

Next of kin to people with dementia attending farm-based
daycare: Characteristics, experiences, and respite

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Liv Bjercknes Taranrød

Abstract in Norwegian

Bakgrunn

Å være pårørende til en person med demens påvirker mange områder i livet og kan over tid, føre til belastning og redusert livskvalitet. Selv om pårørende opplever belastning, beskriver pårørende også positive forhold i omsorgsrollen. Informasjon, støtte og avlastning til pårørende, er viktige temaer i demensomsorgen. Dagaktivitetstilbud for personer med demens som avlastning er ett av flere tilbud til pårørende og personer med demens. Intensjonen med dagaktivitetstilbud er å støtte og avlaste pårørende, og dermed bidra til å øke deres helse og velvære samt motivere pårørende til omsorg, og å gi personer med demens mulighet til å delta i meningsfulle aktiviteter i trygge omgivelser og bedre deres livskvalitet. Norges tre demensplaner (2015,2020,2025) understreker behovet for ulike typer dagaktivitetstilbud. Dagaktivitetstilbud på gård for personer med demens er etablert som én type dagaktivitetstilbud med tilsvarende formål som andre dagaktivitetstilbudtilbud for personer med demens og deres pårørende. Dagaktivitetstilbud på gård er en tjeneste som tilbyr et bredt spekter av aktiviteter for deltakerne, knyttet til driftsbygninger, hager, dyr og uteområder. Forskning om pårørende til personer med demens som deltar på denne type tilbud er begrenset.

Mål

Det overordnede målet med avhandlingen var å få økt kunnskap om pårørende til personer med demens som deltar på et dagaktivitetstilbud på gård i Norge, og deres erfaringer med tjenesten. Avhandlingen består av tre studier. Studie 1 undersøkte karakteristika ved pårørende og hvilke individuelle pårørende karakteristika, karakteristika ved personer med demens og ved gården som var assosiert med pårørendes omsorgsbyrde og livskvalitet. Studie 2 utforsket pårørendes erfaringer med dagaktivitetstilbud på gård og hvordan denne tjenesten påvirket deres daglige liv. Studie 3 undersøker pårørendes erfaringer med overgangsprosessen for deres nærmeste med demens fra dagaktivitetstilbud på gård til en annen tjeneste i kommune.

Metoder

De tre studiene i denne avhandlingen har ulike design og både kvantitative og kvalitative metoder ble brukt. I studie 1, en tverrsnitts- studie, deltok 94 dyader med pårørende og

personer med demens som hadde et dagaktivitetstilbud på gård. Deltakernes individuelle karakteristika ble kartlagt ved bruk av standardiserer instrumenter. Lineære regresjonsmodeller ble benyttet til å undersøke assosiasjonen mellom pårørendes livskvalitet, omsorgsbyrde og deres individuelle karakteristika, karakteristika knyttet til personer med demens og gårds karakteristika.

I studie 2 og 3 ble det gjennomført semi-strukturerte intervjuer med åtte pårørende i hver av studiene. Intervjuene ble analysert i henhold til kvalitativ innholdsanalyse av Graneheim og Lundman (2004).

Resultater

Studie 1, viste at pårørende besto av to grupper: 58 (62%) ektefeller og 36 (38%) i hovedsak barn /nær familie. Femtisju av ektefellene bodde sammen med ektefellen med demens, ingen av de resterende deltakerne bodde sammen med slektningen med demens. Disse to gruppene var forskjellige i alder, utdanningsnivå, arbeidsforhold, opplevd sosial støtte, angstsymptomer, depresjonssymptomer, omsorgsbelastning og livskvalitet.

Ektefellene til personene med demens opplevde en større belastning og rapporterte lavere livskvalitet enn de som ikke bodde sammen med personen med demens. Sosial støtte påvirket både omsorgsbelastningen og livskvaliteten positivt. Til tross for at ektefellene som omsorgsgivere opplevde mer omsorgsbyrde og lavere livskvalitet enn barn/nær familie, rapporterte de fleste av pårørende å ha en god livskvalitet.

I de lineære regresjonsmodellene ble hele utvalget inkludert. Økt belastning var assosiert med å bo sammen med en person med demens, angstsymptomer, lavere opplevd sosial støtte og nevropsykiatriske symptomer hos personen med demens. Økt livskvalitet hos pårørende var assosiert med å ikke bo sammen med personen med demens, få angstsymptomer og opplevd sosial støtte.

I studie 2 ble tre hovedkategorier beskrevet om hvordan deltakerne opplevde dagaktivitetstilbud på gård og hvordan tjenesten påvirket deres daglige liv: (1) Jeg har det bra når du har det bra, (2) Viktige aspekter ved tjenesten på gården, og (3) Dagaktivitetstilbud på gård som en del av demensforløpet. Pårørendes opplevelser av avlastning var knyttet til at deltakerne på gården hadde det bra på gården. Fra pårørendes

perspektiv tilrettelata personalet meningsfulle aktiviteter for deltakerne med en personsentrert omsorgstilnærming. Pårørende opplevde en god dialog med personalet i tilbudet og å ha noen å dele omsorgen med.

I studie 3, ble tre hovedkategorier beskrevet om hvordan pårørende opplevde prosessen da deres pårørende med demens sluttet i dagaktivitetstilbudet på gård og ble overført til en annen omsorgstjeneste i kommunen: (1) Å bære byrden, (2) Å være i overgang, og (3) Å føle seg støttet. Perioden før personene med demens skiftet omsorgstilbud fra dagaktivitetstilbud på gård til en annen kommunal tjeneste var svært belastende for pårørende, på grunn av det økende omsorgsbehovet til personene med demens.

Konklusjon

Den samlede konklusjonen i denne avhandlingen er at dagaktivitetstilbud på gård for personer med demens bidro til at de pårørende opplevde støtte og avlastning i en periode av demensforløpet, før omsorgsbehovene til personene med demens oversteg hva dagaktivitetstilbudene på gård kunne dekke. Funnene indikerer at dagaktivitetstilbud på gård har god kvalitet og innhold, bygd på en personsentrert omsorgstilnærming. Videre viser funnene viktigheten av at dagaktivitetstilbudet og omsorgstjenesten i kommunene støtter og har en tett dialog med pårørende og personer med demens gjennom demensforløpet. En plan for overgang fra dagaktivitetstilbud på gård til en annen tjeneste i kommunen kan forhindre uplanlagte overganger, økt belastning og stress for pårørende og personer med demens. Dagaktivitetstilbudet på gård og omsorgstjenesten i kommunen bør ha som mål å gi slik støtte og dermed styrke pårørendes evne til å takle sine roller som omsorgspersoner uten å risikere helsen. Funnene i de tre studiene kan bidra til utvikling av avlastnings tjenester for pårørende og personer med demens, da elementer fra dagaktivitetstilbud på gård kan være fordelaktig i andre typer avlastnings tilbud. Dagaktivitetstilbudet på gård har forbedringspotensiale knyttet til å tilby mer fleksible åpningstider.

Abstract

Background

Being the next of kin to a person with dementia affect many areas of one's life and, over time, lead to strain, burden and decreased quality of life (QoL). In spite of these, next of kin also experience positive aspects of their caregiving role. Providing caregivers with information, support and respite is a major factor in dementia care. Daycare as respite is one of several services for next of kin and people with dementia. Its purpose is to offer support and respite to next of kin, thereby contributing to their health and well-being and offering those with dementia opportunities to engage in meaningful activities in a safe setting designed to increase their own well-being. The Norwegian dementia plans (2015, 2020, 2025) underscore the need for various types of daycare services. Farm-based daycare (FDC) is a service that offers attendees adapted farm activities related to the environment and addresses the intentions of daycare, including respite for next of kin. Yet research regarding next of kin to people with dementia attending FDC is sparse.

Aims

The main objective of the present thesis is to gain knowledge about the next of kin of people with dementia attending an FDC in Norway and their experiences with the service. The present thesis comprises three studies. Study 1 describes the characteristics of next of kin and explores the association between this group and persons with dementia regarding the next of kin's burden of care and quality of life (QoL). Study 2 examines next of kin's experiences with FDC and how this service influences their daily life. Study 3 investigates next of kin's experiences of the transition process for their relative with dementia from FDC to another municipality service.

Methods

The three studies in the present thesis have different research designs, and quantitative and qualitative methods were used. In Study 1, a cross-sectional design was adopted with participation of 94 dyads with next of kin and their relatives with dementia attending an FDC. The participants' individual characteristics were described using standardized instruments. In two regression models, the associations between next of kin's burden of care,

QoL and individual characteristics, the individual characteristics of those with dementia and the characteristics of the farms providing daycare services, were explored.

In Studies 2 and 3, semi-structured interviews were conducted with eight participants in each study and analyzed in accordance with qualitative content analysis by Graneheim and Lundman (2004).

Results

For Study 1, next of kin comprised two groups: 58 (62%) spouses and 36 (38%) mainly children/close family (38%). Fifty-seven of the spouses lived with their husband or wife with dementia, none of the remaining next of kin lived with the relative with dementia. The two groups were characterized by significant differences in age, education level, employment, perceived social support, depression symptoms, burden of care and quality of life. The findings showed that a majority of next of kin living with a spouse with dementia, experienced a greater burden and reported lower QoL than those not living with the person with dementia; however, perceived support positively influenced both burden of care and QoL. Despite experiencing a burden, most of the participants reported having a good QoL.

In the linear regression models, the entire sample was included. The burden of care was associated with next of kin living with a person with dementia, anxiety symptoms, perceived social support and neuropsychiatric symptoms of the relative with dementia. Better QoL was associated with the next of kin not with living with the person with dementia, fewer anxiety symptoms, and more perceived social support.

In Study 2, three main categories described the participants' experiences of FDC and how the service influenced their daily life. These categories were (1) I am fine when you are fine, (2) significant aspects of the service at the farm, and (3) FDC as part of the dementia trajectory. The findings revealed that next of kin's experiences of respite were linked to the well-being of their relative at the FDC. The staff facilitating meaningful activities for the attendees using the farm environment and social interaction with a person-centred care approach. These experiences of respite were also linked to the next of kin having someone to share their caregiving responsibilities as well as to beneficial dialogue with the FDC staff

In Study 3, three main categories described the next of kin's experiences of the transition of their relative with dementia from FDC to another care service in the municipality. The categories were (1) bearing the burden, (2) being in transition, and (3) feeling supported. The period before their relative with dementia transitioned from FDC to another municipal service was highly stressful for next of kin, because of the increasing care needs of the relative with dementia.

Conclusion

The overall conclusion is that FDC for people with dementia contributed to the next of kin's experiences of support and respite at a time during the course of the dementia before their relatives' needs had progressed beyond those that could be met within the FDC service. The findings in the three studies can contribute to the development of respite services for next of kin and people with dementia based on the principles of a person-centred care approach. Elements from FDC can be beneficial in other types of respite services. Our findings underscore the importance of maintaining a close dialogue with the FDC and with healthcare professionals throughout the course of the dementia. A timely plan for the transition from FDC to another service may prevent unplanned transitions, an increased burden and stress for the next of kin and the persons with dementia.

The FDC staff and the municipality healthcare system should aim to provide such support and, thereby, strengthen next of kin's ability to cope with their roles as caregivers without risking their health. In addition, FDC may potentially be improved by increasing scheduling flexibility regarding hours of attendance and number of days offered per week.

List of papers

Paper I: Taranrød, L., Eriksen, S., Pedersen, I., & Kirkevold, Ø. (2020). Characteristics, Burden of Care and Quality of Life of Next of Kin of People with Dementia Attending Farm-Based Daycare in Norway: A Descriptive Cross-Sectional Study *Journal of Multidisciplinary Healthcare*, 13 1363–1373

Paper II: Taranrød, L. B., Pedersen, I., Kirkevold, Ø., & Eriksen, S. (2021). Being sheltered from a demanding everyday life: experiences of the next of kin to people with dementia attending farm-based daycare. *International Journal of Qualitative Studies on Health and Well-being*, 16(1), 1959497.
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Paper III: Taranrød, L. B., Kirkevold, Ø., Pedersen, I., & Eriksen, S. (2023). The transition of care from farm-based daycare for people with dementia: The perspective of next of kin. *International Journal of Qualitative Studies on Health and Well-being* Accepted for publication 18 June 2023.

Abbreviations

ADL	Activities of day living
CDR	Clinical dementia rating
CDR-SOB	Clinical dementia rating sum sum-of-boxes
FDC	Farm-based daycare
GP	General Practitioner
HAD-A	Hospital Anxiety and Depression
ICC	Intraclass correlation coefficient
ICD-10	International Statistical Classification of Diseases and Related Health Problems, 10th revision, 5th edition
IADL	Instrumental activity of daily living
NPI -12	Neuropsychiatric symptoms inventory
NPS	Neuropsychiatric symptoms
NSD	Norwegian Centre for Research Data
MADRS	Montgomery Åsberg Depression Rating Scale
OSS-3	Oslo Social Support Scale
PSMS	Physical Self-Maintaining Scale
PWD	People with dementia only in figure 1
RSS	Relative Stress Scale
QoL	Quality of life
QoL-AD	Quality of life in Alzheimer's disease
WHO	World Health Organisation
WP	Work package

1 Introduction

This thesis is about the next of kin of people with dementia attending farm-based daycare (FDC). Dementia is considered one of the greatest global challenges for health and care systems in this century and affects people with dementia and their next of kin (Livingston et al., 2017; World Health Organization [WHO], 2012). Caring for a person with dementia can be a long-term commitment due to disease progression, which can continue for several years (Alzheimer's Association, 2021; Ornstein et al., 2019). This implies a continuing process of several years for the next of kin as caregiver, and as dementia symptoms increase in severity, the amount of time for caregiving increases.

Being a next of kin caring for a person with dementia is associated with burden of care; reduced physical, mental, and social health and well-being; and financial challenges related to care tasks (Adelman et al., 2014; del-Pino-Casado et al., 2018; Prince et al., 2015). However, research also reveals that next of kin have positive experiences caring for a person with dementia that may include a sense of personal accomplishment and gratification, feelings of mutuality in a dyadic relationship and an increase in family cohesion (Yu et al., 2018; Zarit, 2012).

Internationally as well as in Norway, the standard policy is that people with dementia should continue living in their own homes for as long as possible, with support from health and care systems in the municipalities and next of kin (Norwegian Ministry of Health and Care Services, 2015, 2018; WHO, 2017). This requires good quality services for those with dementia and their the next of kin. During recent decades, the Norwegian government has focussed on the development of services for people with dementia and their next of kin; one of these is daycare (Norwegian Ministry of Health and Care Services, 2007, 2015, 2020a). Daycare services facilitated for people with dementia have the goal of offering meaningful activities for this population that enhance their quality of life and contribute to respite and support for their caregivers (Norwegian Ministry of Health and Care Services, 2015, 2020a; Tretteteig et al., 2016). Norway's municipalities are obliged to provide necessary support such as respite, training, and guidance for next of kin (Helse og omsorgstjenesteloven, 2011, § 3-6).

To meet the various needs of people with dementia, the Norwegian Dementia Plans 2015, 2020 and 2025 emphasize the importance of offering different kinds of daycare services (Norwegian Ministry of Health and Care Services, 2007, 2015, 2020a). Farm-based daycare (FDC) for people with dementia has been established as one type, with a purpose similar to that of other types of daycares and offering support and respite for next of kin (Ibsen et al., 2018; Norwegian Ministry of Health and Care Services, 2015). However, knowledge about the next of kin and their experiences with FDC is limited and insufficient (Eriksen et al., 2019). Therefore, the programme *Farm-based daycare services for people with dementia: quality development through interdisciplinary collaboration* was developed to explore this service from several perspectives (Eriksen et al., 2019). The main objective of the present thesis was to gain knowledge about the next of kin of people with dementia attending an FDC in Norway and their experiences with the service.

2 Background

2.1 Dementia and caregiving

2.1.1 *The dementia syndrome and prevalence*

Dementia is described as a syndrome, usually of a chronic progressive nature, caused by various diseases. Among the population of older people, the most common degenerative type of dementia is Alzheimer's disease, which contributes to approximately 60–70% of cases. This is followed by vascular conditions, then Lewy body dementia, frontotemporal dementia, and Parkinson's disease (Gale et al., 2018; Hou et al., 2019; WHO, 2021). Several forms of brain damage that are secondary to other conditions, e.g. chronic alcohol abuse, infections and traumatic brain injury, can also lead to dementia (Gale et al., 2018). Dementia diseases are described and classified in different international statistical classifications of diseases. In Norway, the *International Statistical Classification of Diseases and Related Health Problems*, 10th revision, 5th edition, (ICD-10) is used:

Dementia (F00–F03) is a syndrome due to disease of the brain, usually of a chronic or progressive nature, in which there is disturbance of multiple higher cortical functions, including memory, thinking, orientation, comprehension, calculation, learning capacity, language and judgement. Consciousness is not clouded. The impairments of cognitive function are commonly accompanied, and occasionally preceded, by deterioration in emotional control, social behaviour, or motivation. This syndrome occurs in Alzheimer disease, in cerebrovascular disease, and in other conditions primarily or secondarily affecting the brain. (WHO, 2016)

The development of most neurodegenerative diseases, including dementia, is closely linked to ageing processes (Hou et al., 2019). The *Dementia prevention, intervention, and care: 2020 report of the Lancet Commission* listed 12 modifiable risk factors: 'minor education, hypertension, hearing impairment, smoking, obesity, depression, physical inactivity, diabetes, and low social contact (...), excessive alcohol consumption, traumatic brain injury, and air pollution' (Livingston et al., 2020, p. 413). In total, these risk factors account for

about 40% of dementia cases worldwide that, theoretically, may have been prevented or delayed (Livingston et al., 2020).

Dementia affects functions such as memory, thinking, orientation, comprehension, calculation, learning capacity, language, and judgement as well as changes in mood, emotional control, behaviour and motivation that influence function and interfere with daily life (Gale et al., 2018). The loss of function depends on the location of the brain damage and the progression rate, and symptoms vary among individuals (Gale et al., 2018). The dementia syndrome is characterized by a decline in cognitive capacity, behavioural changes, and decreased ability to manage everyday activities, and most people with dementia develop some type of neuropsychiatric symptoms (NPS) during the course of dementia. NPS include psychiatric symptoms, e.g. hallucinations, delusions, euphoria, anxiety and depression, and behavioural symptoms such as disinhibition, aberrant motor behaviour, appetite disorder, irritability, sleep disorder, aggression, and apathy (Radue et al., 2019). Studies conducted among home-dwelling people with dementia have found that 71–97% have at least one NPS (Steinberg et al., 2008; Wergeland et al., 2014). The most common NPS are anxiety, depression, apathy, irritability, and agitation (Borsje et al., 2018; Steinberg et al., 2008; Wergeland et al., 2014). NPS negatively affect quality of life (QoL) for both the person with dementia and the next of kin, and they may lead to the use of psychotropic drugs as well as increasing the risk of early institutionalization (Borsje et al., 2018). As dementia symptoms progress, the person with dementia will be more dependent on support and help from next of kin and healthcare services to manage daily life (Engedal & Haugen, 2018). Worldwide, about 55 million people are believed to have dementia, and this number is expected to nearly triple by 2050 (WHO, 2021). In Norway, the total number of people with dementia was estimated to be about 100,000 in 2020 and is expected to increase to 240,000 by 2050 (Gjøra et al., 2021).

2.1.2 Next of kin of people with dementia

To care for each other as family or friends is often a mutual obligation based on a shared relationship. Giving care to someone is an extension of that relationship and an expression of caring about that person. In this way, care and caregiving are embedded in any close relationship and present in all relations where people attempt to protect or enhance each other's well-being (Pearlin, 2010). In some cases, however, the care changes from the ordinary exchange of caring between people to a particular and unequally distributed burden. In a relationship where one person develops dementia and becomes dependent on the other, the relationship and roles will be affected (Alzheimer's Association, 2022).

Greenwood and Smith (2019) described three main reasons for next of kin to care for a family member with dementia: (i) a desire to keep the family member or friend at home, (ii) proximity in the relationship to the person with dementia, and (iii) the next of kin's perceived obligation to the person with dementia. Reasons including reciprocity, a sense of duty, loyalty, obligation, commitment, love, social pressure and responsibility are all assumed to be motivations for becoming a caregiver to a person with dementia (Brodaty & Donkin, 2009; Greenwood & Smith, 2019). Norway's Patient and User Rights Act, section 1-3 b (1999), defines the closest next of kin as:

(...) the person whom the patient names as his or her kin or next of kin. If the patient is incapable of naming his or her next of kin, the next of kin shall be the person who to the greatest extent has had lasting and continuous contact with the patient, based however on the following order: spouse, registered partner, persons who live with the patient in a relationship resembling a marriage or partnership, children of full legal age and legal capacity, parents or other persons with parental responsibility, siblings of full legal age and legal capacity, grandparents, other family members who are close to the patient, guardian or provisional guardian. (Pasient- og brukerrettighetsloven, 1999, § 1-3)

Most next of kin who take on the responsibilities of caring for people with dementia are close family members such as spouses/partners, children, or children-in-law, and most are women (Brodaty & Donkin, 2009; WHO, 2021).

A Norwegian study of next of kin caring for people with dementia found that most (67%) were children of people with dementia or spouses (21%). About 60% of the next of kin were women and about 27% were living with the person with dementia (Ydstebø et al., 2020). In Norway, 90% of people with dementia receive help from a close next of kin (Vossius et al., 2015). The Norwegian Health Association has estimated that at least 400,000 people in Norway are close next of kin to a person suffering from dementia (Norwegian Health Association, 2021). Approximately 70,000 of the 100,000 people with dementia in 2020 lived in their own homes, and an estimated 30,000 lived alone (Gjøra et al., 2021; Sommerfeldt, 2021; Vislapuu et al., 2021).

According to Brodaty and Donkin (2009), next of kin caring for a person with dementia are involved in providing 'hands-on' care, e.g. dressing, toilet visits, meal preparation and eating, personal hygiene and supporting people with dementia or organizing care delivered by others. Spouses tend to be more hands-on, while adult children and other close next of kin tend to organize care delivery or act as care managers (Brodaty & Donkin, 2009).

Being a next of kin caring for a person with dementia is associated with both positive and negative experiences (Adelman et al., 2014; del-Pino-Casado et al., 2018; Prince et al., 2015; Yu et al., 2018; Zarit, 2012). Studies comparing caregivers of people with dementia with caregivers of people with other disabilities but without dementia have found that those who provide care to people with dementia report a greater burden and more strain, depression, and financial difficulty, as well as relationship complications and less time to participate in social activities (Nordtug & Holen, 2011; Ory et al., 1999; Riffin et al., 2017; Wolff et al., 2016). In general, next of kin of people with dementia report poorer global health and take more medications for mental and physical problems than non-caregivers (Alzheimer's Association, 2022; Bremer et al., 2015). Experiences of stress over time may increase levels of the biomarker cortisol. Cortisol contributes to the development of impaired cognitive function; however, the exact underlying relationship between next of kin providing dementia care and stress and ill health remains unclear (McAuliffe et al., 2021; von Känel et al., 2012). Further, caregivers for persons with dementia appear to use more healthcare services than non-caregivers (Rahman et al., 2019).

According to the Alzheimer's Association (2021), 57% of next of kin who were working in the previous year and providing care to a person with dementia reported that they sometimes needed to arrive at work late or leave early, compared to 47% of next of kin caring for persons without dementia. Moreover, 18% of next of kin caring for a person with dementia reduced their work hours due to caregiving responsibilities, compared to 13% of next of kin caring for persons without dementia (Alzheimer's Association, 2021).

2.1.3 Positive experiences of caregiving

Even though caring for people with dementia is often associated with burden, next of kin also report positive experiences of being a caregiver. Moreover, experiences of burden are not necessarily obstacles to positive experiences; both are possible (Lawton et al., 1991; Yu et al., 2018). In recent years, the importance of investigating and describing caregiving's positive aspects has been a focus of research. In an integrative review, Yu et al. (2018) described positive experiences or gains as perceived benefits of the care role or ways that care positively influences the caregiver's life. Positive experiences are considered to have protective health effects on close next of kin. According to these authors, positive aspects of care such as feelings of mutuality in the relationship with the person with dementia, a sense of increased unity in the family, as well as experiences of personal growth, mastery, and purpose in life (Yu et al., 2018). Positive caregiving experiences are more likely to occur when the next of kin experiences personal and social affirmation in the caring role and when he or she has effective cognitive-emotional regulation and is in a context where they find meaning in the caregiving experience (Yu et al., 2018). Both experiences, i.e. burdens and positive aspects of caring, may also influence QoL (Chappell & Reid, 2002).

2.1.4 Loss and grief

As dementia symptoms progress, not only will the person with dementia become increasingly dependent but also the next of kin will have to cope with the interpersonal loss of a likely meaningful relationship. This experience of loss is described as burdensome for the next of kin and influences the quality of the relationship. It may also occur because of loss of communication, social interaction, health status and opportunities to resolve issues from the past (Givens et al., 2011; Noyes et al., 2010). Grief is a normal emotional reaction in response to actual or perceived loss (Chan et al., 2013). In the context of caregiving to persons with dementia, grief is a unique experience for the next of kin because it occurs and

continues throughout the course of dementia in response to prolonged losses and before the death of the person with dementia (Arruda & Paun, 2017; Noyes et al., 2010). This kind of grief is described in the literature as anticipatory grief or predeath grief (Givens et al., 2011; Liew et al., 2019; Wilson et al., 2017). According to Liew et al. (2018), findings in their multivariate analyses of burden and predeath grief revealed that there were three shared risk factors: the later stage of dementia, NPS of the person with dementia, and the primary caregiving role. The authors also identified three risk factors that were unique for predeath grief: (i) younger age of the person with dementia, (ii) lower educational level of the next of kin, and (iii) being a spousal caregiver. Boss (2016) used the term *ambiguous losses* when a person is physically present but psychologically absent at the same time.

Meuser and Marwit (2001) described feelings of grief related to the next of kin's perceived personal sacrifice and adverse influence on her or his social and family life including social isolation and a decrease in perceived social support. The grief reactions are not constant but fluctuate over time, and they are influenced by the stage of dementia and may be determined by the next of kin's relationship to the person with dementia. Uncertainty about the future, anger, frustration and guilt are factors that contribute to the next of kin's grief (Chan et al., 2013). Spouses, in particular, may experience a sense of loneliness that is exacerbated by the loss of their companion and, for partners, a loss of their identity as a couple (Meuser & Marwit, 2001; Noyes et al., 2010).

2.1.5 Social support

Socially supportive relationships with others are considered, in general, to be important for maintaining mental health and reducing the risk for depression and anxiety (Bøen et al., 2012; Turner & Brown, 2009). Furthermore, social support is a significant factor in how next of kin may master the role of caregiver (Snyder et al., 2015). Social support refers to material and emotional resources that are available to a person through his or her interpersonal contacts (Turner & Brown, 2009) and how these can benefit a person's ability to cope with stressful situations (Cohen, 2004). It is reported to be a factor that may moderate the effects of caregiving such as depression or psychological distress and increase the next of kin's sense of personal competence as well as her or his QoL (Finfgeld-Connett, 2005; Pearlin et al., 1990). Factors such as gender, socioeconomic status and marital status may affect the availability of social support. The degree to which social support affects a

caregiver's mental health or mediates the effects of stress varies across different social status groups of the population (Turner & Brown, 2009). It is also likely that an individual's personality and mental health status influence his or her perception of social support (Turner & Brown, 2009), as well as those available to offer support in the caregiver's social network and whom the caregiver wants to approach for support in a stressful situation, e.g. caregiving for someone with dementia.

Among researchers, there is agreement on describing social support as encompassing two broad domains: functional and structural support (Kocalevent et al., 2018; Lett et al., 2009; Schwarzer & Knoll, 2007). Structural support refers to the size of one's network, the existence of relationships and the frequency of contact within the network (Grav et al., 2012; Lett et al., 2009). Functional support refers to the experience or expectation of receiving support from family, friends, or neighbours when it is needed (Grav et al., 2012; Kocalevent et al., 2018). Functional support includes emotional support in the sense of being appreciated or valued and instrumental support as practical assistance and/or information that helps a person to cope with or to evaluate a situation (Grav et al., 2012). Schwarzer and Knoll (2007) distinguished between received support and perceived support. In general, perceived social support is regarded as beneficial in the context of being able to cope with mental health challenges (Moak & Agrawal, 2010). In a meta-analysis of the connection between social support and subjective burden in caregivers, del-Pino-Casado et al. (2018) concluded that this depended on whether the social support was measured as perceived or received. Perceived social support had a greater effect on subjective burden than did received social support. The authors also stated that perceived social support may be a good predictor of subjective burden (del-Pino-Casado et al., 2018). For the studies in this thesis, the next of kin's perceived support is measured using a self-reported scale (Oslo Social Support Scale (OSS-3) (Dalgard et al., 2006).

2.1.6 Transitions in the course of dementia

The next of kin's experiences of transitions can be seen through the lens of Afram Meleis's transition theory (Meleis, 2015), developed over the last forty years through clinical research and theoretical work (Chick & Meleis, 1986; Meleis, 2015; Meleis et al., 2010; Meleis et al., 2000). The transition theory provides a framework within the nursing and healthcare fields, 'to describe the experience of individuals who are confronting, living with, or coping with an

event, a situation, or a stage in growth and development that requires new skills, sentiments, goals, behaviours, or functions' (Meleis, 2015, p. 363). Click and Meleis (1986) defined transition as 'a passage from one life phase, condition, or status to another' (p. 239). Transitions experienced by the next of kin of people with dementia include the dementia diagnosis, healthcare considerations, financial concerns, managing the many different symptoms of dementia, such as neuropsychiatric symptoms, reduced cognitive ability and changes in the activities of daily life. They will also experience changes in care settings and preparing for nursing home admission (Rose & Lopez, 2012). The next of kin who care for relatives with dementia over time often experience an increased burden of care, impaired physical and mental health, sleep disturbances, reduced social well-being and financial strains (Adelman et al., 2014; del-Pino-Casado et al., 2018) (described in section 2.2.5). At a certain point, many caregivers become unable to sufficiently meet the needs of their relatives with dementia, and a shift in care services or admission to a nursing home becomes unavoidable. In this period, the next of kin strive to balance the care needed by the person with dementia and their own needs to care for themselves, and they especially require help and support from the healthcare system during this time (Black et al., 2013; Larsen et al., 2020;). Having strong formal and informal social networks available in transition periods could play a significant role in promoting positive health outcomes for the next of kin and positively affect the health of the care recipient (Davies, 2005).

A transition is associated with change, takes place over time, and may comprise a shift in how a person perceives their identity, various roles, health status, abilities, and relationships (Meleis, 2015). Click and Meleis (1986) describe the transition theory as a complex and multifaceted concept embracing several components, such as *change triggers*, *properties of transitions*, *condition of change* and *patterns of responses of transition*.

Change triggers

Click and Meleis (1986) describe four types of situations that trigger a transition experience characterized by some type of change. Change is related to an external event, while transition is an internal process. The first two sets of triggers are *developmental transitions*, exemplified by life phases such as changes in age or roles (e.g., adolescence, parenthood, retirement, mothering, fathering, marrying, divorcing) and *organizational transitions*, linked to organizational rules and functioning (e.g., changes in structure or dynamics) (Schumacher

& Meleis, 1994). The third trigger is *situational*, which is linked to a change in professional role, widowhood or nursing home placement. The next of kin's transitions into caregiving role are considered a *situational* transition, caused by changes in the health of the person with dementia. This creates a process of transition for the next of kin during which time they are more vulnerable to risks, such as caregiver distress (Meleis et al., 2000; Peacock et al., 2017). A transition constitutes a period of instability and uncertainty that represents a passage from one state to another. There are indications that individuals may be more vulnerable to health risks during periods of transition, but interventions can facilitate positive transitions and thus reduce negative health outcomes (Bohner, 2017; Meleis et al., 2000). The fourth trigger described in the theory is a change in the *health or illness* situation, of which a diagnosis of dementia or another condition is an example.

Properties of transitions

Click and Meleis (1986) pointed out that transitions are characterized by five properties. The first, *time span*, begins from the moment an event or a situation comes to the awareness of an individual. For the next of kin to people with dementia, this could be the first symptom of dementia (Lee et al., 2019). The second property that defines transition is *process*. The beginning and end of this process will differ for each next of kin. Third, *disconnectedness* 'reflects a disruption in a person's feeling of security associated with what is known and familiar' (Meleis, 2015, p. 365). *Awareness* is the fourth property of transition. The next of kin become aware that changes are underway in a person's perception, knowledge and recognition of the transition. A shift in awareness may result in periods of instability or distress in which the person is at risk of making unhealthy decisions. On the other hand, awareness could generate active engagement in the process of transitioning, e.g., the next of kin searches for information, prepares for the process, and makes preventive changes (Meleis, 2015). The final property is *milestones*. These can be turning points in the transition experience and are important to identify and understand so as to be able to facilitate appropriate interventions.

