

# The impact of day care designed for persons with dementia on their family caregivers

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## Abstract

Being a family caregiver to a person with dementia infringes on many areas of life and can cause stress and strain over time, thus increasing the risk of depression and anxiety disorders. Providing family caregivers with good information, support and respite is therefore an important fundamental objective of dementia care. Day care is one of several support and respite services for family caregivers, whose purposes include increasing the health and well-being of caregivers and motivating family caregivers to provide care.

Earlier research shows a positive correlation between day care and family caregivers' reduction of stress and burden, but the studies that exist are small and the results are uncertain and inconsistent. Another problem is the lack of standardization of the service, with variations in both content and organization. The existing knowledge in the field therefore needed to be summarized and synthesized as part of the effort to ensure a more standardized and knowledge-based service.

Although the role of family caregiver is often associated with stress and burden, many people also experience positive aspects of the role. Positive aspects of the care can increase the caregiver's sense of well-being by serving as a buffer to the negative psychological and physiological consequences of caregiving. There has been a growing focus recently on positive dimensions of care, where a sense of meaning and coping are central values. Experiencing these values can be viewed in the context of family caregivers' resilience; which is described as a positive adaptation to a challenging situation that can protect them from a large burden even where the family caregiver experiences high care demands. In this context, it was therefore interesting to investigate how day care centres can support and motivate family caregivers to provide care based on an understanding of what gives them motivation, meaning and the ability to cope in the role.

Four studies were conducted. In the review study (article I), 19 studies were included and analysed with a view to providing an extended understanding of the impact of day care centres designed for people with dementia, on family caregivers. The study showed that family caregivers experienced the day care centres both as a respite service, and to some extent as a support service, improving their competence in caring for the person with dementia. The study indicates that day care has the potential to reduce the caregiver's burden, and increase their motivation in their role as a caregiver. However, these outcomes depend on the quality of treatment, and how the service meets the family caregiver's needs for flexibility, support, information and responsibility sharing.

In the survey study (presented in the thesis only), 151 family caregivers responded to a questionnaire on how they perceived the information and cooperation with the day care centres, and the extent to

which the service was tailored to their needs. The questionnaire was made up of 35 statements related to the following themes: the information received about the day care in advance, the date on which the placement was made and the scope of the day care, and the contact with the staff, the transport to and from the day care centre, the content and quality of the day care, and the day care as a way of providing respite and help to cope with the role of family caregiver. The descriptive analysis showed that family caregivers were generally very pleased with the day care, but that there was room for improvement in relation to the flow of information, cooperation and the provision of individual support to family caregivers. The survey showed that spouses/cohabitants agreed more strongly than children/sons-in-law/daughters-in-law that day care offered them the opportunity to be more social. They also agreed to a significantly greater extent that day care gave them more time to perform practical tasks than children/sons-in-law/daughters-in-law. The study showed no significant gender disparities.

The next study (article II) had a qualitative descriptive design, using in-depth interviews with 17 family caregivers of people with dementia attending day care centres. The data analysis was undertaken using systematic text condensation. This study described how caregivers experience their role as a complex role, with added responsibilities, new tasks, and emotional and relational challenges that are expressed through distressing emotions and a need for interaction. Additionally, the caregiving role leads to positive experiences, such as acceptance and adaptation, support and help, and positive changes in the relationship. Further, the study describes that day care relieves family caregivers by meeting the person with dementia's needs for social interaction, nutrition, physical activity, and structure and variety in everyday life. Using a day care centre led to a higher quality in the time spent together and easier cooperation, but it also produced some hard feelings and challenging situations. Day care centres gave the caregivers a feeling of freedom and increased the time available to attend to their own needs, to be social and to work or do practical tasks undisturbed. The results indicate that a more individualized programme, in addition to flexible opening hours, would make day care centres even more effective as a respite service, and would have a positive influence on the family caregiver's motivation and ability to care and postpone the need for placement in a nursing home.

The last study (article III) described how day care can support family caregivers and impact on their care-related values and motivation to care. The study has a qualitative design with a case study approach, based on individual interviews. The interviews were analysed using a narrative method. Five narratives describe how five family caregivers cope with their situation in meaningful ways and how day care impacts on this coping. Their challenges and coping strategies were related to their relational ties; to enhance, maintain or let go, and how to find a good balance between meeting their



own needs and the needs of the person with dementia. The family caregivers describe how day care has a positive impact on their relationship-oriented coping and experience of meaning. The findings indicate that day care can support family caregivers to find a balance between attending to their own needs and the needs of the person with dementia. Additionally, day care has the potential to increase the family caregiver's motivation to care by supporting their capacity to make competent and autonomous choices and, thus, increase their feeling of mastery.

The overall conclusion of the thesis is that day care for people with dementia gives family caregivers support and respite, but that there is room for improvement in relation to communication, information and flexibility. The study shows that day care helps family caregivers to master a complex care role by giving them a greater sense of meaning and coping in the role. Day care reduces the time a family caregiver spends on care and helps them to meet the needs of the person with dementia. The service thus gives family caregivers a greater opportunity to find a balance between attending to their own needs and meeting the needs of the person with dementia. The care can also have a positive impact on the relationship between the family caregiver and the person with dementia. Overall, this helps increase the family caregiver's motivation to provide care in line with their care-related values and goals. Day care centres have room for improvement in relation to offering more flexible opening hours, as well as offering content that is more individually tailored to the person with dementia. There is also room for improvement among staff at day care centres in relation to giving family caregivers more empathetic support, and providing training and guidance adapted to their situation.

## Abstract in Norwegian

Å være pårørende til en person med demens er inngripende på mange områder i livet og kan føre til stress og belastning over tid, og dermed øke risikoen for depresjon og angstsykdommer. Det å tilby pårørende god informasjon, støtte og avlastning er derfor et viktig prinsipielt mål i demensomsorgen. Dagtilbud er ett av flere støtte- og avlastningstilbud til pårørende, der hensikten blant annet er å øke omsorgsgivernes helse og trivsel, og motivere pårørende til omsorg.

Tidligere forskning viste positiv sammenheng mellom dagtilbud og pårørendes reduksjon av stress og byrde, men de studiene som fantes var små og resultatene usikre og sprikende. Et annet problem var mangelen på standardisering av tilbudet, noe som gjorde at tilbudene kunne variere både i forhold til innhold og organisering. Som et ledd på veien mot en mer standardisert og kunnskapsbasert tjeneste, var det derfor behov for å oppsummere og sammenstille den kunnskapen vi hadde på feltet.

Selv om pårørenderollen ofte er forbundet med stress og byrde, opplever mange også positive sider ved rollen. Positive aspekter ved omsorg kan muligens være en buffer for negative psykologiske og fysiologiske konsekvenser av omsorgsgivning da slike positive aspekter kan øke pårørendes opplevelse av velvære (well-being). I senere tid har det vært et økende fokus på positive dimensjoner ved omsorg der opplevelsen av mening og mestring er sentrale verdier. Opplevelsen av disse verdiene kan sees i sammenheng med resilience hos pårørende; som betegnes som en positiv tilpasning til en krevende situasjon som virker beskyttende for opplevelsen av omsorgsbyrde selv om pårørende opplever at personen med demens har stort omsorgsbehov. I den sammenheng var det derfor interessant å undersøke hvordan dagtilbud kunne støtte og motivere pårørende til omsorg ut fra en forståelse av hva som ga dem motivasjon, mening og mestring i omsorgsoppgaven.

Det ble gjennomført fire studier. I review-studien (artikkel I) ble 19 studier inkludert og analysert med den hensikt å øke forståelsen av hvordan tilrettelagte dagtilbud for personer med demens innvirker på pårørende. Studien viste at pårørende opplevde at dagtilbudet ga dem avlastning i omsorgen, og en del opplevde også at dagtilbudet ga dem støtte i rollen og økte deres omsorgskompetanse. Review-studien indikerer at dagtilbud har potensialet til å redusere pårørendes byrde og øke deres motivasjon i omsorgsrollen, men dette er avhengig av kvaliteten på behandlingen dagtilbudet gir personen med demens, samt hvordan de møter pårørendes behov for fleksibilitet, støtte, informasjon, og det å ha noen å dele ansvaret for omsorgen med.

I servey-studien (kun publisert i denne avhandlingen) svarte 151 pårørende på et spørreskjema om informasjon og samarbeid, og i hvilken grad dagtilbudet var tilpasset deres behov. Spørreskjemaet

inneholdt 35 utsagn relatert til temaene: Informasjonen om dagtilbudet før oppstart, tidspunktet for tildeling av plass og omfanget av dagtilbudet, kontakten med personalet, transporten til og fra dagtilbudet, innholdet i og kvaliteten på dagtilbudet, og dagtilbudet som avlastning og hjelp til å mestre pårønderollen. Den deskriptive analysen viste at pårørende var generelt godt fornøyd med dagtilbudet, men at tilbudet hadde forbedringspotensialet knyttet til informasjonsflyt, samarbeid og individuell støtte til pårørende. Spørreundersøkelsen viste at ektefeller/samboere var signifikant mer enig i at dagtilbudet ga dem mulighet til å være mer sosiale, enn barn/svigerbarn. De var også signifikant mer enige i at dagtilbudet ga dem mer tid til å utføre praktiske oppgaver enn barn/svigerbarn. Studien viste ingen signifikante forskjeller mellom kjønn.

Den neste studien (artikkel II) har et kvalitativt deskriptivt design der 17 pårørende til personer med demens som hadde dagtilbud, ble dybdeintervjuet. Systematisk tekstkondensering ble brukt i analysen av dataene. Studien beskriver at pårørende opplevde sin rolle som kompleks med økt ansvar, nye oppgaver og følelsesmessige og relasjonelle utfordringer som ble uttrykket gjennom vanskelige følelser og krevende samhandling med personen med demens. I tillegg kunne omsorgsrollen føre til positive erfaringer som tilpasning til situasjonen, støtte og hjelp og positive endringer i relasjonen. Videre beskriver studien at dagtilbud kunne avlaste pårørende gjennom å dekke personen med demens behov for sosialt fellesskap, ernæring, fysisk aktivitet og struktur og variasjon i hverdagen. Bruken av dagtilbud førte også til høyere kvalitet på den tiden pårørende var sammen med personen med demens og det ble lettere å samarbeide, men det kunne også føre til vanskelige følelser og utfordrende situasjoner. Dagtilbudet ga pårørende en opplevelse av frihet og økt tid til å dekke egne behov, være sosiale, og til å jobbe eller gjøre praktiske oppgaver uforstyrret. Resultatene indikerer at dagtilbud har potensialet til forbedring gjennom mer individuelt tilrettelagt innhold, mer fleksible åpningstider og tettere samarbeid med pårørende. En slik forbedring kan gi pårørende bedre forutsetninger til å gi omsorg og økt omsorgsmotivasjon. Dette kan igjen føre til utsatt behov for heldøgnsomsorg.

Den siste studien (artikkel III) beskriver hvordan dagtilbud kan støtte pårørende og på den måten påvirke deres omsorgsrelaterte verdier og motivasjon til å gi omsorg. Studien hadde et kvalitativt design med en case-studie tilnærming basert på individuelle intervjuer. Intervjuene ble analysert ved bruk av narrativ metode. Fem narrativer beskrev hvordan pårørende mestret situasjonen på en meningsfull måte og hvordan dagtilbudet innvirket på denne mestringen. Deres utfordringer og mestringsstrategier var relatert til deres relasjonelle bånd; å bevare eller utvikle en god relasjon, holde fast eller gi slipp, og hvordan de skulle finne en god balanse mellom å dekke egne behov og dekke personen med demens sine behov. Pårørende beskrev hvordan dagtilbudet hadde en positiv innvirkning på deres relasjonsorienterte mestring og opplevelse av mening. Funnene indikerer at dagtilbud kan støtte pårørende til å finne en god balanse mellom å dekke egne og personen med demens sine behov. I tillegg har dagtilbud potensialet til å

øke pårørendes motivasjon i omsorgsarbeidet ved at tilbudet gir mulighet til å ta kompetente og autonome valg, og gjennom det øke deres opplevelse av mestring.

Den samlede konklusjonen i avhandlingen er at dagtilbud til personer med demens gir pårørende støtte og avlastning, men at tilbudet har forbedringspotensialer knyttet til kommunikasjon, informasjon og fleksibilitet. Studien viser at dagtilbud hjelper pårørende til å mestre en kompleks omsorgsrolle gjennom økt opplevelse av mening og mestring i rollen. Dagtilbud reduserer antall omsorgstimer og hjelper pårørende med å dekke personen med demens sine behov. Tilbudet gir dermed pårørende bedre mulighet til å balansere mellom ivaretagelse av egen behov og personen med demens sine behov. Tilbudet kan også ha en positiv innvirkning på relasjonen mellom pårørende og personen med demens. Til sammen er dette med på å øke pårørendes motivasjon til å gi omsorg i tråd med deres omsorgsrelaterte verdier og mål. Dagtilbud har forbedringspotensialet knyttet til å tilby mer fleksible åpningstider, samt tilby mer individuell tilrettelegging av innholdet til personen med demens. Ansatte ved dagtilbudet har forbedringspotensialet knyttet til å gi pårørende mer empatisk støtte, opplæring og veiledning, tilpasset deres situasjon.

## List of papers

- I. Tretteteig, S., Vatne, S. & Rokstad, A.M.M. (2016). The influence of day care centres for people with dementia on family caregivers: an integrative review of the literature. *Aging and Mental Health*, 20(5):450-62. doi: 10.1080/13607863.2015.1023765
- II. Tretteteig, S., Vatne, S. & Rokstad, A.M.M. (2017). The influence of day care centres designed for people with dementia on family caregivers – a qualitative study. *BMC Geriatrics*, Jan 5;17(1):5. doi: 10.1186/s12877-016-0403-2.
- III. Tretteteig, S., Vatne, S. & Rokstad, A.M.M. (under review). Meaning in family caregiving for people with dementia - a narrative study about relationship, values and motivation and how day care influences these factors. *International Psychogeriatrics*. Submitted Jan. 2017.

## Abbreviations

ADL	Activities of daily living
DCC	Day care centre
ECOD	Effects and Costs of a Day Care Centre Program Designed for People with Dementia - A 24 Month Controlled Study
FC	Family caregiver
IADL	Instrumental activities of daily living
MMAT	Mixed methods appraisal tool
PWD	Person with dementia
QoL	Quality of life

Abbreviations used in the tests and scales in the studies included in the review article are presented in table 1 in article I.

## 1. Introduction

Dementia is one of the greatest challenges in health care in the 21st century, and affects both people with dementia and family caregivers (Huang, Lee, Liao, Wang & Lai, 2012; Scheltens et al., 2016; Alzheimer's Disease International & WHO, 2012; WHO, 2016a, 2016b, 2016c). Both nationally and internationally, there is a growing trend towards people with dementia living in the community and in their own homes for as long as possible (WHO, 2016c). This requires good home-based services and respite services for family caregivers. Day care for people with dementia has been described for many years as the *missing link in the health and care services* in dementia care in Norway (Helse- og omsorgsdepartementet, 2007, 2015). This reflects both the number of day care places (Gjøra, Eek & Kirkevold, 2015) and the lack of knowledge about the effect of the care (Reinar, Fure, Kirkehei, Dahm & Landmark, 2011; Taranrød, 2011).

Being a family caregiver to a person with dementia is often associated with burden and stress (Balla et al., 2007; Ory, Hoffman, Yee, Tennstedt & Schulz, 1999; Thyrian et al., 2016). It can lead to a change of roles and responsibility for new tasks (Wadham, Simpson, Rust & Murray, 2016). This increases the overall risk of anxiety and depression (Etters, Goodall & Harrison, 2008; Schulz & Beach, 1999; WHO, 2012), but recent research has shown that the role of caregiver can also have positive aspects, such as a sense of meaning and coping (Tarlow et al., 2004; Zarit, 2012).

Family caregivers who provide care for people with dementia often do so for a large part of the day, sometimes over several years (Engedal & Haugen, 2009; WHO, 2012). They may therefore need support and respite, which they are entitled to under the provisions of the Health and Care Services Act (section 3.2 subsection 6d) if they meet the criteria for *particularly burdensome care work in the home* (Helse- og omsorgstjenesteloven, 2011). Although a variety of day care services are available, the definitions of day care used in Norway and abroad show that in addition to serving as an activity programme for people with dementia, day care should provide support and respite for family caregivers. The main objectives of such support and respite are to increase family caregivers' energy and to motivate them to provide care for the people with dementia. If day care manages to achieve this, the need for a person with dementia to be institutionalized may be postponed or no longer necessary (Alzheimer's association, 2017; Gaugler & Zarit, 2001; Helse- og omsorgsdepartementet, 2007, 2015; Tester, 1989, 2001; Westerberg, 2009).

Documenting the effect of day care both for people with dementia and their family caregivers has proven to be difficult. When this study started in 2013, little research had been done on the field,

and the studies that were available were small and the results uncertain (Reinar et al., 2011). An extensive research project was therefore initiated to investigate various aspects and effects of day care using different methods. (*Effects and costs of a day care centre program designed for people with dementia – a 24 month controlled study (ECOD)*) (Rokstad et al., 2014). This PhD study is part of the research project, which is a quasi-experimental, controlled trial using quantitative measures in a two-year follow-up period. At the family caregiver level, this quantitative part of the ECOD study will provide knowledge about caregivers' stress levels, symptoms of depression and quality of life and possible differences between the group of family caregivers of people who attend and of those who do not attend day care.

Through a review study, a survey and two qualitative studies, this PhD study also generates more knowledge on how day care for people with dementia impacts on their family caregivers.



## 2. Background

### 2.1 Being a family caregiver to a person with dementia

#### 2.1.1 Dementia

##### ***Definition, symptoms and prevalence***

Dementia syndrome poses major challenges, not only for those who have dementia, but also for family caregivers and health care workers (Huang et al., 2012). Dementia is described as a syndrome, and is mainly caused by progressive brain diseases or brain damage. It is characterized by cognitive impairment, changes in emotions and personality, as well as a reduced ability to function in everyday life. Dementia leads to dependency and a need for round-the-clock assistance as the disease progresses. This affects the entire lives of both the person who is sick and their family caregiver (Engedal, 2005; Engedal & Haugen, 2009), and in moderate to severe cases of dementia, the risk of a long-term stay in an institution and death increases (Snowden et al., 2017).

The most dominant cognitive symptom of dementia is the memory loss. Other symptoms of dementia are language impairment, spatial and directional problems, as well as impaired thinking and communication, and disorientation. The person will have problems using learned skills and performing everyday tasks. Lack of insight and reduced motor skills can also be a part of the dementia syndrome, as well as aggressiveness and symptoms such as anxiety, depression, hallucinations and apathy (neuropsychiatric symptoms). Many people with dementia will be depressed and anxious during the initial phase, and will withdraw into themselves. Later in the process there may be major changes in their personality and manner. Around 60% of people with dementia have Alzheimer's disease. Other common forms of dementia are vascular dementia, dementia with Lewy bodies, Parkinson's-related dementia and frontotemporal dementia. In addition to this, dementia can occur in a number of less common brain diseases (Engedal, 2005, 2009; WHO, 2016b).

In 2015, dementia affected 47 million people worldwide (or roughly 5% of the world's elderly population), a figure that is estimated to increase to 75 million in 2030 and 132 million by 2050. (Prince et al., 2015). There are no studies that can provide a precise estimate of the incidence of dementia in Norway. Using data from studies in other European countries, Alzheimer Europe has estimated that the incidence of dementia in Norway was over 77 000 in 2012. Many of the studies are based on the number of people who have been diagnosed with dementia. However, in Norway,

as in many other countries, a considerable share of the people with dementia have not been diagnosed. This means that the estimate is probably too low (Alzheimer's Association, 2015; Helsedirektoratet, 2015).

Although there are strong indications of a large increase in the number of people with dementia both in Norway and around the world, there are now summaries of studies showing that the number of new incidences of Alzheimer's disease may decline in the western world in the future. If current developments continue, treatment and prevention of Alzheimer's disease will see a significant improvement from 2025. This will be achieved through better surveys, mapping and treatment of risk factors, vascular care and improved brain health. This could have a positive effect on both the prevalence and progression of the disease (Scheltens et al., 2016).

### ***Family caregivers of people with dementia***

The lack of reliable figures on the prevalence of dementia also means that there are no reliable figures on the number of family caregivers for people with dementia. Based on the 2012 estimate of 77 000 people with dementia in Norway, empirical evidence suggests that each one of them has at least two close family caregivers, but the National Association for Public Health has multiplied the number by 5 and claims that there are approximately 350 000 family caregivers for people with dementia in Norway (Nasjonalforeningen for folkehelsen, 2016). We can assume that 60–65% of people with dementia in Norway live at home alone or with a family member (Engedal, 2005).

The Directorate of Health defines family caregivers as closely related persons in the life of the patient or the user; immediate family, grandparents, grandchildren, aunts, uncles, friends, etc. Immediate family are spouse/partner/cohabitant, parents, children and siblings (own, step-children and foster children) of the patient or the user (Helsedirektoratet, 2017). Family caregivers of people with dementia are mainly close family members. Women are strongly overrepresented in the role of main caregiver, and most of these are wives and daughters (Alzheimer's Association, 2015; Brodaty & Donkin, 2009; Bruvik, Ulstein, Ranhoff & Engedal, 2012). The gender disparity may be explained by the fact that women live longer than men and that wives are often younger than their husbands. Adult children who are family caregivers for their parents often share care responsibilities, while a spouse is more likely to be the sole caregiver (Bruvik et al., 2012).

Family caregivers who live with the family member with dementia normally provide a different kind of support and assistance than those who do not live with the person. For example, spouses help with practical tasks, while adult children more often organize measures and services (Brodaty & Donkin, 2009). Compared with family caregivers of other chronically ill people, family caregivers of people with dementia spend significantly more time on care tasks (Ory et al., 1999). In addition, they

help out with more activities of daily life and are more involved in protecting the person's interests by acting as their spokesperson in legal and financial matters. Another feature of this group of family caregivers is that their care tasks last longer than those of family caregivers of other chronically ill people (Alzheimer's Association, 2015; Bruvik, 2016).

### 2.1.2 Family caregivers' experiences of stress and strain

Being a family caregiver of a person with dementia can lead to stresses and strains. A new study shows that between 71 and 92% of caregivers consider the care role to be stressful where the functional and cognitive dysfunctions in the person with dementia are significant factors (Thyrian et al., 2016). For spouses and cohabitants, the feeling of belonging together as a couple may be threatened when one of them gets dementia. The balance of power in the relationship changes, and this can affect their individual identities (Wadham et al., 2016). Adult children who are family caregivers can experience grief associated with 'losing' a parent at a young age, and have concerns about inheriting the disease (Kjällmann-Alm, Norbergh & Hellzen, 2013). A family caregiver's experiences of stress and strain can include physical, mental, social and financial aspects (Balla et al., 2007; Ory et al., 1999), and many also provide round-the-clock care over a long period of time (WHO, 2012). Overall, these aspects increase the risk of depression and anxiety disorders (Etters et al., 2008; Schulz & Beach, 1999). Summarized research from 2005 shows that over 22% of family caregivers of people with dementia suffered from depression (prevalence range 15–32%) (Cuijpers, 2005), one in three suffered from anxiety, and between 50 and 75% had depressive and/or anxiety symptoms (Akkerman & Ostwald, 2004).

Factors such as gender, relationship, culture and personal qualities impact on family caregivers' experiences of the situation and their ability and capacity to provide care (Etters et al., 2008). Women, both wives and daughters, experience a greater sense of burden in the role of family caregiver compared to husbands and sons. However, they also experience a higher level of self-esteem in the role (Chappell, Dujela & Smith, 2015). Female family caregivers have a higher level of anxiety and more depressive symptoms than men, and are sometimes less satisfied with the situation (WHO, 2012). Having a good two-way relationship with the person with dementia increases the likelihood of satisfaction in the family caregiver role and makes it more likely that the person needing care is valued as a person and not only seen as a problem or burden (Andren & Elmstahl, 2005).

Studies show that family caregivers of people with dementia can also experience physical changes in their body in the form of elevated levels of the stress hormone cortisol and an impaired immune system. Family caregivers also score worse than others on tests of attention and on executive functions such as planning, cognitive flexibility and abstract thinking. Interventions aimed at reducing family caregivers' stress levels have, to varying degrees, led to a reduction in cortisol levels (Allen et al., 2017).

Functional and cognitive difficulties, challenging behaviour and personality changes in the person with dementia are described as *primary stress factors* for family caregivers. They get tired and stressed from assisting, supporting and taking responsibility for care work that can stretch out over a number of years. Primary stressors can lead to *secondary stress factors*, which is stress that is related to roles and activities outside of the family caregiver role, i.e. negative consequences on other parts of life. For example, it may be that a family caregiver no longer participates in recreational activities, or is unable to work full time because they are either too tired or cannot leave the person with dementia. The sum of primary and secondary stressors increases the risk of mental health problems and reduced well-being for the caregiver (Ask et al., 2014). Respite measures outside the home can be a good way of reducing family caregivers' secondary stress factors (Etters et al., 2008).

In 2017, the Directorate of Health issued a revised version of its guide for family caregivers. The guide states that typical health challenges among family caregivers are sleeping problems, concentration problems, reduced energy levels, worry, stress, anxiety and depression. Being a family caregiver can also lead to various pain disorders, an impaired immune system and diet-related problems. Family caregivers with long-term care responsibilities, including family caregivers of people with dementia, are particularly at risk of health problems, and should therefore be offered support and respite (Helsedirektoratet, 2017).

### 2.1.3 Family caregivers' positive experiences

Although the family caregiver role is often associated with stress and burden, many family caregivers also experience positive and satisfactory aspects of the role. Stress and the feeling that the family caregiver role is a burden are not necessarily obstacles to experiencing satisfaction in the role. On the contrary, it would appear that family caregivers can experience both a moderate sense of burden and satisfaction in the role simultaneously (Andren & Elmstahl, 2005). Positive aspects can increase the caregiver's sense of well-being by serving as a buffer to the negative psychological and physiological consequences of caregiving (Semiatin & O'Connor, 2012). In recent times, there has

therefore been a growing focus on investigating and describing positive dimensions of care. Such dimensions may include experiences, cooperation, emotions and the strengths and resources that family caregivers can draw on when faced with these challenges (Zarit, 2012). Family caregivers may feel that there is a use for them and that the care they provide is beneficial. A key part of the family caregivers' positive experiences is therefore mainly related to experiences of meaning and coping in the role of caregiver (Tarlow et al., 2004).

### ***Meaning-focused coping***

According to Solem and Ingebretsen, the Norwegian term *mestring* combines the two English concepts of *coping* and *mastery*. The difference between these concepts is explained as follows: "Coping is what a person does to overcome difficulties and avoid being harmed by stresses in life, while mastery is the experience of achieving the desired result from what one is doing" (Solem & Ingebretsen, 2002, p. 7). Here we will use the term coping, but this study also often includes elements from the concept of mastery.

The experience of meaning is often associated with the concept of coping. In order to better understand the relationship between meaning and coping, it may be useful to look at the concept of *meaning-focused coping*. Based on stress and coping theories (Folkman, 1997; Lazarus & Folkman, 1984; Park & Folkman, 2007), Folkman describes meaning-focused coping as:

Appraisal-based coping in which the person draws on his or her beliefs (e.g., religious, spiritual, or beliefs about justice), values (e.g., 'mattering'), and existential goals (e.g., purpose in life or guiding principles) to motivate and sustain coping and well-being during a difficult time (Folkman, 2007, p. 7).

The term 'meaningful coping' has influenced research related to the positive aspects of care experienced by family caregivers, where caregivers describe both negative and positive emotions during periods of high stress. Meaning-focused coping strategies and the experience of control are central to feeling positive emotions through life's challenges. They can also have a positive effect on the family caregiver's ability to reappraise situations and, if necessary, find new solutions (Folkman, 2007; Zarit, 2012). Knowledge on differences in family caregivers' motivation for providing care and the variation therein, what they perceive as meaningful and what strategies they use to achieve meaningful goals will be useful with a view to providing individually tailored support and respite that strengthens the underlying positive aspects of care. This can further enhance the family caregiver's motivation to provide care.

### ***Relationship-oriented coping***

A key part of caring for a person with dementia is the challenges and the sense of coping associated with the relational aspects. Relationships are often built over a long period of time, and for many, a good relationship can be an important motivational factor for providing care (Andren & Elmstahl, 2005). The nature of the relationship with a person with dementia often changes as the disease progresses, which can be difficult to accept and may require adjustment by both parties. The situation can be particularly testing if the person with dementia experiences personality changes and/or displays challenging behaviour (Thyrian et al., 2016). Ingebretsen uses the term *relationship-oriented coping* to describe how family caregivers cope in different relationships, both in relation to the spouse with dementia and to other people that he or she can rely on (Ingebretsen, 2006). She describes five different aspects of relationship-oriented coping, as follows: 1) relationship orientation in relation to the partner, i.e. emphasizing communication and interaction that has a positive effect on the partner (try to be understanding, create good moments, do not get angry, etc.), 2) positive problem orientation in relation to the partner, which entails maintaining a problem-solving approach to the challenges of dementia (get professional help, do not change daily routines, etc.), 3) positive problem orientation in relation to own needs, where the family caregiver also attends to their own needs (be sociable, recognize own limitations, etc.), 4) relationship orientation in relation to others, which entails seeking comfort and support in others (talk to others, explain the situation to others, etc.), and 5) emotional orientation, which is about reinterpreting the situation so that it becomes less stressful (accept, do not worry in advance, etc.). Although the spouses are aware of these good strategies, it can be difficult to follow them in practice. This may be due to lack of patience and energy. According to Solem and Ingebretsen, support and respite services can help give spouses more energy and equip them to carry out their good relationship coping strategies (Solem & Ingebretsen, 2002).

Because relationships are an important part of people's lives and are positive meaningful experiences, we need relationship-sensitive research methods to investigate how strengthening and maintaining relationships can prevent or reduce the burden for family caregivers. Molyneaux et al. (2011) pointed out the need to focus on the quality of the relationships and the interactions between the caregiver and the person with dementia (Molyneaux, Butchard, Simpson & Murray, 2011). The experience of meaning in the family caregiver role should therefore be seen in the context of close interpersonal relationships.

#### 2.1.4 Family caregivers' positive experiences in the context of Gaugler's resilience model

One way to understand how respite and support can have a positive effect on the family caregivers of people with dementia may be to consider it in the context of the concept of resilience and Gaugler's conceptual resilience model (Gaugler, Kane & Newcomer, 2007). The concept of resilience is derived from developmental psychology, where the term describes children who perform well despite difficult psychological adversities during their childhood. Resilience can be understood as positive experiences and experiences in the face of adversity or risk, and focuses on strengths rather than weaknesses (Joling et al., 2016). Resilience is regarded as positive or successful adaptation, competence and functioning in the face of stressful experiences (Egeland, Carlson & Sroufe, 1993; Egeland & Aberly, 1991).

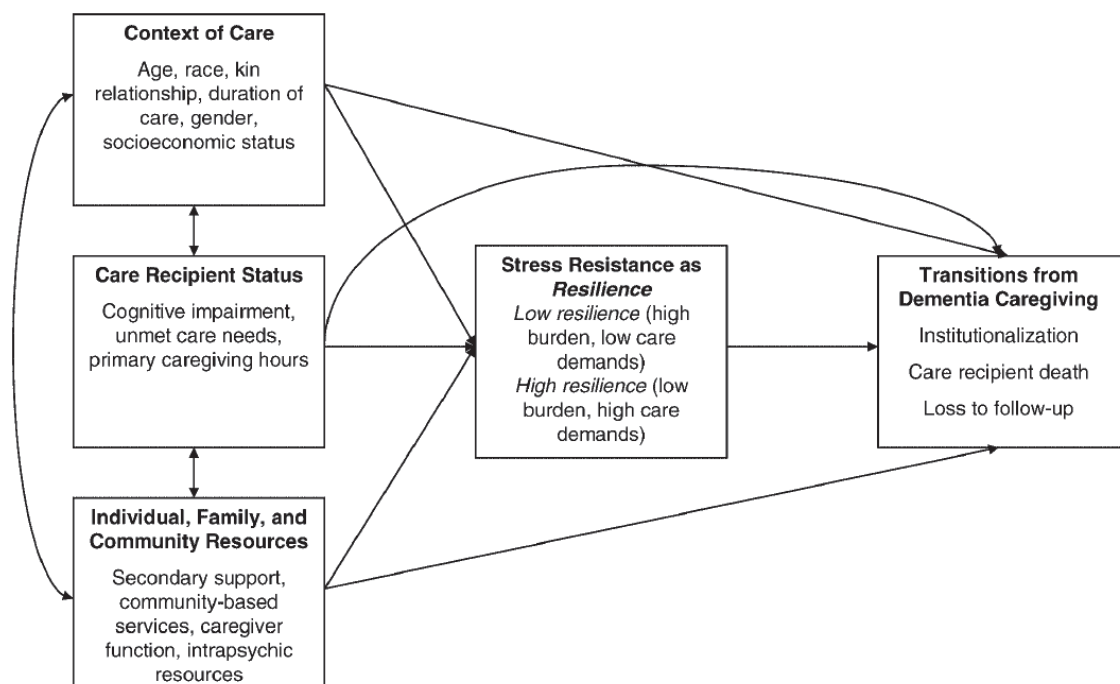
##### ***Resilience among family caregivers***

The concept of resilience has recently been used to describe a kind of stress resistance that is apparent in some family caregivers. Inspired by ecological systems theory (Bronfenbrenner, 1994), Windle and Bennett developed a theoretical resilience framework for caregivers (Windle & Bennett, 2011). This recognizes that caregivers will draw on individual resources, but also interact with their environment by drawing on community and societal resources which may facilitate or hinder resilience (Joling et al., 2016). Resilience among family caregivers of people with dementia is often associated with the experience of stress and burden versus the degree of impairment in personal activities of daily living (PADL)/instrumental activities of daily living (IADL) and challenging behaviour from the person with dementia. Resilience describes the characteristics of or the circumstances surrounding these family caregivers that protect them from the experience of stress and burden (Gaugler et al., 2007). It can be described as a positive process that helps family caregivers to cope, adapt, readjust and thrive in the face of care-related challenges (Petriwskyj, Parker, O'Dwyer, Moyle & Nucifora, 2016). Thus, the concept of resilience can help us understand what characterizes family caregivers who, to a greater extent than other family caregivers, experience positive aspects of the role of caregiver.

