Norwegian University of Life Sciences
Faculty of Landscape and Society
Department of Public Health Science

Philosophiae Doctor (PhD)
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Quality of care at farm-based day care services for people with dementia – the farm as a setting for promoting health, well-being and quality of life

Kvalitet i omsorga ved dagaktivitetstilbod på gard for personar med demens – garden som arena for fremjing av helse, velvære og livskvalitet

Bjørnar Finnanger Garshol

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Preface and acknowledgments

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Summary

Background: There is an increasing prevalence of dementia worldwide, with an estimated 35.6 million people living with dementia in 2010. This number is expected to double by 2030 and double again by 2050. The increasing number of people with dementia and the burden the disease places on those affected and their informal caregivers have prompted the World Health Organization to name dementia a global public health challenge. In Norway, the national dementia plans have highlighted day care services for people with dementia as a “missing link” in the care pathway, and state that they should provide their participants with activities, stimulation, good experiences and meaningful days. Most day care services in Norway are so-called regular day care services situated at already existing care facilities such as nursing homes. There has been a call for diversification of day care services, and farm-based day care services for people with dementia have been highlighted as an innovative service. These are day care services located at farms using the farm-setting and activities actively in the service. Previous research has noted many potential benefits of farm-based day care services for people with dementia, but there is still a need for further research.

Aim: The aim of this thesis is therefore to investigate the quality of care at farm-based day care services for people with dementia. To aid in this, the thesis had sub-aims looking at physical activity, emotional well-being and quality of life and subjective well-being for participants at farm-based day care services.

Method: We conducted a longitudinal study where we followed participants at farm-based day care services for 12 months. We collected data on a range of measures, including quality of life, at start-up, 6 months and 12 months. We also gathered physical activity data using actigraphy for a subsample of the participants in conjunction with the data collection at 6 months. For both the longitudinal data and activity data we also included comparison groups from regular day care. Lastly, researchers in the Farm-based Dementia Care Project, conducted an observational study using the Maastricht Electronic Daily Life Observation-tool, looking at different aspects of daily life at both farm-based and regular day care services for people with dementia.

Results: Based on the collected data on physical activity we found that participants at farm-based day care services had a higher level of physical activity than participants at regular day care services.

Further, the participants at farm-based day care services were more physically active the days they were at the farms, compared with the days they were not at the farms.

We also found based on observational data that participants at day care services for people with dementia generally had good emotional well-being while at the service, but that the participants at farm-based day care services had higher emotional well-being for several of the factors and activities at the day care services compared to those attending regular day care services. We also found, adjusting for activities and other factors, that attending farm-based day care services was associated with higher emotional well-being. In addition, social interaction and the activities exercise and dancing, and quiz, music and spiritual activities were associated with emotional well-being regardless of the type of service.

Lastly, based on the longitudinal data we found a larger, but not clinically significant, decrease in self-reported quality of life after 12 months among the participants of farm-based day care services compared to regular day care services. Further analyses suggested that changes in the social domains were the main difference between the two groups. Additionally, with-in group analyses of those attending farm-based day care services showed that subjective well-being remained stable throughout the 12 months. Further, among the service-related factors at farm-based day care services, time spent outdoors at the service and number of participants were associated with quality of life, while time spent outdoors was associated with subjective well-being.

Conclusion: Based on the findings the overall conclusion of this PhD-thesis is that farm-based dementia day care services provide quality care for its participants through providing physical activity, social activity and good experiences for the participants. Further, the quality of care at farm-based day care services are equal to regular day care. Based on the findings farm-based services can, especially regarding physical activity and good experiences, potentially provide more quality care than regular day care services. Farm-based day care services can therefore help alleviate the need for additional care services for people with dementia, and promote health and well-being for the participants.

Samandrag

Bakgrunn: Prevalensen av demens aukar globalt og ein antek at 35.6 millionar personar levde med demens i 2010. Dette talet er venta å doble seg innan 2030, og doble seg igjen innan 2050. Det aukande talet på personar med demens og byrda sjukdommen legg på dei som har den og deira pårørande har ført til at Verdas Helseorganisasjon no ser på demens som ein global folkehelse utfordring. I Noreg har dei nasjonale demensplanane framheva dagaktivitetstilbod for personar med demens som det «manglande mellomleddet» i omsorgskjeda. Ifølgje demensplanane skal slike dagaktivitetstilbod tilby deltakarane aktivitetar, stimulering, gode opplevingar og meiningsfulle dagar. Dei fleste dagaktivitetstilbod i Noreg er såkalla ordinære dagtilbod lokalisert saman med eksisterande omsorgsteneste, slik som sjukeheimar. Det har vore fokus på å auke mangfaldet av dagaktivitetstilbod og dagaktivitetstilbod på gard har blitt framheva som eit innovativt tilbod. Slike tenester er dagaktivitetstilbod tilknytt gardar og som nyttar gardsmiljøet og gardsaktivitetane aktivt i tenesta. Tidlegare forsking har funne fleire potensielle positive effektar av dagaktivitetstilbod på gard for personar med demens, men det trengs framleis ytterlegare forsking.

Mål: Målet med denne avhandlinga er difor å undersøke omsorgskvaliteten ved dagaktivitetstilbod for personar med demens. For å hjelpa med å svara på denne målsettinga, har avhandlinga fleire undermål som går på fysisk aktivitet, emosjonelt velvære (well-being) og livskvalitet og subjektivt velvære (well-being).

Metode: Vi utførde ein langsgåande studie der vi følgde deltakarar frå dagaktivitetstilbod på gard i 12 månadar. Vi utførde datainnsamling med diverse måleverktøy, inkludert livskvalitet, ved oppstart, etter 6 månadar og etter 12 månadar. Vi samla også inn data om fysisk aktivitet ved hjelp av aktigrafar i samband med datainnsamlinga etter 6 månadar. For både langsgåande data og aktivitetsdata hadde vi samanlikningsgruppe frå ordinære dagtilbod. Til slutt gjennomførde forskarar i Demensomsorg på gard-prosjektet ein observasjonsstudie ved hjelp av Maastricht Electronic Daily Life Observation-Tool, der ein såg på ulike aspekt ved dagleglivet på både dagaktivitetstilbod på gard og ordinære dagaktivitetsilbod.

Resultat: Basert på innhenta data om fysisk aktivitet fann vi at deltakarar på dagaktivitetstilbod på gard hadde eit høgare fysisk aktivitetsnivå enn dei på ordinære tilbod. Vidare var deltakarane på

dagaktivitetstilbod på gard meir aktive dei dagane dei var på garden samanlikna med dei dagane dei ikkje var på garden.

Data frå observasjonsstudien viste at deltakarar på dagaktivitetstilbod generelt hadde godt emosjonelt velvære, men at deltakarar frå dagaktivitetstilbod på gard hadde høgare emosjonelt velvære for fleire faktorar og aktivitetar samanlikna med deltakarar frå ordinære tilbod. Vi fann og, etter å ha justert for alle faktorar og aktivitetar, at deltaking på dagaktivitetstilbod på gard var assosiert med høgare emosjonelt velvære. I tillegg var sosial interaksjon og aktivitetane trim og dans, og quiz, musikk og åndelege aktivitetar assosiert med emosjonelt velvære uavhengig av tilbodstype.

Data frå den langsgåande studien viste ein større, men ikkje klinisk signifikant, nedgang i sjølv-rapportert livskvalitet hos deltakarar på dagaktivitetstilbod på gard samanlikna med dei på ordinære tilbod. Vidare analysar fann at endringar i det sosiale domenet stod for mesteparten av forskjellen mellom dei to gruppene. Vidare viste analysar innan gruppa av deltakarar frå dagaktivitetstilbod på gard at deira subjektive velvære heldt seg stabil. I tillegg såg ein at blant dei tilbodsrelaterte faktorane så var tid utandørs og talet på deltakarar assosiert med livskvalitet, medan tid utandørs var assosiert med subjektivt velvære.

Konklusjon: Basert på funna er den overordna konklusjonen til denne avhandlinga at dagaktivitetstilbod på gard gir kvalitetsomsorg til deltakarane gjennom å bidra med fysiske og sosial aktivitetar i tillegg til gode opplevingar. Vidare kan omsorgskvaliteten ved dagaktivitetstilbod på gard seiast å vere lik den ved ordinære tilbod, og i enkelte tilfelle, særskild med tanke på fysisk aktivitet og gode opplevingar, indikerer funna at dagtilbod på gard potensielt kan ha betre omsorgskvalitet. Dermed kan dagaktivitetstilbod på gard for personar med demens hjelpe med å lette på det aukande behovet for omsorgstenester og samtidig fremje deltakarane si helse og velvære.

List of papers

1. **Finnanger-Garshol, B., Ellingsen-Dalskau, L. H., & Pedersen, I. (2020). Physical activity in people with dementia attending farm-based dementia day care – a comparative actigraphy study. *BMC Geriatrics, 20*(1), 219. doi:10.1186/s12877-020-01618-4**

2. **Finnanger-Garshol, B., Pedersen, I., Patil, G., Eriksen, S., Ellingsen-Dalskau, L. (2020) Emotional well-being in day care services for people with dementia – a comparative study between farm-based day care and regular day care. Manuscript**

3. **Finnanger-Garshol, B., Pedersen, I., Eriksen, S., De Bruin, S., Rokstad, A.M., Patil, G., (2020) Quality of life in people with dementia attending farm-based dementia day care – A comparative, longitudinal study. Submitted.**

Abbreviations

AIC – Akaike Information Criterion

ART – Attention Restoration Theory

CDR – Clinical Dementia Rating

CPM – Counts per minute

CSDD – Cornell Scale for Depression in Dementia

ECOD – Effects and Costs of a day Care Centre Program Designed for People with Dementia Study

FDC – Farm-based day care service for people with dementia

GMHR – General Medical Health Rating

HRQoL – Health Related Quality of Life

I-ADL – Instrumental activities of daily life

LCB – Locus of Control of Behaviour

MADRS – Montgomery and Aasberg Depression Rating Scale

MEDLO – Maastricht Electronic Daily Life Observation Tool

MoCA – Montreal Cognitive Assessment Scale

NPI – The Neuropsychiatric Inventory Scale

NPI-Q – The Neuropsychiatric Inventory Questionnaire

OSS3 – Oslo Social Support Scale

P-ADL – Personal activities of daily life

QoL – Quality of life

QoL-AD – Quality of Life in Alzheimer’s Disease

RAID-N – Rating Anxiety in Dementia – Norwegian Version

REED – Anosognosia Rating Scale

RUD – Resource Utilization in Dementia

SRT – Stress Reduction Theory

TUG – The Timed Up and Go-test

WHO – World Health Organization

WHO-5 – The WHO-5 Well-being Index

1.0 Introduction

An estimated 35.6 million people were living with dementia in 2010, and this number is expected to double in 2030 and double again in 2050 (Prince et al., 2013). This increasing prevalence, together with the burden dementia places on those affected by the disease and their informal caregivers, has caused the World Health Organization (WHO) to name dementia a global public health challenge (World Health Organization, 2012). The WHO further states that dementia should be considered part of the public health agenda in every country as the condition is a leading cause of disability and dependency among older people worldwide. Among the important focus areas are the need for programs to improve quality of life (World Health Organization, 2012) and to empower people with dementia to live in the community and receive care according to their own wishes and preferences (World Health Organization, 2017).

One potential setting for promoting health and improving quality of life for people with dementia is day care services for people with dementia. The WHO considers them a part of respite care and highlight the importance that such services provide the participants with opportunities for engagement and socializing (World Health Organization, 2012). In Norway, the national Dementia Plan 2015 named them “the missing link” in the care pathway for people with dementia and stated that they should provide activities, stimulation, good experiences and meaningful days (Ministry of Health and Care Services, 2007). This was followed up in Dementia Plan 2020, which reiterated the importance of day care services for people with dementia, suggested they be made mandatory for the municipalities to provide, and stated that the provision of physical, social, cultural and spiritual activities is an fundamental part of the comprehensive care services for people with dementia (Ministry of Health and Care Services, 2015).

The aim of this thesis is to investigate the quality of care for one type of day care services for people with dementia, namely farm-based day care services (FDCs). These are day care services which are situated at farms and use the farm setting and resources actively in the service. Such services could aid in covering the increasing need for day care services for people with dementia, along with a need for diversification in the agricultural sector (Ministry of Local Government & Ministry of Agriculture and Food, 2013). FDCs can be considered a complementary service to the regular day care services. Regular day care services are here day care services that are typically co-located with other care institutions in the municipality, such as long-term care facilities or retirement homes, and they constitute about 70% of the day care services for people with dementia in Norway (Gjøra, Eek, &

Kirkevold, 2015). As regular day care services are the most common type of day care service for people with dementia, I will in this thesis compare participants at FDCs with participants at regular day care services. This is both to show the complementary nature of the services and to see if FDCs provide the same care or something different than regular day care services.

The focus of the investigation is on quality of care, which can be described as having two principal components: access and effectiveness (Campbell, Roland, & Buetow, 2000). Access pertains to whether the users get the care they need, while effectiveness pertains to whether the care is effective when they get it. In this thesis I will focus on the effectiveness aspect of quality of care by looking at different outcomes such as physical activity, well-being and quality of life. Not only are these important with regards to health promotion for people with dementia in general, they are also in line with what both international and national strategies believe day care services for people with dementia should encompass.

So, to investigate quality of care at farm-based day care services for people with dementia this thesis will base itself on three research aims, corresponding to the three articles included:

1. Investigate the association between physical activity, type of day care service, and attendance at farm-based day care services for people with dementia.
2. Investigate the association between the different aspects of the day care services and the activities provided with emotional well-being, and to investigate if there are any potential differences between farm-based day care services and regular day care services.
3. Investigate the association between quality of life and type of day care services for people with dementia over time, and factors associated with quality of life over time.

I will start this thesis by providing some background on dementia and the situation for people with dementia. I will then provide some background and context on dementia care, and in particular day care services for people with dementia. I will further describe relevant theoretical and empirical frameworks, before describing the previous research conducted on farm-based dementia care. After that I will present the aim of this thesis before describing the methods used in this PhD-project. I will then present the included papers and their findings, before discussing these in the context of quality of care and within the theoretical and empirical frameworks. Lastly, I will provide a conclusion and implications for practice and research.

2.0 Background

In the subsequent chapter I will describe dementia and the challenges surrounding dementia, both for the people with dementia and for society. I will then describe the context of dementia care, with a particular focus on the Norwegian context and the provision of day care services for people with dementia.

2.1 Dementia

Dementia is considered a clinical syndrome caused by neurodegeneration. It is characterized by an inexorably progressive deterioration in both cognitive ability and capacity for independent living (Prince et al., 2013). Due to the increasing proportion of older people all across the globe, and consequently the increasing proportion of people with dementia, there is an growing focus on dementia and its consequences (Wu et al., 2016). Currently, there is no known cure for dementia and the World Health Organization considers it one of the major causes of disability in later life and one of the leading causes of dependency among older people (World Health Organization, 2012).

2.1.1 Prevalence and incidence of dementia

In 2010 an estimated 35.6 million people lived with dementia worldwide and the number is expected to rise to 65.7 million in 2030 and 115.4 million in 2050 (Prince et al., 2013). Building on these numbers in a later report, Prince et al. (2015) revised the estimates to 46.8 million people living with dementia worldwide in 2015, with a projected increase to 74.4 million in 2030 and 131.5 million in 2050. Based on the World Bank's classification of income-level, 58% of people with dementia lived in low or middle-income countries in 2015, and this is estimated to rise to 63% in 2030 and 68% in 2050 (Prince et al., 2015). One of the main reasons for the estimated increase in dementia prevalence is the increasing number of older people in the world, with older people constituting an increasingly higher proportion of the total population (Prince et al., 2013; Prince et al., 2015)

It is estimated that there are over 9.9 million new cases of dementia world-wide each year (Prince et al., 2015). Globally the incidence rate is 3.9 per 1000 person years for the age group 60-64, growing to 104.8 per 1000-person year for those 90 years or more. The age and gender standardized (using Western Europe as the standard population) global incidence rate overall for those aged 60+ is 17.3 per 1000 person years. In higher income countries it is slightly higher at 18.39 per 1000 person years, while it is lower in low- and middle-income countries at 14.06 per 1000 person years (Prince et al., 2015). A review (Prince et al., 2016) looking at the trends of dementia prevalence and incidence found that were no clear evidence for any trends in dementia prevalence, but some evidence for a decline in incidence rate in high-income countries.

For Norway there are no estimates based on country-wide data (Strand et al., 2014), but, based on adjusted estimates from older studies, it is estimated that there are between 88 000 and 104 000 people with dementia living in Norway (Reneflot et al., 2018). Similarly to the situation globally, the number of people living with dementia in Norway is expected to double within the next 35 to 40 years (Engedal & Haugen, 2018b). While there is also little research on the incidence rate in Norway it has been suggested that one can base oneself of the WHO's estimate for high income countries, giving a incidence rate of 3,4 per 1000 person year for those age 60 to 64, increasing to 158 per 1000 person years for those age 95 years or more (Reneflot et al., 2018). Another estimate is there are 10 000 new cases of dementia in Norway each year, and that this will double to 20 000 per year in the next 35 to 40 years (Engedal & Haugen, 2018b).

2.1.2 Risk factors and dementia prevention

Several risk factors have been suggested for developing dementia. Livingston et al. (2017) divided these into potentially modifiable and non-modifiable factors. The primary non-modifiable factor is ageing, and this is considered the greatest risk factor for dementia overall. Another potentially non-modifiable factor is the having the genotype ApoE $^{\varepsilon}4$ (Livingston et al., 2017).

Livingston et al. (2017) uses a life course model to show when different modifiable factors contribute to increased risk of dementia. In early life they note less education as a risk factor for dementia, potentially due to less education leading to less cognitive reserves. For midlife they highlight hearing loss, hypertension and obesity. For hearing loss, the underlying mechanisms are unclear, but hypertension and obesity are thought to be risk factors as they can lead to brain damage in the form of vascular damage. In addition, obesity is linked to pre-diabetes (Livingston et al., 2017). For late life, they found that smoking, depression, physical inactivity, social isolation and diabetes caused increased risk for dementia. Smoking caused increased risk through its role in developing cardiovascular pathology and the presence of neurotoxins in smoke. Depression has an unclear causality with dementia, but one hypothesis is that it causes increased risk through changes in the brain's biochemistry. Physical inactivity was a risk factor for dementia as physical activity plays a role in maintaining cognition, while social isolation was a risk factor for dementia as it is linked with hypertension, coronary heart disease and depression, in addition to it causing cognitive inactivity. For diabetes the mechanics behind its role as a risk factor are decrease in the brains insulin production leading to impaired amyloid clearance and higher glucose levels that might lead to impaired cognition (Livingston et al., 2017).

Livingston et al. (2017) found little evidence to suggest that head injuries, visual impairments and sleeping disorders lead to increased risk of dementia. There were also some potential risk factors they were not able to account for in their model, such as diet, alcohol, living near major roads and sleep quality, all of which could be risk factors for dementia (Livingston et al., 2017).

