

Facilitation of activities for people with dementia in day care: a qualitative study exploring the experiences of staff

This article was published in the following Dove Press journal:
Journal of Multidisciplinary Healthcare

Margit Gausdal Strandenæs¹⁻³

Anne Lund⁴

Anne Marie Mork Rokstad^{1,5}

¹Norwegian National Advisory Unit on Ageing and Health, Vestfold Hospital Trust, Tønsberg, Norway; ²Department of Geriatric Medicine, Oslo University Hospital, Oslo, Norway; ³Institute of Health and Society, Faculty of Medicine, University of Oslo, Oslo, Norway; ⁴Faculty of Health Sciences, Department of Occupational Therapy, OsloMet – Oslo Metropolitan University, Oslo, Norway; ⁵Faculty of Health Sciences and Social Care, Molde University College, Molde, Norway

Background: Day care service (day care) is recommended as an activity service for home-dwelling people with dementia in Norway. However, there is limited knowledge about strategies to promote engagement and participation in activities at day care. The aim of this study was to gain understanding of the staff's experiences on how to enhance engagement and participation in activities for attendees.

Methods: The study has a qualitative design, using group interviews with staff and field observations at day care designed for people with dementia. Thematic content analysis was used to analyze interviews, and the findings from the observations were used to illuminate the findings in the interviews. Three group interviews including a total of 10 staff participants were conducted. Additionally, 35 attendees were observed during 2 days of field observations at each day care.

Results: The main theme that emerged from the analysis was the staff's primary objective to make meaningful days for the attendees. To achieve this, the importance of having individual knowledge about the attendees to enhance relationships, creating a balanced group composition, personal competence and skills of the staff, and the importance of using activities in different ways, was highlighted. Most findings from the field observations coincide with those in the interviews. However, the observations revealed that the staff seemed to have insufficient knowledge of offering individual tailored and structured meaningful activities to the attendees. There is a potential of including the attendees even more in the ongoing activities.

Conclusion: Staff play an important role in promoting and facilitating activities to increase engagement and participation in activities. There is a potential for greater structured use of activities and cognitive stimulation. To avoid occupational injustice and the risk of decreased health and well-being among home-dwelling people with dementia, more differentiated and individual tailored services are needed.

Keywords: day care, dementia, activities, participation, engagement, facilitating

Introduction

Dementia is a growing, global age-related disease,^{1,2} and with no cure in sight, developing and evaluating programs that enhance the quality of life for those afflicted are crucial. Day care service (hereafter, day care) is recommended as an appropriate service for people with dementia living at home.³⁻⁷ Despite several similarities in the goals and intentions of day care programs offered by service providers, the target groups, organization, location, and content of the services seem to differ. This means that day care is not standardized and, therefore, presents

Correspondence: Margit Gausdal Strandenæs
Norwegian National Advisory Unit on Ageing and Health, Vestfold Hospital Trust, PO Box 2136, Tønsberg 3103, Norway
Tel +479 921 6521
Email margit.gausdal@aldringoghelse.no

challenges to research.⁸ However, day care is described as aiming to meet three main intentions: 1) to increase the health and well-being of attendees, 2) to increase the health and well-being of caregivers, and 3) to motivate family caregivers to provide care and, thereby, delay or eliminate the need for nursing-home admittance. The content is linked to everyday activities, addressing safe surroundings, social interaction, and physical and cognitive stimulation.⁹ Day care for people with dementia might contribute to the reduced incidence of behavior problems, a lower burden of care for family caregivers, and less use of psychotropic drugs. No effect on level of functioning is revealed.^{10,11}

In Norway, day care designed for people with dementia is a health-care service mainly run and financed by the municipalities and offered to home-dwelling people with dementia in about 70% of the municipalities.¹² The provision of day care for people with dementia was one of the main priorities of the first governmental Norwegian Dementia plan,¹³ and maintained in the second Dementia plan.¹⁴ From year 2020 day care for people with dementia will by law be established in every municipality.¹² The dementia plan does not provide detailed description of the content and organization of the day care, and these paves for local adaption and variations. Day care is most often given on daytime in weekdays, but some is also open at afternoon and weekends.^{12,15} The size of the day care varies regarding size of the municipalities and demands. How many days the attendees go to day care varies regarding how many days the day care is open and the attendees and family caregiver needs.¹⁵ However, attending 2 days a week is considered as a minimum and it is recommended to have smaller groups (6–8) with minimum two staff present. Day care is most common as a traditional model established in institution/nursing home and as a center model established in centers for older adults.^{12,15} Staff working at day care is mainly health-care professionals and have experiences working with people with dementia.¹⁶

Activities to the attendees are offered as a way of meeting the intentions of day care. In an occupational science, perspective activities can be described as occupations understood as “chunks or units of activities, classified and named by the culture according to the purpose they serve.”¹⁷ Occupational science is a multiprofessional field that understands humans as occupational beings and addresses the relation between occupation and health and well-being.¹⁸ Thus, occupations can be understood as

meaningful activities created by the individuals.¹⁸ During the progression of the dementia disease process, people experience challenges in maintaining their abilities to participate in previously valued occupations.¹⁹ Thus, the loss of the ability to engage in occupations, as occurs in progressive dementia, can contribute to unmet human needs and threaten the health and well-being of those with dementia.²⁰