Compared to other family caregivers, those defined as resilient report relatively high levels of psychological well-being when exposed to different types of stressors that place high demands on them. These high demands relate to a serious degree of dementia and/or behavioural problems, providing a significant amount of care and having limited opportunities for attending to their own basic needs (Joling et al., 2016). In family caregivers of people with dementia, resilience is found to

be inversely related to depression, anxiety, psychoactive drug use and perceived burden, and positively related to health and well-being. Resilience is also a predictor of a longer period of home-based care and includes factors that offer protection from the need for institutional care (Gaugler et al., 2007). Factors that foster resilience are related to biological, social and cultural conditions, as well as the environment in which the person lives. Biological factors are brain size, neurotransmitter reuptake and stress hormones such as cortisol and dehydroepiandrosterone. Personal, social and cultural factors include personality traits, coping strategies, social support, positive personal relationships, and access to education and employment. Environmental factors include stability, good neighbourhood and the absence of violence, trauma and ill-treatment. Although some believe that resilience is strongly linked to personality traits, there is growing support for the notion that a person's resilience can be changed through psychological processes (Herrman et al., 2011). As described earlier, family caregivers' experiences of stress and a sense of burden can be affected by psychological processes, such as meaning-focused coping and relationship-oriented coping. The ability to influence resilience through influencing these psychological processes can support the intention and importance of good support and respite measures for family caregivers. In the conceptual resilience model (model 2.1), Gaugler (2007) shows how the different factors, both within and outside the caregiver role, can foster resilience, and how the factors influence each other (Transitions from Dementia Caregiving).

**Model 2.1 Conceptual Resilience Model (Gaugler et al., 2007, p. 39)**





Caregivers with a low level of stress resistance or a low degree of resilience will more often consider the role of caregiver to be stressful. As a result, the person with dementia may need to be placed in an institution sooner if this group of caregivers gives up the home care role after a shorter period of time than caregivers with a high level of stress resistance or a high degree of resilience.

According to this model, resilience among family caregivers can be influenced and fostered in various ways, such as reducing the care recipient's unmet needs, reducing the number of hours each day that a family caregiver needs to meet these needs, improving the family caregiver's relationship with the person with dementia and/or with their network, or strengthening the family caregiver's intrapsychic resources. The support the family caregivers receive from the public sector and the family caregiver's functional level both influence how their resilience is fostered. If the day care has a positive impact on the factors in the boxes at the left of the model, then the care as we understand it from this model can help build resilience among family caregivers.

## 2.2 Day care for people with dementia

### 2.2.1 Development and establishment of day care

#### ***Day care in a historical perspective***

In Norway, the first known daytime activity programmes for people with dementia were established in 1987 (Eek & Nygård, 2006), but it was not until the early 2000s that they became an area of focus in Norway. Report No. 25 (2005-2006) to the Storting, Long-term care – future challenges (2005-2006) (St.meld.nr.25. (2005-2006), 2006) identified important challenges and focus areas in the future care of the elderly, and a meaningful everyday life was highlighted as an important part of care of the elderly, where good services were in short supply. The term *active care* was central in the white paper, and the focus was on the content of services fostering activity and involvement among users both inside and outside institutions. Together with the intention of the earlier legislation on social health services (now the Health and Care Services Act) to ensure that *each individual has the opportunity to live and dwell independently and to have an active, meaningful existence in fellowship with others* (Lov om kommunale helse- og omsorgstjenester m.m., 2011), there was a clear need for a national focus on daytime activity programmes for people with dementia.

*Care Plan 2015* together with the subplan *Dementia Plan 2015 – Making the most of the good days* were follow-ups to white paper no. 25 (Helse- og omsorgsdepartementet, 2007). Day care was clearly

highlighted as one of three main focus areas in Dementia Plan 2015. This was the start of a major national day care initiative that saw the introduction of a development programme for day care and respite schemes for people with dementia in 2007. Table 2.1 shows how the percentage of municipalities and the number of day care centre places have increased from the 1996–1997 survey to 2014 in Norway. The table shows that the percentage and the number of municipalities offering day care, as well as the number of users increased considerably between 2007 and 2014.

**Table 2.1 Day care designed for people with dementia in Norway (Gjøra et al., 2015, p. 21)**

	1996-1997	2000-2001	2004-2005	2007	2010-2011	2014
Percentage of municipalities with day care designed for people with dementia	18,2%	23,0%	24,0%	30,2%	43,7%	71,3%
Number of municipalities with day care designed for people with dementia	79	100	104	130	188	305
Total number of users	671	1377	1540	2351	3257	6318

Based on the figures on the prevalence of dementia from Dementia Plan 2015, the coverage rate in 2014 was approximately 17%. This means that there were day care places for 17% of all people with dementia living at home, compared with 4% in 2004–2005 (Taranrød, 2011). The figures in table 2.1 therefore suggest that the focus on day care in Norway has been successful, but they also show that coverage remains low. In addition, the reports show that there is a need for more knowledge about what constitutes good content and how day care can serve as good support and respite for family caregivers (Gjøra et al., 2015; Taranrød, 2011). The focus on day care was therefore continued in Dementia Plan 2020 (Helsedirektoratet, 2015).

Beyond Norway’s borders, the first known day care for adults was in Russia in the 1920s, with day hospitals aimed at treating people with mental illnesses. After World War II, these day care centres were used to treat war veterans with war-related traumas. In Montreal, day care was first offered in the 1940s, but little is known about the form and content of the care (Gaugler et al., 2003a; Hunter, 1992; Weissert, 1976; Weissert et al., 1989). The first known day care for the elderly in the USA was at Hudson Day Center in New York in 1954. This included medical assistance and social support where care for family caregivers also formed part of the service (Hunter, 1992). This model was further developed through a geriatric day hospital programme in the 1950s, and the development

gathered pace when de-institutionalisation was initiated in the 1960s. Much of the research on day care for people with dementia has been conducted in the USA, and this remains the case today. In Europe, the Netherlands started developing day care for people with dementia based on psychogeriatric day care. This was provided in specialized psychogeriatric nursing homes, where people with dementia also lived. In 1977, the Dutch government decided to fund specialized psychogeriatric day care under the national insurance system by way of the General Exceptional Medical Expenses Act. This had a major impact on the propagation of day care provision in the Netherlands (de Jong & Boersma, 2009).

Dementia planning in Europe has been of major importance to the development of day care in recent years, but in 2016, only 29 governments out of the 194 WHO member states have developed a plan on dementia (WHO, 2016c). France, which was the first country to have a dedicated dementia plan (2001–2005), described dementia as one of six main focus areas. The goal was to provide financial support for people with dementia, establish day care centres and create local dementia information centres. The work in France has continued, and two of the key focus areas in its third dementia plan are providing assistance in users' homes and increasing support for family caregivers (Alzheimer Europe, 2015). In Denmark, day care occupies a more modest space in the dementia plan, but it describes how Denmark intends to focus on not only more, but more meaningful day care and respite care, with the following justification: 'Meaningful activities and social interaction provide both content and enjoyment in the everyday life of a person with dementia, while family caregivers receive respite from the demanding role on the sidelines' (Sundheds- og Ældreministeriet, 2017, p. 33).

Based on national initiatives that reflect the different histories, societal structures and cultures of the countries, it is easy to understand why different day care models have evolved. This is also evident in research from the 1970s and 1980s up to the present day, which confirms that day care is far from a homogeneous service (Gaugler et al., 2003a; MetLife, 2010). It will therefore be useful to examine different definitions of day care.

### 2.2.2 What is day care?

#### ***Definition of day care***

The literature describes a multitude of goals and intentions for day care for people with dementia. There are nevertheless many similarities between the different countries' descriptions (Måvoll & Malberg, 2007). Overall, we can say that the aim of day care is to aid independence and autonomy

for people with dementia by providing opportunities for social interaction, rehabilitation and treatment, examinations and treatment, as well as providing support to family caregivers (Tester, 1989). Although there are many similarities between the goals and intentions of the various day care provisions, target groups, organization, location, operation and content tend to differ. This means that day care is not standardized to any great extent, and therefore challenging to research (Manthorpe & Moriarty, 2014). This challenge is reflected in the research literature, where there is a multitude of definitions, some of which are vague and incomplete. However, based on the descriptions found, we find that day care has three main intentions: 1) to increase the health and well-being of participants, 2) to increase the health and well-being of caregivers, and 3) to motivate family caregivers to provide care and thus postpone or eliminate the need for nursing home care (Gaugler & Zarit, 2001; MetLife, 2010; Måvoll & Malberg, 2007; Tester, 2001).

Since day care for people with dementia is largely an extension of or a part of the geriatric and psychiatric day care, it may be useful to examine some descriptions of such care. In the USA, Hall and Buckwalter describe day care for adults as a community-based, supervised, daytime care programme offering planned activities and health care monitoring for dependent, and often cognitively impaired, elderly people living at home. It is an environmental intervention comprised of multiple variables that may be manipulated (Hall & Buckwalter, 1987). This description suggests that day care is a supervised service for people who are dependent on medical assistance, including those with impaired cognitive functions. The description is relatively detailed in terms of organization, content and target groups. Hunter (1992) describes in her definition how one of the aims of day care for the elderly is to enable them to be able to live at home and be part of the family for as long as possible, but unlike Hall and Buckwalter's description, she writes that users must be able to cooperate and communicate well, and not be in a confused state. Day care should offer education and provide individual care plans, and the goal is a good quality of life for the elderly (Hunter, 1992).

A British definition of day care describes it as follows:

A day care service offers communal care, with paid or voluntary caregivers present, in a setting outside the user's own home. Individuals arrive or are brought to use the services, which are available for at least 4 hours during the day, and return home on the same day (Tester, 2001, p. 37).

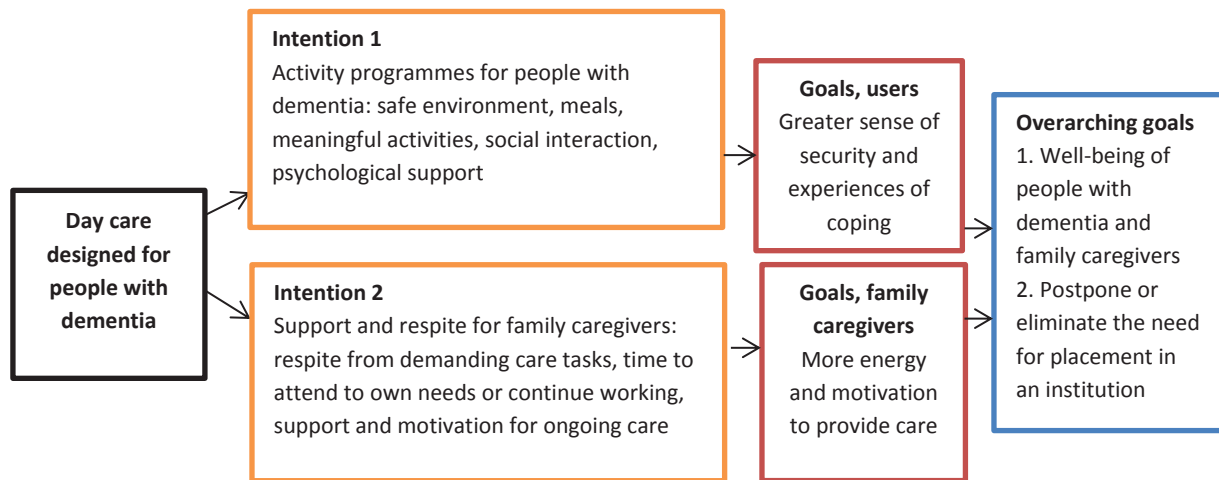
This definition gives specific recommendations for organization and staff, but there is little mention of the content of the care, user groups or respite for family caregivers. It may therefore be useful to consider Tester's definition in conjunction with the description of day care by the American Geriatrics Society's Health in Aging Foundation, which observes that adult day care is commonly used to care

for people who need supervision and help with activities of daily living (for example, patients with dementia) while primary caregivers are at work. It may also serve as a form of respite for caregivers (American Geriatrics Society's Health in Aging Foundation, 2012). The US Alzheimer's Association's website states that their day care offers people with Alzheimer's disease or other forms of dementia the opportunity to socialize and participate in activities in a safe environment. The day care centres also provide an advisory service for family caregivers and people with dementia, as well as medical assistance and help with nutrition and personal care, such as showering or hair care. Some day care centres also offer contact with various therapists (Alzheimer's association, 2017).

In Norway, day care for people with dementia who live in their own homes is described as adapted treatment (psychosocial interventions) at day time (Eek & Nygård, 2006). The purpose is to give people with dementia a meaningful everyday life in an environment where the focus is on social interaction, safety and the experience of coping. The activities that form part of the services are aimed at helping to maintain the everyday functioning of users (Westerberg, 2009). This understanding of day care is continued in Dementia Plan 2015, but here the role of day care is also described as a respite service for family caregivers. The plan describes two main intentions of day care: 1) to activate and stimulate users, and 2) to provide respite for family caregivers who undertake care tasks, with a view to helping spouses and family members cope with a challenging care situation. Together with home-based services, day care will help to postpone or eliminate the need for placement in an institution (Helse- og omsorgsdepartementet, 2007). Dementia Plan 2015 does not provide a detailed description of the content of the day care, and does not explain how support for family caregivers is to be organized. This paves the way for local adaptations and variations. The plan recommends that day care for people with dementia is organized as a separate service, or as separate groups of day care services. This distinction is less clear in the international definitions.

In summary, we can say that the synthesis of day care descriptions is a good indication of the intentions, target groups, content and organization, even though the definitions differ somewhat. The content is linked to everyday activities, with a focus on safe surroundings, social interaction and physical and cognitive stimulation. In addition, the day care is also aimed at providing respite for family caregivers. The descriptions are overarching to a degree that allows room for local adaptations and variations. By defining day care as both an activity programme for the users and a respite service for family caregivers, the overall goal is to improve how users cope with daily life and increase family caregivers' motivation to provide care. If day care can achieve this, this may help to postpone or eliminate the need for placement in an institution. These descriptions are summarized and illustrated in model 2.2.

## Model 2.2 Day care designed for people with dementia, intentions and goals



### ***Different models and different organization***

In 1993, the main features of two day care models in the USA were described; a medical model with the emphasis on traditional nursing and a social model where the main emphasis was on social initiatives and supervision. The social model offered activities such as playing games, watching TV, making and eating lunch together, and singing. This model seems to be the one that was best suited to people with a mild degree of cognitive dysfunction. Providing respite for family caregivers was also an important part of this care (Cefalu & Hauser, 1993). Norwegian day care has many similarities to the social model in the USA, with a strong focus on activities, meals and social interaction. A national survey from 2007/2008 shows four different models for organizing day care in Norway:

- Traditional model – established in institutions/nursing homes/care centres/sheltered housing
- Centre model – established in centres for the elderly
- Remote model – established in homes/farms with no affiliation to an institution or elderly centre
- Mobile model – established in the users' own homes or community

(Taranrød, 2011, p. 20)

In Norway, day care services are mainly run and financed by the municipalities, where the *traditional model* and the *centre model* are the most widespread (Gjøra et al., 2015). However, other models are also applied to some extent, such as day care for people on farms or in isolated areas (remote model) and respite in the user's home (mobile model). What separates the models is primarily their location and premises, but in general we can say that the remote model uses the outdoors to create good experiences and activities for the participants to a much greater extent than the centre model. The

mobile model is a one-on-one model, and as such is better able to meet the needs of the individual than day care with several users. However, the mobile model provides less opportunity for social interaction with other people with dementia than the other models (Taranrød, 2011).

Day care can be organized and run by health and social services in both the public and private sector, or by voluntary organizations. In Germany, day care is described as a social responsibility (Graham, 1989), while in the USA, many day care centres are affiliated with and financed through a state-wide network (Cho, Zarit & Chiriboga, 2009; Gaugler et al., 2003a, 2003b). Day care can also be affiliated with universities, as in the Netherlands and Italy (Dröes, Breebaart, Meiland, Van Tilburg, & Mellenbergh, 2004a; Mossello et al., 2008). Day care can be financed by the government, either through transfers to the municipalities, or through national insurance systems, such as in the Netherlands. In Norway, the municipalities fund day care in the public sector, but users generally have to pay a small share of the daily cost. If the day care is defined as respite for a family caregiver (as opposed to an activity programme for the person with dementia), users do not pay any share of the cost (Gjøra et al., 2015).

### 2.2.3 Support and respite for family caregivers

Day care is one of several support and respite services for family caregivers. It may therefore be useful to take a closer look at how support and respite services are defined and where day care is placed in the hierarchy of respite services. As described, support for family caregivers is an important part of dementia care, and providing family caregivers with sufficient information and support was highlighted as one of WHO's five key principles for good dementia care (WHO, 2016a). The research describes respite initiatives as a supportive service provided in or outside the home to give the informal caregiver a temporary relief or break from caregiver duties (Mason et al., 2007; Neville, Beattie, Fielding & MacAndrew, 2015; Vandepitte et al., 2016). This description focuses on organization, who the service is aimed at and the intention of the service. A report by the Ministry of Health and Long-Term Care in Canada (The Medical Advisory Secretariat) from 2008 defines day care as one of several respite services for family caregivers. The report emphasizes that respite care should be based on the needs of family caregivers, and allows for a wide diversity of services:

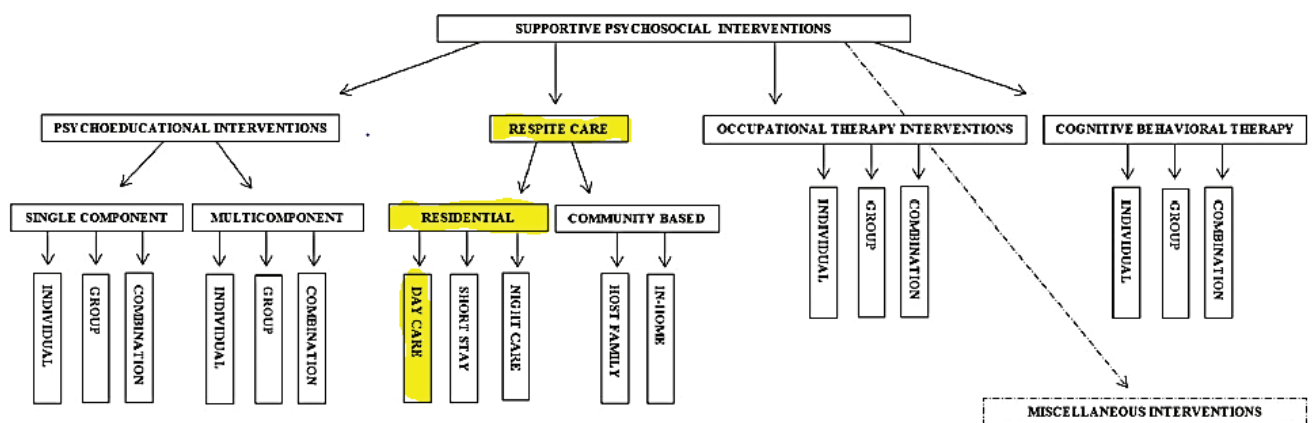
Respite care is defined as a break or relief for the caregiver. In most cases, respite is provided in the home, through day programs, or at institutions (usually 30 days or less). Depending on a caregiver's needs, respite services will vary in delivery and duration. Respite care is carried

out by a variety of individuals, including paid staff, volunteers, family, or friends (The Medical Advisory Secretariat, 2008, p. 11).

Both definitions state that the respite care should provide family caregivers with a break from their care tasks and are open to variation in terms of location, duration and whether the service is provided by professionals or volunteers. The key point is that day care must be adapted to the different needs of the family caregivers.

There are currently many types of supportive interventions aimed at giving family caregivers respite and preventing them from experiencing burnout. According to Vandepitte (2016), these interventions can be termed *supportive psychosocial interventions*, and can be divided into four main areas: 1) psychoeducational interventions, 2) respite care, 3) occupational therapy interventions, and 4) cognitive behavioural therapy (see figure 2.1). According to Vandepitte’s model, respite care can be divided into community-based and residential respite care, where respite through day care centres is classed as a type of residential-based respite. Respite care provided at institutions or day care centres is the most common form of respite for the elderly (Vandepitte et al., 2016). In Norway, respite is offered to family caregivers with elderly relatives who live at home, including people with dementia, mainly as rolling stays (days or weeks) in a nursing home and/or as a result of a municipal decision to provide day care at a day care centre or nursing home. Respite services are mainly offered to recipients who live with a family caregiver (Jessen, 2014).

**Figure 2.1 Classification of psychosocial supportive interventions for caregivers (Vandepitte et al., 2016, p. 1280)**





### ***What do we know about the impact of day care as a support and respite service?***

In 2011, the Norwegian Knowledge Centre for the Health Services (Knowledge Centre) produced a summary of available research on the impact of day care services adapted for people with dementia and their family caregivers. Together with a national focus on day care in the dementia plans (Helse- og omsorgsdepartementet, 2007, 2015) and experiences from earlier national projects (Taranrød, 2011), the Knowledge Centre's summary formed an important part of the basis for the ECOD research project, of which this study is a part.

The Knowledge Centre's summary contains research findings related to how day care can postpone or eliminate the need for institutionalization, and the impact on, inter alia, the users' level of function and quality of life. Research related to the impact of day care on the family caregivers' experiences of stress and sense of burden is also included. The report shows that studies of the field are small, the level of quality is low (measured using the GRADE<sup>1</sup> quality assessment tool) and the findings are uncertain and somewhat inconsistent. There are no randomized control trials that can determine whether day care has any effect on family caregivers in the form of stress and burden reduction, or whether it improves the quality of the family caregivers' care. Findings from qualitative research, on the other hand, strongly indicate that day care as a respite measure has a positive impact on family caregivers. The summary concludes that more research is needed in the field (Reinar et al., 2011).

Table 2. 2 shows an overview of themes, numbers of participants and studies, and the quality and results of the studies by the Knowledge Centre that are relevant to this study. The table is divided into themes: 1) the impact of day care on family caregivers, and 2) the impact of day care on the behaviour of people with dementia.

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<sup>1</sup> The Grading of Recommendations, Assessment, Development and Evaluation (GRADE) is a method for assessing the quality of evidence and strength of recommendations. GRADE's quality assessment: outcome, number of studies, design, risk of bias, inconsistency, indirectness, imprecision, other limitations. Quality of the evidence: four-step assessment scale (high, moderate, low, very low). Source and further reading: GRADE working group, [www.gradeworkinggroup.org](http://www.gradeworkinggroup.org)

**Table 2.2 Extract from the Knowledge Centre’s summary of the evidence on the effect of day care adapted for people with dementia (Reinar et al., 2011, p. 36)**

Outcome	No. of participants (studies)	Quality of the evidence (GRADE)	Result
<b>Theme: Impact of day care on family caregivers</b>			
Burden	426 (3)	⊕⊖⊖⊖ Very low	Significantly less strain In favour of day care
Studies: (Zarit, Stephens, Townsend, & Greene, 1998) (Mossello et al., 2008) (Zank & Schacke, 2002)			
Emotion	426 (3)	⊕⊖⊖⊖ Very low	Inconsistent results, but largest study concluded in favour of day care
Studies: (Zarit et al., 1998) (Zank & Schacke, 2002) (Mossello et al., 2008)			
Satisfaction	204 (2)	⊕⊖⊖⊖ Very low	No significant disparities
Studies: (Zarit et al., 1998) (Zank & Schacke, 2002)			
<b>Theme: Impact of day care on people with dementia</b>			
Behaviour	504 (3)	⊕⊖⊖⊖ Very low	Inconsistent results
Studies: (Dröes et al., 2000) (Femia, Zarit, Stephens & Greene, 2007) (Zarit et al., 1998)			
Behaviour	RCT, 25 (1)	⊕⊕⊖⊖ Low	Significantly lower incidence of behavioural problems in the intervention group
Study: (Ishizaki J, 2002)			

The results from the studies in table 2.2 will be described in more detail here with results from other studies taken from the review study: *Effectiveness of respite care in supporting informal caregivers of persons with dementia: a systematic review* (Vandepitte et al., 2016).

The findings of studies that have assessed the *impact of day care on family caregivers’ stress and burden* are inconsistent. One study found a significant reduction in stress in family caregivers on day care days compared to non-day care days (Zarit et al., 2011). Two studies found that when people with dementia attended day care their family caregivers experienced significantly reduced levels of stress compared to the control group (Kwok, Young, Yip & Hi, 2003; Mossello et al., 2008), with one of the studies finding that day care gave family caregivers more time for their own activities. These family caregivers also had higher expectations for life and a greater reduction in family conflicts

(social burden) than the control group, but perceptions of the state of their own health were not significantly better than in the other group (Mossello et al., 2008). Another study found day care to have no significant impact on the family caregivers' burden (Zank & Schacke, 2002). One study found that when family caregivers received respite through a person with dementia attending day care, they felt significantly less overloaded compared with the control group. In relation to experiencing worry or strain, or the feeling of being held in captivity, there were no significant disparities between the groups (Zarit et al., 1998).

A study *comparing respite at day care centres and institutions* found that when people attended day care centres for respite care, their family caregivers felt less socially isolated than those whose respite was provided by an institution (Colvez, Joel, Ponton-Sanchez & Royer, 2002). Other studies show that institutional respite may, in some cases, have negative effects on family caregivers, such as not sleeping well when the person with dementia is in respite care or increased levels of stress when they return from respite care (Neville & Byrne, 2008). This may indicate that respite at day care centres has a greater impact than institutional respite. It is difficult to determine whether respite at day care centres has a more positive effect on the family caregiver's well-being compared to other health services, and summarized research emphasizes the need for further investigation to elicit more knowledge on the impact of specific respite measures (Fields, Anderson & Dabelko-Schoeny, 2012; Vandepitte et al., 2016).

Three studies have assessed the *impact of day care on the emotional symptoms* of family caregivers. One study showed a significantly lower incidence of depression compared with the control group (Zarit et al., 1998). The other two studies found no difference in depressive symptoms among family caregivers who received respite through day care centres compared to the control group (Mossello et al., 2008; Zank & Schacke, 2002).

Two studies have assessed the *impact of day care on the family caregivers' satisfaction*. In the assessment of positive emotions, there was no difference between the intervention group and the control group (Zarit et al., 1998). On the matter of subjective well-being, there were also no significant differences in impact between the groups (Zank & Schacke, 2002).

In addition to the direct impact that day care has on family caregivers, it may be useful to examine *whether day care influences challenging behaviour in the person with dementia* since the extent of challenging behaviour can have a major impact on the relationship and communication between the person with dementia and the family caregiver (Thyrian et al., 2016). There were also few studies in

this area, and the studies that were found were small and of poor quality. Two studies found a significantly lower incidence of behavioural problems in people who received day care compared to those who did not (Droes, 2000; Ishizaki J, 2002). This was also the finding of the study by Dröes et al. from 2004 (Droes, Meiland, Schmitz & van Tilburg, 2004), particularly in relation to inactivity and antisocial behaviour. Dröes et al. also showed that respite through day care centres can increase family caregivers' competence in the care work, which is assumed to have a positive effect on how they prevent and/or tackle challenging behaviour. Three other studies, on the other hand, found no significant differences in challenging behaviours in people with dementia who attended day care compared to those who did not (Femia et al., 2007; Wimo, Mattsson, Adolfsson, Eriksson & Nelvig, 1993; Zarit et al., 1998).

The need for long-term care in a nursing home is often seen in the context of family caregivers' motivation and ability to provide care for the person with dementia in their own home. Because day care aims to improve the ability and motivation of family caregivers to provide care, it is therefore interesting to summarize studies related to the *impact of day care on admission to a nursing home*. Once again, the findings are inconsistent. A randomized study found no significant effect on the average number of days in a nursing home for short-term stays (Engedal, 1989), while a non-randomized study showed a significantly lower uptake of beds in nursing homes in the intervention group (Wimo et al., 1993). Contrary to the intention, two studies found that respite through day care centres can hasten institutionalization (Kuzuya, Izawa, Enoki & Hasegawa, 2012; McCann et al., 2005). These results may be explained by family caregivers waiting too long to apply for day care, resulting in people with dementia needing a place in an institution within a short period of time. Other explanations may be that family caregivers who are offered respite through day care centres are under more strain than other family caregivers, or that the day care does not offer a sufficient number of days and therefore the respite does not have a sufficient effect (Vandepitte et al., 2016).

#### 2.2.4 Mature care – an alternative care philosophy

In order to understand how day care can provide support and respite for family caregivers, it may be useful to consider this in a philosophical care perspective, where the values of society and family caregivers help create expectations vis-à-vis the role of caregiver. Family caregivers' ideals regarding care are influenced by these values, and can influence how they perceive their own role. Family caregivers, the person in need of help, family and friends, the support services and society can all have expectations, and these can be related to the perception of what good care by a family caregiver entails and how the caring family caregiver acts and thinks. The extent to which family

caregivers perceive they are meeting their own or others' expectations can affect how they feel they are coping in the role, whether they feel comfortable in the role and whether the role feels meaningful.

Throughout history, the altruistic care philosophy, with compassion as a central component, has been regarded as the ideal care philosophy. Altruistic care is selfless and is given unconditionally, based on the helper's unprompted compassion and self-sacrifice. Altruistic care affects the balance of the relationship. From being two independent people, where both sets of needs are equal, the helper ideally has to put his or her own needs aside and give priority to the needs of the person in need of help for as long as necessary. According to the altruistic care ideal, the need for help is largely assessed and determined based on the helper's understanding of the needs of others. Such an altruistic care ideal entails some challenges and ethical dilemmas. There may be challenges related to who defines what the help needs are and how the wishes of the person in need of help are identified and protected. A care philosophy of this nature can raise questions such as: what if the need for care is bottomless – can the helper set limits and how can these limits be ethically justified? What if the person who is ill takes advantage of the caregiver's willingness to help? What if the helper becomes ill or no longer feels compassion for the person in need of help? Should he or she continue to provide care in this case, or is it ethically correct to leave the care to others? There may also be situations where the caregiver exploits the situation to exercise control and power over the person in need of help, or has ulterior motives, such as garnering pity and admiration from others (Pettersen, 2012). Such dilemmas suggest a need for an alternative care philosophy based on *relational autonomy*, with greater relational reciprocity and equilibrium between the person in need of help and the helper.

Mature care is an alternative care philosophy in which the needs, interests and values of caregivers and those in need of care are equal. According to mature care, good care is based on communication between the parties, information and competence, as well as continuous reflection on the situation. The caregiver must reflect on how interaction with the other party occurs, and how well he or she understands and responds to the other person's needs. Another key element is how the caregiver attends to his or her own needs, which is considered to be vital to providing good care. The mature care philosophy entails a reduced risk of paternalism and exploratory care because the moral provisions are based more on dialogue than monologically established norms (Pettersen, 2012). According to the mature care philosophy, it is immoral to set aside one's own values and needs, particularly over a long period of time. Taking into account both one's own values and needs as well

as those of others when making care-related choices, such as deciding to accept professional help or respite, is good moral care according to the mature care philosophy.

### 2.2.5 Self-determination theory – a theory of motivation

As previously described, one of the goals of support and respite is to increase the family caregivers' well-being and motivation to provide care, thereby helping to postpone the need for institutionalization. In order to understand how day care can motivate family caregivers to provide care, it may therefore be useful to examine the concept of motivation and what can engender motivation.

Self-determination theory (SDT) is a macro theory that deals with human motivation in the choices we make and the extent to which a person's behaviour is governed by intrinsic or extrinsic motivation. Intrinsic motivation relates to performing an activity because it is interesting or satisfactory in itself. This is in contrast to starting and carrying out an activity in order to reach an external goal (extrinsic motivation), i.e. a goal that is beyond the action itself. Behaviour that is governed by intrinsic motivation is the actions we do naturally and spontaneously when we feel free to follow our own interests. Extrinsically motivated behaviour is when we feel controlled or driven by an external reward (Deci & Ryan, 2000).

According to the theory of *goal-directed behaviour*, human behaviour is driven by initiative, actions and goals. Which behaviours are considered to be appropriate is weighed up against the extent to which the action will lead to the desired outcome or goal. What defines the desired outcome and goal for the individual is influenced by: 1) our basic psychological needs (e.g. feeling safe, being respected, having faith in oneself), 2) what goals we think are achievable for us, and 3) which regulative processes make us progress towards our goal. Based on this theory, our autonomous choices are based on assessments we make in relation to these three factors (Deci & Ryan, 2000).

Human behaviour is often composed of both intrinsically and extrinsically motivated actions, but if the action is based more on intrinsic than extrinsic motivation, it may have some positive consequences. In order for a person to be able to set goals that are driven by the person's intrinsic motivation, and to make the necessary choices and carry out the necessary actions that lead to these goals, there are three universal inherent psychological needs that influence us, according to SDT: 1) the experience of possessing the *competence* to achieve the goal (i.e. knowing which actions are appropriate), 2) the experience of a *relational affiliation* to the person(s) who guide or help us (i.e.

receiving support from a warm and caring person), and 3) the experience of *autonomy* in the situation. According to SDT, the experience of autonomy strengthens a person's ability to set goals and act based on intrinsic motivation. If goals and actions are driven by intrinsic motivation, this makes the person more creative in terms of finding solutions. The person also becomes more cognitively flexible when problem-solving, which makes them more receptive to learning new things (Deci & Ryan, 2000). Daily life presents many challenges for family caregivers of people with dementia, and it is easy to see that creativity, flexibility and the ability to learn new things can be useful qualities when tackling the new challenges. According to Deci and Ryan, goals and actions based on intrinsic motivation, through experiences of competence, relational affiliation and autonomy, foster good mental health and well-being. Based on what we know about the situation of family caregivers, their mental health is at risk and there is the danger that providing long-term care will result in them falling ill. With this perspective, support and respite that give family caregivers more autonomy in their daily lives will have a positive effect on their health and well-being.

### 2.3 Summary and basis for the study

As described in chapter 2, there is insufficient knowledge about the impact of day care as a support and respite measure on family caregivers. The studies found are small, and the results are uncertain and inconsistent. However, overall, the studies show a weak positive correlation between day care and family caregivers' reduction of stress and burden. Another challenge is the lack of standardization in the care, which means that the provision available can vary in terms of content and organization. In an effort to move towards more standardized and knowledge-based day care, there is therefore a need to compile, summarize and analyse the knowledge available on the field. A review of this nature will enable us to describe what we know about the impact of day care on family caregivers, to highlight possible contexts and to clarify areas that require more knowledge.

The inconsistent and uncertain findings in the studies on this field may be related to the lack of knowledge about how day care can support family caregivers and meet their needs in an appropriate manner. Research shows that being a family caregiver can be a burden, but that it can also have positive aspects, such as meaning and a sense of coping. In order to gain a better understanding of how day care can have a positive impact on family caregivers and meeting their needs, it is therefore useful to learn more about how they perceive their situation and their role, what expectations they have vis-à-vis day care and how day care can help increase their motivation to provide care through more meaning and a greater sense of coping in the role of family caregiver.