In order to prevent dementia Livingston et al. (2017), based on their established risk factors, suggested active treatment of hypertension, more childhood education, exercise, maintaining social engagement, reduce smoking, and management of depression, hearing loss, diabetes and obesity. They estimate that following these recommendations could potentially prevent a third of dementia cases (Livingston et al., 2017). The WHO gave similar, but expanded recommendations in *Risk reduction of cognitive decline and dementia: WHO guidelines* (World Health Organization, 2019). They recommend the following measures for risk reduction:

1. Physical activity, both to reduce the risk of cognitive decline and reduce the risk of further cognitive decline
2. Smoking cessation, which could lead to reduced risk of cognitive decline, among other health benefits
3. Having a healthy balance diet based on the WHOs recommendations or maintain a Mediterranean-like diet
4. Reduction or cessation of hazardous or harmful alcohol consumption
5. Cognitive training for older adults or older adults with mild cognitive impairment
6. Weight management, particular avoiding mid-life overweight and/or obesity
7. Management of hypertension for adults with hypertension
8. Management of diabetes mellitus, both in the form of medication and lifestyle changes
9. Management for dyslipidaemia, that is abnormal amounts of lipids in the blood

Additionally, while there was insufficient evidence for dementia-specific recommendations, the guidelines recommended social activity to maintain social participation and support, management of depression and timely screening of hearing loss and provision of hearing aids (World Health Organization, 2019).

2.1.3. Diagnosis

A dementia diagnosis is set on the basis of symptoms and how they present themselves related to a person's functioning. In Norway, dementia is commonly diagnosed on the basis of ICD-10 criteria (Engedal & Haugen, 2018b). The ICD-10 – Diagnostic Criteria for Research set the following criteria for dementia, of which all must be present (World Health Organization, 1993):

I. A decline in memory, which is most evident in the learning of new information
    a. Mild: Memory loss impacts daily living
    b. Moderate: Memory loss represents a serious handicap to independent living
    c. Severe: Memory loss characterized by the complete inability to retain new information and only fragments of previously learned information remain

II. A decline in other cognitive abilities, characterized by deterioration in judgment and thinking
    a. Mild: Decline in cognitive abilities causes impaired performance in daily living
    b. Moderate: Decline in cognitive abilities makes the individual unable to function without the assistance of another in daily living
    c. Severe: Decline in cognitive abilities is characterized by an absence, or virtual absence, of intelligible ideation

III. Preserved awareness of the environment

IV. A decline in emotional control or motivation, or change in social behaviour; at least one of the following:
    a. Emotional lability
    b. Irritability
    c. Apathy
    d. Coarsening of social behaviour

V. The condition must have been present for at least six months

According to the ICD-10 criteria the overall severity of the dementia is best expressed as the level of decline in memory or other cognitive abilities, whichever is more severe. For example, if there is a mild decline in memory, but a moderate decline in cognitive abilities, the dementia severity should be considered moderate (World Health Organization, 1993).

In Norway, it is primarily the general practitioners that set the dementia diagnosis (K Engedal & PK Haugen, 2018). If no certain diagnosis can be set, the person is often referred to the specialist health care, for example memory clinics, geriatric or neurological polyclinics. Younger people, those younger than 65 years, are almost always refereed to specialist health care as there may be rare neurological diseases causing the dementia symptoms (Engedal & Haugen, 2018).

2.1.4 Different types of dementia

There are several forms of dementia, with Alzheimer's disease, vascular dementia, Lewy body, and frontotemporal dementia being the most common (Prince et al., 2013). While the exact distribution is not known, one estimation is that Alzheimer's disease account for about 50-75% of all cases of dementia, vascular dementia accounts for 20-30% of the cases, Lewy Body accounts for <5%, and frontotemporal dementia accounts for 5-10% of the cases (Alzheimer's Disease International, 2009). While there are similarities between the conditions, there are also some differences. Alzheimer is characterized by impaired memory, depression and apathy and has a gradual onset. Vascular dementia is similar to Alzheimer's, but memory is often less impaired, while mood fluctuations are more prominent. In addition, Vascular dementia is characterized by physical frailty and a stepwise onset. Dementia with Lewy Body is characterized by visual hallucinations, marked fluctuations in cognitive abilities and parkinsonism. Finally, frontotemporal dementia is characterized by personality and mood changes, disinhibition and language difficulties (Alzheimer's Disease International, 2009). There is some uncertainty to the exact distribution of the different conditions and one of the primary reasons for this is that the borders between the conditions are not distinct and studies have shown that a mix of different types is more common than previously thought (Alzheimer's Disease International, 2009).

In addition to the more common types of dementia, there are several other subtypes of dementia, including, but not limited to: alcohol-related dementia, dementia due to other degenerative diseases (e.g. Huntington's disease and Creutzfeldt-Jackob's Disease), dementia due to infections (e.g. HIVassociated dementia) and dementia due to traumatic brain injuries (Brækhus, 2018; Engedal & Haugen, 2018a).

2.1.5 Progression

The progression of dementia and how it presents itself depends on the underlying conditions and the people themselves and as such varies from person to person but will become more and more similar as the dementia progresses (Engedal & Haugen, 2018b).

In general, challenges linked to dementia can be understood in three stages: early stage, middle stage and late stage (World Health Organization, 2012). In the early stage symptoms are often overlooked and because of gradual onset it is difficult to pinpoint exactly when they began. Common symptoms at this stage are forgetfulness, difficulty in finding words, loosing track of time and place, difficulty in making decisions and carrying out complex tasks, and changes in mood and behaviour (World Health Organization, 2012).

In the middle stage the disease has progressed, and limitations and challenges become clearer and more restricting. Common symptoms at this stage are increased forgetfulness, difficulty comprehending time, place and events, increasing difficulty with speech and comprehension of speech, needing help with personal care, inappropriate behaviour and behaviour changes in general such as wandering, hallucinations etc. (World Health Organization, 2012).

The last stage is characterized by nearly complete dependence on others and inactivity. Common symptoms at this stage are difficulty understanding what is happening around them, unawareness of time and place, not able to recognize relatives, friends or familiar objects, not able to find ones way in the home, needing assistance when eating, increased need for assistance in self-care, incontinence, decreased mobility, and more expressed behaviour changes, such as aggression and agitation (World Health Organization, 2012).

While the decline in memory and cognitive functioning might be the most well-known symptoms when it comes to dementia and its progression, another important aspect is neuropsychiatric symptoms. Neuropsychiatric symptoms is a term used for many different symptoms (Selbaek, 2018).

These symptoms include psychotic symptoms such as delusions and hallucinations, affective symptoms such as depression, anxiety and apathy, and agitational symptoms such as aggression, euphoria, lack of inhibition, irritability and aberrant motor and vocal behaviour (Selbaek, 2018). While not all symptoms may be present, most people with dementia will experience neuropsychiatric symptoms at some point. The number of and severity of symptoms generally increase as the dementia progresses, with psychosis being more common at the middle stage and apathy and agitation being more common in the late stage (Selbaek, 2018). As dementia progresses, all these aspects impact how they live their lives.

2.2. Health promotion for people with dementia

While dementia is characterized by progressive degeneration there are also opportunities to improve and maintain function and to promote the health of people with dementia. Health promotion is defined by the WHO as the process of enabling people to take control over the determinants of their health and thereby improve their health (World Health Organization, 1986). An important part of this is to enable people with dementia to make use of their remaining resources to maintain or improve their health, be it physical or mental. This is also in line with one of the stated goals of the national dementia strategy, since it aims to have people with dementia living at home for as long as possible (Ministry of Health and Care Services, 2015). The national strategy highlights the importance of providing physical, social and cultural activities for people with dementia. Additionally, in the hearings leading up to the strategy people with dementia themselves also highlighted the importance of physical activity and activities that were meaningful for the individuals (Ministry of Health and Care Services, 2015). All of these aspects could be part of day care services for people with dementia.

By offering physical activities as a way of promoting physical activity, one could improve health for people with dementia. People with dementia have been found to be less physically active, more sedentary and more susceptible to physical decline than others in similar age groups (Auyeung et al., 2008; Burns, Mayo, Anderson, Smith, & Donnelly, 2008; Hartman, Karssemeijer, van Diepen, Rikkert, & Thijssen, 2018; van Alphen, Volkers, et al., 2016). Both national (Lexell, Frändin, & Helbostad, 2008) and international guidelines (World Health Organization, 2010) highlight the importance of physical activity for older people to improve their health. Further, studies have found that physical activity can improve physical functioning and activities of daily living (Blankevoort et al., 2010; Telenius, Engedal, & Bergland, 2015), it can help reduce levels of depression(de Souto Barreto, Demougeot, Pillard, Lapeyre-Mestre, & Rolland, 2015) and have a positive effect on cognitive function (Groot et al., 2016). Therefore, finding ways to promote physical activity among people with dementia can have several benefits.

Creating social activities for people with dementia could also improve health as social interactions have been linked with positive affect (Jao, Loken, MacAndrew, Van Haitsma, & Kolanowski, 2018) and better mood (Beerens et al., 2018) among people with dementia in long-term care. Enabling people with dementia to meet others with dementia could also improve health as people with dementia have reported that they appreciate the opportunity to be together with their peers (Eriksen et al., 2016). Social activities could also foster feelings of social support, which have been linked to mood and well-being among older adults (Golden et al., 2009). Conversely, a lack of social support has been linked to psychological distress among older people living at home (Bøen, Dalgard, & Bjertness, 2012). Further, there is some evidence that social support groups for people with dementia can foster improved quality of life and self-esteem, while reducing depression (Leung, Orrell, & Orgeta, 2015). Therefore, enabling people with dementia to participate in social activities might promote their health.

2.3 The experiences of living with dementia

One very important aspect is how people experience living with dementia. While the experiences of living with dementia is probably as varied as the people experiencing them, researchers have attempted to find some commonalities. De Boer et al. (2007) found that there where little support for the assumption that dementia is necessarily just a state of dreadful suffering. While people with dementia experienced losses and negative emotions, they did not go through the disease passively. They found that people with dementia used different types of coping strategies to deal with the challenges. In the same vein, Bjørkløf et al. (2019) found in their meta-synthesis on coping that people with dementia had two main resources for coping, humour and support, both practical and emotional. In addition, people with dementia reported four overall strategies for coping: First. keep going and holding on to life as usual; Second, adapting and adjusting to the demands of the situation; Third, accepting the situation; Fourth, avoiding the situation (Bjørkløf et al., 2019).

The strategy of keep going and holding on to life as usual consisted of three sub-categories. The first, preserving identity, was about working to maintain their identity through maintaining social roles and relations and anchoring their identity to past achievements. The second, normalising the situation, was about trying to carry on with their lives and maintain normalcy in their daily life. Thirdly, contributing to society, was finding value in still being able to do meaningful activities and feeling useful (Bjørkløf et al., 2019). The coping strategy of adapting and adjusting to the demands of the situation had two sub-categories. The first, taking control and compensating, was about continuing to be physically and cognitively active, while finding new ways of doing things to compensate for cognitive decline. The second was reframing identity. This was about building an identity through thinking differently about themselves and comparing their lives to those they perceived as worse off (Bjørkløf et al., 2019). The strategy of accepting the situation based itself on an acceptance of the diagnosis and of memory loss and an acceptance of what they could do for themselves and when they needed help from others. This had one sub-category, position in life, which dealt with acknowledging the consequences of dementia, while focusing on strength and possibilities (Bjørkløf et al., 2019). The last strategy, avoiding the situation, dealt with trying to avoid stressful situations. This could include not thinking about the future, withdrawal or not taking initiative, so as to avoid exposure of cognitive decline (Bjørkløf et al., 2019)

Research has also been conducted on how people with dementia experience social relationships. Eriksen et al. (2016), in their meta-synthesis, found that people with dementia reported that the changes brought on by dementia led to new social roles and social statuses. This was brought on by declining functional levels that impacted the person’s position in the family and the relationships with other people. Further, people with dementia also experienced a change in relations, were they felt being disconnected, being dependent, being a burden and being treated (Eriksen et al., 2016). Being disconnected was described as distance from their social relations and activities, either through themselves distancing or other distancing them. Being dependent was described as a consequence of increasing functional impairment and decreasing cognitive and social function, wherein the person with dementia had to rely more on others. Being a burden was described as the experience of friends and family struggling with them and being sensitive to the consequences for the caregivers. Being treated was the experience of lack of autonomy, of care without choices or the ability to influence what was happening (Eriksen et al., 2016). People with dementia also reported on maintaining meaningful aspects in life through supportive interactions and being with peers. Supportive interactions were described as adjusting to and accepting the situation through practical and emotional support, for example from friends and family. Being with peers was the experience of being with others in the same situation and how this was considered both valuable and meaningful, and reduced the feeling of isolation (Eriksen et al., 2016).

Researchers have also investigated how people with dementia view and experience formal dementia care. In a focus group-study, involving different stakeholders from different countries in Europe, people with dementia reported several aspects of formal care that either kept people with dementia from seeking formal care or that facilitated people with dementia seeking formal care (Stephan et al., 2018). One barrier to formal care was lack of services, and related to it, lack of information about services. Another barrier, potentially tying into the lack of information, were that people with dementia had no or vague expectations to formal care. One final barrier was the perception of formal care as a threat to independence, that accepting formal care would impinge upon their autonomy. Among the facilitators were clear and accessible information and being involved in the decision making when it came to formal care. Other facilitators where continuity in care personnel and having one key contact person one could turn to. A final facilitator was having personal motivation to attend, this was often framed as wanting to protect informal carers from feeling burdened (Stephan et al., 2018).

2.4 Dementia Care

The approach to dementia care differs from country to country (World Health Organization, 2012). Several countries have dementia policies, plans or strategies where they outline their goals for dementia care and the actions to be taken to reach these goals. Examples of countries that have such plans are Australia, Japan, England and Norway. While there is no single approach to dementia care, The World Alzheimer Report 2009 (Alzheimer's Disease International, 2009) presented a seven-stage model for planning a care pathway for dementia services:

I. Pre-diagnosis
II. Diagnosis
III. Post-diagnostic support
IV. Co-ordination and care management
V. Community services
VI. Continuing Care
VII. End of life palliative care

The WHO classifies most of the stages after diagnosis as longer term care (World Health Organization, 2012), and states that community services, respite care and residential care are examples of such care. Community services are housekeeping, cooking, shopping, transport and personal care assistance, and these are often provided by care workers (World Health Organization, 2012). Residential care is based in providing care and accommodation for the person with dementia, for example in a nursing home (World Health Organization, 2012). Respite care is temporary provisions of care for a person with dementia by people other than the primary caregiver. The term is used to cover a wide variety of services and can take place in the home of the person with dementia, in the community, in a day-care setting or in a residential setting. The aim of the service is to provide respite for the caregiver while providing opportunities for engagement and socializing for the person with dementia (World Health Organization, 2012). How such services are organized depend on the individual countries.

2.4.1 Dementia Care in Norway

In Norway a guiding principle is that people with dementia should live at home as long as possible (Ministry of Health and Care Services, 2015), as this is believed to be the best for the individual and less resource intensive for the society (Gjøra & Michelet, 2018). It is estimated that about 60% of those with dementia in Norway are living in their own home, with the remainder living in long term residential care and nursing homes (Gjøra & Michelet, 2018). Providing care services for people with dementia is primarily the responsibility of the municipalities. This is enshrined in the law of municipal health and welfare services (Health and Care Services Act, 2011). The main types of care services provided by the municipalities for people with dementia are domiciliary nursing and care, day care services, short-term residential care, respite care and long-term residential care, such as nursing homes (Gjøra & Michelet, 2018). Domiciliary nursing and care are care given in the persons home and can consist of practical care, such as help with showering or food preparation, and medical care, such as help with medication (Gjøra & Michelet, 2018). Short term care stays are when a person has a short term stay at a care institution, based on the person's needs. In this situation the focus is often on examination, treatment or rehabilitation. Respite care, not to be confused with the more overarching concept of respite care, is given either at an institution or at home to provide some respite for the care giver while also providing care for the patient (Gjøra & Michelet, 2018). Long term residential care consists primarily of nursing homes, and are care provided when a person no longer can live in their own home (Gjøra & Michelet, 2018)

As a part of their focus on dementia the Norwegian government has issued two dementia plans, Dementia Plan 2015 and Dementia Plan 2020, stipulating important areas for development and change (Ministry of Health and Care Services, 2007, 2015), and one of the highlighted areas were day care services for people with dementia. A new dementia plan is slated to be presented in late 2020 (Hveem, 2019)

2.4.2 Day care services for people with dementia

Day care services for people with dementia is one type of community services. The WHO classifies it as a type of respite care aimed at providing respite for primary caregivers and opportunities for engagement and socialization for people with dementia. Day care services for people with dementia is a wide concept with varying content (Reinar, Fure, Kirkehei, Dahm, & Landmark, 2011), but share the goal of providing support for people with dementia and their caregivers.

As mentioned previously, there has been an increasing focus on day care services for people with dementia in Norway and the Norwegian Dementia Plan 2015 called them “the missing link” in the care pathway for people with dementia. The stated goals for day care services in Norway are that they should provide activity, stimulation, good experiences and meaningful days for people with dementia. In addition, they should provide respite for informal caregivers (Ministry of Health and Care Services, 2007). In Norway such services are usually connected to existing municipal services such as retirement homes or nursing homes (Gjøra et al., 2015), and these are what are considered regular day care, and will be referred to as such in this thesis. In a rapport about day care services in Norway they are referred to as the traditional model (Taranrød, 2011). Other models are the centre model, which are located in senior centres, the detached model, located in a separate building (like a house or farm), and lastly the ambulatory model, located in individual homes or in the community. Regular day care services are often targeted at community dwelling people with dementia and do not generally stipulate any specific age groups or degree of dementia (Taranrød, 2011). In the report by Taranrød (2011) the general goals of the day care centres were to provide meaningful days containing social activities, well-being and feeling of safety. A later study, looking primarily at regular day care centres, found that staff focused on providing meaningful activities and days for the attendees (Strandenæs, Lund, & Rokstad, 2019). Despite this focus, observations indicated that staff had insufficient knowledge on how to offer individually tailored and structured meaningful activities for the attendees (Strandenæs et al., 2019). In addition to the general goals regular day care centres also reported that they focused on maintaining and improving physical, psychological and social functioning, postpone nursing home admission and provide respite for the next-of-kin (Taranrød, 2011). The activities at regular day care services usually happened on-site or in adjoining areas, with most having access to outdoor areas, varying from a terrace to sensory gardens with pathways. The focus of the activities was often on maintaining and improving activities of daily living through meals, singing, music and exercise (Taranrød, 2011).

As day care services are considered an important and fundamental part of the care pathway for people with dementia, there has been a focus from the government on establishing more day care services and making the provision of day care services mandatory by law for the municipalities (Ministry of Health and Care Services, 2015). When the first dementia plan launched in 2007, 30,2% of the municipalities reported that they had some kind of day care service for people with dementia, and this has increased to 87,8% in 2018 (Norwegian Directorate of Health , 2018).

With the increasing focus on dementia and dementia care there has also been research into the effects and impacts of day care services for people with dementia. Reinar et al. (2011) did a review of the literature concerning day care services and the potential benefits. They concluded that it was uncertain if attending day care service postponed transition to long-term residential care. They did find some potential benefits like that day care services could potentially contribute to reduced incidence of behavioural problems, decreased use of psychopharmica and less burden for carers. No clear effect was found on functioning or quality of life (Reinar et al., 2011). Later studies have found that people with dementia attending day care services had higher quality of life than those living in nursing homes (Olsen et al., 2016) and those not attending any kind of service (Rokstad et al., 2017). Interview studies have found that day care services can give family caregivers support, relief and have a positive impact on the relationship between carer and the person with dementia (Tretteteig, Vatne, & Rokstad, 2017), and have a positive influence on the physical functioning, cognition, well-being and situation at home for those attending (Strandenæs, Lund, & Rokstad, 2018). However, a longitudinal study conducted over two years found that attending day care services for people with dementia did not postpone the need for nursing home admission (Rokstad, Engedal, Kirkevold, Benth, & Selbaek, 2018).