Conditions of change

Change triggers initiate a process of response that may be either functional or dysfunctional (Meleis, 2015). A person's experiences of change triggers are influenced by personal, community, societal or global conditions, as well as the person's experience of meaning,

values attributed to the change and the context. Furthermore, the level of knowledge, skills and beliefs related to the change will influence the transition experience (Meleis, 2015).

Patterns of responses of transition

Transitions can also be described as patterns, which can be '*single, sequential, multiple, or simultaneous*' and may occur within a given period (Schumacher et al., 1999, p. 4). The patterns can be related or unrelated. The outcome of a successful transition can be determined, for example, by the next of kin's ability to master life events and reach a state of well-being (Schumacher et al., 1999; Schumacher & Meleis, 1994). Health or social care staff can play an important role in facilitating healthy transitions by recognizing critical points and changes and supporting the next of kin in the transition process (Aspö et al., 2023).

2.2 Quality of life and burden of care

Caring for a person with dementia may affect the next of kin's life in many ways as described above. These next of kin are at risk for caregiving to negatively affect their own QoL and exacerbate their experiences of burden through the course of dementia. A number of different factors may influence their experiences of QoL and burden of care. In this section, the focus is on these two important issues.

2.2.1 Quality of life

The term *quality of life* or QoL was introduced in the 1960s in the medical literature and has been used increasingly in recent decades (Post, 2014). QoL refers to a person's feelings of satisfaction, experiences of meaning and sense of belonging and engagement in life, and it is often used to measure the effects or evaluation of medical treatments, interventions and health and care services (Brown et al., 2019). Through advances in medicine, public health and living standards in the past decades, researchers and government policymakers have focused on measuring QoL in different patient or caregiver groups as well as in Norway's general population (Haraldstad et al., 2019; Nes et al., 2018). Politically, there has been recognition that knowledge about a population's QoL can help politicians and authorities to develop a healthier and more equitable society. Therefore, measuring QoL has become an important political goal, and the population's quality of life is considered one of Norway's most significant resources. In addition, QoL is negatively related to negative emotions and

positively related to happiness and well-being (Nes et al., 2018). The term *well-being* also refers to perceived QoL and satisfaction with life (Taylor, 2015). Distinguishing between the two terms can be difficult; therefore, they are often used interchangeably (Nes et al., 2018; Taylor, 2015).

There is no uniform definition of QoL. However, WHO has outlined one as: ‘(...) an individual’s perception of their position in life in the context of the culture and value systems in which they live and in relation to their goals, expectations, standards, and concerns’ (WHO, 1995, p. 1405). Further, QoL incorporates the person’s physical health, psychological state, level of independence, social relationships, and personal beliefs and their relationship to salient features of the environment. The definition highlights QoL as being subjective and including both positive and negative aspects as well as being multidimensional (WHO, 1995). According to Lawton (1997), QoL incorporates objective and subjective factors related to generalized psychological well-being, behavioural competence, and one’s environment, with self-perception as a main component. In this thesis, QoL is described in the context of next of kin serving as caregivers for persons with dementia.

2.2.2 Quality of life of next of kin caring for people with dementia

The literature demonstrates that next of kin’s experiences of reduced QoL are associated with reduced QoL of the person with dementia (Bruvik et al., 2012), the next of kin’s advanced age (Oliveira et al., 2015) and higher economic costs (Prince et al., 2015). A systematic review described that better physical and mental health in next of kin were strongly associated with their higher QoL (Farina et al., 2017). Furthermore, when next of kin had possibilities to participate in activities without caregiving duties, this was positively associated with better QoL (Farina et al., 2017).

The fact that next of kin of persons with dementia are at high risk for depression and burden of care may explain their reduced QoL. According to Contreras et al. (2021), these factors are critical predictors of caregivers’ QoL. Furthermore, several additional factors may impact QoL, including the health of the next of kin, their sleep habits, the QoL of the person with dementia and the next of kin’s ability to access respite and social support. The quality of the relationship with the person with dementia also influences the next of kin’s QoL

(Andren & Elmstahl, 2007; Vellone et al., 2012). When comparing the QoL of next of kin living with a person with dementia with that of next of kin who do not live with the person with dementia, the caregiver living with a person who has dementia reported lower QoL (Bruvik et al., 2012; Santos et al., 2014).

Other factors that have a negative impact on the next of kin's QoL are increased time devoted to caregiving, stress, and worrying about the future (Bruvik et al., 2012; Vellone et al., 2008). The presence of a high degree of negative emotion in the relationship between the next of kin and the person with dementia is also associated with reduced QoL (Bjørge, 2018). Dyads with good relationships seem to report better QoL and to demonstrate greater flexibility in their problem-solving strategies compared to those who are less adaptable (Braun et al., 2009; Ulstein, 2017).

Two systematic reviews have identified a clear link between NPS, reduced function in activities of daily living (ADL) and cognition in persons with dementia, and reduced QoL in next of kin (Contreras et al., 2021; Farina et al., 2017). Apathy, as an NPS, has been associated with reduced QoL in spouses of persons with dementia mediated by the deterioration of the marital relationship (De Vugt et al., 2003). Furthermore, Vellone et al. (2008) argued that the comorbidities and disease progression of those with dementia were associated with reduced QoL for their next of kin. Several studies found little or no association between the severity of cognitive impairment of the person with dementia and the next of kin's QoL (Bruvik et al., 2012; Nogueira et al., 2015; Santos et al., 2014). By contrast, functional impairment of the person with dementia was often reported as being negatively associated with the next of kin's QoL; thus, the relationship between these factors is unclear (Bruvik et al., 2012; Nogueira et al., 2015; Serrano-Aguilar et al., 2006). Factors such as age and educational level of the person with dementia appeared to be unrelated to the next of kin's QoL (Bruvik et al., 2012; Santos et al., 2014).

2.2.3 Measuring QoL in caregivers

Quality of life is a term frequently used in the literature, yet there is a lack of consensus on the most suitable scale(s) to best assess QoL in next of kin caring for people with dementia (Dow et al., 2018; Jones et al., 2012; Page et al., 2017). In general, the most used QoL assessment scales are the 36-Item Short Form Health Survey (SF-36), the World Health

Organization Quality of Life assessment (WHOQOL) and the EuroQoL (EQ-5D) (Contreras et al., 2021; Jones et al., 2012). According to Dow et al. (2018), these types of assessment scales have been criticized for lacking validity and for not being sufficiently sensitive to measure the psychological consequences and positive aspects of caregiving to people with dementia. In their review, Page et al. (2017) emphasized that it is important to develop robust, disease-specific measures of caregivers' QoL. In the present study, the Norwegian version of the Quality of Life in Alzheimer's disease (QoL-AD) scale, a measure of self-rated QoL (Logsdon et al., 1999), was used. The QoL-AD was originally designed to measure QoL in people with Alzheimer's disease. The scale is described in section 5.1.3 *Measures*. For several Norwegian studies, however, the QoL-AD has been used to measure not only the QoL of persons with dementia but also that of their next of kin (Bruvik et al., 2012; Hvidsten et al., 2020; Rokstad et al., 2014; Rosness et al., 2011).

2.2.4 *Burden of care*

Next of kin who care for persons with dementia face many challenges and obstacles throughout the course of the disease due to its progressive character, its generally long duration, and the lack of curative treatment. Dementia also has impacts on the cognitive and practical functions of people with the disease, which in turn increases their dependence on others. As a result, next of kin may observe the reduced and/or diminishing judgement and orientation skills of their relatives in the middle and later stages of dementia, as well as their reduced ability to understand and communicate effectively (Chiao et al., 2015). All of those changes mean that persons with dementia increasingly require practical and emotional support in their daily lives, typically provided by their next of kin as well as healthcare services. To describe the stressful situation experienced by the next of kin of people with dementia, words such as *burden*, *strain*, *stress* and *distress* often appear in the literature (Donaldson et al., 1997; Mahoney et al., 2005). Among them *distress* refers to the emotional component of burden and includes worries, uneasiness, and concern.

Burden of care refers to a multidimensional concept including *subjective* and *objective elements*, describing how caregiving impacts the mental, physical, social and financial strain commonly experienced by next of kin of people with dementia (George & Gwyther, 1986; Zarit et al., 1986). Within burden of care, the *subjective elements* refer to the next of kin's emotional or mental reaction to the caregiving situation as one that causes fatigue, feelings

of being trapped, depression and/or anxiety (Wolfs et al., 2012; Zarit et al., 1986). By contrast, *the objective elements* primarily capture concrete problems resulting from providing daily care in light of the characteristics of the person with dementia, including the amount of time that the next of kin has to devote to caregiving. It also reflects the care responsibility assumed by the next of kin (Hughes et al., 2014). Considering those elements, other factors and resources can act as mediators of burden. Examples of mediators are social support, formal and informal help, knowledge about dementia and adequate coping strategies (Pearlin et al., 1990; Vedhara et al., 2000). The next of kin's pre-morbid level of satisfaction with their relationship with the person with dementia affects their experience of burden. A high level of pre-morbid satisfaction is associated with less burden, a better ability to solve problems, less reactivity to dementia-related problems and better communication (Steadman et al., 2007).

The family is considered to be the closest, most influential interpersonal context throughout life and thus affects the next of kin's stress processes (Mitrani et al., 2006). The definition of *family* can vary substantially depending on the theoretical perspective taken (Brown, 1990). Maurović et al. (2020) have thus formulated a pragmatic definition of *family* as 'at least two or more people who interact in a relationship that they define as familial' (p.2).

The complex dynamics of different family structures in different societies have been extensively studied, which has resulted in the development of several different theories of. The most referenced theories are *structural family theory* developed by Salvador Minuchin in the early 1970s (Mitrani et al. 2006) and *family system theory* developed by Murray Bowen in 1974 (Brown, 1999). Both theories were developed in the context of family therapy (Baroncelli et al., 2022; Brown, 1999). On the one hand, *structural family theory* views families as structures in which family members interact across several dimensions, including while handling disagreements and distance or closeness (Mitrani et al., 2006). On the other, *family systems theory* explains how family's function and how family members interact with each other (Brown, 1999). In both theories, is how family members interact play a role of experiences of stress (Brown, 1999 Mitrani et al., 2006).

2.2.5 *The stress process model*

Stress process theory explains how stress affects individuals and families. The theory suggests that although stressors can negatively affect individuals and families, the effects can

be reduced by various means, including social support (Zarit & Whitlatch, 2022). Stress process theory has been applied in studies on caregiving, often as a theoretical framework for understanding the next of kin's burden of care (Brodaty & Donkin, 2009; Guay et al., 2017; Mitrani et al., 2006; Schlomann et al., 2021; Son et al., 2007).

Within stress process theory is the somewhat complex stress process model developed by Pearlin et al. (1990), the major elements of which are described briefly in this thesis. Pearlin et al.'s (1990) model theorises the next of kin's experiences as caregivers throughout the progression of dementia as well as how those experiences can influence their health and well-being. The next of kin's relationship with the care recipient is also affected as the symptoms of dementia intensify and the person with dementia becomes increasingly dependent.

The stress process model identifies four essential direct and indirect sources that affects the experiences of stress among caregivers: *background and context*, *stressors*, *mediators*, and *outcomes*. Those sources of stress interact with each other and create different conditions that cause stress. The first source, *background and context*, refers to factors that influence the caregiving situation, including the next of kin's health, personality and socioeconomic status. Other interpersonal factors also impact the caregiver situation, especially the next of kin's history and relationship with the person with dementia. That impact also stems from access to resources and networks, including formal services, which are available from municipalities.

The second source is *stressors*, defined by Pearlin et al., (1990) 'conditions, experiences, and activities that are problematic for people; that is, that threaten them, thwart their efforts, fatigue them, and defeat their dreams' (p. 286). In their model, the authors distinguish *primary stressors* from *secondary stressors* as circumstances that are problematic for the next of kin. On the one hand, *primary stressors* are associated with, for example, the cognitive status and NPS and ADL function of the person with dementia. On the other, *secondary stressors* emerge from the primary stressors and include the next of kin's experiences of role strain and intrapsychic role strain. Whereas role strain relates to the conflicts that the next of kin feels when other roles are affected (e.g. having to work outside home), intrapsychic strain mostly involves the dimensions of self-perception and related

psychological states. According to Pearlin et al. (1981) conditions of lasting strain, self-perceptions can be damaged. To that, Pearlin et al. (1990) have added the positive term '*competence and gain*' because some next of kin also experience feelings of personal growth, mastery and increased self-esteem, as well as positive change in their relationship with the person with dementia and a greater sense of meaning in the role of caregiver. Experiences of coping and social support are important mediators of those positive experiences.

Third, *mediators* in the stress process model refer to the ways in which the next of kin copes with situations as well as act and respond to care demands and experiences of social support. Social support incorporates both received and perceived support available to the next of kin. Fourth and finally, *outcomes* in the stress process model refer to different aspects of well-being, physical and mental health, along with the next of kin's ability to maintain the role of caregiver.

2.2.6 Burden of care: factors related to the person with dementia

The objective factors of the next of kin's burden are associated with the level of dependency of the person with dementia. In addition, NPS are considered the most important predictors of the burden of care together with decreased cognitive and ADL functions (Etters et al., 2008; Kim et al., 2021; Radue et al., 2019). According to Radue et al. (2019), NPS are most prevalent in the moderate stage of dementia; the symptoms are described as worrying and demanding for both the person with dementia and the next of kin, and they affect QoL for both caregiver and care recipient.

NPS such as agitation, aggression, hallucinations, and delusions can be especially distressing and dangerous for the person with dementia and the next of kin (Deardorff & Grossberg, 2019). A study conducted by Arthur et al. (2018) found that the presence of four or more NPS appears to be a tipping point for burden. The most common NPS were arguing, anxiety, restlessness, verbal aggression, refusal of care, agitation and waking and getting up at night. The authors strongly suggested increased levels of support for next of kin and those with dementia at greatest risk for NPS (Arthur et al., 2018).

A meta-analysis found that the burden of care for next of kin increases with the severity of the care recipient's dementia (Rodríguez-González & Rodríguez-Míguez, 2020). It also increases when the person's ability to perform ADL (Bergvall et al., 2011; Onishi et al., 2005; Poulshock & Deimling, 1984; van der Lee et al., 2014). Smith et al. (2014) found that next of kin providing more than 10 hours of care per week were more burdened than those who provided fewer hours each week. In general, living with a person who has dementia appears to be more burdensome than not living with a person who suffers from this disease (Kasper et al., 2015; Smith et al., 2014).

2.2.7 Burden of care: factors related to the next of kin

The subjective factors of burden of care refer to the next of kin's psychological responses to caregiving, e.g. distress, anxiety, depression, irritation and/or feelings of exhaustion (Lacey et al., 2018; Poulshock & Deimling, 1984). Studies have found that approximately 40% of next of kin who provide care for people with dementia have clinically significant depression or anxiety, while other next of kin have important but less severe psychological symptoms (Cooper et al., 2007; Mahoney et al., 2005). Armstrong et al. (2019) found that the burden was more prominent for spouses living with a person with dementia than for non-spouses; however, depressive symptoms were more prominent in non-spouses. Further, they claimed that the next of kin may experience reduced burden or fewer depressive symptoms over time as a result of adjusting to the functional status of the person with dementia (Armstrong et al., 2019). The manner in which the next of kin communicates with the person with dementia, for example, with impatience, irritation or in an angry way, may contribute to increased aggression in the person with dementia (de Vugt et al., 2004).

De Vugt et al. (2004) emphasized that the ability of the next of kin to provide care for a person with dementia depends largely on his or her ability to adequately adapt and respond to the NPS and the needs of the person. Nevertheless, next of kin differ regarding their strategies, and some caregivers cope more successfully than others. The next of kin's burden, depression and anxiety symptoms may also have a negative impact on the NPS of the person with dementia and may amplify these symptoms and increase the probability of early admission to a nursing home (Liang et al., 2016). Further, burden of care is associated with several other factors, e.g. being a woman, reduced physical and mental health, and level of support (Adelman et al., 2014; Armstrong et al., 2019; Brodaty & Donkin, 2009; Bruvik et

al., 2012; Campbell et al., 2008; Eppers et al., 2008; Pearlin et al., 1990). Mahoney et al. (2005) stated that poor quality of the relationship between a next of kin and a person with dementia was a predictor of the next of kin's experiences of anxiety and depression. Likewise, living with a person with dementia was found to be more likely to cause anxiety than depression (Mahoney et al., 2005). By contrast, the next of kin's resources, e.g. personality traits and feelings of competence, may act as mediators between the impact of the NPS of the person with dementia and burden of care, with the potential to promote mental health (van der Lee et al., 2014).

2.2.8 Measures of burden of care

For several decades, different scales have been used to describe the next of kin's experiences of the burden of care and to assess the burden (Van Durme et al., 2012). A literature review identified nearly 50 different scales for measuring the burden of care of the next of kin of people with dementia (Van Durme et al., 2012). Most of the scales are intended to measure the impact of caregiving on the next of kin's subjective aspects of health. In the present thesis, Green et al.'s (1982) Relative Stress Scale (RSS), a caregiver self-reported scale, was used. The scale covers different aspects of burden of care (Greene et al., 1982). The scale is frequently applied in research and clinical settings in Norway and internationally (Engedal et al., 2012; Ulstein et al., 2007a; Van Durme et al., 2012) and is described in greater detail in section 5.1.3.

3 Dementia care for home-dwelling people with dementia

3.1 Health policy and dementia

In Norway, health and social services are mainly a public responsibility and based on taxes and not on personal financial situation or health insurance. This means that citizens have access to the same level of healthcare and social services (Sandvin et al., 2020). The Norwegian government's healthcare strategy states that a person shall receive care/services in accordance with his/her care/service needs, meaning that services shall be allocated at the lowest effective level of care (Daatland et al., 2012; Norwegian Directorate of Health, 2016).

The regional healthcare trusts in Norway are responsible for the hospital specialist healthcare services. The municipalities have the responsibility for primary healthcare services such as general practitioners (GPs) and home care help (e.g. home nursing, home help and practical assistance with housework, meals on wheels, sheltered housing with available home care, and daycare services) as well as support and respite for next of kin (Norwegian Ministry of Health and Care Services, 2011). The municipalities are obligated to provide support and respite to next of kin according to the following guideline: 'with particularly burdensome care work, the municipalities shall offer the necessary support for next of kin, among other things in the form of: training and guidance, respite measures and care allowance' (Helse- og omsorgstjenesteloven, 2011 §3,6). To receive support and respite, the next of kin must apply, and the healthcare service in the municipalities will then assess her or his needs (Holm et al., 2017).

Norway's Dementia Plan 2025 is based on the experiences of the two previous Dementia Plans and has four main focus areas: 1) co-determination and participation, 2) prevention and public health, 3) good and coherent services and planning, and 4) competence and knowledge development (Norwegian Ministry of Health and Care Services, 2020a). The goal from a political perspective is for people with dementia to remain living at home as long as possible, ensuring a good quality of life for them and for their next of kin through, e.g., timely support, care services and respite, and by contributing to building a dementia-friendly society (Norwegian Ministry of Health and Care Services, 2015, 2020a, 2020b).

3.2 Daycare service in the Dementia Plans

Daycare service is described as a service for home-dwelling people with dementia and respite for the next of kin and was one of the main issues in the first action plan on dementia in Norway. Daycare service was described as a ‘missing link’ in the care chain between living at home and the need for a nursing home (Norwegian Ministry of Health and Care Services, 2007). Therefore, in 2007, the government initiated a *Three-year development programme for day programmes for persons with dementia 2007–2010* to gain more knowledge about different kinds of daycare services (Norwegian Ministry of Health and Care Services, 2007; Taranrød, 2011). A survey conducted in relation to this programme found that the most common locations for daycare services in Norway were in a healthcare institution or service centre for older adults, often referred to as regular daycare. At the time of the survey, there were few daycare services established on farms (FDC), and few ambulatory daycare services provided in the home of the person with dementia (Taranrød, 2011). In this thesis, the term daycare or daycare service is used when referring to daycare facilitated for people with dementia in general and not to a specific location.

According to the Dementia Plan 2015, all municipalities in Norway were expected to be able to offer organized daycare services for people with dementia when the plan was fully implemented in 2015 (Norwegian Ministry of Health and Care Services, 2007). As this goal was not achieved by 2015, the funding was extended to December 2019, giving the municipalities additional time to establish daycare services for people with dementia (Norwegian Directorate of Health, 2019). The number of municipalities offering daycare services and the number of people with dementia attending these services have increased from 2007 to 2018 (Table 1) (Norwegian Directorate of Health, 2019). Since 2020, all Norwegian municipalities have been obliged to offer daycare service for people with dementia (Lov om endringer i helse- og omsorgstenesteloven, 2019, § 3-2, no 7).

Table 1. Daycare services design for people with dementia in Norway (Norwegian Directorate of Health, 2019, p. 38)

	1996	2000	2004	2007	2010	2014	2018
Proportion of municipalities with daycare	18.2%	23.0%	24.0%	30.2%	43.7%	71.3%	87.8%
Number of municipalities with daycare	79	100	104	130	188	305	354
Total number of people with dementia attending daycare*	671	1377	1540	2351	3257	6318	7909

*The numbers are subject to some uncertainty; in particular, the reporting from the major cities, including Oslo, is uncertain. There is also a lack of information from several other municipalities. In addition, the question is worded differently in the different surveys.

3.3.1 Daycare services for people with dementia

In Norway, daycare services facilitated for people with dementia are a relatively new concept. The first description of such a service was in 1987 in Oslo. However, it was not until the early 2000s that the need for daycare services adapted specifically for people with dementia emerged as an area of focus in Norway (Norwegian Ministry of Health and Care Services, 2006).

The definition of daycare is not standardized (Maffioletti et al., 2019). Thus, daycare services vary with regard to the target group, location, organization and service contents (Maffioletti et al., 2019). In the literature, there is a shared notion that daycare services facilitated for people with dementia shall offer them opportunities to engage in meaningful activities in a safe setting to increase their quality of life. Further, daycare services shall promote social interaction, safety, and experiences of coping among the participants (Norwegian Ministry of Health and Care Services, 2007, 2015; Tretteteig, 2017).

3.3.2 Person-centred care

In the past two decades, person-centred care has been an important approach to dementia care. Person-centred care is based on the care philosophy of English psychologist Tom Kitwood, who introduced the concept of person-centred care in dementia care in the 1990s (Kitwood & Brooker, 2019). The approach is considered to be synonymous with good care and is based on Kitwood's philosophy of care (Brooker, 2013;). In Norway, the person-centred care approach has been referred to in formal documents and the Dementia

Guidelines and Dementia plans (Norwegian Directorate of Health, 2017; Norwegian Ministry of Health and Care Services, 2015, 2020a).

Central to Kitwood's philosophy of care is the term *personhood*, used to describe a person's value and defined as 'a standing or status that is bestowed upon one human being by others, in the context of relationship and social being' and that 'implies recognition, respect and trust' (Kitwood & Brooker, 2019, p. 7). Kitwood (1993) argues that impairments and limitations due to dementia do not diminish personhood. A person with dementia has the same basic psychological needs as any other person. From that perspective, a person-centred care approach can contribute to increasing the well-being of persons with dementia by ensuring that the care environment meets their psychological needs. By extension, Kitwood describes five basic psychological needs—*comfort, attachment, inclusion, occupation, and identity*—that overlap and coalesce into the central need for *love* (Kitwood & Brooker, 2019). First, in daycare services, the need for *comfort* can be met when both emotional and physical suffering is eased, and a feeling of safety is promoted. Second, the need for *attachment* can be met by reassuring people with dementia of their relationships with those close to them and reminding them of people who give them a feeling of security. Third, the need for *inclusion* among persons with dementia can be met by inviting them to participate in facilitated activities and social activities, further showing appreciation for their participation. Fourth, Kitwood describes *occupation* as being 'involved in the process of life in a way that is personally significant and which draws on a person's abilities and powers' (Kitwood & Brooker, 2019, p. 94). In other words, to be occupied, the person's resources need to be both revealed and used in the facilitated daily activities and in the social activities at the service. Fifth and finally, *identity* refers to knowing who one is both in cognition and feelings in a way that has continuity with the past and how one is perceived by others. Using their life stories can help the person with dementia in finding a feeling of continuity between the past and present (Kitwood & Brooker, 2019).

Dawn Brooker, whose work builds upon Kitwood's theory, has described person-centred care as having four major elements that together form an acronym, VIPS: '1) Valuing people with dementia and those who care for them (V). 2) Treating people as individuals (I). 3) Looking at the world from the perspective of the person with dementia (P). 4) A positive

social environment in which the person living with dementia can experience relative well-being (S)' (Brooker, 2004, p 216). Altogether, VIPS suggests that care needs to be arranged in ways that recognise the perspective of the person with dementia on their situation. How a person experiences a situation is characterised by personality, personal history, physical health, symptoms (e.g. of dementia) and social environment. If a person with dementia is viewed as being incapable and is judged in relation to their symptoms, then negative feelings can emerge, and the individual's personhood can be undermined. To unintentionally ignore, disempower and objectify people with dementia is what Kitwood terms *malignant social psychology* (Kitwood & Brooker, 2019).

Kitwood also describes *positive person work* (Kitwood & Brooker, 2019), a term referring to types of positive interactions that strengthen personhood in persons with dementia. To achieve positive person work, the healthcare staff (e.g., staff at day care services) must possess knowledge about dementia, how to provide person-centred care and how to interact with recipients of care with empathy and understanding (Norwegian Directorate of Health, 2017). A person-centred care approach emphasises that healthcare staff should value and respect the recipients' experiences and their perspectives, as well as encourage and facilitate activities that promote coping and social engagement (Brooker, 2013; Kitwood, 1997).

3.3.3 The influence of daycare services on people with dementia

Studies of the influence of daycare services on the health, function and QoL of people with dementia have found that daycare service might contribute to a reduced incidence of behaviour problems, less use of psychotropic drugs and a decreased burden of care on next of kin (Maffioletti et al., 2019; Reinar et al., 2011). However, the same studies were unable to determine whether daycare services influenced the level of functioning of people with dementia. A study by Rokstad et al. (2016) compared the self-reported QoL of persons with dementia attending a regular daycare service designed for people with dementia and people with dementia not attending daycare. The study revealed that those who attended regular daycare service had a significantly higher self-reported QoL. Interviews of people with dementia attending a regular daycare show that daycare provides a sense of structure and routine in their lives, promotes social relationships, and prevents social isolation (Strandenæs et al., 2018). Yet despite these positive findings, Strandenæs et al. (2019) emphasized that

regular daycare services have the potential to provide more activities that strengthen attendees both physically and cognitively.

Dröes et al. (2004) and Fields et al. (2014) claimed that attending daycare service can postpone the need for nursing home placement. However, Rokstad et al. (2018) compared people with dementia attending a regular daycare with non-users of daycare and found no evidence to confirm that regular daycare services postponed the need for nursing home admission. Rokstad et al. (2018) concluded that admission to a nursing home seems to be influenced by a complex mix of personal and functional characteristics of people with dementia and their next of kin.

3.3.4 Farm-based daycare services

Structural changes in Norway's agricultural sector have led to innovative ways of using resources on farms in addition to farming (Norwegian Ministry of Local Government and Regional Development and Ministry of Agriculture and Food, 2013). Farmers offer adapted and quality-based healthcare and welfare services using farm resources to promote health and well-being through engagement in farm activities (Hine et al., 2008; Pedersen et al., 2016). Different client groups attend services at farms, and clients are referred from the school system, the Norwegian Labour and Welfare Administration, or the healthcare system (Pedersen et al., 2016).

In Norway, there is a public system to certify farm-based daycare (FDC) through a quality system in agriculture. Stiftelsen NorskMat (earlier called Matmerk), an independent foundation 'that contributes to increased diversity, quality and value creation in Norwegian food production, approves farms for an 'Inn på tunet' certification (Matmerk, 2021). Certified farms offer activities that provide meaningful work and opportunities for mastery, development and well-being using animals in relation to therapy, working with gardening, and mastering specific tasks on the farm (Matmerk, 2021).

FDC is offered in several countries to different target groups (e.g. Germany, the United Kingdom, the United States, South Korea and Japan) (de Bruin et al., 2020). In Norway and in the Netherlands, FDCs are typically located on productive agricultural farms (Haubenhofner et al., 2010). In Europe, the Netherlands has the highest number of FDCs,

totalling about 1,100 farms aimed at different target groups (de Bruin et al., 2020). The number of FDCs for different target groups in Norway is somewhat uncertain. A report about trends in Norwegian agriculture estimated that there were about 1,000 FDCs for various target groups (described above) in Norway in 2018 (Zahl-Thanem et al., 2018).

3.3.5 Farm-based daycare for people with dementia

FDC for people with dementia is one example of healthcare service at private farms (Ibsen et al., 2018). The municipality has the responsibility for the funding and to ensure the quality of care at the FDC through a collaboration between the farmer and the municipality (Ibsen et al., 2018). People with dementia are a prioritized target group in the Norwegian action plan for care farming (Norwegian Ministry of Local Government and Regional Development and Ministry of Agriculture and Food, 2013). In the Dementia Plan 2015, the government expressed a desire to develop variation in the types and settings of daycare services for people with dementia, with one example being FDCs (Norwegian Ministry of Health and Care Services, 2007). FDC facilities for people with dementia have been offered since the early 2000s (Strandli et al., 2007).

Several national surveys of services for people with dementia in the municipalities show that the number of FDCs for people with dementia has increased from 10 in 2007 to 40 in 2014 (Eek & Kirkevold, 2011; Gjøra et al., 2015; Westerberg et al., 2009). The National Survey from 2018 does not specify the number of FDCs (Norwegian Directorate of Health, 2019).

Most Norwegian FDCs have people in an early stage of dementia or in early-onset dementia as their main target group (Ibsen et al., 2018). Ibsen et al. (2019) found that FDCs had a higher proportion of men, and the participants were younger, more often lived with a spouse/partner and had a higher educational level compared to the participants at regular daycare services. These findings are in line with a study comparing participants at FDCs and daycare services located in nursing homes in the Netherlands (de Bruin et al., 2012).

For people with dementia, FDC is a complementary service to regular daycare services (Ibsen et al., 2018). FDC and regular daycare facilitated for people with dementia in Norway have the same purpose and most often similarities in organization, daily structure, and as well as the number of healthcare personnel (Ibsen et al., 2018). The main difference between

FDCs and regular daycare services is the physical environment. FDCs use the farm's resources and its environment actively, for example, using farm activities as part of the service, whereby activities and collaboration between participants and staff are enabled (Ibsen et al., 2018; Solum Myren et al., 2017). Although FDCs and regular daycare services have different physical settings, many regular daycare services also have access to outdoor areas and possibilities to stage various outdoor activities (Taranrød, 2011; Tretteteig et al., 2017a).

The core components of the services offered at FDCs are being outdoors, being physically active, and interacting socially with people and animals (de Bruin et al., 2012; Ellingsen-Dalskau et al., 2021; Ibsen et al., 2018). Norwegian studies from the research programme *Farm-based daycare services for people with dementia: quality development through interdisciplinary collaboration 2016–2020* (described in section 4.3) indicated that people with dementia who have participated at FDCs have higher levels of physical activity and spend more time outdoors compared to participants in regular daycare services (Finnanger-Garshol et al., 2020). Attending FDC is also associated with more social interaction and more positive emotions among the participants (Ellingsen-Dalskau et al., 2021). Schols and van der Schriek-van Meel (2006) found that participating at an FDC may reduce NPS and the use of psychotropic drugs. De Bruin et al. (2011) found that food intake among FDC participants was higher compared with those who participated in regular daycare services. In addition, several studies that conducted interviews with people with dementia who attended FDCs revealed that they enjoy the social community and activities offered at the farm and that they felt useful (Ibsen & Eriksen, 2020; Sudmann & Børsheim, 2017).

3.5 Support and respite services for next of kin

To meet the various needs of people with dementia and their next of kin, the Norwegian government has, through its three Dementia Plans, emphasized the importance of offering different kinds of services (Norwegian Ministry of Health and Care Services, 2015, 2020a). Thus, all municipalities are obliged to offer a range of services to support the next of kin who are caring for *someone with demanding care needs*, such as those experienced by caregivers to people with dementia (Helse- og omsorgstjenesteloven, 2011).