Based on this need for knowledge, it was appropriate to study various aspects of the topic using different methods, which, when synthesized, could provide more knowledge about how day care impacts on family caregivers.



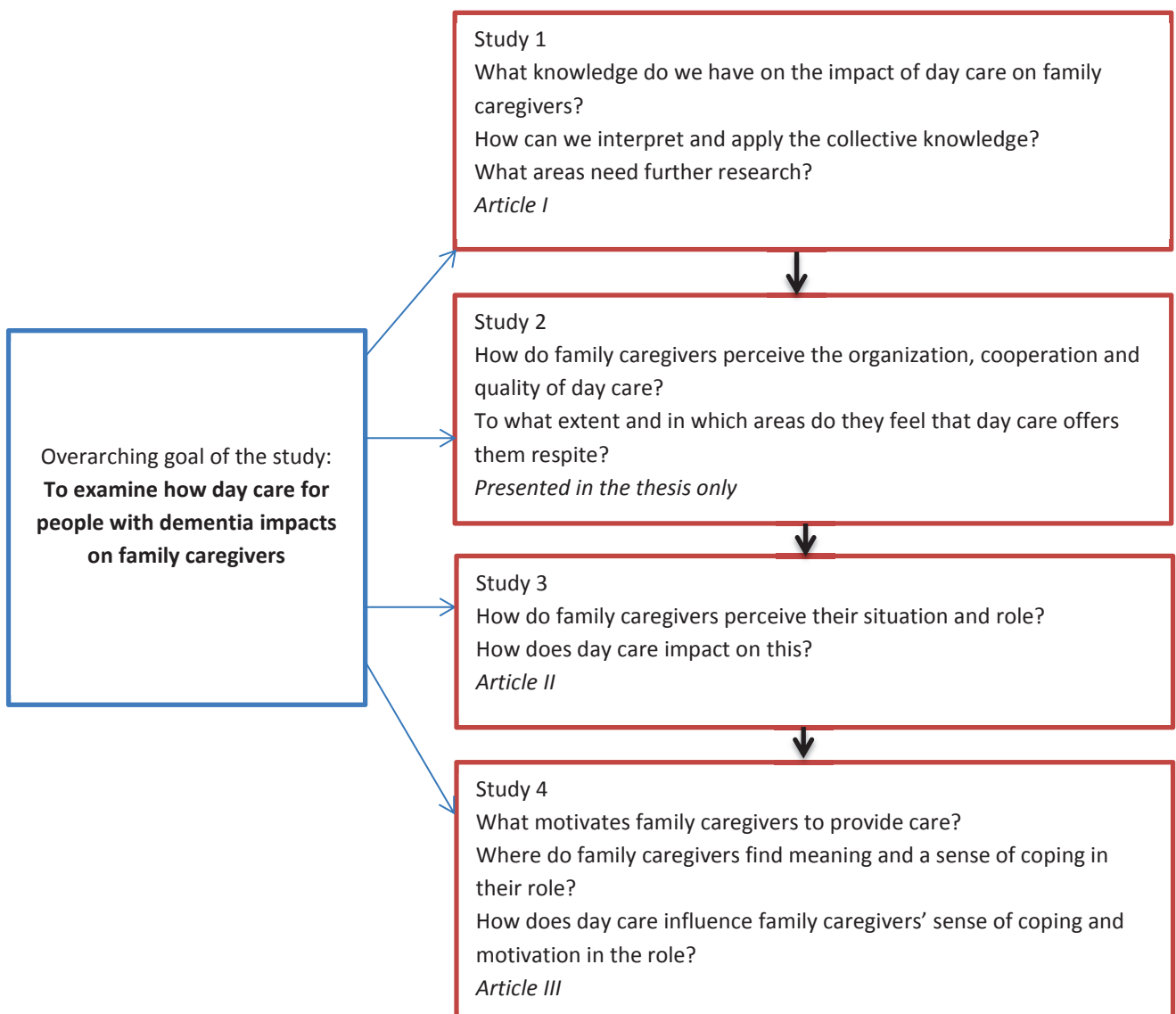
## 3.0 The thesis

### 3.1 Objectives

The overall objective of the thesis was to study how day care for persons with dementia impacts on their family caregivers.

Based on the theoretical foundation of the study, which shows the need for more knowledge on the field, some research questions were formulated which the study set out to answer. The development and execution of the studies was a process in which the results from each study led to new research questions and new studies. This process is illustrated in model 3.1.

#### Model 3.1 Overarching goals and research questions in the study



### 3.2 Studies included in the thesis

**Table 3.1** An overview of the studies included in the thesis

Study	Design/method	Participants	Analyses/evaluation method
<p><i>The influence of day care centres for people with dementia on family caregivers: An integrative review of the literature</i></p> <p>Tretteteig, Vatne, and Rokstad, 2015</p>	Integrative review of the literature	19 studies: Qualitative (n=2), Quantitative non-randomized (n=8), Quantitative descriptive studies (n=7), Mixed-method design (n=2).	Content analysis of the included studies' results  The included studies were rated by the <i>Mixed Methods Appraisal Tool (MMAT)</i>
<p><i>Information and cooperation-questionnaire to family caregivers of people with dementia who attend a day care centre designed for this group of users</i></p> <p>Presented in the thesis only</p>	Survey  Questionnaire including comments	151 family caregivers of persons who attend day care specially designed for people with dementia	Descriptive analyses  Frequency analysis
<p><i>The influence of day care centres designed for people with dementia on family caregivers – a qualitative study</i></p> <p>Tretteteig, Rokstad and Vatne, 2017</p>	Qualitative descriptive design using in-depth interviews	17 family caregivers	Systematic text condensation
<p><i>Meaning in family caregiving for people with dementia - a narrative study about relationship, values and motivation and how day care influences these factors.</i></p> <p>Tretteteig, Vatne and Rokstad Submitted 2017</p>	Qualitative, narrative design using in-depth interviews  A case study approach	5 family caregivers	Narrative performative analysis

## 4.0 Research design and methodology

It was expedient to use different methods in order to answer the different research questions in the study. A multi-method design was therefore chosen.

This study is part of the ECOD project (Rokstad et al., 2014), which investigates different aspects and the impact of day care using different methods. The main study in the ECOD project is a quasi-experimental, controlled trial using quantitative measures over a two-year follow-up period. At the family caregiver level, this quantitative part of the ECOD study will provide knowledge about caregivers' stress levels, symptoms of depression and quality of life and possible differences between the group of family caregivers of people who attend and of those who do not attend day care.

However, these quantitative methods are unsuited to finding answers regarding the wishes and expectations of family caregivers in relation to day care, and what is important in order for family caregivers to feel that the service meets their needs and offers them support and respite. In order to answer this type of question, we need to use qualitative research methods, which describe and interpret phenomena and provide in-depth knowledge about human experiences (Johannessen, Tufte & Christoffersen, 2010; Kvale, Brinkmann, Anderssen & Rygge, 2009; Malterud, 2011).

Therefore, two of the studies in this thesis explore the experiences of family caregivers, as described in their own words. In addition to describing the different aspects of the family caregivers' experiences, the findings can be used to explain and/or validate the findings from the quantitative study.

To summarize and analyse the knowledge in the field, the study began with a review study. The review study summarizes and describes aspects of day care that may be important in terms of how family caregivers view the service. These factors also provided the foundation for the writing of a questionnaire to chart how family caregivers experience different aspects of Norwegian day care for people with dementia. The results of the review article also provided a background for the first qualitative study, and helped shape the themes in the interview guide.

## 4.1 Study 1

### **The influence of day care centres for people with dementia on family caregivers: an integrative review of the literature**

#### 4.1.1 Aim

The aim of this study is to provide an extended understanding of the influence of day care centres on family caregivers, as described in the literature.

#### 4.1.2 Method

As described in chapter 2, there was a need for a summary and analysis of the knowledge about how day care influence on family caregivers. The lack of standardization of day care, and the use of different methods to conduct research on the topic made it difficult to compile and compare the results in a review study. We therefore chose the *integrative review* method, which has a pragmatic design, and allows for both a theoretical framework and studies using both qualitative and quantitative methods (Cooper, 2009).

#### ***An integrative review***

The integrative literature review is a distinctive form of research (Torraco, 2005) which generates new knowledge about a theme. It presents the state of the science, contributes to theory development, and has direct applicability to practice and policy (Whittemore & Knafl, 2005).

According to Cooper (2009), "Literature reviews can attempt

- a) to integrate what others have done and said,
- b) to criticize previous scholarly works,
- c) to build bridges between related theme areas, and/or
- d) to identify the central issues in a field" (Cooper, 2009, p. 4).

According to Whittemore & Knafl (2005) integration is understood as a process of synthesizing isolated bits of information from qualitative, quantitative and mixed-method designs, into a more comprehensive and internally consistent whole. It is based on a pragmatic approach (Whittemore & Knafl, 2005). Including different issues, methods, samples, settings, theoretical placement and social context in the analysis can bring produce a wider understanding of the impact of day care on family caregivers.

#### 4.1.3 Data collection

In order to identify relevant existing research that may answer the research question in this study, searches were made in PubMed, the Norwegian Electronic Health Library – Full Text, AMED (1985–2013), Embase (1996–2013), Ovid MEDLINER (1996–2013) and PsycINFO (1987–2013) in September 2013, with no constraints on date. The search was repeated in September 2014 with non-complementary findings. The search used MeSH terms: relatives/next of kin/family carer/informal carer and day care/day care centre and dementia. In total, 453 papers were identified and cleared of duplicates (n=37) and papers not published in English. All of the abstracts were examined for relevant articles that met the inclusion criteria. I also examined the reference lists of former systematic reviews and research articles in order to complement the search. This searching yielded non-supplementary studies for inclusion.

#### ***Inclusion and exclusion of studies***

The following inclusion criteria were used to identify papers of current interest:

1. Studies including the family caregivers of people with dementia. The family caregivers could be spouses, children/children-in-law and others, such as relatives or friends.
2. Studies describing the needs of family caregivers, their experiences and/or the effects of day care centres on the person with dementia.
3. Studies published in a peer-reviewed publication.

Abstracts of studies that met the aims of the review and the inclusion criteria were appraised (n= 33). Studies that only focussed on the impact of day care centres on the person with dementia (n=10) were excluded. However, studies describing the effect on both the person with dementia and the family caregivers were included. The remaining 23 studies were reviewed in full. After scrutiny of these papers, one was excluded due to its economic focus, and three others based on their emphasis on different models and the organisation of day care centres. This process is illustrated in a flow diagram, paper I.

#### 4.1.4 Assessment of quality

The quality of the papers included was assessed using the Mixed Methods Appraisal Tool (MMAT), designed for the appraisal of complex systematic literature reviews that include qualitative,

quantitative, and mixed-method studies. The tool presents quality-scoring metrics based on different indicators depending on and adapted to the different research methods (Pluye & Hong, 2014; Pluye et al., 2011). Each stage of the studies was systematically reviewed and rated from 1–4, depending on exactly how the paper described each stage of the method implementation, the quality of the sample, and the validation of the results (see MMAT criteria & one-page template, appendix 1). The MMAT-score for the included studies are shown in table 4.1.

**Table 4.1 The included studies assessed MMAT**

Author(s)	MMAT score
<b><i>Qualitative studies (n=2):</i></b>	
Phillipson & Jones (2012)	***
de Jong & Boersma (2009)	****
<b><i>Quantitative non-randomized studies (n=8):</i></b>	
Kim et.al., 2012	***
Mosello et.al., 2008	****
Gaugler et.al., 2003a	***
Gaugler et.al., 2003b	***
Cho et.al., 2009	***
Dröes et.al., 2004	***
Zank & Schacke, 2002	****
Zarit et.al., 1998	***
<b><i>Quantitative descriptive (n=7):</i></b>	
Måvall & Thorslund, 2007	****
Zarit et.al., 2011	****
Berry et.al., 1991	***
Graham, 1989	****
Jarrott et.al., 2000	****
Dziegielewski et.al., 2001	***
Zarit et.al., 1990	****
<b><i>Mixed method (n=2):</i></b>	
Donath et.al., 2011	***
Balla et.al., 2007	*

#### 4.1.5 Data analysis

Optimal approaches to data analysis and synthesis during an integrative review are described as the least developed aspect of the process (Whittemore & Knaf, 2005). As the studies had a different focus and used various data collection instruments, it was not possible to perform a statistical meta-analysis. We extracted data from the primary studies, presented as text.

First, we read all of the material in order to get an overall impression and to identify the objectives and results of the studies (summarised in table 1, paper I). Then the studies were reread more deeply and the data was grouped into main themes. As might be expected, some of the studies covered more than one theme. At this stage, we identified and coded units of meaning across the studies and developed main categories. Because we discovered a lack of consensus in the descriptions of the content, structure, organisation, and purposes of day care centres which could influence the results presented in the studies, it was necessary to perform an analysis of the studies' descriptions of day care centres as a concept, and the purposes of the day care centres related to the family caregivers' needs. We developed data matrices, entered the coded data from the respective reports, and summarised the contents of the coded groups (presented in table 2, paper I). An example of one main category is 'Day care centres: Not a standardized service', with sub-categories 'Not standardized in term' and 'Not standardized in content, structure and organization'.

## 4.2 Study 2

The Survey:

### **Information and cooperation - questionnaire to family caregivers of people with dementia who attend a day care centre designed for this group of users**

The effect studies that were included in the review study did not provide any clear answers regarding the effect of day care on family caregivers but, together with the qualitative studies, they identified areas that had a bearing on whether family caregivers viewed day care as a safe option that offered respite. These areas were: 1) the quality of treatment (for the person with dementia), 2) training and support, 3) responsibility sharing, information and cooperation, and 4) flexibility.

In order to investigate family caregivers' experiences with day care in Norway, a questionnaire was devised, and focused on these areas.

#### 4.2.1 Aim

Describe family caregivers' experiences of how day care centres meet their need for: quality of treatment (for the person with dementia), training and support, responsibility sharing, information and cooperation and flexibility.

#### 4.2.2 Method

A quantitative method was used here, with the data being collected through a questionnaire.

##### ***The Questionnaire***

Based on the results of the review article (Tretteteig, Vatne & Rokstad, 2015) and the description of the objective of day care in national plans (Helse- og omsorgsdepartementet, 2007, 2015), a questionnaire was devised to chart the experiences of family caregivers with Norwegian day care adapted for people with dementia. The questionnaire contained statements regarding the following themes:

- Information provided about the day care centre in advance
- The date on which the placement was made and the scope of the day care
- Communication with the staff
- Transport to and from the day care centre
- The content and quality of the day care
- Day care as respite and help coping with the role of family caregiver

The questionnaire (appendix 2) was devised by the ECOD project group. A Delphi-inspired method was used to write the questionnaire (Hardy, 2004; Kennedy, 2004). The Delphi group consisted of researchers, experienced professionals, volunteers and family caregivers. The Delphi group provided feedback on whether the themes in the questionnaire were relevant and/or whether it felt that any themes had not been covered, as well as whether it was easy to understand the statements.

The questionnaire contained 35 statements, where the options were graded on the *Likert scale* (Haraldsen, 1999) from one to five, with the options: 1 =strongly agree, 2=agree, 3=neither agree nor disagree, 4=disagree and 5=strongly disagree. Statements regarding cooperation with the home-based services (question 18) and statements regarding paid work (questions 27 and 28) were marked 'if applicable', so that family caregivers would disregard them if the statements did not apply to them. In addition, the questionnaire gave respondents the opportunity to make remarks regarding each theme.

The questionnaire was tested in a pilot study that included 17 family caregivers from the target group. The feedback from the pilot study showed that the form was clear and that they had few problems completing it.



### 4.2.3 Sample

The participants were recruited from the research project *Effects and costs of a day care centre program designed for people with dementia – a 24 month controlled study* (ECOD) (Rokstad et al., 2013). The sample from the ECOD study, which this PhD study has recruited participants from, was a strategic sample that consisted of 175 participants who represented the intervention group, i.e. the family caregivers of people with dementia who receive adapted day care. Of the 175 participants, 151 completed the questionnaire (86%), and thus constitute the sample in the survey.

To be included in the ECOD study, the day care attendee needed a close family caregiver who was willing to participate. The intention was for the day care attendee and the family caregiver to have face-to-face contact at least once a week. The person with dementia had to have attended the day care centre for between one month and one year, and had a day care placement of at least two days a week. The participants were invited to take part by the people in charge of the day care centre, and they gave written consent to participate.

The participants in the survey represented 45 different rural and urban day care centres in western, southern and eastern Norway. The average age of spouses/partners was 77, and for children/children-in-law it was 54.

**Table 4x.2 Sample characteristics**

<b>Family caregivers (N=151)</b>	<b>N (%)</b>
<b>Sex</b>	
Women	105 (59%)
Men	46 (41%)
<b>Role</b>	
Spouse/partner	63 (42%)
Adult children/children- in-law	83 (55%)
Others	5 (3%)
Cohabiting with the person with dementia	69 (46%) <sup>1</sup>

<sup>1</sup>6 children, 1 sibling and 62 spouses and partners

### 4.2.4 Data collection

The data was collected through self-reporting and interviews. The data was collected in 2014–2015 using trained health care workers and researchers who had received training in use of the form.

#### 4.3.5 Data analysis

The data was analysed using Statistical Program for Social Sciences (SPSS) version 22. Descriptive analyses were made of the distribution of the answers. Based on the knowledge that the experiences of family caregivers can vary by gender and role, the entire material was examined in order to see whether there were any significant differences between the answers of men and women, and between the answers of spouses/cohabitants and children/children-in-law. It emerged that the answers did not follow a normal distribution, so the Mann Whitney U test was used to examine the differences in the responses between the groups. As a result of a high number of tests (35 statements), the level of significance was set at  $< 0.01$  in order to minimize the risk of random errors.

### 4.3 The qualitative studies

#### 4.3.1 Qualitative design

The last two studies used qualitative research methods. Qualitative methods are research strategies that are suited to describing and analysing characteristics and aspects or qualities of the phenomena to be described. Qualitative methods can help present diversity and nuances, as a single reality can always be described from different perspectives. This is why the subject's and the researcher's perspective are very important in qualitative research (Malterud, 2011). Studies 3 and 4 sought to explore and understand the experiences of family caregivers with day care. The purpose of the qualitative research interview, which is used in the qualitative studies, is to elicit the family caregivers' subjective experiences and how the day care affected these experiences. A keyword in a qualitative design is *meaning* – exploring the content of meaning in social phenomena as experienced by the person in their natural context (Malterud, 2011). It was therefore crucial to understand how day care, as a meaning-making social phenomenon, affected the family caregiver's perception of the situation as a caregiver of a person with dementia. As people, our experiences always occur in a context, i.e. in a setting and in relation to other people (Kvale et al., 2009). This was also true of the experiences of family caregivers, where the relationship with the person with dementia and the others affected how they perceived the situation and how they handled the role of family caregiver. Receiving support and respite from a day care centre entailed new relations and new contexts for both the person with dementia and his/her family caregivers. A method that is suited to describing such experiences was therefore expedient.

Qualitative research can be conducted using different methods, and is characterized precisely by the lack of a sole analytical focus. The diversity of qualitative methods means that *transparency* is of the utmost importance. This means a verifiable, visible, accurate and comprehensive step-by-step description of the method and the choices made at every stage of the research process. Using established research methods in qualitative design can facilitate this work. The data collection method in the qualitative studies was *structured in-depth interviews*, as described in Kvale (Kvale et al., 2009) and Malterud (Malterud, 2011, 2012), among others.

### ***The qualitative research interview***

Interviews are the most common method of collecting qualitative data (Johannessen et al., 2010). Knowledge is produced through the qualitative research interview, as the conversation goes deeper than a spontaneous exchange of opinions. The interview gives the researcher access to another person's life and experiences as experienced and expressed by that person. A cautiously empathetic ask and listen approach is used to evoke stories that consist of full descriptions of a theme or phenomenon. The detailed descriptions provide scope for searching for nuances and values in the story, so that the researcher may gain new knowledge and understanding of a theme/phenomenon (Kvale et al., 2009). In this study, the benefit of using interviews was to identify the variation and breadth in how family caregivers viewed their situation and their role, and how the day care impacted on this. The purpose of the interview was not to identify objective truths, facts or rules, but to obtain a detailed picture of the everyday experiences of family caregivers, as each one perceives them (in accordance with the descriptions of the qualitative design). The qualitative research interview was therefore highly suited to evoking such descriptions (Kvale et al., 2009; Warren, 2012).

### ***Hermeneutics and the hermeneutic circle***

The hermeneutic tradition of understanding deals with interpreting human meaning (Malterud, 2011). *Hermeneutics* is the study of interpretation and deals with issues related to understanding and interpretation. Hermeneutics is described as the study of that which comes to light and shows itself the way the world is experienced by the subject, and can help us understand *how* we understand, and how what happens in the world creates meaning, based on our experiences. Analysing the content of meaning in qualitative texts means that the researcher reads the data in an *interpretive* manner in order to *understand* the deeper meaning of the person's thoughts (Johannessen et al., 2010). Meaningful phenomena can be human activities, or their results and products (Malterud, 2011).

The *hermeneutic circle* shows an important principle of interpretation in hermeneutics. The hermeneutic circle describes a dynamic process of understanding that swings between part and

whole in an attempt to understand phenomena in the best way possible (Johannessen et al., 2010; Malterud, 2011; Thornquist, 2007). Studies 3 and 4 apply two different methods of analysis in the hermeneutic tradition: Malterud's systematic text condensation (Malterud, 2011, 2012) and narrative analysis inspired by Riessman (Riessman, 2003, 2008). These methods are described under each study.

### ***Trustworthiness***

*Relevance* in qualitative research is a matter of considering what role the researcher's contribution can play in the great community of scientific knowledge. It is a matter of questioning the necessity and usefulness of precisely this knowledge, and who the knowledge is relevant and useful for (Malterud, 2011). For this study to produce new, valid and relevant knowledge, it was therefore important to have an overview of the knowledge in the field of research. This overview is described in the background for the studies, and is summarized and analysed in the first article of the study. It was also useful that researchers were familiar with the field such that the research questions that were posed were relevant. The researchers' background in health services and experience with dementia care therefore provided a good basis for developing knowledge that was clinically applicable.

*Validity* is about the researcher's consideration of whether the research answers the research questions that have been posed (internal validity), and how transferable the findings are beyond the context in which the study was performed (external validity). It is a matter of what the methods and material can illuminate, and the scope and transferability of the results (Malterud, 2011). The validity of the studies will therefore be discussed in each article, and in general in the discussion section of the thesis.

*Reproducibility* is often used as a measurement of the validity of medical research; this means that the study is described in such detail that it can be repeated in the same way and achieve virtually the same results. Even with a good description, the data collection, analyses, interpretation and presentation of the results will always be affected to some extent by the researcher as a person. With qualitative research, one objective is to exploit the diversity represented by the researcher and the interviewees, and to acknowledge that there are several valid versions of knowledge, even though not all versions are equally relevant (Malterud, 2011). The sample of participants in the studies therefore represents family caregivers with a good diversity of characteristics, and different day care centres. In order to show that the study's method and the choices made during the research process provided relevant, valid knowledge, this process will be described openly and in detail in chapter 4. Another characteristic of validity is *consistency*; this means that a common thread runs

through the entire research process of the study (Malterud, 2011). This means, among other things, that there is a relationship between the research questions, the method chosen, the focus of the analysis, and the results and answers the researcher is left with after the analysis.

*Reflexivity* in qualitative research means displaying a willingness and ability to question the process and conclusions in one's own project in the form of expressing doubts and reflection (Malterud, 2011). This was partly done by *clarifying the researcher's underlying understanding*, so that the study was not designed or the data analysed with the intention of, consciously or subconsciously, confirming the researcher's assumptions or attitudes. By taking an active stance, the researcher was not only open to surprises, but actively looked for them.

#### 4.3.2 My underlying understanding

As described earlier, clarifying the researcher's underlying understanding in qualitative research is an important prerequisite for the reflexivity of the study. The term underlying understanding is linked to what hermeneutics calls a *horizon of understanding* that encompasses all of our ideas, experiences and expectations (Kvale et al., 2009; Malterud, 2011). Based on this understanding, the researcher brought his/her horizon of understanding or underlying understanding to the encounter with the family caregivers and what was said during the interviews, and further in the encounter with the transcribed material. According to the hermeneutic tradition, this underlying understanding must not be denied, but be an active act.

In both studies 3 and 4, the researcher's underlying understanding was characterized by past experiences as a family caregiver, as a nurse and with theory. Her experience with day care was generally positive, and indicated that it was a good and useful service for family caregivers. The researcher thus increased her awareness by setting aside these positive experiences and looking for possible defects and flaws in day care (particularly in study 3). The researcher had also found it difficult to be the family caregiver of a person with dementia. Actively looking for positive aspects of the role of family caregiver was therefore a conscious act that ran through every part of the research process (particularly in study 4). The researcher's underlying understanding grew during the study; this means that the knowledge she gained in study 3 gave her an expanded underlying understanding, especially with a view to the positive aspects of the role of family caregiver. This had an impact on the development of study 4, which focused on precisely this theme.

## 4.4 Study 3

### **The influence of day care centres designed for people with dementia on family caregivers – a qualitative study**

As described earlier, the results of the review study showed that the effects of day care were uncertain and varied greatly, but that the qualitative studies described positive experiences. This may mean that the day care did not adequately 'meet' the needs of family caregivers, and that there was therefore a need for more knowledge about their situation in order to be able to better tailor day care services. Another reason may be that the quantitative measurements of the study were not adequate or sensitive enough to pick up on any effects. In order to understand how day care can help improve the situation of family caregivers, there was therefore a need for more knowledge about 'where it hurts'; in other words, how family caregivers perceived their role and situation. The review study also identified some areas that may have an impact on family caregivers' sense of security and respite, but pointed out that these areas had not been adequately documented. In addition, the results of the survey showed that family caregivers in Norway are generally satisfied with day care, but that there are great variations in how day care centres handled family caregivers, and there was room for improvement related to information and cooperation with family caregivers. More knowledge about how family caregivers perceived their situation and how day care impacted on it would therefore be useful in order to be able to tailor the service better, and better meet their expectations and needs.

#### 4.4.1 Aim

The aim of this study is to provide a broader understanding of the situation of the family caregiver and to examine the extent to which day care centres can meet their need for support and respite.

#### 4.4.2 Method

The study has a qualitative design, as described in chapter 4.3.1. The data was collected using in-depth interviews with a semi-structured interview guide. The interviews underwent a descriptive interdisciplinary analysis using systematic text condensation (Malterud).

#### 4.4.3 The participants

The 17 participants in study 3 were recruited from the same sample as in the survey (see chapter 4.2.3). Because we wanted the knowledge to be varied and far-reaching, we wanted a strategic sample in this qualitative study that represented different roles, genders, ages, employment statuses and whether they lived with the person with dementia or not. Family caregivers who represented such diversity were therefore recruited. Except for one person, all of the people who were asked agreed to participate in the study. The family caregiver who declined did not provide any other reason than a desire not to participate. The characteristics of the family caregivers' relatives with dementia also varied (see table 1, paper II). The sample represented six different rural and urban day care centres in south-eastern Norway.

#### 4.4.4 Data collection

Family caregivers participated in in-depth interviews with a duration of 60 to 90 minutes. The interviews took place in the family caregivers' home (11), via Skype (2) or at the day care centre their relatives attended (4).

An interview guide was written for use during the interviews. A qualitative research interview must be open, not standardized (Kvale et al., 2009), but in order to structure the interviews within a relatively broad context, it was considered expedient to use a thematic interview guide. The themes in the interview guide were related to how family caregivers viewed their role and situation, and how the day care impacted on this view. A figure was also used in the interview which led the family caregivers to themes from the review article, and to themes related to national policy plans and objectives (Helse- og omsorgsdepartementet, 2007, 2015). Examples of themes in the interview guide were: the situation of the family caregiver after NN was diagnosed with dementia, a typical day where the person with dementia attends a day care centre, and whether the day care postpones the need for placement in an institution. In order to pick up on any new aspects or contexts that had not been described in the past, it was important to also provide space to talk about related themes that were not in the interview guide. The order of the themes and the questions was not followed systematically during the interview. The theme the family caregivers wanted to discuss determined the direction of the interview. The researcher found that the themes in the interview guides generally covered the themes the family caregivers wanted to talk about.

#### 4.4.5 Data analysis

##### ***Systematic text condensation***

Systematic text condensation has a hermeneutic frame of understanding, which means that parts of the text must be interpreted and understood in light of the whole text, in the same way that the whole is a result that must be understood according to the parts (the hermeneutic circle) (Johannessen et al., 2010). Gaining more knowledge about the impact of day care on family caregivers is about taking the whole as the starting point, such as interpreting and understanding family caregivers' total experience of the situation to looking at day care as a phenomenon in this situation.

Systematic text condensation is a method of analysis that is highly suited to a descriptive interdisciplinary analysis of phenomena that are described in material from many different participants. The method is inspired by Giorgi's phenomenological analysis (Giorgi, 1985), modified by Malterud, and has many similarities to the procedure described in grounded theory (Strauss & Corbin, 1990). The purpose of systematic text condensation is to develop new concepts and descriptions (Malterud, 2011, 2012), which made this a suitable method of analysis, based on the objective of this study. Systematic text condensation has the following steps:

1. One reads the entire description in order to get a general sense of the whole statement.
2. Once the sense of the whole has been grasped, the researcher goes back to the beginning and reads through the text once more with the specific aim of discriminating 'meaning units' from within a psychological perspective, with a focus on the phenomenon being researched.
3. Once the meaning units have been delineated, the researcher reviews all of the meaning units and expresses the psychological insight contained in them more directly. This is especially true of the meaning units that reveal the most about the phenomenon under consideration.
4. Finally, the researcher synthesizes all of the transformed meaning units into a consistent statement regarding the subject's experience (Malterud, 2012, p. 796).

The analysis took the form of a back and forth process using Malterud's steps, until the material had been adequately analysed.

The *first step* of the *analysis* resulted in the following themes:

- 1) The effect of dementia on the situation and role of family caregivers.
- 2) The effect of day care on the situation and role of family caregivers.

Once the themes had been formulated, *step 2 of the analysis* began. The text was reread many times in light of these general themes in order to identify thematic meaning units from a psychological



perspective. The meaning units were then sorted into codes and sub-codes. Examples of this work are shown in table 4.3.

**Table 4.3 Examples of meaning units, codes and sub-codes, analysis step 2**

<b>Changes in the person with dementia (related to theme 1)</b>		
<i>Meaning units</i>	<i>Codes</i>	<i>Sub-codes</i>
<p>He is not interested in TV any more. He can't keep up with the plot of films, you know. When the subtitles appear, I realize that he can't keep up with them. That's why he turns it off.</p> <p>She hides things, and she can call me 17 times over a short period of time, and make a fuss about somebody stealing something, that things are missing (...) that she didn't find her key in the morning. I had to go there and drive her to the day care centre afterwards.</p>	Cognitive changes	Memory loss Aphasia Disorientation
<p>He didn't do much before either, but he should be able to. And he gets very irritated and frustrated when he can't manage. He loses his temper easily, which I'm not used to.</p> <p>She keeps running out to her post box, looking for newspapers. She thinks that someone has stolen the newspapers. We try telling her that newspapers aren't delivered at Easter, why don't you check the calendar? This unsettles her and she starts nagging.</p>	Psychological changes	Irritability Anger Frustration Impatience
<p>Sometimes she wets herself because she doesn't get to the bathroom in time. The toilet is in the basement, but we have a toilet chair in the kitchen. So I have to carry it down. I don't make a fuss about it.</p> <p>She spends a lot of time on the sofa. She gets up and has breakfast, then she goes back to sleep for a couple of hours.</p>	Physiological changes	Incontinence Increased need for sleep Decreased appetite
<p>I tried to get him to get his toothbrush yesterday, and it took a very long time, and I thought "What's going on? It's in the glass?" (...) He can't manage the simplest things. He has trouble putting plugs in the socket, and he's an engineer.</p> <p>He stands around, wondering what to do. So I say, "The cups are there. You can bring me a couple of cups." And then there's the cutlery – he stands around, wondering what to do.</p>	Changes in ADL functions	Apraxia Agnosia
<p>I don't mind crazies, as long as they're people. Just a little human contact and I'm OK. He wasn't like this before, he managed quite well on his own.</p> <p>She has become so mean to some of my grandchildren. They have a nice time when it's just them, but as soon as other people arrive, she's mean to him and me.</p>	Social changes	Increased need for contact Personality changes Less control

Technically, step 2 of the analysis was performed using the NVivo qualitative analysis tool, where all of the data and the meaning units and associated quotes are stored.

The meaning units were reviewed again *in step 3 of the analysis*, with a view to eliciting new psychological knowledge related to the phenomena being studied. This insight was developed by questioning the content of the meaning units, along the lines of: what do family caregivers think about having to spend more time helping people with dementia with practical or personal tasks? Or: what do family caregivers think about the day care centre offering people with dementia a social community that includes meals and physical activity? This way the results of the analysis were elevated to an abstracting level that brought out a deeper psychological significance in the meaning units, i.e. how they impacted on the situation and role of family caregivers. The results of step 3 of the analysis led to new main themes, themes, code groups and sub-code groups as presented in table 3, paper II).

In *step 4*, the quotes were finally put back into the context they had come from in order to confirm that the understanding and interpretation of the quotes were correct, based on their original context in the text.

## 4.5 Study 4

### **Meaning in family caregiving for people with dementia – a narrative study of relationships, values and motivation, and how day care influences these factors**

Study 3 found several positive aspects associated with the role of family caregiver in terms of the relationship with the person with dementia. Family caregivers said that the role brought them closer to the person with dementia, they did more things together, and they received positive feedback from their surroundings and from the person with dementia regarding the care they provided. Some family caregivers believed that the day care could help bring out these positive aspects.

Together with dawning scientific interest and knowledge about the experience of meaning and positive aspects of the role of caregiver, the results of study 3 created a need and an opportunity to gain more knowledge about what motivated family caregivers in their role and how the day care could increase this motivation. As previous research showed that the motivation and positive experiences of family caregivers are closely linked to a sense of meaning and coping, where the person's identity, values and relations are key, it was expedient to use a qualitative method that was

well suited to obtaining knowledge about these themes. Study 4 therefore has a qualitative design based on a narrative method.

#### 4.5.1 Aim

The aim of this study was to gain knowledge about family caregivers' sense of meaning in their role as caregiver. The impact of day care on their experience and motivation as a caregiver is also explored.

#### 4.5.2 Method

A narrative method, with a case study approach using individual interviews, was used to obtain an in-depth understanding of family caregivers' sense of meaning in the role of caregiver and how day care supports coping in everyday life. Narrative studies rely on extended accounts that are preserved and treated analytically as units, rather than fragments divided into thematic categories, as is customary in other forms of qualitative analysis. Each interview was therefore analysed as a single unit, in order to highlight points that create contexts or breaks in the story, more than to identify similarities and dissimilarities with the other stories.

