

## **Day care for people with dementia:**

### **A qualitative study comparing experiences from Norway and Scotland**

Authors: Anne Marie M Rokstad, Louise McCabe, Jane M Robertson, Margit G Strandenæs, Signe Tretteteig, Solfrid Vatne

Accepted for publication in *Dementia* published by SAGE. The published version is available at: <https://doi.org/10.1177/1471301217712796>

#### **Abstract**

Potential benefits from day care attendance are reported in the literature for both people with dementia and caregivers, although the evidence-base is limited. The study aimed to explore and compare experiences of day care services for people with dementia as described by day care attendees and their caregivers in Norway and Scotland. Whereas day care receives prominence in Norway's national plan, Scotland does not highlight day care in its national dementia strategy. A qualitative cross-national comparative study was undertaken. Semi-structured interviews were conducted with 17 people with dementia and 17 caregivers in Norway, and 19 people with dementia and 15 caregivers in Scotland. Data were analyzed thematically and comparatively to explore the experiences and outcomes of the participants. Findings indicate positive outcomes from day care for both people with dementia and caregivers. Satisfaction with services related to meaningful activities, getting out of the home, strengthening social connections and careful staff facilitation to create a positive and welcoming atmosphere. There were strong similarities in the content of services and experiences reported in the two countries. Some minor differences were noted, with caregiver support being an area of notable divergence in experiences. Specialist day care for people with dementia seems to provide important support and positive outcomes for people with dementia, and respite and reassurance for their caregivers. More research is needed to further explore the effect of day care designed for people with dementia both on the attendees and their caregivers.

**Keywords:** dementia, day care, family caregivers, qualitative research, quality of life

## **Introduction**

Day care for older people is a long-established service and in recent years day care designed for people with dementia has received increased attention as a positive intervention to increase wellbeing for home-dwelling people with dementia and provide respite for caregivers. At present, there is only limited evidence concerning the effects of day care centers designed for people with dementia. A review of the international literature made by the Norwegian Knowledge Centre for the Health Service (NOKC) (Reinar, Kirkehei, Dahm, & Landmark, 2011) concluded that day care designed for people with dementia might contribute to reductions in the incidence of behavioral problems (Ishizaki et al., 2002), improve perceived quality of life for people with dementia (Strandenaes, Lund, & Rokstad, 2017) and decrease the burden of care (Ishizaki et al., 2002; Mossello et al., 2008; Zarit, Kim, Femia, Almeida, & Klein, 2014; Zarit, Stephens, Townsend, & Greene, 1998). As a respite and support service for caregivers, day care has the potential to provide a feeling of safety and relief, reduce the feeling of burden and provide support in their role as caregivers (Gustafsdottir, 2014; Tretteteig, Vatne, & Rokstad, 2016). However, caregivers may feel reticent about day care (Tretteteig et al., 2016; Zank & Schacke, 2002) while people with dementia may be reluctant to attend (Durand, James, Ravishankar, Bamrah, & Purandare, 2009; Huang, Griva, Bryant, & Yap, 2017; Nogales-González, Losada-Baltar, Márquez-González, & Zarit, 2014). A literature search made by NOKC in 2014 could not identify any relevant new studies on the effects related to day care for people with dementia (Dahm, Hafstad & Dalsbø, 2014). Hence, there is a need for more research to describe the experiences and outcomes of day care designed for people with attending the service and their closest caregivers.

## **Day care policy in Norway and Scotland**

In Norway, dementia care services are mainly run by local authorities. Due to national legislation, the local authorities must offer in-home nursing care and residential care. In the national Dementia Plan 2015 (Norwegian Ministry of Health and Care Services, 2008), active care was one of the main approaches. As part of this strategy, offering day care services designed for people with dementia was a main priority. The Government wanted to emphasize day programs as essential and fundamental elements of integrated care services for people with dementia. Day programs were described as the missing link in the care chain. To increase the capacity and quality of day programs, local authorities are offered funding to

provide day care services for this group of people close to their own home. Despite increased availability, the utilization of day care as a recommended service is still low. Hence, the policy of funding to increase day care availability is continued in the second Dementia Plan 2020 (Norwegian Ministry of Health and Care Services, 2016). Day care users do not pay for the service if it is considered a health care service for the person with dementia. However, if it is defined as a respite service for the family caregiver there is a subsidized payment for attendance. The staff is paid health and social care workers but some day care centres add volunteers to the paid staff. Day care service is offered and regulated by the municipalities. The objectives of day care are to offer meaningful activities and social support and a safe environment to enhance coping and to improve quality of life for the attendees. Additionally, day care should act as a respite service for caregivers and possibly postpone the need for nursing home placement (Norwegian Ministry of Health and Care Services, 2008).