To the best of our knowledge, there is a limited number of studies that examine staff’s experiences concerning how to facilitate meaningful activities in day care service for people with dementia. Two studies from the 1990s focused on the individual perspective and the enhancement of activity to prevent behavior problems²¹ and how the individual perspective in choosing activities could affect well-being.²² Individualization based on personal attention, comfort, and assistance with activities was an integral part of the activities. The aim was to maintain a calm environment by balancing the number of activities. Later, Gustafsdottir⁵ stated that a well-organized and familiar day care based on the approaches of reduced demands, guidance, and accompaniment supports and enriches the lives of the attendees. The staff should seek “normality” and acceptance and minimize the occurrence of stress in the environment.⁵ Qualitative studies of attendees’ experiences with day care revealed the importance of the skills and attitudes of day care staff for the attendees to enjoy and benefit from the service.^{3,6,23,24}

The aim of this study was to gain an understanding of the staff’s experiences regarding how they enhance engagement and participation in activities of attendees with dementia in the day care setting.

Methods

Design

This study has a qualitative design using field observations and group interviews with staff at three day care services designed for people with dementia.^{25,26} The main methodological approach was the group interview; field observations were used to provide additional information and a more comprehensive interpretation of the interview findings.

Sample and setting

The study is part of the research project “Effects and costs of day care centre programmes designed for people with dementia: A 24-month controlled study (ECOD),” which uses both quantitative and qualitative methods to evaluate

the effect of day care on people with dementia and their family caregivers.²⁷ Three day care services who took part in the ECOD study were asked to participate in the present study, and all three accepted the invitation. They were selected to represent both rural districts and cities, as well as various regions of Norway. Two of them were day care as traditional model located at a care institution and one as a center model located in a center for older adults. All three were well-organized and designed for people diagnosed with dementia. The three day care varied in organization, size and number of staff (Table 1).

A total of 35 attendees were observed for six days during their attendance at day care (2 days at each day care). At the end of the second day of observation, group interviews were conducted with staff at each day care when the attendees had left. The number of staff participating in the interviews was determined by the number of staff members present at the day care, and hence, the total number of participants was 10. As listed in Table 1, in day care 1 staff in addition to their leader took part in the interview. For day care 2 and 3 available staff participated. The group size varied from two to five participants. The participants were all female, and their professional backgrounds were as follows: nurses (3), auxiliary nurse (5), occupational therapist (1), and assistant occupational therapist (1). The interviews lasted for 60 mins and were conducted at the day care locations. They were led by the first author (MGS) with support from the third author (AMMR), who took notes and summarized each discussion.

Data collection

Field observation was used to gather information about activities at day care, the amount of time used for each

activity, the engagement and participation of the attendees, and interactions between attendees and staff. Notes were taken continuously during the observations and completed following each session.

A semi-structured interview guide was used in the interviews.^{26,28,29} The questions aimed to gain an understanding of the staff's experiences and reflections on how to enhance attendees' engagement and participation in the day care activities and focused on the following themes: planning the content of the day care activities, actions taken to enhance attendees' engagement and participation, and staff's reflections on their role at the day care. The themes were introduced as open questions and followed by additional questions that explored the responses from the staff in greater depth.

Since the interviews were conducted at the end of the second day of observations, questions about observed occurrences could be added to the interview guide.

Ethical consideration

The project (ECOD) was funded by unrestricted grants from the Research Council of Norway and was accepted by the Regional Committee in Ethics in Medical Research in South-East Norway.

The attendees were informed about the observation to take place at the day care facility. No personal or identifiable information about the attendees was collected, and therefore, written consent was not required to conduct the observations.

As people with dementia are considered to be a vulnerable group, the influence of the researcher's presence was continuously considered. Any indication of

Table 1 Day care characteristics

	Day care 1	Day care 2	Day care 3
Location/model	Public space/ center model	At nursing home/ traditional model	At nursing home/ traditional model
Number of attendees each day	8	8	13
Total number of attendees	8	24	28
Number of opening days for people with dementia	2	3	6
Number of staff per day	2	2	4
Total number of staff	2	2	8
Staff education			
• Without formal education	0	0	3
• High school degree	1	1	4
• University degree	1	1	1

distress or negative influence on the attendees would have resulted in the researcher interrupting the observation and leaving the area.³⁰ If the attendees expressed interest and asked the researcher questions during the observation, these were answered in a friendly manner. Otherwise, the researcher tried not to attract attention.

The participants in the group interviews gave their written-informed consent to take part. Names and other identifying characteristics have been modified to preserve the participants' anonymity.

Analysis

The information from the group interviews was analyzed first, and subsequently, the observation notes were added to illuminate the interview findings.