In a narrative study, attention shifts to the details – how and why a particular event is storied, or what a narrator accomplishes by developing the story that way, and the effect on the reader or listener. In a narrative study, peculiarities and context come to the fore and a good narrative analysis prompts the reader to think beyond the surface of a text, and there is a move toward a broader commentary (Riessman, 2008). Based on this, the analysis not only contained the words that were said, but also other factors, such as *why* things were said, *how* things were said, what was emphasized in the story, and whether there were any recurring themes.

According to Riessman in a narrative inquiry, the analyst:

...is interested in how a speaker or writer assembles and sequences events and uses language and/or visual image to communicate meaning, that is, make particular points to an audience. Narrative analysts' interrogate intentions and language about how and why incidents are storied, not simply the content to which language refers (Riessman, 2008, p. 11).

There are different models for narrative analysis: thematic analysis, structural analysis, interactional analysis and performative analysis (Riessman, 2008). This study used a performative analysis that

focuses on *the person's identity or the character of the person who tells the story*. In the psychological and sociological traditions, the personal narrative encompasses long sections of single or multiple interviews. Even though we had conducted two interviews of each family caregiver by this stage (the first one as part of study 3), we decided to only include the second interview because the interviews in the two studies covered different themes. Narratives do not speak for themselves or have unanalysed merit; they require interpretation when used as data in social research. In this study, we paid special attention to the position the caregivers placed themselves into in their relationship with the person with dementia (Riessman, 2003, 2005).

### 4.5.3 The participants

The participants in study 4 were recruited from the participants in study 3. The description of the original sample (which the participants in study 3 belong to) is described in chapter 4.2.3.

The sample of participants in this study was selected based on themes that came to light during the interview in study 3, i.e. their descriptions of how they experienced meaning and other positive aspects of the role of caregiver. In order to be able to go into even greater depth regarding these themes, these family caregivers were contacted again, and included in study 4. The sample represented variation in the role and age of the family caregiver, whether they lived together with the person with dementia or not, and whether they worked. The role, age and level of dementia also varied in the person they cared for. All of the family caregivers who were asked to participate in the study agreed. The characteristics of each participant are described in table 1, paper III.

### 4.5.4 Data collection

As described earlier in this chapter, the data was collected using qualitative research interviews. The interviews occurred in the family caregivers' home (3), via Skype (1) or at the day care centre their relatives attended (1). The interviews lasted for 60 -90 minutes. The positive aspects the family caregivers had mentioned in the first interview were mentioned again, and they were asked to elaborate on this. An interview guide was also used. The family caregivers felt an immediate sense of trust in the interview situation because they had already established a relationship with the interviewer. This promoted openness in the interview.

#### ***The interview guide***

Inspired by Riessmans' description of the performative analysis, the interview guide focused on three main themes that explored the past and the present in how the family caregivers described: 1)

themselves, their values and goals, and the position they placed themselves into in the role of caregiver, 2) their relationship to the person with dementia, and 3) how day care impacted on their situation. The themes and the sample questions are described in the interview guide in Table 4.4.

**Table 4.4 The interview guide, study 4**

Themes/theme areas	Sample question
1. Introduction	How are you doing, as a family caregiver? How has your situation changed lately?
2. Relational emotional changes	How do you consider your relationship with NN?
3. Positive experiences in the role	Is there anything about your situation now that you consider to be good? <ul style="list-style-type: none"> <li>• What contributes to these good times?</li> <li>• Why do you think you handle this difficult situation so well?</li> <li>• What is important in order for you to help and support NN?</li> <li>• Is there anything health care workers can do so that you have more good times together?</li> <li>• Have you ever thought that you have to give up or 'drop out' of the caregiving?</li> <li>• What keeps you going when things are difficult?</li> </ul>
4. Own needs	What do you think about taking care of yourself? <ul style="list-style-type: none"> <li>• Is it important to prioritize your own needs in your current situation?</li> <li>• Can you prioritize your own needs or those of others?</li> <li>• Are there any conflicts associated with your needs or those of NN?</li> </ul>
5. Conclusion	How does NN attending a day care centre impact on your everyday life? In general, what do you think is important in order for you to do well in your current situation?

#### 4.5.5 Data analysis

##### ***Narrative analysis***

Narrative research is a form of case-centred inquiry (Riessman, 2008). The purpose and benefit of using this method was its suitability for highlighting the unique identity of family caregivers and how the relationship and affiliation with the person with dementia characterized their sense of meaning as a caregiver. Narrative analysis has a hermeneutic frame of understanding (see chapter 4.4.5), which permeated every aspect of the analysis. This study sought to elicit further knowledge about the positive experiences of family caregivers in that role and day care, in light of their overall situation. The analysis allowed the selection of themes and quotes, and they were interwoven into a descriptive narrative, which thus represented a whole in the person's story. The description of identity, relations, sense of belonging etc. were compiled into an overall picture and a descriptive plot, as the researcher interpreted the descriptions. These condensed stories were then seen in the light of a greater whole. This could, for example, be the values of society and attitudes to dementia or to the role of family caregiver.

Inspired by Riessman's understanding of the performative narrative method, we performed a systematic step-by-step analysis in 7 steps, where each interview was analysed separately. These analysis steps are described in textbox 1, paper III, and the analysis process will be described here in greater detail.

The first condensation process took place following the questions in steps 2 and 3. The five interviews were condensed by selecting content that was relevant to these questions. This process condensed each story to 2–3000 words. The stories were then each given a descriptive *plot*, i.e. a brief descriptive sentence about the main theme that carries meaning in the story. Condensation was then carried out again, based on the questions in steps 5 and 6, which resulted in further condensed narratives of 250–350 words. In the last condensation process, each narrative was divided into chronologically thematized stories. The questions from step 5 were then posed to each of these stories. Table 4.5 shows an extract of an example of this process.

**Table 4.5 Extract of the process of condensing narratives in study 4**

<p><b>The Plot</b></p> <p>To obtain the position of the favourite daughter.</p>	<p><b>Questions I asked the narrative:</b>          What is distinctive in the story?          How is the family caregiver's identity described?          How is belonging described?          Are there any conflicts or dilemmas?          How do they describe the position they have chosen?          How are their stories told?</p>
<p><b>The narrative divided into different parts</b></p>	
<p>I am the most caring of us three sisters, the loving one, the one who hugs and touches, who shows an interest in our mother. And that's probably why she says that I'm her favourite in the family. I don't think a mother should say that. You shouldn't even say it even if you have dementia. Before my mother was diagnosed with dementia, she often said "Thank you for your good advice. I should pay you." Sometimes my answers were complicated, but she often said: "But I want to hear your opinion because you give good advice." And she seems to have brought this into her dementia – it's there.</p>	<p>I'm my mother's favourite.           My mother has always asked for my advice.           This is still the case.           It's nice that she likes me best, but it isn't good that she says so.           I'm important to my mother.</p>
<p>When my mother or anyone else visits me, I sit like this. I give my time to whoever is there. I don't do this with my mother all the time now, because it would be tiresome, and things finally go haywire, she talks about</p>	<p>I'm sensible when I'm around my mother.           I'm solution-oriented.</p>

<p>the same thing all the time. My solution is to do different things. It's nice when I see that she's happy, and is having a good time. I think I get less irritated now than I did in the past. And I'm a solution-oriented person, my job is to solve problems. So of course I try to do the same in my private life. I want it to be nice to spend time with her, and for her to be fine when she leaves me; I want her to be left with a good feeling. And I think that that's mostly the case.</p>	<p>I try to do what's best for my mother.  I'm fine if she's fine.  My mother likes being with me.</p>
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Finally, the plot of each story was revised.

The results of the study are presented in the form of these stories that are dense with meaning, with a few comments that sum up each narrative. They are presented in chapter 5.

## 4.6 Ethical approval

As described earlier, the participants were recruited from the research project '*Effects and costs of a day care centre programme designed for people with dementia – a 24 month controlled study*' (ECOD) (Rokstad et al., 2014). The ECOD study has been accepted by the Regional Committee for Medical and Health Research Ethics for South East Norway. Ethical assessments were made at every stage of the research project; from the design of the question and choice of method, to the analysis and publication of the data. Ongoing assessments were made regarding recruitment and assessment and obtaining consent, and whether there were any risks associated with participation in the study.

The National Committee for Research Ethics in the Social Sciences and the Humanities has adopted Research Ethics Guidelines (De nasjonale forskningsetiske komiteene, 2010)). The Guidelines can be summarized as three considerations that must be taken by researchers: the right of the informant to self-determination and autonomy, the duty of the researcher to respect the informant's private life, and the researcher's responsibility to not cause harm (Nerdrum, 1998).

### *The informant's right to self-determination and autonomy*

The participants were invited to participate in the study by the people in charge of the day care centres. As family caregivers, none of the participants had cognitive impairments; they were all competent to grant consent, and they gave written informed consent. They were told that they could withdraw from the study at any time, without giving a reason, and that they could contact the

project leader or interviewer if they had any questions after the conversation. During the qualitative in-depth interviews, the participants consented to the conversation being recorded.

#### *The researcher's duty to respect the informant's private life*

Through in-depth interviews, the interviewees shared very personal and sensitive information about themselves and the person they cared for. Several family caregivers cried during the conversation, but there was also much joy and laughter. Such conversations greatly challenge the professionalism of the researcher. The researcher used an empathetic and supportive style of communication with the family caregivers, whilst also being aware not to take on the role of therapist, guide or friend (Malterud, 2011). The interviewer's background as a nurse was seen as useful when encountering family caregivers in a vulnerable situation, and no major challenges were associated with this.

#### *The researcher's responsibility to not cause harm*

Even though qualitative research is often associated with a low risk of harm, it is important to be careful in studies that address sensitive themes. Risks or burdens in qualitative research may consist of the participant experiencing emotional distress, feeling abused or the content of the conversation being distorted or presented in a manner they do not recognize (Malterud, 2011). Being free to speak openly about the role of family caregiver to me as a nurse and researcher allowed the family caregivers to share their feelings and thoughts about their situation. Some of them had never spoken to a professional or researcher about this before or thought much about the role of family caregiver, while others were in close contact with professionals employed by the local authority. In qualitative research, the researcher and interviewee often form a closer bond than in quantitative research, which may trigger an expectation that the researcher can help the person (Johannessen et al., 2010). During the interviews, some family caregivers asked for advice, for example regarding how to get more help or how to handle difficult behaviour in the person with dementia. When dealing with such specific questions, nursing expertise and experience were useful in order to guide and support the family caregivers through the municipal system, which they were already part of. This felt natural and unproblematic, and did not create any special challenges, as none of the family caregivers were experiencing a serious emotional crisis or in need of emergency help. In general, the family caregivers stated that they greatly appreciated being interviewed, and said that it was good to contribute to research on this topic. Because these people also participated in other parts of the ECOD study, the interviewer was in contact with them both before and after the interviews. This provided a natural opportunity to ask how they were doing, and to gradually wind down the contact.



*Procedures for processing, systemizing, analysing and interpreting data*

Qualitative and quantitative research are characterized by both common and unique ethical challenges. The procedures for processing, systemizing, analysing and interpreting qualitative data in the form of text are different than similar processes for quantitative data such as numbers. The basic principles of qualitative research methods do not differ from established scientific premises that build on the systematic and reflexive furthering of knowledge, where the process is open to observation and objections, and the results are shared with others. Thorough descriptions of the entire research process therefore constitute an important premise for good ethical research.

The data files (study 2), transcripts and audio recordings of the interviews (studies 3 and 4) have been anonymized and safely stored on the secure research server of the Norwegian National Advisory Unit on Ageing and Health.

## 5. Findings

The findings from the literature review and the qualitative interviews are presented in three articles, retold in this chapter in short resumes. The findings from the survey are presented in chapter 5.2.

### 5.1 Paper I

#### **The influence of day care centres for people with dementia on family caregivers: An integrative review of the literature**

The results of the review study show that the purpose of day care is to provide support and respite to family caregivers, but that neither the content, structure nor organization of the service are standardized. The objective of day care is to reduce the burden on family caregivers and give them respite from care work, to help them cope with the caregiving and thus reduce stress and depression. The studies that measure the effect of day care on the caregiver burden and care-related stress are small, and the results are uncertain and inconsistent. The quality of day care impacts on the sense of security of family caregivers and their motivation to use the day care. Family caregivers want and expect day care centres to have qualified personnel and for the content to be individually adapted to the needs of the person with dementia, and for the help for family caregivers to be adapted to their needs. The risk of drop-out from day care and the need for placement in an institution increase when there is a major need for assistance and the behaviour of the person with dementia is difficult. Staff shortages and living with a spouse who experiences a high caregiver burden also increase the risk of drop-out. Day care can help postpone the need for placement in an institution if it manages to motivate family caregivers and increase their competence as caregivers.

### 5.2 Survey

#### **Information and cooperation – questionnaire to family carers of people with dementia who attend a day care centre specially designed for this group of users**

The questionnaire provided information about how family caregivers felt that the day care met their need for support and respite, where family caregivers received information about the service and whether they believed that the service came at the right time. Additional remarks from the questionnaires have been incorporated into the description of the findings.

The descriptive analysis showed that the participants received information about day care through different channels: home-based services (33%), general practitioners (13%), hospital services (13%), friends/family (13%) or others, e.g. web sites, the dementia association, the dementia team/contact, respite in a nursing home (29%). The further results from the survey are presented in table 5.1.

Most family caregivers strongly agreed or agreed that they received day care at the right time, both in terms of their own needs (77%) and in relation to the needs of the person with dementia (73%). 71% strongly agreed or agreed that they had received enough information in advance, and 79% strongly agreed or agreed that the number of days the user attended the day care centre and the number of hours per day were adequate. Only 42% strongly agreed or agreed that the service was sufficiently flexible. In the remarks, the family caregivers said that they wanted more days per week, and that it would be good if the day care centre was also open in the evenings, at the weekend and during holidays.

Family caregivers were mainly satisfied with the communication with the day care centre when they contacted it. 86% strongly agreed or agreed that it was easy to make contact with the staff and 79% strongly agreed or agreed that they had time to talk to them. A smaller number strongly agreed or agreed that the day care centre followed up on what they agreed (66%) or that they received a response to their wishes and input (68%). The family caregivers were less satisfied with the day care centres' communication with them. Only 46% strongly agreed or agreed that they received adequate information about what the person with dementia had done during the day, while 58% strongly agreed or agreed that they received information if anything out of the ordinary had happened to the user.

Only 51% strongly agreed or agreed that they were consulted if there was a need to change the services for the user, and only 36% strongly agreed or agreed that they could attend the day care centre if they wanted to. In the remarks field, the family caregivers wrote that they were invited to barbecues and Christmas parties, but that they had not been invited to help or participate in any other way. The family caregivers were satisfied with the transport to and from the day care centre. 95% strongly agreed or agreed that it was organized well, and 84% strongly agreed or agreed that the people who picked up and dropped off the users knew them well.

Family caregivers were generally very pleased with the content and quality of the day care. 95% strongly agreed or agreed that the person with dementia enjoyed being there and 69% strongly agreed or agreed that the service was adapted to the users' interests and needs. 84% strongly agreed or agreed that the staff were well-suited to their job. Some family caregivers wrote that they rarely

or never spoke to the staff. 18% strongly agreed or agreed that they had to motivate the person to go to the day care centre.

Children/children-in-law did this through phone conversations, while spouses provided motivation in the morning before they left. The family caregivers said that some people with dementia dreaded going to the day care centre, but that this mostly happened in the beginning, and they now liked going.

In relation to the consequences for the family caregivers' everyday lives, a full 97% said that they strongly agreed or agreed that the day care helped them cope with their everyday lives. 61% strongly agreed or agreed that the day care gave them the chance to be more active socially, and 65% said it gave them time to take care of practical tasks without interruption. 91% strongly agreed or agreed that the day care increased their sense of security for the person with dementia. Only seven family caregivers (6%) strongly agreed or agreed that the day care unsettled the person with dementia, and only thirteen (9%) wrote that the person with dementia did not want to go there.

In relation to cooperation and time with the person with dementia, 53% answered that they strongly agreed or agreed that the day care made it easier to cooperate with the person with dementia, while 67% strongly agreed or agreed that the time spent together became more positive as a result of the day care. The family caregivers said that the day care resulted in more pleasant conversations, and some spouses found that they became more patient and looked forward to their partner's return.

In relation to the statements regarding how the day care affected the family caregivers' ability to continue working, only 84 answered statement 27 and 86 answered statement 28, and the answers mainly came from children/children-in-law (82%/78%). Among all of the respondents to the statements, 41% strongly agreed or agreed that the day care made it possible for them to continue working, and 48% strongly agreed or agreed that the opening hours of the day care centre were long enough for them to be able to work. 45% (statement 27) and 36% (statement 28) answered that they neither agreed nor disagreed that the day care had an impact on these work-related statements.

49% strongly agreed or agreed that the day care gave them enough support in their role as family caregiver, but only 28% strongly agreed or agreed that they received useful information or instruction on dementia from the day care centre. Nevertheless, 67% believed that the day care made it possible for the person with dementia to continue to live at home.

**Table 5.1 Summary of the family caregivers' answers to the questionnaire**

Statements	1 =	2 =	3 =	4 =	5 =	Mean (SD)
	Strongly agree	Agree	Neither agree nor disagree	Disagree	Strongly disagree	
	N (%)	N (%)	N (%)	N (%)	N (%)	
<b>Information</b>						
1. I received adequate information about the day care centre in advance (N=150)	66 (44)	40 (27)	25 (17)	11 (7)	8 (5)	2.03 (1.18)
<b>Relationship with the day care centre staff on a day-to-day basis</b>						
2. The staff are easy to reach when I try to contact them (N=151)	104 (68)	25 (17)	19 (13)	2 (1)	1 (1)	1.48 (0.82)
3. The staff have time to speak to me (N=150)	101 (67)	26 (18)	23 (15)	0	0	1.48 (0.75)
4. I receive a positive response to my wishes and input (N=149)	76 (51)	25 (17)	46 (31)	1 (1)	1 (1)	1.83 (0.94)
5. The day care centre follows up on what we have agreed about my relative (N=148)	78 (53)	19 (12)	47 (32)	3 (2)	1 (1)	1.85 (0.99)
<b>The day care centre's contact with me</b>						
6. I am regularly informed about my relative's activities at the day care centre (N=148)	43 (29)	25 (17)	33 (22)	19 (13)	28 (19)	2.76 (1.47)
7. I am informed if something unusual occurs (N=151)	59 (39)	29 (19)	45 (30)	7 (5)	11 (7)	2.22 (1.22)
8. I receive sufficient information about my relative's participation in activities (N=150)	45 (30)	27 (18)	39 (26)	17 (11)	22 (15)	2.63 (1.39)
9. I am consulted if a change is required in the service offered to my relative (N=148)	7 (32)	28 (19)	55 (37)	6 (4)	12 (8)	2.38 (1.24)
<b>The offer to attend the day care centre</b>						
10. My relative received the offer to attend day care at a time that fit my needs as a family caregiver (N=150)	79 (52)	37 (25)	10 (7)	15 (10)	9 (6)	1.92 (1.24)
11. My relative received the offer to attend day care at a time that fit her/his needs (N=148)	72 (49)	36 (24)	15 (10)	16 (11)	9 (6)	2.01 (1.26)
<b>The content of the service</b>						
12. I feel that my relative has been offered an adequate number of days (N=151)	84 (56)	35 (23)	11 (7)	16 (11)	5 (3)	1.83 (1.15)
13. I feel that my relative has been offered an adequate number of hours per day (N=148)	89 (60)	32 (22)	10 (7)	15 (10)	2 (1)	1.71 (1.06)
14. The service is flexible about changing the day he/she attends if needed or is flexible about opening hours (N=148)	40 (27)	23 (16)	74 (50)	5 (3)	6 (4)	2.42 (1.05)

Statements	1 =	2 =	3 =	4 =	5 =	Mean (SD)
	Strongly agree	Agree	Neither agree nor disagree	Disagree	Strongly disagree	
	N (%)	N (%)	N (%)	N (%)	N (%)	
<b>Transport arrangements</b>						
15. The transport arrangements are adequate (N=149)	120 (80)	22 (15)	5 (3)	2 (1)	0	1.26 (0.58)
16. The people who pick up and drop off my relative know him/her well (N=148)	89 (60)	35 (24)	23 (16)	1 (1)	0	1.57 (0.78)
17. I regularly need to spend time motivating my relative to attend the day care centre (N=148)	13 (9)	12 (8)	16 (11)	29 (19)	78 (53)	3.99 (1.33)
18. The home-based services help my relative to get ready in time to go to the day care centre (if agreed) (N=84)	33 (40)	20 (23)	22 (26)	5 (6)	4 (5)	2.13 (1.15)
<b>The content of the day care centre</b>						
19. The content of the day care centre is adapted to the interests and needs of the attendees (N=149)	52 (35)	51 (34)	36 (24)	6 (4)	4 (3)	2.05 (1.00)
20. As a family caregiver, I am invited to participate in the activities at the day care centre (N=147)	27 (18)	26 (18)	82 (56)	6 (4)	6 (4)	2.58 (0.97)
<b>The quality of the day care centre</b>						
21. The staff have the right skills to work at the day care centre (N=148)	97 (66)	27 (18)	22 (15)	2 (1)	0	1.52 (0.80)
22. My relative enjoys being at the day care centre (N=149)	113 (76)	29 (20)	5 (3)	1 (1)	1 (1)	1.52 (0.90)
23. My relative does not want to go to the day care centre (N=147)	7 (5)	6 (4)	14 (10)	23 (15)	97 (66)	4.34 (1.11)
<b>Day care centre as respite care</b>						
24. The day care makes it easier for me to cope with everyday life (N=150)	108 (72)	22 (14)	16 (11)	3 (2)	1 (1)	1.45 (0.82)
25. The day care allows me to be more socially active (N=149)	66 (44)	25 (17)	38 (26)	5 (3)	15 (10)	2.18 (1.31)
26. The day care gives me the opportunity to take care of practical tasks (N=149)	76 (51)	21 (14)	37 (25)	5 (3)	10 (7)	2.01 (1.23)
27. The day care makes it possible for me to keep my job (if working) (N=84)	26 (31)	8 (10)	38 (44)	4 (5)	8 (10)	2.52 (1.25)
28. The opening hours are long enough to enable me to go to work (if working) (N=86)	26 (31)	15 (17)	31 (36)	7 (8)	7 (8)	2.47 (1.18)
29. The day care improves my sense of security in the situation (N=149)	113 (76)	22 (15)	9 (6)	3 (2)	2 (1)	1.38 (0.80)
30. The day care makes my relative worried and distressed (N=147)	2 (1)	5 (3)	11 (8)	21 (14)	108 (74)	4.55 (0.88)
31. The day care makes it easier for me to interact with my relative (N=147)	32 (22)	45 (31)	59 (40)	5 (3)	6 (4)	2.37 (0.10)
32. The day care improves the time we spend together (N=148)	47 (32)	53 (35)	41 (28)	3 (2)	4 (3)	2.08 (0.96)
<b>The support from the day care centre to cope with challenges in everyday life</b>						
33. I receive adequate support from the day care centre in my role as family caregiver (N=148)	40 (27)	32 (22)	55 (37)	9 (6)	12 (8)	2.47 (1.19)
34. I receive useful information about dementia from the day care centre (N=148)	19 (13)	23 (16)	65 (44)	12 (8)	29 (19)	3.06 (1.24)
35. The day care makes it possible for my relative to continue to live at home (N=149)	74 (50)	41 (27)	28 (19)	2 (1)	4 (3)	1.80 (0.97)

The research also looked at whether there were any differences in the responses between genders and the relationship with the person with dementia. The analyses revealed significant differences between the responses of spouses/cohabitants and children/children-in-law for two of the statements. Spouses/cohabitants agreed to a significantly greater extent that *The day care allows me to be more socially active* than children/children-in-law (p value 0.001). They also agreed significantly more that *The day care gives me the opportunity to take care of practical tasks* (p value <0.001) (see Table 5.2). No significant gender differences were found in the response, neither in the entire sample nor when we investigated gender differences within the groups of spouses/cohabitants and children/children-in-law.

**Table 5.2 Differences between the responses of spouses/cohabitants and children/children-in-law**

Statements	Spouses/cohabitants N (Median)	Children/children- in-law N (Median)	p value <sup>1</sup>
25. The day care allows me to be more socially active (N=149)	62 (1.0)	87 (3.0)	0.001
26. The day care gives me the opportunity to take care of practical tasks (N=149)	62 (1.0)	87 (3.0)	< 0.001

<sup>1</sup> Mann Whitney U-test, p value < 0.01 consider significant.

### 5.3 Paper II

**The influence of day care centres designed for people with dementia on family caregivers – a qualitative study**

Caregivers experience a complex role, with added responsibilities, new tasks, and emotional and relational challenges that are expressed through distressing emotions and demands for interaction.

Cognitive, psychological, social and behavioural changes in people with dementia led to a need for supervision, support and practical help from family caregivers. The psychological changes were described as apathy and a lack of initiative and interest, anger and irritation. Family caregivers felt pity for the person with dementia and felt guilty. All of the complaining exhausted them, and they felt that they could never completely relax. Family caregivers felt responsible for meeting the different needs of their relatives. They found that day care relieves them by meeting the person with dementia's need for social interaction, nutrition, physical activity, and structure and variety in everyday life. Additionally, the role of caregiver leads to positive experiences, such as acceptance and

adaptation, support and help, and positive changes in the relationship. Using day care led to the time spent together being of higher quality and made cooperation easier, but it also produced troubling feelings and challenging situations. The dementia led to confrontations and difficult communication, which the family caregivers found painful and tiring. The day care put the person with dementia in a better mood, and resulted in a more natural pattern of sleep and rest. This led to a more natural rhythm in their everyday life and more pleasant conversations.

Day care gave the caregivers a sense of freedom and increased the time available to attend to their own needs, to be social and to work or do practical tasks without disruption. Many family caregivers mentioned getting more time to attend to their own needs as critical in order for them to continue to provide care. A high-quality and adapted service was reported by some as important for the person with dementia being able to enjoy him/herself at the day care centre, which in turn was crucial for the family caregiver being able to feel secure and relax with a clear conscience.

## 5.4 Paper III

### **Meaning in family caregiving for people with dementia – a narrative study of relationships, values and motivation and how day care influences these factors**

Five narratives describe how five family caregivers cope with their situation in meaningful ways and how day care influences this coping.

#### *To obtain the position of the favourite daughter*

This daughter wanted to have a close relationship with her mother, and met her needs. Her motivation and sense of meaning in the role of caregiver were greatly linked to the experience of closeness with her mother, and filling the role of 'favourite daughter'. She believed that she had the time, professional knowledge and good personal qualities required to best help her mother. The dementia had led to a closer relationship where also her need for a 'real mum' was now met to a greater extent than before her mother became ill. The mother enjoyed attending the day care centre, and the daughter found that the service was also positive in terms of her role as family caregiver, as it gave her respite from meeting her mother's needs.

#### *To do one's duty without emotional involvement*

This son's motivation for providing care was related to doing his duty as a good son. He had had a complicated relationship with his father throughout his life, but the illness had resulted in them



having more contact. Even though he did not enjoy the role of caregiver much, the role gave him a good conscience. This made him a better caregiver for his father than his father had been for him, and he thus met his care values. The father enjoyed the day care centre, and the son found that his father nagged him less after he started going there. He also said that the day care was good for his father.

*To maintain relationships through routines and control*

This wife linked her meaning in everyday life to her relationship with her husband. They had lived together for many years, and she had a strong desire for them to remain together, and therefore did her utmost to make things work. She managed their everyday life through strict routines, which was critical to her well-being and control over the situation. The wife said that the day care was crucial to her managing her everyday life. Her husband enjoyed going to the day care centre, and her needs were met while he was there.

*To balance between the need for a social network and the wife's needs*

This husband found meaning in his life through his adaptation and control of their lives. He strove to maintain the same everyday lives and social network they had had before his wife became ill. There were confrontations with his wife, and she created chaos in his systems through what he called meaningless activities. The day care gave him freedom and the opportunity to attend to his own needs. It gave them a break from each other, and gave his wife external stimulation.

*To cope with the dilemma of staying or letting go*

This wife had a very close relationship with her husband. They had been married for a long time, and the husband was now very dependent on her. She found it meaningful to help and support her husband, but she was tired, and torn between his needs and her own. She wanted them to be together, but she felt she would not be able to shoulder the responsibility or provide care for much longer. This made her worry, and she felt guilty. When her husband was at the day care centre, she enjoyed her freedom, but she was also worried that he would soon need to go into a nursing home.

## 6. Discussion

### 6.1 The main findings

The purpose of the study was to investigate how day care designed for people with dementia impacts on family caregivers. In summary, the main findings in the study show that day care offers the potential to relieve family caregivers from increased responsibility and new tasks, as well as support to cope with emotional and relational changes. In addition, day care may have a positive influence on the family caregivers' motivation to provide care. These main findings are based on family caregivers' views on how key elements of the day care met their needs and impacted on the situation they were in. I will discuss here some of these elements in light of theories and earlier research, and to conclude will look at how Gaugler's resilience model can improve the understanding of how these various day care elements can collectively serve as a multi-component family caregiver intervention.

#### 6.1.1 Someone to share the responsibility with

##### *Responsibility for meeting basic needs*

The studies confirm earlier research showing how, as the dementia progressed, family caregivers experienced increased responsibility for meeting the basic needs of the person with dementia, which most often leads to stress and strain (Balla et al., 2007; Deci & Ryan, 2000; Ory et al., 1999; Thyrian et al., 2016; Wadham et al., 2016). The role of day care as 'someone to share responsibility with' was therefore described in the review article as an important factor for ensuring that the care provided support and respite. This also proved to be a key theme in the qualitative studies. The help that family caregivers received through day care to meet the person with dementia's needs for nutrition, physical activity and social interaction, giving them a good rhythm to their day and filling their time well, was considered to be positive. For the few family caregivers who worked, it was absolutely vital that the person with dementia had these needs met during the day to enable them to continue living at home. The fact that the family caregivers considered these activities to be central and positive is consistent with how people with dementia themselves feel that mealtimes and the social aspect are two positive elements of day care (Strandenæsa, Lund & Rokstad, 2017). The fact that day care helped family caregivers to meet these needs also had an impact on the days that the person with dementia was not in day care. For example, when they had had four to five good dinners at the day care centre during the week, it did not matter too much if they only had sandwiches the other days.

This also applied to physical exercise and social interaction with others. For some family caregivers, the meals themselves became a strain due to challenging behaviour or motor problems, such as irritation, restlessness and problems swallowing. Summarized research from 2016 shows that aberrant motor behaviour and irritation are two of the behavioural symptoms that cause the greatest strain on family caregivers and are most closely associated with stress (Feast, Moniz-Cook, Stoner, Charlesworth & Orrell, 2016). Giving family caregivers respite from meeting basic needs can therefore directly influence their perceived burden.

Even though day care relieved family caregivers from meeting several of the basic needs, there were still some needs that were not met by day care. Needs related to elimination and hygiene were a major burden for several of the family caregivers in the qualitative studies. Some had assistance from the home nursing service, but some did not want this for various reasons. However, even family caregivers who had such assistance still provided a great deal of help because the nurse was only there for a limited number of hours during the day, and 'accidents' rarely occurred during that time. Elimination problems also led to a need for more laundry and cleaning. As one daughter said, 'I always wash the door handles when I'm at my mother's house because I know she gets faeces on her hands'.

#### *Responsibility for assessing care needs*

Family caregivers found that assessing what help and what level of care was needed for the person with dementia was a challenge. Spouses in particular thought it was difficult to receive (more) help, and to be the one to say they were no longer coping with the care at home and that the person with dementia had to move to a nursing home. For the spouses in study 4, *staying together* was a core care value, and they felt a sense of defeat and that they were letting the person with dementia down if they had to admit that they could no longer cope. The fact that the day care staff knew the person with dementia and knew how he or she functioned in everyday life was therefore a help to family caregivers in these assessments. Several also said that the day care centre manager helped them to justify and apply for other services in the municipality, such as more help from the home-based care service or short-term stays in nursing homes. Being relieved of shouldering this responsibility alone was considered a positive experience. The fact that day care staff agreed that it was right and necessary to apply for more municipal services helped to maintain a good relationship with the person with dementia, ref. relationship-oriented coping (Ingebretsen & Solem, 2002).

#### *The importance of good quality*

Both in the survey and the qualitative studies it emerged that the quality of day care was an important prerequisite for family caregivers to feel secure and not have a bad conscience when they

left the responsibility for the person with dementia to day care staff. In relation to good quality, they emphasized the tailored activities and the employees' competence and ability to see them as individuals – both the users and family caregivers. A support and respite service that extends over months or years, as is often the case in day care, can facilitate familiarity and good relationships between the person with dementia, family caregivers and day care staff. This can make it easier to tailor the care based on individual needs. Both the survey and the interview studies showed that family caregivers were largely pleased with the quality of the day care and the suitability of the employees. Nevertheless, it emerged that the activities were not always adapted to the individual user's interests and level of function, which became a strain on family caregivers because the person with dementia did not enjoy their time at the day care centre and objected to going there. According to the family caregivers, employees did not have any particular focus on collecting information about the needs of individual users and/or family caregivers. This can be viewed in conjunction with the lack of systems for communication between employees and family caregivers. Both the survey and the qualitative studies showed that family caregivers were not very involved in influencing the content of the care and that there was little interest shown in the family caregivers' needs. The absence of regular planned conversations may indicate that day care staff did not consider this type of information retrieval or follow-up of family caregivers to be part of the service, or for various reasons could not give priority to this. The family caregivers found that day care was offered as a *package solution* that included transportation, meals, activities and social interaction. Family caregivers generally had few expectations of being able to influence the content of the care, but they said that tailored content was pivotal to their relatives thriving at day care. Thus, regular planned conversations with family caregivers can be regarded as a partially untapped potential, both with a view to tailoring the care for the users and to meeting the family caregivers' individual needs for support and respite.

### 6.1.2 Support to be a good family caregiver

In the qualitative studies, family caregivers described how it could be difficult to find a good balance between meeting their own needs and the needs of the person with dementia. Living up to their care-related values and goals as the situation became more demanding and the care tasks more extensive could be a challenge. Study 3 shows that the family caregivers had a bad conscience, they felt sorry for the person with dementia and they were tired. The situation also required them to seek new solutions that were adapted to the person with dementia's needs, which the family caregivers gave many examples of in studies 3 and 4.