The situation for day care in Scotland is rather different to that found in Norway. While dementia has occupied a prominent position in policy rhetoric and action over the past ten years with a slew of policy documents including national strategies, standards for dementia care and a charter of rights for people with dementia (Robertson et al., 2016), day care as a service option has seen a parallel lack of attention. Day care is not mentioned in either of the two Scottish dementia strategies (Scottish Government 2010; 2013a) nor in the consultation for the upcoming strategy to be published in 2017. The focus of these strategies has been on early diagnosis, post-diagnostic support and acute hospital care. Recent legislation for social care in Scotland (The Social Care (Self-directed support) (Scotland) Act 2013) promotes personalization and self-directed support, the provision of personal budgets or direct payments that enable people to decide on their own support. This might involve employment of a personal assistant or payment for a respite break. In England, where a similar policy approach is seen, it has been argued personalization has led to the closure of day centers (Needham, 2013). Day care is means tested and some will get it paid for while others will pay themselves. There may also be some direct costs to attendees for lunch or transport. Day care is provided by statutory, private and third sectors organisations. Alzheimer Scotland is the biggest provider of dementia day care for people with dementia and there is a mix of paid professional staff and volunteers. All social care services are regulated by the Care Inspectorate.

## **Aim**

The study aimed to explore and compare the experiences and outcomes of day care services designed for people with dementia as described by day care attendees and their caregivers in Norway and Scotland. The research question asked was: What are the experiences and outcomes from day care attendance for people with dementia and their caregivers in Norway and Scotland?

## **Design and methods**

The study had a qualitative descriptive design (Graneheim & Lundman, 2004) where qualitative interviews with people with dementia attending day care and their caregivers were conducted in Norway and Scotland.

The study was initiated by the collaboration between Norway and Scotland in the planning of the ECOD study (Rokstad et al., 2014). The research group consists of six researchers who collaborated through a number of on-line and face to face meetings. The work involved concretizing of the study design, inclusion criteria and interview guides, followed by joint data analysis.

## **Sample and recruitment**

The inclusion criteria for participants were: persons with dementia attending day care designed for people with dementia, and caregivers of attendees. When possible, dyads of people with dementia and their caregivers were both included. People with dementia had to have the capacity for communicating in an interview and giving written informed consent.

The participants in Norway were recruited from the ECOD study (Rokstad et al., 2014). Seventeen people with dementia and caregivers were recruited from six centers. In Scotland, the project was conducted in collaboration with a third sector organization that funded the project and acted as gate keepers. A total of 19 people with dementia and 15 caregivers from six centers participated.

The characteristics of the participants are described in Table 1. A purposive sample of participants represented both genders, a variety of ages and different relationships to the person with dementia (spouses, children/children in law, living together with the person or

not). All but one of the caregivers had face-to face- contact with the person with dementia a minimum of once per week. Both urban and rural areas were represented.

<b>Table 1. Sample characteristics</b>		
	<b>Norway</b>	<b>Scotland</b>
<b>Day care attendees:</b>	17	19
Gender: male/female	7/10	9/10
<b>Caregivers:</b>	17	15
Gender: male/female	5/12	12/3
<b>Relationship:</b>		
Spouses <sup>1</sup>	8	7
Daughters/daughters in law	6	6
Son	3	1
Niece		1

<sup>1</sup> all spouses lived together with the day care attendee

### **The interviews**

Based on the study aim, a semi-structured interview guide that enabled cross-country comparison was developed.

The key themes covered in the interviews were:

- Experiences of attending day care
- Impact of day care on the lives of people with dementia and their caregivers and outcomes experienced
- Impact of day care on relationships between people with dementia and their family as well as with staff at day care
- Experiences of caregivers with day care services and their relationships with staff.

Interviews of people with dementia in Norway were carried out at day care centers (n=17) in March and April 2015. People with dementia in Scotland were interviewed either at the day care center (n=17) or in their own home (n=2) in the period from November 2014 to April 2015. Not all participants had the ability to elaborate on all questions in the interview guide. Interview length varied from 10 to 35 minutes.

Interviews of caregivers in Norway were conducted face-to-face at day care centers (n=4), by Skype (n=2) or at home (n=11). In Scotland, interviews were conducted at the day care center (n=7), by telephone (n=2) or at home (n=6). Interviews lasted from 30 to 90 minutes.

### The data analysis

Thematic analysis (Graneheim & Lundman, 2004) of the data followed three steps: 1) Total impression – from chaos to *themes*. 2) Identifying and sorting *meaning units* – from themes to codes, the codes being a text fragment containing information about the research question. 3) Condensation – from code to meaning, where data were reduced to a decontextualized selection of meaning units and sorted as *thematic code groups* (Malterud, 2012). Initially, analyses took place separately in the two countries, before comparing and combining thematic frameworks and identifying mutual themes.

### Ethical considerations

People with dementia are considered a vulnerable group; however it is possible to include people in interviews if the settings and questions are tailored to their individual physical and cognitive abilities. In this study, interviewers were experienced in communicating with people with dementia, through active listening that was sensitive to the person and their views. All participants were able to give informed written consent to take part in the study. Established ongoing consent processes were followed (Dewing, 2007).

### Findings

The findings developed from qualitative fieldwork conducted in Norway and Scotland. Four main themes with subthemes (illustrated in Table 2) emerged relating to the experiences of people with dementia attending day care services and their main caregivers, and the outcomes they reported. Commonalities and some important differences were found across the data from the two countries and these are presented within these four themes.