Analysis of the group interviews

Thematic content analysis was used with the purpose of identifying, analyzing, and reporting patterns and themes in the transcribed material.³¹ The analyses were performed in accordance with a thematic six-step analysis: 1. familiarization with the data through repeated readings of the transcripts; 2. systematically generating initial codes across the entire dataset; 3. searching for themes and identifying themes among the generated codes; 4. identifying themes to check for internal and external validity reviewing themes; 5. identifying and naming themes; and 6. reporting.³¹ NVivo 10 software was used for data management and coding. The analysis was inductively driven and searched for themes emerging in the entire body of material rather than attempting to fit the material into a pre-existing coding frame.³¹ However, the authors were not without theoretical understanding in the analysis as themes and sub-themes became apparent in the context of the study's objectives and existing theory.³¹ Codes were initially assigned by the first author and then discussed with the co-authors repeatedly to reach consensus on the naming of themes and sub-themes. During the process of identifying and naming themes, we alternated between semantic and latent interpretations of the themes and sub-themes.

Analysis of the field observations

The objective of the observations was predetermined and looking for the attendees' engagement in activities and their interaction with staff, and hence, the notes were structured to align with these objectives. The first degree of interpretation involved sorting the descriptive notes into

activities, the amount of time used for them, and attendees' levels of engagement and interaction with staff and other attendees. The process of analyzing the field observations began while data were gathered and field notes were written.²⁵ The descriptive notes taken during observations were not analyzed separately but were combined with the findings of the group interviews, and together they provided a second degree of interpretation.²⁵ As the findings from the observations were used to illuminate the findings of the group interviews, no extended analysis of the entire body of observation material was conducted.

Results

Findings of the group interviews

One main theme with four sub-themes emerged from the analysis, as listed in Table 2. The main theme was meaningful days as the main objective. The sub-themes were: (1) the importance of individual knowledge about the attendees to enhance relationships; (2) the challenge of group composition; (3) the need for personal competence and skills among staff; and (4) activities used in different ways to create a meaningful day. In the presentation of the findings, representative quotations will be used to illuminate findings and to illustrate staffs' experiences and reflections.

Meaningful days as the main objective

The staff seemed to be in agreement about the main objective of the day care: to create a meaningful day for the attendees. To achieve this, they made an effort to fill the days with humor and laughter, to give attendees a sense of belonging by accepting and including the attendees, and to facilitate activities that the attendees could master and enjoy.

Everyone should feel well... Everyone should be seen... and everyone should leave day care with a good feeling – a feeling of well-being and mastery. [Day care 3]

Table 2 Main findings presented as theme and sub-themes

Theme	Sub-theme
Meaningful days as the main objective	Importance of individual knowledge about the attendees to enhance relationships The challenge of group composition The need for personal competence and skills among staff Activities used in different ways to create meaningful days

The importance of individual knowledge about the attendees to enhance relationships

The staff mentioned the attendees as individuals, indicating that they all have unique personalities, preferences, and different functional levels. They stated the importance of knowing the attendees in order to create a meaningful day for them, and the only way to gain this knowledge was to talk with them. During the first period in the day care, the staff usually have a lot of time for individual conversations with the attendees and opportunities to get to know who they are and what they prefer to do at day care.

Observation was also used to assess what the attendees enjoyed and what they disliked doing. The staff at one of the day care centers made a home visit prior to day care admission in order to get to know the person in his or her own home.

The importance of establishing contact with family caregivers in order to obtain information about the attendee's life history and previously preferred activities was emphasized.

The process of obtaining individual knowledge about the attendees was experienced as easier when the attendee was admitted to day care in an early stage of dementia. Then, he or she could tell his or her own story, supplemented by family members. In a later stage of dementia, the staff had to rely more on information from family caregivers, other health-care staff, and their own observations.

If they start at day care in an early stage of the disease, we are lucky, as we then have a good opportunity to get to know them... the person they were... and then it is easier when the disease progresses with reduced memory. Our hope is to get them into the service, the sooner the better. [Day care 2]

However, none of the staff shared any experiences or knowledge about how to tailor and plan activities based on the individual knowledge they had obtained. They only stated the importance of getting this information.

The challenge of group composition

The objective to enhance group activities at day care was discussed in all interviews. To include attendees with broad variations in levels of cognitive and physical functioning and individual preferences in one group activity was experienced as challenging. If the attendees differed too much in their levels of cognitive and/or physical functioning, the activities

often had to be adjusted to meet the capabilities of those with the most severe level of impairment. The solution was to divide the group of attendees during the day when enough staff were present to make this possible.

Interviewer: Does the variation in the group have any influence on what activities you can offer?

We need to consider what the plan is for the day. We can separate and do different activities. Some would like to go outside and have more physical activity, and others don't want to take part in that at all. [Day care 1]

As an alternative to dividing the group during the day, attendees with similar cognitive and functional abilities could be grouped together and attend day care on different days in order to make the groups more homogeneous. The staff at the day care that made home visits ahead of admittance to day care services was able to determine whether the applicant would fit into the existing group based on his or her functional level, occurrence of depression, or challenging behaviors.

We have different days with different activities. For example, we have some activities on Monday and Tuesday, but other activities on Wednesday because then we have a group of younger and more physically fit people and we can take a longer walk outside. [Day care 3]

Occurrence of challenging behaviors or an increased need for practical assistance indicated that day care was not the appropriate program for the applicant. The argument in defense of this practice was based on the potential negative impacts on the individuals currently in the group and their limited ability to take part in the available activities.

Interviewer: When is the time to quit day care?