Caregiver school (training) and courses (in Norwegian: Pårørendeskole) are measures designed to meet the next of kin's needs for information and knowledge about the dementia disease, its progression, and its effects. Caregiver school consists of lectures about dementia and group discussions, and its main purpose is to support next of kin who provide care to a person with dementia (Hotvedt, 2019). It also aims to contribute to the next of kin's learning about and coping with their caregiver role to the person with dementia (Hotvedt, 2019; Larsen et al., 2020). A national survey conducted in 2018 found that approximately 74% of the municipalities in Norway arranged caregiver schools or courses (Norwegian Directorate of Health, 2019).

Another important municipality measure designed to support people with dementia and their next of kin are multidisciplinary teams, often referred to as memory teams or dementia teams (Norwegian Directorate of Health, 2017). In the present thesis, the term *multidisciplinary team* is used to refer to this form of support. In some municipalities, complete teams have not yet been established, but most often they have one or more resource persons, often called dementia coordinators. These teams/coordinators have expertise in dementia and often assist GPs in the assessment and diagnosis of people suspected to have dementia. The multidisciplinary teams also provide important support and guidance to the next of kin to home-dwelling people with dementia (Norwegian Directorate of Health, 2017). Norway's national guidelines on dementia (2017) stated that the municipalities should have their own team(s) with expertise in dementia as part of their support services to those with dementia and their next of kin. In 2018, 90% of the municipalities had a multidisciplinary team (Norwegian Directorate of Health, 2019).

One goal of Norway's healthcare policy is for the public health service and informal care to complement each other. Accordingly, next of kin provide practical and emotional support to people with dementia, while more intensive care tasks are mainly the responsibility of the healthcare system. This combination should make it possible for people with dementia to live at home (Norwegian Ministry of Health and Care Services, 2013). The healthcare personnel in the municipality, in consultation with the next of kin, determine what services the municipality can offer. These may include guidance, training, respite, and other services for next of kin and for the person they are caring for (Table 2).

Table 2. An overview of several common support and respite services for next of kin in Norway

Services	Comments
Support, information, and guidance from the healthcare service in the municipality	The municipality is obliged to offer the next of kin support, information, and guidance (Helse- og omsorgsdepartementet, 2017, § 3-6). The healthcare service in the municipality, if the municipality has a multidisciplinary team or dementia coordinator, also provides support, information, and guidance (Norwegian Directorate of Health, 2019).
Education programmes, e.g. caregiver school/course	Often organized in collaboration with the municipality's healthcare service and voluntary organizations (often the Norwegian Health Association).
Respite Examples of respite services <ul style="list-style-type: none"> • daycare (in-home respite, regular daycare, FDC) • respite care at a nursing home • home help 	The municipality is obliged to offer a range of respite care services (Lov om endringer i helse- og omsorgstjenesteloven, 2017).
Economic support <ul style="list-style-type: none"> • care benefit 	No person has a statutory entitlement to a care benefit, but the municipality has a duty to offer this and must consider the care benefit to be the most appropriate way of providing services in each case (National Online Health Services in Norway, 2022).

The national government has strengthened the services offered to next of kin (and people with dementia) through several Dementia Plans and legislation during the past 15 years (Norwegian Ministry of Health and Care Services, 2007, 2015, 2020a). Despite these efforts, feedback from next of kin and organizations (e.g. Norwegian Health Association, Norwegian Alliance for Informal Carers) indicates that there is still room for improvement to support next of kin. Therefore, a new government document was presented in 2020, *We – the next of kin: A governmental next of kin strategy and action plan*, where two of the main objectives are ‘i) to recognize relatives as a resource, and ii) to provide good and comprehensive care of all next of kin so that they can live good lives of their own and combine the role of caregiving with education and work’ (Norwegian Ministry of Health and Care Services, 2020b, p. 9).

One of the overarching goals of the Dementia Plan 2025 is that people with dementia and their next of kin shall receive high-quality and personalized services. For next of kin, respite schemes, including daycare as respite care, are such a service (Norwegian Ministry of Health and Care Services, 2020a).

3.5.1 Respite

Next of kin often report always being ‘on duty’ and indicate that respite is a pressing need and that respite care interventions provide a temporary rest from caregiving while the person with dementia receives care in a safe environment (Alzheimer’s Association, 2021, 12 September).

Several models of respite services exist. These include respite in the home, residential respite, and different daycare services. The respite services may vary in terms of who provides the service, where it is provided (location), its duration and its frequency (Maayan et al., 2014). Respite services are considered a key formal supportive intervention to provide relief to next of kin in their caregiving role (Norwegian Ministry of Health and Care Services, 2007). Despite the positive development of respite care (daycare) in Norway, there are still challenges for next of kin and people with dementia because the respite service is not tailored to different individuals’ needs. Many next of kin explain that they do not receive sufficient information about respite services (Norwegian Ministry of Health and Care Services, 2020a; Vossius et al., 2015). In the literature, respite is described as a service intervention directed toward the next of kin and the person with dementia (Evans, 2013; Zarit et al., 2017).

One of the main aims of daycare for persons with dementia is to provide respite for next-of-kin caregivers. That aim is also true of the FDC described in this thesis (see Section 3.3.5). In the evaluation of the FDC, it is important to understand how, when, and why the services can give respite to caregivers and which factors are important or unimportant in determining when those programs do not give respite.

O’Shea et al. (2019) has developed a model that can be useful in determining those outcomes. The model builds on conceptual and empirical literature addressing respite that includes the perspectives of key stakeholders in dementia care across several health disciplines.

The authors have suggested that the term *respite* can also be explained as ‘a service that provides a physical break for the carer and as a psychological outcome, i.e. a mental break for the carer, which can be facilitated by formal services, under certain conditions’ (p. 1447).

O’Shea et al. (2019) proposed that respite care be based on the principles of person-centred care (described in section 3.3.2) and, thereby, include the person with dementia in the decision-making process regarding care. Further, they propose a new term, *restorative care*, as an alternative for ‘respite care’ that ‘can encompass the perspectives of both the carer and the person with dementia in relation to the use of health and social care services that currently aim to provide a break in the caregiving relationship’ (O’Shea et al., 2019, p. 1461). O’Shea et al. (2019) described a model of respite care and referred to factors previously associated with the model (antecedents). The model includes client factors and service factors that are interconnected and may influence the outcome of respite, i.e. a physical and mental break for the next of kin, as illustrated in Figure 1. The model depicts the role of health and social care services in facilitating respite as an outcome for caregivers of people with dementia.

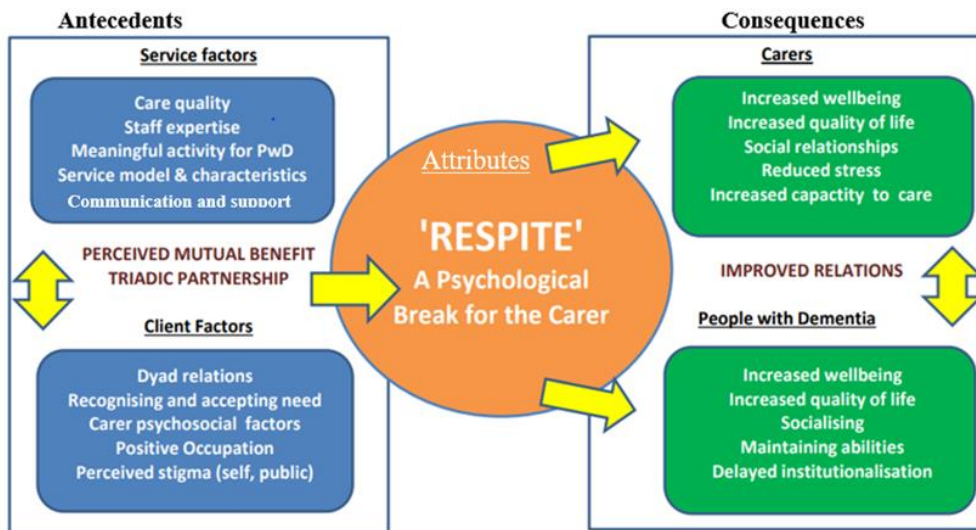


Figure 1. Model of respite: The role of health and social care services in facilitating respite as an outcome for carers of people with dementia, as described by O’Shea (2020, p. 67) (Figure used with permission of Emma O’Shea, March 2022).

In the model, five client factors are suggested that impact the caregiver’s ability to experience a mental break through service use. These refer to both persons with dementia and next of kin and consist of the following: ‘*dyad relations, carer psychosocial factor, recognizing and accepting need, positive occupation, and perceived stigma*’ (O’Shea et al., 2019, p. 1452).

More specifically, *dyad relations* involve aspects of the relationship between the person with dementia and the next of kin and how these aspects may emotionally promote or impede the next of kin's respite experience. *Carer psychosocial factors* refer to the next of kin's 'personal and social factors that influence the experience of respite' (O'Shea et al., 2019). *Recognizing and accepting need* are about the next of kin acknowledging their own needs for respite and the ability to restore their health or feelings of well-being when they have a break from caregiving (O'Shea et al., 2019). *Positive occupation*, or restorative occupation, refers to activities that next of kin may undertake to achieve a mental break and to become re-energized (Watts & Teitelman, 2005). *Perceived stigma* involves classifying an individual or a group in an undesirable and stereotypical way (Batsch et al., 2012).

Next, the *service factor* areas comprise the following: '*service model and characteristics, care quality and staff expertise, meaningful occupation for the people with dementia, and communication and support*' (O'Shea et al., 2019, p. 1455). These are factors that are important and necessary for next of kin and people with dementia to experience respite and its benefits. *Service model and characteristics* play a significant role in the next of kin's willingness to use the services and their ability to experience a mental break. *Care quality and staff expertise* are about the quality of care offered in respite services, and *meaningful occupation for the person with dementia* is considered meaningful when it enables a person to stay involved in everyday activities and personal relationships (Phinney, 2006). *Communication and support* for the dyad are about how respite service managers interact with the next of kin and the person with dementia to fulfil the purpose of respite (O'Shea et al., 2019).

Last, O'Shea et al. (2019) have added that next of kin need to perceive that both they and the person with dementia can benefit from using respite services. In that way, the next of kin needs to perceive that using the services can mutually benefit the person with dementia as well as themselves if they are to achieve a mental break.

3.5.2 Daycare as respite for the next of kin

The aim of daycare service is to provide respite and support for the next of kin, contributing to a reduction or prevention of the burden of care while maintaining QoL and prolonging the period during which they can provide care at home to the person with dementia (Du Preez et al., 2018; Norwegian Ministry of Health and Care Services, 2007, 2015).

Due to an increasing focus on people with dementia and their next of kin, research has explored the impacts that daycare services may have on next of kin. Studies have revealed that daycare may reduce the burden and stress on next of kin and contribute to their respite (Maffioletti et al., 2019; Tretteteig et al., 2016). Moreover, respite in the form of daycare has been shown to contribute to increasing the next of kin's patience and energy for coping with the everyday challenges of caregiving. Additionally, the experience of respite may prevent conflicts and improve the quality time that the next of kin can spend with the person with dementia (Tretteteig et al., 2017b). The daycare staff should be knowledgeable about the person with dementia's identity and how the possibility of individualized care can influence the next of kin's experience of respite (Gustafsdottir, 2011). Further, collaboration and dialogue with the daycare staff are crucial for the next of kin to experience having someone to share the care of their relative with dementia (Tretteteig et al., 2016; Tretteteig et al., 2017b). Finally, Vandepitte et al. (2016) indicated in their review that daycare service use was associated with an accelerated time to institutionalization. The authors speculated that this might be due to service use being initiated when the dementia symptoms have already progressed significantly.

3.5.3 Farm-based daycare as respite for the next of kin

FDCs have been found to prevent an increase in caregiver burden over time (De Bruin, 2009). However, knowledge about next of kin's experiences with FDCs is limited. Two qualitative studies with interviews of next of kin found that FDCs appear to promote the health of both the person with dementia and his or her caregiver (Solum Myren et al., 2013; Strandli et al., 2016). Strandli et al. (2016) reported that the staff's dedication to caregiving and to facilitating individual activities was important for the next of kin's experience of relief and the safety of their relative.

I have performed several literature searches to find literature on next of kin to people with dementia attending FDC using the following criteria:

- Population: Next of kin of people with dementia;
- Intervention: Farm-based daycare/care farming;
- Outcome: Any outcomes related to next of kin of people with dementia attending a farm-based daycare; and

- Type of literature: Peer-reviewed published articles.

The most recent search in the same databases with the same MeSH terms and keywords was conducted on 9 March 2022 to look for updates. The searches were conducted in PubMed, CINAHL, PsycINFO and AgeLine using search combinations of the following terms (MeSH terms and keywords): Next of kin OR informal caregiver OR family caregiver AND dementia AND daycare service AND care farm OR green care OR farm-based daycare. In all, 31 articles were found (29 in PubMed, one in CINAHL, none in PsycINFO and one in AgeLine).

Initially, I read and reread the abstract of each paper to identify information on the study context. Then, the full texts of papers that met the criteria were read. In addition, references in the selected articles were checked for the possibility of identifying additional relevant articles. The results of pertinent national and international studies on next of kin of people with dementia attending FDCs are presented in Table 3. The studies are listed chronologically.

The present PhD project was begun in August 2016. At that time, I found only three studies about next of kin to people with dementia attending a FDC, and these had been conducted in Norway and the Netherlands. The three studies were published before 2016; I found two articles published after 2016; see Table 3.

The study by de Boer et al. (2019) explored the experiences of next of kin to people with dementia who attended green care farms, regular small-scale living facilities, and traditional

Table 3. Overview of single studies on next of kin to people with dementia attending an FDC

Author(s) and Country	Year	Type of study (Method)	Sample	Aim	Main findings
de Bruin, Oosting, Enders-Slegers, & van der Zijpp The Netherlands	2009	A 1-year cohort study	Community-dwelling people with dementia and their next of kin (daycare on green care farms [GCFs])	Describe the rate of change in caregiver burden of family caregivers of dementia patients receiving daycare at GCFs or at regular daycare	Quality of life, emotional distress, and feelings of competence remained rather stable in both family caregivers of people with dementia attending daycare at GCFs and attending regular daycare.

			and regular daycare)		
Solum Myren, Enmarker, Saur, & Hellzen Norway	2013	Interviews	Next of kin of home-dwelling people with dementia daycare at green care farms	To explore the everyday lives of eight relatives of people with dementia receiving daycare services	Daycare on green care farms offers respite care and gives both the next of kin and people with dementia a meaningful day.
Strandli, Skovdahl, Kirkevold, & Ormstad Norway	2016	Interviews	Spouses of home-dwelling people with dementia attending daycare on green care farms	To gain knowledge about how spouses/partners experience their relatives' daycare at a green care farm	The participating spouses/partners experienced daycare as health promoting, both for their relative with dementia and for themselves.
de Boer, Verbeek, Zwakhalen, & Hamers The Netherlands	2019	Interviews*	Next of kin of people with dementia attending green care farms, regular small-scale living facilities, or traditional nursing homes	To explore from the perspective of next of kin of people with dementia positive and negative experiences with green care farms, regular small-scale living facilities, and traditional nursing homes	Next of kin perceived green care farms as better able to provide residents with a stimulating environment that provides person-centred care compared to traditional nursing homes. The experiences were often related to individual nursing staff and their interpersonal, 'human' qualities.
de Bruin, Buist, Hassink, & Vaandrager The Netherlands	2021	Interviews	Community-dwelling older people with dementia, their family carers, and service providers	(a) To examine factors influencing the decision to choose nature-based services in urban areas among people with dementia and their family carers and (b) to delineate their importance to the health and well-being of people with dementia and their family carers	The participants reported that the nature-based services might have positively influenced the health and well-being of people with dementia and their family caregivers. The services support contact with nature and animals, activity engagement, physical activity, structure, social interaction, healthy eating, a sense of meaning in life and a focus on normal daily life for the people with dementia.

*Interviews: next of kin whose relative attended a green care nursing home and a regular nursing home

3.6 Summary and basis for the present study

Taking care of a person with dementia over time often has serious consequences for next of kin such as increased burden of care, reduced QoL or reduced physical and mental health. At

the same time, next of kin may experience caregiving as rewarding and meaningful. Daycare services may provide next of kin with respite and an opportunity to take care of themselves. As described in section 3.5.3, insufficient knowledge exists about the next of kin of people with dementia attending an FDC, their characteristics, and their experiences with the FDC. Furthermore, the potential benefits for next of kin in relation to this form of respite service remain unexplored. Few studies have been found and they are small. However, one study found that the daycare break prevented an increase in the burden of care over time for the next of kin and that, with this support, they were able to prolong their caregiving role (de Bruin, 2009). Two studies found that FDC appears to be health-promoting for both next of kin and people with dementia (Solum Myren et al., 2013; Strandli et al., 2016).

Given that people with dementia should remain at home if possible and that next of kin should contribute to this goal, it is vital for the next of kin to have access to different respite services. Based on a lack of knowledge about the next of kin's experiences with FDC, it was appropriate to study various aspects of this topic. This knowledge is important for facilitating beneficial and efficient service.

4 The present thesis

4.1 Aim and research questions

The main objective of the present thesis was to gain knowledge about the next of kin of people with dementia attending an FDC in Norway and their experiences with the service.

The following five research questions were formulated:

1. What are the characteristics of the next of kin to persons with dementia attending FDC? (Study 1)
2. Which characteristics of next of kin and people with dementia attending FDC are associated with the burden of care and the quality of life of next of kin? (Study 1)
3. What are the experiences of the next of kin to persons with dementia attending FDC? (Study 2)?
4. How do FDCs influence the next of kin's daily lives? (Study 2)
5. How do next of kin experience the transition process for people with dementia from FDC to another service in the municipality? (Study 3)

4.2 Studies included in the present thesis

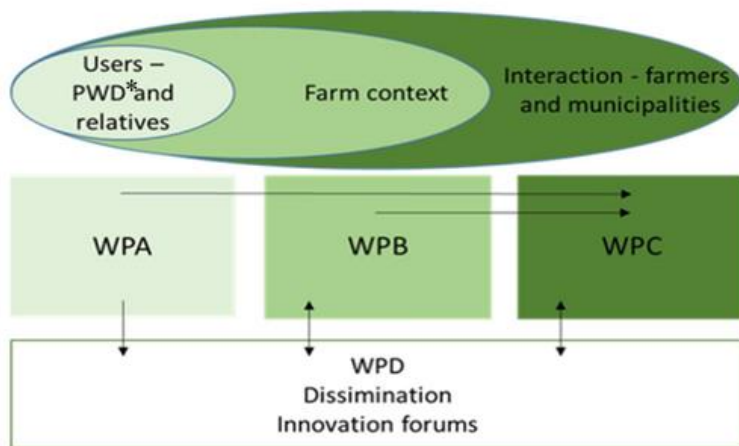
This thesis comprises the three studies presented in Table 4.

Table 4. Design, sample, and analyses used in the three studies

Study	Design/Method	Participants	Analysis
Characteristics, burden of care and quality of life of next of kin of people with dementia attending farm-based daycare in Norway: A descriptive cross-sectional study (Taranrød et al., 2020)	A descriptive cross-sectional study	94 next of kin and their relatives with dementia	Descriptive statistical analyses and a regression analysis
Being sheltered from a demanding everyday life: Experiences of the next of kin to people with dementia attending farm-based daycare (Taranrød et al., 2021)	A qualitative, descriptive design Semi-structured interviews	Eight next of kin of people with dementia attending an FDC	Qualitative content analysis
The transition of care from farm-based daycare for people with dementia: The perspective of next of kin (Taranrød et al., 2023 (accepted for publication June 18, 2023))	A qualitative, descriptive design Semi-structured interviews	Eight next of kin of people with dementia in transition from an FDC to another care service in the municipality	Qualitative content analysis

4.3 Research collaboration

The present PhD project is part of a large research programme titled *Farm-based daycare services for people with dementia: quality development through interdisciplinary collaboration, 2016–2020*. This programme was organized as several qualitative and quantitative studies and conducted over a period of four years (2016–2020) (Eriksen et al., 2019). The primary objective was to provide knowledge for the innovative, quality-based development of FDCs in Norway from different perspectives. The project programme was divided into four work packages/projects (WPA, WPB, WPC and WPD; Figure 2), each with its associated research group. Work package A (WPA) aimed to explore the experiences and benefits of FDCs for people with dementia and their next of kin. Work package B (WPB) aimed to investigate how different resources in the farm context contribute to and are used to create an environment that facilitate person-centred care for people with dementia. Work package C (WPC) aimed identified factors that enable a successful collaboration between farmers offering FDC and the municipalities. The last work package, WPD, aimed to share knowledge, promote FDC for people with dementia, and establish discussion forums for innovation in farm-based dementia care programmes. There has been comprehensive collaboration between and within each WP. Figure 2 illustrates the four work packages in the farm-based dementia care programme.



*People with dementia

Figure 2. The four work packages in the farm-based dementia care project

In WPA, there were three PhD projects. Two of these had as their focus people with dementia attending FDCs (Finnanger Garshol, 2020; Ibsen, 2021); the present thesis

focussed on the next of kin. We met regularly during the project period, and the researchers for WPA were involved in data collection. The study protocol for WPA was published in 2019 (Eriksen et al., 2019).

5 Methods

This PhD project focusses on the next of kin to people with dementia attending an FDC and the next of kin's experiences with the service. To answer the research questions, quantitative and qualitative methodologies were used.

A quantitative cross-sectional design was used to examine and describe the next of kin's characteristics and to identify factors that are associated with their burden of care and quality of life (Study 1). A cross-sectional design is appropriate when the purpose is to find the prevalence of outcomes or to investigate associations between factors and outcomes of interest for a population (next of kin) within a given time point (Creswell, 2014). The present study used baseline data from the prospective longitudinal study of people with dementia attending a farm-based daycare and their next of kin, based on standardized assessment scales (Eriksen et al., 2019).

Qualitative, individual interviews were conducted to explore the experiences of next of kin with FDC and to learn how FDC might impact their daily lives (Study 2). In addition, qualitative interviews were used to explore how next of kin experienced the process of transition for persons with dementia from FDC to a higher level of care (Study 3).

5.1 Study 1

Characteristics, burden of care and quality of life of next of kin of people with dementia attending farm-based daycare in Norway: A descriptive cross-sectional study

5.1.1 Aim

This study aimed to describe the characteristics of next of kin and to explore the association between next of kin and people with dementia with a focus on characteristics associated with the next of kin's burden of care and quality of life.

5.1.2 Design

The design was quantitative and cross-sectional based on standardized assessment scales. As part of the FDC project (WPA), this study used baseline data from the prospective longitudinal study of people with dementia and their next of kin (Eriksen et al., 2019).

Prior to the data collection, three pilot interviews were conducted to ensure that the procedure did not overload the participants, namely people with dementia and their next of kin. Based on the evaluation of the pilot interviews, we decided to utilize all measures.

In study 1, the interviews with the next of kin and the people with dementia were mainly conducted by two researchers; one interviewed the next of kin, and the other interviewed the person with dementia.

5.1.3 Measures

The FDC project (WPA) had a list of core measurements collected from both the next of kin and the people with dementia. Table 5 shows the list of measures used in the present study regarding next of kin. Table 8 describes measures used in the present study regarding people with dementia.

Table 5. An overview of instruments used with next of kin in Study 1

Next of kin	Instruments	Domains
Sociodemographic information		<ul style="list-style-type: none"> - Age, sex, marital status, level of education, occupational status and living arrangement - Hobbies/interests - Physical activities (weekly) - Respite: number of days per week that the person with dementia was attending FDC or another daycare - Whether the next of kin attended caregiver school and/or support groups - Other support services and/or individual consultations about their own situation; number of days spent assisting or looking after the person with dementia during the preceding month
Burden of care	Relative Stress Scale (RSS)	The Relative Stress Scale (RSS) has 15 items; each is rated from 0–4.
Quality of life	Quality of Life in Alzheimer’s disease (QoL-AD)	The Quality of Life in Alzheimer’s disease questionnaire (QoL-AD) comprises 13 items.
Anxiety	The anxiety section of the Hospital Anxiety and Depression Scale (HADS-A)	The Hospital Anxiety and Depression Scale (HADS-A), has seven items.
Depression	Montgomery–Åsberg Depression Rating Scale (MADRS)	The Montgomery–Åsberg Depression Rating Scale (MADRS) is a 10-item, interview-based questionnaire that screens for depressive symptoms.
Social support	Oslo Social Support Scale (OSS-3)	The Oslo Social Support Scale (OSS-3) assesses the participant’s subjective perceived social support with three questions.

Next of kin

The measures used in Study 1 were self-reported measures that the next of kin completed themselves, except for the Montgomery–Åsberg Depression Rating Scale (MADRS), which was administered at the interview (Montgomery & Åsberg, 1979).

Burden of care

The Relative Stress Scale (RSS) (Greene et al., 1982) evaluates general difficulties in the caregiver role such as emotional distress, experiences of social restrictions, and negative feelings towards the person with dementia. The RSS consists of 15 items, with each rated from 0 to 4 (0 = never, 1 = rarely, 2 = sometimes, 3 = frequently, 4 = always/to a high degree), resulting in a sum score ranging from 0–60. A score >23 indicates an increased risk of clinically significant psychological distress, and a score ≥ 30 indicates that the person should be referred for psychiatric assessment and treatment when required (Ulstein et al., 2007b). In an earlier Norwegian study, the version used in this study had an internal consistency evaluated by Cronbach’s alpha as 0.90 (Ulstein et al., 2007b).

Table 6. Relative Stress Scale (Greene et al., 1982)

1. Do you ever feel you can no longer cope with the situation?
2. Do you ever feel you need a break?
3. Do you ever get depressed by the situation?
4. Has your own health suffered at all?
5. Do you worry about accidents happening to...?
6. Do you ever feel that there will be no end to the problem?
7. Do you find it difficult to get away on holiday?
8. How much has your social life been affected?
9. How much has the household routine been upset?
10. Is your sleep interrupted by...?
11. Has your standard of living been reduced?
12. Do you ever feel embarrassed by...?
13. Are you at all prevented from having visitors?
14. Do you ever get cross or angry with...?
15. Do you ever feel frustrated at times with...?

Quality of life

The Quality of Life in Alzheimer’s disease questionnaire (QoL-AD) (Logsdon et al., 1999) is a disease-specific measurement comprising 13 items: physical health, energy, mood, living situation, memory, family, marriage, friends, self, ability to do chores around the house, ability to do things for fun, money, and life as a whole (Table 7). The items are rated on a

four-point scale as poor = 1, fair = 2, good = 3, and excellent = 4. The total score is the sum of all 13 items, with a total ranging from 13–52; a higher score indicates better QoL (Logsdon et al., 1999).

Table 7. Quality of Life in Alzheimer’s disease questionnaire (Logsdon et al., 1999)

1. First of all, how do you feel about your physical health? Would you say it’s poor, fair, good, or excellent?
2. How do you feel about your energy level? Do you think it is poor, fair, good, or excellent?
3. How has your mood been lately? Have your spirits been good, or have you been feeling down? Would you rate your mood as poor, fair, good, or excellent?
4. How about your living situation? How do you feel about the place you live now? Would you say it’s poor, fair, good, or excellent?
5. How about your memory? Would you say it is poor, fair, good, or excellent?
6. How about your family and your relationship with family members? Would you describe it as poor, fair, good, or excellent?
7. How do you feel about your marriage? How is your relationship with (spouse’s name)? Do you feel it’s poor, fair, good, or excellent?
8. How would you describe your current relationship with your friends? Would you say it’s poor, fair, good, or excellent?
9. How do you feel about yourself—when you think of your whole self and all the different things about you, would you say it’s poor, fair, good, or excellent?
10. How do you feel about your ability to do things like chores around the house or other things you need to do? Would you say it’s poor, fair, good, or excellent?
11. How about your ability to do things for fun that you enjoy? Would you say it’s poor, fair, good, or excellent?
12. How do you feel about your current situation with money, your financial situation? Do you feel it’s poor, fair, good, or excellent?
13. How would you describe your life as a whole? When you think about your life as a whole, everything together, how do you feel about your life? Would you say it’s poor, fair, good, or excellent?

Anxiety

To measure anxiety symptoms, the anxiety portion of the Hospital Anxiety and Depression Scale (HADS-A) was used (Zigmond & Snaith, 1983). The scale has seven items rating anxiety symptoms: Item A/1 I feel tense or wound up, A/3 I get a sort of frightened feeling as if something awful is about to happen, A/5 Worrying thoughts go through my mind, A/7 I can sit at ease and feel relaxed, A/9 I get a sort of frightened feeling like ‘butterflies’ in the stomach, A/11 I feel restless as if I have to be on the move, and A/13 I get sudden feelings of panic. The items are scored from 0 (not present) to 3 (considerable), yielding a possible sum score of 0–21. A 0–7 score is considered normal; an 8–10 score represents a possible case of anxiety; and a score of ≥ 11 is defined as a case of anxiety.

Social support

How the next of kin perceived experiences of social support was assessed with the Oslo Social Support Scale (OSS-3) (Dalgard et al., 2006). The OSS-3 asks three questions: How many people are you so close to that you can count on them if you have serious problems? (given as number of people); How much concern do people show in what you are doing? (rated from none to a lot); and How easy is to get practical help from neighbours if you should need it? (rated from very easy to very difficult) (Dalgard et al., 2006, pp. 450–451). A sum score will range from 3 to 14 and is grouped into three categories: (1) a 3–8 score indicates ‘poor support’, (2) a 9–11 score shows ‘moderate support’, and (3) a 12–14 score is a sign of ‘strong support’ (Bøen et al., 2012).

Depression

We used the Montgomery–Åsberg Depression Rating Scale (MADRS) (Montgomery & Åsberg, 1979) to measure symptoms of depression. The MADRS is a 10-item scale using an interview-based questionnaire to screen for depressive symptoms. The 10 items are apparent sadness, reported sadness, inner tension, reduced sleep, reduced appetite, concentration difficulties, lassitude, inability to feel, pessimistic thoughts, and suicidal thoughts. Each item yields a score of 0–6, and the overall score ranges from 0–60. The cut-off score for no depression is 6; a score of 7–19 indicates mild depression symptoms; 20–34 indicates moderate depression symptoms, and a score of 35–60 indicates severe symptoms of depression (Montgomery & Åsberg, 1979). The scoring was based on an interview with the next of kin.

People with dementia

To collect information about the people with dementia, the next of kin completed the questionnaire as a proxy, except for the Clinical Dementia Rating Scale (CDR) (Hughes et al., 1982). The CDR score was based on the information obtained from next of kin and people with dementia. The overall score was reached by two researchers who reviewed the data and performed the rating based on the rules described in Hughes et al. (1982). Table 8 shows an overview of information and instruments used in Study 1 with people with dementia

Table 8. An overview of information and instruments used in Study 1 with people with dementia

People with dementia	Instruments	Domains
Sociodemographic information		- Sex, age, living arrangements - Number of months with dementia symptoms - Number of months the person with dementia had been attending FDC
Function in everyday life activities	Physical Self-Maintenance Scale (PSMS) Instrumental Activities of Daily Living Scale (IADL)	Personal and instrumental activities of daily living; a higher score on both scales indicates poor functioning
Cognition	Clinical Dementia Rating Scale (CDR)	Measures the severity of dementia; a higher score indicates more-severe dementia
Neuropsychiatric symptoms	Neuropsychiatric Inventory Scale (NPI-12)	Neuropsychiatric symptoms are measured with 12 items; a higher score indicates more-severe symptoms

Function in Everyday Life Activities

To measure the function of people with dementia and their ability to perform activities of daily living, the Physical Self-Maintenance Scale (PSMS) and the Instrumental Activities of Daily Living Scale (IADL) (Lawton & Brody, 1969) were used. The PSMS consists of six items: toilet, feeding, dressing, grooming, ambulation, and bathing, with a sum score ranging from 6 (no impairment) to 30 (total impairment). The IADL Scale comprises eight tasks: telephone use, shopping, meal preparation, housekeeping, laundry, use of transportation, responsibility for medication intake, and handling finances. The scoring is not uniform, and items are scored 1–3, 1–4 or 1–5, with a sum score ranging from 8–31 and higher scores indicating increasing impairment. For both scales, a higher score indicates poorer functioning.