### *Support to make choices based on intrinsic motivation*

The qualitative studies show that the breathing space that day care gave family caregivers could make them more motivated to provide care. This partly manifested itself in higher energy levels and the strength to make appropriate and good choices. As described in chapter 2, *self-determination theory* (SDT) can be useful for understanding the relationship between the family caregivers' motivation and making choices driven by intrinsic motivation, which is described as more suitable than choices driven by extrinsic motivation. SDT points to some universal psychological needs that influence the human condition of making choices driven by intrinsic motivation.

*The sense of having the competence to achieve the goal* is one of these psychological needs, which means in this context that the person considers him or herself to have knowledge about what actions are appropriate for achieving the goals he or she has set. According to Deci and Ryan (2016), competence and the feeling of autonomy are the most important characteristics for a person being able to make choices in line with his or her intrinsic motivation. In study 4, the family caregivers described various care-related values and goals that were challenged as the condition of the person with dementia worsened. For one family caregiver, *maintaining their common social network* was a goal that conflicted with the wife's need for rest. For another, the *desire to stay together* was now a challenge due to the person with dementia's growing need for assistance and their increasing dependence on the family caregiver. These family caregivers had partly found their coping strategies through routines and control, but clearly stated that the day care was crucial for them having the energy and patience to maintain these coping strategies, which they themselves considered appropriate.

According to SDT, realizing ethical values and goals is also about having sufficient autonomy to make choices that are in line with these values. In the *mature care philosophy*, *relational autonomy* is crucial for family caregivers being able to make good choices with a good balance between meeting the needs of the person with dementia and their own needs (Pettersen, 2012). In the qualitative studies, the family caregivers described many situations where this is a challenge. These situations are easy to relate to the ethical challenges presented in the altruistic care philosophy. Family caregivers said that the person with dementia was largely dependent on them for all types of activities in their daily lives. Due to cognitive impairment and reduced insight into the situation, many decisions in everyday life were taken by the family caregivers. Depending on the situation, this can be both sensible and appropriate, but according to the mature care philosophy, requires ethical reflection on the situation. In such reflection, the caregiver's values and goals can be highlighted and assessed in line with the person with dementia's will and perspectives (Pettersen, 2012). Dementia

can bring about changes in personality and behaviour that can be extremely challenging for family caregivers (Feast et al., 2016; Thyrian et al., 2016). Along with the complex situation described by the family caregivers, being a *patient and altruistic caregiver* 24 hours a day, perhaps for several years, can test even family caregivers with the highest ethical values. A breathing space in everyday life was thus vital to having the energy to make good choices that met both their own and the person with dementia's needs, which according to the mature care philosophy helps to strengthen the relational autonomy and the ability to provide good care.

The study shows that the family caregiver's own health and level of function also had a large impact on their everyday lives and ability to provide care. Spouses/cohabitants, but also children/children-in-law, struggled with failing health and used the respite time to rest and/or get treatment for their own health problems. Many of the family caregivers thought that day care was necessary to give them the energy to provide care and the opportunity to attend to their own health, and some believed it was their own health that was the deciding factor in whether they would manage to continue to provide care. Studies 2 and 3 showed that several family caregivers did not know if they could ask for extra days at day care if, for example, they had a doctor's appointment. Among those who had asked, some said it was possible, while others' requests had been turned down. Better communication and a more flexible day care service could have increased the family caregivers' ability to take care of their own health.

The results of the qualitative studies show that day care helped increase family caregivers' relational autonomy by improving their ability to provide care in line with their own values and expectations. The wish to be free of providing care affected their relational bonds, and some family caregivers felt they were letting the other person down and going against their own values. Day care helped the family caregivers to enjoy a breathing space without compromising these care values. Based on this, the relational autonomy described in the mature care philosophy can be of help when family caregivers explain why they should also prioritize their own needs. According to this philosophy, the ethical value of attending to your own needs is just as important as taking care of someone else's needs, and it is actually unethical *not* to do so.

#### *Getting support to find good solutions*

As described in chapter 2, the role of family caregiver can lead to both primary and secondary stressors (Ask et al., 2014). Secondary stressors can lead to a sense of being held captive, where having to change routines or stop doing your own activities so that you can attend to the person with dementia's needs leads to stress and strain. According to SDT, people become more creative and

flexible about finding solutions if goals and actions are driven by intrinsic motivation. The qualitative studies showed many examples of how family caregivers adapted and found solutions that made daily life work. Here, help from family and friends was important, as well as specialist knowledge about professional help. Spouses in particular described how they changed their everyday routines, but this was also the case for children. Constantly having to adapt to the person with dementia without compromising their own values was considered a challenge. The welcome breathing space that day care provided therefore gave family caregivers the energy to find solutions and make choices that were in line with these values. Day care also gave them more flexibility to work, or to tidy and clean their parents' homes without interruption. It was also important in terms of giving them energy to provide care.

As mentioned earlier, the mature care philosophy puts the needs of caregivers on a par with the needs of the person they are caring for (Pettersen, 2012), but the qualitative studies showed that finding the balance between meeting their own needs and the needs of others seemed impossible for some family caregivers. Some experienced an almost bottomless need for care, where it was difficult to set limits in relation to, for example, frequent phone calls or uncritical behaviour during family dinners. Such situations could lead to ethical dilemmas that were difficult to resolve. As a result, they often denied their own needs, such as turning off their phone and sleeping in peace, or spending time with their children and grandchildren. The breathing space that day care provided helped them to be good family caregivers as determined by their care values and goals, without hurting the person with dementia or having a bad conscience. That way, they maintained the relational autonomy. This time is 'just mine' as one spouse said, because during that time she did not have to put the needs of her husband before her own.

### 6.1.3 Positive influence on relations

The qualitative studies confirmed earlier research showing that being the spouse of a person with dementia can lead to changes in identity and roles (Wadham et al., 2016). The great need for assistance led to a shift in the relationship; from being two equal parties that help and support each other, to one depending entirely on the help of the other. As described in chapter 2, being a family caregiver of a person with dementia can entail relational challenges in which positive problem-solving, flexibility, seeking support from others and attending to their own needs help to improve relational coping (Ingebretsen, 2006; Ingebretsen & Solem, 2002). According to Ingebretsen and Solem, such relational coping requires energy and patience, which family caregivers in a demanding role may lack.

The fact that day care contributed to family caregivers (spouses/cohabitants and children/children-in-law children) experiencing a greater sense of relational coping was apparent in both the survey and in the qualitative studies. Attending day care could make the person with dementia more naturally tired, calmer and put them in a better mood, which had a positive impact on the cooperation and relationship with the family caregivers. Day care also resulted in less nagging and more pleasant conversations, and some spouses found that they themselves became more patient and looked forward to their partner coming home. In addition to increased relational coping in the relationship with the person with dementia, day care could also strengthen the family caregivers' relationships with others. Family caregivers, particularly spouses/cohabitants, had more opportunities to be socially active when the person with dementia was at day care.

The qualitative studies found that some family caregivers had respite through the person with dementia spending some time in a nursing home in addition to day care, which they described as an emotional relational challenge. As described in chapter 2, earlier research shows that day care respite can offer better relief than institutional respite. It leads to more social activity, less stress and less of a bad conscience among family caregivers than institutional respite (Colvez et al., 2002; Neville & Byrne, 2008). This was confirmed both in the survey and in the qualitative studies. Several family caregivers reported that they had a bad conscience when the person with dementia was to attend respite care at the nursing home, and some had declined such respite for this reason. In order to make their departure less painful, some family caregivers had arranged with the day care centre for their spouse to travel directly from the centre to the nursing home when he or she was going there for a respite stay. This helped alleviate some of the pain of departure for the family caregivers, but respite still sometimes led to a bad conscience and the feeling of letting the person with dementia down. Day care, however, was not associated with negative feelings to the same extent.

#### *Having a positive relationship with helpers*

In addition to the experience of autonomy and competence, SDT shows that a person's ability to act in line with their intrinsically motivated goals is also influenced by the opportunities for receiving guidance and support from a warm and caring person (Deci & Ryan, 2000). As described earlier, the family caregivers greatly appreciated the support they received from friends and family and the support that staff gave them when faced with difficult choices. Both the survey and the qualitative studies showed that family caregivers were seldom offered guidance or other planned discussions as part of the day care service. Even though the contact was sporadic, the family caregivers nevertheless felt that the employees had time to talk with them when they contacted them. According to Deci and Ryan, knowing that you have safe relationships with people that help you when you need them serves as a back-up or distal support for intrinsic motivation, and gives a sense



of security that makes the expression of this innate growth tendency more likely and more robust. Based on this, the ability to seek employees' support and guidance serves as a safety net for family caregivers. Knowing that there *is someone there* if they need them can help them trust more in their own strengths. Thus, it is not necessarily the frequency or systematization of the contact between employees and family caregivers that is crucial, but having an established line of communication and trust between them such that the family caregivers feel they can make contact if they need to.

The family caregivers felt to varying degrees that they received support from the staff, but some did not feel they received any support. This can be viewed in conjunction with the absence of planned discussions and the lack of focus on the family caregivers' individual needs. As mentioned earlier, this represents important potential for development and improvement. Both earlier research and the qualitative studies show that the role of family caregiver changes as the disease progresses. As the dependence on the family caregiver grows, the strain and the need for knowledge and good coping strategies often become more intense (WHO, 2012). Based on the theory of meaning-focused coping and coping strategies (Folkman, 2007) and SDT (Deci & Ryan, 2000), employees should ideally have more time and expertise to guide family caregivers in relation to the individual's care-related values and goals. However, this may be unrealistic given the way that day care services are currently organized. One alternative, therefore, is that employees have good practices for how to identify family caregivers' needs for guidance, and put them in touch with, for example, the municipal dementia team or others with dementia and guidance expertise.

Meaning-focused coping strategies and a feeling of control can have a positive influence on a family caregiver's ability to re-appraise situations and find new solutions when necessary (Folkman, 2007; Zarit, 2012). If day care staff or other advisors have knowledge of the family caregiver's motivation to provide care (based on individual values and goals), this can be actively used to provide guidance and support that promotes autonomous choices (ref. the mature care philosophy).

When day care staffs show family caregivers warmth and care, this can also support them in their *relational coping*. Having good relationships that can be relied on when the relationship with the person with dementia is challenging can increase family caregivers' relational coping. This involves talking to others, sharing experiences and being understood (Solem & Ingebretsen, 2002). Along with the respite that day care represents, the employees have a unique opportunity here to provide such relational support. They follow families over time and have in-depth knowledge of the progression of the disease, the person's behaviour and any challenges that family caregivers face at the relational level. Both the survey and the qualitative studies show that family caregivers spend little time at the day care centres or in conversations with the staff. The study therefore has no grounds to claim that

this contact has any effect. Thus, the family caregivers' personal factors must have evolved indirectly, as a result of the breathing space that day care gave them or in relation to changes in the person with dementia.

#### 6.1.4 Day care as a multi-component family caregiver intervention

Earlier research shows a lack of correlation between different support and respite measures for family caregivers of people with dementia, and that the measures vary in form and content. There is therefore a need for better coordination and understanding not only of *what* measures work but also *how* they work (Parkinson, Carr, Rushmer & Abley, 2016). In order to understand how support and respite services can impact on family caregivers, it may be useful to see the main findings of the study in light of *Gaugler's resilience model* (p. 23). The model illustrates how the *context of care, care recipient status and individual, family and community resources* impact on the caregivers' stress resistance in terms of resilience, and on the need for residential care for the person with dementia.

One of the strengths of Gaugler's model, in relation to the findings of this study, is his description of *the correlation* between how intrinsic and extrinsic factors can impact on family caregivers.

Traditionally, the concept of resilience has been linked to risk factors and protective factors related to the person's earlier experiences such as infant nurturance, adversity-loss, poor relationships, negative life events, war and natural disasters (Herrman et al., 2011). What is interesting about Gaugler's model is that it expands the resilience concept to include present-time factors related to the person's care burden, relationships, surroundings and various external resources, and that these factors both in isolation and collectively impact on the family caregivers' resilience.

One of the main findings of the study was that *family caregivers needed someone to share the responsibility with* because, among other things, meeting the needs of the person with dementia was described as a strain. According to Gaugler's resilience model, the person with dementia's unmet needs, cognitive impairment and the scope of family caregivers' care are key factors that affect their experience of stress. These factors are described in the factor group care recipient status, but according to Gaugler's model, the study's findings show that there are correlations and interplay between the content of the factor groups *context of care, care recipient status and individual, family and community resources* (Gaugler et al., 2007). Examples of such correlations are how relationships (context of care), relational coping and other coping strategies (individual resources) were closely linked to the person's goals and values (individual resources) and how these collectively impacted on the family caregivers' experience of responsibility and burden in the care role.

In Gaugler's model, the *gender* of family caregivers is also described as a factor that can impact on their resilience (context of care). As described in chapter 2, being a woman, and especially a daughter, can increase the risk of a care-related burden, but the role also gives daughters a high degree of self-esteem compared to other groups. This may mean that despite experiencing the burden of care, the burden for daughters is not generalized to what they feel about themselves, suggesting it is not as salient for their perceptions of self and identity (Chappell et al., 2015). Also in resilience research, being a male caregiver has a positive effect on the experience of the burden of care (except for in cases of severe dementia) (Joling et al., 2016), but our study showed no clear correlations here, either in the survey or in the qualitative studies. In study 4, spouses of both sexes described emotional and practical challenges, and there were no particular gender disparities in relation to how they coped with the situation. On the contrary, husbands found the confrontations to be the most upsetting and hurtful aspect, both for them and their wives.

When it came to *relations*, the qualitative studies showed that it was more stressful both emotionally and physically to be a family caregiver of a spouse than a parent. This corresponds to other research that shows how married couples can feel a strain as a result of identity and role changes (Wadham et al., 2016). The qualitative studies showed that spouses helped meet the basic needs of the person with dementia to a greater extent than children, and were therefore more tied to the role of carer. These findings are supported by the results of the survey, which showed that spouses/cohabitants agreed to a far greater extent than children/children-in-law that day care increased their ability to do practical tasks and attend to their own social needs.

A review study from 2016 shows that *being a spouse* in itself is not a negatively associated factor linked to resilience, as opposed to the cohabiting or higher care burden factors, both of which were negatively associated with resilience ( $p$  value  $< 0.01$ ) (Joling et al., 2016). All the spouses in our study, and only a small number of the children (six in the survey) lived with the person with dementia. Living together therefore largely coincides with being married/cohabiting in our study. This may mean that the strain of *living with* a person with dementia was the real factor that had the greatest importance for the experience of stress, not the role of spouse per se. On the other hand, the qualitative studies showed that the emotional strain of the family caregiver role could be greater for spouses than for children, which may not necessarily solely be due to the fact that they lived together.

The study showed that the family caregiver's age and individual resources in terms of health could have an influence on their experience of the caregiver role. Gaugler also believes that this factor has an impact on the care recipient's status. The spouses in the study, but also some of the children, had

both age-related and non-age-related health problems. This had a bearing on how much time and energy they had to provide care, as they needed a lot of rest and time to attend to their own health needs.

Another main finding of the study was about *family caregivers' opportunities to realize their care-related values and goals*. These values influenced how relatives wanted to fill the caregiver role, but several struggled to master the role in the way they wanted. As we interpret Gaugler's resilience model, realizing their values and mastering the role in line with these, is viewed in the context of the person's personal qualities and resources (intrapsychic resources). Resilience is characterized by a sense of sustained competence or positive development, while experiencing continual threat or stress, and in resilience research, so-called protection factors and risk factors for the possibility of such positive stress mastery is described and discussed (Herrman et al., 2011). According to Gaugler's model, these risk or protection factors for stress can be linked to personal, biological and environmental system factors, where the personal factors can also be viewed in conjunction with the *family caregivers' intellectual function, cognitive flexibility, social adaptability and positive self-concepts* (Gaugler et al., 2007). By studying the family caregivers' coping skills in the qualitative studies in light of this theory, we see how these personal factors influenced the family caregivers' ability to realize their values and achieve their goals. A common feature of the family caregivers was their determination not to give up, and a willingness to go that extra mile, be creative, and find new solutions. In study 3, we see this expressed through, for example, the ability to *accept and adapt to the new situation*. In order to master this, support from family, friends and professionals, a religious belief and the use of humour were all helpful.

Use of control and routines were very prominent coping strategies for two of the spouses in study 4. These strategies were based on the fact that routines were helpful for the person with dementia, but it was also a strategy that helped them to master the social, practical and emotional challenges associated with the role. Earlier research shows that family caregivers who believe that what happens to them is the consequence of their own actions are likely to be less burdened than caregivers who do not expect to have control (Bruvik, Ulstein, Ranhoff & Engedal, 2013). In this study, the control and the strict regime in the organization of daily life enabled family caregivers to cope with the situation, but also to deal with difficult confrontations, particularly for one of the couples. The strategy worked better for the second couple because the husband had a greater tendency to let his wife make the decisions – as she had always done.

Common for all the family caregivers in study 4 was that they considered the caregiver role to be meaningful through the value of *being useful*, but beyond that, their motivation for providing care

differed. The son who cared for his father justified this through the value of *doing his duty*, despite the fact that this was not a *dream role*, as he expressed it. He helped his father with practical things and kept in touch with the municipality, and was a link between his siblings. The son's value of duty was in contrast to the daughter's motivation for providing care, where her need *to be her mother's favourite daughter* was a core value. In this role, she wanted a close relationship with her mother, something she had not had previously. Like the son in the study, she spent about one day a week with her mother, she helped her with practical things and they enjoyed their time together. Although these children had different motivations for providing care, the care tasks and the responsibility appeared to be relatively limited and clear for both. The spouses' situations and motivations were more complicated. Their motivation was largely found in the values of *staying together and being there for one another*, where reciprocity and the experience of being a couple were put to the test as the disease progressed. This led to the spouses experiencing ethical dilemmas, and having more of a bad conscience than the children.

The son in study 4, who justified his help for his father with the *duty to help*, is an example of how family caregivers who have little emotional attachment can provide good care due to *cognitive flexibility*. He had a rational justification for providing care; he did not want to let his father down like his father had let him down earlier in life. This motivated him to provide care in line with his values and goals, and helped him to stay within the boundaries he had set for providing help.

As described earlier in the discussion, the family caregivers found that the *dementia challenged them at the relational level*, but that it could also lead to positive relational experiences. In Gaugler's resilience model, relationships have an important place in several of the factor groups. Based on both the findings of the study and our interpretation of Gaugler's model, relationships can be said to be one of the factors that has the greatest influence on family caregivers' experience of the situation, both as a single factor and as a factor that impacts on the other parts of the model.

#### *The role and influence of day care as a community resource*

In Gaugler's model, community-based services are described as one of several resources that can have a direct impact on family caregivers' resilience. However, as described earlier in the discussion, the study has shown that day care, as a community-based service, can also impact on the other factors in the model. One example of this is how day care provided support and respite to family caregivers with what Gaugler refers to as *unmet care needs* by reducing *family caregivers' primary caregiving hours*. However, in addition to reducing the number of hours of care, day care also provided indirect support, which impacted on the ability to cover these needs and on other factors in Gaugler's model.

Another example of this is how day care affected the family caregivers' energy to *realize their care-related strategies and goals*. According to self-determination theory (SDT), day care's contribution to this can increase their ability to master the role. A strong intrinsic motivation based on competence, relational belonging and autonomy could therefore, according to SDT, help family caregivers to make choices and act in line with their value-based goals (Deci & Ryan, 2000). As described earlier, the study shows that day care can impact on family caregivers' motivation and personal strategies, partly by giving them more energy to realize their care-based values and goals. Another example of this is the family caregivers in study 4, who felt they had good coping strategies in their care roles, but still needed the respite and support that day care offered. This confirms earlier studies claiming that mastering the family caregiver role does not mean they do not experience stress (Andren & Elmstahl, 2005). Although personal factors in the resilience concept are largely related to biology and personality, there is growing support for the reasoning that more of these factors can be influenced (Herrman et al., 2011; Petriwskyj et al., 2016). The study shows that day care may help to strengthen family caregivers' personal and individual resources – a finding that supports this research.

According to Gaugler's resilience model, characteristics such as intellectual function and cognitive flexibility contribute to family caregivers' resilience (Gaugler et al., 2007). As described earlier, day care can increase family caregivers' relational coping by strengthening their ability to find positive solutions to problems and to attend to their own needs, as well as improving their flexibility. In addition to showing the correlation between resilience and family caregivers' personal characteristics, this theory also highlights qualities in the family caregivers' networks that impact on their ability to cope in their situation. Family caregivers in the qualitative studies described how they had friends and family who helped them and supported them. The fact that day care helped the family caregivers to maintain their social network thereby strengthened their relational coping. Some spouses wanted to protect or shield their children. For example, they would not ask the children for help because they lived far away, had stressful jobs or had their own family challenges. They felt that going to day care meant they did not have to ask their children for as much help as when they did not have day care, and that the help from the children thereby became a supplement to the day care. The daughters and sons of family caregivers in the study also felt that day care was an important respite, and they found they had someone to share the responsibility with to a greater degree than spouses. One family caregiver said that while she was looking after her daughter's children, her daughter went to visit her grandmother (the family caregiver's mother), who had dementia. That way, she got to spend time with the grandchildren, whilst also getting respite from her mother. The study also showed that day care provided the person with dementia with social and cultural experiences and impulses that gave them more to talk about with their family caregiver, and

that this was positive for their relationship. In the process of accepting and adapting to the situation, the family caregiver's social network also played a central role. According to our interpretation of Gaugler's model, the fact that day care helped enable family caregivers to safeguard and use their network made them more resilient.

An integrative international data analysis of resilience factors in family caregivers from 2016 shows that a high care burden (measured with different stress scales) is the factor that most often has a negative association with resilience ( $p$  value  $<0.01$ ), closely followed by the cohabiting factor ( $p$  value  $<0.01$ ) (Joling et al., 2016). Support and respite measures that impact on the experience of the burden of care are, therefore, in the light of resilience theory, of great importance to how family caregivers experience their situation and their role, but living together is also of great importance.

Although there is currently some research on the factors that promote and inhibit resilience among family caregivers of people with dementia, there are few studies that describe *how* different support and respite interventions can build resilience within this group. The few studies that exist show that such interventions are believed to have a positive effect, but that identifying which interventions improve resilience and which do not in a population is a challenge (Petriwskyj et al., 2016). The fact that it is difficult to distinguish between the effect of individual factors may mean that it is the combination or the sum of the factors that produces the effect. It may therefore be appropriate to develop comprehensive models that offer a range of interventions tailored to individual needs.

Another strength of Gaugler's resilience model is that it shows the complexity of the family caregivers' situation and demonstrates the heterogeneity of the group of family caregivers. This heterogeneity confirms the need for an individual and open approach to the family caregiver's situation and needs. According to Gaugler, the majority of earlier research has had a tendency to regard family caregivers as a relatively homogeneous group, something that may increase the risk of insufficient breadth in studies and measures aimed at meeting the needs of family caregivers (Gaugler et al., 2007). The actual concept of resilience has evolved as the scientific knowledge about it has increased, but there is still no consensus on an operational definition (Herrman et al., 2011). Few studies have examined what might promote or inhibit resilience in family caregivers of people with dementia. Consequently, there are limited insights into how it should be understood, defined and measured. There is therefore reason to interpret and use Gaugler's resilience model with caution. In a study from 2010, factors such as: perceived control, commitment to living, challenge versus stability, related to resilience in family caregivers of people with dementia (O'Rourke et al., 2010). Another study described a wide range of resilience factors for the same group, using the Delphi method (a panel of experts and family caregivers). These factors were: presence of



behavioural problems (patient), caregiver's care-related competence and social support, the quality of the relationship with their relative and enjoying spending time together. Coping skills, experiencing positive aspects of caregiving, and a good quality of life of caregivers were also included in the term (Joling et al., 2017). This shows that the resilience concept is not a standardized concept, but is constantly evolving.

Whether resilience is the best concept for describing stress-resistance or the presence of positive experiences in the role of family caregiver is also a matter for discussion. A recently published review article on positive psychology outcome measures for family caregivers of people living with dementia showed that resilience was one of several outcomes in research in this field. In addition, emerging constructs of self-efficacy, spirituality, rewards, gain and meaning were in line with positive psychology theory (Stansfeld et al., 2017). Along with other mastery theory in the field, this study shows a variety of possible positive outcomes related to the role of family caregiver, which confirms that we must exercise caution in favouring or emphasizing one theory over another. With a strong focus on the role of family caregiver, and the search for positive psychological outcomes therein, there is also a greater risk of losing sight of the fact that many family caregivers primarily find the role a strain, despite its positive aspects.

In Gaugler's model, institutionalization, care recipient death or loss to follow-up are final outcomes. The problem with a model in which final outcomes are seen in relation to, or measured by factors related only to the status of the person with dementia, is that family caregivers are regarded as a means to achieving the goals, and not as goals in themselves. If a parallel and equal final outcome that is related to the family caregiver's quality of life was added to the model, the family caregiver's intrinsic value would be shown. Returning to the day care model illustrated on page 29, we see that this model has such a duality in its description of the main intentions of day care. If Gaugler's model were to be further developed with a view to describing complex family caregiver interventions, the family caregiver's quality of life could be a comparable final outcome in combination with existing final outcomes.

### 6.1.5 Organization of the day care

*Do people with dementia receive day care in time?*

We will now move away from the resilience concept, and will look at how family caregivers view the organization of day care. The survey shows that most family caregivers were pleased with the timing of the offer of day care, both in terms of their own needs and the needs of the person with



dementia. This was somewhat surprising, as the average age of new day care attendees in Norway is 81, and their average score on the Mini-Mental State Examination was 20.4, which indicates the lower end of mild degree of dementia (25-30) (Rokstad et al., 2017). This indicates that the people who attend day care often are very old and have significant loss of function. This fits in well with what the family caregivers in the qualitative studies said about the need for care. As described in chapter 2, only 6 318 people with dementia received day care in 2014, which corresponds to 17% coverage (Gjøra et al., 2015). These figures indicate that there are many potential users who either have not been offered day care or who have declined such an offer. Even though the family caregivers who answered the survey believed that they received the offer early enough, it is uncertain whether their opinion is representative of those who had not received an offer or those who declined. Both in the survey and in the qualitative studies, family caregivers stated that the person with dementia was initially reluctant to attend the day care centre. Some family caregivers even said that they had to put pressure on the person with dementia or trick them in order to get them to go. It is possible that part of the reason for the low participation rate in day care can be found here, and that this reluctance reflects scepticism towards day care in people with dementia, family caregivers and/or in general in the population. The studies show that scepticism and reluctance were a transient problem. This is useful knowledge for both family caregivers and employees at day care centres. It shows that it may be necessary to carry out intensive motivational and acclimatization work in order to help the person with dementia become familiar with and enjoy day care. This study says little about why some people do not feel a sense of integration with the service or leave for other reasons, as this group was not included.

#### *Is the service flexible enough?*

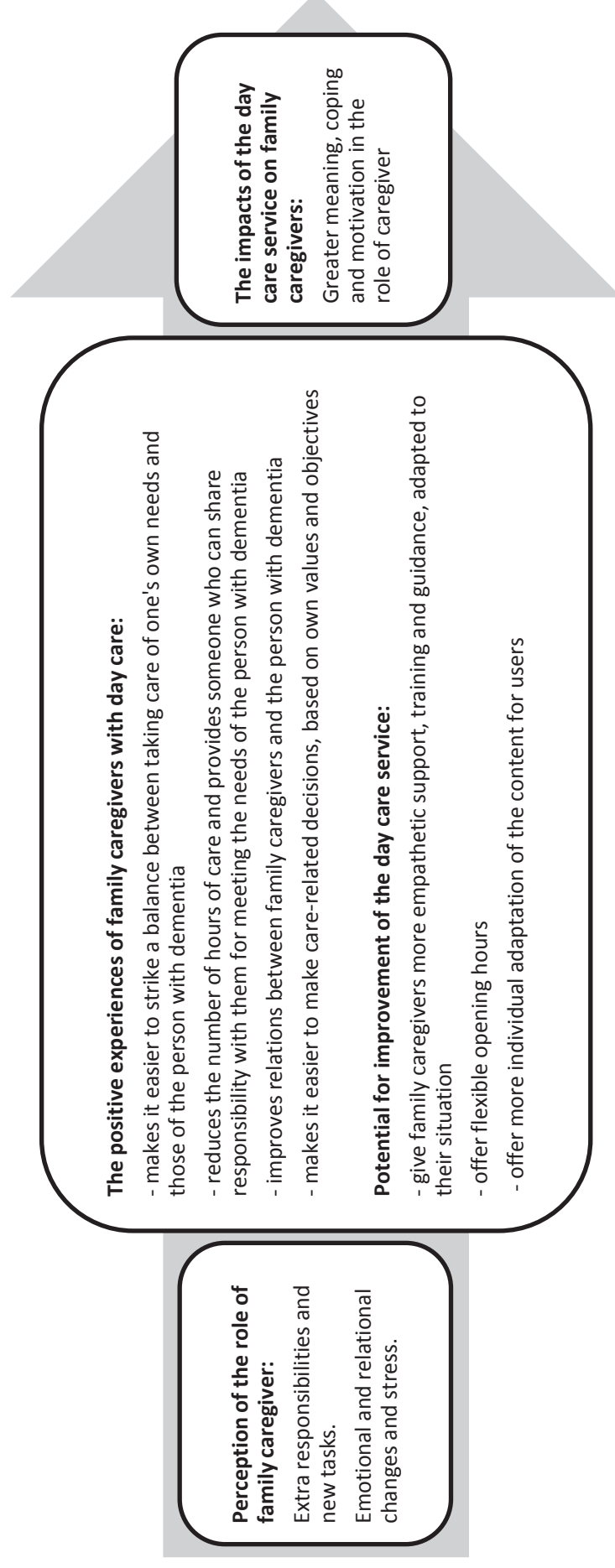
The survey showed that, in general, family caregivers were satisfied with the number of days and the number of hours the person with dementia attended the day care centre. Study 3 nonetheless shows that some people wanted more days, up to 7 days a week if possible, but this varied greatly. It was also clear here that there was a need for greater flexibility regarding opening hours, and in terms of the centre also being open at the weekend, and during holidays and public holidays. This would allow more tailored daily respite, and would give family caregivers greater freedom to travel and/or spend time with their other family members. In some cases, the day care could disrupt the pattern of everyday life, as the person with dementia did not remember which days he/she was supposed to go there. This could result in frustration, distress and uncertainty, putting a strain on family caregivers. Day care centres that are open every day could provide a better pattern and predictability for both family caregivers and for the person with dementia.

An expanded and more flexible day care service may meet the needs of family caregivers of people with moderate or severe dementia to a greater extent. This group was not included in this study, but previous studies show that respite, for example at day care centres, *may* postpone the need for full-time care, but that this is not always the case (Kuzuya et al., 2012; McCann et al., 2005; Vandepitte et al., 2016). One of the reasons for this may be that day care centres in their present form are not open long enough to give these family caregivers enough respite to cope with everyday life. It may also be a matter of the content and the organization of the service not being adequately adapted to people with severe dementia. It may also be a matter of the person with dementia being offered this service too late and actually needing full-time care (Vandepitte et al., 2016). The ideal time for switching from day care to full-time care requires a complex assessment, where both the situation of family caregivers and their level of resilience are important (Gaugler et al., 2007).

### 6.1.6 Summary of the main findings of the study

The main findings of the study are summarized in figure 6.1, where the positive experiences of family caregivers with day care are shown, as well as the potential for improvement of the day care service. This potential will be described in detail in chapter 6.3.

**Figure 6.1 The impacts of the day care service designed for persons with dementia on family caregivers**



## 6.2 Methodological issues

### 6.2.1 The integrative review

In order to synthesize and analyse existing research in the field, an integrative review was conducted where studies using different methods were included, which made the findings comprehensive. The inclusion of studies using a variety of designs made it possible to review the topic from a broad perspective. The *Mixed Methods Appraisal Tool* (MMAT) was used to assess the quality of the studies included (Pluye et al., 2011). As described in chapter 2, there were few studies about how day care for people with dementia influenced family caregivers, and the studies that did exist used different methods. The benefit of using the MMAT was that the tool makes it possible to assess and compare the quality of studies conducted using different methods systematically. A reliability study of the MMAT concluded that the MMAT is unique, making the reliability of the pilot MMAT promising. The study showed that the agreement between reviewers was moderate to perfect with regard to the MMAT criteria, and substantial with respect to the overall quality score of appraised studies (Pace et al., 2012). This corresponds with what was seen in this study, where some of the studies included were assessed independently by two researchers. There was a strong correlation between how these researchers assessed the quality of these studies.

As described in paper 1, there are flaws associated with using the MMAT to assess the quality of studies with small samples. Another limitation is that the MMAT was designed to appraise the methodological quality of the studies retained for a systematic mixed studies review, not the quality of their reporting (writing). This distinction is important, as good research may not be 'well' reported. If reviewers want to genuinely assess the former, companion papers and research reports should be collected when some criteria are not met, and authors of the corresponding publications should be contacted for additional information (Pluye et al., 2011).

The lack of standardization of day care centres as an intervention made it difficult to compare and validate the studies' results. Additionally, most of the studies were from the USA (11 out of 19), which made it difficult to know how best to generalise the results to other countries, as they have different cultures and demographics. The US health care system is dominated by private players and the payment of services through health insurance. Even though American definitions of day care do not differ considerably from European definitions, in terms of content and purpose (see chapter 2), the financial foundation for the operation of day care can vary, compared with public services. This

may result in a different composition of users.

### 6.2.2 The survey

The choice of topics and formulation of statements in the questionnaire is based on a thorough review of theory (summarized in the review study), and the Delphi group's and the research group's experiences and expertise. The pilot study showed that the statements on the questionnaire were clear and relevant, and the respondents did not report that any themes had not been covered. This confirmed the study's face validity. If the qualitative interviews had been conducted before the survey, experiences from these studies could also have confirmed or refuted the relevance of the themes, and may have added themes. However, it was difficult to achieve this in practical terms due to the study's progress plan. It later transpired that the qualitative studies did not reveal any new themes that should have been included in the survey. The order in which the studies were conducted thus probably did not make a material difference. However, the results of the qualitative interviews following the survey should help confirm the relevance of the themes in the questionnaire, and thus the validity of the study.

The study has some limitations in terms of the transferability of the results and whether generalizations can be made. Based on the inclusion criteria in the ECOD study, which the survey sample was recruited from, the family caregivers of people with severe dementia ( $MMSE \geq 15$ ) were not included in the study. The same applied to the family caregivers of people who had attended day care for more than one year or attended day care for less than two days per week, and family caregivers who spent less than one day per week with the person with dementia. There is also a limitation in the study in that it does not include the family caregivers of people with moderate to severe dementia. Based on the ECOD study only recruiting family caregivers if the person with dementia was able to consent to participation in the study and had an MMSE score of  $\geq 15$ , the desire to include the family caregivers of people with moderate to severe dementia conflicted with the desire to collect data from dyads. Despite this limitation, there is reason to believe that the results are also valid for the family caregivers of people with moderate to severe dementia, as the need for support and respite is greater in this group, compared with the family caregivers of people with mild to moderate dementia (Thyrian et al., 2016). There is still some uncertainty associated with this, which has been discussed in greater detail in chapter 6.1.