Table 2. Themes emerged from the comparative analysis	
Main themes	Subthemes
The experience of day care	<ul style="list-style-type: none"> <li>• From reluctance to acceptance and enjoyment</li> <li>• Day care structures the days</li> </ul>

	<ul style="list-style-type: none"> <li>• Conversations, mealtimes and meaningful activities</li> </ul>
The importance of relationships	<ul style="list-style-type: none"> <li>• The affirmation of the person with dementia made by the staff</li> <li>• Being in it together</li> <li>• Being apart improves being together</li> <li>• Caregiver support from staff</li> </ul>
Outcomes for people with dementia	<ul style="list-style-type: none"> <li>• Increased wellbeing</li> <li>• Positive impact on function</li> </ul>
Outcomes and experiences of caregivers	<ul style="list-style-type: none"> <li>• Reassurance and respite</li> <li>• Challenges for caregivers</li> </ul>

Quotations are used to illustrate the findings. These are identified by using acronyms including information about country, attendee or caregiver, and gender (N= Norway, S= Scotland, A= attendee, C= caregiver, F= female, M=male).

### **The experiences of people with dementia**

The experiences of attending day care were described by attendees and supplemented by the viewpoint of their caregivers.

#### *From reluctance to acceptance and enjoyment*

Most of the people with dementia in Norway and Scotland spoke about an initial reluctance to attend, with some caregivers describing their relative actively resisting.

*I think I nearly stopped because one night she said to me, there is somewhere and I don't remember where it is, but there is somewhere I go and I don't like it and I don't want to go, and I thought I can't do this anymore.*

*SCF*

However, reluctance quickly turned to acceptance and enjoyment as people were positively met by staff and other participants. Caregivers were usually the ones who initially had to persuade the person with dementia to go.

*I had a lot of skepticism to start with but I soon realized that this was something very good. My son gave me very strong advice to go there in the beginning when I strived against it.*

NAF

To take the role as the persuader was not easy for many. Negative feelings of guilt and doubt were described. Some caregivers expressed the need to “trick”, while some used low-tech devices such as a white board to orient the person about their upcoming attendance at day care and incorporate this into their daily routine. Growing acceptance of day care among people with dementia developed through their everyday experiences at the centers.

*Day care structures the days*

An important aspect of day care, as described by both attendees and caregivers, is that it structures the day with routine and repeated activities. Most centers in Norway and Scotland had a schedule similar to the one described by the following person.

*A typical day is that I get picked up by the bus and brought here. Then we have breakfast, then she, one of the ladies here, reads the newspaper so we get to know what's happening in our town, than we have a quiz and some physical exercise ..... Then we have dinner and after that we drive home again.*

NAF

The social aspects of day care were central to the routines and activities within this structure and centered on conversations, mealtimes and activities.

*Conversations, mealtime and meaningful activities*

The content of day care in Norway and Scotland was similar, with conversation and laughter often mentioned as motivation to attend the service. Experiences of inclusion and social support were highlighted as particularly important by those attending.

*We talk a lot together, and we make jokes....*

NAF

However, some participants appreciated the flexibility to withdraw from social activity during the day, just sitting at a distance and follow the conversation without taking part.

When people were asked to describe the content of day care, almost everybody mentioned meals as an important part of the service. Caregivers were reassured that their relatives were eating a good diet. Participants described tasty and nice-looking food and the positive atmosphere and social interaction during meals.



*We eat breakfast and talk ... it can take up to two hours .... we talk so much .... it is very pleasant!*

NAF

Meaningful activities were also important. Activities included singing, physical games and exercising, arts and crafts, word games and quizzes. Activities were set at a level thought to be appropriate for the day care attendees with an emphasis on fun and humor.

*Well we play dominoes or other card games and things like that and we're very good at cheating each other, you know. So people realize it's only a game, it's not looking for somebody with an Einstein brain, because there aren't many of them, so.*

SAF

These activities provided enjoyment and meant day care was a pleasant experience for most who were interviewed. Caregivers underlined the importance of meaningful and individualized activities that supported people to feel useful, such as cooking. A few people felt that some of the activities provided were not meaningful for them and could be childish.

*...I feel it's strange filling in your time throwing a ball across the room trying to hit a skittle, you know, and there isn't an awful lot of end product.*

SAF

The Norwegian participants mentioned the frequent opportunity to go out for a walk with staff and other attendees. This was an opportunity to continue their existing lifestyle.

*We walk down here in a group, all the way to the church and back .... That's alright, I have been doing that all my life ..... so I enjoy it!*

NAM

Scottish participants reported positively on outings, such as Christmas dinner at a local hotel, but these seemed to be infrequent and some people wanted to go out more often.

Increased social interaction was a particularly important outcome of activities, and therefore relationships between staff, attendees and caregivers shaped experiences of day care for all.

### **The importance of relationships**

This section looks in turn at the relationships between and within these three groups

*The affirmation of the person with dementia by staff*

Positive relationships with staff were mentioned frequently in both countries. The importance of staff being friendly with a positive approach was underlined, particularly around understanding the experience of living with dementia. Staff were described as patient, engaged, pleasant and smiling.