When they [attendees] are not able to get out. Because they can't be an obstacle for five others. [Day care 1]

The need for personal competence and skills among staff

The staff reflected on the kinds of personal competence and skills required to work at a day care and be able to facilitate a good day for attendees. These skills were listed as knowledge about dementia, an understanding of how to communicate with people with dementia, and the ability to modify activities based on the various attendees' abilities and levels of functioning. Additionally, the staff's ability to use their own-lived experience to be personally

involved in the lives of the attendees was highly recommended.

Not only do you need to be professional, you have to take the risk to go outside your comfort zone and give a lot of yourself. [Day care 3]

The staff had to use their personal skills and a positive approach to motivate and guide the attendees to participate in activities. They emphasized the ability to be flexible, to be secure, to use humor, and to be creative and empathic in order to enhance activities. It was important for them not only to do a job they were paid for but also to have a personal desire to make a difference in another person's life.

To stimulate collegial teamwork, the need for regular meetings in the morning and at the end of the day was highlighted. The staff was collaborating closely and felt dependent on each other. The way they acted as a team influenced their job satisfaction and was considered to affect the well-being of the attendees and, furthermore, the results of the activities they offered.

To have a good mood and good collegial teamwork have a major implication for how well you work together. (Day care 2)

Activities to create meaningful days

The staff expressed that most of the attendees enjoyed day care. This statement was based on the observations of the attendees' engagement, awareness, and smiles and laughter. Additionally, their counting of the number of days until the next day they would attend day care and the care and consideration they showed for the staff were interpreted as positive signals of well-being.

We have one man here on Mondays... He expresses: "Oh... is it a whole week until next time?" Every time he leaves, he comments that he looks forward to next Monday. This is something positive with day care; the attendees get something to look forward to. [Day care 2]

The staff could sometimes experience that attendees arriving in the morning with a reserved attitude and in a negative mood went home in the afternoon with a smile on their face and their heads held high. These observations were shared by the staff as proof that they had reached their goal of providing a meaningful day for the attendees.

The staff described that the activities they offered had to be continuously evaluated and adjusted to tailor the attendees needs and level of function. Thus, there was a need for flexibility and creativity on a day-to-day basis.

As most of the staff had been working at the day care for a long time, they had experiences regarding what kinds of activities were considered successful. Singing, dancing, taking a walk, and talking about the daily news or earlier happenings around the table were activities mentioned as likely to enhance well-being. Trips in the area with their mini-bus were also appreciated. The attendees were always invited to contribute to the planning of activities, but as experienced by the staff, they seldom came up with any suggestions. On those occasions when the attendees had requests, the staff usually followed up on them.

The attendees don't have many suggestions for activities; we try activities and evaluate. Eventually we have experienced what kinds of activities that are considered to be successful. [Day care 1]

Staff from one of the day care services underlined the importance of not being too restrictive regarding activities. The attendees' levels of functioning and their abilities had to be taken into consideration. However, the staff stated that the focus tended too often to be on the attendees' limited capacities rather than on their resources. They wanted to practice a more open-minded attitude and looked at the possibilities.

We like to think that there are no limitations. We are not afraid to try. To be diagnosed with dementia does not mean that you are not able to be active anymore... you just need some guidance and facilitation. [Day care 3]

Findings in the field observations

Activities offered

The activities offered at the participating day cares did not differ essentially. The days started and ended with a meal, and mealtimes occupied most of the time during the opening hours. Other activities offered were sitting at the table making small talk and sharing news, having quizzes, reminiscing, and singing. These activities filled the gaps between other activities such as physical exercise sessions, taking walks around the neighborhood, or playing games.

During the observations, one of the day cares offered music and dancing, while another had a weekly trip to the woods for a walk.

The level of engagement and participation

In general, the attendees were engaged, and they participated in activities and seemed motivated to stay at day care. This interpretation is based on the observation of smiles, awareness, eye contact and their willingness to participate

in activities. However, a couple of the attendees seemed to have a difficult day and were in need of extra support and comfort. They expressed sadness, and some acted restless and started wandering. In these cases, the staff was present to give support and comfort. Occasionally, the staff shielded the uncomfortable person by leading him or her to a quieter environment for one-to-one support.

The duration of engagement varied as a few attendees were engaged and participated during the whole stay; others were passive at first but showed increasing engagement; and a couple did not engage in activities at all. These attendees were wandering or stirring about in the room or down on the floor, sometimes with closed eyes. Activities with high levels of engagement were meals and those involving music. Additionally, gymnastics and walking enhanced engagement and participation.

Music and dance seemed highly valued as observed from the attendees' smiles, laughter, and engagement. However, at the end of the day some seemed a bit tired and exhausted. During a trip to the forests for a walk, the group ended up waiting for the bus to take them back to the day care. During this period of waiting, little engagement was observed, and one of the participants started wandering around.

Before mealtimes, the attendees usually sat waiting and watching the staff making preparations. There was only one observation of an attendee engaged in meal preparations or in cleaning the dishes afterwards.

Abilities to enhance and facilitate activities

The flexibility and adjustment regarding activities was visible. The staff seemed to sense when to adjust or end an activity. Most of the time, staff organized the activities and provided the attendees with the equipment they needed without engaging them to take part.