Answering questionnaires requires certain memory skills. The answers can be affected both by memory loss and what Wårneryd (1990) calls *telescoping*, which is about remembering the order or time frame of events (Wårneryd, 1990). Determining how much family caregivers agree or disagree with the statements about past experiences therefore carried a greater risk of error than assessing statements associated with the 'here-and-now experience'. It was therefore important for family caregivers to have recent experience with both the beginning of day care attendance (one year maximum) and everyday operations. The researcher may consider assessing statements related to day care to be straightforward, but some family caregivers found it difficult to distinguish this service from other municipal services. One example was where a family caregiver ticked the box indicating that they agreed that the day care centre gave them useful information, and then commented that they received it through the family caregiver training offered by the municipality. The questionnaire was yet another form regarding day care for family caregivers to answer in connection with the ECOD study, which increased the probability that the answers of family caregivers were based on their experiences with day care. Some of the questionnaires were completed face-to-face with an interviewer trained in health care, while others completed the questionnaire on their own. According to Wårneryd (1990), face-to-face interviews have the advantage of the interviewer being able to provide explanations while the questionnaire is being completed, but also carry a greater risk of the interviewee's answers being influenced by the interviewer (Wårneryd, 1990). Because some family caregivers completed the questionnaire with the aid of an interviewer, while others did not receive this guidance, this may mean that the family caregivers have had different starting-points for interpreting and understanding the statements in the questionnaire.

One strength of the sample is that it represented a large number of day care centres (45), with a good geographical distribution. This increases the probability that the results may be transferable to the day care service throughout Norway and in comparable countries.

### 6.2.3 The qualitative studies

As described in chapter 2, the lack of clear results regarding the effect of day care on family caregivers has been measured using quantitative tests. One of the reasons may be that the description of the phenomenon *being the family caregiver of a person with dementia who attends day care* was inadequate. This may be a reason why day care has not fully met the needs of family caregivers and why it was difficult to measure the effect. Another explanation could be that the

phenomenon *day care for the person with dementia* was not a synonymous phenomenon in terms of content, organization and quality, which made it difficult to measure the effect because in reality these were different services that may have had different effects.

In qualitative research, *validity* is about the extent to which a method studies what is intended (Kvale et al., 2009). This makes it necessary to assess and explain why in-depth interviews were the best method for learning about the phenomena the study wanted to investigate.

Family caregivers described the role of family caregiver and their situation based on current and past experiences, where thoughts about the future were part of the experience. Being a family caregiver was described as a process where the people's roles and relationship were different today, compared with in the past. Their experiences with the role of family caregiver and how day care influenced it therefore became part of a number of unique subjective experiences – as understood and interpreted by family caregivers. In-depth interviews are a method that is highly suited to obtaining this type of personal knowledge (Kvale et al., 2009; Malterud, 2011), unlike *group interviews in focus groups*, which is a different form of qualitative interview. In group interviews, the group dynamic itself is a key part of the method, as it helps mobilize the participants' associations with the theme. Such a method is therefore less suitable for sensitive or intimate themes (Johannessen et al., 2010; Malterud, 2011). Group interviews could have been a good alternative if the intention of the studies was to observe the group dynamic itself or the interactions between the informants (Johannessen et al., 2010), but this type of knowledge was considered less important, based on the themes in the studies. Past research shows that people can have different understandings of the role of family caregiver based on gender, role, values and relationship. This was a further indication that individual interviews would provide the best descriptions of the themes of the qualitative studies.

During the in-depth interviews, the stories of family caregivers were told through a dynamic interaction between the interviewer and family caregivers, where the objective was a new perspective and understanding of the situation among both parties. Such a new understanding can be hindered or restricted if the researcher asserts his/her own attitudes or knowledge during an interview (Kvale et al., 2009; Malterud, 2011). It was therefore critical that the researcher was aware of this underlying understanding and put it to one side during the interview in order to be able to meet the family caregivers' stories with openness and curiosity, and acquire new knowledge in a reflective manner. Without this openness and reflection, both the stories and their analysis could be guided in a direction that prevented or limited the production of new knowledge. This could also have led to family caregivers feeling devalued and to the information that was elicited primarily being related to researchers' experiences and opinions, not those of family caregivers. The family

caregivers in the studies said that they thought being interviewed was positive and useful. One family caregiver said the following, 'It's good to talk about this. Without these conversations, I would not have reflected on my role in this way'. Such a positive experience provided a good foundation for eliciting the truth based on their experiences and reflections.

According to Kvale (2009), there are five main methods for the analysis of meaning in qualitative interviews. They are: condensation, categorization, narrative structuring, interpretation and ad hoc methods (Kvale et al., 2009). In this study, the analysis methods used were systematic text condensation (categorization) (study 3) and the performative narrative method (study 4). The strength of following a validated analysis method for qualitative data is that it requires the researcher to systematically process the data using scientifically valid procedures.

Malterud's systematic text condensation method represents a middle course in terms of the extent to which the theoretical frame of reference controls the analysis (Malterud, 2011). As the purpose of the study was to investigate and assess a service that was already well researched, it was expedient to use a method of analysis that could use this knowledge. Malterud's method was inspired by Giorgi's phenomenological analysis (Giorgi, 1985), modified as systematic text condensation. Unlike a purely phenomenological method of analysis, where the objective is to disregard existing knowledge and only focus on the person's lifeworld, Malterud's method made it possible to build on existing knowledge. According to Malterud, an important process in systematic text condensation is to return the descriptions of content and any terms to the original contexts in the text they were retrieved from – a process known as recontextualization. The idea is to check that the results match the raw data, and learn whether the new knowledge is based in much of the material or if it mainly comes from individuals. Finally, the findings are assessed against existing empirical knowledge and theory in order to determine the relevance of the findings and whether they bring any new knowledge to the field. If not, the researcher should consider conducting new analyses in order to elicit new dimensions (Malterud, 2011). Malterud's systematic text condensation shares many similarities to the analysis procedure described in grounded theory (Strauss & Corbin, 1990). However, the method differs from grounded theory in that it is critical of researchers starting with theory as a starting-point for interpretation, as this will guide the analysis and interpretation of the results (Johannessen et al., 2010; Strauss & Corbin, 1990).

Existing knowledge, summarized and analysed in study 1, provided important background knowledge for study 3, which characterized the interview guide for this study. Together with theory regarding the positive aspects of the role of family caregiver, the results from study 3 played a key role in



shaping the themes in study 4. In order to prevent existing theory from obscuring new knowledge, the interview guide also contained open-ended questions, and it was important that the researcher pursued new themes that the family caregivers brought into the interview, so that they were elaborated on.

A performative narrative method was chosen to analyse the findings in study 4 (Riessman, 2008, 2005). Compared with a structural and interactional narrative analysis, performative analysis provided greater scope for including and emphasizing experiences in the past and self-representation in the analysis. This was important in order to show family caregivers' experiences in relation to values, relations and identity.

Even though the narrative method is a validated and recognized method, there is no clear list or established procedure for validity that fits every project (Riessman, 2008). Key elements of narrative analysis were therefore included in a customized 7-step analysis. Customizing such an analysis model required good knowledge about narrative analysis, about the field the study would examine, and awareness of the perspectives and the commitment researchers brought to the situation through their existing knowledge. In order to safeguard the quality of this process, it was important that the analysis model was designed under the guidance of two experienced researchers, and that they assured the quality. These two were also involved in the process of selecting key utterances that were descriptive of global, local and themal contexts (see the explanation further down in this chapter).

According to Riessman, narratives are always partial – committed and incomplete; they do not reflect reality, but reflect part of the storyteller's past (Riessman, 2008, 2005). The stories of family caregivers therefore could not be seen as the whole and the full truth, but were stories that were put together, interpreted and told in light of the situation of the family caregiver. What was interesting was therefore how family caregivers chose events and made them meaningful in this context. With narrative methods, the understanding of meaning is more important than the verification of facts, and the researcher's task is to look for meaning through global, local and themal contexts within each interview. If the researcher could argue in favour of an utterance being understood in light of these three contexts, the interpretation was credible (Riessman, 2008). This differs from systematic text condensation, where the themes and concepts are formed across the material. Because the researcher condenses data through a horizontal analysis in narrative analysis and does not move across the material, the data remains in its context, and there is less risk of the data being separated

from its context. This is why there is no need to recontextualize the data, as one does with systematic text condensation.

Each story was analysed with a view to global, local and themal contexts using the 7-step analysis. The analysis showed many utterances with contexts on these levels, for example statements linked to the social needs of family caregivers and opportunities to meet these needs. Narrative methods also give qualitative components a structure, with a beginning, middle and end (Riessman, 2008). All of the family caregivers in the qualitative studies had cared for a person with dementia for several years. They had also had a relationship with the person for several years before then, perhaps throughout their life. A narrative method that includes *time* as a key aspect was therefore well suited to describing and finding meaning in the stories of family caregivers in study 4. The earlier relationship and the person's medical history had an impact on the family caregivers' care values and goals. A narrative method that elicits contexts in a life course perspective was therefore well suited to achieving this in the material. A different qualitative analysis method would not have yielded the same opportunities to elicit these contexts. The study would then possibly have lost key aspects associated with how family caregivers viewed their role and their needs, and their expectations of the day care service.

When using narrative research methods, there is a real danger of overpersonalization of the narratives and that the data will only repeat an unprocessed subjective truth (Bury, 2001). In order to prevent this, it was important that the researcher viewed her interpretations critically. This is why it was important to view the results in the context of other research, assess the consistency of the statements and internal logic, and discuss their relevance to the field of practice. These *truth criteria* apply to all qualitative research and can help us determine whether the results are valid, and are no less important in narrative methods (Bury, 2001; Kvale et al., 2009).

In relation to the *generalizability* of the results of the qualitative studies, the understanding of generalization differs to that applied in the positivistic version of social research, which is dominated by quantitative research methods. The objective of the positivistic tradition is to find laws of human behaviour that can be generalized and made universal. This is in contrast to the humanistic research tradition and case studies, which focus on identifying the unique aspect of different situations and exploring the internal structure and logic of phenomena through qualitative methods (Kvale et al., 2009). There are different forms of generalization in these two traditions. An *analytical generalization* involves a justified assessment of the extent to which the findings from a study can be used as a guide to what may happen in a different situation. That form of generalization is the

objective of the positivistic research tradition, and is based on an analysis of similarities and differences between two situations. In qualitative research, the researcher bases his/her generalization statements on *assertory logic*. In order to perform such an analytical generalization, and thus show and justify such a logic, it is very important that the researcher has access to enough information (Kvale et al., 2009). Based on assertory logic, the in-depth interviews of family caregivers yielded rich material for such an analytical generalization. Kvale refers to Schofield (1990), who proposes three generalization questions in qualitative analysis: 1) *what is* (what is typical, general or normal in that situation?), 2) *what can be* (can these unique experiences apply to several people?) and 3) *what could be* (can these unique or exceptional situations tell us something about how things could be?) (Schofield, 1990). The results of the qualitative studies cannot be generalized statistically, but according to Schofield's generalization questions, the results can give an indication of what is typical for family caregivers of a person with dementia who attends day care. One can ask whether their experiences also apply to others, and/or whether the results can say something about whether the day care service is ideal in its current form, or whether it should be shaped, organized or adapted in a different way in the future. Such an analytical generalization was conducted through a detailed analysis of the results. In order to consider the generalizability of similar situations, it is necessary to take into consideration possible differences, for example, those linked to geography and culture. As described in chapter 2, there are many similarities between day care services in western countries (Europe and the USA), in terms of intention, content, structure and organization. This means that the findings in the study are likely to be relevant to day care services in other western countries as well.

### 6.3 Clinical implications and future research

As described in the previous section, discussing clinical implications is an important part of the validity of the study. It is also important in order to show the importance of the findings to other researchers and practitioners. The study shows that day care can provide good support and respite for family caregivers, but that there is potential for improvement associated with information flow, communication and individual support. We therefore recommend clarification and concretization of how these areas can be dealt with. Such clarification will be useful for the day care staff because it affects the content and focus of everyday operations. It will also be relevant for those who plan and organize day care, as they should look at day care in the context of other municipal services and assess the need for competence among employees. It may therefore be a good idea to clarify several objectives and phase-related focus areas. A concrete example of this is described in table 6.1.

**Table 6.1 Day care as support and respite for family caregivers – an example of primary objectives and focus areas**

<b>Primary objectives:</b>		
<ol style="list-style-type: none"> <li>1. Give family caregivers respite by meeting the basic needs of the person with dementia (nutrition, social stimulation and physical activity).</li> <li>2. Foster respite and a sense of security for family caregivers by giving the person with dementia a customized high-quality service.</li> <li>3. Give family caregivers individual support through encouragement, comfort and guidance in relation to the care-related values and goals of family caregivers.</li> </ol>		
<b>Phase</b>	<b>Focus area</b>	<b>Objective</b>
Motivation and acclimatization phase (2–3 weeks)	Become familiar by: <ul style="list-style-type: none"> <li>- gaining knowledge about each user's interests, level of function and needs</li> <li>- charting the family caregivers' need for support and respite</li> <li>- clarifying the distribution of responsibilities and roles between the day care, transport and any other service providers and family caregivers.</li> </ul>	Motivate users and family caregivers to use day care by: <ul style="list-style-type: none"> <li>- building trust and good relations</li> <li>- creating security and satisfaction for the user in the group.</li> </ul>
Support and respite phase	Have an open and regular dialogue with family caregivers, focusing on: <ul style="list-style-type: none"> <li>- the needs of family caregivers linked to their experience of the situation and their role</li> <li>- the user's needs and adaptation of day care.</li> </ul> Offer flexible day care that meets each person's needs.	Offer family caregivers support and respite, depending on their individual needs.
Completion phase	Clarify the distribution of responsibilities and roles between day care, residential care and family caregivers.  Offer family caregivers comfort, support and guidance.	Make the transition to residential care smooth and secure for both the user and the family caregiver.

The benefit of such a phase-related template is that it can help ensure that everyone receives equal treatment, but it can also remove the focus from the individual. The study shows that a number of family caregivers were pleased with the existing service. They did not miss scheduled conversations, but trusted that the employees would contact them if necessary. This is why it is important to listen to each person's needs also here. At the same time, the results give no indication whether these family caregivers would have thought that the service was good if they had actually had one or more such conversations. Regardless of the needs of the family caregivers, the study shows that good

information flow and communication are key in order to be able to adapt the content of the service to the person with dementia. If employees do not talk to family caregivers regularly, this information flow must be safeguarded in other ways.

The study highlights the importance of the success of the first critical phase. A great effort is required here from both family caregivers and employees in order for the person with dementia to settle in and be happy. A stronger focus on marketing day care can also be useful here. Increasing knowledge about the content of day care and its use for both people with dementia and family caregivers can increase the demand for the service also during the early phase of the disease.

Opening hours must be more flexible than at present in order for day care to provide the best support and respite. The centres should therefore consider expanding their opening hours on weekdays and opening during evenings, weekends, holidays and public holidays. This would be good for family caregivers who need an expanded or more flexible service, but the disadvantage may be that it will lead to a less stable, predictable group, with greater variation in users and personnel. This can make people with dementia feel insecure, especially in the latter phase of the disease. This means that family caregivers may have to deal with more people. Content characterized by individual adaptation and high quality is important to family caregivers' sense of security and a good conscience. The personnel should therefore have qualifications and practical experience in dementia care, as well as have the right personal skills. In order to meet the needs of family caregivers, the employees also need knowledge about how it feels to be a caregiver and how they can offer them good support and guidance. There should be a discussion regarding whether responsibility for following up family caregivers should be assigned to the manager, or whether it should be assigned according to the primary contact model. Experiences from the study show that the manager is often the person with the most advanced degree in health care, and the person who often is in a key position to be able to assess the level of function in terms of the correct level of care. The manager often communicates with the heads of other municipal health services, and may serve as a representative in the group that assesses and grants municipal health services. At the same time, the manager often has less contact with users than other employees, and is therefore completely dependent on good communication with the staff in order to be able to provide and receive information. Support for family caregivers can be an exciting and challenging task, also for other employees. Follow-up of family caregivers using the primary contact model may therefore lead to a more interesting, varied working day for employees.

### *Future research*

There is a need for more research on what motivates people with dementia to begin attending day care, and how the day care service can be an attractive and popular service for both users and family caregivers. The study shows that both quality and flexibility are important to family caregivers' experience of day care, but the study does not answer the question of why people with dementia stop going to day care. Research on this may provide useful knowledge about how day care can be better adapted in order for this group to keep attending day care for longer.

We still lack knowledge about how day care can support and provide respite for the family caregivers of people with severe dementia (MMSE score below 15). These people belong to a high-risk group in terms of the burden that may lead to a need for full-time care. This is why more research is needed about how day care can provide support and respite for this group of caregivers. Evaluation studies related to more flexible day care models may provide us with more knowledge about how day care can become a real alternative to full-time care.

## 7. Conclusion

The general conclusion is that day care for people with dementia gives family caregivers support and respite, but that the service has potential for improvement linked to communication, information and flexibility.

The study shows that day care provides family caregivers with respite from care for the person with dementia, and that it can increase their chances of finding a good balance between attending to their own needs and meeting the needs of the person with dementia. Day care can also provide support to family caregivers when determining the need for help of the person with dementia, and the correct level of care. A good-quality service promotes security among family caregivers, which influences the sense of support and respite. Individually tailored activities and qualified personnel are key factors here in terms of quality.

Day care can provide family caregivers with support and more energy in the role of family caregiver. This means that they can realize their care-related values and goals through better opportunities to make intrinsically motivated choices, which in turn may increase their motivation to provide care. The day care can also positively influence the relations of family caregivers with both the person with dementia and family and friends. The respite can give them more energy and patience, and expand their capacity for maintaining their social network.

The study shows that day care can be a multi-component family caregiver intervention which, following Gaugler's conceptual resilience model, may help family caregivers to cope with their complex caregiver role through increased stress resistance in the form of resilience.

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# Papers








RESEARCH ARTICLE

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# The influence of day care centres designed for people with dementia on family caregivers – a qualitative study

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## Abstract

**Background:** Dementia is one of the most challenging age-related illnesses for family caregivers, whose care-related burden is well known. Research indicates that day care centres (DCCs) can reduce the caregiver burden and help family caregivers to cope with demands; however, the current body of knowledge is still tentative and inconsistent, and more research is recommended. The aim of this study is to provide an extended understanding of the situation of family caregivers and to examine to what extent DCCs can meet their need for support and respite.

**Methods:** This study has a qualitative descriptive design using in-depth interviews with 17 family caregivers of people with dementia attending DCCs. The data analysis was undertaken using systematic text condensation.

**Results:** Caregivers experience a complex role, with added responsibilities, new tasks, and emotional and relational challenges that are expressed through distressing emotions and demands for interaction. Additionally, the caregiving role leads to positive experiences, such as acceptance and adaptation, support and help, and positive changes in the relationship. Day care relieves family caregivers by meeting the person with dementia's needs for social community, nutrition, physical activity, and structure and variety in everyday life. Using a DCC led to a higher quality of time spent together and easier cooperation, but it also produced some hard feelings and challenging situations. DCCs gave the caregivers a feeling of freedom and increased the time available to be spent on their own needs, to be social and to work or do practical tasks undisturbed.

**Conclusions:** DCCs for people with dementia can give family caregivers support and relief and have a positive impact on the relationship between the family caregiver and the person with dementia. A more individualized program, in addition to flexible opening hours, would make DCCs even more effective as a respite service, positively influencing the family caregiver's motivation and ability to care and postponing the need for nursing home placement.

**Keywords:** Dementia, Family caregiver, Day care centres, Respite, Support

## Background

Dementia is one of the most challenging age-related illnesses, not only for those who have been diagnosed with dementia but also for their family caregivers and healthcare professionals [1]. During the course of dementia, the need for assistance in the activities of daily living (ADL) increases, and the burden of continuous care and an extensive need for support falls on both

family caregivers and social and health care service providers [2]. In the last decade, there has been a trend towards increased attention to day care facilities as an important part of community services [3]. Day care centres (DCC) offer both an activity programme for the service users and a respite service for the family caregivers [4–7]. The term 'respite care' is used to cover a range of services that can occur in the home [8], in a DCC, or in a residential setting [9].

The caregiver's role and burden is well known and includes physical, psychological, social, and financial aspects [10, 11]. The term 'caregiver burden' is often

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used to describe this phenomenon, and it can be defined as “the degree to which a carer’s emotional or physical health, social life or financial status have suffered as a result of caring for their relative”[12]. Caregiver burden increases the risk of depression and anxiety disorder [13–17], and informal caregivers of people with dementia living at home experience care as more burdensome compared to informal caregivers of recently institutionalized people with dementia [18].

The caregiver burden can be associated with two main dimensions, the characteristics of the patient and the characteristics of the caregiver. *Patient characteristics* include the behavioural or psychological, disease-related, and socio-demographic factors related to the patient [19]. The *caregiver’s characteristics* (socio-demographic and psychological factors) influence their experience of caregiving. Female gender and cohabitation with the patient are associated with a larger burden, as are poor psychological health and poor religious coping skills [19].

Even though the majority of research has focused on burden and other negative aspects of family caregiving, positive aspects have been presented [20, 21], including a sense of meaning, a sense of self-efficacy, satisfaction, a feeling of accomplishment, and improved wellbeing and quality of relationships [22]. These positive experiences can help sustain family members in their work as caregivers [21].

DCCs providing a respite and support service have the potential to give family caregivers relief, reduce caregiver burden, and increase their motivation for their role as a caregiver [3, 7, 23]. These benefits can be summarized under four headings. 1) DCCs *facilitate separation time*, thereby giving family caregivers time that can be used for undisturbed work [8, 24, 25], rest, or other pursuits [6, 9, 25]. 2) DCCs seem to *reduce behavioural problems and the need for assistance with ADL*, but research on these effects is largely undocumented and tentative [6, 26, 27]. 3) *DCCs may reduce care demands, stress, and depression as well as increase wellbeing* [9, 28–30], but the results from previous research conflicts with this [5, 27]. Some studies indicate decreased symptoms of depression in caregivers when the person with dementia attends a DCC [9, 28], but other studies find no significant effect on wellbeing [25, 27]. 4) DCCs increase *motivation for care and postponement of the need for residential care* as they offer information and support regarding dementia-related topics, with the intention to reduce care-related stress [5, 8, 11, 25, 28, 31, 32]. Support for family caregivers aims to develop knowledge and skills in dementia care and prevent the risk of early institutional placement [11, 33].

Previous research indicates that DCCs can reduce the caregiver burden [34] and help family caregivers to cope with demands [5, 8, 27, 28, 35, 36]; however, current

knowledge is tentative and inconsistent, and more research is recommended [7]. The aim of our study is to provide an extended understanding of the situation of the family caregiver and examine to what extent DCCs can meet their need for support and respite.

## Methods

This study has a qualitative descriptive design [37, 38]. In-depth interviews with family caregivers of people with dementia attending a DCC were used to explore their situation and the influence of the DCC on their needs for support and respite. To attain an extended understanding of their situation, we searched for family caregivers reflecting a variety of genders, ages and relationships with the person with dementia. In the in-depth interviews, the participations were given the opportunity to share detailed descriptions of their everyday life experiences, giving the researcher access to the world of their life [39]. These descriptions of lived experience can provide us with an extended understanding of the influence of DCCs on the family caregivers’ experience of relief and support.

The participants were recruited from the research project ‘*Effects and costs of a day care centre programme designed for people with dementia – a 24 month controlled study*’ (ECOD) [40]. The ECOD study has a quasi-experimental design including a group of day care users and their closest family caregivers (intervention group) and a comparison group of people with dementia, with no access to day care, and their caregivers. The ECOD study is funded by unrestricted grants from the Research Council of Norway and has been accepted by the Regional Committee in Ethics in Medical Research of South-East Norway.

The criteria for the inclusion of participants in the present study were that they are family caregivers to a person with dementia attending a DCC designed for people with dementia and, furthermore, that they have face-to-face contact with this person a minimum of once a week. Additionally, the sample of participants was chosen to represent both genders, a variety in age and different relationships to the person with dementia (spouses, children/children-in-law, living together with the person or not). There were no exclusion criteria. The participants gave written, informed consent to take part in the study at the time they were recruited.

Seventeen individual semi-structured interviews were carried out in March and April 2015. A stratified sample for qualitative interviews based on gender, age, relationship to the person with dementia, and cohabitation was chosen from the participants in the ECOD study (see Table 1). The variations in the characteristics of the participants represented different needs and settings, and thus, there was diversity in the data collected. The participants were connected to six DCCs located in rural districts and cities.



**Table 1** Characteristics of the participants and the persons with dementia

Family caregiver's role	Family caregiver's age	Living together with the person with dementia	Working	Person with dementia's role	Severity of dementia (CDR <sup>a</sup> )	Person with dementia's age
1. Son	52	No	No	Father	Very mild	74
2. Daughter	56	No	No	Mother	Mild	77
3. Wife	74	Yes	No	Husband	Mild	77
4. Daughter	59	No	No	Mother	Very mild	80
5. Daughter-in-law	47	No	No	Mother-in-law	Mild	82
6. Son	47	No	Yes	Mother	Mild	80
7. Wife	79	Yes	No	Husband	Moderate	83
8. Son	46	No	Yes	Mother	Very mild	76
9. Wife	77	Yes	No	Husband	Mild	87
10. Wife	72	Yes	No	Husband	Moderate	81
11. Wife	86	Yes	No	Husband	Mild	92
12. Daughter	58	No	No	Mother	Mild	81
13. Husband	76	Yes	No	Wife	Mild	74
14. Daughter	70	No	No	Mother	Mild	96
15. Daughter	65	No	No	Mother	Moderate	87
16. Husband	77	Yes	No	Wife	Mild	72
17. Wife	74	Yes	No	Husband	Mild	79

<sup>a</sup> CDR Clinical Dementia Rating Scale

There were 17 family caregivers who participated in the study, and they were recruited by the leaders of the DCCs. These participants had attended a DCC with activities designed for persons with dementia for approximately 2 - 18 months, 2 - 5 days a week. The interviews were made face-to-face at the DCC (n = 4), by Skype (n = 2), or in the participant's home (n = 11). The interviews lasted for 30 - 90 minutes.

Based on the aims of the study, research findings, and national political documents, the interview guide (Table 2) was arranged using open themes that invited the participants to describe their situation and experiences with the DCC.

The data analysis was performed using systematic text condensation [37, 38], according to the following four steps: 1) Total impression – from chaos to *themes*. The whole text was read through several times to get an overview of the total content and to identify the overall themes to be further analysed. Three themes describing how the family caregivers experienced their complex caring roles and four themes related to how the day care centre influenced this role were identified. 2) Identifying and sorting *meaning units* – from themes to codes, with the codes being a text fragment containing some information about the identified themes of interest. 3) Condensation – from code to meaning, where the data were reduced to a decontextualized selection of meaning units and sorted as *thematic code groups* across the individual participants. In this step, we went back to the transcript of interviews

seeking meaningful quotations describing the content of the codes. The quotations demonstrate both similarities and differences in how the family caregivers experience their role and how the DCC influence theirs. Differences in role, gender and age are presented in the summary of

**Table 2** The interview guide

Themes	Sample question
1. Introduction - relationship	Please tell me about your situation after NN got dementia? In what way does the dementia disease affect your daily life? In what way does the dementia disease influence your relationship?
2. Day care - in the beginning	How did you experience the process ahead of DCC attendance and the first days and weeks?
3. A typical day	Can you describe a typical day when NN is attending the DCC (before, during and after)?
4. Day care as a support and respite service	To what extent and in what way do you experience the DCC to be a respite service for you as a family caregiver?
5. The content and quality of the DCCs	What are your experiences with the content and quality of the DCC? Are there some elements of the DCC service that are more important than others for you?
6. Summary questions	DCCs are considered to postpone the need for residential care. What do you think about that? What do you think about the future? In summary, what does the DCC represent for you?

results. Initially, the first author performed this process, while further discussions and reorganization occurred in collaboration with the co-authors. The Nvivo qualitative data analysis program was used. 4) Synthesizing the codes into descriptions and concepts [38].

## Results

Two main themes were identified: the family caregivers' complex caring roles, and the influence of the DCC on the caregivers' situations. The individual descriptions of their role as caregivers are important to understand the influence of the DCC service on their situation. The themes are presented with code groups and sub-code groups in Table 3, and they will be further described in the following sections.

### The complex caring role of the family caregiver Added responsibilities and new tasks

The burden related to the symptoms of dementia and the person with dementia's need for help have a major impact on the family caregivers' role, which is described as a complex caring role. How the disease influenced the person with dementia was related to cognitive, psychological, social, and behavioural changes. These changes increased the need for guidance, support, and practical assistance, which was mainly covered by the family caregivers:

*He stands still and wonders what to do. Then, I say to him: The cups are placed over there; you may pick up a couple of cups and then find the cutlery. Then, he stands there wondering again (wife, 11).*

A family caregiver's daily life is full of such situations. Even if they receive public or private services at home, they still have to assist the person with dementia in organizing their day, remembering appointments, cleaning the house, taking care of the laundry, and so forth. To receive public service support in practical tasks every third week does not fulfil their needs – such as cleaning a fouled-up toilet. Family caregivers spend a lot of time and effort cleaning and washing, and some of them stated that assistance in these tasks gave them the best kind of respite:

*My feeling of respite is related to the fact that they clean her apartment, they vacuum the floor and change her bed linen (...). For me, that's respite (daughter, 15).*

Some family caregivers stated that increased problems related to hygiene and bowel incontinence could be the main reason for the need of a nursing home placement.

*As long as the brain can tell her that she needs to go to the toilet, I think we will fix it. But if the brain doesn't tell her, it will be a problem. I think everybody*

*will understand that (...). Yes, it will be difficult (...), there will be a bad smell all over the place (son, 8).*

Psychological changes in the person with dementia, such as apathy, lack of inhibition, anger, and offensive comments, influenced the family caregivers, and they became less socially active than before, due to the person with dementia's waning interest in their children and grandchildren. Additionally, the person with dementia could get irritated or angry for what the caregiver regarded as no apparent reason.

### Emotional and relational challenges

Family caregivers described experiencing challenging emotions and demanding interactions. The caregivers felt sorry for the person with dementia because he or she had become dependent, and they struggled with a guilty conscience when they left them alone.

*Mostly, I can do the things I need to do when he is at home, but I have a guilty conscience for letting him sit in a chair when I do other things (wife, 17).*

This was mainly the case for spouses but also for some of the children. Some of the family caregivers experienced a lot of nagging and felt that they had to lie, which made them feel bad. For instance, some did not mention that they planned to visit family members living far away because they wanted to avoid a lot of worry and continuous telephone calls from the person with dementia before and during the visit. Both spouses and children/children-in-law felt that they were trapped in their caregiver role. Many of them stated that they could never relax and that they worried about what might occur when the person was alone. This was the case both for family caregivers living with the person and for those living separately.

*She isn't the kind of person who goes out and disappears (...), but all the time you are on guard (husband, 13).*

Continuous monitoring of the person with dementia resulted in exhaustion, and some caregivers described a lack of sleep. Several stated that the person with dementia was confused and called them repeatedly around the clock. Additionally, some caregivers received accusations and had agonizing confrontations:

*He was very concerned about something that I had done wrong, it was something wrong with me all the time. I had stolen money or destroyed things (wife, 7).*

Being wrongfully accused or repeatedly involved in confrontations was an especially sensitive experience for

**Table 3** Main findings sorted as themes, code groups, and sub-code groups

Themes	Code groups	Sub code groups
The complex caring role of the family caregiver		
Added responsibilities and new tasks	Guiding and assistance in activities of daily living	Providing assistance in <ul style="list-style-type: none"> <li>• practical tasks</li> <li>• personal hygiene</li> </ul> Being sensitive to the persons' psychological needs Adapting to changes in person's social skills
Emotional and relational challenges	Distressing emotions	Feeling <ul style="list-style-type: none"> <li>• guilty conscience</li> <li>• sorry for</li> <li>• being tied down</li> </ul>
	Demanding interaction	Increased dependency Disagreements and misunderstandings Confrontations Nagging Lack of interests and engagement Adapt to the needs of the person with dementia
Resources affecting the situation positively	Acceptation and adaptation	Accept the situation Find new solutions Use humor With God's help
	Support and help	Help from friends and family Seek knowledge in the literature Receive professional help
	Positive changes in the relationship	Doing things together Positive contact Positive feedback
The influence of the DCCs on the family caregiver situation		
Respite – assistance to meet the needs of the person with dementia	More fellowship	Inclusion Social support
	Meeting basic needs	Nutrition, sleep, and rest
	Improved structure in everyday life	Schedule of daily events
	More variation, activity and meaning	Physical activity Do something meaningful Get out of home
Positive and negative influence on the relationship	Higher quality of time spent together	Less nagging More calm, tired, and positively exhausted Something to talk about
	Easier to cooperate with	Increased wellbeing Increased engagement and level of function Fewer conflicts
	Hard feelings and situations	Tricking and lying
Increased separation time - more time to meet their own needs	Increased time to spend on own needs	Rest and relaxation Activities Work undisturbed Practical activities Family and friends Feeling of freedom
Needs that are not met by the DCCs	Flexibility	Flexible and long opening hours and days
	Information, communication and information	Needs of <ul style="list-style-type: none"> <li>• information about schedule and content of activities in the DCCs</li> <li>• feedback about the participant</li> <li>• information about dementia-related topics (was obtained in classes for family carers )</li> </ul>
	Quality and content designed for people with dementia	Lack of tailored activities Lack of inclusion and social support

the spouses. Some of them cried when they were talking about this, and they described the experience as getting stuck in a role that they strongly disliked. That the person with dementia took less of an interest in daily life was also described as a burden:

*If I comment on something on the TV or in the newspaper and he is not interested, he seldom responds to me (wife, 11).*

The fact that the person with dementia no longer showed interest in matters of daily life was described as a loss, especially for the spouses.

#### **Resources affecting the situation positively**

Although the descriptions shared by the family caregivers contained mostly difficult situations, they also presented positive experiences as to how they accepted and adapted to the new situation, and they received support and help. An example of adaptation was a spouse who stopped driving and sold the car in solidarity with her husband, who did not understand that he had lost his driving license. By doing this, she avoided difficult confrontations.