*It is very important that the staff are nice and friendly. Otherwise it would not have been so easy for us. It all depends on them.*

NAF

Facilitation of activities by staff involved a balance between directing activities and keeping a relaxed atmosphere. People with dementia highlighted the approachability of staff, the sense of fun they created and how they worked hard to look after those attending day care.

*They speak to you, you can talk to them.... Everything is done for you, you know. It's great to think now you can be looked after like this, you know.*

SAM

The quality of day care seemed to be highly dependent on the way staff organized the service and engaged with people. It was clear the involvement of staff was valued.

#### *Being in it together*

The relationships between people attending day care varied. Many participants in Norway described having somebody they felt close to and with whom they spent most of their time. However, people were accepting of preferences around the level of closeness.

*You realize quite quickly when people are interested in contact or not .... if not, you let them in peace. Nobody force themselves on anybody.... I am satisfied with that.*

NAM

In Scotland, although there were some examples of particular friendships, people did not usually form close relationships but enjoyed spending time with a familiar group.

*Do you have any particular friends amongst the group or...?  
Och, no, we're all...we're all in together.*

SAF

Participants seemed to have a feeling of being in the same situation and this created a sense of togetherness, which those attending appreciated and appeared to benefit from.

#### *Being apart improves being together*

Attending day care also appeared to benefit the relationship between the person with dementia and their family caregiver. Having a break from each other was considered supportive, for example giving couples something to talk about from outside the home.

*It gives him a break from me and it gives me a break from him. Then when he comes home I'm saying, have you had a good day? It gives you something else to talk about to each other.*

SCF

Some people with dementia also described respite for their relatives having a positive impact.

*To be at home and just stepping on each other's toes all day long ..... that's not good. So I don't mind coming here.*

NAM

Sustaining relationships between people with dementia and their caregivers in this way appeared to improve wellbeing for both.

#### *Family caregiver support from staff*

Some caregivers in Scotland talked about the advantage of having support from staff although this was not a formalized service. Having someone to talk to was particularly helpful for those who no longer had access to caregiver support groups due to reported cuts in funding for such services. Knowledge of dementia was an important aspect of this support.

*What I find is... it was just the fact that you were talking with someone that understood what you were saying..... just somebody to talk to.*

SCF

In Scotland, staff would take the initiative in contacting caregivers, and caregivers felt that they could call on the service themselves if they needed support. The role of the manager could be particularly important as a first point of contact. In Norway, communication between staff and caregivers varied from that described in Scotland. Some expressed the need for more direct communication, feedback and information on what happens in day care.

*There is no kind of communication between them and me. I would have liked that, now and then, to get some feed-back*

NCF

The need for more information about daily activities at the centers was requested by some caregivers, given memory problems could make it difficult for the person with dementia to tell their caregivers about what had happened during day care.

### **Outcomes for people with dementia**

A range of positive outcomes related directly to people's experiences at the centers but often had a wider impact. These outcomes included: increased wellbeing while at day care and afterwards, increased social engagement at day care and with others, small improvements in function and mood, improved relationships with caregivers, and overall satisfaction with the service. Social and relational aspects have been discussed above, and this section focuses on increased wellbeing for people with dementia and outcomes relating to function.

#### *Increased wellbeing*

Due to an emphasis on more concrete aspects of day care in interviews, discussion around therapeutic aspects was limited amongst people with dementia. When caregivers were asked about therapeutic elements of day care, they tended to focus on the general benefits of their relative getting out and having company, and increased wellbeing in a more general sense.

*My mother blossoms when she is there (...) Otherwise, she is not keen to dress up or change clothes.*

*NCF*

Keeping engaged was an important theme discussed by people with dementia and caregivers in relation to wellbeing. This active engagement incorporated mental and social involvement.

*That engages her mind, it certainly does, because she comes back and she tells me, oh, I've helped here*

*SCF*

Such engagement often led to noted improvement in mood.

*Though she might not remember what she's done, she still has a nice...a good mood, a lifted feeling about her that she's been out and that she's been somewhere.*

*SCF*

Physical activity was also an important aspect of wellbeing, although caregivers and people with dementia did not elaborate on its therapeutic benefits.

### *Positive impact on function*

People took part in a wide range of activities, as presented above. Activities were intended to be enjoyable and also to provide stimulation. Both people with dementia and caregivers reported that activities were helpful for providing mental stimulation.

*You learn things, they do things, quizzes and stuff and I always liked learning things and doing quizzes and stuff like that.*

SAF

Some caregivers reported improvements in levels of cognitive impairment and this was also expressed by some people with dementia.

*I would not be like this [cognitive abilities] if I didn't attend day care...I am almost certain of that*

NAM

Other caregivers noted an improvement in awareness and communication, linking this to the benefit of social stimulation.

While these are individual examples that may not be generalizable, they do point to the therapeutic impact of attendance at day care for some people with dementia.

### **Outcomes and experiences for caregivers**

Caregivers described outcomes of day care and how the service influenced their situation.

#### *Reassurance and respite*

Reassurance was a key outcome for many caregivers in both countries. This reassurance related to confidence in the staff firstly to notice any changes in the person and secondly to communicate these changes to caregivers.