Along with a focus on increasing the amount of dementia care, there has also been a focus on diversifying dementia care and as a part of this nature-based interventions (NBI) have been introduced in dementia care. NBIs are programmes, activities or strategies that aim to engage people in nature-based experiences with the specific goal of achieving improved health and well-being (Shanahan et al., 2019). A related concept is green care, a concept based on using animals, plants and nature in an active process to offer health-promoting activities (Haubenhofer, Elings, Hassink, & Hine, 2010). Interventions goals in NBIs can be the prevention of chronic health conditions, the promotion of general well-being, and treatment of specific physical, mental or social health and well-being issues (Shanahan et al., 2019).

NBIs encapsulates many types of approaches to care and health promotion, including, among others: care-farming, horticulture therapy, animal-assisted therapy, wilderness therapy, provision of gardens at care institutions, outdoor exercise groups and provision of community gardens (Shanahan et al., 2019). Among these, care farming is a growing service for people with dementia, in for example the Netherlands, providing both long term care and day care services (de Bruin, de Boer, Beerens, Buist, & Verbeek, 2017). Sempik, Hine, and Wilcox (2010) defines care farming as the use of commercial farms and agricultural landscape as a base for promoting mental and physical health, through normal farming activities. Care farms providing services to people with dementia are found mainly in Europe, especially in the Netherlands and in Norway, but are also present and growing elsewhere, such as Japan and the United States (de Bruin et al., 2017). De Bruin, Oosting, van der Zijpp, Enders-Slegers, and Schols (2010) presented an integrative framework for the expected benefits of care farms for people with dementia. They looked at the evidence for dementia related interventions and related these to the care farm setting. They concluded that care farming interventions are naturally integrated in the environment, and are present simultaneously and continuously, which could be more difficult to accomplish at regular day cares. This led them to the hypothesis that farm-based day care would have more health benefits for people with dementia than regular day care (de Bruin et al., 2010).

In Norway farm-based dementia day care is a part of the national dementia strategy through “Inn på tunet” (IPT) [Into the farmyard] (Ministry of Health and Care Services, 2015) and it has also been highlighted in an IPT-action plan (Ministry of Local Government & Ministry of Agriculture and Food, 2013). IPT is defined as customized and quality assured welfare services at farms. The service should foster coping, development and well-being and the activities in the service is linked to the farm and the life and activity there (Matmerk, 2020). IPT is also a certification given by Matmerk, an Norwegian foundation, and it entails that to be able to call a farm an IPT-farm it has to adhere to the definition above and the rules and regulations set down in the “kvalitetssystemet for landbruket”

(KSL) [Quality system for the agricultural sector] given by the Ministry for Agriculture and Food (Matmerk, 2020).

A recent study found that as of early 2017, 33 farms in Norway provided day care services for people with dementia (Ibsen, Eriksen, & Patil, 2018). The study found several similarities between farm-based services and regular day care services with regards to organization, daily structure and number of personnel with health care background. The main difference between farm-based and regular services were that the farm-based services had a different care setting, the farm, and could and did utilize the activities and resources at the farm actively in the service. The different resources were for example the farm building, the animals, gardens and outdoor areas. Examples of activities at the farms were walking outside, meal preparation, gardening, feeding animals and harvesting (Ibsen et al., 2018). Strandli et al. (2007) found that typical indoor activities at FDCs were eating/drinking, conversation, reading, listening to or playing music, games, exercise, kitchen activities and crafts. Typical outdoor activities were hikes in the surrounding area and farm and animal activities such as gardening, wood working, harvesting, filling hayracks, feeding and caring for the animals etc. (Strandli et al., 2007).

Research into the context and contents of FDCs in Norway is limited, but research into farm-based care for other target groups have highlighted other aspects of the care setting. Pedersen, Dalskau, Ihlebæk, and Patil (2016) noted five key components of care farms. Firstly, a variety of work activity, based on the variety of activities that could be pursued at the farms, everything from maintenance to feeding the animals. Secondly, adaptation of work tasks, based on the adaptability of the tasks and activities to the individual users, for example based on the users wishes or needs. Thirdly, the farmers' role and support, as the farmers planed together with the users and could provide extensive supervision and support according to individual needs. Fourthly, experiencing nature, as the users could experience nature in different ways, for example through contact with animals, hiking in the forest or working in the woods. Lastly, providing enhanced structure in everyday life, as care farms provided structure in everyday through being a stable service with set times for arrival and departure and which provided transportation and meals at set times (Pedersen et al., 2016). The role of the service provider at care farms has also been highlighted in other research, where the service provider has been noted as a significant other for the participants (Steigen, Kogstad, & Hummelvoll, 2016), and also a facilitator, enabler and guide for the participant (Ellingsen-Dalskau, Morken, Berget, & Pedersen, 2016; Pedersen, Ihlebaek, & Kirkevold, 2012).

There has been some research on the experiences and benefits of attending farm-based care for people with dementia and this while be presented later in the thesis, in Chapter 4.0: Previous research on farm-based care for people with dementia.

3.0 Theoretical and empirical frameworks

In this chapter I will describe the theoretical and empirical frameworks used in this thesis. These will be used in the discussion of the findings in Chapter 9.0. I will start by describing quality of life, and quality of life in dementia especially. I will then describe subjective well-being, before giving a definition and overview over the concept of quality of care. Lastly, I will describe a framework for how nature and green space can influence health and well-being. I include this framework on the basis that nature and green space is intrinsically linked to the farm setting and that it therefor can play a role in the provision of care at care farms.

3.1 Quality of life

Quality of life has established itself as a significant concept and as an important outcome in research and practice (Haraldstad et al., 2019). At the same time, quality of life is viewed as a complex concept which is both interpreted and defined differently within and between various disciplines (Haraldstad et al., 2019). The aim of this section is to shed some light on the concept of quality of life, how it relates to dementia and how it has been viewed in this thesis.

For a general definition of quality of life one can use the WHO's definition which states that quality of life is an "individual's perception of their position in life in the context of the culture and value system in which they live and in relation to their goals, expectations, standards and concerns"(Whoqol Group, 1995). Further, WHO considers it a broad ranging concept, incorporating the complexity of individuals' physical health, psychological state, social relationships, level of independence, personal beliefs and their relationship to the salient features of the environment. The definition is meant to highlight the view that quality of life is subjective, includes both positive and negative facets, and is multidimensional (Whoqol Group, 1995). In the Norwegian context Barstad et al. (2016) argue for a broad understanding of the concept of quality of life, similar to the one used by Eurostat, where quality of life is defined as the full range of factors that influence what people value in living, beyond the purely material aspects . They suggest that quality of life consist of eleven basic components (Barstad et al., 2016):

1. How life is experience by the individual – the subjective quality of life
2. Physical and mental health
3. Knowledge and skills
4. Economic and material security
5. Physical security

6. Democratic participation and equal rights
7. Social and care/welfare
8. Work and education
9. Leisure time, culture and games
10. Nature and the local environment
11. Accumulation of advantages and disadvantages

Barstad et al. (2016) considers quality of life complex concept that cannot be observed directly, but rather, must be measured using indicators that capture important aspects of quality of life. Further, they highlight the need for indicators for both subjective and objective quality of life (Barstad et al., 2016). While there are many attempts to find a general definition of quality of life, in this thesis I will primarily focus on quality of life in the context of people with dementia.

3.1.1. Quality of life in dementia

There have been many different attempts to characterize and measure quality of life for people with dementia and Missotten, Dupuis, and Adam (2016) found a great diversity in QoL-definitions, theoretical models of QoL, and domains and dimensions constituting QoL for people with dementia. The lack of consensus is also evident in the number of measures for quality of life for people with dementia and Bowling et al. (2015) found 16 different measures in their review and noted that few were based on rigorous conceptual frameworks. The most common measure seemed to be the Quality of Life in Alzheimer's Disease (QoL-AD) which referenced Lawton's model of quality of life (Bowling et al., 2015). The framework of Lawton is one of the more frequently used theoretical models when developing QoL-measures for people with dementia (Missotten et al., 2016). Other perspectives on quality of life for people with dementia commonly used in dementia research are health related quality of life (HRQoL), quality of life definitions specific to dementia and quality of life definitions based on utility theory (Missotten et al., 2016). Within all these perspectives there are different definitions and approaches to quality of life, and I will not attempt to describe these in depth. The thesis will primarily focus on quality of life as described by Lawton. This is both due to its prevalence within dementia research and due to the fact that the measure used to assess quality of life in this project, Quality of life in Alzheimer's Disease (QoL-AD), is partly based on Lawton's work (Logsdon, Gibbons, McCurry, & Teri, 1999, 2002)

Lawton (1991) views quality of life for all as the multidimensional evaluation, by both subjective and social-normative criteria, of the behavioural and environmental situation of the individual, both past, present and future. He further divides this into four sectors of good life, which to some degree overlap (see Figure 3.1). These are: behavioural competence, perceived quality of life, the objective environment, and psychological well-being, where behavioural competence and the objective environment are considered objective, while perceived quality of life and psychological well-being is considered subjective.

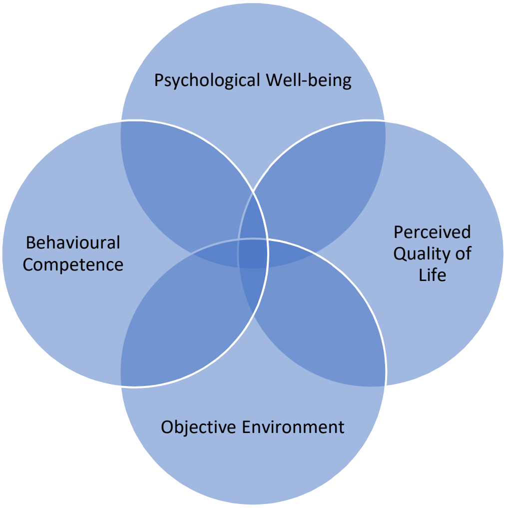


Figure 3.1. Lawton's four sectors of good life/quality of life (Lawton, 1983)

Behavioural competence is the social-normative evaluation of the person's functioning in the dimensions of health, cognition, time-use and social behaviour (Lawton, 1991). According to Lawton (1991) there is a five-level hierarchy of behavioural competence containing: health, functional health, cognition, time-use and social behaviour. Functioning within each level can be viewed as autonomous, but Lawton (1991) states that there are reciprocal association between the levels. The content and indicators of the five levels are (Lawton, 1991):

1. Health, the function of the body, the organ, the cells and the system as a whole.
2. Functional health, the person's ability to do instrumental and physical activities of daily life, do financial management, and the ability to have paid employment.
3. Cognition, function in sensory reception, perception, memory, classical and operant conditioning, symbolic thinking, problem solving and creative innovation

4. Time-use, the persons competence when it comes to stimulus variation, curiosity, recreation, exploration and creative innovation.
5. Social behaviour, the persons competence when it comes to sensory contact, casual contact, intimacy, nurturance and creative leadership, love, parenthood and altruistic behaviour.

Lawton (1991) suggested that as one moves up the hierarchy from health to social behaviour the evaluative criteria of competence become increasingly person-preferential, social-normative and the environment has a larger contribution. The concept of behavioural competence is broad and encompasses many aspects of a person, and this was done, according to Lawton (1991) to allow any facet of competence to be accommodated within the proposed hierarchy of competence. M. Lawton (1991) states that behavioural competence should be measured by performance or observation.

Perceived quality of life on the other hand, is based on a person's subjective evaluation of function in any of the behavioural competencies (Lawton, 1991). One example of this is how a self-reported health rating would be a subjective evaluation of the health aspect of behavioural competency. Lawton (1991) suggests that perceived quality of life has the same breadth as behavioural competence, and as such is able to accommodate any facet of perceived quality of life. He suggests that the larger categories always be present when assessing quality of life, while more specific dimensions should be custom-picked to match the purpose of the study (Lawton, 1991). This comes into play when Lawton (1994) develops what is important for quality of life for people with dementia, which will be described later.

The objective environment are the different aspects of the environment, both physical and social. According to Lawton (1991), these different aspects are thought to afford some forms of behavioural competence, while they might also not afford others forms of behavioural competence. He sees the links between this domain and the others as somewhat diffuse, as the links can be both direct and indirect. As an example of a direct link he highlights how environmental factors such as air and water quality are directly relevant for behavioural competences in health, while through the richness of behaviour settings the environment directly influences competences in time use, e.g. a richness leading to increased exploration (Lawton, 1991). Other aspects of the environment are more indirect and should be viewed more as something that can facilitate behavioural competences, but that does not guarantee it. An example here could be that living in a neighbourhood can facilitate social behaviour, but does not guarantee it (Lawton, 1991). While environmental aspects could be evaluated subjectively, Lawton (1991) argues that one should find objective aspects of the environment that can be evaluated based on physical or consensual criteria, independent of the individual.

Psychological well-being is viewed by Lawton (1991) as the “ultimate outcome in a causal model of the open type”. He defines it as the weighted evaluation of a person’s competence and perceived quality in all domains of contemporary life. Lawton views the weighting not only as sum of competences and satisfaction, but rather a process influenced by a person’s sense of self, which provide a template for interpreting all aspects of past, present and future experiences (Lawton, 1991). According to Lawton, psychological well-being can be measured in various ways, for example as mental health, life satisfaction or the experience of positive or negative emotions (Lawton, 1991).

While Lawton (1994) states that quality of life for people with dementia comprises the same domains as in people in general, he argues that for people with dementia, one should assess QoL in multiple domains: cognitive function, competence in activities of daily living, socially appropriate behaviour, engagement in positive activities and the presence of positive or absence of negative affect. He states that while cognitive function is not ordinarily included as an element of QoL, he includes it because of the nature of dementia and the importance of competency within the concept of quality of life (Lawton, 1994). Further, he views competence in daily living as an indicator for quality of life on the basis that competent behaviour is a goal for all people, regardless of impairment. Socially appropriate behaviour he states, can be viewed as an indicator for quality of life as the anxiety, depression, agitation and inappropriate behaviours that are apparent to external observers can be presumed to both result from negative subjective experiences and evoke negative social response from others (Lawton, 1994). Engagement in positive activities can be linked to Lawton’s concept of behavioural competence. He argues that behaviours can be continued and create positive subjective states even if there is a decline in cognitive function (Lawton, 1994). The presence of positive and absence of negative affect could be linked to the concept of psychological well-being. As Lawton (1997) states: “emotions and mood have long been known to compose major aspects of the quality of daily life”.

Lawton (1997) argues that while quality of life assessments must include subjective and objective components, the nature of dementia might mean that for some, one should use assessments that do not depend on self-report. Lawton further states that one should try to determine the limits of cognitive functioning within which such subjective reports are valid (Lawton, 1997). Finally, Lawton also states that he considers quality of life an attribute that cannot be reduced to a single numerical estimate and that therefore many measures of quality in different domains should make up the representation of quality of life (Lawton, 1997).

Despite the lack of consensus on the content of quality of life, there has been conducted much research, albeit based on different definitions, on what influences quality of life for people with dementia. Martyr et al. (2018) found in their meta-analysis that factors associated with relationships, social engagement and functional ability were associated with better quality of life. Factors indicating poorer physical and mental health, and poorer carer well-being were associated with poorer quality of life. Holopainen, Siltanen, Pohjanvuori, Makisalo-Ropponen, and Okkonen (2019) investigated in their review both factors associated with quality of life and interventions associated with improved quality of life. They found that the following factors were associated with improved quality of life: experience of well-being and health, relationships to others, feeling heard and understood, functionality and participation, spirituality, care staff being trained in the care of people with dementia, sufficient staff at care settings, home-like environment at care settings, and consideration of the special needs of people with dementia. The following factors were associated with reduced quality of life: Lewy body disease, early disease onset, depression, anxiety and agitation, dependency, pain, lack of interaction, loneliness, feeling of not belonging, nurses' burden, restriction of mobility and falling (Holopainen et al., 2019). The following interventions were associated with improved quality of life: activation of those with dementia living at home, cognitive stimulation for those in institutional care, physical activity, listening to music, guidance and counselling, reminiscence and life history for those in institutional care, social support, presence of animals and aromatherapy (Holopainen et al., 2019). In addition, they found that improving safety in the home environment and offering support to family members could improve quality of life for people with dementia.

3.2 Well-being

A concept related to quality of life is well-being, with the two being somewhat difficult to disentangle (Carlquist, 2015). Previously quality of life was viewed as an objective assessment, while well-being was view as a person's more subjective assessment. In later years quality of life as included increasingly subjective components, but in general, quality of life can be said to pertain to well-being in a general sense with a focus on objective factors, such as for example living conditions (Carlquist, 2015). The definitions of well-being are as varied as quality of life, but in this thesis, I will focus on well-being as subjective well-being. This is both because I wish to highlight the importance of the subjective experiences, but also to juxtapose it with the potentially more objective concept of quality of life. Subjective well-being can be defined as the presence of positive emotions, the absence of negative emotion and a satisfaction with life (Carlquist, 2015).

Subjective well-being can be said to include people's appraisal and evaluations of their own lives (Diener, Oishi, & Tay, 2018). It includes reflective judgments, such as life satisfaction, and emotional responses. These emotional responses are responses to ongoing life in terms of positive or pleasant emotions versus unpleasant and negative emotions (Diener et al., 2018). One important aspect of this is the subjective nature of these judgments and responses. For example, when people reflect upon their lives and give judgment, either on their life as a whole or on more specific domains such as health, they do so on the basis of the standards they have for a good life (Diener et al., 2018). As such, what contributes to their satisfaction with life can be said to be determined not by the researcher, but rather the respondent. The same can be seen in emotional responses, where people experiences positive emotions because they are responding to events and circumstances they, not the researcher, evaluate as desirable (Diener et al., 2018). In research the reflective judgements are labelled as a cognitive component of subjective well-being, while the emotional responses are labelled as an affective component (Linton, Dieppe, & Medina-Lara, 2016). This affective portion of subjective well-being has in research often been linked to the concept of happiness (Linton et al., 2016).

There has been conducted little research on subjective well-being and people with dementia (Martyr et al., 2018). Zank and Leipold (2001) found that people with mild dementia reported less life satisfaction than people with more severe dementia if there were few constraints on their physical health. Despite the unclear linkage between severity of dementia and life satisfaction, a more cognitive component of subjective well-being, it could be argued that the affective component is especially important for people with dementia. This due to the fact that emotional responses could persist regardless of the severity of dementia. While not necessarily linked to the concept of subjective well-being, more research has been conducted on what influences affective states of people with dementia. Brett, Traynor, and Stapley (2016) found some evidence that physical activity could influence mood and depression in people with dementia in nursing homes. Having social interactions have been linked to both positive affect (Jao et al., 2018) and better mood (Beerens et al., 2018) among people with dementia. Lastly, having positive and enjoyable engagement in activities has also been linked to well-being in people with dementia (Chung, 2004).