Cognition

The Clinical Dementia Rating (CDR) Scale was used to measure the level of dementia. The CDR is a global rating scale covering six domains: memory, orientation, judgement and problem-solving, community affairs, home and hobbies, and personal care. Each domain is rated from 0–3, where 0 is no dementia, 0.5 is possible dementia, 1 is mild dementia, 2 is moderate dementia and 3 is severe dementia. The rating is based on available information to evaluate the person with dementia (Hughes et al., 1982). The ratings are then calculated as an overall score, giving precedence to memory, based on the same 0–3 scale. Alternatively,

the ratings can be summarized in a sum-of-boxes ranging from 0–18. A CDR-SOB score of 0.5–4 is rated as questionable dementia, 4.5–9 indicates mild dementia, 9.5–15.5 reflects moderate dementia, and a score of 16–18 is considered severe dementia (O’Bryant et al., 2008). According to O’Bryant et al. (2008), this method provides a greater number of values and, as such, is more sensitive to changes over time.

Neuropsychiatric Symptoms

The Neuropsychiatric Inventory (NPI-12) (Cummings et al., 1994) evaluates 12 behavioural domains common in dementia: delusions, hallucinations, depression/dysphoria, anxiety, agitation/aggression, euphoria, disinhibition, irritability/lability, apathy, aberrant motor activity, sleep and night-time behavioural disturbance, and appetite and eating abnormalities. Each item is scored as present or not present during the four weeks prior to the evaluation, and if present, the symptom is scored according to severity (score 1–3 = mild to severe) and frequency (score 1–4 = occasionally to very frequently). The severity score and frequency score are multiplied for an item score ranging from 0–12. Then, the 12 items are added together for a score up to 144, with a higher score indicating more-severe symptoms.

5.1.4 Participants and recruitment

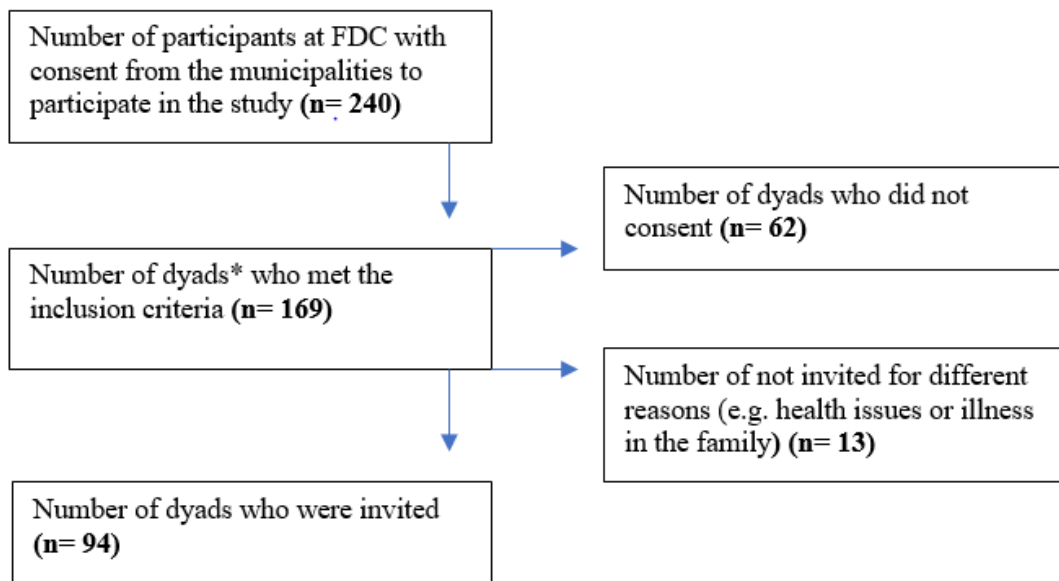
The recruitment for the FDC project started in late 2016. First, all farms in Norway that provided farm-based daycare for people with dementia were contacted; at that time, this was a total of 35 farms. Oral and written information about the study was provided, and providers of FDC service were invited to participate in the FDC project. We also contacted the healthcare authorities in the municipalities with information about the FDC project and invited them to participate, and if they agreed, we asked for their written consent to recruit people with dementia and their next of kin to the project. If both the FDC provider and the local healthcare authorities agreed to participate, the FDC was enrolled in the project. Further, the service providers at each farm, or in some cases healthcare personnel from the municipalities, recruited persons with dementia and their next of kin based on the following inclusion criteria:

- Being the next of kin of a person with dementia living in his or her own home and attending an FDC for at least three weeks;
- Being 18 years of age or older;

- Physically meeting with the person with dementia a minimum of once a week on average; and
- Both next of kin and the person with dementia being willing to give their written consent to participate.

The only exclusion criterion was the next of kin or his or her relative with dementia not wanting to participate in the study.

In the period from January 2017 to January 2018, 30 different FDCs agreed to participate, with a total of about 240 users (Figure 3). Based on the inclusion criteria and the single exclusion criterion, 169 dyads (people with dementia and their next of kin) were eligible to participate. Of these, 62 did not wish to participate, and an additional 13 dyads were not invited to participate by the service providers or municipal care staff for reasons other than the exclusion criterion (e.g. family or health issues). In the end, 94 dyads from 25 FDCs agreed to participate in the study, representing 55.6% of all those eligible to participate. For this project, no data were collected about FDC users or their next of kin who declined to participate in the study.



*Dyads: People with dementia and their next of kin

Figure 3. Flowchart showing the inclusion process for participants in Study 1

5.1.5 Data collection

Seven researchers and three research assistants collected the data. Before the data collection started, all the collectors attended a one-day training session on the use of the different measures. In addition, a structured guide was prepared to provide guidance on completing the scales. Questions that were raised during the data-collection process were discussed by the research team in WPA.

After receiving the names of potential participants from the farmer or healthcare personnel in the municipality, the researcher contacted the next of kin, provided additional information about the study, and scheduled the interview. In some cases, the researcher also contacted the person with dementia. The data collectors worked in pairs as this could ease the burden for both the participants and the researchers; one collector interviewed the person with dementia and the other interviewed the next of kin at the same time but in separate rooms, usually in the participant's own home. For practical reasons, six next of kin (of 94) were interviewed either by phone or at a place other than at their homes; these six had received the forms by e-mail in advance. Some people with dementia were interviewed at the FDC they attended. The interview with the next of kin usually lasted 60 to 90 minutes, but several lasting up to two hours, while the interviews with the people with dementia lasted about an hour.

5.1.6 Data Analysis

Missing values. The different assessment forms had missing values; therefore, we imputed on the item level for the cases with at least 50% of the items available. Imputed values were random numbers drawn from the observed distribution in the dataset. The items most imputed were from the RSS (6 cases), the QoL-AD (5 cases), the MADRS (4 cases) and the OSS-3 (4 cases).

Statistical analyses. In Study 1, different statistical analyses were used, and in the following section, the descriptive and univariate and multiple linear regression statistical models are described.

Descriptive statistics. The descriptive statistical analyses were conducted with IBM SPSS® v. 26 (IBM Corp., Armonk, NY, USA). The characteristics of the next of kin and the people with dementia were presented as numbers, percent, means, ranges when appropriate, standard deviations (SD) and p-value. For the descriptive analyses, the significance level was set at $\alpha = 5\%$.

Histograms, Q-Q plots and box plots. The distribution of each variable was examined by inspecting histograms, Q-Q plots and box plots. The continuous variables were fairly normally distributed except for the MADRS score variable, which was heavily skewed.

Correlations. Correlations between continuous variables were tested with the Pearson product-moment correlation coefficient (Pearson's r).

Chi-squared (χ^2) tests and Fisher's exact test. To explore bivariate associations, dichotomous variables were compared with the Chi-squared (χ^2) test or Fisher's exact test when appropriate (variable: Being physically active).

Student's t-test and Mann-Whitney U test. Continuous variables were compared with a t-test when normally distributed or the non-parametric Mann-Whitney U test when the variable was heavily skewed (e.g. the MADRS score variable).

In the descriptive analyses, we hypothesized that the characteristics of the next of kin would be influenced by whether they live with a person with dementia or not, as described in an earlier study of next of kin (Bruvik et al., 2012). Therefore, the sample ($n = 94$) was divided into two groups: next of kin living with the person with dementia (Group 1, $n = 57$) and those not living with the person with dementia (Group 2, $n = 37$).

To prepare for the regression analysis, all variables were checked for multicollinearities and interactions. A point-biserial correlation procedure in SPSS was used to measure the strength and direction of the association that exists between the variable 'age' and dichotomous variables such as 'living' (with a person with dementia, no = 0, yes = 1); 'education' (0 = primary school/high school, 1 = college/university); 'employed outside household' (0 = no, 1 = yes); and 'relation' (0 = spouse/partner, 1 = child/other). All were highly correlated ($r >$

0.715) except 'education' ($r = 0.493$). Therefore, the 'living' variable was chosen to represent the variables described above in the regression analyses.

The IADL and PSMS scales were also highly correlated ($r = 0.657$). The IADL variable was used in the analyses. Further, all the variables in the regression analyses were checked for multicollinearity. An intercorrelation between the variable QoL-AD and MADRS was found, and an interaction variable was created for use in the regression analyses with QoL-AD as a dependent variable. Further, unadjusted (bivariate) and adjusted (multiple) models were performed with the QoL-AD score and the RSS total score as dependent variables.

We started with a high number of variables in the unadjusted analyses, examined for significance. In the adjusted (multiple) models, independent variables with a p -value ≤ 0.20 were included. According to Green's rule of thumb, there should be no more than one explanatory variable per 10 respondents in a regression analysis (Green, 1991). In the present study, there were 94 participants, indicating that there should be no more than nine or 10 explanatory variables in the model (Field, 2018); we ended up with 11 explanatory variables.

Univariate and multiple regression models. The univariate and multiple regression analyses were performed by a multilevel analysis using MLwiN v3 (Centre for Multilevel Modelling, University of Bristol, UK) to explore associations with the dependent variables QoL-AD score and RSS score and the potential independent variables. It is possible that the 'effect' on the next of kin of having a relative with dementia attending an FDC might differ systematically between the FDCs (the 'effect' depends on which FDC the person with dementia was attending). This is often called a 'cluster effect'. By using a multilevel analysis, we can check and adjust for a cluster effect between the different FDC sites (Hox, 2002). To evaluate the cluster effect, the intraclass correlation coefficient (ICC) is calculated. The ICC is how large the proportion of the variance is that is explained by a cluster effect. The ICC for an empty model was $>5\%$ for both models and should, thereby, be adjusted for (Kirkwood & Sterne, 2003). The ICC was 10.5% for the RSS score and 11.7% for the QoL-AD score. Therefore, the regression analyses were adjusted for cluster effects.

5.2 The qualitative studies: Study 2 and Study 3

A qualitative research design was adopted for Studies 2 and 3. Qualitative methods are suited for describing and analyzing characteristics and aspects or qualities of the phenomenon to be described. The purpose is to understand the world from the subject's point of view (Kvale & Brinkmann, 2015).

In a qualitative study, it is essential to identify meaning or to explore the content of the meaning of a social phenomenon as experienced by the person (next of kin) in their natural context. Therefore, it was important to understand how FDC, as a meaning-making social phenomenon, influenced the next of kin's perception of their situation as caregiver for a person with dementia. Our experiences as humans always occur in a context, i.e. in a setting and in relation to other people (Kvale & Brinkmann, 2015). Receiving support and respite from an FDC meant both new relations and new contexts for the person with dementia and for their next of kin, and thus, it was appropriate to use interviews to gain insight and understanding about the experiences of the next of kin with the FDC. Therefore, an introduction to the qualitative interviews is provided that explains the chosen method and describes the underlying scientific philosophy and my pre-understanding, which might have influenced the results of my studies (2 and 3).

5.2.1 The qualitative research interview

A qualitative interview is a planned conversation that goes deeper than a spontaneous exchange of opinions. The conversation gives the researcher an opportunity to access another person's life experiences as expressed by that person (Kvale & Brinkmann, 2015). In Studies 2 and 3, I sought to explore and understand the experiences of next of kin with FDC.

In a qualitative interview, data are produced through the interaction between the interviewer and the interviewee. Therefore, the quality of the interview is closely connected to the performance and competence of the interviewer. Kvale and Brinkmann (2015) underscored that good qualitative research is based on good craftsmanship, i.e. on how the interview is conducted, whether necessary notes are made along the way, and how the transcription and documentation are performed. Further, the interview should be conducted in an atmosphere of kindness; the questions should be asked in an empathetic way; and the participant's responses should be listened to carefully (Kvale & Brinkmann, 2015).

For both Studies 2 and 3, semi-structured interviews were used, with interview guides consisting of open-ended questions on the topics. The participants were encouraged to talk freely about the topics included in the guide and other issues that complemented the topics (Kvale & Brinkmann, 2015). When appropriate, questions to elucidate their stories were asked in order to reach an understanding of the participants' experiences. The goal of the interviews was not to identify objective truths, facts or rules but to gain a picture of the everyday experiences of the next of kin as each one perceived them (Kvale & Brinkmann, 2015). The participants provided detailed descriptions of the relevant themes and, thereby, gave the interviewer opportunities to search for nuances and values in their narratives, as well as providing new knowledge and understanding of the phenomenon. The present studies were conducted in accordance with a phenomenological hermeneutical approach.

5.2.2 Phenomenological hermeneutical approach

A phenomenological hermeneutical approach is used to explore and interpret people's everyday life experiences as collected through qualitative research. The aim of the phenomenological approach is to gain knowledge about a person's everyday life experiences by examining the meaning of a phenomenon from the person's perspective (Finlay, 2012; Kvale & Brinkmann, 2015). The phenomenological hermeneutical approach is rooted in a philosophical tradition developed by Edmund Husserl (1859–1938) and Martin Heidegger (1889–1976). Husserl is considered to have founded phenomenology about 100 years ago. He considered that the science of his time was concerned with explaining natural objects or events in science, while the understandable meaning of these objects or events and the meaning of the phenomenon received little attention. Husserl focussed on human beings' naïve and unreflected experiences of their life worlds and considered that reality is what each individual recognizes it to be.

To focus on the phenomenon that an interviewee experiences requires that an interaction between the researcher and the interviewee be – to the extent possible – free from prejudice and premises. The researcher must put aside his or her pre-understanding and examine the phenomenon with an open mind; only then can a rich description of the phenomenon of interest be generated (Kvale & Brinkmann, 2015).

Hermeneutics is the study of interpretation. Heidegger and, later, Hans-Georg Gadamer (1900–2002) described a hermeneutical approach as a method of finding meaning and deeper understanding of a phenomenon of everyday experiences (Kvale & Brinkmann, 2015). An everyday experience depends on the individual's interpretation of it, but this interpretation is, in turn, dependent on the everyday experience. This is a reflexive and circular process where there is a reciprocal relationship between the subject and the experience, which is referred to as the hermeneutic circle (Kvale & Brinkmann, 2015). Analyzing the content of meaning in qualitative texts means that the researcher reads the text in an interpretive manner to understand the deeper meaning of the person's thoughts (Kvale & Brinkmann, 2015).

5.2.3 *Pre-understanding*

In qualitative research, the researcher is the primary instrument of data collection, because data are produced through dialogue and interaction between the interviewer and the interviewee or interviewees (Kvale & Brinkmann, 2015). Therefore, it is important for the researcher to clarify their pre-understanding and to maintain an open mind throughout the process of a study. The term *underlying understanding* relates to what hermeneutics describes as the *horizon of understanding*, which embodies all of one's ideas, experiences, and expectations. According to the hermeneutic tradition, researchers need to be aware of that underlying understanding (Kvale & Brinkmann, 2015).

As a registered nurse with many years of clinical experience spent interacting with people with dementia and their next of kin in a hospital setting, added to experience with management and project leadership in the field, I considered it to be important to reflect upon how my previous work and knowledge could influence my role as the researcher. To help me to develop a conscious awareness of my own pre-understanding, I was interviewed by one of my supervisors. The interview was recorded, and I listened to it repeatedly in order to reflect on my pre-understanding of the topic. I also reflected on how my previous work could influence my role in the research being conducted for the thesis. One conclusion was that, owing to my clinical work, I am familiar with therapeutic conversations. However, on that count, Kvale and Brinkman (2015) have emphasised the importance of being conscious of the differences between therapeutic conversations and interviews in qualitative research. Therefore, I conducted a pilot interview with an experienced colleague in the field to raise my awareness of what conducting interviews for research entails.

In all interviews, I explained my role as a researcher and the purpose of the interview. I also reminded the interviewee that I was acting in the role of researcher and that I was neither part of the healthcare system nor in a position to give them additional help in those matters. In some of the interviews, it was difficult to listen without attending to my reflections on certain topics, and in some cases, after the interview, an interviewee asked for information about different topics, and I provided the information that was requested. Most often, I had information about where they could get advice and guidance in the municipality.

5.3 Study 2

Being sheltered from a demanding everyday life: experiences of the next of kin to people with dementia attending farm-based daycare

5.3.1 Aim

The aim in Study 2 was to explore the next of kin's experiences with FDC and how the service may have influenced her or his daily life.

5.3.2 Design

The study adopted a qualitative descriptive design described earlier in this chapter (section 5.2). Eight semi-structured interviews were conducted, and I was the interviewer for all of these.

5.3.3 The participants and recruitment

A purposeful sample of eight participants was recruited from among the 94 participants described in section 5.1.4. These eight participants were recruited from seven different farms and regions of Norway through the FDC providers or healthcare personnel in the municipalities.

The intention of choosing a purposive sampling is to select individuals who have special knowledge or experience with a phenomenon of interest (Creswell, 2014). The inclusion criteria for this study were as follows: being the next of kin to a person with dementia attending an FDC, meeting with the person with dementia at least once a week and being willing to participate in the study. The sample comprised three men and five women. Four

were spouses cohabiting with the person with dementia, and the other four were two sons, a daughter, and a niece not cohabiting with the person with dementia. Six of the participants had more than one year's experience with FDC and two had less than a year of experience. The characteristics of the participants and of the people with dementia are presented in Table 9, which describes the participants and their relatives with dementia. The participants are described according to the relationship, by age group in five-year intervals, and whether they were living with the person with dementia or not. The people with dementia were described by sex, age group, severity of dementia and number of days at the FDC per week. No names were used in either group to ensure participants' anonymity.

Table 9. Characteristics of the next of kin and of the people with dementia

Next of kin			People with dementia			
Relationship	Age group	Living with a relative with dementia	Sex	Age group	Severity of dementia	FDC per week
Son	50–54	No	Male	80–84	mild	3
Niece	50–54	No	Male	70–74	moderate	3
Son	50–54	No	Female	86–90	mild	2
Wife	65–69	Yes	Male	70–74	mild	4
Husband	70–74	Yes	Female	70–74	mild	2
Wife	85–89	Yes	Male	80–84	moderate	3
Wife	55–59	Yes	Male	65–69	mild	2
Daughter	45–49	No	Female	70–74	mild	2

5.3.4 Data collection

The interviews were conducted from June 2017 to February 2018 and lasted for 25–60 minutes. Four interviews took place in the participants' homes, two in other appropriate places chosen by the next of kin, and two were conducted by phone. The interviews were dialogue-based and supported by an interview guide with open-ended questions. Samples of the questions in the interview guide are shown in Table 10.

Table 10. Interview guide, sample questions

Sample questions	
The situation before FDC	Please describe your care situation now with FDC compared to the situation before FDC. Can you describe how your family member’s dementia has affected your daily life? How did you find out about FDC?
Experience of FDC	Please describe your care situation now with FDC compared to the situation before FDC. Can you describe in what ways FDC has affected your daily life? Can you describe to what extent and in what ways you experience the FDC to be a respite service for you as the next of kin? What are your experiences with the content and quality of the FDC? Are there some elements of the FDC service that are more important to you than others?
Future	What are your thoughts about the future for your relative and for yourself?
Summary	In summary, what does the FDC represent for you?

The interviews were conducted by me and audio recorded. They were then transcribed verbatim by me and one research assistant as accurately as possible. Pauses and emotional expressions (e.g. laughter) were also recorded to capture the dialogue as precisely as possible.

5.3.5 Analysis and interpretation of the text

The transcribed interviews were analysed following the method of qualitative content analysis outlined by Graneheim and Lundman (2004), which includes both a manifest level and latent level of analysis. Although Graneheim and Lundman (2004) have not referred to a particular philosophy of science as a basis for their method of analysis, it is my understanding that they were inspired by both phenomenology and hermeneutics. In any case, the *manifest level* of their analytical method refers to content directly expressed in the text: what the text states and makes visible and what is explicit and comprehensible in the material. That understanding aligns with the phenomenological perspective’s emphasis on the immediate. The *latent level*, by contrast, refers to the underlying meaning in the material. That level concerns the researcher’s interpretation and relationship to the text (Graneheim & Lundman, 2004; Graneheim et al., 2017), which aligns with the hermeneutical perspective.

To meet the criteria of scientific quality, all steps in an analytical process applied in a study should be transparent to readers (Graneheim & Lundman, 2004). According to Graneheim and Lundman (2004), ‘A text will always involve multiple meanings and there is always some degree of interpretation when approaching a text’ (p. 106).

For the qualitative studies in this thesis, NVivo 12 Pro (QSR International Pty Ltd, 2020) was used to support both coding and the organisation of the data, whereas all other analyses were performed manually.

The analytical process completed for this thesis, which I undertook with the close cooperation of my supervisors, has been described as a six-step procedure (Graneheim & Lundman, 2004). In the research for the thesis, those six steps were as follows:

1. Each transcribed interview was read several times to gain an overall impression of the data material.
2. The direct text was extracted and divided into units of meaning, and condensed units were formed (i.e. manifest content).
3. In step three, the condensed units were further extracted and coded. The codes were closely related to the text but also reflect the subjective interpretations of the researcher.
4. Based on similarities and differences, the codes were compared and grouped into subcategories.
5. The subcategories were clustered and grouped as categories.
6. The categories were summarised and reflected upon to reach a latent presentation of the text based on an overall theme (Graneheim & Lundman, 2004).

The sixth step was undertaken only in Study 2.

5.4 Study 3

The transition of care from farm-based daycare for people with dementia: The perspective of next of kin.

5.4.1 Aim

The aim of this study was to explore the next of kin's experience of the transition process for people with dementia from FDC to another municipality service.

5.4.2 Design

A qualitative descriptive design, as described earlier in this chapter (section 5.2), was also adopted for Study 3. Semi-structured interviews were conducted with the next of kin of eight

people with dementia who had transferred from an FDC to another care service in the municipality.

5.4.3 The participants and recruitment

A purposeful sample of eight participants was recruited from among the 94 participants described in section 5.1.4. These eight were recruited from six FDCs and different regions of Norway through the FDC providers.

The inclusion criterion was being the next of kin of a person with dementia who had recently ended participation in FDC and transferred to another care service. Nine next of kin were invited to participate in the study, one of whom withdrew before the interviews took place. Table 11 describes the participants and their relatives with dementia (relationship, age in five-year intervals, sex, living with the person with dementia or not; no names were used to ensure anonymity).

Table 11 Characteristics of next of kin and people with dementia

Next of kin				People with dementia	
Relationship	Age	Sex	Living with a relative with dementia	Sex	Age
Spouse	70–74	Male	Yes	Female	70–74
Spouse	50–54	Female	Yes	Male	65–69
Adult child	55–59	Male	No	Female	75–79
Spouse	75–79	Female	Yes	Male	80–84
Spouse	55–59	Female	Yes	Male	60–64
Spouse	60–64	Female	Yes	Male	70–74
Spouse	65–69	Female	Yes	Male	70–74
Spouse	75–79	Female	Yes	Male	75–79

5.4.4 Data collection

Data collection, performed using individual interviews, took place from June 2017 to January 2018, between 6 weeks and 7 months after the attendees at the FDC had stopped attending the service. One participant chose to be interviewed via video conference, one by phone and the other six in-person in their homes. The interviews lasted 30–90 minutes, were audio-recorded and were subsequently transcribed verbatim by a research assistant and me. The data were collected using questions from the semi-structured interview guide, and I performed the interviews. The interview covered topics about the next of kin’s experiences

with their situation support and decision-making before and during the transition of the relative with dementia that ended in attendance at the FDC.

5.4.5 Analysis and interpretation of the text

In Study 3, the transcribed interviews were analysed following the method of qualitative content analysis described by Graneheim and Lundman (2004), as detailed in Section 5.3.5. Unlike Study 2, in which data were analysed on both a manifest and latent level, in Study 3 data were analysed at the manifest level only due to the nature of the data material. I followed the first five steps of the analytical procedure (see Section 5.3.5). When the supervisors and I summarised and reflected on the categories and material as a whole, no obvious latent and overall themes were identified.

5.5 Ethics

When conducting research, a researcher must adhere to ethical norms in line with the Helsinki Declaration (World Medical Association Declaration of Helsinki, 2004). As a researcher, one is responsible for all persons participating in the research and must respect and protect their human dignity and ensure fundamental equality, freedom, self-determination and informed consent (National Committee for Medical and Health Research Ethics (NEM), 2010).

5.5.1 Ethical approval

Ethical approval to conduct this study was granted by the Norwegian Centre for Research Data (NSD, No. 49799) on 31 October 2016.

5.5.2 Participants' rights to dignity and self-determination

The ethical guidelines emphasize the importance of each participant's informed consent to participate in research and of documenting this consent (NEM, 2010).

To participate in the WPA project, the dyad, i.e. the person with dementia and her or his next of kin, were required to give consent to participate in the study. As described in section 5.1.4, the FDC providers or healthcare personnel in the municipalities contacted the dyad and provided the initial information about the project in both oral and written form and

explained that participation in the project was voluntary. This information was repeated when the researchers contacted the potential participants, and those who wished to participate in the project were asked to give their written consent. Their participation was voluntary and that they could at any time withdraw from the project. The next of kin included as participants in our study all gave written informed consent. In Study 1, we also used data from the relatives with dementia. A procedure developed to evaluate whether the person with dementia was able to provide informed consent was described and approved by the NSD. In that study, three persons with dementia did not have the capacity to provide consent, so the next of kin consented for them.

The next of kin who participated in Studies 2 and 3 were given specific statements of the purpose of the studies and provided their consent to participate as well as to have their conversations audio recorded. The participants were informed that they could withdraw from the studies at any time without giving a reason, and that, if so, then all information given from them or about them would be deleted, if not already used in publications. The participants were able to contact the project leader or interviewer if they had any questions following the interview.

5.5.4 Respect for people's privacy and family life

In all three studies, the participants shared personal and sensitive information about their lives concerning both themselves and their relative with dementia. As a researcher, I was aware of the participants' rights to privacy, and I avoided putting any pressure on the participants when I asked questions. Some of the next of kin expressed sadness during the conversation, especially when they talked about the challenges that dementia presented to their relative with dementia and to their own lives as well. But there were also many moments of laughter during the conversations. In all the interviews, I used an empathetic and supportive approach, and I was conscious of not taking on the role of therapist (Kvale & Brinkmann, 2015). However, my background and experience as a nurse were useful when encountering next of kin in a vulnerable situation. In these sensitive situations, no major challenges arose in this regard.

As a researcher, it was also my responsibility to avoid causing participants any unreasonable stress. As described above, the next of kin expressed sadness about their situation, and they revealed how they attempted to fulfil their roles as caregivers. As Kvale and Brinkman

(2015) stated, a conversation like this can be felt as a relief by putting words to one's emotions; however, such conversations can also be painful for the next of kin. Therefore, I consistently ended each interview by making sure that the participant was doing well. The interviewees also had my telephone number if they needed or wanted to talk again following the interview. In addition, they were in contact with the municipality's multidisciplinary team and could talk with its members as well when needed.

5.5.5 De-identification of the data and data storage

All collected data (quantitative and qualitative) have been de-identified. We created a list of codes that linked each participant to the research project. The participants in the qualitative studies (2 and 3) are described by relationship, sex, age in five-year intervals, severity of dementia (people with dementia) (Study 2) and number of days with FDC (Study 2). No names have been used in order to ensure their anonymity. The persons with dementia were described by sex, age group (Studies 2 and 3) and severity of dementia and days of FDC per week (Study 2).

The stored data are secured in the research server of the Norwegian National Centre for Ageing and Health. The list of codes linked to the participants in the quantitative study was deleted by 31 December 2020. The coding lists of the participants in the qualitative studies and audio recordings were deleted by 15 August 2021.

6 Findings

In this chapter of the thesis, the main findings from each study will be summarized.

6.1 Study 1 and additional findings

Characteristics, burden of care and quality of life of next of kin of people with dementia attending farm-based daycare in Norway: A descriptive cross-sectional study.

Characteristics of next of kin

The next of kin comprised two groups: spouses (62%) living with a person with dementia ($n = 57$) and those who did not live with the person ($n = 37$), with significant differences in regard to age, education level, employment, perceived social support, depression symptoms, burden of care and QoL. In addition, more next of kin living with a relative with dementia had participated in caregiver school than next of kin who did not live with the person. The people with dementia who lived with a spouse were found to have a significantly higher CDR-SOB score and higher IADL score compared to those who did not live with a spouse.

6.1.1 Burden of care

In multiple regression models, the whole sample included RSS as a dependent variable. The burden as measured by RSS was associated with living with a person with dementia, anxiety symptoms, perceived social support and with neuropsychiatric symptoms of the people with dementia (measured with the NPI-12). The explained variance between participants (R_1^2) was $0.620 = 62\%$.

6.1.2 Quality of life

In multiple regression models, QoL was associated with living with the person with dementia, anxiety symptoms and perceived social support. The explained variance between participants (R_1^2) was $0.400 = 40.0\%$.

6.1.3 Additional findings

We found that 86% of those living with their spouse with dementia stated that they had a good to excellent relationship with the spouse with dementia (QoL-AD scale, question 7: How do you feel about your marriage? How is your relationship with (spouse's name)? Do

you feel it's poor, fair, good, or excellent?). In addition, nearly all the participants stated that they had good to excellent relationships with their family members (QoL-AD scale, question 6: How about your family and your relationship with family members? Would you describe it as poor, fair, good, or excellent?).

6.2 Study 2 and additional findings

Being sheltered from a demanding everyday life: experiences of the next of kin to people with dementia attending farm-based daycare

Eight semi-structured interviews with next of kin were conducted. Three main categories were identified describing how the next of kin experienced FDC and how the service influenced their daily life. These categories were (1) I am fine when you are fine, (2) significant aspects of the service at the farm, and (3) FDC as a part of the dementia trajectory.

6.2.1 I am fine when you are fine

The participants experienced FDC as a support service for themselves and the relative with dementia. FDC positively influenced their daily lives and offered them a break from their caregiving duties. It gave them an opportunity to recharge when they felt worn out from caregiving and allowed them to pursue hobbies and participate in social life without worrying about the relative with dementia. Respite experiences were also connected to the well-being of their relatives with dementia at the FDC. For these relatives, attending an FDC influenced the everyday rhythm of their lives in a positive way, so that they slept better and had something to look forward to and enjoy.

6.2.2 Significant aspects of the service at the farm

The participants described that the context of FDC was important for them to experience a respite. A major component of this was the staff's ability to create an inclusive community where the relatives with dementia could be themselves, with their individual resources and challenges. The staff's training and experience caring for people with dementia and the respectful way they approached the relatives with dementia and facilitated meaningful activities was seen as a highly significant benefit. The next of kin also described the farm

environment as natural and free, with possibilities for meaningful activities connected to the farm surroundings.

6.2.3 FDC as part of the dementia trajectory

The participants described that they reached a point in the dementia trajectory where they and the relative with dementia needed additional measures to relieve their burden. Contact with the municipal health services was experienced as positive, and they reported having been well taken care of. The participants considered the contact with the healthcare service as crucial in regard to the agonizing choices they had to make at the present time as well as in the future when the dementia would progress. The participants whose relatives with dementia attended an FDC found that this gave them an important break from their daily struggles.

Additional findings

The seven FDCs had an average of six participants attending each day and two staff members on site. The people with dementia spent five to six hours per day in FDC. The staff there provided transport to and from the FDC, and next of kin considered the transport arrangement as safe for the relatives and an advantage that the relatives recognized and appreciated.

6.3 Study 3

The transition of care from farm-based daycare for people with dementia: The perspective of next of kin.

Eight semi-structured interviews with next of kin were conducted. Three main categories described how the next of kin experienced the transition of a relative with dementia from FDC to another care service in the municipality. The categories were (1) bearing the burden, (2) being in transition, and (3) feeling supported.

6.3.1 Bearing the burden

The participants described behavioural changes of the relatives with dementia several months before the transition, and they reported experiencing this period as exhausting due to the exacerbation of the dementia symptoms. The changes increased the burden for the

participants and resulted in very limited opportunities to leave their homes. Despite these experiences, the participants focussed on making the best of the situation, and they put their lives on hold to ensure the well-being of their relatives with dementia.