*I think when you've got a member of staff phoning you up saying well she's just slightly more confused today, you know, something I can act upon.*

SCF

This reassurance provided 'peace of mind' from the knowledge that their relative was being well cared for.

*It feels so good to know that my mother-in-law is in a place where she enjoys herself.*

NCF

As discussed above, caregivers were able to benefit from a break or ‘respite’ while their relative attended day care. Knowing their relative was being well looked after enabled caregivers to feel comfortable taking a break from their caring role. This was a key outcome for nearly all caregivers in the study. Having time for themselves allowed caregivers to catch up with housework and shopping, in addition to having time to enjoy hobbies and pastimes. Spending time with friends and family was another important aspect of having a break.

*When I wake up in the morning, I know that this day is mine ...*

*NCF*

Where people were routinely taken to the day care center by their relatives in Scotland, caregivers felt they benefited from being able to stay and talk with staff.

*Yes, it's supposed to be my break and I should just drop her and go, but I stay for a while and sit with her and then I tend to just stay with them for a while and just get a chat, because it's just so nice and relaxed.*

*SCF*

This kind of ongoing support for caregivers was not as common in Norway due to differences in service structure as discussed above.

#### *Challenges for caregivers*

While caregivers reported positively on day care they did reflect on the challenge of getting the person ready in time for pick-up. A number of caregivers described this as ‘a struggle’. Challenges could involve getting the person washed and dressed in time, or difficulties getting the person to the toilet at the right time to avoid problems with continence.

*Then she needs the toilet, that's what happened today, I thought we were late. That's the only thing, it's not negative about the center, it's just for me I get quite stressed trying to get her ready.*

*SCF*

However, for some, this challenge could be managed by scheduling home care services to fit in with the service pick-up time. Most people described transport arrangements as satisfactory, whether using cars or a minibus. However, there were some who found the minibus service challenging, either if the person was at the beginning of a long pick-up schedule, or if the imprecise timing of the pick-up caused the person to become agitated.

*Mum will sort of wait at the window and there's a rough idea of the time because obviously it depends who's picked up before and after and things, so Mum will sort of wait, which she finds tricky, the waiting.*

SCF

Some caregivers felt that flexibility in the timing of sessions and additional days at day care would be a bonus, although due to waiting lists and demand this was not always possible.

*Yes, it gives me relief. Absolutely! However, when the day care is closed for some days, or you want to go for a vacation or something like that, it is really difficult.*

NCF

Others were satisfied with their current number of days of attendance. Overall, caregivers' experiences and outcomes from day care were very positive.

## **Discussion and Implications**

### **Different policies but similar outcomes in the two countries**

Both in Norway and in Scotland, a high level of satisfaction with day care designed for people with dementia is described by day care attendees and caregivers. Policies regarding day care as a service for people diagnosed with dementia is different in the two countries. While in Norway day care is prioritized in both dementia plans (Norwegian Ministry of Health and Care Services, 2008, 2016), such a service is not mentioned in either of the Scottish dementia strategies (Scottish Government 2010; 2013a). These differences in national policy might influence the number of centers available but do not seem to have any major impact on the value and quality of the service as described by people with dementia and their caregivers. There are similarities in the way day care is organized and in the content of activities that are offered in the two countries. There are also similar views about the importance of staff skills and competence. Additionally, the availability of meaningful activities is important. The attendees described the need for getting out of the house and spending time apart from their relatives. This seemed to influence the relationship positively as described both by day care attendees and caregivers.

### **The outcomes of day care for people with dementia**

According to the Norwegian Dementia Plan 2015 (Norwegian Ministry of Health and Care Services, 2008), the objectives of day care services are to offer meaningful activities, social

support and a safe environment to enhance coping and improve quality of life for people with dementia. Research suggests broadly similar aims across different countries (Moriarty and Manthorpe, 2012; Mossello et al., 2008; Zarit et al., 2014). The findings in our study confirm the potential of day care services in both countries to meet these objectives. There might be a challenge to offer tailored and meaningful activities to all attendees as there are a variety of individual needs according to functional level, cognitive impairment and personal preferences in the groups. Some people with dementia expressed a positive impact from day care attendance on their level of cognitive functioning. The potential to maintain or improve the level of cognitive functioning might be extended if staff were able to offer cognitive stimulation programs as part of the service. There are some promising results from such cognitive stimulation programs for people with dementia in mild to moderate stages of the condition (Woods, Aguirre, Spector, & Orrell, 2012).

The major contributors to satisfaction with day care as described by attendees and caregivers were: competent staff with a positive attitude, knowledge of dementia, sensitivity, and the ability to facilitate and provide the level of support needed for interaction in the group. The possibility for social connections at the day care was underlined to be important. However, for some participants, the possibility to withdraw from socialization in the group was stated as a necessity. ‘Getting out’ to another environment beyond their home was an important outcome for all who participated in the study, which benefited the individual as well as supporting family relationships. In Norway, ‘getting out’ extended beyond the day care center to incorporate outside activities, an aspect of day care that was less prominent in Scotland.

### **Day care as a respite service for caregivers**

According to the findings, there was a high level of satisfaction among caregivers concerning the experiences of day care as a respite service. They had time apart from their relative and time to do the things they needed to do for themselves. However, there were some practical and emotional challenges linked to day care that they faced.