3.3 Quality of care

One important aspect of dementia care is the quality of the care and there are different ways of defining the concept of quality of care. One way is to view it as composed of two principal dimensions: access and effectiveness (Campbell et al., 2000), see Fig. 3.2. While Campbell et al. (2000) focuses on more clinical settings, such as hospitals, I believe their definition is also applicable in dementia care settings in the community. In their definition of quality of care access is whether users get the care they need, while effectiveness is about how effective the care is once received. Access contains important elements such as geographical and physical access, availability and affordability for the user, and, on a population level, equitability (Campbell et al., 2000). While access is important, this thesis will focus on effectiveness.

	Care		
Quality	Structure: Care system	Process: Patient-centred care	Outcome: Consequences of care
Accessibility	Geographic access Physical access Affordability Availability	Affordability Availability	Health Status User evaluation
Effectiveness		Effectiveness of clinical care Effectiveness of inter-personal care	Health Status User evaluation

Fig. 3.2: Dimensions of quality of care for individuals (Campbell et al. 2000)

Effectiveness is the extent to which the provided care delivers its intended outcome or results in a desired process, in response to need (Campbell et al., 2000). The concept consists of two key elements: effectiveness of clinical care and effectiveness of inter-personal care. Clinical care can be described as the interventions used in care and the effectiveness of these are if the interventions have the desired effect or outcome (Campbell et al., 2000). Interpersonal care is the interaction between the care provider and the users, and important aspects of inter-personal care are communication, building relationships, understanding and empathy. Effectiveness of inter-personal care can therefore be described as the inter-personal relations and how these result in a desired process. Such a desired process could be one that emphasizes care planned for and with the individual, that takes into consideration the users experiences, and aligns the agendas of the care provider and the users. Both the clinical and inter-personal part of the process of care is by Campbell et al. (2000) viewed as patient-centred. The concept of patient-centred is often used primarily in hospital settings and can be regarded as interchangeable with the term person-centred which is used more generally (Morgan & Yoder, 2012).

The importance of person-centred care to quality of care have been noted by others (Morgan & Yoder, 2012) and within dementia care person-centred care is increasingly being proscribed as the preferred approach (Rokstad & Røsvik, 2018). The origin of person-centred care in dementia care can be traced back to the work of Tom Kitwood in the late 80s and 90s (Fazio, Pace, Flinner, & Kallmyer, 2018). Kitwood (Brooker & Kitwood, 2019) stated that beyond ensuring just physical needs dementia care needed to assist people with dementia in maintaining their personhood, the person is in the centre. Personhood he defined as "a standing or status that is bestowed upon one human being, by others, in the context of relationship and social being. It implies recognition, respect and trust" (Brooker & Kitwood, 2019). Kitwood further stipulated in conjunction with person-centeredness five main needs of people with dementia. These needs must to be met in order to maintain personhood, and they are comfort, attachment, inclusion, occupation and identity (Brooker & Kitwood, 2019). Comfort is here seen as the provision of warmth and strength to enable persons to carry on and remain in one piece. Attachment is the need to bond with other people and the assurances they provide. Inclusion is the need to be a part of a group, but also to be included in care. Occupation is the need to be involved in the process of life and activities in a way that one considers personally significant and which draws on one's abilities and powers. Identity is the need to know who oneself in cognition and feeling, in a sense the need to know one's life narrative (Brooker & Kitwood, 2019). In essence, according to Kitwood's framework, person-centred care for people with dementia is about meeting the persons needs in order to maintain their personhood (Fazio et al., 2018).

The field of person-centred care has evolved since Kitwood, and there have been several attempts to describe and characterize what person-centred care for people with dementia is and how it should be practiced (Fazio et al., 2018). One important one is Dawn Brookers VIPS-definition, building on Kitwood, where person-centred care is said to be characterized by the following: 1. Valuing people with dementia and those who care for them; 2. Treating people as unique individuals; 3. Looking at the world from the perspective of the person with dementia; 4. Providing a social environment that supports psychological needs (Brooker & Latham, 2015). In Campbell et al. (2000) person-centred care is seen as a part of the process of providing care, and therefore a part of quality of care.

So, given all these aspects of care, how can one investigate quality of care? According to Campbell et al. (2000) the processes of clinical care and inter-personal care have distinct outcomes, or consequences of care. For clinical care the relevant outcome is health related outcomes, such as health status, functional status, symptom relief etc. For inter-personal care the outcomes are user evaluations, satisfaction with care and enablement (Campbell et al., 2000). In the Norwegian context the national dementia strategies provide guidance for dementia care provision in Norway. These stipulate that day care services should provide physical, social, cultural and spiritual activities while ensuring that the users have good experiences and meaningful days (Ministry of Health and Care Services, 2007, 2015). It is therefore relevant to see these as indicators for how to measure the quality of care at day care services for people with dementia. In this thesis the focus has primarily been on what Campbell et al. (2000) labels clinical care as we have measured several different outcomes related to health and well-being among participants at FDCs, in essence to investigate the potential effectiveness of the service.

3.4 Nature

Nature is a defining component of any Nature based intervention (NBI), and FDCs are no exception with their immediate access to nature and nature experiences. Researcher have previously linked exposure to nature with positive effects on both health and well-being. Markevych et al. (2017) proposed a framework for how greenspace could affect health and well-being through three main pathways: Mitigation, restoration and instoration (See fig 3.3). The last two of which could be considered especially relevant for the farm-context.

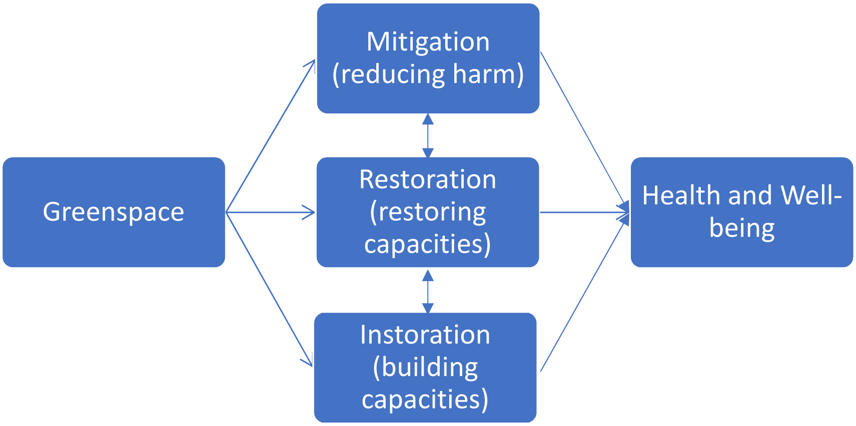


Figure 3.3. Three pathways linking greenspace to health and well-being (Markevych et al., 2017).

Mitigation is concerned with reducing harm. Through accesses to green space people might reduce their exposure to environmental stressors such as noise, heat and pollution (Markevych et al., 2017). Examples of this could be reducing exposure to heat through providing shade and the cooling effects of vegetation, especially in cities. Another example could be reduced exposure to air pollution and noise due to green spaces acting as buffers for the sources of these exposures (Markevych et al., 2017). While this might not be the primary pathway when it comes to the farm-context, farms are unlikely to be situated near large sources of pollution or large roads, providing some buffer from harmful exposures, and vegetation and trees can provide shade from the sun.

The next pathway, restoration, is concerned with restoring capacities through exposure to green space. The prominent concept here is psychological restoration, and how green space can foster such restoration of depleted mental capacity. Two important theories in this field is Stress Reduction Theory (SRT) and Attention Restoration Theory (ART) (Markevych et al., 2017). In this thesis I have elected to focus on SRT, and ART will therefore not be described. I chose SRT as it has less of a focus on active cognitive processes and can as such be viewed as applicable for people with dementia regardless of cognitive capacity. SRT is based on the works of Roger Ulrich (Ulrich et al., 1991), and he argues that people's response to an environment is one of generalized affect, that is one either likes or dislikes the environment. This response happens without conscious recognition or processing

(Joye & van den Berg, 2013). Positive affective responses occur when specific or preferred environmental features are present. Such features are thought to include, among other, the presence of natural content, such as trees and vegetation. These positive affective responses initiates, according to SRT, the restorative process through providing a reprieve from stress, reduced levels of arousal and negative feelings, couple with the experience of liking and positive feelings. According to SRT this progresses into a more conscious processing, with the potential for a more deliberate and conscious restorative experience, given that the environment is perceived as interesting enough (Joye & van den Berg, 2013). The farm-setting can be thought to provide such positive affective responses with its green spaces, animals and closeness to nature. Further, based on SRT, with its focus on the response happening without conscious recognition and processing, the farm-environment might provide this regardless of the cognitive decline seen in people with dementia.

The final pathway, instoration, is concerned with building capacities through exposure to green space. This is primarily thought to happen through physical activity and/ or social interaction/cohesion (Markevych et al., 2017). Green spaces are thought to promote physical activity in several ways. For one they can provide an accessible, attractive and safe setting to conduct physical activity. Further, there is some evidence suggesting that physical activity in green spaces provide greater psychological and physiological benefits, compared to physical activity in other settings (Markevych et al., 2017). Green spaces can also facilitate social interaction and cohesion by providing settings for contact with other people and the opportunity to do something together in this setting (Markevych et al., 2017). The farm-setting can provide both of these as it as setting where one can do physical activity, either task-related or for its own sake, and it can provide a setting where one can meet others and do activities together, thus promoting both physical activity and social cohesion. As such the concept of instoration is much related to the concept of health promotion, with its focus on building capacity as a way of improving health and well-being.

4.0 Previous research on farm-based care for people with dementia

In preparation for writing this thesis I searched for relevant literature regarding farm-based dementia care. I searched in PubMed, Web of Science and Google Scholar for research that pertained to people with dementia using farms as a care-setting and used the following criteria:

- Population: People with dementia
- Intervention: Farm-based dementia care/Care farming for people with dementia
- Outcome: Any, but the outcomes had to be related to the participants, that is people with dementia
- Type of literature: Peer-reviewed, published articles

I went through the potential articles together with a colleague who had done similar searches independently and we compared our findings and arrived at a number of articles fitting our criteria. The result is presented in table 4.1.

Table 4.1. Previous research on farm-based care for people with dementia

Authors, title, journal	Year	Type	Sample	Main Findings
Schols JM, van der Schriek-van Meel C. *Day care for demented elderly in a dairy farm setting: positive first impressions*. J Am Med Dir Assoc.	2006	Observational study	Community dwelling people with dementia attending day care services (green care farms and regular day care)	People with dementia attending FDCs showed fewer behavioral problems, used, on average, fewer drugs, including psychotropic drugs, and were more actively involved in normal daily activities.
De Bruin SR, Oosting SJ, Kuin Y, Hoefnagels E, Blauw YH, Groot LCD, Schols JM. *Green care farms promote activity among elderly people with dementia.* Journal of Housing for the Elderly.	2009	Observational study	Community dwelling older people with dementia	Activities of elderly people at green care farms were more frequent, occurred outdoors more often, were of a higher physical intensity, and more often were aimed at individuals than activities at regular day care facilities

De Bruin S, Oosting S, Tobi H, Blauw Y, Schols J, De Groot C. *Day care at green care farms: A novel way to stimulate dietary intake of community-dwelling older people with dementia?* The journal of nutrition, health & aging.	2010	Cross-sectional comparative study	Community dwelling older people with dementia	Attending FDCs stimulates dietary intake
de Bruin, S., Oosting, S., Tobi, H., Enders-Slegers, M.-J., van der Zijpp, A., & Schols, J. M. G. *Comparing day care at green care farms and at regular day care facilities with regard to their effects on functional performance of community-dwelling older people with dementia.* Dementia	2011	Observational longitudinal study	Community dwelling older people with dementia	No difference in maintaining functional performance between FDCs and regular day care
de Bruin SR, Stoop A, Molema CC, Vaandrager L, Hop PJ, Baan CA. *Green Care Farms: An Innovative Type of Adult Day Service to Stimulate Social Participation of People with Dementia*. Gerontol Geriatr Med	2015	Interview study	Community dwelling older people with dementia and their family care giver	FDCs can stimulate social participation
Sudmann T, Børsheim I. *'It's good to be useful' activity provision on green care farms in Norway for people living with dementia.* International Practice Development Journal.	2017	Comparative case studies/observations	Community dwelling people with dementia and service providers at farms	FDCs provide contact with animals and nature, physical activity, communal meals, social interaction. They enable/reable attendees and reduces risk of embarrassment and stigma
Myren G, Enmarker I, Hellzen O, Saur E. *The influence of Place on Everyday Life: Observations of Persons with Dementia in*	2017	Observational study	Community dwelling people with dementia attending day care services	Day care services contributes to enabling activities and collaboration between participants

Regular Day care and at the Green Care Farm. Health.				and staff, and this was more evident at FDCs.
de Boer B, Hamers JPH, Zwakhalen SMG, Tan FES, Verbeek H. *Quality of care and quality of life of people with dementia living at green care farms: a cross-sectional study.* BMC Geriatr.	2017	Cross-sectional study	People with dementia living at three different types of nursing homes (green care, small scale living, traditional)	The quality of care was comparable between settings, but participants living at green care farms scored higher on QoL than those living at traditional nursing homes
de Boer B, Hamers JP, Zwakhalen SM, Tan FE, Beerens HC, Verbeek H. *Green care farms as innovative nursing homes, promoting activities and social interaction for people with dementia.* Journal of the American Medical Directors Association.	2017	Longitudinal observation study	People with dementia living at three different types of nursing homes (green care, small scale living, traditional)	Green care farm residents were more outdoors, more physically active, more engaged and had more social interactions
de Bruin, S. R., Buist, Y., Hassink, J., & Vaandrager, L. ‘*I want to make myself useful’: the value of nature-based adult day services in urban areas for people with dementia and their family carers. Ageing & Society*	2019	Interview study	Community dwelling people with dementia attending nature-based adult day care, their family caregivers and the service providers	Respondents indicated that nature-based services positively affected the health and well-being of people with dementia. They support contact with nature and animals, activity, engagement, physical activity, structure, social interactions, healthy eating, a sense of meaning in life and a focus on normal daily life

We found 10 articles that satisfied our criteria. Five of these were published prior to the PhD-project starting in 2016, while the remaining five had come later. All the articles reported on individual studies. Schols and van der Schriek-van Meel (2006) found in their observational study that people with dementia attending FDCs showed fewer behavioural symptoms, used fewer drugs and were more actively involved in normal daily activities. A later observational study found that activities of people with dementia at FDCs were more frequent, occurred outdoors more often, had higher physical intensity and were more often aimed at the individual compared to activities at regular day care services(de Bruin et al., 2009). FDCs has also been shown to stimulate dietary intake in people with dementia compare to regular day care services (de Bruin et al., 2010). One study looked at the functional performance of people attending either FDC or regular day care over a one year period, and could find no change in functional performance or any difference between the two settings (de Bruin et al., 2011). De Bruin et al. (2015) investigated in an interview study the social aspects of FDC and found that FDCs could stimulate to social participation. Sudmann and Børsheim (2017) found that FDCs provided contact with nature and animals, physical activity, communal meals and social interactions. Further, they found that they enabled or re-enabled the participants and reduced the risk of stigma and embarrassment. Myren, Enmarker, Hellzen, and Saur (2017) found that day care services for people with dementia contributed to enabling activities and to being able to collaborate in daily life and daily activities. They further reported that this was more in evidence at FDCs compared to regular day care. Investigating farm-based nursing homes, de Boer, Hamers, Zwakhalen, Tan, Beerens, and Verbeek (2017) found that while the quality of care was similar, people with dementia in farm-based nursing homes had higher quality of life compared with regular nursing homes. In another study they found that people with dementia at farm-based nursing homes were more outdoors, more physically active, more engaged and had more social interactions compared to those at regular nursing homes (de Boer, Hamers, Zwakhalen, Tan & Verbeek, 2017). Finally, de Bruin, Buist, Hassink, and Vaandrager (2019) found in an interview study on urban nature-based day care for people with dementia, which included participants from urban farms, that participants reported that such services positively influenced their health and well-being. They further reported that such services provided contact with nature and animals, activity, engagement, physical activity, structure, social interactions, healthy eating, a sense of meaning in life and a focus on normal daily life.

The existing literature show many benefits for people with dementia attending farm-based care, but there are some gaps in the research. Firstly, only two studies (Myren et al., 2017; Sudmann & Børsheim, 2017) have looked at FDCs in the Norwegian context. Both studies are based on small samples from specific areas of Norway, and both have a limited scope regarding outcome measures and changes over time. As such more comprehensive research including a larger sample of people and implementing a number of outcome measures, preferably over time is needed. Secondly, the only study investigating quality of life (de Boer, Hamers, Zwakhalen, Tan, & Verbeek, 2017) is based on farm-based nursing homes, and as such may not be representative for the day care setting. Therefore, research into the association between quality of life and farm-based day care attendance is necessary to establish any links between the two. Thirdly, as far as I know, no studies have investigated the well-being of the participants while at the service and the factors influencing it. Well-being while at the service could both indicate quality care and satisfaction with the service, in addition to general well-being and research investigating this could shed light in the experiences of attending farm-based day care. Fourthly, the research on physical activity at farm-based day care (de Bruin et al., 2009) have so far been based on observations over a limited time span. To further investigate the physical activity at FDCs, research using more objective measures over a longer time span is needed. Addressing these gaps in the research is a part of the overall aim of this thesis.

5.0 Aims of the thesis

This thesis aims to contribute knowledge for the development of day care services for people with dementia. The overarching aim of the thesis is to investigate the quality of care at farm-based day care services for people with dementia. In order to answer this overarching aim, several sub-aims were devised and used to inform data collection, data analyses and papers for publication. These aims subsequently became the aims of the different papers in this thesis, and they are as follows:

Paper 1

"Physical activity in people with dementia attending farm-based dementia day care – a comparative actigraphy study"

Aim: Investigate the association between physical activity, type of day care service, and attendance at farm-based day care services for people with dementia.

Paper 2

"Emotional well-being in day care services for people with dementia – a comparative study between farm-based day care and regular day care"

Aim: Investigate the association between the different aspects of the day care services and the activities provided with emotional well-being, and to investigate if there are any potential differences between farm-based day care services and regular day care services.

Paper 3

"Quality of life in people with dementia attending farm-based dementia day care – A comparative, longitudinal study"

Aim: Investigate the association between quality of life and type of day care services for people with dementia over time, and factors associated with quality of life over time.

6.0 Methods and materials

6.1 Research approach

This PhD-project is a part of a larger research-project, titled “Farm-based day care services for people with dementia: quality development through interdisciplinary collaboration” (FDC-project), investigating the concept of farm-based day care services for people with dementia. The primary objective was to provide knowledge for innovative quality-based development of FDCs. The secondary objectives/research questions were threefold: 1. Investigate the experiences and benefits of FDCs for people with dementia and their family caregivers; 2. Understand the key unique elements on the farm that make a farm suitable for providing high quality day care services; 3. Identifying and understand how to enable a successful interaction between farmers offering FDCs and the municipalities. Further the main project aimed to use a triangulation of different theories and methods to ensure valid data and balanced knowledge, and consisted of several work-packages, A, B, C and D, related to the research aims (see Fig. 7.1). The aim of work package A was to investigate the characteristics, experiences and possible benefits of FDCs for people with dementia and their next of kin. Work package B aimed to develop an understanding of how resources in the farm context contribute to and are used to create an environment that facilitate person-centred care for people with dementia, and to compare the farm environment to care environments at similar institutional services. The aim of Work package C was to identify and understand how to enable a successful interaction between the service providers at FDCs and the municipalities. The aim of the final work package, D, was to share knowledge, promote FDC for people with dementia and establish innovation forums for innovation in farm-based dementia care programs.

