead of the attendees', which appeared to be contradictory to the idea of avoiding an 'us and them'.

A break from everyday life

Coming to the meeting centre was described as a break from everyday life. It gave the opportunity to be involved and influence others by talking about one's life. One attendee explained:

It's lovely to get away for a while, even though I'm on my own – it is at any rate lovely to get away and chat with people. (Interviewee 2)

In the interviews, attendees talked about what it would be like in the future when they would no longer be able to live at home alone or together with their families, but this did not seem to be something they pondered about a lot:

...when they discovered that I had a plaque then ... And then another year later, I had two plaques ... then you know ... I'm going downhill. And at least at present there is no method for eliminating or reducing it, so to speak, and so I try to envision things a bit differently than just feeling sorry for myself, so to speak. (Interviewee 3)

During the interviews the attendees said that painting was an appreciated and enjoyable activity and created a nice relaxing moment. For some, the main purpose of going to the group was to paint while others painted only if they felt like it. We observed that during the hour that the attendees were painting they sat together in another room where they would be undisturbed and calm music was played. It was pointed out to us that the painting should take place undisturbed so that the attendees could disconnect from the surroundings and go into the painting. During the hour of painting, it could happen that a person who did not wish to participate in the painting sat alone or that two persons sat together talking. Staff said that it was usually the same attendees who were painting. Some attendees did not want to paint at all but sometimes did so anyway. The staff said that they could see from the paintings how the attendees felt. For example, sometimes when they used dark colours this showed that they were not feeling so well.

The attendees described that they appreciated having the opportunity to get away from home and meet others. Some visited the meeting centre twice a week and appreciated that they could be there all day. Others were content with visiting the meeting centre once a week and said that they had other activities to do, as well as family and friends to hang out with at home. The attendees described that on other days they also did things outside the home such as going to the gym, downtown or for a walk.

The staff, on the other hand, said that there had been requests that the meeting centre should be open every weekday, for which there were no resources. During

the fieldwork we noted that some attendees said they wished the meeting centre would be open several days a week, and also that the premises were larger. It could get quite crowded when the attendees first gathered around the dining table for coffee and extra chairs had to be brought out and the attendees had to squeeze in. It could also get hot in the room. Despite this, the attendees said in the interviews that they enjoyed the room and that they felt at home there.

The meeting centre's location due to COVID-19 was in a beautiful setting with a historic indoor and outdoor environment that was appreciated by the attendees. It also provided topics of conversation about the view from the windows, and about the paintings and old furniture. The attendees said that if they had not come to the meeting centre, they might not have experienced this environment.

To share knowledge and develop new skills

According to staff, the meeting centre was meant to be a platform for networks of people with dementia where they could share what it is like to live with dementia and learn from each other. The attendees emphasised the importance of sharing their experiences with others who had dementia. As one attendee put it:

...a place ... where I can, like, be involved and [have an] influence, feels like it at any rate ... that I can chat ... and be a part and, for example, talk about how ... how my life is. (Interviewee 5)

The staff explained that the initiative to start the group had come from people with dementia who attended another activity organised by their organisation. During the conversations around the coffee table, questions were also asked about other activities for people with dementia, e.g. for people with YOD. As mentioned, we as researchers were also asked if anything new had emerged in research on dementia. The staff said that it was valuable that the attendees could exchange experiences and give tips and advice to each other. In addition, the staff said that they could tell the attendees how persons with new-onset dementia can apply for assessment of activities and assistance, such as home care and day care. The exchange of information between attendees and staff is, in other words, mutual, they co-produce knowledge together at the meeting centre.

For some attendees, the painting sessions provided a possibility to develop their skills. The attendees expressed surprise at their own ability to paint. Some said they had not painted since they had gone to school; others also painted at home. One of the attendees said:

...for my own part, I'm really pleased that I've started to paint with watercolours, which I hadn't done, yeah, I did it at some point in grade school. But I never thought that I would be able to paint, it was draw with watercolours or paint with pencils or something like that, so I haven't, I've always thought 'I can't do that' so I've, like, tried to find something else in such cases. But now I've found that this here is actually really fun, and I'm truly inspired by doing it. (Interviewee 3)

There were other, easier activities such as Googling for information on a topic being discussed. The internet was also used by the staff to find questions to use for

spontaneous quizzes. Staff had asked the attendees what activities they would like to do and had received suggestions such as parlour games and quizzes, which had been acquired. Occasionally, the group also visited museums or concerts, or made excursions, trips and other arrangements for easy-to-access activities. They had access to an allotment that they looked after during summertime.