The staff showed interest in the attendees and affirmed their uniqueness by talking about their life stories, their personal characteristics, and their likes and dislikes. This information was used to motivate them to take part in activities or to confirm their identity during activities. Smiles and touches were used to encourage participation in the activities. In contrast, some observations revealed that the attendees were simply told what to do without an invitation to participate.

Discussion

The staffs' intentions of creating meaningful days for the attendees and their reflections about how to facilitate activities are discussed under the following headings: (i) A meaningful day, (ii) Facilitating activities to enhance

engagement and participation. Additionally, we will discuss access to day care activities by people with dementia enlightened by a human rights perspective related to the findings that occurrence of challenging behaviors or an increased need for practical assistance indicated that day care was not the appropriate program for the applicant.

Meaningful days

Contributing to a good and meaningful day was stated as the main objective of day care. In previous research, the effect of day care is inconsistent, and the results are based on findings from studies with limited quality.^{10,17} Due to the variety of content and organization of day care, it is difficult to compare results from studies and identify clear evidence of possible effects.⁷ However, it is reasonable to presume that having a good day, meeting other people, and coping with activities all promote well-being and reduce feelings of loneliness and isolation in day care attendees. The positive influence of day care to provide structure to everyday life, as shown in previous studies, could be considered beneficial.^{3,5,6,32} Additionally, interviews with day care attendees have demonstrated the importance of their subjective feelings of day care contributing to cognitive and physical stimulation.^{3,23}

The aim and content of day care, as described in the current study, are not fully in line with the intentions and Norwegian national guidelines recommendations. The Norwegian government has addressed the importance of offering cognitively and physically stimulating activities, as well as social activities, in order to promote a meaningful day and enhance well-being that, in turn, can help people with dementia to remain in their own homes.³³ The importance of physical activity was highlighted by the staff. However, they tend to organize pleasant and comfortable activities like going for a walk at a moderate pace and doing some simple physical exercises rather than offering specific training that aims to strengthen the attendees' physical capacity. Cognitive stimulation was not mentioned in the interviews nor was it observed. According to the national guidelines, there should be a focus on maintaining and/or improving ADL and cognitive functioning in addition to physical exercise to enhance health and well-being.³³

Previous research has revealed the effects of interventions with activities that focus on cognitive and physical performance. The recently published Lancet report – Dementia, prevention, intervention, and care concludes that group-based cognitive stimulation therapy (CST) improves cognition in patients with mild to moderate dementia.² This is also emphasized in a recent exploratory study on CST.³⁴

Physical exercise programs for people with mild to moderate dementia have been found to be feasible and well tolerated. Studies have shown small but positive effects of such programs on physical functioning.² A recent meta-analysis revealed the potential of combining cognitive and physical exercise interventions to elicit cognitive benefits in older adults with mild cognitive impairment or dementia.³⁵ Additionally, community occupational therapy has been found to be effective for older people with dementia, having shown improvement in their daily functioning, quality of life, mood, and health status.³⁶ These findings are relevant for the content of day care services, and hence, it is reasonable to presume that there is a potential to promote health and independency for day care attendees by using more structured physical and cognitive training activities.

Facilitating activities to enhance engagement and participation

The staff underlined several factors of importance for enhancing participation in activities including general knowledge about dementia, knowledge of the attendees' individual needs, communicative skills, facilitation, normalization, and teamwork. The presence of these factors was illustrated during observations, and they correspond with the findings of Gustafsdottir⁵ and Phinney.³⁷ They also align with the theory of person-centered care (PCC),^{38,39} although the PCC terminology was never used by the staff in the interviews. Person-centred care includes valuing people with dementia, using an individual approach, adopting the perspective of the individual, and providing a supportive social environment.⁴⁰ In occupational science, the focus on the individual can be seen to improve the perspective of being and belonging by feeling accepted and included. The staff used individual information about the attendees in conversations and to motivate them to take part in activities. However, as noticed during the observations, this information was not used to tailor activities for the attendees.

The staff was aware of their need for more knowledge about dementia, how to communicate with attendees, and how to facilitate activities based on attendees' individual abilities and levels of functioning. Additionally, they stated the importance of using their own-lived experience in their work with the attendees. The approaches used were characterized by flexibility, support, humor, creativity, empathy, and being present. These approaches were also emphasized in the studies of Hasselkus²² and Gustafsdottir.⁵ The staff stated the need for a personal desire to make a difference in the attendees' lives.

The presence of these staff skills was experienced and highly appreciated by day care attendees as illustrated in a previous study.³

To be engaged in activities, the attendees were highly dependent on the initiative of the staff to guide, lead, or prompting them. The observed passivity in the group of attendees might be a result of the dementia disease, role expectations, or strategies to avoid behavior perceived as inappropriate or unwanted. Furthermore, this might demonstrate that the staff did not manage to adapt and facilitate meaningful activities by modifying and adapting activities to meet the varying levels of abilities of the attendees. As most of the staff were nurses and auxiliary nurses, they might not be familiar with modifying and adapting activities to meet the varying levels of ability of the attendees as part of their basic professional knowledge. For example, the staff seldom took the opportunity to include attendees in activities connected to meals, such as preparing food, setting the table, serving, or clearing the table and cleaning up. This could be a meaningful activity for some of the attendees and an important opportunity for stimulation through daily activities.³⁶

The activities were mostly facilitated to fit the functional level of the attendees. However, it could be beneficial to focus on strategies for individual adaptation or modification in order to promote their engagement and participation. Additionally, a greater variety of activities to be individually meaningful to support each person's identity in a social setting would be beneficial.