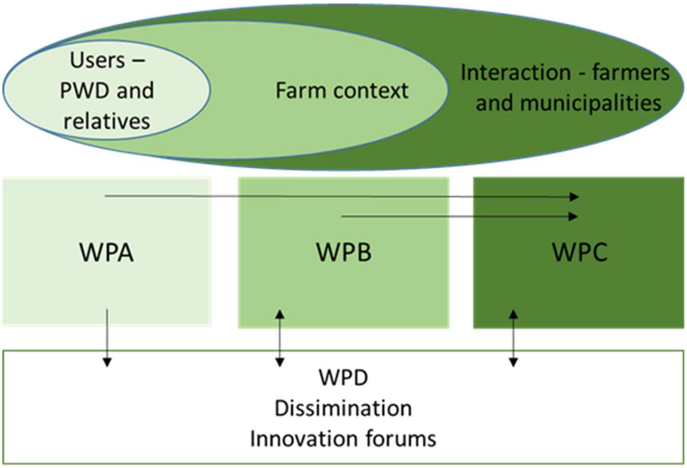
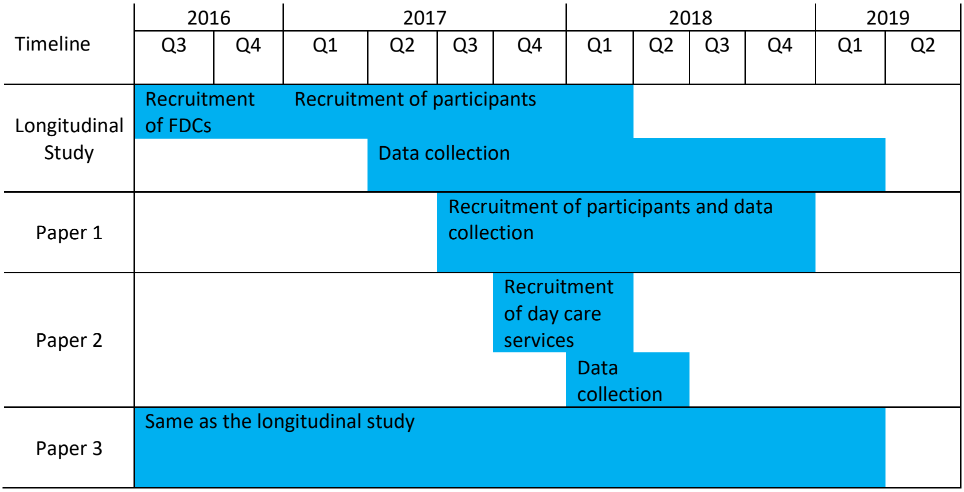


Fig. 6.1. The different work packages in the Farm-based Dementia Care-project

This PhD-project is a part of work package A and was planned as a longitudinal study following the participants of FDCs for a one-year period and with three rounds of data collection. The PhD-project also includes data from work package B which were used in papers 1 and 2. The longitudinal study was considered the main component and will therefore be presented first in the subsequent sections. A protocol for the longitudinal study and work package A has been published by the FDC-project (Eriksen et al., 2019).

Paper 1 is a cross-sectional study of activity levels at day care services from people with dementia using actigraphy data and data collected concurrently from the second round of data longitudinal study. Paper 2 is an observational study investigating emotional well-being based on ecological momentary assessments of participants from two different types of day care services. It uses data collected after closing the recruitment for the longitudinal study, and the data was collected completely separate from the longitudinal study. Paper 3 is a longitudinal study based on the longitudinal data gathered in the project. In addition, paper 1 and paper 3 includes data from other projects and studies. This data was gathered from people with dementia attending regular day care services and was included to provide a comparison group. See Figure 7.2 for an overview over recruitment and data collection related to the longitudinal study and the different papers.



Timeline	2016		2017				2018				2019	
	Q3	Q4	Q1	Q2	Q3	Q4	Q1	Q2	Q3	Q4	Q1	Q2
Longitudinal Study	Recruitment of FDCs	■	Recruitment of participants	■	■	■	■					
				Data collection	■	■	■	■	■	■	■	
Paper 1					Recruitment of participants and data collection	■	■	■	■	■		
Paper 2						Recruitment of day care services	■					
							Data collection	■				
Paper 3	Same as the longitudinal study	■	■	■	■	■	■	■	■	■	■	

Figure 6.2. Timeline for recruitment and data collection for the PhD-project

As the different papers used different data and methods, I will in the subsequent sections first describe the aspect of the general FDC-project. I will then expand upon the different aspects of the three papers in their respective subheadings in the subsequent sections.

6.2 Participants and recruitment

The recruitment phase of the FDC-project longitudinal study started in late 2016. We approached all farms in Norway that provided farm-based day care for people with dementia, at the time, 35 farms. They were given information about the project and asked if they would like to participate. We also approached the municipalities which the FDCs provided for and asked if they agreed to participate. If both agreed to participate, the FDC was enrolled in the project. In total 30 different FDCs agreed to participate, with a total of about 240 users. The service providers or municipal care staff conducted the recruitment of the participants based on the inclusion and exclusion criteria.

The inclusion criteria for people with dementia were that they had attended a FDC for at least three weeks, lived together with next-of-kin or saw him/her at least once a week on average, and be able to express themselves verbally and have the cognitive capacity to participate. The exclusion criteria were that next-of-kin did not want to participate. For next-of-kin the inclusion criteria were that they were 18 years or older, lived with the person with dementia or meet him/her at least once a week on average and could give written consent. Next-of-kin were excluded if the person with dementia did not want to participate.

Based on these criteria 169 dyads were eligible to participate. 62 of these did not want to participate, while a further 13 dyads were not invited to participate by the service providers or municipal care staff for other reasons than the inclusion criteria (e.g. family or health issues). In the end 94 dyads from 25 farm-based day care services agreed to participate in the study, representing 55,6% of all those eligible to participate. The day care services generally had few users, and to protect their privacy, we did not collect any data about those who did not participate.

After first contact had been established by the service providers or municipal care staff, those that expressed an interest in participating and consented to being contacted were approached by the researchers who then provided additional information and made arrangements for the first round of data collection.

6.2.1 Paper 1

For Paper 1 participants were recruited from among the participants of the longitudinal study. In conjunction with the second round of data collection, 6 months after the initial round, participants were asked if they would like to participate in the activity study. The inclusion criteria were therefore the same as the longitudinal study, but we also chose to approach participants that either were living with someone or seemed to have a close follow-up from next of kin. The reason for this was that we wanted someone at hand to aid the participant in wearing the activity measure. We recruited participants from late 2017 to late 2018. A total of 30 participants were recruited from 15 FDCs from all across Norway.

In addition, we included participants from a different study investigating regular day care for people with dementia (Olsen et al., 2016). In that study the development centres for dementia in three counties enrolled municipal day care centres for participation in the study. The staff at the enrolled centres conducted the recruitment of participants. The inclusion criteria were 65 years or older and the person had to have either a dementia diagnosis or a score of <25 on the Mini-Mental State Examination-test. A total of 115 participants from 23 day-care centres in the south-eastern part of Norway were included (Olsen et al., 2016).

6.2.2. Paper 2

Care farms offering day care services for people with dementia were approached to participate in the study. These were located in different regions of Norway. Simultaneously, regular day care centers were recruited from the same geographical area as the FDCs. Recruitment was conducted from November 2017 to May 2018. As the FDCs generally had smaller groups, more FDCs than regular day care centers were recruited so as to have approximately the same number of participants in each group of day care service. In the end, 10 FDCs with 42 participants and 7 regular day-care centers with 46 participants were recruited, totaling 17 day-care centers and 88 participants.

6.2.3 Paper 3

Paper 3 used the participants in the longitudinal study who completed all three rounds of data collection, a total of 45 dyads. It also included data from the Effects and Costs of a day Care Centre Program Designed for People with Dementia (ECOD) (Rokstad et al., 2014). In the ECOD-study, participants were recruited through invited day care centres. The inclusion criteria for participants were: 65 years or older, had an existing dementia diagnosis, a mini-mental state examination (MMSE) score equal to or more than 15, had the capacity to give informed consent, attended a day care centre at least twice a week, not attended a day care centre for more than one year, and had a carer willing to participate and who saw the person with dementia at least once a week (Rokstad et al., 2014).The recruitment period lasted from late 2013 to mid-2015, and data collection from late 2013 to mid-2017. 183 participant-carer-dyads were recruited (Rokstad et al., 2017) and 100 of these dyads were still in the project at 12 months.

6.3 Setting

The main setting of the project was the FDCs. FDCs in Norway have been described by Ibsen et al. (2018). They noted that while FDCs in Norway have similarities with other types of day care services with regards to organization, daily structure and number of health education personnel, they differ in that FDCs have a different care environment. The care environment at FDCs have a wide variety of activities related to the farm setting and also a wide variety of resources available, such as farm building, animals, gardens and outdoor areas.

6.4 Data collection

The FDC-project conducted a longitudinal data collection, with data collection at “baseline”, after 6 months and after 12 months. The researchers and research assistants collected the data. All data collectors attended a training day on the use of the different measures before data collection began. In addition, for the FDC-project the measures were tested in three pilot interviews to evaluate the acceptance and feasibility for the participants and to ensure that people with dementia would be able to answer them. Based on the pilot we decided that the person with dementia and their next-of-kin would be interviewed in parallel by two different researchers. One would begin jointly with both to ensure that they felt comfortable and secure and then conducted the rest of the interviews separately. The reasoning was that this would take less of their time and lessen any potential burden of participating. The interviews therefore usually took place in the home of the person with dementia and lasted approximately one hour, with one researcher interviewing the person with dementia, and the other interviewing next-of-kin. In addition, next-of-kin also filled out some of the forms by themselves.

Paper 1 and 3 used data from the longitudinal study, with Paper 1 also using activity data collected concurrently with the second round of data collection. Paper 2 collected data separately from the longitudinal study and after the longitudinal recruitment phase. Data collection will be further described under the paper subheadings below.

6.4.1 Paper 1

Paper 1 uses data collected in the FDC-projects longitudinal data collection, specifically data collected at 6 months. In addition, it uses activity data collected using an accelerometer, an actigraph. Data collection was conducted in conjunction with the second round of data collection in the longitudinal study and was conducted between late 2017 and late 2018. The participants recruited to this study from the main project agreed to wear the actigraph for 24 hours a day, for seven days, starting immediately after recruitment. After the seven days the actigraph was returned to the researchers for analyses.

6.4.2 Paper 2

Data for paper 2 was collected March and June 2018 by colleague researchers in the FDC-project. They spread the observations at FDCs and at regular day care centers evenly within this period to account for any seasonal variations. The observations were conducted by three researchers working in alternating pairs. Observations started in the morning with a meeting with the staff at the day care center to plan the day. Staff were informed that they could at any time stop the observations if any of the participants did not feel comfortable with the situation. The ensure that the observations were as unobtrusive as possible, the observers greeted the participants when they arrived and often participated in half of the morning meal before starting their observations. An ordinary day often consisted of breakfast in the morning, a period of activities or relaxation, then a coffee break in the middle of the day, followed by another period of activities or relaxation, before ending with dinner in the afternoon. The observers did two hours of observations in the morning, followed by a 30 minutes break, and then two hours of observations in the afternoon. This observational pattern meshed well with the opening hours of most day care centers. Participants were observed in random order for one minute, three times an hour. This resulted in 12 observations for each participant. At the end of data collection, a total of 1056 observations had been conducted. 504 observations from the FDCs and 552 observations from the regular day care centres. The observations were anonymous and as such no demographic data was gathered about the participants.

6.4.3 Paper 3

The data collection for paper 3 is the same as the data collection for the FDC-projects longitudinal data collection. In addition, paper 3 used data collected in the ECOD-study. The ECOD-study gathered data at "baseline", 12 months and 24 months (A. M. M. Rokstad et al., 2014). In paper 3 only the data collected at baseline and 12 months were included (see Fig. 7.3). Data collection in the ECOD-study was conducted similarly to how the data collection was conducted in the FDC-project (see description above). Data collected from a total of 45 dyads from the FDC-project and a 100 from the ECOD-study were included in the analyses.

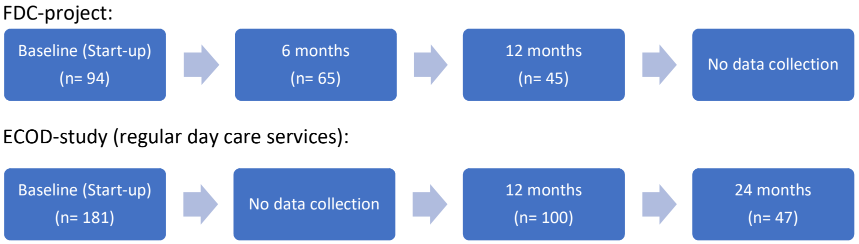


Fig 6.3. Time points for data collection in the FDC-project and the ECOD-study

6.5 Measures

The FDC-project had a list of core measurements collected from both the participants and their next of kin. Table 7.1 shows the complete list of measurements related to the participants themselves and the papers in which they were used. Paper 1 used additional data, while Paper 2 used an entirely different dataset, both of which be presented separately. Paper 3 used solely the longitudinal data. The measures used will be described more in depth under the relevant subheadings, with added attention on the measures used in the different papers.

Table 6.1. Measures in the longitudinal study related to the participants of farm-based day care services

Construct	Assessment Instrument(s)	Used in[1]
Sociodemographic information	Demographic data - Gender, age, education level, living arrangements Prescribed medication - Types of medication and dose Dementia diagnosis and other diagnosis - Type of dementia, other diseases - Degree of dementia Hobbies/interests etc.	Paper 1 and 3
Quality of life	Quality of life – Alzheimer's Disease (QoL-AD) - Questionnaire - Measures quality of life	Paper 3
Subjective Well-being	The WHO-5 Well-being Index (WHO5) - Questionnaire - Measures degree of subjective well-being	Paper 3
Cognitive Functioning	Montreal Cognitive Assessment (MoCA) - Screening-test, cognitive test for mild cognitive impairment - Measures cognitive impairment and degree of cognitive impairment	Not used in papers or analyses
	Anosognosia Rating Scale (REED)	Paper 3

	- Questionnaire/Assessment done by researcher of participants - Measures insight into participants own memory deficiencies	
Degree of Dementia	Clinical Dementia Rating (CDR) - Assessment done by researcher - Degree of dementia in participants	Paper 1 and 3
Psychological functioning	The Neuropsychiatric Inventory Scale (NPI) - Questionnaire, posed to next-of-kin - Measures psychiatric and behavioural symptoms of the participants	Paper 3
Depression	Montgomery-Aasberg Depression Rating Scale (MADRS) - Questionnaire - Measures depression and degree of depression	Paper 3
	Cornell Scale for Depression in Dementia (CSDD) - Questionnaire, posed to next-of-kin - Depression and degree of depression in participants with dementia	Paper 3
Anxiety	Rating Anxiety in Dementia – Norwegian version (RAID-N) - Questionnaire - Measures anxiety and level of anxiety in people with dementia	Not used in papers or analyses
Physical functioning	The timed up and go test (TUG) - Physical test - Measures physical functions such as balance and need for walking aid.	Paper 1
Coping skills	Locus of Control of Behaviour (LCB) - Questionnaire - Measures perceived coping and internal vs. external locus of control	Not used in papers or analyses

Activities of daily living	Personal activities of daily living (P-ADL) - Questionnaire, posed to next-of-kin - Measures degree of management of personal activities of daily living	Paper 3
	Instrumental activities of daily living (I-ADL) - Questionnaire, posed to next-of-kin - Measures degree of management of instrumental activities of daily living	Paper 3
General Health	The General Medical Health Rating (GMHR) - Questionnaire/Assessment made by the researcher - Measures medical comorbidity/somatic health	Paper 3
Social Support	Oslo Social Support (OSS3) - Questionnaire - Measures perceived social support	Paper 3
Health care resources	Resource Utilization in Dementia (RUD-del 1) - Questionnaire - Measures participants use of health care resources	Not used in papers or analyses
[1] This includes being in used in preliminary analyses, before the final models had been established		

Sociodemographic information

We collected sociodemographic information about the participants. This was information such as their gender, age, marital status, living situation, if they were living with someone, their education level, former professions, hobbies and interest. We also gathered information on past and present neurological diseases, heart diseases, cerebral diseases and depression. In addition, we gathered information about physical activity, given as number of times the person had been physically active in a week with a duration of more than 20 minutes and where they had experienced elevated heart rate and perspiration, and use and type of medication.

Quality of life

The Quality of life in Alzheimer's Disease (QoL-AD) was used to measure quality of life. QoL-AD is a 13-item measure, each item rated as either 1 (poor), 2 (fair), 3 (good) or 4 (excellent) giving a total score ranging from 13 to 52 (Logsdon et al., 1999). The items are: Physical health, energy, mood, living situation, memory, family, marriage, friends, self as a whole, ability to do chores around the house, ability to do things for fun, money, and life as a whole. In the development of QoL-AD the researcher used the domains of QoL proposed by Lawton (Logsdon et al., 1999, 2002). QoL-AD for people with dementia was rated both by the persons with dementia themselves and by next-of-kin. In addition, next-of-kin also rated their own quality of life according to QoL-AD.

Some cut-offs for QoL-AD have been suggested. A score of less than 33 is considered low quality of life, 33-37 is considered moderate quality of life, while a score above 37 is considered high quality of life (Conde-Sala et al., 2016). In addition, a change equal to or greater than three points has by several studies been considered as clinically significant (Beerens et al., 2015; Clare et al., 2014; Conde-Sala et al., 2016; Hoe et al., 2009; Selwood, Thorgrimsen, & Orrell, 2005).

In order to further explore the different aspects included in QoL-AD we also used the subscale proposed by (Revell, Caskie, Willis, & Schaie, 2009). They presented three different subscales:

1. Physical QoL-AD comprised of the items: Physical health, Energy, Ability to do chores and Ability to do things for fun.
2. Social QoL-AD comprised of the items: Living Situation, Family, Marriage, Friends and Money.
3. Psychological QoL-AD comprised of the items: Mood, Memory, Self as a whole and Life as a whole.

Subjective Well-being

To measure subjective well-being, we used the World Health Organizations Well-being Index (WHO5). It is a short generic global rating scale that measures subjective well-being (Topp, Ostergaard, Sondergaard, & Bech, 2015) and is considered to give an insight into people's positive psychological health and more specifically their positive affect (Nes, Barstad, & Hansen, 2018). The WHO5 consists of 5 items/statements, rated from 0-5, with 0 being "At no time" and 5 being "All the time". The ratings are summed up to give a score between 0-25. The score is multiplied by 4 to give a percentage scale from 0 to 100. A change of 10% is considered a significant change (Topp et al., 2015). While WHO-5 has not been validated for use with people with dementia, it has been validated for older people (Heun, Burkart, Maier, & Bech, 1999), and it has been used previously in dementia-related research (Jha, Jan, Gale, & Newman, 2013; Rippon et al., 2019). The WHO-5 was rated by the people with dementia themselves.