Challenges for the meeting centre

The meeting centre faced several challenges, and the attendees and staff also faced challenges on a personal level. One organisational challenge was finding financial and personnel resources. According to the staff, the running of the meeting centre was dependent on financial support from the municipality and from their own non-profit organisation. Staff said that it was a constant struggle to finance the meeting centre. They felt that the difficulty of obtaining financing showed that society does not see the value of this kind of supportive post-diagnostic activity for persons with newly diagnosed dementia. Another organisational challenge was that it was difficult to spread information about the meeting centre. There was information on the internet and brochures were sent out regularly to memory clinics. The staff periodically contacted the clinics to ask if they had any brochures left and to try to establish contact with the staff at the clinics. This was challenging because clinicians often changed positions, which meant that new contacts had to be established. It was not clear how much this affected recruitment, as in the interviews, the attendees were usually unsure of how they had received information about the meeting centre.

Yet another organisational challenge was that running the centre with two personnel made the situation vulnerable as it was only the two staff who could stand in for each other. The staff at the centre mostly worked alone and they needed to be comfortable with this; also, they needed to be qualified to run the centre, which included having knowledge of dementia, managing serving coffee, preparing lunch, and hosting and facilitating the meeting. Staff said it was important to find the right person who could provide continuity and security to the group. In the interviews, the attendees expressed satisfaction with the staff, and the staff said that the attendees were more like friends to them.

The staff described that it was challenging to motivate the attendees to do something else than to sit still and talk all the time. They wanted the attendees to be more active and take part in planning what to do at the next session. However, the attendees expressed satisfaction with the activities they could do at the centre:

... there are things that you can do, you can paint, you can do ... beads, you can go out and take a walk if you like and ... And there are some hours so that ... I don't know what more I should find to do in such cases, and that's a bit difficult. But I am quite pleased all the same. (Interviewee 4)

Staff also described that it was a challenge to assess whether attendees who wished to join the group would benefit from joining. As previously described, the attendees had to be able to manage by themselves with all that this entails, be social, find their way and get to the centre by themselves. It was challenging to inform an attendee and sometimes their families that they would not be able, or would no longer be

able, to manage at the centre, because this could cause distress to the attendee and family members. One attendee told that they had been contacted by phone and informed that continued participation was not possible. The attendee was shocked and wondered if something had happened or gone wrong. At the next visit to the centre the attendee asked to have a talk with the staff, who apologised, but the attendee never found out why this had happened.

In addition to the challenges constantly facing the organisation and attendees, they currently also struggled with challenges due to the restrictions brought on by the COVID-19 pandemic. During our fieldwork, we were informed by staff that there were several people with dementia who wanted to join the meeting centre, but because of the restrictions on distancing and the number of people allowed to gather, it was not possible to include new attendees. The management of the meeting centre also found it challenging to decide about shutting down the centre, because of its importance to the attendees.

Discussion

These findings add to previous research, showing the importance for people with dementia to feel socially included, and their vulnerability in this respect (*see e.g. Hedman et al., 2014, 2016*). The meeting centre stood out as a safe haven where attendees described that they were accepted and appreciated despite their cognitive difficulties. However, it was also evident that at some point, the progressing impairments would put an end to their participation. Therefore, the social inclusion was not unconditional. Support to people with dementia, in Sweden and similar high-income countries, is typically organised in blocks running from various forms of early support (as in this study), to day care and eventually nursing home care (Lethin *et al.*, 2018). Recently, the Swedish National Board of Health and Welfare (2020) stated that people with dementia can attend day care while living in a nursing home; however, to our knowledge, this is unusual. Examples of integrated organisations, in which, for example, day care and nursing home care share the same staff and localities, exist but are not common. This means that persons with dementia are likely to be rejected from their social networks and referred to new ones repeatedly during the dementia trajectory. Such transitions are likely to be challenging for people with dementia, because of their communication and other impairments that decrease their ability to present themselves in social situations (Sabat and Harré, 1999) and remember new acquaintances. Ideally, it may be beneficial for people with dementia if services provided support and care with more seamless transitions, running from support to the newly diagnosed person to end-of-life care. This would also increase the chances for staff to become acquainted with the care recipients, their families and their life stories in an early phase, and thus enhance their ability to provide person-centred care in the more-advanced stages. An example of integrated services, which included domiciliary care, day care and respite care, but not post-diagnostic support and nursing home care, has been described by Woolrych and Sixsmith (2013). Co-production of such services, in which the service users participate in the management and provision of services, would help to ensure that the services were adapted to the needs of the users, and also imply a transfer of power to users and give them the

opportunity to contribute and be useful. The meeting centre described in this article has clear elements of such co-production, not least in how the active interactions between attendees and staff provide qualities the staff could not provide themselves. Attendees and staff also engage in co-production of knowledge about dementia and YOD. There are clear similarities between these findings and co-production as 'peer educator experiences' as described in the mental health field, *e.g.* at different varieties of recovery centres (Gill, 2014; Crowther *et al.*, 2019). Efforts to enhance user involvement have also been made in day care provision, *e.g.* in the Netherlands (Van Haeften-van Dijk *et al.*, 2017). On a societal level, it appears to be important to empower people with dementia to take an active part in the organisation and provision of their services. This could promote psychological wellbeing and postpone the need for formal support.