People with dementia and their right to day care services

Day care is highly recommended as a service for home-dwelling people with dementia.³³ However, the staff highlighted a number of challenges with a group-based service for people with dementia due to the variety of personalities, stages of dementia, and levels of functioning. An adequate composition of the groups was discussed as one important factor for creating a meaningful day. To some extent, they managed to alternate attendees of different ages and functional levels to different activities or days to form more homogeneous groups. This made it less challenging to offer appropriate activities and maintain a calm environment. If any of the attendees had a progression in dementia or began to demonstrate behavioral problems, day care was no longer considered a suitable place to be. The staff evaluated the composition

of the group regularly. The selection of suitable attendees had the intention of creating positive group dynamics and, hence, contributing to a meaningful day. However, when people are selected and considered to fit in, the consequence is that others will be excluded. Most likely, those people will be left without any alternative activity service. Hence, day care is a service for a selected group of home-dwelling people with dementia, and therefore, there is a lack of services for people who do not fit into day care. Thus, people with dementia are at increased risk for experiencing inequalities, injustice, marginalization, and discrimination. This is defined as a human rights issue.^{41,42} To be excluded from day care due to staff deciding that a person does not fit in can contribute to occupational injustice and lead to occupational deprivation. Occupational deprivation can be defined as the lack of occupational choices that is beyond the control of an individual.^{43,44} To enhance occupational justice, all people should have access to the resources they need to engage in chosen or meaningful activities, regardless of age, disability, gender, culture, or geographical location.⁴⁴ Hence, those persons excluded from day care services are at risk for decreased health and quality of life because they are not given an opportunity to engage and participate in day care.^{18,19}

WHO claims that human rights are often overlooked regarding people with dementia.^{41,42} Because of different national dementia strategies that emphasize human rights, dignity, self-respect, and the rights of the individual to choose how to live his or her own life, the research reminds us that, even in countries with policy plans, there is a gap between the plans and the everyday lived experience of the individual with dementia.

Occupational science focuses on the relation between occupation and health and well-being. Day care services have the potential to meet the individuals needs for engagement in meaningful activities. Hence, the services should be adjusted to the attendees' functional levels instead of the opposite, where attendees must fit the service. A challenge in achieving this is that day care is supposed to embrace all home-dwelling people with dementia and be a service that offers tailored activities to this population. Based on the findings from the current study, this vision might be unrealistic since there are people excluded from the service. The potential exists for more differentiated and tailored services to meet the needs of all home-dwelling people with dementia.

Methodological considerations

The present study has several limitations as well as strengths. Two qualitative methods were used to illuminate the objective of the study, and this was considered a strength. The combination of observations and group interviews was chosen to increase our understanding of how day care staff contribute to attendees' engagement and participation in activities. The interviews were used to validate the observations, which provided important additional information in the interpretation of the interviews.

The use of group interviews was considered efficient for collecting the viewpoints of several people and because the interaction within the group could lead to richer opinions. The group interviews were organized at each day care, making the groups homogeneous. Groups of staff from different day care services would have resulted in more heterogeneous groups and, thereby, the potential for a richer discussion and more expressions of opinions. However, having a group discussion with colleagues makes the setting safer and more beneficial as staff feel free to reflect on their own practices. The interviews were conducted at the end of 2 days of observations made by the first author. A possible benefit of this was that the staff were familiar with the researcher, making the interview setting more comfortable and leading to potentially greater openness. A possible limitation of collecting data in this manner is that the researcher had several preconceptions that could interrupt the interview setting and influence the findings. To avoid this possible bias, a second researcher took part in the interviews.

The observations were led by the main objective and were structured. A more open observation could have led to alternative and broader observations.²⁵

The purpose of qualitative studies is not to generalize the findings, and the results of the current study are not representative for all day care services for people with dementia. However, the interviews were conducted in different parts of Norway and were thus not affected by each other to the same extent that day care services in the same region or municipality might have been.

Further research is needed on the effects of day care services, what the aim and content of a day care program designed for people with dementia should be, and how the occupational needs of the attendees should be addressed by staff and service providers. There is a need for investigations and interventions to meet the risk for potential occupational injustice and occupational deprivation for people with dementia.

Conclusion

Staff play an important role in promoting and facilitating activities in order to engage and increase participation among attendees at day care services for people with dementia. This study underlines the potential of day care for people with dementia to contribute to a meaningful day by enhancing social and physical stimulation. The aim and content of day care services, as described in the current study, do not fully align with the intentions of the Norwegian national guidelines. To meet the primary aims of day care, activities are suggested to be more individually tailored and include cognitive stimulation. There is a potential for a more structured use of meaningful activities. To avoid occupational injustice that can potentially have a negative influence on the health and well-being of home-dwelling people with dementia, there is a need for more differentiated and tailored services.