Cognitive functioning

We used the Montreal Cognitive Assessment Scale (MoCA) to measure cognitive function and impairment. MoCA is a 10-minute cognitive screening tool (Nasreddine et al., 2005). It consists of 11 items: Alternating trail making, visuoconstructional skills (cube), visuoconstructional skills (clock), naming, memory, attention, sentence repetition, verbal fluency, abstraction, delayed recall and orientation. Each item is scored based on performance and summed up to a total sum between 0 and 30. To account for differences in education levels, people with 12 years of education or less have one point added to their total score (Nasreddine et al., 2005). In this project the test was administered by the researchers to the participants following a standardized instruction. MoCA was not used in any of the analyses but is presented here as it was considered to be used in the longitudinal comparison between the group attending FDCs and the group attending regular day care services.

We also used the REED-scale to asses awareness of memory loss in the participants. The Reed Scale is a one item scale for rating awareness of memory loss in people with dementia (Reed, Jagust, & Coulter, 1993). The scale has four different ratings: Denies memory loss, no awareness of memory loss, shallow awareness of memory loss and full awareness of memory loss (Reed et al., 1993). In the project this was rated by the researchers based in their conversations with the people with dementia and their next-of-kin.

Degree of dementia

To measure degree of dementia we used the Clinical Dementia Rating (CDR). This is a 6-item scale, each rated from 0 to 3, were 0 is no dementia, 0.5 is possible dementia, 1 is mild dementia, 2 is moderate dementia and 3 is severe dementia (Hughes, Berg, Danziger, Coben, & Martin, 1982). The ratings are then translated into an overall score, giving precedence to memory. This score is based on the same 0 to 3 scale. Alternatively, the ratings can be summed up in a sum-of-boxes, ranging from 0 to 18. This method provides a greater number of values and as such is more sensitive to changes over time (O'Bryant et al., 2008). CDR has been used in Norwegian settings previously and has been shown to accurately detect dementia, and is viewed as a valid substitute in dementia assessment and grading (Engedal & Haugen, 1993; Nygaard & Ruths, 2003). In this project CDR was rated by the researchers based on information gathered from both people with dementia and their next-of-kin. The overall score was made by two researchers going through the data and rating it based on the rules stipulated in Hughes et al. (1982).

Psychological functioning

To measure psychological functioning, we used the Neuropsychiatric Inventory (NPI). NPI assesses psychopathology in people with dementia (Cummings, 1997). NPI consist of 12 items, each evaluating different neuropsychiatric disturbances. The 12 items are: delusions, hallucinations, agitation, dysphoria, anxiety, apathy, irritability, euphoria, disinhibition, aberrant motor behaviour, night-tome behavioural disturbances, and appetite and eating abnormalities. Each item was graded on severity (1= mild, 2= moderate, 3= severe) and frequency (from 1= occasionally, less than once a week to 4= very frequent, once or more per day/continuously) and caregiver distress (from 0= No distress to 5= Very severe/extreme distress). The severity and frequency for each item was multiplied with each other and the resulting scores were added together to give a sum score. Higher score indicating higher levels of neuropsychiatric symptoms. Caregiver distress was summed up separately, with higher scores indicating higher levels of distress (Cummings, 1997). The grading of the items was based on a structured interview with next-of-kin.

Depression

We used Montgomery and Aasberg Depression Rating Scale (MADRS) to measure depression. MADRS is a depression rating scale designed to be sensitive to change (Montgomery & Asberg, 1979). It consists of ten items: apparent sadness, reported sadness, inner tension, reduced sleep, reduced appetite, concentration difficulties, lassitude, inability to feel, pessimistic thoughts and suicidal thoughts. Each of these items are rated from 0 to 6, resulting in a sum score of 0 to 60. A higher score indicates more severe depression symptoms (Montgomery & Asberg, 1979). MADRS has been validated for use in memory clinic patients (Knapskog, Barca, & Engedal, 2011) and for people with early onset dementia (Leontjevas, van Hooren, & Mulders, 2009). The grading was based on a semi-structured interview with the person with dementia.

In addition, we used the Cornell Scale for Depression in Dementia (CSDD) to also measure depression. CSDD is a 19-item instrument to measure depression in people with dementia (Alexopoulos, Abrams, Young, & Shamoian, 1988). The 19 items are: anxiety, sadness, lack of reactivity to pleasant events, irritability, agitation, retardation, multiple physical complaints, loss of interest, appetite loss, weight loss, lack of energy, diurnal variation, difficulty falling asleep, multiple awakenings during sleep, early morning awakening, suicide, self-deprecation, pessimism, mood-congruent delusions. Each item is scored as either 0 (absent), 1 (mild or intermittent), 2 (severe). Additionally, it if no rating is possible, for example due to lack of observation, an item can be rated as “unable to evaluate”. The rated items are summed up in a sum score and a higher score indicates higher levels of depressive symptoms (Alexopoulos et al., 1988). CSDD was rated based on interviews with next-of-kin.

Physical functioning

We used the Timed Up-And-Go-Test (TUG) to measure physical function in the participants. The timed Up and Go-test is a physical test were the participant rises from a chair, walks three meters, turns, walks back and sits down, while the test-administrator takes the time (Podsiadlo & Richardson, 1991). TUG has been shown to be feasible for assessing physical function in people with dementia (van Iersel, Benraad, & Olderikkert, 2007). The test was administered according to the Norwegian version by Botolfsen and Helbostad (2010), i.e. the testers repeated the test up to two times and the final score was the mean of the time, in seconds, for the two attempts. In some cases where there were, for different reasons, not possible to do the test two times, the time for the first attempt was used.

Activities of daily living

To measure activities of daily living we used Personal Activities of Daily living (P-ADL), also known as Physical Self-maintenance scale (PSMS) and Instrumental activities of Daily Living (I-ADL). P-ADL and I-ADL are two scales measuring function and ability to perform activities of daily living (Lawton & Brody, 1970). P-ADL consists of six items: Toilet, feeding, dressing, grooming, physical ambulation and bathing. Each are rated from 1 to 5 and summed up to provide a sum score of 6 to 30. Higher score indicates decreasing ability to perform personal activities of daily living. I-ADL consists of eight items: ability to use telephone, shopping, food preparation, housekeeping, mode of transportation, responsibility for own medications, and ability to handle finances. The scoring is not uniform, and items are scored from either 1-3, 1 to 4 or 1-5. The sum score is between 8 and 31, with higher scores indicating decreased ability to perform instrumental activities of daily life (Lawton & Brody, 1970). The two scales were graded by interviewing next-of-kin.

General Health

We used the General Medical Health Rating (GMHR) to measure the participants general somatic health. This is a rapid global rating scale of medical comorbidity in people with dementia and is rated on a scale from 1 to 4, with 1 being “Poor” and 4 being “Excellent” (Lyketsos et al., 1999). The rating for this scale was based on the researcher’s perception of the person with dementia.

Social Support

We used the Oslo Social Support Scale (OSS3) to measure perceived social support. This scale consists of three items. One item on how many people one feels one can rely on (given as number of people); one item on how much concern people show (rated from none to a lot); one item on how easy it is to get help from the neighbours (rated from very easy to very difficult) (Dalgard et al., 2006). The responses are scored and gives a sum ranging from 3 to 14. 3-8 constitutes “poor support”, 9-11 constitutes “moderate support, while 12-14 constitutes “strong support” (Bøen et al., 2012). OSS3 is not validated for people with dementia, but has previously been used in research with older people (Bøen et al., 2012). In this project the scale was rated through interviews with the people with dementia.

Other measures

We also looked at anxiety, the use of health care resources, and coping using Rating Anxiety in Dementia (RAID) (Shankar, Walker, Frost, & Orrell, 1999), Resource Utilization in dementia (RUD) (Wimo, Jonsson, & Zbrozek, 2010; Wimo & Nordberg, 2007) and Locus of Control of Behaviour (LCB) (Craig, Franklin, & Andrews, 1984), but these were not included in any of the preliminary or final analyses. They are therefore not described further.

Next of kin

We also collected information on the next-of-kin, see table 7.2. Among these only QoL-AD for next-of-kin was used extensively in the analyses, and it is the same as described for people with dementia above. As they were only in limited use in the analyses and only QoL-AD for next-of-kin was used in the final analyses, the remaining measures will not be presented in depth.

Table 6.2. Measures used in the FDC-project for the next-of-kin of people with dementia
Demographic and background information - Age, gender, education, living situation, relation, etc.
Initiating Transition of Care (ITC) (Kraijo, Brouwer, de Leeuw, Schrijvers, & van Exel, 2014)
Oslo Social Support Scale (OSS3) (Dalgard et al., 2006)
Resource Utilization in Dementia (RUD Part 2 – Next-of-kin's use of health services) (Wimo et al., 2010)
Quality of Life – Alzheimer's Disease (QoL-AD) (Logsdon et al., 1999)
Montgomery and Aasberg Depression Rating Scale (MADRS) (Montgomery & Asberg, 1979)
Anxiety scale of the Hospital Anxiety and Depression Scale (HAD-A) (Zigmond & Snaith, 1983)
Relative Stress Scale (RSS) (Greene, Smith, Gardiner, & Timbury, 1982)
RAND 36 – Measure of Health-Related Quality of Life (Loge, Kaasa, Hjermstad, & Kvien, 1998; Ware Jr & Sherbourne, 1992)
Locus of Control of Behaviour (LCB) (Craig et al., 1984)

6.5.1 Measures used in Paper 1

The main outcome of the paper was physical activity and we used actigraphs (Actisleep+, Actigraph, Pensacola, US) to measure the level of physical activity. The actigraph used, Actisleep+, is a 3-axis accelerometer approximately the size of a wristwatch, and measures physical activity levels, light exposure and sleep patterns. The device measures movement along three axes: Vertically (Up and down), laterally (side to side) and longitudinally (forward and backward). It further measures the frequency and intensity/force of these movements. Using the associated software, this is translated into measures of physical activity. The actigraph does not register type of activities, nor their location. Actigraphy has been validated as a method for monitoring sleep and activity levels in people with dementia (Ancoli-Israel, Clopton, Klauber, Fell, & Mason, 1997). In addition, Erickson et al. (2013) demonstrated the feasibility of using actigraphy to measure physical activity in people with dementia. Further, several previous studies have used actigraphy to study levels of physical activity in people with dementia (Olsen et al., 2016; van Alphen, Volkers, et al., 2016). The researchers introduced the actigraph for the participants both orally, visually and in written form in both studies. It was introduced both to the person with dementia and to their caregivers/relatives. In both studies, the participants wore the actigraph on the left wrist continuously for seven days, and these days included both days while at the day care services and days while not at the day care services. The participants could remove the actigraph, for example when showering, but were encouraged not to do so. Caregivers and relatives were also instructed to encourage the participants to put it back on if it had been removed by mistake.

In addition, Paper 1 used the following measures from the longitudinal study, collected during the 6-month follow-up: demographic information (age, gender, education, living situation), Clinical Dementia Rating (CDR) and Timed-Up-and-Go (TUG).

6.5.2 Measures used in Paper 2

In paper the Maastricht Electronic Daily Life Observation-tool (MEDLO) (de Boer, Beerens, et al., 2016) was used to provide the data for analysis. Researchers in the project used MEDLO to observe and register the different aspects of daily life at the day care services. MEDLO has been shown to be both valid and reliable (de Boer, Beerens, et al., 2016). Additionally, the tool was piloted at one FDC and one regular day care centre to ensure inter-rater reliability. Observed aspects of the daily life at the day care centres included: Mood, activity, engagement, physical effort, location and social interaction. Table 7.3 gives and overview over how these aspects were measured.

Table 6.3: Categories of mood, activities, engagement, physical effort, social interaction and location as used during analyses and observation

Aspects of daily life	Categories used in analysis	Categories registered during observation
Mood	1: Great signs of negative mood	Great signs of negative mood
	2: Considerable signs of negative mood	Considerable signs of negative mood
	3: Small signs of negative mood	Small signs of negative mood
	4: Neutral mood	Neutral mood
	5: Small signs of positive mood	Small signs of positive mood
	6: Considerable signs of positive mood	Considerable signs of positive mood
	7: Great signs of positive mood	Great signs of positive mood
Activity	Sitting Eating/drinking	Sitting Eating and drinking

	Quiz/music/spiritual	Playing cards, playing a game, doing a puzzle; Music and singing; Handcrafts/arts; Spiritual or religious activity
	Walking outdoors	Walking outdoors
	Exercise and dancing	Chair exercise/sports; Dancing; Walking indoors (does not include pacing)
	Reading	Reading (being read to), writing, crossword puzzle; Watching television or listening to the radio
	Farming and animal activities	Gardening, taking care of plants; Maintaining the farm; Working with firewood; Cultivation of grains, fruits, berries etc.; Interacting with pets; Working with animals (physical contact); Working with animals (no physical contact); Interaction with farm animal (including observing animals)
	Domestic and cooking	Domestic activities Cooking and preparing food
	Self-care	
	Social activities	
	Unobservable/other	Unobservable; Other
Engagement	0: Not engaged in activity	Sleeping; Gazing in the air; Focus on something else than activity
	1: Engaged in activity	Focus on activity taking place Active participation in activity
Physical effort	1: Sedentary	Lying or sitting without movements; Sitting quietly (awake)
	2: Light activity	Light-to-moderate sitting activities; Standing or light-standing activity
	3: Moderate activity	Standing activity or walking; Walking activity or cycling; Whole-body movements
Location	0: Indoors	Indoors at the unit; Indoors outside the unit
	1: Outdoors	Being outdoors
Social Interaction	0: No social interaction	No social interaction; Participant attempts to interact, but gets no response; Environment attempts to interact, participant do not respond
	1: Social interaction with someone else	Social interaction with one other person
	2: Social interaction with two or more	Social interaction with two or more

Activities

Activities as measured by MEDLO are activities performed by or occurring in the immediate vicinity of the participants (de Boer, Hamers, Zwakhalen, Beerens, & Verbeek, 2016). Examples of activities are eating, walking, reading and gardening.

Engagement

Engagement is the participants engagement in performed activities or activities occurring in their immediate vicinity. Engagement has five categories in MEDLO: active engagement (participating in activity), passive engagement (focus on activity), engagement with something else, not engaged (gazing without focus) and not engaged (sleeping) (de Boer, Hamers, et al., 2016). In our analyses we used two categories: engaged (active and passive engagement) and not engaged (engaged with something else and not engaged (gazing and sleeping).

Physical effort

Physical effort is the physical effort the participants exert doing the observed activity. In MEDLO this is graded on a 7-point Likert Scale with the following categories: Lying or sitting down without movements (participant is gazing or sleeping), sitting quietly (participant is awake), light-to-moderate sitting activity, standing or light-standing activity, standing activity or walking around, walking activity or cycling, and whole-body movement (de Boer, Hamers, et al., 2016). In our analyses we used three categories: sedentary activity (lying or sitting without movements and sitting quietly), light activity (light-to-moderate sitting activity and standing or light-standing activity) and moderate activity (standing activity or walking around, walking activity or cycling, whole-body movements).

Mood

Mood is the observed mood of the participants during the observed activities. In MEDLO this is rated on a 7-point Likert scale: great signs of negative mood, considerable signs of negative mood, small signs of negative mood, discomfort or boredom, neutral (no positive or negative signs observable), contentment and small signs of well-being, considerable positive mood and very high positive mood (de Boer, Hamers, et al., 2016). Negative mood could be characterized by crying, groaning, moaning, shouting, screaming and/or tensed facial expression (e.g. frowning) or tensed body language. Positive mood could be characterized by smiling, chuckling, laughing, relaxed facial expression and body language and/or humming a tune. For both types content and tone of verbal and non-verbal interactions gave added information about the mood. Mood was considered as neutral when no negative or positive mood was observable (de Boer, Hamers, et al., 2016). We were primarily concerned with mood as an outcome variable in our analyses and therefore included all 7 categories.

Social Interaction

Social interaction is the level of social interaction of the participants during the observed activities. In MEDLO this has five categories: no social interaction, participants attempt to interact (gets no response), environment attempts to interact (participant does not respond), interaction with someone and interaction with two or more (de Boer, Hamers, et al., 2016). In our analyses we three categories: no interaction (no social interaction, participant attempts to interact (gets no response), environment attempts to interact (participant does not respond)), interaction with someone and interaction with two or more.

Location

Location is the location of the participant during the observed activities. In MEDLO there are five categories: communal area on the ward, own room, communal area of the ward, bathroom/toilet, and outside (de Boer, Hamers, et al., 2016). In our analyses we elected to use location as a dichotomous variable and split it into the participants being inside or outside. The reason for this was the MEDLO was originally conceived to be used in long-term care facilities, as such some of the locations were not considered locations of interest for our study. We wanted to focus on whether the participant was inside or outside and if that had any association with mood.

Agitation

Agitation were signs of agitation in the participants during the observed activities. In MEDLO agitation is defined as the presence of aberrant vocalization, motor agitation, aggressiveness or resisting care, and it is rated using a 5-point Likert scale: not present, low volume (not disruptive), louder than conversational and mildly disruptive, loud and disruptive, and extremely loud and highly disruptive (de Boer, Hamers, et al., 2016). No agitation was observed among the participant in the project and as such it was not included in our analyses.

Primary outcome variable

In the development of the MEDLO-tool the researchers considered mood and agitation the most relevant aspects of emotional well-being in daily life (de Boer, Beerens, et al., 2016). As mentioned, there was no observed agitation among our participants, so we considered mood alone as an indication of the emotional well-being of the participants. Mood, as a sign of emotional well-being, was therefore considered the primary outcome variable for paper 2.

6.5.3 Measures used in Paper 3

The main outcome in Paper 3 was QoL-AD, which was measured in both the longitudinal FDC-study and in the comparison group from the ECOD-study. In addition, WHO5 Well-being Index was used in intragroup analyses of factors influencing quality of life and well-being for the participants from the FDC-project. The ECOD-study had a large overlap with the measures used in the longitudinal study, but with some differences. Only overlapping measures were included in the comparative analyses and models (See Table 11.1 in the appendix showing the measures which overlapped, and which did not)

One main difference between the two were that the FDC-project used MoCA to asses cognitive function, while the ECOD-study used Mini-Mental Status Evaluation (Rokstad et al., 2014). There have been attempts to provide methods of converting a score on one scale into a score on another (Bergeron et al., 2017; Trzepacz et al., 2015), but we elected to not use these and rather solely use CDR. This was due to the fact that CDR was deemed to be more precise as it had been conducted in both studies and did not require any type of conversion.

Additionally, the ECOD-study used NPI-Q, as opposed to the full NPI used in the FDC-project. The NPI-scores from the FDC-project was therefore converted to NPI-Q-scores based on the severity score as this is the score that founds the basis for NPI-Q and is rated similarly in both forms (Kaufer et al., 2000)

6.6 Statistical Analyses

In this section I will describe the statistical consideration that were done and how this manifested itself in each of the articles.

Power

We elected to not do any power-analyses in the FDC-project. This was based on two considerations. Firstly, as FDCs in Norway are not a widespread service with many users, we wanted to include as many as possible and not base ourselves on a set amount provided by the power calculations. Secondly, as the project planned on measuring many different aspects of the people with dementia, everything from QoL to cognitive functioning, a power calculation based on just one measure would have been overly restrictive and doing power calculations for each measure would not have been very feasible.