Co-production is not an unequivocal concept (Brandsen and Pestoff, 2006; Ewert and Evers, 2014). A common understanding is that 'the involvement of the third sector (whether as groups of citizens or organizations) transforms the delivery of public services' (Brandsen and Pestoff, 2006: 496). Co-production can take place on a micro, meso and macro level, and exists in the form of co-governance, co-management and co-production (Brandsen and Pestoff, 2006; Bovaird and Loeffler, 2012; Alford, 2013). At the meeting centre described in the present study, the co-production consisted of the centre having been started on requests from users, it was run by a third-sector not-for-profit organisation and the attendees were engaged in the planning of daily activities. This is similar to the types of co-production described in previous research (Pestoff, 2019). However, we also argue that the activity most appreciated and valued by the attendees and staff, namely the social interaction and peer support between attendees, could also be described as a form of co-production. The peer support was the core of the meeting centre's function and could not exist without users' engagement. The beneficial effects of peer support were further strengthened by an inclusive and non-stigmatising relationship between the attendees and staff, one that sought to avoid a division between the groups as 'us' and 'them'. This egalitarian or democratic approach separates co-production from many other forms of service delivery and shows that the meeting centre practised what Arnstein (2019) would call 'partnership' rather than 'therapy'.

The meeting centre can also be described as a managed self-help group, according to Schubert and Borkman's (1991) typology of self-help groups. The typology is based on the level of professionals' involvement in the management and leadership of the groups, and the use of professional *versus* experiential knowledge in activities. Managed groups are organised and run by professionals, while activities are built around the members' experiential knowledge. Essential decisions, *e.g.* about membership and opening hours, are made by professionals. According to Schubert and Borkman (1991), such groups have more in common with professionally driven support groups than with self-help groups, which typically rely more on voluntary and lay engagement. Although self-help groups and networks that are run to a high degree by people with dementia themselves have been described (Beard and Fox, 2008; Örvulv, 2012), many people with dementia are likely to have difficulties with arranging activities, and are dependent on family or professionals to support them. For people with dementia, managed self-help groups may therefore be a

viable alternative. Balancing the power in such groups, so that people with dementia are involved in the decision making, will then be important.

Although this study was conducted in an urban area in a high-income country, it was obvious from the findings that other services offering easy-access, post-diagnostic support were scarce. This has also been previously described elsewhere (Bunn *et al.*, 2012; Millenaar *et al.*, 2016). Except for a few attendees who had also attended a cognitive stimulation group, none of the attendees knew of other centres similar to this one. The dearth of post-diagnostic support is puzzling, given the severe and widespread consequences of dementia. Reasonably, there should be societal gains in strengthening this support, given that the number of people with dementia is increasing, with rising costs as a result. Reasons for this dearth of support can only be speculated. It may be that traditional conceptions of dementia as associated with normal ageing still contribute to downplaying the severity of dementia and its practical and psychological impact on those who have it. Furthermore, the widespread view of people with dementia as lacking awareness (complete or partial) of their condition may possibly be impacting the appreciation of their need for psychosocial support. Clearly, their family members' support needs have often been acknowledged more than have their own in the development of services and research (*see e.g.* Symonds-Brown *et al.*, 2021). This study adds to previous research showing that people with dementia in fact do have awareness of their present situation (Clare *et al.*, 2008) and understanding of the difficulties that most likely lie ahead of them (Hellström and Torres, 2016). To increase knowledge and correct misconceptions about dementia among the public, policy makers and, sadly, also many professionals in the care and support of people with dementia, it is crucial to foster an understanding of the difficulties and support needs that people with dementia experience, and thus motivate the development of appropriate support. In this study, peer support and the access to a few experienced professionals made a large difference to the attendees. It seems likely that this type of support can prevent crises and more costly interventions, thus being cost-effective in the long run.

This study was carried out in one meeting centre for newly diagnosed people with dementia and accessed a small sample. It is possible that more interviews could have provided additional information to the data. However, the combined data with interviews, field work and written material gave a substantial insight into the meeting centre and what it meant to the attendees. The findings can be a starting point for further studies about how co-production can be developed in services for people with newly diagnosed dementia in countries and regions where there is a dearth of this kind of support.

Conclusions

The aim of this study was to describe an open, co-produced meeting centre for people with dementia. The findings showed that the meeting centre provided a place for human encounters, a break from everyday life, and a place to share knowledge and develop new skills. Co-production consisted of the attendees being encouraged to take part in the planning of activities and in attendees learning from each other and providing mutual support. The opportunity to

meet others with similar experiences was highly valued by the attendees and the meeting centre was considered an important complement to the support from family and health-care professionals. An important aspect was that the meeting centre was open and that no needs assessment was required before first-time attendees could attend. Challenges consisted of uncertain financial provision, dependence on a few dedicated staff persons and the challenge to reach out with information to people with dementia who would benefit from attending the meeting centre.

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