Acknowledgments

We would like to thank all the participants who took part in the group interviews for their enthusiasm and their effort.

Disclosure

The authors report no conflicts of interest in this work.

References

- Prince M, Bryce R, Albanese E, Wimo A, Ribeiro W, Ferri CP. The global prevalence of dementia: a systematic review and metaanalysis. *Alzheimers Dis*. 2013;9(1):63–75. doi:10.1016/j.jalz.2012.11.007
- Livingston G, Sommerlad A, Orgeta V, et al. Dementia prevention, intervention, and care. *Lancet*. 2017;390(10113):2673–2734. doi:10.1016/S0140-6736(17)31363-6
- Strandenæs MG, Lund A, Rokstad AM. Experiences of attending day care services designed for people with dementia – a qualitative study with individual interviews. *Aging Ment Health*. 2017;22:1–9.
- Måvall L, Malmberg B. Day care for persons with dementia: an alternative for whom? *Dementia*. 2007;6(1):27–43. doi:10.1177/1471301207075627
- Gustafsdottir M. Beneficial care approaches in specialized daycare units for persons with dementia. *Am J Alzheimers Dis Other Dement*. 2011;26. doi:10.1177/1533317511402315
- Rokstad AM, McCabe L, Robertson JM, Strandenæs MG, Tretteteig S, Vatne S. Day care for people with dementia: a qualitative study comparing experiences from Norway and Scotland. *Dementia*. 2017;1–17. doi:10.1177/1471301217712796
- Rokstad AM, Engedal K, Kirkevold O, Saltyte Benth J, Barca ML, Selbaek G. The association between attending specialized day care centers and the quality of life of people with dementia. *Int Psychogeriatr*. 2017;29(4):627–636. doi:10.1017/S1041610216002015
- Manthorpe J, Moriarty J. Examining day centre provision for older people in the UK using the Equality Act 2010: findings of a scoping review. *Health Soc Care Community*. 2014;22(4):352–360. doi:10.1111/hsc.12065
- Tretteteig S. *The Impact of Day Care Designed for Persons with Dementia on Their Family Caregivers*. Oslo: Faculty of Medicine, University of Oslo; 2017.
- Reinar L, Dahm K, Landmark B. *Effekten Av Tilrettelagt Dagsentertilbud*. [Effect of Day Care Centers for People with Dementia]. Oslo: Kunnskapssenteret; 2011.
- Ki D, Dalsbø TK. *Effekten Av Tilrettelagt Dagsentertilbud* [The Effect of Day Care Centers for People with Dementia]. Oslo: Kunnskapssenteret; 2014.
- Gjøra L, Kirkevold Ø, Eek A. *Nasjonal Kartlegging Av Tilbud Til Personer Med Demens 2014*. Tønsberg: Aldring og helse; 2015.
- Helse- og omsorgsdepartementet. [Norwegian Ministry of Health and Care Services]. *Demensplan 2015 “Den Gode Dagen”* [Dementia Plan 2015 – “The Good Day”]. Oslo: Helse-og omsorgsdepartementet; 2007.
- Helse- og omsorgsdepartementet. *Demensplan 2020. Et Mer Demensvennlig Samfunn* [Dementia Plan 2020. A More Dementia-Friendly Society]. Oslo: Helse-og omsorgsdepartementet; 2015.
- Helsedirektoratet, Aldring og helse [The Norwegian Directorate of Health, Norwegian National Advisory Unit on Ageing and Health (Ageing and Health)]. *Etablering Og Drift Av Dagaktivitetstilbud for Personer Med Demens* [Establishment and Operation of Day Care Service Dagaktivitetstilbud for People with Dementia]. Tønsberg: Forlaget Aldring og helse; 2012.
- Ibsen TL, Eriksen S, Patil GG. Farm-based day care in Norway – a complementary service for people with dementia. *J Multidiscip Healthc*. 2018;11:349–358. doi:10.2147/JMDH.S167135
- Kaae Kristensen H, Mærsk JL. *Nordisk Aktivitetsvidenskab* [Nordic Occupational Science]. København: Munksgaard; 2017.
- Christiansen CH, Townsend EA. *Introduction to Occupation. The Art and Science of Living*. Essex: Pearson Educational International; 2011.
- Egan M, Sandra S, Fearing V. Dementia and occupation: a review of the literature. *Can J Occup Ther*. 2006;73(3):132–140. doi:10.2182/cjot.05.0015
- Perrin T. Occupational need in severe dementia: a descriptive study. *J Adv Nurs*. 1997;25(5):934–941.
- Hasselkus BR. The meaning of activity: day care for persons with alzheimer disease. *Am J Occup Ther*. 1992;46(3):199–206.
- Hasselkus B. Occupation and Well-being in dementia: the experience of day-care staff. *Am J Occup Ther*. 1997;52:423–434.
- Brataas HV, Bjugan H, Wille T, Hellzen O. Experiences of day care and collaboration among people with mild dementia. *J Clin Nurs*. 2010;19(19–20):2839–2848. doi:10.1111/j.1365-2702.2010.03270.x
- Hochgraeber I, Riesner C, Schoppmann S. The experience of people with dementia in a social care group: case study. *Dementia*. 2013;12(6):751–768. doi:10.1177/1471301212444300
- Fangen K. *Deltagende Observasjon. 2.Utgave*. [Participating Observation. 2.Edition]. Oslo: Fagbokforlaget; 2010.
- Malterud K. *Kvalitative Metoder I Medisinsk Forsknig. En Innføring. 3. Utgave* [Qualitative Methods in Medical Research. An Introduction. 3.Edition]. Oslo: Universitetsforlaget; 2011.
- Rokstad A, Halse I, Barca M, et al. Effects and costs of a day care centre program designed for people with dementia – a 24 month controlled study. *J Clin Trials*. 2014;4:182. doi:10.4172/2167-0870.
- Kvale S, Brinkmann S. *Det Kvalitative Forskningsintervju. 2.Utg* [The Qualitative Research Interview. 2.Edition]. Oslo: Gyldendal Akademiske; 2009.
- Freeman T. ‘Best practice’ in focus group research: making sense of different views. *J Adv Nurs*. 2006;56(5):491–497. doi:10.1111/j.1365-2648.2006.04043.x
- Ruyter KW, Solbakk JH, editors. *Medisinsk Og Helsefaglig Etik* [Medical and health related ethics]. Oslo: Gyldendal Akademisk; 2014. Norwegian.
- Braun V, Clarke V. Using thematic analysis in psychology. *Qual Res Psychol*. 2006;3(2):77–101. doi:10.1191/1478088706qp0630a