The practical challenges associated with getting people ready to be picked up in the morning are significant. Previous research has shown that people whose behavior is perceived to be challenging, and who need assistance with dressing and continence, are those most likely to discontinue with day care (Mavall & Malmberg, 2007). Similarly, these aspects were



reported to cause difficulty for caregivers in this study. Assistance from home care services may be necessary to assist caregivers if this is considered to be an ongoing challenge.

It could also be difficult to motivate the person with dementia to attend day care at the beginning. Some caregivers had to deal with feelings of guilt because they left the person with dementia at the center. If a person with dementia refuses to go or expresses dissatisfaction with day care placement, it often creates feelings of guilt and stress (Zank & Schacke, 2002). However, the data that emerged from this study indicated that the initial resistance to attend day care is temporary for most attendees. This knowledge could be used to reassure caregivers that, even though the person with dementia may be reluctant to attend the service in the beginning, there is a high possibility that they will come to enjoy the service fairly quickly.

The positive potential for day care to alleviate feelings of burden and stress among caregivers has been well-documented (Zarit et al., 2014). Yet, the need for caregivers to be convinced that their relative will be well cared for at day care should not be underestimated. Previous research shows that caregivers need to be reassured that day care is a high quality service: they need to know the person with dementia will be well treated and that staff have high competence in dementia care (Tretteig et al., 2016). Additionally, the existence of a tailored program based on specific knowledge of the person's needs and a feeling of shared responsibility with staff are described as examples of good quality (de Jong & Boersma, 2009; Phillipson & Jones, 2012). If we wish caregivers to support the use of day care, evidence about the quality of care therefore needs to be available and accessible.

Moreover, the wellbeing of caregivers is found to be a predictor of entry to residential care (Cohen-Mansfield & Wirtz, 2009; Liu, Kim, & Zarit, 2015). Services that have a positive impact on caregivers' wellbeing and their relationship with the person with dementia may therefore have the potential to delay the entry to residential care. This is potentially an important contribution of day care. Given the positive outcomes of day care to provide respite and reassurance as reported by caregivers in this study, this would suggest that day care services should be prominent in national policy frameworks as a means for families to manage the challenges associated with supporting a person with dementia to live at home.

### **Limitations and gaps in day care**

While the findings are mainly positive, there were some identified limitations and gaps in services. The utilization of day care in Norway is described as low (Norwegian Ministry of Health and Care Services, 2016) and there could be several explanations for this. People attending day care in this study describe their initial reluctance about using the service. The challenges connected to initial attendance were also articulated by caregivers. The potential benefits of day care both for people with dementia and their caregivers could be highlighted more fully by local authorities. The possibility for a gradual transition might be offered, as the initial reluctance seemed to turn to acceptance and enjoyment after a short period of time.

A lack of flexibility in the service was a limitation in both countries. The findings suggest a need for more flexible opening hours and some participants asked for additional days at day care. The inappropriateness of some activities was also mentioned: there is a need to tailor activities to meet individual needs and cultural acceptance. A person-centered approach (Kitwood, 1997) as a value base for day care is therefore necessary.

The need for caregiver support from the staff was mentioned from participants in both countries. Caregivers in Scotland experienced a higher level of face-to-face communication and support from staff than participants in Norway. Caregiver support in most municipalities in Norway is organized in ‘Schools for caregivers’ offering four to six meetings with information about dementia and participation in support groups. The existence of this program may explain the lack of support offered to caregivers by staff in Norwegian day centers. Previous research indicates that support provided by day care staff to improve caregivers’ knowledge and skills in dementia care might delay the need for institutional placement (Balla et al., 2007; Cho, Zarit, & Chiriboga, 2009). Evidence also suggests that day care which provides respite for caregivers may be cost-effective in the long-term (Knapp, Iemmi, & Romeo, 2013). Therefore, greater support for caregivers within day care service structures might have long-term beneficial outcomes in addition to having immediate value for caregivers. However, as the dementia disease develops and the symptoms of cognitive and practical impairment increases there will be need for a higher level of care than can be offered by day care services.

### **Methodological considerations**

The use of in-depth interviews with people with dementia and caregivers was considered a suitable method to understand experiences and outcomes of day care. Talking to people with

dementia attending day care was crucial to understanding their experiences. However, people with dementia were more comfortable talking about concrete aspects of day care such as activities and meals, rather than more subjective topics relating to the impact of the service. While this should not hinder researchers conducting interviews with people with dementia, complementing interviews with observational research may enhance our understanding of day care outcomes. To gain broader knowledge and understanding of the content and structure of the service, adding interviews with staff would have been useful.

### **Implications for policy and practice**

Based on findings in the current study, the positive impact of day care designed for people with dementia seem to be clear. Day care should be recognized as an important service for home-dwelling people with dementia and, while individual preferences must be respected, people could be encouraged to attend based on the finding of initial reluctance turning relatively quickly to enjoyment. Highlighting the potential benefits may be particularly helpful for those who live alone and persistently refuse to attend, given research has indicated that many in this group may be living with undiagnosed depression and hold misconceptions about day care services (Durand et al., 2009).