Nevertheless, some family caregivers also experienced positive changes in their relationship, which were described as an increased emotional presence or thankfulness from the person with dementia:

*When I see how easily I can please her, I think, why don't I do this more often? (daughter, 4)*

Some family caregivers stated that the person with dementia had become more tolerant, was seeking more contact, and was increasingly socially active. In one family, the contact between the father with dementia and the children was restored after many years without a relationship. Many described positive experiences in their interactions with public health services, which offered rapid help and high-quality support.

#### **The influence of the DCCs on the family caregiver situation** **Respite – assistance to meet the needs of the person with dementia**

Family caregivers experienced the DCC as a service that represented something safe and routine in the person with dementia's daily life. They knew that the person was occupied with something meaningful, which gave them a break from the need to pay a visit on those days (children). The fact that they got themselves out of their home and were included in an organized fellowship was a relief for the caregivers. Without such a service, the person with dementia would have spent most of the day on their own, a situation that would reinforce the caregiver burden:

*For me, it feels so good to know that my mother-in-law is in a place where she enjoys herself. I know she is active and something is happening in her life from half past nine to half past two, Monday to Friday. (...) She gets exercise. It is this mix of mental and physical activities that increases her wellbeing. Otherwise, she would have been sitting at home watching television (daughter-in-law, 5).*

To meet the person's nutritional needs was described as a challenge: if the person with dementia had a poor appetite, altered experience of taste, or offensive behaviour during the meal, then a situation commonly associated with pleasure and enjoyment became a burden. Therefore, mealtimes offering good food and fellowship were described as one of the most important activities at the DCCs.

The DCCs influenced the circadian rhythms of the people with dementia, regulating the structure of the day in a positive way; they had better sleep at night because they were more active and awake during the day:

*She is often tired when she is back from the day care centre, but she generally sleeps a lot. She often lies down and sleeps a lot; she is very tired (daughter, 14).*

Better sleep at night entailed better nights for the caregivers as well; spouses were less on alert, and children and children-in-law received fewer telephone calls during the night.

The new situation, in which the person with dementia should be attending DCC, could be emotionally difficult for family caregivers, especially when they felt that they had to persuade or dupe the person to go to there. This was described especially as a challenge in the very first days or weeks and led to worries and feelings of guilt. It was therefore important that the person with dementia was motivated by the DCC's activities, tailored day programmes and activities. Social support was reported to be helpful in this situation.

Physical activities were described as an important part of the DCC service. Some family caregivers, mainly spouses, often took responsibility to get the person with dementia outdoors to have some daily exercise. On the days when their spouses attended the DCC, they were released from this duty. Some of the persons with dementia associated the DCC with their previous work and with being a useful person. Many of them also had regular tasks to perform at the DCCs, and this increased their motivation to go there without their caregivers making too much of an effort.

#### **Positive and negative influences on the relationship**

Attendance at a DCC influenced the person with dementia positively, giving rise to better moods, less nagging, and more calmness. Confrontations were less

common, and the individuals with dementia had more to talk about in conversations. Furthermore, their cooperation was better, and they shared more pleasant moments with each other:

*Mostly there is no rush when he is at day care. One telephone call maybe, but then we mostly have a pleasant chat or give each other short messages. It's not the same nagging about things as it was previously (son, 1).*

Some caregivers preferred to call their parents on the days of DCC attendance because they experienced a nicer chat on those days compared to the days when they stayed at home. Additionally, DCC attendance increased their engagement, practical functioning, and wellbeing. For instance, the person with dementia was often concerned about what to wear, and they got dressed up to go there.

*She blossoms when she is there (...). Otherwise, she is not keen to dress up or change clothes (daughter, 2).*

#### **Increased separation time - more time to meet their own needs**

Only two of the caregivers, both children of people with dementia, were working. The rest of the participants were retired or out of work for other reasons. The two that were still working experienced the DCCs as a respite from their worries during work hours. The fact that their mothers received food and support while the family caregivers were at work was absolutely essential for the mothers to be able to stay at home. For those not working, day care gave more time for rest and relaxation, both for spouses and children:

*The day care means a lot. It gives me at least two days a week to do what I want. I can pay some attention to my own needs as I usually use all my time to attend to his needs (wife, 3).*

Many family caregivers used the separation time for activities and practical tasks at, or away, from home. They spent time with family and friends, and several of them expressed the sense of freedom they achieved when the person with dementia stayed at the DCC:

*When I wake up in the morning, I know that this day is mine. Today I can do things I cannot do the other days: be at home, together with grandchildren or with my daughters, or just be myself (daughter, 2).*

The description of this sense of freedom testifies to the strong commitment that many family caregivers experience.

#### **Needs that are not met by the DCCs**

Overall, the family caregivers were very satisfied with the DCCs. However, they described some needs the DCCs did not meet, such as the need for an extended number of opening days if they were going away on vacation and longer and more flexible opening hours in the evenings, at night, or during the weekends:

*I would have liked some days at the day care centres to be a little longer because if I, for instance, go out to have lunch with my nieces, they like to eat at 13.30, not at 12. As my husband comes home half past two, I am in a bit of a hurry, you see (spouse, 11).*

Family caregivers described difficulties during holidays and vacations due to closed DCCs. This situation caused a break in the daily routines, which could lead to increased confusion and more stress for the family. Additionally, it was not easy for family caregivers to go away for a vacation when the DCC was closed:

*Yes, it gives me relief. Absolutely! However, when the day care centre is closed for some days, or you want to go for a vacation or something like that, it is really difficult (daughter, 15).*

The need for information about dementia-related topics was mainly covered by courses for family caregivers, which were offered as a service in most municipalities but not organized by the DCC. However, some caregivers expressed the need for more direct feedback and information from the DCC staff about the schedules and the content of the days at the DCC. The memory problems arising from dementia make it difficult for the person with dementia to communicate and share experiences about what has occurred during the day. Hence, both children and spouses would like to have more information about the daily activities and schedules of the DCCs.

Some of the family caregivers reported a lack of individualized care and had the impression that the DCC staff failed to be inclusive and give social support to the people with dementia. The activities were also not adequately tailored to the interests and functional levels of the individuals with dementia:

*My opinion of the content and quality of the day care? Well, I don't know what to say. I am sure it is OK for those who belong to this district (...) but she did not grow up here, she didn't attend any of the schools in this area. So when they are driving along looking at these schools, it means nothing for her (daughter, 2).*

If the service fails to tailor the activities to the service users' interests and needs, then the motivation to go there



decreases. As a result, the person with dementia is dissatisfied, and the family caregivers feel bad because they have to increase their efforts to motivate the person to go to the DCC. This situation can add to the caregiver burden.

The DCCs gave the family caregivers a valuable break from the responsibility, the workload of practical tasks, and the feeling of being tied down. However, in addition, they stated that their own care and support were crucial in enabling the person with dementia to stay at home. If, for various reasons, they were not able to continue in the caregiving role, then the DCC as the only support would not be adequate to meet the person with dementia's care-related needs.

## Discussion

Participants described many elements of their situation that resulted in a rich and powerful resource for understanding how DCCs influence their role as caregivers. The findings are presented by utilizing the major themes: (a) Respite and shared responsibility, (b) Day care attendance and the influence on the relationship between the family caregiver and the person with dementia, (c) Limited opening hours - consequences for the caregiver's social life, (d) Quality through an individualized programme and cooperation with caregivers, and (e) Does DCC attendance postpone the need for nursing home placement?

### Respite and shared responsibility

Day care relieves family caregivers by meeting the person with dementia's needs for social community, nutrition, physical activity, and structure and variety in everyday life. This experience of relief was independent of the relationship to the person (i.e., spouse or children), gender, and whether they lived in the same household. The results from previous research shows that day care provides family caregivers with a feeling of shared responsibility, in the sense that someone is able to take responsibility for the person with dementia if the family caregivers should become ill or die. If this happens, then the caregivers feel safe that the staff at the DCC know the person with dementia's situation and condition and can give that information to other relevant health units in the municipality [7]. The present study shows that DCCs additionally provide the families with a sense of shared responsibility and relief while they are still active in their caregiving role.

The caregiver's responsibility leads to a feeling of commitment. Previous research shows that female caregivers find themselves tied into the care situation to a larger extent than do men [41]. Our study shows that men and women and spouses and children all feel the need to be on their guard, adapting themselves to the needs of the person with dementia all the time, as it feels difficult to

leave them alone. The DCC gives the relatives valuable respite from the experience of being tied down, but because of the limited opening hours and days, this service cannot fully meet the person with dementia's needs if the relatives are unable to provide care for various reasons. In these situations, the person with dementia would need help from other family members, more frequently home-based services or residential care.

The increased need to handle practical tasks can be a physical burden for family caregivers, especially those in poor health. Many of these caregivers do all the cooking and cleaning, and they take care of the laundry. These tasks are to be taken care of in addition to, or instead of, receiving public or private practical assistance. Attendance at a DCC makes these daily responsibilities less demanding for family caregivers as they can carry out the necessary practical tasks without being disturbed. Bowel incontinence of the person with dementia was described as a great burden that could trigger the need for nursing home placement. We may assume that family caregivers would like to use more of the separation time to rest and take part in pleasant activities if they were relieved from the large amount of practical tasks with which they are often saddled. Individualized and tailored arrangements and flexibility in assistance with practical tasks at home can likely improve the caregiver's situation.

This study revealed important information about the complexity of the family caregiver role according to the challenging relationship, new tasks and the added responsibility for meeting the needs of the person with dementia. Family caregivers felt that the DCC definitely gave respite and a feeling of shared responsibility for the caring tasks, although there were some limitations, which will be further discussed below.

### Influence of day care attendance on the relationship between the family caregiver and the person with dementia

The fact that the caregivers' basic need for rest is met gives them new energy and more patience to handle relational challenges. The mental burden that comes with caring for a spouse with dementia can be associated with losing a sense of community with the partner [42], and this was confirmed by the participants in our study. Additionally, the study reveals that children also experience this kind of loss. However, day care provides new impulses and gives the people with dementia more to talk about. A person with dementia cannot always remember their experiences at day care, and so the caregivers ask for information about what is occurring at day care so that they can use it in conversations. Information from the staff shared in a notebook, by SMS, or mail can facilitate daily chats.

The family caregivers experienced fewer conflicts and less nagging when the person with dementia participated in the DCC. That change led to increased wellbeing and a higher quality of the relationship with the person with dementia. A good relationship increases the probability of a positive and meaningful experience in the role of caregiver. Knowledge about dementia can lead to a new understanding and more empathy for the person with dementia and hence increased acceptance of their caring role [43]. Maintaining or building a good relationship between the caregiver and the person with dementia might have a positive impact on the role of the caregiver. Previous research reveals that caregiving tasks that are experienced as meaningful can be a potential buffer against caregiver burden and influence the caregiver's mental health positively [44]. The experience of a good relationship increases the likelihood of the caregiver valuing the person with dementia more and not focusing mainly on the problems. Furthermore, caregivers who experience a high degree of mutuality in the relation tolerate staying in the caregiving role longer than do caregivers who experience low levels of mutuality [45]. Thus, being a caregiver might fill a need for meaning in life, which can motivate and empower people to handle even the most difficult situations. According to Logo-therapy (Frankl, 1963), shifting the focus away from our own needs to concentrate on satisfying others is health-promoting and can make life more meaningful [46, 47]. The DCC's contribution to a better relationship and a deeper understanding of the situation between the family caregivers and the person with dementia can strengthen the caregivers' ability to care and reduce the caregiver burden.

#### **Limited opening hours - consequences for the caregiver's social life**

This study reveals that limited opening hours at the DCCs influence the caregiver's potential to have a social life. Short and fixed opening hours and the lack of service during public holidays and vacations give relatives limited opportunities for an active social life, especially in the evenings. The need for flexible opening hours, as expressed by the family caregivers, confirms previous research that showed that flexible opening hours and programmes are important for the DCCs to provide respite [31, 36, 48]. Social stress is one of the factors affecting the burden on the family caregiver [10, 12]. Therefore, helping families to address their need for 'social capital' (contact that gives access to social, emotional, and practical support) has a positive impact on the caregiver burden [49]. To meet these needs, DCCs should be open during holidays and weekends, and opening hours should be longer and more flexible.

#### **Quality through an individualized programme and cooperation with caregivers**

Some family caregivers reported that the DCC programme was not adjusted to the person's background and functional level and that the person with dementia felt uncomfortable. The caregivers felt guilty, and the situation increased their feeling of burden. Staff knowledge about the person's identity and the possibility of individualized care had an influence on the family's feeling of respite. Previous research describes that the quality and expertise of dementia care, shown by tailored day programmes and activities for the person with dementia, give the person social support and activities, which enhance coping [3–5].

In contrast to previous research showing the need for information and support for family caregivers to be offered by the DCC, the caregivers in our study received this type of information at classes for family caregivers; these classes were provided through a support and educational programme organized by the municipalities [50]. Those who attended these classes had lower expectations of education and support from the DCC than had emerged in previous research [7]. A few of the participants were offered individual support and structured meetings with the DCC staff, and they found this service very useful. In these meetings, caregivers received information about the DCC programme and individualized care, and this information made them confident of the quality of the service. Only a few caregivers had been offered individual meetings, but many of them expressed a need for this. As many families have limited or no daily contact with the DCC staff, individual meetings are important for cooperation, the exchange of information, and support. Additionally, such meetings gave the caregiver the opportunity to share important information with the staff about the person with dementia. Hence, regular meetings with family caregivers to exchange information and experiences should be given high priority.

#### **Does DCC attendance postpone the need for nursing home placement?**

Some of the family caregivers stated that the DCC, combined with their own running care, surprisingly postponed the need for nursing home placement. It should be noted that a premise for this statement is the need for the family caregiver to be relatively healthy in addition to the functional level of the person with dementia, especially with relation to hygiene. Many of the family caregivers in the study were convinced that the person with dementia was unable to live on their own, even with the availability of more home-based public care. To postpone nursing home placement, daily support from family caregivers is crucial in addition to support from the DCCs.

### Summary of implications

To summarize the implications of the findings in this study, the following aspects are important. The family caregivers feel responsible for the person with dementia's need for nutrition, physical activity and social stimulation. To share this responsibility with the DCC gives them relief that presupposed individual adaptation of the service. Therefore, meeting these needs should be a high priority in DCCs.

Day care seems to have a positive influence on the relationship between family caregivers and the person with dementia; it provides family caregivers with more energy and patience, reduces behavioural challenges and provides the family caregiver and the person with dementia with positive topics of conversation. Information about content and schedules at the DCC will help family caregivers in their daily conversation with the person with dementia.

According to this study, DCCs might contribute to the postponement of nursing home placement. However, this result depends on flexible opening hours, high quality of the DCC programme and regular cooperation with family caregivers.

### Methodological considerations

The aim of this study was to provide an enhanced understanding of the impact on family caregivers of DCCs designed for persons with dementia. The in-depth semi-structured interviews provided a rich source of material with personal descriptions related to the aim of this study. The participants represented a diversity of genders, ages, and caregiver roles (spouses, children, living together or separately). Moreover, the sample represented caregivers of people with various degrees of dementia and with different numbers of hours and days at the DCCs, which is a strength of the current study. There were only two participants still working (both sons), which resulted in limited information about job-related issues. There are also other limitations of this study. Only one interview was made with each participant, and hence, there was no possibility to study the researchers' interpretations of the data or for the participants to add further information. The data were originally collected to explore the influence of DCC on family caregivers and not to focus on describing their situation generally. Other limitations due to sampling techniques may influence the external validity, and, because of this, the results cannot be generalized to other groups of caregivers. However, the results can elucidate the needs of similar groups of family caregivers, their situations, and how their needs for support and respite can be met.

### Conclusion

The current study supports findings from previous studies describing caregiver burden and the need for caregiver support. Our findings add an extended understanding to how DCCs designed for persons with dementia can offer relief and support for family caregivers and increase their ability to meet the needs of the person with dementia on a day-to-day basis. This study reveals a possible positive impact of DCCs on the relationship between the family caregiver and the person with dementia and the possibility to postpone the need for nursing home placement.

Future research should focus on how the person with dementia experiences day care attendance and further explore how DCCs influence the relationship between the person with dementia and their family caregiver.

### Abbreviations

DCC: Day Care Centres

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### Availability of data and materials

The dataset from the study is available from the corresponding author upon reasonable request.

### Authors' contributions

ST performed the data acquisition and data analysis and drafted the manuscript. AMMR and SV contributed to the study design, the interpretation of the data, and editing of the manuscript. All authors agreed on the final content of the manuscript.

### Competing interests

The authors declare that they have no competing interests.

### Consent for publication

Not applicable.

### Ethics approval and consent to participate

The study was accepted by the Regional Committee in Ethics in Medical Research in South-East Norway. The participants gave written, informed consent to take part in the study.

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# **Meaning in family caregiving for people with dementia – a narrative study of relationships, values and motivation, and how day care influences these factors**

*Signe Tretteteig, Solfrid Vatne, Anne Marie Mork Rokstad*

## **Abstract**

**Background:** In addition to care-related burdens, most caregivers of a person with dementia perceive a variety of positive and satisfying experiences such as feeling needed and useful in their family caregiving role. “Meaning-focused coping” describes aspects in family caregiving as both positive and negative emotions in periods with high levels of stress. Day care service may have the potential to support family caregivers, increase their positive experiences and meaning-focused coping, and positively influence the interpersonal relationship between the caregiver and the person with dementia.

**Method:** A qualitative design based on individual interviews was used. The interviews were analyzed using a narrative method and a case-study approach.

**Findings:** Five narratives describe how five family caregivers cope with their situation in meaningful ways and how day care influences this coping. Their challenges and coping strategies were related to their relational ties; to enhance, maintain or let go, and how to find the good balance between meeting their own needs and the needs of the person with dementia. The family caregivers describe how day care positively influences their “relationship-oriented coping” and experience of meaning.

**Conclusion:** This study revealed that finding meaning in the role as family caregiver for persons with dementia is closely connected to the caregivers’ own values and goals. Finding a balance between attending to their own needs and the needs of the person with dementia is crucial. Day care has the potential to increase the family caregiver’s motivation to care by supporting their capacity to make competent and autonomous choices and, thus, increase their feeling of mastery.

**Key words:** dementia, family caregivers, day care, meaning, values, relationship-oriented coping

## Introduction

Dementia is one of the most challenging age-related illnesses not only for those diagnosed with dementia but also for their family caregivers and healthcare professionals (Huang *et al.*, 2012; WHO, 2016). The burdens associated with caregiving for people with dementia, including physical, psychological, social, and financial aspects, are well known (Balla *et al.*, 2007; Pearlin, 1990). However, most caregivers also perceive a variety of positive and satisfying experiences as feeling needed and useful in their role. Much can be gained by examining the positive dimensions of caregiving, including experiences, appraisals, emotions, and the strengths and resources that caregivers can call upon in managing the challenges they face (Zarit, 2012). Positive experiences are mainly associated with the way caring becomes meaningful (Tarlow *et al.*, 2004). Based on stress and coping theory (Folkman, 1997; Lazarus and Folkman, 1984; Park and Folkman, 2007), the meaning-focused coping concept has been previously described. In its essence, Folkman presents meaningful coping as follows: *appraisal-based coping in which the person draws on his or her beliefs (e.g., religious, spiritual, or beliefs about justice), values (e.g., “mattering”), and existential goals (e.g., purpose in life or guiding principles) to motivate and sustain coping and well-being during a difficult time (Folkman, 2007)*. This concept has influenced research on the positive aspect in family caregiving. Caregivers describe both positive and negative emotions during periods with high levels of stress. Meaning-focused strategies and experiences of control are central to experiencing positive emotions during life challenges, and meaning-focused coping strategies have positive influences on the family caregivers’ re-appraisal (Folkman, 2007; Zarit, 2012). Knowledge about the variety of family caregivers’ sources of motivation, meaning focus in their caregiving role and their strategies to achieve this meaning will be useful for health care staff. Such knowledge will improve their ability to support family caregivers and enhance the underlying positive aspect of caregiving.

A central dimension of caregiving during the course of dementia is the need for caregivers to re-appraise their relationship with the person with dementia. The term “relationship-oriented coping” was used by Ingebretsen (2006, 2002) to describe coping in spousal relationships (Ingebretsen, 2006; Ingebretsen and Solem, 2002). As a sustained and robust relationship is central to the human experience, efforts need to be invested regarding sensitive approaches to prevent or reduce caregiver burden. Molyneaux *et al.* (Molyneaux *et al.*, 2011) advocated for the need to refocus attention on the quality of relationships and interactions between spousal partners, both family caregivers and the person with dementia. The need for refocus might be central to parents and children as well. Hence, the meaning of family caregiving should be explored as experiences of living with people with dementia in the context of close interpersonal relationships.

Day care service designed for people with dementia may have the potential to support family caregivers' relationship-oriented coping. Caregivers describe their role as complex (Tretteteig *et al.*, 2015). The relief the day care service provides contributes to increasing their patience, their energy to cope with everyday challenges and ability to plan activities while considering the person with dementia. Furthermore, the experience of relief prevents conflicts and improves the quality of the time they spend together. For example, the activities that the person with dementia takes part in at the day care center might positively influence the conversation with the family caregiver. Day care can increase the families' opportunity to relationship-oriented coping by maintaining a good relationship with friends and other family members (Tretteteig *et al.*, 2015; 2016).

Based on theory and previously research, there are reasons to believe that family caregivers' positive experiences of meaning and coping are related to how they can achieve their values, beliefs and/or existential goals despite caring for people with dementia. Furthermore, the interpersonal relationship between the caregiver and the person with dementia needs to be further explored.

The aim of this study was to gain knowledge about family caregivers' sense of meaning in their role as caregiver. The impact of day care on their experience and motivation as a caregiver is also explored.

## **Methods**

This study has a qualitative design based on a narrative method (Fossland and Thorsen, 2010; Riessman, 1993; 2008). A case-study approach with individual interviews was used to obtain in-depth insight into family caregivers' experience of meaning in the caregiving role and how day care service can support coping in everyday life.

According to Riessman (2008) in a narrative inquiry, *the analyst*:

*...is interested in how a speaker or writer assembles and sequences events and uses language and/or visual image to communicate meaning, that is, make particular points to an audience. Narrative analysts' interrogate intentions and language about how and why incidents are storied, not simply the content to which language refers (Riessman, 2008).*

A narrative method with a performative analysis focuses on the person's identity or the character of the person who tells the story. In this study, we paid special attention to what position the caregivers placed themselves into in the relationship to the person with dementia (Riessman, 2003; 2005).

Five family caregivers participated in in-depth interviews lasting one to one and one-half hours. The interviews occurred in the family caregivers' home or at the day care center attended by their relatives. The participants were recruited from the study: "Effects and costs of a day care centre program designed for people with dementia – a 24 month controlled study" (Rokstad *et al.*, 2014). The caregivers and the person they cared for comprised a range of ages, male and female, and cohabitation and relationship statuses. The severity of dementia varied between very mild to mild (see Table 1).

**Table 1 Characteristics of the participants and the persons with dementia**

Family caregiver's role	Age of the family caregiver	Living together with the person with dementia	Working	Role of the person with dementia	Severity of dementia (CDR <sup>1</sup> )	Age of the person with dementia
Case 1, daughter	59	No	Part time	Mother	Very mild	80
Case 2, son	52	No	No	Father	Very mild	74
Case 3, wife	74	Yes	No	Husband	Mild	77
Case 4, husband	77	Yes	No	Wife	Mild	72
Case 5, wife	86	Yes	No	Husband	Mild	92

<sup>1</sup> CDR: Clinical Dementia Rating Scale

An interview guide was used focusing on three main themes exploring the past and the present in how the family caregivers described 1) themselves, their values and goals, and the position they placed themselves into in the caregiving role, 2) their relationship to the person with dementia, and 3) how day care influenced their situation.

Inspired of Riessman (Riessman, 2008), the interviews were organized and analyzed by using the steps as listed in textbox 1.

**Textbox 1. Narrative step-by-step analysis**

1. Transcription	From oral speech to text.
2. Searching for the narrative's overall theme.	What is the core content of the narrative?
3. Organizing the narrative in three main themes as described by the study objective.	<i>Identity</i> Who am I? Who am I/are we in this situation? Are there any conflicts or dilemmas related to who I am and who I want to be?
	<i>Relationship</i> To whom did I belong? To whom do I belong? How do I experience belong to a person with dementia today? Are there any conflicts or dilemmas related to the need of belonging and/or separation? What position do I take toward the person with dementia?



	<p><i>The influence of day care</i></p> <p>How does the day care service influence on who I am/who I want to be in this situation?</p> <p>How does the day care service influence on my needs for belonging/separation/proximity and distance?</p>
4. Searching for the narrative's plot.	Write down one or two sentences describing the narrative's plot/main content.
5. Organizing the narrative into meaningful stories. Analysing these stories through questions aimed to concretise and complement the main themes (point 3).	<p>Ask the questions:</p> <ul style="list-style-type: none"> <li>• What is distinctive in the story?</li> <li>• How is family caregivers' identity described?</li> <li>• How is belonging described?</li> <li>• Are there any conflicts or dilemmas?</li> <li>• How are their choices of position described?</li> <li>• How are their stories told?</li> </ul>
6. Summing up the analyses of the meaningful stories in 5 to 10 sentences to describe the condensed content.	<p>Are there any repeating themes?</p> <p>Are there any relationships between the present and past?</p>
<p>7. Write down a short version of the condensed narrative based on the analyses and the adjusted plot.</p> <p>Name the narrative with a short descriptive sentence.</p>	The short version of the narrative should give a characteristic view of the family caregiver's identity, his or her experience of meaning and the relationship to the person with dementia, and how day care can support him or her to cope.

Based on the narrative analyses, the five interviews were transformed into five short condensed narratives that summarize the stories' plots (theme). Each story was given a name. We present the findings as spots on each story's uniqueness and the variation between the stories.

## Findings

The following condensed and entitled narratives are presented and outlined:

1. To obtain the position as the favorite daughter
2. To do one's duty without emotional involvement
3. To maintain relationships through routines and control
4. To balance between the need for a social network and the wife's needs
5. To cope with the dilemma of standing or letting go

### **Case 1. To obtain the position of the favourite daughter**

*Mom has always asked me for good advice. Among us three sisters, I am Mom's favorite. When I was in my 20s, she called me daily for support in her difficult relationship with my dad. My sisters and I thought she should leave our dad, for our and for her own sake, but it was only in the recent past that they lived separately. After my Mom got dementia, I found that she became more a like "real mom" for me. Before she got sick, she was concerned only about her own problems, but our relationship has now changed and our closeness has increased; she is more concerned about how I feel. I feel like I understand Mom better than my sisters, and it is probably because of my job and my strong interest to be with her. We are often together in my house doing housework, she likes that and this gives us a nice time together. Once we laid in the double bed chatting, I felt so close to her— I felt she was a "real mom" for me, interested in my life. When I was on long-term sick leave, I had plenty of time to spend with Mom. Now I am working and I am more tired, and therefore, I have to give her less priority because I also want to spend time with my boyfriend. To be with him gives me strength. Mommy is an effort.*

Day care provides relief from responsibilities

*Mom likes to participate in day care. It gives her content in her days, and when she is there, she is not visiting dad so often. On the days she attends day care, I do not need to visit her because her social needs have been met and she has had healthy meals. I also think Mom enjoys day care, but in my opinion, there should have been more activities there.*

This daughter appreciates the experience shift in the relationship with her mother. Her mother has changed from being a selfish and suffering person to a mother more interested in her daughter's life during the course of dementia progression. New roles have emerged in the daughter-mother relationship with more long-awaited intimacy between them, which she has missed earlier.

Nevertheless, she still wants to play the old role as her mother's supportive partner. Based on her education and job-experience and the fact that she spends more time with her mother than her sisters, in her own opinion, she is the daughter who is best qualified to understand her mothers' needs. This maintains her position as the mother's 'favorite-daughter'. She wants to influence her sisters' caregiving and give them advice, but she feels that they are not particularly receptive to her advice. Day care keeps her mother active during the days, and this helps the daughter to maintain the role as a good daughter, even though she spends less time with her.

## **Case 2. To do one's duty without emotional involvement**

*Although I am not fond of my father, but I feel it is my duty to help him in his current difficult situation. He met another woman when I was a teenager, and he left our family (my mother and his children). Since then, contact has been sporadic. In spite of this, I have no reason to avenge myself on him for what happened to us. I have good relationships with my siblings, and we cooperate well as family caregivers. Dad has given us different roles. He calls me the project-leader—it is really a poor job, but I help him when it suits me, so it is fine. I think it is an advantage not to be emotionally involved. It would have been worse if this was happening to a person closer to me. Now it does not affect my daily life. I visit him once a week, fix things for him and have a cup of coffee. I stay for about half an hour and that is long enough both for him and for me.*

Day care reduces daily nagging

*Participating in day care gives him rhythm in everyday life, something to regularly attend. He could easily go every day – for the rest of his life. This is good for my siblings too, as he does not nag us as much as he did before he began going. It is ok to visit him occasionally. It would not have worked out without day care, otherwise he would have had to move into a nursing home.*

This story is about a son's willingness and opportunity to do his duty. He emphasizes that he is not like his father: he does not run away from his responsibilities, as his father did. The development of dementia gives him a reason to reconnect with his father and help him even though he is not fond of him. His father needs him, and he responds to his father's needs by searching for the best in himself. The relational distance helps him to set limits for himself and avoid being too emotionally involved.

## **Case 3. To maintain the relationships through routines and control**

*I am so dependent on my husband; we have been married for 56 years. For me, there is absolutely no question of sending him to a nursing home, I could not bear to do that. What should I do then? Before, he was so handsome and handy, and now I have to help him with almost everything; he is almost like a child. At home, I have routines for everything. That is what works for me, but it is very tiring. My "happiness thief" is called stress; I cannot rest or sleep before I have everything under control. Actually, I am a testy person, one who can snap too. But now, I have to use a soothing voice, otherwise he gets angry. My husband wants me to lie on his arm as I did when we were young, but now I cannot bear that kind of intimacy. I am too concerned about keeping my routines and getting things done. Because of his awkward comments, it is difficult to be social with people we do not know very well, but we still have some good friends who I can invite to our home. Additionally, I have a neighbor who we have known for many years, and she relieves me and supports me. I take care of*

*him around the clock, so if we did not have the day care service, I could not have endured the situation.*

Day care makes it possible to stand the situation

*Day care gives me time to be with my friends and pay attention to my own needs. He enjoys himself in day care and on day care days, he gets up, takes a shower, and everything is on schedule. On these days, I am in good mood as well. He says they praise him at the day care, while I just nag at him at home. Nevertheless, he says he loves me. I can't make it without day care, but it hurts. He has become a patient. It was not like how it was meant to be. Nevertheless, I need to have him near; it is still the two of us, you know.*

This wife struggles with the relationship with her husband. They are still a couple, but the relationship has become asymmetric and demanding. To make it, she has to change her behavior and stick to strict routines. She is tired of the situation, but she feels she can handle it, largely because of the day care service. Without day care, she is not able to keep the two of them together the way she wants.

#### **Case 4. To balance between the need for a social network and the wife's needs**

*My wife and I have moved several times because of my job. Hence, we have always been close and quick in adapting to new places and making new friends. We have many friends that we have traveled with, friends we visit and invite to our home. Because of my wife's sickness, now we have to adapt our social life to her needs. That is ok, because I am a good cook, so we still often invite family and friends for dinner or coffee. If we are invited to friends' homes, I have to make sure that she gets rest, and I give her an extra tablet so she can stand it a little bit longer. However, when she has her anxiety attacks, it is hard to handle. When she gets anxious, I just have to wait, I cannot help her. We are coping with our everyday life, but when she starts with her meaningless activities, e.g., washing the floors repeatedly, we often end up arguing. When I ask her to stop, it provokes confrontations and I feel helpless.*

Day care gives me freedom

*My wife is attending a day care center and has regular periods of respite in a nursing home. This gives me freedom to travel and time for rest. People tell me that I have a hard job with my wife, but I think it is fine. If the situation does not get worse, there is no problem.*

This husband works hard to maintain their social network. He invites family and friends, he cooks, and he plans their visits when they are invited to other homes. Even though he thinks the dementia is challenging, their friends and their social life are links to their “normal life”: a life this husband is trying to hold on to. What he describes as meaningless activities irritates him, takes him out of control and makes him angry. This is hard for both of them. On day care days, they spend some hours separately, and this makes him more patient in the relationship. She likes to go there, especially when they do activities such as weaving and bannock baking.

#### **Case 5. To cope with the dilemma of staying or letting go**

*We have been married for over 60 years, and we have always been together. We have worked together, and I have been in charge of the company's finances. He was very dependent on me, I could not travel any places without him. Now his dementia is severe, so I have to look after him constantly. God helps me, but now it is very hard because of my own health problems. It is like looking after a two-year-old baby; the roles are completely changed, and he speaks very little. I have regular respite when he is in nursing home. It is wonderful! Then, I can sleep as long as I need, and I do not have to rush. I relax when he is away, but I also feel guilty because I have "sent him away". Our sons are supporting me; they say it is too hard for me to care for him at home. They say he needs long-term care in a nursing home. The staff at the home care service also tell me so. I know I will be fine if he moves, but I am afraid that he will feel abandoned.*

Day care gives my respite without feeling guilty

*When my husband is at day care, I can go for shopping or for a cup of coffee with my nieces. I really enjoy these moments. When he is there, I feel no guilt the way I do when he stays at the nursing home. The staff says he enjoys being there, and so I have to rely on them. Although, I think I will notice if he is not enjoying the day care, because we know each other very well.*

This wife struggles with two conflicting feelings. Partly she wants her husband to stay at home, but on the other hand, she has to accept letting him go. This is a difficult process for her, and she seeks legal arguments and support to justify her feelings and her choices. To living separately seems to be an easier life, but the risk that her husband will feel abandoned makes her insecure and vulnerable in this decision-making process. The husband's participation in day care gives the wife less feelings of guilt than when she “sent him” to the nursing home for relief. Day care as a respite-service is on one hand the best option for her, but on the other hand, she is extremely tired and is in need of more respite than the day care can offer.

## Discussion

According to Folkmann (2007) meaning-focused coping regards the opportunity to realize a person's central goals and values. The five narratives present a picture of how family caregivers cope with the new situation in different meaningful ways. These results are discussed in three main themes:

- 1) The relational ties: to enhance, maintain or let go
- 2) To find a good balance between caring for one's own and the other's needs
- 3) The day cares provides the possibility to increase family caregivers' motivation to care

### **The relational ties: to enhance, maintain or let go**

The family caregivers' descriptions incorporate a variety of strategies they use to cope with their relational ties. Should they maintain and strengthen the emotional relationship with the person with dementia or let it go? They describe different relational and emotional coping strategies ranging from a desire for emotional closeness to the need for distance and from the need of to hold onto the connection to acknowledging the need to gradually let it go.