32. Gustafsdottir M. Keeping up health promotion practices in specialized day care units for people with dementia. *Am J Alzheimers Dis Other Dement*. 2011;26(6):437–442. doi:10.1177/1533317511424893
33. Helsedirektoratet [Norwegian Ministry of Health and Care Services]. *Nasjonale Faglige Retningslinjer Om demens* [Norwegian Guidelines on Dementia]; 2017. Available from: <https://app.magicapp.org/app#/guideline/2273>. Norwegian.
34. Rehling T, Sixsmith J, Corr S, Chard G. *An Occupational Therapy Perspective on Cognitive Stimulation Therapy: Targeting Occupational Performance Outcomes for People with Dementia*. Cape Town/South Africa: World Federation Occupational Therapists congress; 2018.
35. Karssemeijer EGA, Aaronson JA, Bossers WJ, Smits T, Olde Rikkert MGM, Kessels RPC. Positive effects of combined cognitive and physical exercise training on cognitive function in older adults with mild cognitive impairment or dementia: A meta-analysis. *Ageing Res Rev*. 2017;40:75–83. doi:10.1016/j.arr.2017.09.003
36. Graff MJ, Vermooij-Dassen MJ, Thijssen M, Dekker J, Hoefnagels WH, Rikkert MG. Community based occupational therapy for patients with dementia and their care givers: randomised controlled trial. *Bmj*. 2008;333(7580):1196. doi:10.1136/bmj.39001.688843.BE
37. Phinney A, Chaudhury H, O'Connor DL. Doing as much as I can do: the meaning of activity for people with dementia. *Ageing Ment Health*. 2007;11(4):384–393. doi:10.1080/13607860601086470
38. Brooker D. Understanding dementia and the person behind the diagnostic label. *Int J of Person Centered Medicin*. 2012;2(1):7.
39. Brooker D. What is person-centred care in dementia? *Rev Clin Gerontol*. 2003;13(3):215–222. doi:10.1017/S095925980400108X
40. Brooker D, Latham I. *Person-Centred Dementia Care: Making Services Better with the VIPS Framework*. Second ed. London: Jessica Kingsley Publishing; 2017.
41. Cahill S. *Dementia and Human Rights*. Great Britain: Policy Press; 2018.
42. Dixon J, Laing J, Valentine C. A human rights approach to advocacy for people with dementia: a review of current provision in England and Wales. *Dementia*. 2018. doi:10.1177/1471301218770478
43. Wilcock AA. Older people and occupational justice. In: McIntyre A, Atwal A, editors. *Occupational Therapy and Older People*. Oxford: Blackwell Publishing Ltd; 2005:14–25.
44. Stadnyk RL, Townsend EA, Wilcock AA. Occupational justice. In: Christiansen CH, Townsend EA, editors. *Introduction to Occupation: The Art of Science and Living*. 2nd. Essex: Pearson Education Limited; 2014:307–336.

Journal of Multidisciplinary Healthcare

Dovepress

Publish your work in this journal

The Journal of Multidisciplinary Healthcare is an international, peer-reviewed open-access journal that aims to represent and publish research in healthcare areas delivered by practitioners of different disciplines. This includes studies and reviews conducted by multidisciplinary teams as well as research which evaluates the results or conduct of such teams or healthcare processes in general. The journal

covers a very wide range of areas and welcomes submissions from practitioners at all levels, from all over the world. The manuscript management system is completely online and includes a very quick and fair peer-review system. Visit <http://www.dovepress.com/testimonials.php> to read real quotes from published authors.

Submit your manuscript here: <https://www.dovepress.com/journal-of-inflammation-research-journal>