The need for skilled and competent staff in day care is important to meet the needs of people with dementia and their caregivers. The possibility for face-to-face- communication and support from staff for caregivers should be emphasized. The described differences in staff roles could lead to cross-national learning. Models to increase flexibility in the service should be explored and experiences from such projects should be shared internationally.

### **Conclusion**

Specialist day care seems to provide important support and care for people with dementia and valued respite and reassurance for caregivers. This paper has added depth to an under-researched aspect of dementia care to provide knowledge about outcomes and experiences. It has enhanced understanding of the potential contribution of day care to the support of people with dementia and their caregivers and highlighted commonalities across two countries despite significant differences in policy contexts. Day care could be viewed as a key service for people with dementia and access to it enabled through policy and practice frameworks. However, more research is needed in a larger sample to further explore the effect of day care designed for people with dementia both on the attendees and their caregivers.

## Funding

The work was supported by the Norwegian Research Council (222083/H10) and Alzheimer Scotland.

## References:

- Balla, S., Simoncini, M., Giacometti, I., Magnano, A., Leotta, D., & Pernigotti, L. M. (2007). The daily center care on impact of family burden. *Archives of Gerontology and Geriatrics*, 44 Suppl 1, 55-59. doi:10.1016/j.archger.2007.01.008
- Cho, S., Zarit, S. H., & Chiriboga, D. A. (2009). Wives and daughters: the differential role of day care use in the nursing home placement of cognitively impaired family members. *The Gerontologist*, 49, 57-67. doi:10.1093/geront/gnp010
- Cohen-Mansfield, J., & Wirtz, P. W. (2009). The reasons for nursing home entry in an adult day care population: caregiver reports versus regression results. *Journal of Geriatric Psychiatry and Neurology*, 22, 274-281. doi:10.1177/0891988709335799
- Dahm, K. T., Hafstad, E., And Dalsbø, T. K. (2014). *Effekten av tilrettelagt dagsentertilbud til personer med demens - oppdatert systematisk litteratursøk*, [eng: The effect of day care centers for people with dementia-an updated literature review]. Oslo: Norwegian Knowledge Centre for the Health Services. <http://www.kunnskapssenteret.no/publikasjoner/effekten-av-tilrettelagt-dagsentertilbud-til-personer-med-demens>
- de Jong, J. D., & Boersma, F. (2009). Dutch psychogeriatric day-care centers: a qualitative study of the needs and wishes of carers. *International Psychogeriatrics*, 21, 268-277. doi:10.1017/S1041610208008247
- Dewing, J. (2007). Participatory research: a method for process consent with persons who have dementia. *Dementia*, 6, 11-25.
- Durand, M., James, A., Ravishankar, A., Bamrah, J. S., & Purandare, N. B. (2009). Domiciliary and day care services: Why do people with dementia refuse? *Aging & Mental Health*, 13, 414-419. doi:10.1080/13607860902879318
- Graneheim, U. H., & Lundman, B. (2004). Qualitative content analysis in nursing research: concepts, procedures and measures to achieve trustworthiness. *Nurse Education Today*, 24, 105-112. doi:10.1016/j.nedt.2003.10.001
- Gustafsdottir, M. (2014). The Family's Experience of Sharing the Care of a Person with Dementia with the Services in Specialized Day-Care Units. *Dement Geriatr Cogn Dis Extra*, 4(3), 344-354. doi:10.1159/000358823

- Huang, S., Griva, K., Bryant, C. A., & Yap, P. (2017). Non-use of day care services for dementia in Singapore - a dilemma for caregivers. *Int Psychogeriatr*, 29(3), 455-466.  
doi:10.1017/S1041610216001940
- Ishizaki, J., Meguro, K., Ohe, K., Kimura, E., Tsuchiya, E., Ishii, H., . . . Yamadori, A. (2002). Therapeutic psychosocial intervention for elderly subjects with very mild Alzheimer disease in a community: the tajiri project. *Alzheimer Disease & Associated Disorders*, 16, 261-269.
- Kitwood, T. (1997). *Dementia reconsidered : the person comes first*. Buckingham: Open University Press.
- Knapp, M., Lemmi, V., & Romeo, R. (2013). Dementia care costs and outcomes: a systematic review. *International Journal of Geriatric Psychiatry*, 28, 551-561. doi:10.1002/gps.3864
- Liu, Y., Kim, K., & Zarit, S. H. (2015). Health trajectories of family caregivers: associations with care transitions and adult day service use. *Journal of Aging and Health*, 27, 686-710.  
doi:10.1177/0898264314555319
- Malterud, K. (2012) Systematic text condensation: a strategy for qualitative analysis. *Scandinavian Journal of Public Health* 40,795-805.doi:10.1177/1403494812465030
- Mavall, L. & Malmberg, B. (2007) Day care for persons with dementia. *Dementia*, 6, 27-43.
- Moriarty, J. & Manthorpe, J. (2012) Research Report: Diversity in older people and access to services – an evidence review. London: AgeUK
- Mossello, E., Caleri, V., Razzi, E., Di Bari, M., Cantini, C., Tonon, E., . . . Masotti, G. (2008). Day Care for older dementia patients: favorable effects on behavioral and psychological symptoms and caregiver stress. *International Journal of Geriatric Psychiatry*, 23, 1066-1072.  
doi:10.1002/gps.2034
- Needham, C. (2013). Personalized commissioning, public spaces: the limits of the market in English social care services. *BMC Health Services Research*, 13 Suppl 1, S5. doi:10.1186/1472-6963-13-S1-S5
- Nogales-González, C., Losada-Baltar, A., Márquez-González, M., & Zarit, S. H. (2014). Behavioral Intervention for Reducing Resistance in Care Recipients to Attending Adult Day Care Centers: A Pilot Study. *Clinical Gerontologist*, 37(5), 493-505. doi:10.1080/07317115.2014.907592
- Norwegian Ministry of Health and Care Services (2016). *Dementia plan 2020. A More Dementia-friendly society*. Oslo: Ministry of Health and Care Services.  
[https://www.regjeringen.no/contentassets/3bbec72c19a04af88fa78ffb02a203da/dementia\\_-\\_plan\\_2020\\_long.pdf](https://www.regjeringen.no/contentassets/3bbec72c19a04af88fa78ffb02a203da/dementia_-_plan_2020_long.pdf)
- Norwegian Ministry of Health And Care Services(2008) *Dementia Plan 2015 - Making the most of the good days*. Oslo: Ministry of Health and Care Services.