6.3.2 Being in transition

Being in transition entailed making decisions about a change in care service, most often to a nursing home. The participants put a significant amount of work into the application to a nursing home. They also reported having good dialogues about the care situation with the FDC staff. The healthcare service made the final decision about the relative leaving FDC. A planned transition seemed to be a key factor for a smooth transition. By contrast, an unplanned transition was extremely demanding and highly stressful for both the next of kin and the person with dementia.

6.3.3 Feeling supported

Most of the participants perceived having support and beneficial conversations with the head of the FDC and the multidisciplinary healthcare team regarding the care situation for their relative with dementia during the transition period. Overall, the participants perceived support from family and friends, although they did not involve them in all aspects of the

6.4 Summary of the main findings of the three studies

- The next of kin of persons with dementia attending the FDC consist of spouses or partners living with a relative with dementia and adult children not cohabitating with them. The next of kin were most often caregivers of men with dementia in an early stage of the disease.
- The spouses living with a relative with dementia reported a greater burden of care and a lower level of QoL than the next of kin who were not cohabitating. Most reported having a good relationship to the relative with dementia.
- The participants experienced FDC as a high-quality service. Their relatives with dementia received good care, and conditions contributed to their well-being. Those experiences were crucial for the next of kin's experiences of respite.

- The experience of respite persisted until the symptoms of dementia increased to a level that was difficult for both next of kin and the FDC to handle.
- During the course of dementia, the experience of support from the FDC and the healthcare system, as well as informal support, was highlighted as being pivotal. Even so, a timely care plan for the person with dementia was often lacking.
- The process of transition was an exceptionally demanding and stressful period for the next of kin, and information about care options was sometimes lacking. The need for a higher level of support was a core element of the transition.

7 Discussion

The main objective of the present thesis was to gain knowledge about the next of kin to people with dementia attending an FDC in Norway and their experiences with the service.

Study 1 looks specifically at the characteristics of the next of kin and explores factors associated with their burden of care and QoL. Study 2 focuses on the next of kin's experiences with the FDC and how the service influences their daily life in regard to burden of care and the experience of respite. Study 3 describes the experiences of the next of kin during the period when the person with dementia is in the transition process from the FDC to another care service in the municipality.

One of the main intentions with daycare for the next of kin is experience of respite. As mentioned in section 3.5.1, in the evaluation of the FDC, it is important to understand how, when, and why the services can give respite to the caregiver and which factors are important or unimportant in determining when these programs do not give respite. Therefore, I have chosen to structure the discussion according to the model of respite proposed by O'Shea et al. (2019, 2020) as described in section 3.5.1. The respite model consists of *client and service factors* that are related to each other and may influence the next of kin to experience respite. The main findings will be discussed across the three studies. However, not all topics of the respite model are touched upon in each study, and in such cases, the results from the relevant paper are discussed. The impact of FDC services on people with dementia have been thoroughly investigated and discussed in two PhD theses, one by Ibsen (2021) and the other by Finnanger Garshol (2020). The focus of the present thesis is the next of kin's situation.

7.1 Client factors

O'Shea et al. described five client factors that may impact the next of kin's ability to experience respite, a physical and mental break through service use, as follows: *Dyad relations, Carer psychosocial factors, Recognizing and accepting need, Positive occupation/restorative occupation, and Perceived stigma* (2019, pp. 1452-1454), as illustrated in Figure 1, in Section 3.5.1.

7.1.1 Dyadic relations

The first client factor is dyadic relations that may impact the next of kin's ability to experience respite. We found that the participants had a long-term relationship with their relatives with dementia. From the next of kin's point of view, most experienced this relationship as positive. In all, 86% of the married dyads reported having a good to excellent relationship with their spouse (question 7 in the QoL-AD). The adult children and close relatives who served as caregivers reported having a good to excellent relationship with the relative with dementia (question 6 in the QoL-AD) (Study 1). The participants described the relationship in an empathetic way; they cared about the well-being of the relative with dementia and truly wanted him or her to have good days with accomplishments and enjoyment (Study 2). From a structural family theory point of view, the family is considered to be the closest and influential interpersonal context throughout the life span and clearly plays a role in the next of kin stress processes (Mitrani et al., 2006). Our studies found the experience of a good relationship can be interpreted as a mediator for the next of kin's experience of burden (Steadman et al., 2007; Vedhara et al., 2000), as well as a factor that may have promoted our participants to seek respite service and, in addition, experiencing respite for both persons in the dyad (O'Shea et al., 2019; Leocadie et al., 2018).

During the course of dementia, the participants described a change in the relationship from one of mutuality to becoming more like a caregiver who increasingly had to take over tasks and responsibilities in the daily life of their relative with dementia. This situation can be interpreted as a transition into a caregiver role triggered by a change in health/illness situation (dementia) of a relative. Such situations are a period where the next of kin are more vulnerable to the risk of burden of care (Meleis et al., 2000; Peacock et al., 2017).

Furthermore, these changes are described as one reason to apply for respite or other care services (Brodaty & Donkin, 2009; Leocadie et al., 2018).

The participants in Study 2 experienced both grief and worry about the care situation for the relative with dementia, and this may have influenced their decision to apply for a respite service and later to seek other municipality services. The participants also reported mixed feelings, such as irritation, and described how their patience was being continually put to the test, thus affecting the relationship. Whether these feelings contributed to seeking respite for our participants is somewhat unclear. However, studies have described the next of kin to

people with dementia experiencing mixed feelings, such as guilt, betrayal or having abandoned the person with dementia attending a daycare service (Solum Myren et al., 2013; Tretteteig et al., 2017b). Yet, although our participants did not directly express feelings of having abandoned the relative with dementia at the FDC, they were worried about how the relative with dementia would adapt to the FDC and whether they would want to stay there or would refuse to attend. None of the eight participants reported that their relative with dementia opposed attending the FDC (Study 2). However, in the light of stress theory such issues may occur as stressors and can lead to conflict in the dyad and increased feelings of frustration and burden for the next of kin (Pearlin et al., 1990; Robinson et al., 2012). According to Meleis' theory, a transition into a caregiver role affects the next of kin's feelings as described above and can be difficult for the next of kin to deal with without proper support from both an informal and a formal network (Meleis, 2015).

Another important finding is that the participants expressed a strong commitment and obligation to help their relative with dementia, even though doing so might affect their own well-being (Studies 2 and 3). Both stress theory and previous research has highlighted that family relationships and a shared history are strong factors in the decision to provide care for a relative with dementia (Greenwood & Smith, 2019; Pearlin et al., 1990; Quinn et al., 2015). Relationships are described as being dynamic and complex in nature, especially in married couples or people living in a partnership (Evans & Lee, 2014). Previous studies have found that spouses have reported greater feelings of closeness to their spouse with dementia in the present than in the past, despite changes in their relationship (De Vugt et al., 2003; Joling et al., 2010; Roth et al., 2009). As described earlier in this section, the present study found that the dyads had a good relationship. However, it provided no information as to how the dementia influenced the relation due to feelings of closeness.

As the dementia symptoms and NPS increased, the participants assisted their relatives more, and this assistance continued to increase as the disease progressed. Furthermore, the burden of care increased as the caregiving demands soared and the FDC could no longer meet the relatives' increasing needs for care, so that a transition to another service, usually to a nursing home, was needed. Few of the participants seemed to be offered more time at the FDC or other services to support them and their relatives with dementia during this difficult

period, while waiting for a place at a nursing home. This corresponds to the findings of a previous Norwegian study about resource use in the course of dementia, which found that the next of kin increase the amount of time they devote to caring for their relative, while at the same time, the municipal healthcare increases its services only slightly just before the relative's transition to a nursing home (Vossius et al., 2015). Lack of respite services is a challenge for municipalities, which have a responsibility to support and tailor interventions to next of kin and their relatives with dementia (Helse og omsorgstjenesteloven, 2011; Norwegian Directorate of Health, 2017).

The dyadic relationship and carer psychosocial factors are related to each other and may influence the next of kin's experience of respite.

7.1.2 Carer psychosocial factors

Next of kin may experience numerous psychological and social barriers that influence them to seek and to experience respite (O'Shea et al., 2019). The experience of burden is one of these factors, with more than half of our participants living with a relative with dementia had an RSS score above 23, indicating a high level of burden (Study 1). In addition, we found associations between burden (RSS) and the NPS score of people with dementia, living with a relative with dementia, anxiety symptoms, and perceived social support. NPS and ADL impairment of the person with dementia are associated with primary stressors that affect the next of kin's burden of care (Pearlin et al., 1990; Zarit, & Whitlatch, 2022). Increased NPS represents a well-documented reason for caregivers to seek services, especially nursing home placement, and such symptoms are significantly associated with the burden of care (Toot et al., 2017; Wergeland et al., 2015). Also, living with a person with dementia has been found to be more likely to cause anxiety than depression (Mahoney et al., 2005). However, the participants in the present study, reported few anxiety symptoms and most were within the normal range on HAD-A (0–7) (Zigmond & Snaith, 1983) (Study 1). In the qualitative studies, the participants expressed a worry for the future, a finding which can be understood as experiencing general worries over their situation more than a case of anxiety symptoms (Zigmond & Snaith, 1983). Thus, the findings in the three present studies do not support the notion that those who live with a person with dementia is more likely to develop anxiety symptoms.

The three studies in this thesis have shown that living with a relative with dementia is associated with increasing amounts of time devoted to caregiving and experiencing the burden and a lower level of QoL. Many next of kin experience being "on duty" 24/7 and do not get the opportunity to relieve themselves and rest. Studies have demonstrated that more time spent on caregiving, together with experiences of strain and worrying about the future, are negatively associated with the next of kin's QoL (Brodaty & Donkin, 2009; Bruvik et al., 2012). As expected, those who lived with a relative with dementia were older than those who did not, and older age is considered a factor that may promote seeking respite (Alzheimer's Association, 2021). We also found that living with a relative with dementia, anxiety symptoms, and perceived social support were associated with the participants' QoL (QoL-AD). Previous studies have indicated that perceived support is highly significant for next of kin in the caregiver role and for their experience of QoL and the burden (Bøen et al., 2012; del-Pino-Casado et al., 2018; Kourakos et al., 2016). Our findings indicate that increased perceived support is associated with less of a burden and better QoL. Lack of or little perceived social support may be a factor in seeking respite for our participants. Living with a person with dementia often increases the risk of social isolation and decreases perceived social support, especially as the dementia symptoms progress (Au et al., 2009; Roth et al., 2009). Resources such as social support, formal and informal help, knowledge about dementia and adequate coping strategies can act as mediators of burden (Pearlin et al., 1990; Vedhara et al., 2000).

Although many of the participants expressed having experienced a burden, they still reported a high QoL (QoL-AD score ≥ 37) (Study 1). Several factors may influence the experience of QoL. Chappell and Reid (2002) argued that there is an association between the QoL of the person with dementia and that of the next of kin. When the relative with dementia reported a high subjective QoL (as described in Ibsen et al., 2019), this may have acted as a mediator that influencing the next of kin's high QoL (Pearlin et al., 1990). The participants stated that the well-being of their relative with dementia has great significance for their own well-being (Study 2).

More than half the participants in Study 1 had attended caregiver school, and most were spouses. We did not find that attending caregiver school was associated with a lesser burden or an improved QoL (Study 1). However, Jensen et al. (2015) concluded in a systematic

review and meta-analysis that educational programmes have a moderate effect on the caregiver burden, but their effect on the QoL is unclear. Another study showed that next of kin find value in meeting others with similar experiences to their own, e.g. in caregiver school or in courses (Hotvedt et al., 2016; Larsen et al., 2020). Furthermore, the social support provided through this service is perceived as important for participants and may contribute to a more understandable and manageable life situation for caregivers of people with dementia (Larsen et al., 2020). According to both transition theory and stress theory, knowledge – here about dementia and care systems (as gained at caregiver schools) – can be considered a mediator of negative caregiving challenges and with the potential to promote coping strategies and positively influence mental health (Meleis, 2015; Pearlin et al., 1990; van der Lee et al., 2014). However, neither in Study 2 nor Study 3 did the participants mention either positive or negative experiences in relation to attending caregiver school. Therefore, we do not have a clear picture of how attendance may or may not have affected their experiences of respite or coping strategies.

During the period before the people with dementia and the next of kin applied for respite service, the daily life of each dyad gradually changed as the symptoms of dementia increased and NPS rose (Studies 2 and 3). The relative with dementia become increasingly more passive and less interested in taking part in social activities and performing daily tasks, and thus, the next of kin took on the responsibility for tasks that his or her relative had done before. Most next of kin stated that they found their life circumstances to be challenging and burdensome, and this led to contact with the healthcare service in the municipality with the agreement of the relative with dementia. This is in line with previous Norwegian studies with similar findings (Moholt et al., 2018; Solum Myren et al., 2013; Tretteteig et al., 2017b). The next of kin were in a situation where they came to realise that something must change in the dyad's life (Meleis, 2015). According to Meleis, a shift in awareness may result in both periods of instability and/or distress. In these periods the next of kin are at risk of making unhealthy or healthy decisions (Meleis, 2015). For our participants, this awareness contributed to a search for information and services that could help to ease their situation (Studies 2 and 3). On the other hand, the next of kin may experience personal, psychological, and social barriers to seeking respite. An example of this phenomenon is the fear of losing control of the care of the person with dementia. Moreover, when others take over caregiving duties, the next of kin may feel that they have failed in the caregiver role,

causing them to question their own coping abilities (Phillipson & Jones, 2012). In a study about barriers and facilitators to formal dementia care, Stephan et al. (2018) found that lack of knowledge and information regarding dementia and available services may hinder the next of kin from seeking support in the municipality. The psychosocial factors are individual to each next of kin and are interwoven with dyadic relational factors and the perception of need as well as the service factors (section 7.2). According to O'Shea et al. (2019), services play a significant role in assisting the next of kin to overcome these barriers and achieve respite as a mental break.

7.1.3 Recognizing and accepting needs

Strang (2000) suggested that the first step towards achieving a mental break from caregiving is to acknowledge the need for a respite, or as Meleis formulated it, to come to *awareness* (Meleis, 2015). This must be followed by a process whereby the next of kin accepts this need and allows herself or himself a break from time to time. Stephan et al. (2018) argued that the next of kin to people with dementia in an early stage of the disease may not experience a need for help and, therefore, do not seek services. In contrast, our findings indicated that the relative with dementia was typically at an early stage of the disease when the participant reached a point where she or he recognized that the life situation, especially for the relative with dementia, had become challenging as symptoms had increased. It was difficult for the participants to watch their relatives with dementia undergo these changes, and they experienced both sadness and concern about the situation for their relative. These feelings turn led the next of kin to contact the healthcare services, and their relative with dementia was offered a place at an FDC. In the lens of transition theory, our next of kin described their experiences and feelings that characterize such a transition process (Meleis, 2015), with the transition constituting a period of instability accompanied by uncertainty that represents a passage from one state to another (Meleis et al., 2015).

7.1.4 Positive occupation

Positive occupation, or restorative occupation, is any activity performed to achieve a mental break and to re-energize (Watts & Teitelman, 2005). Activities like enjoyable hobbies, being physically active or being socially engaged are examples of positive occupation that may contribute to this (Watts & Teitelman, 2005). According to Farina et al. (2017), possibilities to participate in activities without caregiving duties were positively associated with better

QoL. Although most of the participants in Study 1 reported having hobbies and being physically active, we found no significant associations between hobbies or being physically active and the QoL or the burden. In contrast, Bruvik et al. (2012) asserted that, for next of kin of home-dwelling people with dementia, having a hobby was significantly associated with a better QoL. The authors indicated that being able to spend time on a hobby might benefit the next of kin's mental health (Bruvik et al., 2012). In the present study, the participants highlighted the opportunity to engage in activities on their own, such as pursuing a hobby or engaging in a social activity without feeling guilty about leaving the relative with dementia unattended (Study 2). Another important aspect for the participants was having time to take care of their own health, to rest and re-energize when they felt worn out from caregiving. These findings may indicate that the next of kin experienced the FDC as a respite, that is, a break that enabled them to return to caregiving with renewed energy or, as O'Shea et al. (2019) described it, with the 'increased capacity to care' (p. 1458). The participants also reported that they used the respite service as a chance to complete as many chores and errands as possible (e.g., shopping, household tasks) and to socialize by meeting others (Study 2). Our findings are consistent with those of other studies regarding these matters (Lund et al., 2009; Tretteteig et al., 2017b). In O'Shea et al. (2019), the experience of respite is connected to maintaining social relationships, which also corresponds with our findings. Watts and Teitelman (2005) emphasised the importance for next of kin to engage in activities that provide a distraction from the stress of caregiving as these activities are central for 'renewal' and 'mental clarity'. The next of kin might also experience what in stress theory is described as 'competence and gain' feelings of mastery and increased self-esteem in the situation (Pearlin et al., 1990).

When their relative's symptoms of dementia increased and a transition to another care service became necessary, most of the participants experienced limited time to re-energize. They described that they 'put their lives on hold' and that the care situation had affected their life and health (Study 3). Our findings align with those of other studies of next of kin and their experiences when the dementia symptoms increase and lead to a need for a higher level of services, in particular, a trigger in the transition to nursing home care (Meleis, 2015). For the next of kin this is a stressful experience (Afram et al., 2015; Rose & Lopez, 2012; Ryan & Scullion, 2000). Half the transitions were unplanned, and the time before the transition (Study 3), whether planned or not, was extremely demanding for the participants and for

their relatives, as described in other studies (Afram et al., 2015; Jacobson et al., 2015). Planning and fostering familiarity with the new service prior to the move may partially mitigate the next of kin's sense of lost control that is common during a relative's transition to a nursing home (Jacobson et al., 2015). Moreover, our findings indicate that in this transition period the next of kin did not experience respite as a mental break and an attribute of respite service as described in O'Shea et al. (2019). Health or social care staff can play an important role in facilitating healthy transitions by recognizing critical points and changes and supporting the next of kin in the transition process (Aspö et al., 2023; Meleis 2015).

7.1.5 Perceived stigma

According to Batsch et al. (2012), a stigma is a way of classifying an individual in an undesirable and stereotypical way. A stereotype is a negative belief about a group of people and may negatively impact service use (Alzheimer's Disease International, 2012; Werner & Heinik, 2008). The results of the three studies gave no clear indication of whether the next of kin perceived a stigma in relation to their relative with dementia. The participants in Study 2 were explicit about the importance of a service that had 'an atmosphere of real life' as opposed to a constructed 'institutional life'. They wanted their relative with dementia to be able to participate in the normal setting found on a farm in contrast to 'institutional life' as most daycare services in Norway are located within institutions (Norwegian Directorate of Health, 2019). This may be understood as a stigma since attending a service in a nursing home is often associated with illness or disease, advanced age, end of life or simply a life outside society in relation to transition theory, the society's or social network's attitudes about people with dementia (or stigma) can affect the next of kin negatively in the process of transition.

The three studies showed that experiences of burden or strain were prominent, especially among the next of kin living with a relative with dementia. Werner et al. (2012) found a link between a caregiver stigma and a caregiver burden in dementia; whether this stigma represented an obstacle to seeking respite is unclear. According to Robinson et al. (2012), a stigma is a key factor in terms of respite service for people with dementia. From the point of view of some next of kin, attendance at a respite service leads to feelings of insecurity and increases anxiety among people with dementia (Robinson et al., 2012). However, no participants reported such experiences (Studies 2 and 3). About 53% of our participants had

participated in caregiver school and received information about dementia. I suggest that participating in this service may have helped them overcome a potential stigma about respite service (Study 1). Werner et al. (2012) suggested the use of psychosocial interventions to target stigmatizing beliefs, thereby, reducing the caregiver's burden.

7.2 Service factors

In this section, the FDC service factors and their potential influence on the next of kin's experiences of respite will be discussed. The four service factors are *Service model and characteristics*, *Care quality and staff expertise*, *Meaningful occupation for the person with dementia*, and *Communication and Support* (O'Shea et al., (2019, p. 1455). The findings are mainly from Study 2, in which the participants described their experiences with an FDC.

7.2.1 *Service model and characteristics*

The participants highlighted that the FDC and its characteristics were important for them regarding their experience of respite. The findings indicated that the participants viewed the FDC as part of community life since the service took place on farms with agricultural production as described in section 7.1.5. It was important to them that their relatives with dementia could spend time in an environment where they could participate in different activities, such as having contact with farm animals, which most of the FDCs have. This was especially true for attendees who had had experience with animals earlier in their lives. Hassink et al. (2017) found that contact with animals at an FDC had several potentially positive influences on attendees, including being busy and occupied, which distracted them from their problems and made their days more meaningful. Other studies have described how spending time in nature and with animals was one of the health-promoting elements of care farms/FDCs (de Bruin et al., 2017; Pedersen et al., 2012). However, not all participants reported that their relatives enjoyed being with animals. These participants emphasized their relatives' participation in other enjoyable activities facilitated by the staff and based on the individual preferences of each person with dementia. These findings can be understood as the staff facilitating what Kitwood described as inclusion and occupation at the FDC (Kitwood, 1997; Kitwood & Brooker, 2019).

The participants described the environment, buildings, and outdoor areas of the FDC as offering opportunities for different activities that promoted participation as well as a feeling of freedom for their relative with dementia. The physical environment, especially, stimulated the attendees to maintain physical functions by participating in activities such as gardening, walking in the forest, cutting and stacking wood, or feeding the animals, in addition to offering a social community and other enjoyable activities. These findings align with those of other studies of next of kin's experiences with an FDC (Solum Myren et al., 2017; Strandli et al., 2016). The environment at the farm gave attendees opportunities to be more active in their daily lives and a change from the passivity that characterized their lives before the FDC. In these ways, the next of kin considered the FDC as beneficial for their relative. In contrast, the next of kin may hesitate to use services that they do not perceive as beneficial for the person with dementia (Neville et al.; 2015).

Ibsen et al. (2018) compared an FDC and regular daycare and found that the services have similarities regarding organization, daily structure, and number of staff with a health education. The main difference was the type of care environment. An FDC features a wide range of activities and available resources such as farm buildings, gardens, farm animals, and outdoor areas. As described in section 7.1.5, some people with dementia and their next of kin find it difficult to accept a regular daycare service located in a nursing home or other institutional setting, while a farm setting makes its daycare location more acceptable (Strandli et al., 2016). From the next of kin's perspective, both persons in the dyad appreciated the FDC's home-like environment with its small group of attendees (6–8 people). These attributes made it possible for attendees to interact with each other, and to experience a sense of community with others in the same situation, as well as make new friends. An environment that supports positive interactions contributes to supportive social psychology, which is an important factor in person-centred care (Brooker, 2013; Kitwood, 1997). Finnanger Garshol et al. (2021) found in their study a positive association between social interaction, social activities, and emotional well-being in the participants attending the FDC and regular daycare. In addition, they indicated that a positive association between FDC and emotional well-being may potentially reflect a positive influence of the farm setting and the farm service providers. Our findings indicate a similar positive association from the next of kin's perspective. Participating in an environment that facilitates

community and emotional well-being was beneficial not only for the relatives with dementia but also for their next of kin's experience of respite. The findings described above correspond with the S in Brookes (2004) acronym (V+I+P+S, described in section 3.3.2) for person-centred care: that a positive social environment can contribute to an experience of well-being for the person with dementia. The relative with dementia attending the FDC seems to have a positive impact on the relationship as the dyad had more to talk about and share than before the relative attended an FDC. In stress theory, this experience can be interpreted as a mediating factor to the burden of care for the next of kin and the relationship to the relative with dementia (Pearlin, 1990). This also corresponds with a positive outcome of respite described in the model by O'Shea et al. (2019).

Studies have shown that it is important to the next of kin for daycare to be flexible in terms of meeting the needs of the person with dementia and the next of kin regarding availability, opening hours, activities, transport, and meals (Taranrød, 2011; Tretteteig et al., 2016; Tretteteig et al., 2017b). We found that the next of kin considered the transport arrangement to be safe for their relative and an advantage that the staff provided, also allowing the relatives to recognize the staff and feel safe. The transport arrangement is an important part of daycare; if it does not work well for the person with dementia, it can be a reason for not using the service (Taranrød, 2011). The participants had an average of two and a half days of respite per week. This included regular daycare as 17 relatives with dementia attended this service in addition to the FDC (Study 1) because the FDC had limited opening days per week. Regarding flexibility in terms of opening hours and days per week, a study by Ibsen et al. (2018) found that FDCs offered, on average, fewer days per week and fewer hours per day compared to regular daycare. The findings in our study indicate that the FDC did not have the capacity to cover the full need for respite; several participants reported a need for additional respite time than they were offered. We did not find a significant association between days of respite per week and RSS or QoL-AD (Study 1). This may indicate that the amount of respite time is not adequate to reduce the burden or that those with a higher burden may have waited too long to seek help and respite (Vandepitte et al., 2016). However, although the participants reported a need for more days of respite, they still described experiencing the respite as positive for helping to ease their burden of care. From

the next of kin's perspective, the FDC contributed to a better everyday life for both them and the relatives with dementia.

7.2.2 Care quality and staff expertise

The quality of care offered at the FDC is a major issue for the next of kin (Studies 2 and 3). The participants highlighted the quality of care and attributed it to the staff's ability to facilitate an inclusive community for the attendees. Moreover, the participants had great confidence in the staff and how they approached their relatives with respect, dignity, and care. In contrast, an absence of confidence in the service and a low quality of care provided by staff are barriers to a positive respite experience for the next of kin (Leocadie et al., 2018; Tretteteig et al., 2016). The participants also noted that the staff's dementia-specific knowledge and awareness of each person with dementia and his or her social competencies were central for the next of kin's perceptions of quality care and, thereby, for their respite experience. These findings are in accordance with several other studies on the subject (Neville et al., 2015; Stephan et al., 2018; Tretteteig et al., 2016). Also, Ibsen et al. (2018) found that 78% of all FDCs had staff with some health education, and for FDCs with more than four attendees, this figure was 92%. This is approximately the same as in daycare for people with dementia in nursing homes in Norway (Gjøra et al., 2015). In addition, 81% of the staff at the FDCs had formal or informal agricultural competence, which is important for facilitating safe activities for attendees (Ibsen et al., 2018). In Norway, as in many other countries, a person-centred approach is state of the art for care and is characterized by empathy, respect, and understanding in caring for the individual person with dementia (Brooker, 2013; Norwegian Directorate of Health, 2017). From the participants' descriptions of the staff's *care quality and staff expertise*, it can be understood that the staff have a person-centred approach as described in Kitwood and Brooker (2019). In addition, the daily programme at the FDC was organized in a supportive way so that the attendees enjoyed staying at the FDC. In line with what Gustafsdottir (2011) pointed out, a well-organized daycare provides support and enriches everyday life for people with dementia as well as for their next of kin.

7.2.3 Meaningful occupation for the person with dementia

The intentions of daycare for people with dementia include increasing their well-being by facilitating and engaging them in meaningful activities within a safe environment and

promoting respite for their next of kin (Norwegian Ministry of Health and Care Services, 2015). The participants' experiences of respite were closely connected to that their relatives enjoyed the activities at the farm and having a meaningful day there.

According to Phinney (2006), activities are considered meaningful when they involve doing things that matter and when they enable a person to stay engaged in everyday activities and in personal relationships. Tierney and Beattie (2020) described activities as meaningful when a person enjoys the activities, when the activities are tailored to the individual's interests and abilities, and when the activities are related to the person's goals. In addition, such activities express and reinforce the attendee's identity (Kitwood & Brooker, 2019); examples of activities at the farm are described in section 7.2.1. Our findings indicate that the participants were satisfied with how the staff facilitated the activities based on their relatives' wishes and opportunities. In addition, the next of kin found that their relatives' moods were improved and that they could better communicate what they had experienced during the day compared to the situation before attending the FDC. These experiences affected the dyadic relationship in a positive manner; the pair had more to talk about and to share, and this can be understood as a positive outcome experience of respite in O'Shea et al.'s (2019) model and may have acted as a moderator of the burden of care (Pearlin, 1990). The participants commented that these positive experiences were connected to their relatives having meaningful days at the FDC. Also important to the next of kin was that the relative with dementia was physically active at the FDC, which helped to delay physical deterioration. The participants further experienced that their relative slept better after a day at the FDC, and this resulted in more restful nights with fewer interruptions for the participants. Similar findings have also been reported in other studies of the next of kin with relatives attending regular daycare (Tretteteig et al., 2017b). Our participants attributed the experiences of respite to their relatives having a good day with meaningful activities at the FDC, and these findings align with those of other studies that looked at caregiver respite related to FDCs (Solum Myren et al., 2013; Strandli et al., 2016) and with O'Shea et al.'s (2019) model of respite.

In addition, from the next of kin's point of view, the time at the FDC contributed to the well-being of their relatives and thereby positively affected the dyadic relationship. This experience can be interpreted as a factor contributing to improving or maintaining the dyadic relationship and acting as a factor mitigating the negative effects of the next of kin's stress

experience, in line with stress and structural family theory (Mitrani et al. 2006; Pearlin et al., 1990).

The next of kin's experience of the opportunities for their relatives with dementia to participate in varied and meaningful activities at an FDC is a notable strength of the FDC that is of great importance for the next of kin's experience of relief and is an example to be followed when new services are to be established.

7.2.4 Communication and support

The importance of communication, support and information between staff in respite services and the next of kin is highlighted in several studies as significant for the next of kin's perceptions of respite (Donath et al., 2009; O'Connell et al., 2012; O'Shea et al., 2017). The participants described the first meeting with the municipal healthcare service as a positive experience: they were met with understanding and given information about municipal services. In addition, in their meeting with staff at the FDC, the next of kin were provided with valuable information about the programme. The participants also described an open and beneficial dialogue with the staff, for instance, by text message, telephone call, email, or a chat when the relative was picked up at his or her home. Some FDCs invited next of kin to meetings regularly or when needed. The participants highlighted the close contact between the staff and the healthcare system in conveying the needs of relatives with dementia and their next of kin. The support from the FDC was crucial for the participants, knowing that they had someone with whom to share the responsibility for care, thus giving them a sense of security and comfort. One can interpret the decision to seek respite and attend the FDC as a response to its positive outcome for both members of the dyads and being in line with what Meleis calls a *healthy transition decision* (Meleis, 2015). However, this pattern can also take a contrary drift. In contrast to our findings about the positive dialogue with the staff, another study reported that the next of kin felt that the services could better support them if the staff engaged in dialogue with them about their relatives with dementia and their care needs (Phillipson & Jones, 2011).

At a certain point, in the progression of dementia, the situation for the dyad resulted in that the FDC was no longer an option, thus necessitating transition to another care service. Our findings indicate that when participants' care tasks increased, their feeling of burden also

increased due to their relative's reduced state of health. In such situations, both members of the dyad are in a vulnerable situation, and support from the health service takes on even greater importance (Alzheimer's Association, 2021; Egilstrod et al., 2019). We learned that the participants experienced helpful dialogues with the head of the FDC and the multidisciplinary team regarding the care situation. Despite some negative experiences related to receiving information about care options from the healthcare system, the participants felt supported. Our findings further indicate that, although the participants' situations had become more demanding, the support provided by the FDC and the multidisciplinary team was inadequate to meet the increasing needs of their relatives with dementia and, thereby, the next of kin's need for respite.

Six of the eight persons with dementia in our study transitioned to a nursing home and two to a daycare in a nursing home (Study 3). Four of the transitions had been planned; thus, the dyads were somewhat prepared for the transition. By contrast, the four transitions that were not planned involved several relocations for the persons with dementia. The periods before and during the transition were experienced as highly stressful for the next of kin. They did not experience adequate support from the healthcare system, and they 'put their lives on hold' and concentrated on making everyday life as good as possible for their relatives with dementia until a permanent place in a nursing home could be arranged (Study 3). According to transition theory, health or social care staff play an important role in facilitating healthy transitions by recognizing critical points and changes and supporting the next of kin in the transition process (Aspö et al., 2023; Meleis, 2015). Unfortunately, for some of the participants, this was not the case. The next of kin must be offered timely help that aims to prevent and ease the caregiver burden as well as the situation for the relative with dementia (del-Pino-Casado et al., 2018).

Finally, according to O'Shea et al. (2019), respite service is 'in more recent years coming to be understood from the carer's perspective, i.e. as a psychological outcome of a mental break for carers' (p. 1459).

In summary, the findings we present in this thesis indicate that the next of kin experienced a mental relaxation by having the FDC as a respite service. The most notable finding was that the next of kin's experience of respite as a mental break was strongly connected to the

relative's well-being and having a good day at the FDC. Therefore, it can be said that respite experiences are closely associated with the characteristics of the FDC (section 7.2) in an interaction with client factors (section 7.1).