According to the daughter in case 1, the new situation gives her an opportunity to fulfil her desired need for emotional closeness to her mother. She likes to have the position as her mother's closest and preferred daughter and she seeks appreciation from her mother – as she always has done. The new intimacy motivates her to act in accordance with her values. This includes being a good caregiver for her mother and, by doing so, she simultaneously satisfies her own needs for emotional closeness.

The son in case 2 experiences a duty to provide care for his father despite the emotional distance he feels to him - a distance he describes as expedient and rational in his role as caregiver. The duty implies supporting and helping his father without taking revenge for the betrayal by his father he experienced earlier in his life. The emotional distance makes it easier to limit his involvement and, at the same time, do his duty in accordance with his own values. This son meets his obligations as expected by the community and receives gratitude from his father.

The spouses in this study describe different relational changes. The wife in case 3 struggles to maintain emotional closeness to her husband. Her superior value or goal is to stay together with her husband in the marriage. This value gives her motivation to care for him even if she is stressed and tired. She describes a potential situation without this caregiving role as empty, lonely and meaningless.

The wife wants to fight for her strong relationship with her husband. It is an important value even though the relationship has significantly changed because of her husband's dementia. To handle her challenges, she initiates an every-day-life schedule to maintain her need of predictability and control. That schedule helps her in her role as family caregiver and brings their life under control. In addition, the husband in case 4 introduces stricter routines and control with the purpose to maintain the relationship. By doing so, he intends to retain their social network. He gains his need for a social network by taking responsibility for the housekeeping, invitations to social events and customizing their travels to fit his wife's needs and functional level.

Regarding the wife in case 5, the relational emotional challenge is connected to the hard process of "letting go". She knows that she has to loosen the emotional ties to her husband. This is painful because "staying together" is one of her most important values. This process brings forth ambivalent feelings; she wants to keep the closeness to her husband, but she is very tired and longs for freedom and time to meet her own needs. In this process, she becomes sad when she dwells on the possibility that their long cohabitation could end. She has to entrust her husband to professional health care workers. Her relational focus changes from "staying together" to "fixing their lives separately". In this process, she needs acceptance and support from family members and health care workers at the day care center. According to Molyneaux *et al.* (2011), this re-focus is expedient to reducing the family caregiver's burden. However, this wife describes this experience as painful.

These five cases demonstrate in various ways how meaningful relationships motivate family caregivers to act in accordance with their own values and goals. These results confirm the "relationship-oriented coping" theory (Ingebretsen, 2006) and previous research describing how family caregivers find their role to be meaningful (Folkman, 2007; Zarit, 2012).

All the family caregivers feel that the day care center positively influences the relationship between themselves and the person with dementia. The person with dementia attending the day care can then introduce several topics to later discuss with the family caregiver, and additionally, he or she is calmer and satisfied on the days of day care attendance. This leads to less nagging and conflicts between them, and hence, day care has a positive influence on the ability of family caregivers to cope in the caregiving role.

### **Finding a good balance between caring for one's own and the other's needs**

The family caregivers describe challenges connected to finding a balance between maintaining the needs of the person with dementia and taking care of his or her own needs. This dilemma can be

elucidated by the ideal of altruistic care that influences the community and affects the family caregiver's own expectations and demands in their role as caregivers.

The Norwegian philosopher Petterson (Pettersen, 2012) criticizes the ideal of the altruistic, compassionate caregiver, which has been the prevailing caregiving ideal throughout human history. Altruistic care indicates that the caregiving should be selfless and, furthermore, that the caregiving behavior should be unconditionally based on spontaneous compassion and sacrifice. The altruistic care ideal can disallow caregivers' needs of support and relief. In the altruistic care philosophy, the caregivers' feeling of doing "the right thing" is their reward and their motivation to care or to do their duty. This means putting their own needs aside in favor of the other persons' needs (Pettersen, 2012).

To do their duty is a prominent value in family caregivers' motivation to care. However, how this value is expressed and justified varies. The wives' stories (cases 2 and 5) reflect their feelings of marital duty based on their own expectations of being supportive and the desire to preserve the emotional closeness in their life-long relationships with their husbands. The son in case two justifies his feeling of duty based on values from his childhood inherited from his mother and grandparents. The emotional distance that he has from his father helps him in an expedient way to balance his own needs with his father's needs. According to The Mature Care philosophy, these limits help the son to provide mature care.

The daughter in case 1 is motivated by her own needs for intimacy with her mother. The mixture of her own and her mother's needs must to be made visible and reflected in the caregiving role. According to the Mature Care philosophy, regular reflections about the situation can increase the caregiver's understanding of their role as caregiver and the care recipient's needs. Reflection might lead to new understanding and help the caregiver balance his or her needs and the care recipient's needs. If the primarily need of the caregiver is intimacy and not recipient care, the caregiver might take advantage of the situation. If meeting the needs of the caregiver is the main option, the person with dementia could be insulted based on the total dependency of the caregiver and their limited ability to leave the relationship. However, the mutual needs for satisfaction between the caregiver and the care recipient could balance their relationship.

In the mature care philosophy, the caregiver and the care receiver's needs, interests and values are described as equivalent. Hence, mature care philosophy violates the traditional altruistic care ideal, as it is based on communication between equal partners, information, expertise and continuous reflection of the situation. According to the mature care philosophy, is it immoral to put one's own values and needs as caregiver aside, at least over time (Pettersen, 2012).



The mature care philosophy criticizes the altruistic care ideal based on the risk of negative consequences for both the caregiver and the care recipient. The family caregivers, particularly the spouses, describe how they give the person with dementia's needs priority over their own needs. They try to balance their own needs and the needs of the person with dementia and, hence, maintain equal roles.

According to Pozzebon *et al.*, (2016), the process of losing a partner with dementia can be experienced in four phases: 1) acknowledging change, 2) being in crisis, 3) adapting and adjusting, and 4) accepting and moving forward (Pozzebon *et al.*, 2016). The wives in the current study describe their situation according to these phases. They alternate between adapting the situation by following tight routines and trying to accept the need for more help from professional health workers. Their shifting emotions include thankfulness, love, happiness, anger, powerlessness and despair. Both women try to spare their husbands from experiencing their negative feelings. Being angry or sad gives them both bad conscience. To cope with everyday life, regular morning- and afternoon routines are crucial for the wife in case 3. Having these routines maintains her needs for control and mastery of the situation.

This study reveals that family caregivers have more time to attend to their own needs when the person with dementia attends day care. According to the mature care philosophy, day care increases the family caregivers' opportunities to maintain a balanced relationship to the person with dementia. In all stages of dementia, support from the day care staff is important to relieve the family caregivers from feelings of bad conscience as they seek to meet their own needs. This is especially important in situations where they have to consider the need for homecare or institutional services. In these situations, family caregivers need to be supported to be able to re-define their values and goals and to adapt to new or adjusted "meaning focus" in their caregiving role.

### **The day care's potential to increase family caregivers' motivation to care**

The family caregivers describe the relationships with the person with dementia as essential in their motivation for caregiving. According to motivation theory, human acting and making choices are guided by our motivation (Lewin, 1936; Tolman, 1932). Our motivation is linked to what extent the actions we make will lead us to the desired outcome and goal. Additionally, it refers to the processes that lead to the achievement of the goal.

The motivation to act can be led by intrinsic motivation and/or extrinsic motivation. Intrinsic motivation refers to initiating an activity for its own sake because it is interesting and satisfying in itself, as opposed to doing an activity to obtain an external goal (extrinsic motivation). In self-

determination theory (SDT), Deci and Ryan (2000) focused on the differences between intrinsic and extrinsic motivation and described three psychological needs that motivate the self to initiate behaviors that are essential for psychological health and well-being (Deci and Ryan, 2000).

Competence refers to the perception that one's behavior results in the intended outcomes and effects. Relatedness refers to feeling connected to others and the capacity to receive feedback from them. Autonomy refers to the experience that one can choose activities, make decisions, and regulate behavior in accordance with one's goals (Custers *et al.*, 2010; Ryan and Deci, 2002).

According to this theory, support and relief by day care has the potential to enhance family caregivers' motivation to care. The family caregivers' competence is important. It is important to be able to choose the actions that are necessary to achieve their value-based goals of caregiving. As previously described, respite gives family caregivers more energy and patience in their complex caregiver role. They become more competent as caregivers. In addition to respite, the day care staff has the possibility to offer support and guidance to family caregivers, presupposing that the staff has knowledge about the relative values and their goals for caregiving.

According to the mature care philosophy, day care as a respite and support service can increase family caregivers' autonomy and ability to meet their own needs, which was described by the participants in the study. The support from day care staff is central to being able to make autonomous choices and maintain these choices. The staff has to respect the family caregivers' various choices in their care providence and empower them to act in accordance with their own values.

According to SDT, the relationship between the person who provides support and the person who receives support is an essential effective factor. Therefore, the staff must be emphatic and know the family caregivers' individual situations when they support family caregivers.

The family caregivers describe in different ways and with varying strengths how their feeling of duty affects their actions. This feeling of duty is related to their values but also to the values and expectations of society. Through this feeling of duty, the family caregivers describe how the *aim of the action* motivates them to care (extrinsic motivation) more than *the action itself* (intrinsic motivation). According to SDT, the activities motivated by "intrinsic motivation" are activities or situations where the "activities themselves" are the primary motivating factor. The family caregivers describe how day care contributes to enhancing the possibility for several good moments together with the person with dementia, *e.g.*, having a pleasant telephone call, a nice meal or emotional intimacy. Based on this, day care as a support and relief service can contribute to facilitating the family caregivers' motivation of care toward a more intrinsic direction. Activities based on intrinsic

motivation are more rooted in the integrity of the person than activities based on extrinsic motivation. Furthermore, activities rooted in a person's integrity have a higher potential to increase the person's psychological health and well-being (Deci and Ryan, 2000).

### **Methodological considerations**

The in-depth semi-structured interviews provided a rich source of material with personal descriptions related to the aim of this study. The participants represented diversity with respect to gender, age, and caregiver roles (spouses or children living together or separately), and the sample represented caregivers of people with various degrees of dementia. According to the aim of the study, the narrative method was an appropriate because it provides relevant knowledge about the participants' experiences of meaning based on their values, goals and relationships.

There are some limitations of this study. Only one interview was carried out with each participant, and hence, there was no possibility to verify the researchers' interpretations of the data or for the participants to add further information. Other limitations due to the sampling technique may have influenced external validity. and therefore, the results cannot be generalized to other groups of caregivers. However, the results can elucidate the needs of similar groups of family caregivers, their situations, and how their needs for support and respite can be met.

### **Conclusion**

This study reveals that finding meaning in the role as family caregiver for persons with dementia is closely connected to the caregivers' own values and goals. Finding a balance between attending to their own needs and the needs of the person with dementia is crucial. Day care has the potential to increase the family caregiver's motivation to care by supporting their capacity to make competent and autonomous choices and, thus, increase their feeling of mastery.

### **Conflicts of interest declaration**

The authors declare that there are no conflicts or competing interests.

### **Description of authors' roles**

ST performed the data acquisition, data analysis, and drafted the manuscript. AMMR and SV contributed to the study design, the interpretation of the data, and editing of the manuscript. All authors agreed to the final content of the manuscript.

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# Appendix







### Mixed Methods Appraisal Tool (MMAT) – Version 2011

For dissemination, application, and feedback: Please contact [pierre.pluве@mcgill.ca](mailto:pierre.pluве@mcgill.ca), Department of Family Medicine, McGill University, Canada.

The MMAT is comprised of two parts (see below): criteria (Part I) and tutorial (Part II). While the content validity and the reliability of the pilot version of the MMAT have been examined, this critical appraisal tool is still in development. Thus, the MMAT must be used with caution, and users' feedback is appreciated. Cite the present version as follows.

Pluye, P., Robert, E., Cargo, M., Bartlett, G., O'Cathain, A., Griffiths, F., Boardman, F., Gagnon, M.P., & Rousseau, M.C. (2011). *Proposal: A mixed methods appraisal tool for systematic mixed studies reviews*. Retrieved on [date] from <http://mixedmethodsappraisaltoolpublic.pbworks.com>. Archived by WebCite® at <http://www.webcitation.org/5fTRTe9yI>

**Purpose:** The MMAT has been designed for the appraisal stage of complex systematic literature reviews that include qualitative, quantitative and mixed methods studies (mixed studies reviews). The MMAT permits to concomitantly appraise and describe the methodological quality for three methodological domains: mixed, qualitative and quantitative (subdivided into three sub-domains: randomized controlled, non-randomized, and descriptive). Therefore, using the MMAT requires experience or training in these domains. E.g., MMAT users may be helped by a colleague with specific expertise when needed. The MMAT allows the appraisal of most common types of study methodology and design. For appraising a qualitative study, use section 1 of the MMAT. For a quantitative study, use section 2 or 3 or 4, for randomized controlled, non-randomized, and descriptive studies, respectively. For a mixed methods study, use section 1 for appraising the qualitative component, the appropriate section for the quantitative component (2 or 3 or 4), and section 5 for the mixed methods component. For each relevant study selected for a systematic mixed studies review, the methodological quality can then be described using the corresponding criteria. This may lead to exclude studies with lowest quality from the synthesis, or to consider the quality of studies for contrasting their results (e.g., low quality vs. high).

**Scoring metrics:** For each retained study, an overall quality score may be not informative (in comparison to a descriptive summary using MMAT criteria), but might be calculated using the MMAT. Since there are only a few criteria for each domain, the score can be presented using descriptors such as \*, \*\*, \*\*\*, and \*\*\*\*. For qualitative and quantitative studies, this score can be the number of criteria met divided by four (scores varying from 25% (\*) -one criterion met- to 100% (\*\*\*\*) -all criteria met-). For mixed methods research studies, the premise is that the overall quality of a combination cannot exceed the quality of its weakest component. Thus, the overall quality score is the lowest score of the study components. The score is 25% (\*) when  $QUAL=1$  or  $QUAN=1$  or  $MM=0$ ; it is 50% (\*\*) when  $QUAL=2$  or  $QUAN=2$  or  $MM=1$ ; it is 75% (\*\*\*) when  $QUAL=3$  or  $QUAN=3$  or  $MM=2$ ; and it is 100% (\*\*\*\*) when  $QUAL=4$  and  $QUAN=4$  and  $MM=3$  (QUAL being the score of the qualitative component; QUAN the score of the quantitative component; and MM the score of the mixed methods component).

**Rationale:** There are general criteria for planning, designing and reporting mixed methods research (Creswell and Plano Clark, 2010), but there is no consensus on key specific criteria for appraising the methodological quality of mixed methods studies (O'Cathain, Murphy and Nicholl, 2008). Based on a critical examination of 17 health-related systematic mixed studies reviews, an initial 15-criteria version of MMAT was proposed (Pluye, Gagnon, Griffiths and Johnson-Lafleur, 2009). This was pilot tested in 2009. Two raters assessed 29 studies using the pilot MMAT criteria and tutorial (Pace, Pluye, Bartlett, Macaulay et al., 2010). Based on this pilot exercise, it is anticipated that applying MMAT may take on average 15 minutes per study (hence efficient), and that the Intra-Class Correlation might be around 0.8 (hence reliable). The present 2011 revision is based on feedback from four workshops, and a comprehensive framework for assessing the quality of mixed methods research (O'Cathain, 2010).

**Conclusion:** The MMAT has been designed to appraise the *methodological quality* of the studies retained for a systematic mixed studies review, not the quality of their *reporting* (writing). This distinction is important, as good research may not be 'well' reported. If reviewers want to genuinely assess the former, companion papers and research reports should be collected when some criteria are not met, and authors of the corresponding publications should be contacted for additional information. Collecting additional data is usually necessary to appraise *qualitative research and mixed methods studies*, as there are no uniform standards for reporting study characteristics in these domains ([www.equator-network.org](http://www.equator-network.org)), in contrast, e.g., to the CONSORT statement for reporting randomized controlled trials ([www.consort-statement.org](http://www.consort-statement.org)).

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**PART I. MMAT criteria & one-page template (to be included in appraisal forms)**

Types of mixed methods study components or primary studies	Methodological quality criteria (see tutorial for definitions and examples)	Responses		
		Yes	No	Can't tell
Screening questions (for all types)	<ul style="list-style-type: none"> <li>Are there clear qualitative and quantitative research questions (or objectives*), or a clear mixed methods question (or objective*)?</li> <li>Do the collected data allow address the research question (objective)? E.g., consider whether the follow-up period is long enough for the outcome to occur (for longitudinal studies or study components).</li> </ul>			
	<i>Further appraisal may be not feasible or appropriate when the answer is 'No' or 'Can't tell' to one or both screening questions.</i>			
1. Qualitative	1.1. Are the sources of qualitative data (archives, documents, informants, observations) relevant to address the research question (objective)?			
	1.2. Is the process for analyzing qualitative data relevant to address the research question (objective)?			
	1.3. Is appropriate consideration given to how findings relate to the context, e.g., the setting, in which the data were collected?			
	1.4. Is appropriate consideration given to how findings relate to researchers' influence, e.g., through their interactions with participants?			
2. Quantitative randomized controlled (trials)	2.1. Is there a clear description of the randomization (or an appropriate sequence generation)?			
	2.2. Is there a clear description of the allocation concealment (or blinding when applicable)?			
	2.3. Are there complete outcome data (80% or above)?			
	2.4. Is there low withdrawal/drop-out (below 20%)?			
3. Quantitative non-randomized	3.1. Are participants (organizations) recruited in a way that minimizes selection bias?			
	3.2. Are measurements appropriate (clear origin, or validity known, or standard instrument; and absence of contamination between groups when appropriate) regarding the exposure/intervention and outcomes?			
	3.3. In the groups being compared (exposed vs. non-exposed; with intervention vs. without; cases vs. controls), are the participants comparable, or do researchers take into account (control for) the difference between these groups?			
	3.4. Are there complete outcome data (80% or above), and, when applicable, an acceptable response rate (60% or above), or an acceptable follow-up rate for cohort studies (depending on the duration of follow-up)?			
4. Quantitative descriptive	4.1. Is the sampling strategy relevant to address the quantitative research question (quantitative aspect of the mixed methods question)?			
	4.2. Is the sample representative of the population under study?			
	4.3. Are measurements appropriate (clear origin, or validity known, or standard instrument)?			
	4.4. Is there an acceptable response rate (60% or above)?			
5. Mixed methods	5.1. Is the mixed methods research design relevant to address the qualitative and quantitative research questions (or objectives), or the qualitative and quantitative aspects of the mixed methods question (or objective)?			
	5.2. Is the integration of qualitative and quantitative data (or results*) relevant to address the research question (objective)?			
	5.3. Is appropriate consideration given to the limitations associated with this integration, e.g., the divergence of qualitative and quantitative data (or results*) in a triangulation design?			
	<i>Criteria for the qualitative component (1.1 to 1.4), and appropriate criteria for the quantitative component (2.1 to 2.4, or 3.1 to 3.4, or 4.1 to 4.4), must be also applied.</i>			

\*These two items are not considered as double-barreled items since in mixed methods research, (1) there may be research questions (quantitative research) or research objectives (qualitative research), and (2) data may be integrated, and/or qualitative findings and quantitative results can be integrated.

**PART II. MMAT tutorial**

Types of mixed methods study components or primary studies	Methodological quality criteria
<p><b>I. Qualitative</b></p> <p>Common types of qualitative research methodology include:</p> <p>A. Ethnography The aim of the study is to describe and interpret the shared cultural behaviour of a group of individuals.</p> <p>B. Phenomenology The study focuses on the subjective experiences and interpretations of a phenomenon encountered by individuals.</p> <p>C. Narrative The study analyzes life experiences of an individual or a group.</p> <p>D. Grounded theory Generation of theory from data in the process of conducting research (data collection occurs first).</p> <p>E. Case study In-depth exploration and/or explanation of issues intrinsic to a particular case. A case can be anything from a decision-making process, to a person, an organization, or a country.</p> <p>F. Qualitative description There is no specific methodology, but a qualitative data collection and analysis, e.g., in-depth interviews or focus groups, and hybrid thematic analysis (inductive and deductive).</p> <p>Key references: Creswell, 1998; Schwandt, 2001; Sandelowski, 2010.</p>	<p><b>1.1. Are the sources of qualitative data (archives, documents, informants, observations) relevant to address the research question (objective)?</b></p> <p>E.g., consider whether (a) the selection of the participants is clear, and appropriate to collect relevant and rich data; and (b) reasons why certain potential participants chose not to participate are explained.</p> <p><b>1.2. Is the process for analyzing qualitative data relevant to address the research question (objective)?</b></p> <p>E.g., consider whether (a) the method of data collection is clear (in depth interviews and/or group interviews, and/or observations and/or documentary sources); (b) the form of the data is clear (tape recording, video material, and/or field notes for instance); (c) changes are explained when methods are altered during the study; and (d) the qualitative data analysis addresses the question.</p> <p><b>1.3. Is appropriate consideration given to how findings relate to the context, e.g., the setting, in which the data were collected?</b></p> <p>E.g., consider whether the study context and how findings relate to the context or characteristics of the context are explained (how findings are influenced by or influence the context). “For example, a researcher wishing to observe care in an acute hospital around the clock may not be able to study more than one hospital. (...) Here, it is essential to take care to describe the context and particulars of the case [the hospital] and to flag up for the reader the similarities and differences between the case and other settings of the same type” (Mays &amp; Pope, 1995).</p> <p>The notion of context may be conceived in different ways depending on the approach (methodology) tradition.</p> <p><b>1.4. Is appropriate consideration given to how findings relate to researchers’ influence, e.g., through their interactions with participants?</b></p> <p>E.g., consider whether (a) researchers critically explain how findings relate to their perspective, role, and interactions with participants (how the research process is influenced by or influences the researcher); (b) researcher’s role is influential at all stages (formulation of a research question, data collection, data analysis and interpretation of findings); and (c) researchers explain their reaction to critical events that occurred during the study.</p> <p>The notion of reflexivity may be conceived in different ways depending on the approach (methodology) tradition. E.g., “at a minimum, researchers employing a generic approach [qualitative description] must explicitly identify their disciplinary affiliation, what brought them to the question, and the assumptions they make about the topic of interest” (Caeili, Ray &amp; Mill, 2003, p. 5).</p>

Types of mixed methods study components or primary studies	Methodological quality criteria
<p><b>2. Quantitative randomized controlled (trials)</b></p> <p>Randomized controlled clinical trial: A clinical study in which individual participants are allocated to intervention or control groups by randomization (intervention assigned by researchers).</p> <p>Key references: Higgins &amp; Green, 2008; Porta, 2008; Oxford Center for Evidence based medicine, 2009.</p>	<p><b>2.1. Is there a clear description of the randomization (or an appropriate sequence generation)?</b></p> <p>In a randomized controlled trial, the allocation of a participant (or a data collection unit, e.g., a school) into the intervention or control group is based solely on chance, and researchers describe how the randomization schedule is generated. “A simple statement such as ‘we randomly allocated’ or ‘using a randomized design’ is insufficient”.</p> <p><i>Simple randomization:</i> Allocation of participants to groups by chance by following a predetermined plan/sequence. “Usually it is achieved by referring to a published list of random numbers, or to a list of random assignments generated by a computer”.</p> <p><i>Sequence generation:</i> “The rule for allocating interventions to participants must be specified, based on some chance (random) process”. Researchers provide sufficient detail to allow a readers’ appraisal of whether it produces comparable groups. E.g., blocked randomization (to ensure particular allocation ratios to the intervention groups), or stratified randomization (randomization performed separately within strata), or minimization (to make small groups closely similar with respect to several characteristics).</p>
	<p><b>2.2. Is there a clear description of the allocation concealment (or blinding when applicable)?</b></p> <p><i>The allocation concealment protects assignment sequence until allocation.</i> E.g., researchers and participants are unaware of the assignment sequence up to the point of allocation. E.g., group assignment is concealed in opaque envelopes until allocation.</p> <p><i>The blinding protects assignment sequence after allocation.</i> E.g., researchers and/or participants are unaware of the group a participant is allocated to during the course of the study.</p>
	<p><b>2.3. Are there complete outcome data (80% or above)?</b></p> <p>E.g., almost all the participants contributed to almost all measures.</p>
	<p><b>2.4. Is there low withdrawal/drop-out (below 20%)?</b></p> <p>E.g., almost all the participants completed the study.</p>

Types of mixed methods study components or primary studies	Methodological quality criteria
<p><b>3. Quantitative non-randomized</b></p> <p>Common types of design include (A) non-randomized controlled trials, and (B-C-D) observational analytic study or component where the intervention/exposure is defined/assessed, but not assigned by researchers.</p> <p>A. Non-randomized controlled trials The intervention is assigned by researchers, but there is no randomization, e.g., a pseudo-randomization. A non-random method of allocation is not reliable in producing alone similar groups.</p> <p>B. Cohort study Subsets of a defined population are assessed as exposed, not exposed, or exposed at different degrees to factors of interest. Participants are followed over time to determine if an outcome occurs (prospective longitudinal).</p> <p>C. Case-control study Cases, e.g., patients, associated with a certain outcome are selected, alongside a corresponding group of controls. Data is collected on whether cases and controls were exposed to the factor under study (retrospective).</p> <p>D. Cross-sectional analytic study At one particular time, the relationship between health-related characteristics (outcome) and other factors (intervention/exposure) is examined. E.g., the frequency of outcomes is compared in different population sub-groups according to the presence/absence (or level) of the intervention/exposure.</p> <p>Key references for observational analytic studies: Higgins &amp; Green, 2008; Wells, Shea, O'Connell, Peterson, et al., 2009.</p>	<p><b>3.1. Are participants (organizations) recruited in a way that minimizes selection bias?</b></p> <p>At recruitment stage: For cohort studies, e.g., consider whether the exposed (or with intervention) and non-exposed (or without intervention) groups are recruited from the same population. For case-control studies, e.g., consider whether same inclusion and exclusion criteria were applied to cases and controls, and whether recruitment was done independently of the intervention or exposure status. For cross-sectional analytic studies, e.g., consider whether the sample is representative of the population.</p> <p><b>3.2. Are measurements appropriate (clear origin, or validity known, or standard instrument; and absence of contamination between groups when appropriate) regarding the exposure/intervention and outcomes?</b></p> <p>At data collection stage: E.g., consider whether (a) the variables are clearly defined and accurately measured; (b) the measurements are justified and appropriate for answering the research question; and (c) the measurements reflect what they are supposed to measure. For non-randomized controlled trials, the intervention is assigned by researchers, and so consider whether there was absence/presence of a contamination. E.g., the control group may be indirectly exposed to the intervention through family or community relationships.</p> <p><b>3.3. In the groups being compared (exposed vs. non-exposed; with intervention vs. without; cases vs. controls), are the participants comparable, or do researchers take into account (control for) the difference between these groups?</b></p> <p>At data analysis stage: For cohort, case-control and cross-sectional, e.g., consider whether (a) the most important factors are taken into account in the analysis; (b) a table lists key demographic information comparing both groups, and there are no obvious dissimilarities between groups that may account for any differences in outcomes, or dissimilarities are taken into account in the analysis.</p> <p><b>3.4. Are there complete outcome data (80% or above), and, when applicable, an acceptable response rate (60% or above), or an acceptable follow-up rate for cohort studies (depending on the duration of follow-up)?</b></p>



Types of mixed methods study components or primary studies	Methodological quality criteria
<p><b>4. Quantitative descriptive studies</b></p> <p>Common types of design include single-group studies:</p> <p>A. Incidence or prevalence study without comparison group In a defined population at one particular time, what is happening in a population, e.g., frequencies of factors (importance of problems), is described (portrayed).</p> <p>B. Case series A collection of individuals with similar characteristics are used to describe an outcome.</p> <p>C. Case report An individual or a group with a unique/unusual outcome is described in details.</p> <p>Key references: Critical Appraisal Skills Programme, 2009; Draugalis, Coons &amp; Plaza, 2008.</p>	<p><b>4.1. Is the sampling strategy relevant to address the quantitative research question (quantitative aspect of the mixed methods question)?</b></p> <p>E.g., consider whether (a) the source of sample is relevant to the population under study; (b) when appropriate, there is a standard procedure for sampling, and the sample size is justified (using power calculation for instance).</p> <p><b>4.2. Is the sample representative of the population under study?</b></p> <p>E.g., consider whether (a) inclusion and exclusion criteria are explained; and (b) reasons why certain eligible individuals chose not to participate are explained.</p> <p><b>4.3. Are measurements appropriate (clear origin, or validity known, or standard instrument)?</b></p> <p>E.g., consider whether (a) the variables are clearly defined and accurately measured; (b) measurements are justified and appropriate for answering the research question; and (c) the measurements reflect what they are supposed to measure.</p> <p><b>4.4. Is there an acceptable response rate (60% or above)?</b></p> <p>The response rate is not pertinent for case series and case report. E.g., there is no expectation that a case series would include all patients in a similar situation.</p>

Types of mixed methods study components or primary studies	Methodological quality criteria
<p><b>5. Mixed methods</b></p> <p>Common types of design include:</p> <p>A. Sequential explanatory design The qualitative component is followed by the quantitative. The purpose is to explain quantitative results using qualitative findings. E.g., the quantitative results guide the selection of qualitative data sources and data collection, and the qualitative findings contribute to the interpretation of quantitative results.</p> <p>B. Sequential exploratory design The qualitative component is followed by the quantitative. The purpose is to explore, develop and test an instrument (or taxonomy), or a conceptual framework (or theoretical model). E.g., the qualitative findings inform the quantitative data collection, and the quantitative results allow a generalization of the qualitative findings.</p> <p>C. Triangulation design The qualitative and quantitative components are concomitant. The purpose is to examine the same phenomenon by interpreting qualitative and quantitative results (bringing data analysis together at the interpretation stage), or by integrating qualitative and quantitative datasets (e.g., data on same cases), or by transforming data (e.g., quantization of qualitative data).</p> <p>D. Embedded design The qualitative and quantitative components are concomitant. The purpose is to support a qualitative study with a quantitative sub-study (measures), or to better understand a specific issue of a quantitative study using a qualitative sub-study, e.g., the efficacy or the implementation of an intervention based on the views of participants.</p> <p>Key references: Creswell &amp; Plano Clark, 2007; O’Cathain, 2010.</p>	<p><b>5.1. Is the mixed methods research design relevant to address the qualitative and quantitative research questions (or objectives), or the qualitative and quantitative aspects of the mixed methods question (or objective)?</b></p> <p>E.g., the rationale for integrating qualitative and quantitative methods to answer the research question is explained.</p> <p><b>5.2. Is the integration of qualitative and quantitative data (or results) relevant to address the research question (objective)?</b></p> <p>E.g., there is evidence that data gathered by both research methods was brought together to form a complete picture, and answer the research question; authors explain when integration occurred (during the data collection-analysis or/and during the interpretation of qualitative and quantitative results); they explain how integration occurred and who participated in this integration.</p> <p><b>5.3. Is appropriate consideration given to the limitations associated with this integration, e.g., the divergence of qualitative and quantitative data (or results)?</b></p>

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## Carers' questionnaire



**Ageing and Health**

Norwegian Centre for Research,  
Education and Service Development



**UNIVERSITY OF  
STIRLING**

ID-number:

Date:

Information and cooperation- Questionnaire to family carers of people with dementia who attend a day care centre specially designed for this group of users

Where did you get the information about the day care service?	
Home care	
GP	
Hospital service	
Web-site	
Alzheimer's organisation	
Other - who? _____	

Consider to what extent you agree or disagree in the following statements	Strongly agree	Agree	Neither agree nor disagree	Disagree	Strongly disagree
<b>Information</b>					
1. I received adequate information about the day care centre in advance					
Comments:					
<b>Relationship with the day care centre staff on a day-to-day basis</b>					
2. The staff are easy to reach when I try to contact them about my relative					
3. The staff have time to speak to me					
4. I receive a positive response to my wishes and input					
5. The day care centre follows up on what we have agreed about my relative					
Comments:					
<b>About the day care centre's contact with me</b>					
6. I am regularly informed about my relative's activities at the day care centre					
7. I am informed if something unusual occurs					

8. I receive sufficient information about my relative's participation in activities					
9. I am consulted if a change is required in the service offered to my relative					
Comments:					
Consider to what extent you agree or disagree in the following statements	Strongly agree	Agree	Neither agree nor disagree	Disagree	Strongly disagree
<b>The offer to attend the day care centre</b>					
10. My relative received the offer to attend day care at a time that fit my needs as a family caregiver					
11. My relative received the offer to attend day care at a time that fit her/his needs					
Comments:					
<b>The content of the service</b>					
12. I feel that my relative has been offered an adequate number of days					
13. I feel that my relative has been offered an adequate number of hours per day					
14. The service is flexible about changing the day he/she attends if needed or is flexible about opening hours					
Comments:					
<b>About transportation</b>					
15. The transport arrangements are adequate					
16. The people who pick up and drop off my relative know him/her well					
17. I regularly need to spend time motivating my relative to attend the day care centre					
18. The home-based services help my relative to get ready in time to go to the day care centre (if agreed)					
Comments:					
<b>The content of the day care centre</b>					
19. The content of the day care centre is adapted to the interests and needs of the attendees					
20. As a family caregiver, I am invited to participate in the activities at the day care centre					
Comments:					

Consider to what extent you agree or disagree in the following statements	Strongly agree	Agree	Neither agree nor disagree	Disagree	Strongly disagree
<b>The quality of the day care centre</b>					
21. The staff have the right skills to work at the day care centre					
22. My relative enjoys being at the day care centre					
23. My relative does not want to go to the day care centre					
Comments:					
<b>Day care centre as respite care</b>					
24. The day care makes it easier for me to cope with everyday life					
25. The day care allows me to be more socially active					
26. The day care gives me the opportunity to take care of practical tasks					
27. The day care makes it possible for me to keep my job (if working)					
28. The opening hours are long enough to enable me to go to work (if working)					
29. The day care improves my sense of security in the situation					
30. The day care makes my relative worried and distressed					
31. The day care makes it easier for me to interact with my relative					
32. The day care improves the time we spend together					
Comments:					
<b>The support from the day care centre to cope with challenges in everyday life</b>					
33. I receive adequate support from the day care centre in my role as family caregiver					
34. I receive useful information about dementia from the day care centre					
35. The day care makes it possible for my relative to continue to live at home					
Comments:					



## Errataliste

Signe Tretteteig phd. Title of thesis: The impact of day care designed for people with dementia on their family caregivers.

Referansenummer 2013/5561

Side	Linje	Originaltekst	Type rettelse	Korrigert tekst
3	Pnk. 4.4.5	4.4.5 Data analysis <b>Systematic text condensation</b>	Cor	4.4.5 Data analysis