[https://www.regjeringen.no/no/dokumenter/demensplan-2015-den-gode-dagen/id663429/?q=demensplan 2015](https://www.regjeringen.no/no/dokumenter/demensplan-2015-den-gode-dagen/id663429/?q=demensplan+2015)

- Phillipson, L., & Jones, S. C. (2012). Use of day centers for respite by help-seeking caregivers of individuals with dementia. *Journal of Gerontological Nursing*, 38, 24-34. doi:10.3928/00989134-20120307-05
- Reinar, L., Kirkehei, I., Dahm, K., & Landmark, B. (2011). *Effekten av tilrettelagt dagsentertilbud*. Oslo: Norwegian Knowledge Centre for the Health Services. <http://www.kunnskapscenteret.no/nyheter/dagaktivitetstilbud-for-personer-med-demens-kan-vaere-bra>
- Robertson, J. M., Bowes, A., Gibson, G., McCabe, L., Reynish, E. L., Rutherford, A. C., & Wilinska, M. (2016). Spotlight on Scotland: Assets and Opportunities for Aging Research in a Shifting Sociopolitical Landscape. *The Gerontologist*, 56, 979-989. doi:10.1093/geront/gnw058
- Rokstad, A. M., Halse, I., Tretteteig, S., Barca, M. L., Kirkevold, O., McCabe, L., . . . Engedal, K. (2014). Effects and Costs of a Day Care Centre Program Designed for People with Dementia - A 24 month Controlled Study. *Journal of Clinical Trials*, 4. doi:org/10.4172/2167-0870.1000182
- Scottish Government (2010) Scotland's National Dementia Strategy. Retrieved March 16, 2017, from <http://www.gov.scot/Publications/2010/09/10151751/17> (accessed March 16, 2017).
- Scottish Government (2013a) Scotland's National Dementia Strategy 2013 – 2016. Retrieved March 16, 2017, from <http://www.gov.scot/Topics/Health/Services/Mental-Health/Dementia/DementiaStrategy1316> (accessed March 16, 2017).
- Scottish Government (2013b) The Social Care (Self-direct support) (Scotland) Act 2013. Retrieved March 16, 2017, from <http://www.legislation.gov.uk/asp/2013/1/contents> (accessed March 16, 2017).
- Strandenaes, M. G., Lund, A., & Rokstad, A. M. (2017). Experiences of attending day care services designed for people with dementia - a qualitative study with individual interviews. *Aging Ment Health*, 1-9. doi:10.1080/13607863.2017.1304892
- Tretteteig, S., Vatne, S., & Rokstad, A. M. (2016). The influence of day care centres for people with dementia on family caregivers: an integrative review of the literature. *Aging & Mental Health*, 20, 450-462. doi:10.1080/13607863.2015.1023765
- Woods, B., Aguirre, E., Spector, A. E., & Orrell, M. (2012). Cognitive stimulation to improve cognitive functioning in people with dementia. *Cochrane Database Syst Rev*, CD005562. doi:10.1002/14651858.CD005562.pub2

- Zank, S., & Schacke, C. (2002). Evaluation of geriatric day care units: effects on patients and caregivers. *The Journal of Gerontology: Psychological Sciences and Social Sciences*, 57, 348-357.
- Zarit, S. H., Kim, K., Femia, E. E., Almeida, D. M., & Klein, L. C. (2014). The effects of adult day services on family caregivers' daily stress, affect, and health: outcomes from the Daily Stress and Health (DaSH) study. *The Gerontologist*, 54, 570-579. doi:10.1093/geront/gnt045
- Zarit, S. H., Stephens, M. A., Townsend, A., & Greene, R. (1998). Stress reduction for family caregivers: effects of adult day care use. *The Journal of Gerontology: Psychological Sciences and Social Sciences*, 53, 267-277.