8 Methodological considerations

For the present thesis, three studies were conducted using different research methods. In Study 1 with a quantitative method, its strengths and limitations are examined in relation to the reliability and validity of the findings. In Studies 2 and 3 with a qualitative method, the strengths and limitations were evaluated in relation to trustworthiness. The inclusion of both quantitative and qualitative studies to enhance knowledge about the situation of the next of kin of people with dementia is considered a strength of the PhD project.

8.1 Study 1: Validity and reliability

A strength of Study 1 is that standardized scales were used. The scales have been adequately tested and used in clinical practice, research, and in the general population as well as with disease-specific groups and caregivers to people with dementia (RSS, MADRS, HADS-A, QoL-AD). The OSS-3 scale has been used in a study of older adults living at home (Bøen et al., 2012). The scales have been found to have reasonable reliability, meaning that they have good internal consistency between items and temporal stability, i.e. across time. However, there were several considerations regarding the QoL-AD and HADS-A. We decided to use the QoL-AD scale in the absence of a more widely accepted carer measure; it has been used in several Norwegian studies of next of kin (Bruvik et al., 2012; Rokstad et al., 2016; Rosness et al., 2011). Another reason for the extended use of this disease-specific scale with next of kin can be found in Lawton's statement that QoL in dementia illness comprises the same areas as in people in general (Lawton, 1994).

The HADS-A scale is part of the Hospital Anxiety and Depression (HADS) scale. HADS is interpreted mostly as a two-factor measure of anxiety (HADS-A) and depression (HADS-D) (Bjelland et al., 2002; Zigmond & Snaith, 1983), and both subscales are considered reliable and valid instruments for assessing anxiety and depression (distress) in different study populations (Bjelland et al., 2002). The HADS scale is recommended in the European consensus guidelines for next of kin of people with dementia (Moniz-Cook et al., 2008) and has been used in clinical trials of next of kin of home-dwelling people with dementia (Charlesworth et al., 2008; Livingston et al., 2013). Therefore, we chose to apply HADS-A to our mapping tools. However, a study by Stott et al. (2017) questioned the two-factor measure structure of the HADS in a sample comprised solely of next of kin to people with

dementia and, thereby, the construct validity of HADS-A. Stott et al. (2017) conducted a confirmatory factor analysis of HADS to test whether a one-, two-, or three-factor structure best fit the data from next of kin. They interpreted the HADS data as measuring three factors: depression, anxiety, and negative affectivity. The authors recommended that the HADS two-factor model should ‘perhaps be revisited’ and that ‘there is a need for further research’(p. 1279) because the constructs of the subscale HADS-A are unclear. They further recommended using the HADS-D and not the HADS-A as an outcome in research of next of kin to people with dementia (Stott et al., 2017). However, we did not use HADS-A as an outcome, and therefore, we considered that our results were not biased by using this scale.

The interviews with next of kin were mainly conducted face to face, which gave the interviewers opportunities to request additional explanations when needed. However, the presence of an interviewer can influence participants’ answers. Polit and Beck (2021) suggested that participants may provide only socially desirable answers when they have not been guaranteed anonymity. In Study 1, 10 interviewers conducted the interviews, and we may have had different approaches to how we guided the participants through the interviews. Therefore, to minimize differences, we received the same training and a comprehensive manual on how to collect the data. Issues around collecting the data were also discussed in the WPA project group to gain a common understanding. We consider this a strength of the study.

As described in section 5.1.4, it was not possible to include all the next of kin of people with dementia attending an FDC due to inclusion criteria and potential participants who did not want to take part in the study. The validity of our findings may have been strengthened by including a corresponding control group with the same characteristics. A control group would have allowed us to compare the characteristics of next of kin of people with dementia attending an FDC with the next of kin who had another type of respite daycare or no respite at all.

Another factor is that the limited number of participants may have affected the statistical power and representativeness of the sample in Study 1. However, due to the sample size, we included a limited number of variables in the two-regression analysis (Field, 2018; Green,

1991). Although there may be differences between those who accepted the invitation to participate and those who declined, the present study represents five-sixths of all FDCs in Norway and more than half of those who met the inclusion criteria (described in section 5.1.4). Thus, we consider the sample to be representative.

8.2 Studies 2 and 3: Trustworthiness

Trustworthiness refers to the quality, authenticity and truthfulness of the findings of a qualitative inquiry and must be evaluated in relation to the process used to generate, analyse and interpret the findings (Graneheim et al., 2017; Korstjens & Moser, 2018; Lincoln & Guba, 1985). We have attempted to describe the process openly and reflexively, presenting each step of the research in detail and describing the context of the studies (5.3.5).

Credibility refers to the confidence that can be placed in the research findings and the interpretation of them (Polit & Beck, 2021). According to Graneheim and Lundman (2004), the question of credibility arises when making decisions about the focus of the study, the selection of context, the participants, and the approach to gathering data. Polit and Beck (2021) noted that including participants with various experiences increases the possibility of shedding light on the research question from a variety of aspects and, thereby, increases its credibility. A purposive sample with a variety of experiences was chosen to participate in Studies 2 and 3. The samples represented various FDCs and parts of Norway. The participants varied in age, gender and whether they lived with the relative with dementia or not, and this can be considered a strength of the studies. For Study 3, the sample represents transitions to different municipality services and is, thus, also considered a strength of the credibility of the findings. Another way of strengthening the credibility of the studies according to Lincoln & Guba, (1985), is to conduct a member check, e.g. letting the participants read the transcriptions, before we started with the analyses, to confirm exactness. The participants did not read the transcripts. However, in case of ambiguities in the interviews, I asked the participant to describe the topic again to make sure I had understood it correctly.

Dependability refers to the degree to which data changes over time and during modifications made by the researcher during the analysis process (Graneheim & Lundman, 2004). For both

studies, the PhD candidate and supervisors maintained an open dialogue, discussing meanings, similarities, and differences in understanding the data (the next of kin's experiences). To achieve dependability and promote the *voice* of the participants, we strived to stay close to the text and the participants' own words and expressions.

Confirmability refers to the objectivity in research. That is, if two different people had conducted the research, would the results be similar? To achieve confirmability in qualitative research, the results must be reflected in the participants' voices and in the research settings rather than in the researcher's sources of error (bias), motivation or perspectives (Polit & Beck, 2021). During the interviews, I consistently strived to be as objective as possible and to listen carefully to the participants' narratives without letting my pre-understanding be a hindrance. Therefore, to meet this criterion, in the results section we used direct quotations of participants to promote confirmability. The analyses of the data from the studies were conducted by me and three supervisors with different research backgrounds. We consider that this has also promoted confirmability.

The *transferability* of a study is the degree to which the findings can be transferred to other contexts or settings (Korstjens & Moser, 2018; Lincoln & Guba, 1985). Study 2 described elements of importance for the next of kin to a person with dementia attending a particular type of daycare, while Study 3 described significant aspects of the transition process from FDC to another service in a municipality. The studies shed light on common experiences of the next of kin to a person with dementia but within a specific context. Both studies reveal essential structures and topics that could be important for next of kin to people with dementia in similar situations and other contexts.

Finally, *authenticity* implies that we, as researchers, 'have fairly and faithfully tried to show a range of realities' (Polit & Beck, 2021, p. 570) that reflect the participants' experiences so that readers of our studies are able to understand these experiences of next of kin to relatives with dementia attending an FDC. It is desirable for people with dementia to live in their own homes if possible, and to accomplish this, municipalities must find suitable solutions for the target group and their next of kin, including different types of daycare services. Based on the lack of knowledge about the next of kin to people with dementia attending FDC, our study

represents new knowledge that sheds light on important aspects, thereby contributing to the field.

9 Conclusions, implications for practice and future research

9.1 Conclusions

The overall conclusion is that FDC for people with dementia contributed to the next of kin's experiences of support and respite in a period in the course of dementia before the needs of those with dementia exceeded what could be addressed within the FDC service. The findings revealed that the next of kin's experience of respite was closely linked to the well-being of their relative at the FDC. From the next of kin's perspective, the staff at the FDC were a key factor in facilitating meaningful activities for attendees using the farm environment and social interaction. The staff's care practice was found to be consistent with a person-centred approach. Furthermore, the experience of respite was linked to having someone to share care responsibilities and having a good dialogue with the staff at FDC. The findings also identified a preponderance of next of kin (spouses) living with a relative with dementia using FDC as respite. These next of kin experienced a greater burden and reported lower QoL than those not living with the relative with dementia, and perceived support influenced both the burden and QoL positively. Despite experiencing a burden of care, most of the participants reported good QoL. However, the period before people with dementia transitioned from FDC to another municipal service was reported to be highly stressful for the next of kin, and they considered it to be stressful for their relative as well. A plan for transition in the course of dementia may prevent unplanned transitions and burden for the next of kin and reduce stress for their relative.

Our findings underscore the importance of maintaining a close dialogue with the FDC and healthcare professionals throughout the course of dementia. The FDC and the municipality healthcare system should provide this form of support to strengthen next of kin's ability to cope with the caregiver role without risking their health. FDC may be improved by adopting greater flexibility in terms of opening hours and days per week. Further, the findings of the present thesis indicate that, from the next of kin's perspective, FDC as a respite, build on a person-centred care approach, can be described as *restorative care* that 'can encompass the perspectives of both the carer and the person with dementia in relation to the use of health

and social care services that currently aim to provide a break in the caregiving relationship' (O'Shea et al., 2019, p. 1461).

9.2 Implications for practice

The three studies described in this thesis were conducted at FDCs. The findings will have relevance for municipalities, which are responsible for providing respite (here, daycare) for next of kin and their relatives with dementia, especially in regard to quality of care and establishing new daycare services. The next of kin's experiences of respite as (described in section 7.2.4) were closely connected to whether their relative with dementia had good days at FDC and whether the staff practiced a person-centred care approach in their facilitation of daily life at the FDC. The goal of the Norwegian government is for people with dementia to continue living at home as long as possible. Thus, the next of kin bear the heaviest responsibility for this group. As such, next of kin and their relatives with dementia need individually facilitated assistance from the healthcare system, FDC, other respite services and healthcare professionals to manage the many challenges they must face throughout the course of dementia. Finally, our findings underscore the importance of obtaining knowledge about the next of kin as well as about persons with dementia regarding their situation, burden of care and QoL. This knowledge is essential for those responsible for providing the best possible services for the next of kin and for developing targeted interventions to support them and their relative with dementia through the course of the disease. This requires close, ongoing collaboration between the next of kin, the people with dementia, staff in daycare services and other municipal healthcare services. Especially in periods of transition between care services, a coordinator or specific contact person in the municipality should support the next of kin and their relatives throughout the process.

9.3 Future research

In this thesis, we have explored the perspectives of next of kin in regard to FDC and transitions to other care services. There is a critical need to further develop ways or models to support next of kin and their relatives with dementia before and during care transitions to minimize or prevent stressful unplanned transitions. A study of next of kin, staff at FDCs, and multidisciplinary teams exploring their different experiences with these issues would be interesting and valuable. Such research could further explore how staff at FDCs, and

multidisciplinary teams view these issues and whether they realize the challenges the next of kin experience. All the studies in the present thesis have a cross-sectional design. Future research should use a longitudinal design to examine which type of service factors and client factors inhibit or promote the next of kin's QoL, burden over time and respite as restorative care.

To gain more-comprehensive knowledge of all next of kin to those who attend FDC, future studies should adopt wider inclusion criteria that would add next of kin who saw the relative with dementia less than once a week, as we lost a proportion of this group whose relatives with dementia attended FDC. Furthermore, future studies should explore whether some of the most-positive aspects of FDC can be incorporated into other types of daycare services.

9.4 Some reflections after completing the three studies

After conducting these studies and meeting many next of kin and their relatives attending FDCs across Norway, it is striking to me that most next of kin were very satisfied' with the service and especially with how staff engaged with each attendee, met them as they were, and facilitated their day at FDC. I believe that FDC is a good alternative respite service for people with dementia and their next of kin. But unfortunately, there are few FDCs in Norway, and therefore, it is not a service option for many who may need it and would benefit from it.

The staff persons I met most often during the project was the leader (farmer) of the FDC who owned the farm. Most of them demonstrated a strong professional commitment to making the service as good as possible for the attendees and next of kin. I experienced that many of the farmers were what we call *ildsjeler* in Norwegian—they had put a lot of energy and effort into establishing and running the FDC. In addition, as private contractors, they were dependent on good collaboration with the municipality that purchases their services. Since there are so few FDCs in Norway, it seems that the municipalities have not prioritized this service option, possibly due to a tight municipal economy. However, I believe that a professional commitment and dedication to the work are key factors in creating effective care services for users and their next of kin, regardless of where the service is located. This is supported by the findings in this thesis.

10 References

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Characteristics, Burden of Care and Quality of Life of Next of Kin of People with Dementia Attending Farm-Based Day Care in Norway: A Descriptive Cross-Sectional Study

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Purpose: Caring for people with dementia is often associated with burden of care and may influence the quality of life of the next of kin. The aim of this study was to describe the characteristics of the next of kin to people with dementia attending farm-based day care service (FDC) and identify characteristics associated with burden of care and quality of life (QoL) of next of kin.

Participants and Methods: Ninety-four dyads of people with dementia and their next of kin were included from 25 FDCs in Norway in this descriptive cross-sectional study. The Relative Stress Scale (RSS) and the QoL–Alzheimer’s Disease Scale (QoL-AD) were used as outcomes measures.

Results: The participants consisted of those who lived with a person with dementia (spouse/partner, 62%) and those who did not (children), with significant differences in age, education level, work employment, perceived social support, depression symptoms, burden of care, and QoL. In multiple regression models, RSS and QoL were associated with living with the person with dementia, anxiety symptoms and perceived social support. In addition, RSS was associated with neuropsychiatric symptoms (NPS) in the people with dementia.

Conclusion: Our findings underline the importance of obtaining knowledge about the next of kin’s burden of care and QoL, of people with dementia attending an FDC. This knowledge is essential for those responsible for providing the best possible services for the next of kin and for developing targeted interventions to support the next of kin.

Keywords: dementia, family caregiver, adult day care service, green care

Introduction

Caring for a person with dementia is often associated with negative consequences. The term burden of care, defined as a multidimensional construct that includes mental, physical, social and financial elements, is frequently used to describe the situation of the next of kin.¹ The burden of care includes objective and subjective elements. The objective element is associated with the dependency of the person with dementia, the ability to perform activities of daily living (ADL), the number of hours spent daily caring for a person with dementia, and neuropsychiatric symptoms (NPS), which are considered to be the most important predictor of the next of kin’s burden of care.^{2–5} The subjective element refers to the next of kin’s psychological responses, which can include distress, anxiety, depression, irritation, or

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feelings of exhaustion related to the person with dementia and the care obligations.^{3,4,6} The next of kin's burden of care may also influence the frequency and severity of NPS in people with dementia.⁷ Burden of care can have multiple associations – with the female sex, living with a person with dementia, poor physical and mental health, low perceived support, a greater number of hours spent on caregiving, additional poor quality of the relationship with the person with dementia, or inadequate coping strategies.^{8–13} Although next of kin report burden of care, they also emphasize positive aspects of caring for the person with dementia such as enjoying togetherness and sharing activities, accomplishments and mastery.^{9,14–16} Both the burden and the positive aspects of caring may influence the quality of life (QoL) for the next of kin.¹⁷

QoL is a broad concept reflecting a person's psychological state, physical health, personal beliefs, and relationships.¹⁸ Quality of life has been described as a concept reflecting objective and subjective factors related to generalized psychological well-being, behavioral competence and environment, with self-perception as a main component.¹⁹ On average, the QoL of the next of kin of people with dementia is lower compared to the next of kin of those with other chronic disorders.^{20,21} Several factors may impact the next of kin's QoL negatively, such as poor physical and mental health, sleep disorders, a lack of respite, and an absence of social support. Furthermore, the next of kin's QoL may be affected by living with a person with dementia, resulting in a poor relationship with the person with dementia and the person with dementia's QoL.^{17,22–24.}

To meet the next of kin's need for information and knowledge, several municipalities in Norway arrange caregiver school and support groups consisting of lectures about dementia and group discussions.^{25,26}

Day care (DC) services have been developed as part of the municipal services^{26,27} and offer activities for people with dementia and a much-needed respite for the next of kin. DC might provide a feeling of safety and relief, increase motivation and decrease the burden of care.^{28–30} In Norway, the farm-based day care service (FDC) is an established type of DC. The purpose of regular DC and FDC is to facilitate meaningful activities in a safe environment, improve QoL and provide respite for the next of kin.^{26,27} FDC is a service with a wide range of activities related to farm buildings, gardens, animals, and outdoor areas. The majority of Norwegian FDCs have people with early-onset dementia or

dementia in an early stage as their main target group.³¹ Both FDC and DC are found to prevent an increase in the burden of care for the next of kin over time.³² Furthermore, FDC appears to be health-promoting for both the next of kin and the person with dementia.^{33,34}

Reports regarding the next of kin, of people with dementia attending FDC, are sparse. Thus, this study aims to describe the characteristics of the next of kin and investigate their burden of care and QoL. To this end, we have addressed three research questions:

1. What are the characteristics of the next of kin?
2. Which characteristics are associated with a self-reported burden of care?
3. Which characteristics are associated with a self-reported QoL?

Materials and Methods

Study Design

This is a descriptive cross-sectional study of the next of kin of people with dementia attending FDCs across Norway. The study is part of a larger project.³⁵ We hypothesized that the characteristics of the next of kin would be influenced by whether they live with a person with dementia or not,²² and this will be focused on in the analyses.

Inclusion Criteria and Recruitment

Inclusion criteria for participants were as follows:

- Next of kin of a person with dementia living in their own home and attending an FDC for at least three weeks.
- Eighteen years of age or older.
- Physically meets with the person with dementia a minimum of once a week on average. Both next of kin and the person with dementia had to give their consent to participate.

Service providers from 30 FDCs recruited the people with dementia and their next of kin, from January 2017 to January 2018. A total of 169 dyads of people with dementia and their next of kin met the inclusion criteria. Sixty-two of these did not want to participate, and 13 dyads were not invited to participate for other reasons (eg, health issues in the family). In the end, 94 dyads were included from 25 FDCs in Norway, representing 55.6% of those who met the inclusion criteria.

Ethical Aspects

The project was approved by the Norwegian Centre for Research Data (NSD) (no. 49799). The next of kin and the people with dementia received oral and written information about the study and gave their written consent, they were also assured that they could withdraw at any time during the data collection. The next of kin, of people with dementia who had reduced capacity to consent, consented on behalf of them. For this study, the next of kin consented on behalf of three persons with dementia. The study was conducted in accordance with the Declaration of Helsinki.

Measures

Sociodemographic data (age, gender, marital status, level of education, and occupational status) were collected. The next of kin were asked whether they were living with the person with dementia or not, their relationship to the person with dementia, if they had hobbies and if they participated in physical activity at least 20–30 minutes a week. In addition, whether they attended caregiver school and support groups, and their respite (ie, the number of days per week the person with dementia was attending FDC/DC) were recorded, as was the length of time the person with dementia had been attending the FDC. The next of kin estimated the number of days they had spent assisting or looking after the person with dementia during the preceding month. In addition, the following questionnaires were used to capture information about the next of kin.

Quality of Life

The Quality of Life–Alzheimer Disease Questionnaire (QoL-AD)³⁶ consists of 13 items. The items are rated on a four-point scale (poor=1, fair=2, good 3, excellent=4), giving a total score ranging from 13 to 52. Scores of <33 and >37 indicate low and high QoL, respectively.³⁷

Burden of Care

The Relative Stress Scale (RSS)³⁸ consists of 15 items, with each rated from 0 to 4 (0=never, 1=rarely, 2=sometimes, 3=frequently, 4=always/to a high degree), giving a sum score ranging from 0 to 60. A score >23 indicates an increased risk of clinically significant psychological distress, and a score ≥30 indicates the person should be referred for psychiatric assessment and treatment when required.³⁹

Anxiety

We used the anxiety part of the Hospital Anxiety and Depression Scale (HAD-A),⁴⁰ which consists of seven items. The items are scored from 0 (not present) to

3 (considerable), yielding a possible sum score from 0 to 21. A 0–7 score is considered normal, an 8–10 score is a possible case, and a score of ≥11 is defined as anxiety.

Social Support

The Oslo Social Support Scale (OSS-3)⁴¹ assesses the participant's subjective perceived social support. OSS-3 has three questions, with a sum score ranging from 3 to 14. The sum score is grouped into three categories:⁴² (1) a 3–8 score indicates “poor support,” (2) a 9–11 score shows “moderate support,” and (3) a 12–14 score is a sign of “strong support.”

Depression

The Montgomery Aasberg Depression Rating Scale (MADRS)⁴³ is a ten-item interview-based questionnaire screening for depressive symptoms. Each item yields a score of 0 to 6, and the overall score ranges from 0 to 60. The cut-off score for no depression is 6, 7–19 score indicates mild depression, 20–34 score indicates moderate depression, and 35–60 score indicates severe depression.

The questionnaires used to collect data about people with dementia were:

Neuropsychiatric Symptoms

The Neuropsychiatric Inventory (NPI-12)⁴⁴ evaluates 12 behavioral domains common in dementia. All items are scored from 0 to 4 and are calculated by multiplying the frequency score by the severity score from 1 to 3. The sum score ranges from 0 to 144.

Function in Everyday Life Activities

The Physical Self-Maintenance Scale (PSMS)⁴⁵ consists of six items with a sum score ranging from 6 (no impairment) to 30 (total impairment). The Instrumental Activities of Daily Living Scale (IADL) consists of eight items with a sum score ranging from 0 to 31 with increasing impairment. For both scales, a higher score indicates lower functionality.

Cognition

The Clinical Dementia Rating Scale (CDR)⁴⁶ consists of six items assessing the level of dementia. The CDR sum of boxes (CDR-SOB) was used, with scores ranging from 0 to 18.0. Scores of 0.5–4.0 indicate “questionable cognitive impairment,” scores of 4.5–9.0 indicate “mild dementia,” scores of 9.5–15.5 indicate “moderate dementia,” and scores of 16.0–18.0 indicate “severe dementia”.⁴⁷

The number of months with dementia symptoms for each person with dementia was also recorded.

Data Collection

The data collection was performed by ten researchers. All completed a one-day training course in the data collection process. In the present study, we used data from the next of kin, and some data from the people with dementia were included in the analysis. The interviews with the next of kin were mainly face to face, but, for practical reasons, six interviews were conducted by telephone.

The next of kin filled out the questionnaires themselves, except for the Montgomery Aasberg Depression Rating Scale (MADRS), which was conducted through interview. Data regarding people with dementia used in this study were obtained through interviews with the next of kin and are described in Measures. More detailed data of people with dementia are described elsewhere.⁴⁸

Statistics

The descriptive statistical analyses were performed with IBM SPSS[®] v 25.0 (Armonk, NY: IBM Corp) and the regression analysis was done with MLwiN v3.05 (Centre for Multilevel Modelling, University of Bristol, UK). Continuous variables were compared with a *t*-test when normally distributed, or the Mann–Whitney *U*-test when skewed. Dichotomous variables were compared with the χ^2 tests or Fisher's Exact Test when needed. The next of kin were divided into two groups: those living with the person with dementia (group one); and those not living with the person with dementia (group two). This variable is labeled as "Living" (Yes/No).

Univariate and multiple linear regression analyses were applied to explore associations with the dependent variables RSS score and QoL-AD score and potential explanatory variables. The empty models (no independent variables included) were checked for cluster effect. For RSS; the Intra Class Correlation (ICC) was 10.5%, and for QoL-AD score ICC was 11.7%; thus, all the regression analyses were adjusted for cluster effects. All variables in the regression analyses were checked for multicollinearities and interactions. One interaction was detected between the variables "Living" and MADRS, with the QoL-AD as outcome. The interaction variable (MADRS score x "Living") was significant in the linear regression analysis ($p=0.039$), adjusted for MADRS score and "Living." Thus, the interaction variable was included in the model with QoL-AD as outcome.

The following variables were dichotomized: the "Relation" variable into spouse/partner and children/other,

the "Education" variable into primary school/high school and college/university. The dichotomous variables and age were highly correlated with the "Living" variable. Thus, only "Living" is used in the regression analyses. Also, the IADL and PSMS variables were highly correlated, with the IADL variable being used in the regression analyses. The Caregivers school and Support group variables were merged into a variable called "Caregiver school."

The variable "Respite days per week" includes FDC and DC that the person with dementia attended.

Missing values in the different assessment forms were imputed on the item level for the cases with at least 50% of the items available. Imputed values were random numbers drawn from the observed distribution in the dataset. The items most imputed are RSS (6 cases), QoL-AD (5 cases), MADRS (4 cases), and OSS-3 (4 cases).

Having only 94 cases placed a limitation on how many independent variables could be included in the multiple regression models.⁴⁹ To reduce the number of variables in the multiple regression models, variables with $p \geq 0.20$ for RSS score and QoL-AD score in the univariate model were excluded in the multiple regression models.

Results

After dividing the next of kin into the two groups, group one – those living with a person with dementia – was found to consist solely of spouses/partners. Conversely, group two – those not living with the person with dementia – consisted mainly of children (81%) (Table 1). Compared with group two, the next of kin in group one were significantly older, had less education, were significantly less likely to be employed outside the household, and with a significantly lower reported weekly physical activity. The groups differed in mean score on perceived social support (OSS-3), with group two being significantly higher. On closer inspection, in group one 85.5% showed an OSS-3 score ≥ 9 , whereas in group two, 89.5% had an OSS-3 score ≥ 9 , indicating a moderate or better perceived social support.

A significantly larger proportion of the next of kin in group one had attended a caregiver school/support group (64%) compared with those in group two (35%). Group one had a significantly higher mean score on both MADRS and RSS scores and a significantly lower QoL-AD score (Table 1). When looked at in more detail, in group one, 67.9% had a QoL-AD score of ≥ 37 ; while in group two it was 89.2%, indicating a good QoL. Of all the next of kin, only four reported a score of ≤ 33 indicating a low QoL. In group one, 53.6% had an RSS score of > 23 ,

Table 1 Characteristics of the Next of Kin (N= 94)

Next of Kin	All	Living with Group One (n=57)	Not Living with Group Two (n=37)	P-value
Age Mean (SD) Range	63.6 (12.3) 32–87	70.9 (7.9) 54–87	52.7 (9.4) 32–69	<0.001*
Females n (%)	73 (77.7)	45 (78.9)	28 (75.7)	0.710**
Spouses/partner n (%)	58 (61.7)	57 (100)	1 (2.7)	<0.001**
Children n (%)	30 (31.9)	0	30 (81.1)	
Others n (%)	6 (6.4)	0	6 (16.2)	
Education				
Primary school n (%)	18 (19.1)	12 (21.4)	6 (16.2)	0.008**
High school n (%)	35 (37.6)	27 (48.2)	8 (21.6)	
College/University n (%)	40 (43.0)	17 (30.4)	23 (62.2)	
Employed outside household n (%)	42 (44.7)	12 (21.1)	30 (81.1)	<0.00*
Having hobbies (n 93) n (%)	78 (83.9)	45 (80.4)	33 (89.2)	0.257**
Being physically active (n 90) n (%)	83 (92.2)	46 (86.8)	37 (100)	0.039***
Caregiver school (n 93) n (%)	49 (53)	36 (64)	13 (35)	0.006**
Days spent on caring monthly, Mean (SD)	18.4 (10.8)	24.9 (7.8)	9.0 (7.0)	<0.001*
Respite-days per week, Mean (SD)	2.5 (1.0)	2.5 (1.0)	2.5 (1.0)	0.919*
Month with respite (n 92), Mean (SD)	18.6 (18)	16.3 (16.8)	22 (19.3)	0.137*
HAD-A ^a score (n 91), Mean (SD)	4.5 (3.4)	4.4 (3.4)	4.5 (3.5)	0.954*
MADRS ^b score (n 90), Mean (SD)	3.7 (3.9)	4.4 (4.3)	2.6 (2.9)	0.016****
QoL-AD ^c score (n 93), Mean (SD)	40.6 (4.9)	39.5 (4.6)	42.4 (5.0)	0.005*
RSS ^d score, Mean (SD)	20.8 (11.6)	25.3 (11.0)	14.1 (9.0)	<0.001*
OSS-3 ^e score (n 92), Mean (SD)	10.5 (2.2)	10.1 (2.1)	11.2 (2.1)	0.010*

Notes: *Independent samples t-test. **The χ^2 tests. ***Fisher's Exact Test. ****Mann–Whitney U-test.

Abbreviations: HAD-A^a, The anxiety part of the Hospital Anxiety & Depression Scale (HAD);⁴⁰ MADRS^b, Montgomery-Aasberg Depression Rating Scale;⁴³ QoL-AD^c, Quality of Life-Alzheimer Disease questionnaire;³⁶ RSS^d, Relative Stress Scale;³⁸ OSS-3^e, Oslo Social Support Scale.⁴¹

indicating a high level of burden, whereas the remaining participants scored <23, indicating a low level of burden. In group two, 13.5% had an RSS score of > 23, and 86.5% scored <23.

The analyses of the characteristics of people with dementia are listed in Table 2. The people with dementia living with a next of kin had a significantly higher CDR-Sob score and IADL scores than those who did not share a household with their next of kin.

Burden of Care

Results from the linear regression models with the RSS score as outcome are listed in Table 3. The multiple model shows that living with a person with dementia was associated with a higher burden. Anxiety (HAD-A) and lower experienced social support (OSS-3) were both significantly associated with the RSS score. In addition, an increased NPI score for the person with dementia was associated with a higher burden. The variance between farms was = 0.0 in the final model, indicating that 100% of the ICC was explained by the model. The multiple models explained

62% of the variance of the RSS score, between the next of kin (Table 3).

Quality of Life

Results from the linear regression models with the QoL-AD score as outcome are listed in Table 4. The multiple model shows that not living with a person with dementia was associated with a higher QoL. A low anxiety score (HAD-A) and experience of social support (OSS-3) were both significantly associated with a higher QoL-AD score. As for RSS, in the final model of QoL, the variance between farms were 0.0 and 100% of the ICC were explained by the model. The multiple model explained 40% of the variance of the QoL-AD score, between the next of kin (Table 4).

The interaction variable “Living” and MADRS (Interaction MADRS x Living) made it difficult to interpret the regression coefficient for MADRS. Unadjusted, the correlation coefficient was 0.23 for group one and 0.85 for group two and illustrates that the MADRS score had a larger effect on QoL in group two.

Table 2 Characteristics of People with Dementia (n=94)

People with Dementia	All	Living with Group One (n=57)	Not Living with Group Two (n=37)	P-value
CDR-SOB ^a , Mean (SD)	7.4 (3.2)	8.1 (3.4)	6.4 (2.6)	0.012*
NPI ^b score, Mean (SD)	12.1 (12.8)	13.4 (12.1)	10.2 (13.7)	0.236*
IADL ^c score, Mean (SD)	21.7 (5.6)	23.1 (5.4)	19.4 (5.3)	0.001*
Number of months with symptoms of dementia, Mean (SD)	70.6 (55.6)	75.8 (66.0)	62.0 (35.9)	0.223*

Note: *Independent samples t-test.