Missing values

In the data for the longitudinal study there were some missing values the data set, with measures having varying degrees of missing values. For example, for QoL-AD at baseline 72.5% of the persons with dementia had complete measures, 22.5% had completed at least half of the measure, while 5% had completed less than half of the measure. We assumed these missing values were missing at random and elected imputate them at an item level. We performed imputations only in cases were the respondent had answered at least 50% of the items in the measurement in question. The imputed values were random numbers drawn from the observed distribution in the dataset. Some measures were not imputated, this included MoCA and LCB for people with dementia. MoCA was considered inappropriate for imputation as it could be argued that it was not missing at random, since the participants level of cognitive functioning could preclude them from completing the test on cognitive functioning. LCB had so much missing across all respondents, with only 24.5% of the persons with dementia completing the measure, that we deemed the data to not be sufficient for imputation. The forms based on the data collectors' assessments, such as CDR, was also not imputed, as these were either completed or, extremely rarely, not filled out at all. Imputed data from the longitudinal study was used in Paper 3 and in preliminary analyses in Paper 1.

6.6.1 Paper 1

We processed the collected actigraphy data using the ActiLife-software, version 6.13.3 (ActiGraph, Pensacola, USA). In order to measure wear-time of the participants we subjected the data to a wear-time-validation. This process allows the researcher to identify, based on a given set of parameters, invalid data. In this case, invalid data are periods when the actigraph was not worn by a participant. We based the validation on the Troiano (2007) algorithm included in the software, and non-wear time was excluded from the subsequent analyses. During processing we also applied a time filter between 08:00 and 20:00 to focus on day activities, as this is the timeframe where we believe the participants are the most active, and the timeframe in which day care centres could have an impact on the level of physical activity. If there were more than eight hours recorded activity within that period, we included it as a valid day. We decided that in order to be included in the analyses the participants would have to have at least three valid days, which is in accordance with findings from Hart, Swartz, Cashin, and Strath (2011). Of the 30 participants from study 1, only one participant was excluded from the analyses because of too few valid days, while in study 2, 8 participants were excluded because of too few valid days.

We further processed the data via the Scoring functions of the ActiLife-software. We used this to calculate physical activity levels using the Freedson Adult Cut Points (Freedson, Melanson, & Sirard, 1998) in the ActiLife Software. The software calculated activity levels based on the frequency and intensity of the registered movements. These constitute the measure counts and are specified as counts per minute (cpm). The Actilife-software further categorises activity into five levels of physical activity. These are: sedentary (0-99 cpm), light (100-1951 cpm), moderate (1952-5742 cpm), vigorous (5743-9498 cpm), and very vigorous (>9498 cpm). Sedentary activities are for example sitting and watching TV or sitting and listening to a conversation; light activities are for example standing or household activities, while an example of moderate activity is for example walking. The Actigraph recorded the time spent by the participants at the different activity levels in minutes. Actilife subsequently expressed these as a percentage of the overall monitoring time. ActiLife also converts the data for the given time period into steps taken, giving us an estimate of steps taken for each day for each participant. For the data from regular day care, only the percentages of activity levels were available for analysis.

All statistical analyses for Paper 1 was performed using SPSS Statistics 25.0 (IBM Corp, Armonk, NY US) and we set the level of significance at 0.05. We used descriptive statistics to describe the two groups and independent samples t-tests to investigate differences between them. We used linear regression to further investigate the associations between type of day care and levels of physical activity, using data from both studies. We used the different levels of physical activity, based on the mean score for each participant, as the dependent variable and included type of day care service as an independent variable. Additionally, we included covariates that, based on previous research and existing differences between the two groups, could be potential confounders. We used linear mixed models to investigate the difference in activity levels within the FDC-group, comparing days at the FDC and days without FDC. In the linear mixed models, we used only data from Study 1. We set the levels of physical activity and steps taken each day as dependent variables, while attendance or non-attendance at the farm was included as an independent variable. As with the linear regression, we also included covariates that we considered as potential confounders. For both the linear regression analyses and mixed model analyses we analysed each of the levels of physical activity separately and built several models. We discarded covariates from the models if they were not significant or did not significantly contribute to the model, for example by using r (Field, 2013) or Akaike information criterion (AIC) (Fitzmaurice, Laird, & Ware, 2012) to inform our decisions. CDR and Living Alone were not included in the final analyses as they were not significant, and they did not contribute significantly to the model. In addition, despite there being a difference between the two groups on CDR, the group means were both in the "mild dementia"-category, signifying a similar mean level of dementia. We only presented the final models in the paper.

6.6.2 Paper 2

All statistical analyses for Paper 2 were made using SPSS Statistics 25.0 (IBM Corp, Armonk, NY, US). P-values ≤ 0.05 were considered statistically significant. We used descriptive statistics to describe the distribution of observed variables and the mean mood scores for variables of interest. We used t-tests to investigate differences in mean mood-scores on the different activities between farm-based dementia day care and regular day care. We used linear mixed models to further investigate the association between mood and variables of interest. In these models the participants were nested within their respective day care centres to account for potential clustering. We set the mood scores as the dependent variable, with the other variables included as independent variables. For activities, we used eating and drinking as the reference activity. Some variables were not included in the because there were few observations (i.e. social and self-care activities) or because they were present at almost all observations (i.e. Engagement). We evaluated the linear mixed models were based on Akaike's information criteria (AIC), were lower score is better (Fitzmaurice et al., 2012). Additionally, we also looked at interactions for some variables of interest, such as mood when sitting outside, but these were not significant and not included in the final model. We only presented the final model in the paper.

6.6.3 Paper 3

All imputation and statistical analyses in Paper 3 were made using SPSS Statistics 25.0 (IBM Corp, Armonk, NY, US). P-values ≤ 0.05 were considered statistically significant. The missing values in the longitudinal data were imputed (see description above) and the data from ECOD were imputed along the same guidelines and in a similar fashion (Rokstad et al., 2017).

We used descriptive statistics to describe the people attending FDC and people attending regular day care. We used independent samples t-tests to investigate potential differences between them. To further investigate the association between type of day care and QoL over time at 12 months we used linear regression with QoL-AD Sum at 12 months as the dependent variable and controlled for baseline QoL-AD Sum. The was done for both self-reported and proxy-reported QoL-AD and for the different subscales of QoL-AD. We used ANOVA to investigate differences between the three time points for the group attending FDCs. Lastly, we used linear mixed models for within-group analyses investigating factors associated with QoL among people attending FDCs. We chose linear mixed models because of their ability to incorporate all three data collection points. In the linear mixed models, the following were set as dependent variables, in their own separate, but otherwise identical, analyses: QoL-AD Sum, the subscales of QoL-AD and WHO-5.

In both the linear regression analyses and the linear mixed models, we built several models. These were founded on logical assumptions based on previous research and bivariate analyses of QoL-AD and other variables in the dataset. We discarded covariates from the models based on whether they significantly contributed to the model. We based this on r (Field, 2013) for the linear regression, and Akaike's information criterion (AIC) (Fitzmaurice et al., 2012) for the linear mixed models. We did not discard significant covariates. For bivariate correlation between independent variables a recommended cut-off is 0.7 (Pallant, 2013), but due to limitations based on the size of the data set, we elected to discard some variables with moderately high correlation (more than 0.5, but less than 0.7). We only present the data for the final models in the paper.

6.7 Ethics

This PhD-project was conducted in accordance with the Helsinki declaration, which emphasizes the importance of promoting and safeguarding the health, well-being and rights of the participants (World Medical Association, 2013). It also highlights the importance of taking into consideration the risks and burdens of participating in research, the protection of vulnerable groups and the importance of privacy, confidentiality and informed consent (World Medical Association, 2013). Challenges related to the ethical considerations will be discussed in chapter 8.5, while I will describe the approval process for the different studies below.

6.7.1 Paper 1

The study in paper 1 was approved by the Norwegian Centre for Research Data (NSD) (No. 49,799). Olsen et al. (2016), providing data for people with dementia attending regular day care, was approved by the Regional Committees for Medical and Health Research Ethics (REK). We submitted an application to REK for sharing of data from Olsen et al. (2016) to our study. This was approved on the basis that the data was anonymized. All participants gave informed written consent and were informed that they could at any time withdraw from the studies.

6.7.2 Paper 2

The study in paper 2 was approved by the NSD (No. 49,799). Researchers informed both participants and their next of kin about the purpose of the study, the anonymity of the participants and the participants right to decline participation. The researchers obtained oral or written consent from all participants.

6.7.3 Paper 3

The different studies in paper 3 also applied for approval, with The FDC-project being approved by the NSD (No. 49,799) (Eriksen et al., 2019), and ECOD being approved by the Regional Committee for Medical and Health Research Ethics in South-East Norway. ECOD also registered in Clinical Trials (NCT01943071) (Rokstad et al., 2014). The inclusion of data from ECOD in the FDC-project was approved by the Regional Committee for Medical and Health Research Ethics. All participants in the studies gave informed written consent and were informed that they could at any time withdraw from the studies.

7.0 Presentation of papers

Each of the three papers are presented in the following sections.

7.1 Paper 1 – "Physical activity in people with dementia attending farm-based dementia day care – a comparative actigraphy study"

Background and aim: Despite a public focus on the importance of physical activity and research showing the benefits of such activity, people with dementia have been found to be less physically active and have more sedentary behaviour compared to others in similar age groups. In Norway, there is a focus on day care services as a means to allow people with dementia to experience social, physical and cultural activities. Farm based services have been highlighted as an innovative and customized day care service, but little research has been done on physical activity and such services. This paper therefore aimed to investigate the potential of farm-based day care services as services that can promote physical activity for people with dementia

Methods: Cross-sectional actigraphy data from people with dementia attending farm-based day care services (n=29) and people with dementia attending regular day care services (n=107) was used to assess levels of physical activity in each group and to compare the those attending farm-based services with those attending regular day care services. In addition, within-group analyses were conducted comparing days at service with days not at the service for the group attending farm-based day care services.

Results: The findings showed that people attending farm-based day care had significantly higher levels of moderate activity, approximately 23 minutes each day, compared with persons attending ordinary day care (p= 0.048). The time participants spent in sedentary or light activity were similar for both of the groups. Within-group analyses showed that for the group attending farm-based day care services, days at the service, were significantly associated with less time spent in sedentary activity (-25.8 min., p= 0.012) and more time spent in light (40.3 min., p<0.001) and moderate activity (12.5 min., p=0.032), and in taking more steps (1043 steps, p=0.005) compared to days not at the service.

Conclusion: The findings indicate that participants at farm-based day care for people with dementia have higher levels of physical activity compared to ordinary day care. The findings further indicate that farm-based day care increases levels of physical activity for its attendees. Farm based day care services can therefore be said to have the potential to help their participants reach or maintain recommended levels of physical activity. Further research is needed to investigate what facilitates this increase in activity and how such knowledge could be used in all types of day care services.

7.2 Paper 2 – "Emotional well-being in day care services for people with dementia – a comparative study between farm-based day care and regular day care"

Background and aim: Day care services for people with dementia have been highlighted, both nationally and internationally, as a setting which could provide socializing, meaningful activities and well-being for home-dwelling people with dementia. Given the focus on how to provide care for the increasing number of people with dementia it is important to investigate whether the stated goals of day care services are achieved, such as whether the participants experience well-being while at the services. The paper therefore aimed to investigate the association between the different aspects of the day care services and the activities provided with emotional well-being, and to investigate if there are any potential differences between farm-based day care services and regular day care services.

Method: The Maastricht Electronic Daily Life Observation-tool (MEDLO) was used to observe and register different aspects of daily life at day care services. Observations took place at 10 FDCs, with 42 participants, and 7 regular day care centres, with 46 participants. Each day care service was observed for one day and each recruited participant were observed for one minute, three times an hour, resulting in 12 observations per participants. During the observations, the researchers noted the different aspects of daily life: types of activity, engagement in activity, physical effort, social interaction, location and mood. Mood was used as an indicator for the emotional well-being of the participants. The services were compared using unadjusted analyses for the different aspects of daily life. Additionally, we used linear mixed models to investigate the association between type of day care and mood, controlled for all observed aspects of life.

Results: The analyses showed a general positive emotional well-being for all participants, regardless of day care service. The unadjusted analyses showed more emotional well-being for the participants at FDCs when sitting ($p< 0.001$), eating and drinking ($p< 0.001$), and when reading ($p= 0.002$) compared to those at regular day care. They also had more emotional well-being when they were engaged in the activities ($p< 0.001$), when in sedentary activity ($p< 0.001$), when inside ($p< 0.001$) and for all types of social interaction: no social interaction ($p= 0.040$), interaction with someone else ($p= 0.004$), and interaction with two or more ($p= 0.003$). The linear mixed model showed an association between attending FDCs and positive mood ($p= 0.002$), when controlled for all types of activities and other factors. Regardless of service type the activities exercise and dancing ($p= 0.003$), and quiz, music and spiritual activities ($p< 0.001$) were associated with positive mood. Social interaction, either with one ($p< 0.001$) or two or more ($p< 0.001$), were also associated with positive mood regardless of service type.

Conclusion: We found a positive association between FDCs and emotional well-being, potentially a reflection of the positive influences of the farm setting and the service providers at FDCs. Regardless of setting, social interaction was positively associated with emotional well-being. The same was true for the activities quiz, music and spiritual activities and exercise and dancing, all of which could be considered social activities. This highlights the importance of the social aspect of the day care services and future research should investigate how one can facilitate good social interactions at day care services.

7.3 Paper 3 – "Quality of life in people with dementia attending farm-based dementia day care – A comparative, longitudinal study"

Background and aim: The adherent symptoms of dementia can profoundly affect the quality of life of people with dementia, leading to decreased quality of life. Day care services for people with dementia have been suggested as settings with the potential to improve quality of life. There has been a call for diversifying dementia care services, and farm-based day care services have been highlighted as an innovative type of service. So far, little research has been conducted on the association between attending farm-based day care services and the quality of life of the participants. We therefor aimed to explore the association between farm-based dementia day care and quality of life. In addition, we wanted to investigate the individual and contextual factors associated with quality of life and well-being for the participants at farm-based day care services.

Method: A longitudinal study including pairs of attendees and next-of-kin from farm-based day care services for people with dementia care (n=45) and regular day care for people with dementia (n=100) in Norway. Participants completed standardized measures for quality of life (QoL-AD), well-being (WHO-5) and other relevant outcomes at different time points over one year. At start-up, six months and twelve months for those attending farm-based day care, and at start-up and twelve months for those attending regular day care services. We used linear regression to investigate the differences between the two groups and linear mixed models for within-group analyses of the factors associated with quality of life and well-being.

Results: We found a larger, but not clinically significant, decrease in quality of life ($p= 0.009$) after 12 months among participants of farm-based dementia day care compared to those at regular day care. Both groups had high self-reported quality of life, QoL-AD Sum score ≥37, which stayed high across the 12 months. Further analyses suggested that changes in the social domain of quality of life was the main contributor to the difference between the two groups. Additionally, with-in group analyses of the participants of FDCs showed that subjective well-being was stable throughout the year.

Among the service-related factors, time spent outdoors at the service (p= 0.001) and number of participants at the service (p= 0.019), were associated with self-reported quality of life for participants at FDCs, while time spent outdoors (p= 0.039) was associated with well-being.

Conclusion: There are seemingly no clear difference in the association between type of day care and quality of life. Time spent outdoors and number of participants at the service were positively associated with quality of life and well-being among those attending farm-based dementia care suggesting that the influence of these factors should be further explored.

8.0 Discussion

The aim of this thesis was to investigate the quality of care at farm-based day care services for people with dementia. Before I discuss the results in depth, I will summarize the main findings. In paper 1 we found that participants attending FDCs had higher levels of physical activity than those attending regular day care. In addition, those attending FDCs were more physically active on the days they attended the FDC compared to the days they did not. In Paper 2 we found that attending FDCs was associated with more positive mood than attending regular day care services. We also found that social interaction and the activities exercise and dancing, and quiz, music and spiritual activities were associated with positive mood. In paper 3 we found that attending FDCs was associated with a larger, but not clinically significant, decrease in quality of life after 12 months compared to attending regular day care services. Further analyses indicated that changes in the social subscale was the primary reason for the difference between the groups. Both groups maintained high levels of quality of life and for the participants of FDCs the level of well-being remained stable throughout the 12 months. Among the service-related factors of the FDCs, time spent outdoors, and number of participants were positively associated with quality of life and time spent outdoors was positively associated with well-being.

The discussion of these main findings will be separated into two parts. In the first part (8.1-8.4) I will discuss the findings of the three papers within the framework of quality of care presented in chapter 3.3, while also drawing on the other frameworks presented in Chapter 3.0. The Norwegian Dementia Plans (Minsitry of Health and Care Services, 2007, 2015) will be used as a template for what kind of care FDCs should provide, and I will focus on the provision of activity, stimulation and good experiences as indicators for quality of care. In Chapter 8.1 I will discuss the indicators for quality of care and how these are important to the participants. Chapter 8.2. will discuss the findings related to physical and social activity and how FDCs potentially can influence these. Chapter 8.3. will discuss the findings related to good experiences and how FDCs can potentially influence these, while Chapter 8.4 will provide a summary of the preceding discussion within the context of providing quality care. In the second part, chapter 8.5, I will discuss methodological and ethical considerations and issues related to the research presented in this thesis.

8.1 Quality of care in day care services for people with dementia

Campbell et al. (2000) state in their framework for quality of care that effectiveness of care is the extent to which the provided care delivers it intended outcomes or results in a desired process. This can in turn be measured based on outcomes such as measures of health status. The Norwegian Dementia Plans state that day care services for people with dementia should provide activities, physical, social, cultural and spiritual, provide stimulation, meaningful days and good experiences (Minsitry of Health and Care Services, 2007, 2015). These stated goals for day care services in Norway can be a considered a good basis for discussing quality of care, as these tell us something of the expectations to day care services. I will therefore in the subsequent discussion of quality of care use the provision of activities, stimulation, and good experiences as important components of care. I will further use the findings from my studies related to these components as outcomes for quality of care, in line with Campbell et al. (2000) idea of health measures as outcome measures. The provision of meaningful days will not be discussed as there is little data collected on this in this project and as such is beyond the scope of the current PhD. Beyond just being relevant as goals laid out in the Norwegian Dementia Plans, the intended care at day care services, such as physical activity, have individual value and benefits.

Firstly, the provision of physical activities is important to ensure the promotion of health among people with dementia. Our findings from paper 1 show that participants at FDCs have a higher level of physical activity than participants at regular day care services. Further, participants at FDCs are more active the days they are at the service compared to the days they are not at the service. As mentioned in the background, research have found that people with dementia are more susceptible to physical decline, more sedentary, and less physically active than other people in the same age group (Auyeung et al., 2008; Burns et al., 2008; Hartman et al., 2018; Watts, Vidoni, Loskutova, Johnson, & Burns, 2013). There are several positive effects of physical activity, both in general and more specifically for people with dementia. The WHO recommends physical activity for older people in order to maintain physical function and health (World Health Organization, 2010). The Norwegian guidelines also highlights the importance of regular physical activity as important in maintaining health and function in older people (Lexell et al., 2008). The findings from paper 1 suggests that attending FDCs can aid the participants in following these global and national recommendations. In addition, physical activity has been found to improve physical function and performance of basic activities of daily living (Blankevoort et al., 2010; Telenius et al., 2015), reduce levels of depression (de Souto Barreto et al., 2015) and have a positive effect on cognition (Groot et al., 2016) for people with dementia. In addition, there are some evidence that physical activity can influence well-being in people with dementia (Brett et al., 2016). Further, breaking up or preventing sedentary behaviour is important in maintaining physical function in older people (Fujita, Fujiwara, Chaves, Motohashi, & Shinkai, 2006; Shimada et al., 2010). In addition, people with dementia themselves seek to be physically active, seeing it as a way to seek control of and adjusting to dementia (Bjørkløf et al., 2019). Further, physical activity can be linked to quality of life. In Lawton's framework the importance of behavioural competencies is stressed, for example in relation to health and functional health (Lawton, 1991). Lawton (1994) also stresses functional competence, for example activities of daily life, as important for the quality of life for people with dementia. Based on previous research establishing a link between physical activity and health and physical function, there could also be said to be a link between physical activity and quality of life.