Abbreviations: CDR-SOB^a, Clinical Dementia Rating Scale, Sum of Boxes;⁴⁶ NPI^b, The Neuropsychiatric Inventory Scale, Intensity x Frequency;⁴⁴ Lawton & Brody's^c, Instrumental ADL Scale (IADL).⁴⁵

Discussion

Characteristics of Next of Kin

The present study confirms the hypothesis that a clear difference in characteristics of the next of kin exists whether the next of kin lives with the person with dementia or not. The difference in age between the groups is obvious and is explained by being a spouse or a child of the person with dementia. Group two shows a higher education and more often working outside the household, and these conditions could also be explained by age. Participants in group one belongs to a generation with less education and a lower employment rate among

women,⁵⁰ and most of the participants in group one were retired. However, both groups had a slightly higher level of education than the corresponding-year classes in the Norwegian population.⁵¹ Both groups consisted mostly of women. For group one, this is explained by the fact that the attendees at FDCs are most often male with a female spouse.⁴⁸ Group two consisted of many daughters. This is in line with other reports showing that support and care for older people are most often provided by women.^{52,53}

Independent of the group they belonged to, most participants were physically active (92%) and had hobbies (84%). However, the participants in group one were less physically

Table 3 Univariate and Multiple Models' Associations Between the RSS and Next of Kin and People with Dementia Characteristics

Next of kin	Univariate Model		Multiple Model	
	RSS Score	P-value	RSS Score	P-value
Gender (Female =0, Male=1)	-0.167	0.099	-0.056	0.465
Living (No=0, Yes=1)	0.472	<0.001	0.341	<0.001
Having hobbies (No=0, Yes=1)	-0.158	0.115	-0.105	0.161
Being physically active (No=0, Yes=1)	-0.043	0.671		
Caregiver school (No=0, Yes =1)	0.184	0.081	0.033	0.682
Respite - days per week	0.143	0.159	0.012	0.880
HAD-A ^a score	0.481	<0.001	0.276	<0.001
MADRS ^b score	0.466	<0.001	0.163	0.117
OSS 3 ^c score	-0.327	<0.001	-0.209	0.007
People with dementia				
CDR-SOB ^d score	0.109	0.301		
NPI ^e score (Intensity x Frequency)	0.397	<0.001	0.295	<0.001
IADL ^f score	0.154	0.135	-0.065	0.385
Number of months with symptoms of dementia	0.182	0.070	0.062	0.386
Intra Class Correlation (ICC)=0.105 = 10.5%				
Proportion of ICC explained by the model (R_2^2)			1.00 = 100%	
Explained variance between participants (R_1^2)			0.620 = 62.0%	

Abbreviations: HAD-A^a, The anxiety part of the Hospital Anxiety & Depression scale (HAD);⁴⁰ MADRS^b, Montgomery Aasberg Depression Rating Scale;⁴³ OSS-3^c, Oslo Social Support Scale;⁴¹ CDR-SOB^d, Clinical Dementia Rating Scale, Sum of Boxes;⁴⁶ NPI^e, The Neuropsychiatric Inventory scale, Intensity x Frequency;⁴⁴ IADL^f, Lawton & Brody's Instrumental ADL Scale (IADL).⁴⁵

Table 4 Univariate and Multiple Models' Associations Between the QoL-AD and Next of Kin and People with Dementia Characteristics

Next of Kin	Univariate Model QoL-AD		Multiple Model QoL-AD	
	Standardized β	P-value	Standardized β	P-value
Gender (Female =0, Male=1)	0.026	0.799		
Living (No=0, Yes=1)	-0.281	0.005	-0.336	0.004
Having hobbies (No=0, Yes=1)	0.081	0.426		
Being physically active (No=0, Yes=1)	0.103	0.327		
Caregiver school (No=0, Yes=1)	-0.070	0.513		
Respite - days per week	-0.065	0.523		
HAD-A ^a score	-0.587	< 0.001	-0.541	< 0.001
MADRS ^b score	-0.341	< 0.001	-0.221	0.234
RSS ^c score	-0.439	< 0.001	-0.005	0.970
OSS 3 ^d score	0.305	0.002	0.204	0.025
Interaction variable – MADRS x Living*			0.259	0.212
People with dementia				
CDR-SOB ^e score	-0.129	0.200	-0.007	0.934
NPI ^f score (Intensity x Frequency)	-0.160	0.112	0.018	0.846
IADL ^g score	0.043	0.676		
Number of months with dementia symptoms	0.022	0.841		
Intra Class Correlation (ICC)=0.117 = 11.7%			1.00 = 100%	
Proportion of ICC explained by the model (R_2^2)			0.400 = 40.0%	
Explained variance between participants (R_1^2)				

Note: Interaction variable* MADRS: Montgomery-Aasberg Depression Rating x Living variable.

Abbreviations: HAD-A^a, The anxiety part of the Hospital Anxiety & Depression scale (HAD);⁴⁰ MADRS^b, Montgomery Aasberg Depression Rating Scale;⁴³ RSS^c, Relative Stress Scale;³⁸ OSS-3, Oslo Social Support Scale;⁴¹ CDR-SOB^e, Clinical Dementia Rating Scale, Sum of Boxes;⁴⁶ NPI^f, The Neuropsychiatric Inventory scale, Intensity x Frequency;⁴⁴ IADL^g, Lawton & Brody's Instrumental ADL Scale (IADL).⁴⁵

active, and fewer had a hobby than those in group two. These findings are in line with another Norwegian study.²² The participants in group one spent significantly more time assisting the person with dementia in ADL, therefore, time for physical activity and hobbies could be limited for them. The findings may also describe a cohort effect as older adults are less active than younger, and it is more common to have a hobby now than in the past.

Participants in group one more often attended a caregiver school/support group than those in group two. This is in line with a study comparing next of kin who used service with non-service users, finding that the users of service were likely to be older, retired, married, spouses of the person with dementia experienced the burden of care and having health issues.⁵⁴ The spouses living with a person with dementia experience the consequences of dementia daily and, therefore, may seek information and knowledge to cope with the care situation. One could also ask whether health-care personnel have more

of a focus on the next of kin living with the person with dementia than those who do not.

Most of the participants reported moderate to strong perceived social support. However, there was a significant but small difference between the groups in that group one experienced less social support. Other studies support our findings, that living with a person with dementia often increases the risk of social isolation and a decrease of social support over time especially when the dementia symptoms progress.^{55,56}

The participants in group one experienced a higher level of burden of care, more depressive symptoms and a lower QoL than those in group two. Though group one reported a lower QoL than group two, most of the participants in both groups reported a high QoL (≥ 37 QoL-AD). In the present study the participants were next of kin to people with dementia in an early stage of dementia with good QoL.⁴⁸ This may have affected how the next of kin were experiencing their QoL. Even though they

may have reported a burden of care, they were still experiencing a high QoL.¹⁴

Characteristics Associated with Burden of Care

In the present study, the burden of care of the next of kin was associated with lower perceived social support, anxiety symptoms and the presence of NPS in the person with dementia. Living with a person with dementia was the strongest characteristic associated with burden of care, and more than 50% of the participants in group one reported a high level of burden (RSS score > 23). Previous studies emphasize that being a next of kin can be difficult, especially for spouses, because of changes in the quality of the marital relationship and affection. Despite such changes, spouses also report feeling closer to their spouse with dementia now than in the past.^{55,57,58} The association between anxiety symptoms and burden is not a surprise and are in line with other studies.^{5,59} The negative association of perceived social support with the burden of care is also supported by other studies.^{11,14} Perceived social support refers to the appraisal of available support when needed and may be a timely predictor of subjective burden.¹¹ According to Bøen et al (2012),⁴² social support in general is valuable for maintaining mental health (eg, depression and anxiety). Therefore, it is of great importance for the next of kin to experience such support.

NPS are the only characteristics of the people with dementia that are associated with the burden of care. NPS can be very challenging and may change the feelings toward the person with dementia and the quality of the relationship, as well as contribute to social restrictions for the next of kin.⁵⁷ A body of literature confirms that NPS is associated with the burden of care.^{2,4,60–62} It was unexpected that a weekly respite was not associated with the burden of care in the multiple model. Studies have reported that respite service such as day care may decrease the burden of care and other stress-related factors.^{28,30} The average number of days for a respite was 2.5, perhaps indicating that these are too few days to have an effect on burden, or it may also be that those with a high burden waited too long to seek help and respite.³⁰

Characteristics Associated with Quality of Life

Living with the person with dementia, a higher level of anxiety and decreased social support were associated with lower experienced QoL. The relationship between QoL

and the next of kin living with a person with dementia is in line with earlier research.²² Also, the association between reduced QoL and a higher level of anxiety, as well as the experience of less accessible support, is consistent with other studies.^{24,63} Studies underpin that perceived support is of great importance for the next of kin in the care role and for their experience of QoL.^{11,63} We found no relationship between next of kin's QoL and the characteristics of people with dementia, and these findings are in line with other studies.²³

Previous studies have found an association between next of kin experiencing depression and their QoL and the burden of care.^{22,23,64,65} However, in the multiple regression analysis, we found no such association. There is no straightforward explanation for this disparity. There was a strong association between the MADRS score and the outcome in the univariate analysis, but this was not the case when adjusting for other variables. Thus, it is possible that in this sample, depression had little impact on the next of kin's burden of care and QoL. Regarding QoL, it was an interaction between MADRS score and group belonging. In group two, the association between MADRS score and QoL was stronger than in group one. In this sample, there was not enough power to split the data into two and analyze the two groups separately. Thus, we could not pursue this issue further.

Strengths and Limitations

A definite strength of this study is that, to the best of our knowledge, it is one of only a few studies that reports on the characteristics of the next of kin of people in an early stage of dementia attending an FDC. Furthermore, we were able to include participants from 25 of the 30 existing FDCs in 2016/2017,⁴⁸ and therefore, the results are representative for FDC in Norway. There are also some limitations of this research. First, this is a cross-sectional study, and it is not possible to draw causal relationships between the characteristics of next of kin/people with dementia and the burden of care or the QoL. In addition, the QoL of the next of kin was measured using the QoL-AD. This is a validated questionnaire, designed to measure QoL of people with dementia, but it has also been used to evaluate the QoL of the next of kin in several previous studies.^{22,24,66} In the present study, we did not have access to information about subtypes of dementia; thus, we cannot describe how the subtypes may affect the next of kin's burden of care.

Conclusion

This study shows that the spouses/partners living with a person with dementia reported a significantly higher burden, lower QoL and less perceived social support than the next of kin not living with a person with dementia. Regardless of living situation social support affected the burden of care and QoL positively for all next of kin. Our finding underpins the importance of having healthcare professionals who provide services with the best possible support for the next of kin as well for the people with dementia. The FDC should provide such support and thereby strengthen the next of kin's ability to cope with the role as caregivers without risking their health. Further research with a longitudinal perspective is necessary to find out how the FDC service as respite, may affect the next of kin's burden of care and QoL over time.

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Being sheltered from a demanding everyday life: experiences of the next of kin to people with dementia attending farm-based daycare

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ABSTRACT

Purpose: Farm-based daycare (FDC) is a type of daycare service for people with dementia. The aim of the present study was to explore the next of kin's experiences with FDC and how the service may affect their daily life.

Methods: The study has a qualitative, descriptive design. Eight semi-structured interviews with next of kin were conducted. The data were analysed in accordance with content analysis.

Results: We identified three main categories: (1) I am fine when you are fine, (2) Significant aspects of the service at the farm, and (3) FDC as a part of the dementia trajectory. The findings were summarized in one overarching, latent theme: "Being sheltered from a demanding everyday life".

Conclusions: The findings indicate that next of kin's experience of respite is closely connected to the well-being of their relatives at the FDC and the quality of the service. FDC provides significant support through a part of the trajectory of dementia. Despite experiencing respite and support, next of kin continue to struggle with ethical and moral decisions about the futures of their relatives with dementia.

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Introduction

Dementia affects cognitive abilities and activities of daily living. The condition not only has an impact on the person with dementia but also affects the next of kin (Livingston et al., 2020). Next of kin caring for people with dementia have an increased risk for burden of care, including reduced physical, mental and social health. They may also experience financial challenges related to care tasks (Adelman et al., 2014; del-Pino-Casado et al., 2018). In Norway, it is a policy that people with dementia should live in their own homes as long as possible with the support of individually tailored services and next of kin contributing to their care (Norwegian Ministry of Health and Care Services, 2015, 2018; World Health Organization, 2017). About 90% of people with dementia in Norway receive help from their next of kin, and the help increases during the course of dementia (Vossius et al., 2015). The municipalities are obliged to provide necessary support such as respite, training and guidance for next of kin (Act 2011–06–24–30 Helse- og omsorgstjenesteloven, 2021). Daycare (DC) services are intended to facilitate meaningful activities in a safe environment and to improve quality of life for

people with dementia. In addition, they provide respite and support for next of kin (Du Preez et al., 2018; Norwegian Ministry of Health and Care Services, 2007, 2015). Since 2020, all Norwegian municipalities have been obliged to offer DC services for people with dementia (Act 2011–06–24–30 Helse- og omsorgstjenesteloven, 2021).

A review found that DC creates a break from caregiving tasks and reduces feelings of burden, worry and depression among next of kin (Maffioletti et al., 2019). Further, DC may improve quality of life and have a positive influence on the relationship between the next of kin and the person with dementia, leading to improved cooperation and higher quality of time spent together (Maffioletti et al., 2019). Other studies reported that the content and quality of the DC were important for the next of kin's experiences of respite, i.e., having confidence in the staff and knowing that their relatives with dementia are being well cared for contributed to their experience of respite (Rokstad et al., 2017; Strandli et al., 2016).

To meet the various needs of people with dementia, the Norwegian dementia plan emphasizes the

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importance of offering different kinds of daycare (Norwegian Ministry of Health and Care Services, 2015, 2020). Farm-based daycare (FDC) service for people with dementia has been established as one type of DC with a similar purpose, and both offer respite for next of kin (Ibsen et al., 2018; Norwegian Ministry of Health and Care Services, 2015). In Norway, the municipality has the overall responsibility for the quality of the health and social services provided within its jurisdiction (Act 2011–06-24-30 Helse- og omsorgstjenesteloven, 2021). FDCs are a collaboration between municipalities and farmers, the municipalities pay for the services provided at private farms (Ibsen et al., 2018).

FDC has been found to prevent an increase in caregiver burden over time (De Bruin, 2009). A wide range of activities are provided related to farm buildings, gardens, animals, and outdoor areas (Ibsen et al., 2018). Further, the participants at FDC are more physically and socially active, and they spend more time outdoors than those at regular DC (Ellingsen-Dalskau et al., 2020; Finnanger Garshol et al., 2020). However, knowledge about the next of kin's experiences with FDC is limited. Two interview studies found that FDC appears to promote the health of both the person with dementia and his or her next of kin (Solum Myren et al., 2013; Strandli et al., 2016). Strandli et al. (2016) reported that the staff's dedication to caregiving and to facilitating individual activities were important for the next of kin's experience of relief and the safety of their relative. The next of kin's experiences can provide us with an extended understanding of how FDC might influence their daily lives and which elements of FDC can be important. The present study aimed to explore the next of kin's experiences with FDC and how the service may affect their daily lives.

Method

Study design

The present study has a qualitative, descriptive design. The purpose was to gain an understanding of the lived experience from the person's point of view. The study is ontological and epistemological based on hermeneutic phenomenology, as operationalized in Kvale and Brinkmann (2009). The data was collected using qualitative, individual interviews about the participants experiences as caregivers to people with dementia attending an FDC. Kvale and Brinkmann base their approach to the qualitative interview on postmodern, pragmatic and hermeneutic philosophies. They emphasize that knowledge in qualitative research is not achieved by following value- and interest-free methods, because human subjectivity plays a non-reducible role in the development of qualitative knowledge. Further, Kvale and Brinkmann

underline that the importance of good qualitative research is based on good craftsmanship (Kvale & Brinkmann, 2009, p. 78). Therefore, we have strived to be transparent and analysed the data according to the well-recognized method of content analysis (Graneheim & Lundman, 2004; Lindgren et al., 2020).

Participants and recruitment

To gain an extended understanding of the participants' experiences, we included a purposeful sample of next of kin reflecting different sex, ages, and relationships with people with dementia (Patton, 2002). The inclusion criteria were being next of kin to people with dementia attending an FDC and meeting the relative with dementia at least once a week.

A group of eight next of kin, were invited to participate, all agreed to take part in the present study. The participants consisted of four men and four women with age ranging from 45 to 86 years. Four were spouses cohabiting with the person with dementia. Four were sons, daughter and a niece not living with the person with dementia. The relatives with dementia had mild or moderate degree of dementia and attended FDC two to four days a week.

The participants were recruited from seven different farms and regions of Norway through the FDC providers or healthcare personnel in the municipalities. All FDC services took place on farms engaged in agricultural production in suburban or rural areas. Five of the six farms had animals such as sheep, cows, goats, hens, rabbits, dogs, or cats.

The present study is part of the research project "Farm-based daycare services for people with dementia: quality development through interdisciplinary collaboration", a prospective study organized into several qualitative and quantitative sub studies, with a multimethod approach (Eriksen et al., 2019). The participants were unknown for the authors prior to the study.

Data collection

Individual interviews were conducted between June 2017 and February 2018. Four interviews took place in participants' homes, two in other appropriate places chosen by the next of kin, and two by phone. The interviews were dialogue-based and supported by an interview guide with open-ended questions. We addressed topics about being a caregiver before and after the relative started at FDC, experience of FDC and reflections on future care situation.

The interviews lasted 25–60 mins; each was conducted by the first author (LBT) and tape-recorded.

The interviews were transcribed verbatim by LBT and one research assistant.

Data analysis

The transcribed interviews were analysed in line with qualitative content analysis by Graneheim and Lundman (2004) and focussed on both manifest and latent levels of content. NVivo 12 Pro (QSR International Pty Ltd, 2020) was used to support the coding and organizing of the data. The analysis was conducted by LTB in cooperation with two of the co-authors (SE, IP), and the process could be described in six stages.

First, each interview was read several times to acquire an overview of the material, and each was identified as a unit of analysis. Second, the text was divided into meaning units, and condensed units were formed. Third, the meaning units were extracted and labelled with codes. Fourth the codes were compared based on differences and similarities and then grouped into seven subcategories. In Stage five, the subcategories were clustered and grouped as three categories. Finally, in Stage six, the categories were summarized and reflected on to reach a latent presentation of the text based on an overall theme. An example of the process is shown in Table I.

Pre-understanding

The first author (LBT) who conducted all the interviews, is a registered nurse (RN) with a research interest in the care situation for the next of kin of people with dementia. LBT was interviewed by the fourth author (SE) prior to the study with the aim of creating a conscious relationship with her own pre-understanding. The three co-authors (SE, IP and ØK) are researchers with many years of experience in different aspect of dementia care and dementia care research.

Ethical aspect

The present study was approved by the Norwegian Centre for Research Data (NSD) (no.49799) and conducted in accordance with the Declaration of Helsinki

(World Medical Association, INC, 2004) Before each interview was initiated, the next of kin received oral and written information about the study, research topic and gave written consent. The interviewer emphasized that personal confidentiality would be guaranteed and informed that she is a registered nurse (RN).

Results

The results can be divided into three main categories with underlying subcategories. First, "I am fine when you are fine" describing the experiences of being a - caregiver; second, "Significant aspects of the service at the farm" describing the next of kins' experiences of FDC; and third "FDC as a part of the dementia trajectory" describing thoughts about the future (Table II).

I am fine when you are fine

The experiences of being a caregiver for a person with dementia attending FDC could be summed up as "I am fine when you are fine". This describes important aspects for the experience of respite. Most of the participants experienced FDC as a support service for both the relative with dementia and themselves. FDC positively affected their daily lives and offered them respite. They considered FDC to be a safe place and enjoyable for their relatives with dementia. Several described the service as "utterly invaluable regarding our situation". The participants highlighted two important perspectives of respite: (1) Having

Table II. Theme, main categories, and subcategories.

Theme	Being sheltered from a demanding everyday life		
Main Category	I am fine when you are fine	Significant aspects of the service at the farm	FDC as a part of the dementia trajectory
Subcategory	Having time, freedom and fewer worries Mastery and enjoyment for the person with dementia	A dedicated staff An atmosphere of real life	We reached a point Being safe in the system The agonies of choices now and in the future

Table I. Examples of the analysis process.

Meaning unit	Condensed meaning unit	Codes	Subcategory	Category
<i>She gets to help with the farm chores, which she knows about from her childhood. The activities are familiar, but I know that they (the staff) organize tasks that are beneficial. I just know that they are having a good experience and that the tasks they are doing are worthwhile</i>	The next of kin knows that the staff facilitates tasks that the relative with dementia is familiar with and beneficial.	The staff facilitates the tasks individually.	A dedicated staff	Significant aspects of the service at the farm
<i>It's not a nursing home service, but there's a sense of community here, which they contribute to a little bit</i>	Opposite to day care at nursing home, the FDC do not give an institutional feeling	The farm gives a sense of real life	An	
atmosphere of real life				

time, freedom, and fewer worries; and (2) Mastery and enjoyment for the person with dementia.

Having time, freedom, and fewer worries

On days when their relative attended FDC, the participants had opportunities to do things they otherwise could not. Spouses, in particular, underlined the importance of having time to take care of their own health and to rest and recharge when they felt worn out from caregiving.

It means so much, especially when I start to get tired. Tomorrow he's going up to the farm. I can go for a walk or take a trip into town because I think it's sad that he sits alone here at home and sits a lot on the days when he's not up there. Then there's not much else to do. (Spouse)

The participants had time to do things at their own pace when their relative was at FDC. Without feeling guilty about leaving the relative with dementia, they could pursue their hobbies and participate in social life. Some of the participants described that they wished they could have more days of respite. Several, especially those who did not live with the relative with dementia, described worrying about their relative's nutritional status, physical health, and passivity. After their relatives started to attend FDC, these worries eased.

Mastery and enjoyment for the person with dementia

The experience of respite was closely connected to knowing that the relatives with dementia enjoyed their time at the FDC. When the person with dementia expressed mastery and enjoyment this eased the burden for their relatives.

They have put up some shelves and tidied up, not big tasks. (Staff member) says that it should not be unmanageable. It must be something they can accomplish. I think this is very well thought through, and when it's clear, when they are given enough time, they enjoy it. After all, it's the same for us, too. (Spouse)

The FDC staff organized tailored activities that the relatives with dementia were able to master. A daughter said, "The activities are familiar, but I know that they (the staff) organize beneficial tasks."

The activities were something to look forward to for the relatives with dementia in their daily lives. One spouse stated, "The best thing for him is that he gets up in the morning, and when I see how good his mood is ... he has something to go to". The relatives with dementia participated in farm activities such as cutting and stacking wood, tending plants in the garden, and caring for animals. They also took part in other activities such as hiking, baking, singing, reading aloud from the newspaper, and other forms of social interaction. The next of kin emphasized

physical activities as an important part of the day because such activities helped the relatives with dementia to maintain physical function.

Whether they go skiing in the winter or take a walk, whether they are being in the mountain or pasture, or other activities like baking ... there are things that she enjoys and that she thinks are fun to be a part of. Of course, this means a lot to me. I feel reassured when (staff member) is leading the activity. (Son)

The FDC influenced the everyday rhythm of life for the relative with dementia. For example, he or she slept better after a day at the FDC, and this entailed a better night for the next of kin with fewer interruptions. Several next of kin further reported that their relative with dementia was in a better mood and had a more positive attitude towards life after starting at the FDC. These changes were attributed to enjoyable activities, social interaction with other attendees and the staff and animals at the farm, and the opportunity to enjoy the outdoors. The relatives with dementia had expanded their social networks and formed new friendships. Some of the interviewees stated, "Now we have something to share and to talk about", which affected their relationship positively and improved the care situation.

Significant aspects of the service at the farm

The participants emphasized that the context of the day-care was important for them to feel fine. When describing the experience of FDC, they attributed two important aspects: (1) A dedicated staff; and (2) A real-life atmosphere.

A dedicated staff

The participants outlined the staff's ability to create an inclusive community where their relatives with dementia could be themselves with their individual resources and challenges.

Especially with the wonderful staff there with the social and inclusive aspects, and they (relatives with dementia) can be themselves. That is worth its weight in gold, both for me and my mum. (Daughter)

It was important that the staff were educated and had experience caring for people with dementia. One spouse said, "It's the daily care and the staff who show concern, assume responsibility and follow up. I feel as though nothing random happens there". The staff were able to make individual adaptations to activities based on each participant's level of function and preferences. The staff met the relatives with respect, dignity, and care, and this was highly significant for the next of kin's experience of security. In addition, the dialogue with the staff, gaining insights into FDC and being reassured that their relatives were fine were essential.

An atmosphere of real life

For the participants it was important that the FDC had an atmosphere of real life opposite to a constructed, institutional life. The participants emphasized that the buildings at the farm have the opposite of an institutional feeling. The outdoor area was described as natural and free. A son described how the context influenced his father: "He is a little freer, you know. It's a farm, and he can go out in the yard or the garden, listen to the birds and walk over to say hello to the sheep". Being able to have contact with the animals on the farm was beneficial, as several of the relatives attending the FDC had enjoyed experiences with animals in their younger days. Several of the participants expressed that having contact with the animals helped to make the day better for their relatives at the FDC.

They had some rabbits at the farm, and rabbits are something he grew up with and can relate to. So, we walked right over to the rabbit, and we talked about it and had a conversation about the old days. (Son)

The participants expressed that it was an advantage to have small groups of attendants. This made it possible for the relatives with dementia to have time to talk with each other and experience fellowship with someone in the same situation.

FDC as a part of the dementia trajectory

When asked about the future, most of the participants reported that FDC was the first municipal service the person with dementia had received. And they realized that FDC was a part of the dementia trajectory and that the person with dementia would need other care services. Three perspectives were highlighted: (1) We reached a point where we needed help; (2) Being safe in the system; and (3) The agonies of choices now and in the future.

We reached a point where we needed help

For the participants, daily life gradually changed after their relative had developed symptoms of dementia and had become increasingly passive and less interested in taking part in social activities and performing daily tasks. Due to their relatives' changes in cognitive function and in other functions needed to conduct activities of daily life, the participants had to monitor daily activities more closely and take over responsibility for tasks that the relative with dementia used to do. Most of the participants stated that they found their life circumstances to be challenging. They experienced both grief and worry. A son stated, "It's no fun to see a person you love sitting inside and being obviously unhappy about it, when you know she used to enjoy being active and spending time

outdoors". Several participants said that their patience was continually put to the test:

Sometimes I feel a little irritated, but then I look at him and get a bad conscience. After all, he can't help it [...]. Not all the days are bad, but now and then things go a bit wrong' (Spouse).

The participants used different strategies, such as humour, to manage difficult situations; as one spouse said, "We don't make a big deal out of it; we make the best of it".

The participants explained that they had reached a point where they had to ask the municipal health services for measures to relieve their burden. In agreement with the relative with dementia, the participants established contact with the healthcare service in the municipality. When the need for services was assessed, the person with dementia was offered a place in FDC.

Being safe in the system

For many of the participants, FDC was the first service offered for their relatives with dementia. The participants understood that the progression of dementia and new needs for additional or different measures and support would arise at a certain point. The participants described that it was important to establish contact with the healthcare service. All participants described the first contact with the healthcare system as a positive experience.

They felt that the concerns and needs of their relative with dementia were taken seriously and the relative with dementia was offered a place in FDC. A spouse commented, "I think to myself that I'm so happy he attends FDC, and I'm pleased that he is in the system".

From the very first meeting with the FDC staff, the participant felt welcome and received good information about the programme. They describe that both the relatives with dementia and themselves were included in the community the farm.

Several FDCs held regular meetings with the next of kin together with personnel from the healthcare service in the municipality. However, most of the communication with the FDC took place by text messages, telephone calls, emails when considered necessary, or a chat when the relative was picked up at his or her home in the morning. In addition, some of the FDCs used notebooks, monthly newsletters or arranged social events. The participants expressed that the staff at the FDC was caring and supportive about their situation. The staff had close contact with the healthcare system in the municipality and conveyed the needs of individual participants when needed.

The agonies of choices now and in the future

The participants expressed a strong desire for the relative with dementia to live as independently as possible, both now and in the future. Furthermore, they thought about the difficult decisions they would have to make about their relative with dementia in the near future. However, receiving FDC service was a way of preparing for the days to come. A son said, "One of the reasons we wanted the municipality involved was that we could discuss measures and the future with experts in the field. This lays the foundation for adding more services when he gradually becomes worse".

The participants were concerned about their obligations to help and support their relative throughout the course of dementia. A niece stated, "I couldn't stand to see everything fall apart, to put it one way. There's no human dignity in that. We have a responsibility as a family". The participants described challenging discussions in which family members had conflicting ideas about the needs of the relative and when he or she should be moved to a nursing home.

My son says: now you are just pushing him (the father) away. Then I say, yes, but he understands this himself. He knows he's on the list. He has been informed of this, and he agrees. We are not both going to get sick. (Spouse)

Most of the participants considered FDC as a service that could potentially postpone nursing home placement.

(...) If she had not had the service at the farm or similar service (...) it will have meant that she probably (...) we have had to find other solutions in relation to the living situation. I think this (FDC) contributes to her being able to live at home. (Son)

The participants also highlighted concerns about the relatives with dementias' ability to understand their situations and make choices for themselves. A son stated,

I think the matter of consent is a challenge. We have not taken his right to consent from him. Consent in relation to adding new things. I'm thinking of the ethical aspects. I absolutely want to contribute and help my father. He has helped me a lot in my life.

Overall interpretations: "being sheltered from a demanding everyday life"

In the categories presented above, being a next of kin to a person with dementia is described as demanding and as often causing major changes in life for both parties. The participants reached a point where they needed help, and FDC service was experienced as an important form of support and respite that positively influenced daily life for them as well as for their

relative with dementia. This positive experience was strongly connected to the tailored and meaningful activities in natural settings created for the attendees by the staff. Being a next of kin to a person with dementia could be described as "being outdoors in rough weather". FDC was an important part of the dementia trajectory. Having the relative with dementia attending FDC created an important break or shelter from their daily struggle. Therefore, the latent meaning of our findings could be summed up as: "being sheltered from a demanding everyday life".

Discussion

The present study aimed to explore the next of kin's experiences with the service at the farm and how FDC may affect their daily life. The participants were most concerned with the well-being of the persons with dementia. When the next of kin knew that their relatives had a good time at the FDC, they experienced a break from the daily worries and could enjoy time and freedom to follow their interests or meet their own needs. This gave the next of kin a possibility to re-energize and recover from caregiving. Other studies have also reported that FDC may promote personal time, fewer feelings of guilt and an experience of respite for the next of kin (De Bruin et al., 2015; Solum Myren et al., 2013; Strandli et al., 2016). In our study the next of kin reported that relatives with dementia slept better after attending FDC. This, in turn, resulted in more-restful nights with fewer interruptions for the participants. Tretteteig et al. (2017) study of next of kin to people with dementia attending a regular day-care also noted this.

A recent study concerning next of kin of people with dementia attending a FDC reported that the perceived burden of care is dependent on the living situation (Taranrød et al., 2020). The study reported that spouses living with a person with dementia attending FDC experienced a significantly higher burden than next of kin who did not live with their relative (Taranrød et al., 2020). In our study, several participants emphasized a need for more service than the relatives with dementia were currently being offered by the municipality. In Norway, the municipalities have the responsibility to support and tailor interventions to next of kin who experience burden of care (Helse- og omsorgstjenesteloven 2011; Norwegian Directorate of Health, 2017). Enjoyable and meaningful activities which contribute to a feeling of mastery for the person with dementia is the basis for daycare services (Norwegian Ministry of Health and Care Services, 2020). Despite significant effort by the authorities to increase the number of daycare services, there is still a lack of available services to meet the next of kin's needs for relief (Granbo et al., 2019; Norwegian Directorate of Health, 2019;

Norwegian Ministry of Health and Care Services, 2015, 2020).

For next of kin in general, it is not enough that their relatives attend a daycare service; the context of the service and how the service is organized are just as important (Tretteteig et al., 2015). The next of kin may hesitate to use services that are not perceived as beneficial for the person with dementia (Neville et al., 2015). Our participants described FDC as positive for their relatives with dementia and highlighted the atmosphere of “real life” surrounded by farm buildings and outdoor areas. “Real life” was described in contrast to “institutional life” since most regular daycare in Norway are situated in institutions, such as nursing homes (Norwegian Directorate of Health, 2019). Our findings correspond with those of other studies (Solum Myren et al., 2017; Strandli et al., 2016). The farm environment provided opportunities for a variety of useful activities that promoted participation and a feeling of freedom for the person with dementia (Strandli et al., 2016). Solum Myren et al. (2017) also described the farm environment (including staff) as a context that enables attendees to participate more in everyday activities compared to ordinary daycare. To some people with dementia and their next of kin, it is difficult to accept traditional service offered for people with dementia, and a “real-life” setting could make this more acceptable (Strandli et al., 2016). Stephan et al. (2018) found that the attitudes and beliefs informal caregivers had towards formal care were predominantly reticent or negative as most services were currently judged to be too focused on the disease rather than on the person with the disease; additionally, they felt that the psychological and social needs of their relative were often not appropriately considered (Stephan et al., 2018). The Norwegian National guidelines for dementia state that all care and services should be person-centred (Norwegian Directorate of Health, 2017a). Brooker (2014) and Kitwood (1997) specified that an environment that supports positive interaction contributes to supportive social psychology, which is an important factor in person-centred care. From the perspective of our participants, the staff at the farms seemed to use the environment to promote individual care for the persons attending FDC.

Our participants perceived the staff as important for promoting their relatives’ well-being, and they expressed confidence in the staff. The staffs’ expertise in dementia care, their engagement, and their skills in adjusting service to the needs and resources of the persons with dementia were highly valued. The study by Schols and van der Schriek-van Meel (2006) found that next of kin were more satisfied with the service at FDC than that at regular daycare. To our participants, it was important that the staff managed to create an environment for social inclusion and to facilitate

meaningful activities for their relative. This was also seen by Stephan et al. (2018), who found that the competencies of the health and social care professionals, their dementia-specific knowledge and their awareness of each person with dementia and his or her social competencies were important for the next of kin. Other studies have shown that the staff and the farm environment may promote connection and autonomy for the attendees (Ellingsen-Dalskau et al., 2020; Hemingway et al., 2016; Ibsen & Eriksen, 2020) and that well-organized daycare provides support and enriches everyday life for people with dementia as well as their next of kin (Gústavsdóttir, 2011). In addition, next of kin to persons with dementia attending FDC described that meaningful days at the farm and a sense of fellowship were perceived as promoting health both for the person with dementia and the next of kin, who experienced the service as a relief (Solum Myren et al., 2013; Strandli et al., 2016).

Caring for a person with dementia could be described as a dynamic process, meaning that the care responsibilities as well as the next of kin’s experiences change as the dementia progresses (Montgomery & Kosloski, 2009). The participants highlighted the experience of being in the middle of the dementia trajectory where FDC was one, and often the first, service encountered along the journey. The period before receiving FDC was characterized by exhaustion, grief and worries about the situation. At the same time, they experienced substantial responsibilities and multiple roles in the care of their relative with dementia. Our findings align with the findings of earlier research describing the next of kin’s experiences of the life situation before contacting the healthcare system (Moholt et al., 2018; Solum Myren et al., 2013; Tretteteig et al., 2017; Vossius et al., 2015). In the early stage of the disease, next of kin may not experience a need for help and may not identify themselves as “carers” (Stephan et al., 2018). Our participants described having reached a point where help from the healthcare system became a necessity and, in agreement with their relative with dementia, they contacted healthcare services.

Throughout the trajectory of dementia, both the person with dementia and the next of kin’s situation may change considerably due to social isolation and the loss of a social network in addition to increased stress, strain, depression, and other health-related problems associated with caregiving (Brodaty & Donkin, 2009; Lethin et al., 2020). Support from healthcare services is crucial and may reduce the next of kin’s feelings of strain and burden. Stephan et al. (2018) found that next of kin expect to share the responsibility of caring for the person with dementia with healthcare personnel and to receive help for making joint decisions regarding the care. Our participants experienced having rapport and helpful dialogues with the FDC staff. They felt safe knowing that they had someone with whom to share the

responsibility of care. A recent study of next of kin of people with dementia attending an FDC found that social support positively affected the quality of life and burden of care for the next of kin (Taranrød et al., 2020), and in a review by Williams et al. (2019), multicomponent interventions including learning coping strategies and getting emotional support were found necessary to reduce caregiver burden.

Being a next of kin may elicit feelings including commitment and responsibility (Davies & Nolan, 2004). Our participants were in a position where, in the near future, they would have to make difficult decisions about choices for a higher level of care for their relatives with dementia. Making such choices may generate guilt and distress for those who must make them (Davies & Nolan, 2004; Larsen et al., 2020) and seems to be agonizing for the participants in relation to several ethical dilemmas. In a recent qualitative review of spouses' experiences (Egilstrod et al., 2019), lack of control and uncertainty about the future were particularly pronounced. It is important that healthcare personnel are aware of the next of kin's struggles to cope with the situation and that they facilitate adequate support to the next of kin (Larsen et al., 2020).

Methodological considerations

In their own words, the participants in the present study described their experiences of FDC and how the service affected their daily lives. Lincoln and Guba (2000) highlighted five areas of importance for quality in qualitative studies: credibility, dependability, confirmability, transferability, and authenticity. To ensure that we have addressed these five areas, we have attempted to describe the process openly and reflexively, presenting each step of the research in detail. The interviews were analysed on both manifest and latent levels of the content (Graneheim & Lundman, 2004). We are aware that there may be more than one correct interpretation of the transcribed interviews. The data are from only eight participants, and this may have influenced the results and, thereby, the transferability of our findings to other populations may be limited. By contrast, the sample represents different FDCs and regions of Norway. The participants are diverse in regard to age, sex and whether the participant lived with the relative with dementia or not. Thus, we believe the findings elucidate important experiences of next of kin that may be transferable to other next of kin of persons with dementia.

Conclusions

The main finding of this study was that the next of kin's experience of respite was closely connected to the well-being of their relative at the FDC and the quality and content of the service. The next of kin faced the agony of making choices about how to care for their relatives

with dementia, and they seemed willing to take responsibility with support from the healthcare system. Our findings underpin the importance of having someone with whom to share the responsibilities of care and having a good quality healthcare service that supports the next of kin along the trajectory of the progression of dementia. FDC can be an important "shelter" for next of kin and offer good days for people with dementia during this trajectory.

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ORIGINAL RESEARCH

Liv Bjercknes Taranrød et al.,

The transition of care from farm-based daycare for people with dementia: The perspective of next of kin

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Abstract

Purpose: The aim of the present study was to explore the next of kin's experiences with the transition for people with dementia from a farm-based daycare (FDC) to another service in the municipality.

Methods: The study has a qualitative, descriptive design. Eight semi-structured interviews with next of kin were conducted. The data were analysed in accordance with content analysis.

Results: Through the analysis three main categories were developed: (1) Bearing the burden, (2) Being in transition, and (3) Feeling supported. The transition period was highly stressful for next of kin due to the exacerbation of their relatives' dementia symptoms. The next of kin focussed on optimising the everyday lives of their relatives with dementia, even at the expense of their own well-being. Most participants experienced support from FDC, healthcare services and their informal network.

Conclusions: The study contributes important insights into the next of kin's experiences. Good quality service, close dialog, information, and support between the different part in the transition process, can be useful for the further development of services with good quality and to reduce the negative effects of care on next of kin.

Keywords: Next of kin; family caregiver; dementia; farm-based daycare; transition of care in the municipality; support; qualitative; interviews

Introduction

Informal care is considered the cornerstone of dementia care. Most people with dementia live in their own homes and have at least one next of kin, often a spouse or another family member, caring for them (Alzheimer's Association, 2022). Norwegian authorities have adopted a policy whereby people with dementia should continue to live at home, if possible, with support from the municipal healthcare system and their next of kin (Norwegian Ministry of Health and Care Services, 2018, 2020). The municipalities are obliged to provide health and social services to their citizens in accordance with care needs corresponding to the lowest effective level of care (Norwegian Directorate of Health, 2015). According to regulations, they should offer different measures to those next of kin with particularly burdensome care tasks; these measures may include training and guidance, respite and care

benefits (Norwegian Ministry of Health and Care Services, 2011). It is the municipalities that determine how they organise these services and which services they offer each next of kin; thus, the services offered will vary (Norwegian Directorate of Health, 2019b). In Norway, nearly 90% of the municipalities have coordinators or multidisciplinary teams with competence in dementia who provide useful support and information about this condition and the services available to next of kin and those with dementia (Norwegian Directorate of Health, 2019a).

Dementia affects a person's cognitive abilities and activities of daily living as the disease progresses. Therefore, people with dementia will need increasingly comprehensive care and intervention measures (Livingston et al., 2020). In addition, many will experience neuropsychiatric symptoms during the course of their disease, and this aspect of dementia is the most important predictor of burden for next of kin, leading also to transitions to higher levels of care (Toot et al., 2017; Wergeland et al., 2015). Caring for a person with dementia often lead to impaired physical and mental health, sleep disturbances, reduced social well-being and an increasing burden on caregivers as well as a financial strain (Adelman et al., 2014; del-Pino-Casado et al., 2018). A lack of social support for both people with dementia and their next of kin, a low-quality dyadic relationship, and increased caregiver burden or health challenges, among other factors, accelerate a shift in care service (Maffioletti et al., 2019; Toot et al., 2017; Verbeek et al., 2015).

Next of kin living with a spouse / partner with dementia are particularly vulnerable to negative consequences of caregiving compared to other next of kin (Johansson et al., 2021; Taranrød et al., 2020). Although caring for people with dementia is often associated with negative experiences, many next of kin also report experiencing positive aspects of caregiving such as a sense of personal accomplishment, gratification, feelings of mutuality, an increase of family cohesion, and a sense of personal growth and purpose (Yu et al., 2018). Moreover, experiences of negative aspects are not necessarily obstacles to positive experiences; both are possible (Johansson et al, 2022; Yu et al., 2018). Positive caregiving experiences are more probably to arise when the next of kin experiences both personal and social affirmation in the caregiving giving role (Yu et al., 2018).

Daycare service (DC) facilitated for people with dementia is considered an important service for home-dwelling people with dementia (Norwegian Ministry of Health and Care Services, 2020). In Norway, most DCs services are located in a healthcare institution or service centre for older adults and is often referred to as regular DC (Ibsen et al., 2018; Norwegian Directorate of Health, 2019a). Farm-based daycare service (FDC) is one type that represents a daycare service complementary to regular DC (Ibsen et al., 2018). The majority of Norwegian FDCs have people with dementia in early stage as their main target group. In FDC there are more men compared to DC, the participants are younger and more often live with a spouse or partner (Ibsen et al., 2019; Rokstad et al., 2017). In Norway, FDC and DC have similarities with regards to the organization, daily structure, and the number of health education personnel (Ibsen et al., 2018). Compared to DC, FDC have fewer participants per day; more numbers of employees per participants, have open fewer days per week and differ in type of care environment (Ibsen et al., 2018). FDC actively uses the agricultural environments to facilitate for a range of activities for the participants with dementia, connected to the farm buildings, gardens, animals, and outdoor areas (Ibsen et al., 2018). Being physical active, spending time outdoors and being in social interactions with other people are the core components of the service offered at FDC (Ibsen et al., 2018).

For those being next of kin to a relative attending FDC, respite is closely connected to the well-being of their relative with dementia and the quality and content of the service. The FDC is described as person centred care of good quality. The staff at FDC was an important support for the next of kin along the trajectory of the progression of dementia and they felt included (Taranrød et al., 2021).

Both FDC and DC aim to facilitate meaningful activities in a safe environment and to improve the quality of life for people with dementia while providing respite for their next of kin. The intent of these services is to support people with dementia, as well as their next of kin, so that those with dementia can continue to live in their own home as long as possible (Norwegian Ministry of Health and Care Services, 2020).

In this study a 'transition' is understood as a shift between FDC to another service in the municipality. Next of kin typically experience transitions several times because the person with dementia will require more comprehensive care during the dementia course (Cranwell

et al., 2018). In Norway, a person with dementia who stops attending an FDC most often transitions to nursing-home care. Some enter a DC located in a healthcare institution, whereas a few stop attending any form of daycare service. Transition of care may indicate a person's need for more-comprehensive care than FDC can provide or a need for other and not so challenging surroundings (Ibsen et al., 2020). Any transition that involves a change in the physical environment can lead to increased physical and mental strain for both the person with dementia and his or her next of kin (Afram et al., 2015; Caldwell et al., 2014; Eika et al., 2014). Prior to a transition to nursing home, the caregiving that the next of kin provides often increases significantly but not the services from the municipalities (Vossius et al., 2015). Several studies have shown that spouses may face a considerably challenging in their caregiver role and might experience guilt, grief, and multiple losses, including loss of a partner, loss of identity as a couple, and loss of personal freedom during such a transition (Afram et al., 2014; Chan et al., 2013; Jacobson et al., 2015).

There are few studies of next of kin to people with dementia attending a FDC and to our knowledge, no studies investigating the next of kin's experience of the transition from FDC to higher level of care. Thus, the aim of our study was to explore the next of kin's experience of the transition process for people with dementia from FDC to another municipality service.

Method

Design

This study has a qualitative, descriptive design and we used interviews as method to gain a deeper understanding of the nature and meaning of the experiences of the next of kin (Kvale & Brinkmann, 2015). We have made efforts to be transparent and have analysed the data according to the well-recognized method of content analysis (Graneheim & Lundman, 2004; Lindgren et al., 2020).

The present study is part of a larger project, Farm-Based Day Care Services for People with Dementia: Quality Development through Interdisciplinary Collaboration, a prospective study with a multi-method approach (Eriksen et al., 2019). The participants were unknown for the authors prior to the project.

Participants and recruitment

We invited nine people from the larger project to participate in the present study. They were next of kin to persons with dementia who had recently stopped attending FDC and transferred to another service in the municipality. One potential participant withdrew from the study before the interviews were conducted; thus, the sample comprised eight participants. The inclusion criterion was being the next of kin to a person with dementia who had recently stopped attending an FDC and transitioned to another service in the municipality. The participants were recruited from six different FDCs in various regions of Norway through the leader (farm provider) of FDC for what amounted to a purposeful sample reflecting both sexes and different ages (Polit & Beck, 2021). The participants included two men and six women ranging in age from 51 to 77 years and they were next of kin to six men and two women with dementia, at the age of 71 to 83 years old. All the eight participants had a long-term relationship with their relative with dementia. Seven of them were spouses living with the person with dementia, and one was an adult child cohabiting a parent with dementia. Four participants were working, and four were retired. The relatives with dementia attended FDC one to five days a week before they stopped attending FDC.

Data collection

The individual interviews were conducted between June 2017 and January 2018 and took place from six weeks to seven months after the relative with dementia had left FDC. The participants selected the site of the interview; six were interviewed in their homes, one was interviewed via video conference and one by phone. The interviews were based on dialogue and steered by an interview guide with open-ended questions (Kvale & Brinkmann, 2015). In the interviews, the interviewer addressed topics related to the care situation and the next of kin's experiences prior to their relative's discontinuing FDC attendance and up to the time they obtained another service in the municipality, examples of questions are shown in the interview guide (Table 1). All the interviews were conducted by the first author (LBT). The interviews lasted from 30 to 90 min and were recorded; then, LBT and a research assistant transcribed the interviews verbatim.

Table 1. Examples of the questions in the interview guide

Please describe the care situation before your relative discontinued attending the FDC.
How did you experience the transition period?

How did you and your relative with dementia participate in the decision to discontinue FDC and apply for a new service in the municipality?
How did you experience the support from the FDC, and the municipality's healthcare service?
How did you experience the support from close family members and friends?

Data analysis

The transcribed interviews were subjected to a manifest level of content analysis following the guidelines of Graneheim and Lundman (2004) and led by LTB in collaboration with the co-authors. To support the coding and organisation of the data, NVivo 12 Pro was used (QSR International Pty Ltd, 2020). We have strived to describe the analysis process in detail to facilitate transparency in the study (Graneheim & Lundman, 2004; Lindgren et al., 2020). Each interview was identified as a unit of analysis, and the material was evaluated with a focus on manifest levels of content during a five-step analysis (Graneheim & Lundman, 2004).

In step one, the interview transcripts were read several times to obtain an overview of the material. In step two, the text was divided into meaning units, also described as “words, sentences or paragraphs containing aspects related to each other through their content and context” (Graneheim & Lundman, 2004, p 106), and condensed units were created. In step three, the meaning units were extracted and labelled with codes. In step four, codes were compared based on differences and similarities and grouped into six subcategories. For the fifth and last step, the six subcategories were clustered and grouped into three main categories. Differences in interpretations of the data were discussed by the authors until consensus was reached. An example of the process appears in Table 2.

Table 2. Example of the analyse process

Meaning unit	Condensed meaning unit	Codes	Sub-category	Category
<i>I felt that I hit the wall, I was so tired. Lack of sleep and I had to trail after him virtually everywhere, so I was simply unable to go to work.</i>	The next of kin was unable to go on, lack of sleep and having to trail after the person with dementia made her unable to work.	Exhaustion Lack of sleep Sickness leave	Experience physical and mental strain	
<i>Yes, sometimes I get rather frustrated. I shouldn't be angry with her for her inability to do something. I know that the disease is the reason why she cannot do it. When I tell her like for the sixth time what to</i>	The next of kin occasionally feels frustrated about the situation, but isn't allowed to be angry, since the disease is the reason why persons with	Feelings of frustration, sadness, guilty conscience		

<i>do, I get frustrated – I may even snap at her – and she reacts, then I feel sort of bad.</i>	dementia fail to cope with things. The next of kin feels bad.			Bearing the burden
<i>It was about coping with practical matters in general, getting dressed, grooming, he didn't know how to wash himself (...) I couldn't go out, I needed someone to be there when leaving the house, if only for shopping.</i>	The person with dementia has problems with practical matters, getting dressed, grooming. Could not leave the person with dementia alone in the house.	Take over tasks Constricted	Committed to the situation	
<i>I was focused on us making it work, and it did (...) I do have some obligations in various places, and I gave them all up. I just resigned from the world.</i>	The next of kin was focused on finding a solution and succeeded but had to renounce all other obligations.	Renounced all other obligations		

Ethical aspects

Before the interview, each participant received oral and written information about the study and provided written consent. The interviewees were assured that their participation was voluntary, that they could withdraw from the study at any time and that their personal confidential information was guaranteed. The participants were informed that the researcher was a registered nurse (RN). The study was reported to the Norwegian Centre for Research Data (No. 49799) and conducted in accordance with the Declaration of Helsinki (World Medical Association Declaration of Helsinki, 2004). The anonymized written transcripts of the audio recorded interviews are stored in a secured research server at Norwegian National Center for Aging and Health. The audio-recorded interviews and coding list linked to the participants are deleted as required by the Norwegian Centre for Research Data (No. 49799). The participants did not receive any financial or other benefits from participating in the study.

Results

All participants expressed that they were satisfied with the quality of FDC, with how their relatives with dementia had been cared for, and with their experience of support. There were great variations in how long the persons with dementia had attended FDC, from six to 45 months. Two of them had been transferred to a DC facility in a nursing home immediately after leaving FDC, and two had moved into a nursing home. The four other persons with dementia moved back and forth several times between different facilities before being offered permanent residence in a nursing home.

During the transition period when the functioning of the people with dementia decreased and their need for care increased, the beneficial aspects of respite declined especially for the spouses. The transition from FDC to another municipal service is a process developing and taking place in a context and the participants described their situation in light of this context.

The analysis resulted in three main categories: (1) Bearing the burden; (2) Being in transition; and (3) Feeling supported (Table 3).

Table 3. Main categories and subcategories

Categories	Bearing the burden	Being in transition	Feeling supported
Subcategories	Experiencing physical and mental strain	Making decisions	Support from healthcare service
	Committed to the situation	Preparing for admission to new service	Support from family and friends

Bearing the burden

The experiences of ‘Bearing the burden’ had two important perspectives: *Experiencing physical and mental strain* and *Committed to the situation*. The situation leading to the transition lasted from a few months up to a year before the relative with dementia was offered another service. Although, for some the transition went unplanned and quickly due to hospitalization of the relative with dementia.

Experiencing physical and mental strain

All the participants described behavioural changes of the relatives with dementia several months before the transition. Examples of these included episodes of wandering, anxiety, agitation, aggression and/or passivity. Some-participants also experienced the exacerbation of somatic diseases and a decline in ADL for their relative with dementia. All these changes caused both physical and mental strain, especially for the spouses, such as feelings of physical exhaustion, often caused by lack of sleep, and very limited opportunities to leave their homes:

His disease worsened around Christmas last year, and he slept very poorly at night, so we slept something like 2 to 3 hours a night. At the same time, he started to

become unpredictable in his behaviour. So, he couldn't be left alone unsupervised.

(Spouse)

The participants described feelings of guilt, frustration over becoming impatient and sadness at witnessing how dementia had changed their relative with dementia. Several spouses reported being afraid at times due to unpredictable episodes of agitation and threats. If the agitation occurred at the FDC, the relative with dementia was returned home. Episodes with agitation led to less respite than the spouses might otherwise have: '(...) I felt that I hit the wall. I was so tired. Lack of sleep. I had to follow him virtually everywhere, so I was simply unable to go to work' (Spouse). For some of the working spouses, the care situation occasionally caused absence from work. Balancing jobs with caring for relatives also posed challenges for their daily schedules. Several participants managed to mobilised members of their social network or planned with a home-nursing service or FDC to be able to sort out their daily schedule.

Committed to the situation

All the participants were concerned with the well-being of their relatives with dementia. They described a feeling of commitment to caring for their relative. The spouses especially stated that even if their own well-being was compromised, they felt a great responsibility. Their only option was to endure the situation. One spouse said, 'I just had to live in the situation', and another stated, 'I was focussed on us making it work, and it did. (...) I do have some obligations in various places, and I gave them all up. I just resigned from the world.' The spouses also described their relatives increasingly need for help, they worried about how long they would be able to provide care alone.

Being in transition

All the participants were aware that their relative's attendance at the FDC was limited. The process of being in transition was described from two perspectives: *Making decisions* and *Preparing for admission to a new service*.

Making decisions

Making decisions referred to decisions about service options, first, to discontinue the FDC and, second, to apply for other services. In the process of ending FDC, most participants felt

that there had been a good dialogue about the care situation with the FDC staff. However, the final decisions were made by the municipality healthcare service, and the participants felt that they and their relatives with dementia had little influence regarding this decision. One spouse described an absence of dialogue:

We didn't consider leaving the FDC at all; it was the multidisciplinary team, or the service office, that decided that she couldn't continue. We didn't ask for a new service; we just wanted to continue, and no contact was made. (...) We received a letter—that's all. (Spouse)

Regardless of when the application for nursing home placement had been made, all the participants described the decision as agonising but utterly necessary, given the need for care of their relatives with dementia and their own capacity to provide further care at home. At the same time, they expressed sadness that their relative had to leave FDC. 'One can say, it was very sad that she could not continue because she thrives there' (Spouse).

Preparing for admission to a new service

The perspective of *preparing for admission to a new service* refers to the period when the decision to discontinue the FDC was made and before a new care option had been decided. During the transition process some of the participants—and their relatives with dementia were invited to visit the new place. Being introduced to the new DC or nursing home and given an opportunity to become familiar with the service was experienced as positive. One spouse said, 'It was a month in advance; we were up there (DC) talking to the manager, and we felt welcome'. The participants with relatives who were transitioned directly from FDC to a nursing home where the relatives had stayed earlier for a short time were also content since they were familiar with the place and the staff.

Several of the participants reported that their relative with dementia experienced an exacerbation of his or her somatic illness or neuropsychiatric symptoms, which resulted in a short stay in hospital before transitioning to a nursing home. In some cases, the relative with dementia stayed at several wards at different nursing homes before he or she was granted a permanent stay. This was experienced as extraordinarily demanding, exhausting, and mostly beyond their control. They also experienced a lack of information flow between the various

units, and they had to provide the same information about the person with dementia over and over again. Other participants experienced that their relatives with dementia had been placed on a waiting list and had to accept the first vacancy: 'There was no choice. You had to take the nursing home service that was available. The municipality decided' (Spouse). One participant reported that the relative was left without any kind of service for several weeks. Others did not receive any information about care options even if they had asked for it.

Feeling supported

The feeling of support was important to the participants and took mainly place from two sources: *Support from healthcare services* and *Support from family and friends*.

Support from healthcare services

The participants experienced being met with understanding of their situation and offered some practical help from the healthcare service.

Most participants described that, before the transition of their relative with dementia, they had experienced a valuable dialogue with the head of the FDC and the multidisciplinary team. A participant stated, 'Over the last two months, she (the head of the FDC) has been very positive, very supportive, and made all the necessary provisions' (Adult child). The participants also emphasised that their relative with dementia had enjoyed the time at the FDC. The participants therefore felt sad when their relative had to leave this service. Only a few participants were offered extra respite days during the transition period. Several highlighted that the multidisciplinary team had been an important source of support regarding information, guidance and has helped them to cope with the care situation; additionally, some had received help from the home-nursing service.

All participants stated that, it was pivotal that their relatives with dementia received high-quality care after leaving FDC and they had actively sought information about suitable care options for their relatives. When information was insufficient, further frustration occurred. Despite some negative experiences, most of the participants reported that the support from the healthcare system in the municipality, had been important for them in their caregiving situation.

Support from family and friends

Some of spouses experienced losing relationship with friends because of the situation of their relative with dementia, but most participants stated that they had relied on certain family members or friends for support and expressed gratitude for the care and support that they had received. The participants described having received practical support—for instance, accompanying the person with dementia on doctor's visits or staying with him or her when the participants needed to complete necessary chores or errands outside home. One spouse described how she had mobilised her family and friends to help with practical tasks regarding the daily schedule so that she could continue her employment:

(...) the problem is that I start work at half-past eight and the daycare does not open so early; we tried to make it work. One day a week, he was at FDC; three days a week, he was at a daycare in a nursing home; and on the fifth day, my older relative took care of him or our friends that he was confident with (...). All the shifting was too much for him and for me. It did not work; then, we were offered a permanent place before Easter (Spouse)

Several participants reported that they felt emotionally supported by family and friends and that they could share their worries and feelings about the care situation: 'I have a very good friend, a colleague of mine, who called me two or three times a week. You find out who your good friends are—and which ones aren't' (Spouse). On the matter of being open and sharing thoughts about their situation, the participants differed. Several of the spouses expressed that they had not given their families details about their husband /wife`s situation or their own experience of the caregiving situation. They felt much alone. Others had chosen an opposite solution and shared information with their children. This was seen as an advantage in their difficult situations.

Discussion

In this study we found that the transition process was characterised by a longer period of physical and mental strain due to behavioural changes of the relatives with dementia, but the participants were committed to bearing the burden. In relation to the transition process several fundamental and necessary, but agonising decisions had to be made. In addition, they had to prepare themselves and their relatives with dementia for admission to a new service.

Support from health care personnel, family and friends was experienced as especially important.

The transition process was experienced as an exhausting period for the participants. The participants, especially the spouses, described feelings of burden, loss, and grief, and a feeling of uncertainty in relation to their living situation. The negative consequences that caregiving had on their work and social lives were not unexpected and aligned with literature about being a caregiver during the course of dementia (Alzheimer's Association, 2022; Eika et al., 2014; Evans & Lee, 2014).

All the participants in the present study, focused on the well-being of the relatives with dementia often on the cost of their own well-being. The care situation gave the participants, especially the spouses, few possibilities to re-energize and recover from the caregiving. Despite the lack of enough respite, our findings provide knowledge about the participants' views of the service offered. They highlighted the care quality and the support they received from FDC staff as important for them and their relatives with dementia, but the support was not enough to prevent the heavy burden of care that most of the next of kin experienced in the transition process. Even though, the Norwegian authorities have focused on supporting the next of kin in their caregiver roll there is still a lack of available services to meet the next of kin's needs for respite and support (Granbo et al., 2019; Norwegian Ministry of Health and Care Services, 2020).

Even though the main target group for FDC most often is people in an early stage of dementia, two-third of those who stopped attending FDC moved into a nursing home (Ibsen et al., 2018; Ibsen et al., 2020). In our study we saw that the relatives with dementia stayed in FDC even though their dementia condition was in a sever stage. The fact that FDC have fewer participants per day and a staff that has the possibility to provide a variety of activities. This could improve the possibility for offering individually tailored services (Ibsen et al., 2020). I In addition, the next of kin experienced a good dialog with the staff and this could also be a factor for why the persons with dementia stayed at FDC for so long.

Our study found that the multidisciplinary team had provided significant support, offering information and guidance in the trajectory of dementia. Yet, in the process of transition, some reported that the healthcare service failed to give them appropriate information about different services, and this was a bit unexpected. One might wonder if the healthcare service personnel are lacking an adequate overview of the services offered by the municipality, despite the fact that the municipality is obliged to provide information and services according to citizens' needs (Norwegian Directorate of Health, 2015). The participants in our study and their relatives with dementia did not participate in the final decision to leave FDC, the municipality healthcare service made that decision. Despite this, the participants described being engaged in the dialogue about the decision and felt supported by the staff in FDC. Somewhat surprisingly, one of the dyads reported having received only a letter stating that the relative with dementia could no longer attend the FDC, without any dialogue with the healthcare service. This finding indicates that the healthcare services have to improve their routines for supporting next of kin and fulfil their obligations for supporting the caregivers (Norwegian Ministry of Health and Care Services, 1999).

Our findings indicate that, in a planned transition where the next of kin and the person with dementia were given an opportunity to become familiar with the new service and staff before the actual transition, were a positive experience. This is also shown by Tolo Heggstad and Førde (2021) who described the importance of a planned transition and of becoming acquainted with a service as critical factors for a good transition and a positive experience for both the person with dementia and their next of kin. In contrast, when the transition was unplanned and involved several relocations for the person with dementia before he or she made a permanent move, the process and this period were experienced as highly stressful and often included a lack of information, continuity, or predictability in the service to come. The Norwegian guidelines for dementia care (2017) state that deviations like a transition process need to be addressed in order to improve the system and its services. In the transition process, the municipal healthcare service considers the next of kin's voice as crucial (Tolo Heggstad & Førde, 2021), and our findings suggest that the municipality health care service must be strengthened in order to support the next of kin and their relatives with dementia throughout the course of dementia and particularly when the dementia progresses dementia and the burden of care increases.

Our participants emphasized the importance of support from both the family and healthcare services. Even if, for a variety of reasons, our participants did not involve the family in all of the difficult care situations and decisions regarding the relative with dementia, they valued their support. This might indicate that the participants, in particular the spouses, wished to protect both their family members and the person with dementia from being involved in difficult situations. Alternatively, they may have viewed the situation as a marital or child/parent matter that did not require the involvement of family. Another study on the next of kin of people with dementia attending FDC found that perceived support positively affected both the burden of care and the quality of life (Taranrød et al., 2020). In general, social support is considered beneficial not only for maintaining mental health and psychological well-being but also for reducing the risk of depression (Norwegian Directorate of Health, 2021).

Methodological considerations

In qualitative studies *trustworthiness* describes the quality of the study. To ensure trustworthiness of our study, we have attempted to describe the process openly (Lincoln & Guba, 1985). Lincoln and Guba (1985) emphasize five essential elements of trustworthiness: *credibility, dependability, confirmability, transferability, and authenticity*.

One author (LBT), who is a registered nurse with clinical experiences and a research interest in the care situation for the next of kin of people with dementia, conducted all the interviews. Polite and Beck (2021) claim that pre-understanding may prevent us from seeing new and previously unknown aspects of our research. To ensure *confirmability* and *credibility* of the study, the interviewer had to be aware of her pre-understanding. When preparing for the study LBT was therefore interviewed by the last author (SE) about her experiences and pre-understanding of the field. The interview was recorded, and LBT listened to it several times to reflect on her pre-understanding and form a conscious relationship with her prior assumptions and perspectives. Throughout the interviews, LBT sought to be as objective as possible and carefully listen to the interviewees' stories without letting her pre-understanding interfere.

Our participants described their experiences with the transition process of their relatives with dementia from FDC to another municipal service in depth and in their own words. Although

member checking has not been carried out by having the participants read the transcribed interviews afterward, we have attempted to stay true to the participant's description of the process to ensure *dependability*. The analysis process was conducted in an open dialogue among the authors, discussing meanings, similarities, and differences in understanding the data. The three co-authors are researchers with many years of experience in various aspects of dementia care and dementia care research. Each step of the analysis is described in detail, and the presentation of results in our article is supported by quotes to be transparent and describe the participants various experiences.

The sample is small, with data from eight participants, but the participants represent different FDCs, and regions of Norway and they differ in age, gender, and relationship with their relative with dementia. Polit and Beck (2021) state that including participants with various experiences increases the possibility of shedding light on the research question from a variety of aspects and, thereby, increases its *credibility* and the *authenticity*. Among the eight participants, seven were spouses and one was an adult child of a person with dementia, all added important knowledge to the study. This said, it could possibly have strengthened the study's credibility to have several adult children or participants with other relations to a person with dementia. For our study it was not possible to recruit such participants. Another limitation was that the interviews were conducted retrospectively and up to seven months after the relative with dementia had left FDC. We intended to recruit participants shortly after the transition, but we experienced that it was too early and that the next of kin needed some time to process the experience before they were able to talk about it with a researcher.

We believe that the findings elucidate important experiences of next of kin to a relative with dementia that could be *transferable* to others in a similar situation in a different context.

Conclusion

To highlight the experiences of next of kin during the transition process, politicians and healthcare services must understand, acknowledge, and emphasize the next of kin and the persons with dementia situation and needs. Our findings highlight the importance of good quality service, close dialog, information, and support between the different part in the transition process and can be useful for the further development of services with good quality and to reduce the negative effects of care on next of kin. A planned transition and an opportunity to become acquainted with the new service before the transition seemed to be key factors in experiencing a smooth transition. To ensure continuity and ease the burden of

care throughout the course of dementia and in the transition process, the next of kin and the person with dementia should have a contact person who knows them and their situation. This person should act as a coordinator and facilitate the transition process until a permanent stay has been established. Our findings suggest that there is a need for good routines in communication between services in the transition process and with the next of kin. We suggest that the dialog about transitions start early in the process that ensure predictability for people with dementia, the next of kin and the healthcare system.

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