There are also positive effects connected with social activities, and our findings from Paper 2 show that the participants at FDCs experience social interaction and that such social interaction is associated with emotional well-being. The provision of social activities can be seen as important in health promotion for people with dementia, as they can experience changes in social behaviour and social exclusion (World Health Organization, 2012). Helliwell and Putnam (2004) coined the term the social context of well-being. They found that social capital, such as friendship and work-place ties, were linked with subjective well-being in the general populace. As such the social interaction and ties created at day care services have the potential to influence the participants subjective well-being. Social activities could create feelings of social support. Social support have found to be linked to mood and well-being among older community-dwelling adults (Golden et al., 2009), and conversely, lack of social support has been linked to psychological stress (Bøen et al., 2012). Among people with dementia, social interaction has also been linked to positive affect (Jao et al., 2018) and better mood (Beerens et al., 2018). Further, people with dementia report that they appreciate the opportunity to be together and interact with their peers (Eriksen et al., 2016). People with dementia also report that the see the maintaining of social roles and relationships as a coping mechanism to preserve their identity (Bjørkløf et al., 2019). These last to studies highlight people with dementias own desire for social activities and interaction. Finally, social activities have also been linked to improved quality of life for people with dementia. According to a review by Martyr et al. (2018) factors related to social engagement and relationships were associated with higher QoL. Similar findings, showing the link between the quality of relationships and quality of life, have been reported in other studies (Moyle et al., 2011; O'Rourke, Duggleby, Fraser, & Jerke, 2015). Further, Holopainen et al. (2019) found that relationships and social participation improves QoL, while loneliness, a lack of interest and a feeling of not belonging has a detrimental impact on QoL. This could be seen as in line with Lawton's framework for quality of life and his concept of behavioural competencies. One part of the behavioural competencies is social behaviour, encompassing social interaction with others. Lawton (1994) highlight socially appropriate behaviour as an important aspect of this for people with dementia. Through providing social activities, day care services could influence this aspect of quality of life as this could give a feeling of belonging, opportunities for building relationships, and foster social participation. Our findings in paper 3 show for example that the number of participants is associated with quality of life for those attending FDCs.

The provision of good experiences is also an important aspect as these can be connected with feelings of subjective well-being and overall quality of life. Our findings from paper 2 show that participants at FDCs have more emotional well-being while at the service than those attending Good experiences could be seen as experiencing positive emotions, and positive emotions are an important part of subjective well-being (Carlquist, 2015), as this affective part of subjective well-being is related to emotions and how one is feeling, for example happiness (Linton et al., 2016). As stated previously, this affective part of subjective well-being is here termed emotional well-being. Based on this linkage the provision of good experiences could potentially influence the subjective well-being of the participants at day care services for people with dementia. Our findings from paper 2 show that participants at FDCs have more emotional well-being while at the service than those attending regular day care. Within-group analyses from paper 3 show that participants at FDCs have high subjective well-being and that this remain stable across the 12-month period. Further, just as physical and social activities can be linked to quality of life, so can also good experiences. Good experiences, seen as positive emotions, can be linked to Lawton's framework via the domain of psychological well-being. Psychological well-being, Lawton (1991) states, is an important aspect of quality of life and can be measured, for example by looking at the positive or negative emotion experienced by a person. Therefore, providing participants of day care services with good experiences could influence their quality of life. Here our findings are not so clear, as we in Paper 3 found a larger, but clinically insignificant decrease, in QoL after 12 months among participants at FDCs compared to those at regular day care. Despite the decrease, participants at FDCs had high quality of life throughout the 12-month period.

The findings related to physical and social activities and how the FDCs might influence this will be discussed further in section 8.2, while findings related to good experiences and how FDCs might provide these will be discussed further in section 8.3.

8.2 Farm-based day care for people with dementia and the provision of activities and stimulation

One goal for day care services for people with dementia in Norway is the provision of activities and stimulation (Minsitry of Health and Care Services, 2007). The activities should be physical, social, cultural and/or spiritual (Minsitry of Health and Care Services, 2015). Based on the data collected in the FDC-project and presented in this thesis I will discuss physical and social activities, but not cultural and spiritual activities as I have little or no data available on those activities. Activities and stimulation will be discussed as one, as it can be argued that it is through activities that day care services provide stimulation. I will thus briefly discuss stimulation related to or derived from these two activities, while the potential benefits of stimulation derived from the exposure to nature will be discussed in the section on good experiences.

8.2.1 Physical activities

As mentioned above, one important component of day care services for people with dementia, is the provision of physical activities. The findings from paper 1 show that participants at FDCs are more physically active than participants at regular day care services. Additionally, and perhaps more importantly, the findings show that the participants at FDCs are more physically active the days they are at the FDCs compared with when they are not at the FDCs. While attending FDCs they are less sedentary, more physically active and walk more than the days they are not at the FDCs. These findings indicate that FDCs both provide physical activity and in an effective manner. They are also in line with previous research on care farms as a setting for people with dementia, which also found increased physical activity among participants at farm-based dementia care services (de Boer, Hamers, Zwakhalen, Tan, Beerens, et al., 2017; de Bruin et al., 2009; Ellingsen-Dalskau, de Boer & Pedersen, in press). Our findings indicate that FDCs can help maintain or improve physical function to a larger extent than regular day care services. While de Bruin et al. (2011) found no differences in functional performance over time between regular day care and FDCs, other research have found a link between physical activities and improved physical function in people with dementia in general (Blankevoort et al., 2010). Additionally, our within-group analyses of those attending FDCs indicate that being at the FDCs provided a significant increase physical activity compared to not being at the

FDCs. This implies that the FDCs as a service promotes physical activity for its attendees, regardless of comparison to other day care services for people with dementia. Attending FDCs can potentially aid the participants in reaching the recommended levels of physical activity. So how can FDCs influence and promote physical activity?

The observed higher levels of physical activity at FDCs, both compared to regular day care and compared to days not at the service, can have several potential explanations. In this discussion I will highlight the influence of the farm setting and the role of the service provider at FDCs. The farm setting contains several factors that could potentially promote physical activity. One is that the farm setting invites to physical activity, for example through providing space for such activities and by containing tasks that necessitates physical activity. De Bruin et al. (2017) argues that the activities at the FDCs are naturally incorporated into the environment and care provisions, and can as such be said to be continuously present. Ibsen et al. (2018) noted a variety of different activities and resources available to FDCs in Norway. Among the activities provided at FDCs were working with plants, tending and harvesting crops, walking in the surrounding areas, wood-working and feeding and caring for animals. Such activities took place in various locals, such as the barn, the garden, the farm yard, in greenhouses, or in the surrounding uncultivated areas (e.g. forests and trails) (Ibsen et al., 2018). Differences in activities between regular day care services and FDCs was also found by de Bruin et al. (2009). They observed that activities at FDCs were more often outdoor or in another building compared to regular day care. In addition, the activities at the FDCs often involved standing or walking, while activities at regular day care often involved sitting.

The activities at FDCs have also been found to perceived as useful and meaningful by the participants themselves (Sudmann & Børsheim, 2017). This might lead the participants to increase their engagement in the activities and as a consequence increase the intensity with which they perform the activities. The potential of farm setting to invite to physical activity has also been noted by others. Hassink, De Bruin, Berget, and Elings (2017) found that working with animals at care farms implicitly stimulated to physical activity among participants. Most of the FDCs in Norway have some animals present, albeit in varying degrees (Ibsen et al., 2018), which could help stimulate to physical activity.

More in general, Markevych et al. (2017) argues that green spaces commonly encourage physical activity through different factors, such as providing a safe setting for physical activity, providing an attractive setting and by providing an accessible setting for physical activity. All these factors can be said to be applicable to the farm setting. Not only can the farm itself be viewed as a safe setting, but the service providers themselves, along with the other participants, can also contribute to a feeling of safety. The farm setting can be viewed as an attractive setting for physical activity due to the potential draw of the nature elements present. Lastly, the farm setting can provide accessibility to physical activity both through providing activities integrated in the setting that necessitates physical activity, e.g. farm activities, but also through having available space, for example to take a walk in the adjoining uncultivated areas. All these aspects of the farm as setting with integrated natural elements can potentially aid in promoting physical activity among the participants.

Another important explanation is the role of the service provider. Hassink, Elings, Zweekhorst, van den Nieuwenhuizen, and Smit (2010) noted that the personal and involved attitude of the farmer was considered a defining characteristic of care farms in general. In the case of care farms, not only do the service provider have the farm setting with its activities and resources, but they often have a knowhow of farm life that allows for the inclusion of said resources and activities into the service. Firstly, the service provider can act as a facilitator for activities. Sudmann and Børsheim (2017) highlights this and notes the service providers roles as “work leader” and “host”. Secondly, in addition to facilitating, the service provider can also provide guidance and support for the participants and Steigen et al. (2016) highlights the farmer as a significant other for the participants. This support has been highlighted in other care farm settings. Pedersen et al. (2012) found that participants with clinical depression attending care farms reported that the farmer gave them task that they could accomplish, leading them to feeling increased independence and self-confidence. In a farm-based prevocational program the participants reported that the service providers gave guidance, positive feedback and encouraged them to try on new activities Ellingsen-Dalskau et al. (2016). The facilitation, guidance and support given by the service provider could potentially promote physical activity through for example creating opportunities for the participants to experience coping. Low self-efficacy for going outdoors have for example been linked with restricting activities, leading to decreased physical function (Shimada et al., 2010). Through facilitation, guidance and support the service provider could potentially alleviate such feelings and facilitate physical activity.

Meshing with this, the service provider could use their knowledge to facilitate and tailor the activities more to the individual. Activities at FDCs have been noted to be more often aimed at the individuals, while activities at regular day care services have been more geared to towards including the entire group de Bruin et al. (2009). Individualized activities have been noted as a facilitator of physical activity for people with dementia (van Alphen, Hortobagyi, & van Heuvelen, 2016), meaning that by tailoring the activities to the individual, the service providers could be facilitating and/or promoting physical activity among the participants. It is important to note that the service provider can inhabit such these roles at regular day care services too. However, while a recent study noted that while there was a focus on tailoring activities to the individual at regular day care services, there was also a lack of knowledge on how to translate this focus and knowledge about the participants into individually tailored and structured meaningful activities for the participants (Strandenæs et al., 2019). The same study also noted that there was a potential to include participants more in the ongoing activities at regular day care services. Myren et al. (2017) came to similar conclusions as they observed that participants at FDCs were more included in the in the daily activities at the service, e.g. preparing meals, while participants at regular day care services were more passive in the daily activities. This difference in involvement of the participants can help explain the difference observed between the services.

With regards to stimulation physical activity can be said to be stimulating in and of itself, but the farm setting can be said to provide added stimuli. While the actigraphy gives no information on where the participants were physically active, Paper 2 show that participants at FDCs were outdoors in 42,5% of the observations and doing farm or animal related activities in 17.3% of the observations. This suggests that parts of the physical activity take place outdoors and in relation to farm and animal activity. Therefore, the participants can potentially get stimuli both from the physical activity itself, and from the nature aspects of the farm setting as the activities are integrated into the setting. The potential benefits of exposure to nature will be discussed later in the discussion under the section on good experiences.

To summarize, our findings indicate that attending FDCs can potentially facilitate adherence to global and national recommendations and improve physical function and health. It therefore seems as though FDCs can provide quality physical activities and stimulation for their participants and also might provide higher levels of physical activity tan regular day care services.

8.2.2 Social activities

The provision of social activities is also an important aspect of day care services for people with dementia and is highlighted in the Norwegian Dementia Plan (Minsitry of Health and Care Services, 2015). The observational data from paper 2 show that there are social activities in the form of social interactions at day care services for people with dementia. Only 18.8 % of the observations at FDCs did not include any social interactions, while 37.2 % of the observations at regular day care services did not include any social interactions. For the remaining observations the participants had some kind of social interaction, either with someone else or with two or more. Ellingsen-Dalskau et al. (in press), which paper 2 builds off of, found that there was significantly more social interaction at the FDCs compared to regular day care. Previous research has also noted the social aspect of the farm as a care setting for people with dementia, with care farms being noted as promoting social interaction among the participants (de Boer, Hamers, Zwakhalen, Tan, Beerens, et al., 2017; de Bruin et al., 2019; Sudmann & Børsheim, 2017), providing a sense of fellowship (Ibsen & Eriksen, in press) and as stimulating social participation (de Bruin et al., 2015). So how can FDCs promote social activities, such as social interaction? One potential pathway can be the farm setting with its intrinsic link to nature and green space. Markevych et al. (2017) highlight green space as a setting for human contact and as a space which can increase social cohesion, that is the feeling of knowing and respecting each other, that people pose no danger and may help if needed. Green spaces are seemingly a setting inviting to social interaction. While the link between green space and social interaction and cohesion has been shown in research, the exact mechanisms behind it are not fully known (Markevych et al., 2017). Sudmann and Børsheim (2017) argued that the FDCs setting is an environment where the participants enter a different social and material setting together. The care farms create real-life situations for real-life community and interaction (Sudmann & Børsheim, 2017). As such FDCs can be viewed as facilitating social interaction between the participants through the activities that are naturally present at a farm.

Another pathway for promoting social activities can be the service providers and their facilitation of social activities. De Bruin et al. (2019) found that staff facilitated and contributed to social interaction with and between participants at nature-based day care services for people with dementia. Ibsen & Eriksen (2020) found that participants included the service provider as an important part of the fellowship at the FDCs, and that they often were perceived as a type of colleague. The service providers role as support and facilitator have been noted in the literature on care farms in general. Elings and Hassink (2008) found for example that participants highlighted the social aspects of care farms and the service providers role in creating a sociable atmosphere and a feeling of community. Ellingsen-Dalskau et al. (2016) found that the service providers offered both social and emotional support for the participants. This is echoed in Pedersen et al. (2016), which highlight the support, including social support, and supervision given by the service providers to the participants. Thus, the service provider has an integral role in the social life of the service and in the facilitation of social interaction.

The findings from paper 2 do not only tell us of the presence of social interaction, they can potentially also tell us something about the quality of the social interactions. The emotional well-being of the participants was higher for all types of social interaction at FDCs compared to regular day care centres. Further, when adjusting for all other factors at the day care services, social interactions were shown to be associated with positive emotional well-being regardless of type of day care service. The more people involved in the social interaction, the more positive emotional well-being. This mirrors findings in paper 3, were we found that the number of participants at the service, a potential proxy for social interaction or support, was positively associated with quality of life. However, it is important to note one potential caveat in the comparison of social activities between the services. The larger decrease in QoL-AD observed among participants of FDCs in Paper 3 seemingly arose from a larger decrease in the social subscale of QoL-AD compared to participants at regular day care services. While this could indicate that attending FDCs influences the social aspects of a person’s life to a lesser degree than attending regular day care services, I would argue that the social subscale of the contains items not readily influenced by day care services, as it contains the following five items “Living Situation”, “Family”, “Marriage”, “Friendship” and “Money”. While some of these might be influenced by attending day care services, for example marriage, others are more difficult to envision being influenced by day care services. The items living situation and money seem particularly out of reach of any potential influence of the day care service. Therefore, it seems likely that any difference between the groups are rooted in aspects of social life that it is unfeasible for day care services to influence.

As with physical activities, social activities can be said to provide stimuli for the participants in and of themselves, but as with physical activity, the setting in which they happen can provide added stimuli. The exposure to nature and nature-related activities together with others might enhance the experience and stimuli for the participants. The potential benefits of exposure to nature in a social context will be discussed later in the discussion under the section on good experiences.

To summarize, our findings show that participants at FDCs experience social interactions and that these interactions are associated with positive mood. Further, number of participants at the service have been shown to be positively associated with quality of life for the participants at FDCs. As such, the findings indicate that FDCs have the potential to provide quality social activities and stimuli for the participants.

8.3 Farm-based day care for people with dementia and the provision of good experiences – well-being and quality of life

Day care services for people with dementia should also provide their participants with good experiences. While the content of good experiences is not elaborated upon in the Dementia Plans, I view it as experiences that provide the participant with positive emotions and a feeling of well-being. Findings from paper 2 and 3 gives an indication on how the participants experience the day care services. In paper 2 we found that participants at FDCs were generally in a positive mood. The participants of FDCs had for a variety of activities and factors more emotional well-being than participants at regular day care services. In addition, adjusting for all factors and activities, attending FDCs were associated with more emotional well-being compared to regular day care services. As such attending FDCs were positively associated with emotional well-being suggesting that the participants had good experiences. Positive emotions are also an important part of subjective well-being (Carlquist, 2015), and as such one might expect good experiences at day care services to have an impact on subjective well-being. In paper 3 we found that the subjective well-being reported by the participants was high and that it remained stable for the entire year, further supporting the findings from paper 2.

However, the matter was not quite as clear with regards to quality of life. Psychological well-being, exemplified by positive emotions, are also an important part of quality of life for people with dementia (Lawton, 1994). In fact, Lawton (1994) highlights engagement in positive activities, the presence of positive affect and absence of negative affect as important dementia specific domains in assessing quality of life. As such we might expect good experiences at FDCs to influence quality of life for the participants. In addition, the previously described physical and social activities could be viewed as influencing the participants behavioural competencies. Physical activity can for example be linked to health and functional health, while social activities can be linked to the social behavioural competency. And while we in paper 3 found that participants at FDCs had high self-reported quality of life, we also found that there was a larger decrease in self-reported quality of life among participants at FDCs compared to participants from regular day care. However, this observed decrease was not clinically significant according to the available literature on QoL-AD (Beerens et al., 2015; Clare et al., 2014; Conde-Sala et al., 2016; Hoe et al., 2009; Selwood et al., 2005). In addition, the participants level of self-reported quality of life remained high, despite the decrease. Given the other findings, why did we not see an increase in quality of life among the participants? Or that they maintained their quality of life score.

As seen in Lawton (1991) quality of life is a complex concept, with many interacting components. It might therefore be that having good experiences might not impact quality of life as a whole. Based on our findings, it seems as though the participants at FDCs have good days, but that having good days might not necessarily translate into increased quality of life. While Lawton (1991) states that psychological well-being could be seen as an ultimate outcome, it is still only one of four domains. This could mean that the good experiences at FDCs might influence the psychological well-being of a person, but this influence might not lead to a change in the overall quality of life of the person. As mentioned in the section on activities at the FDCs, physical and social activities could also impact quality of life through the concept of behavioural competence. The potential influence through both psychological well-being and behavioural competence could have a greater influence than just one of these domains. Again, based on the findings from self-reported quality of life, it seems as though the influence is not great enough to manifest as an influence on quality of life as a whole. Further, it seems as though there is no clear linkage between the setting of the day care service and increased quality of life. There can be several reasons for this. One is that the day care settings in general do not influence quality of life, another is that the differences in care settings and content might not be substantial enough to lead to a clear difference in quality of life. Even though the association with quality of life is unclear, the remaining findings indicate that FDCs do provide their participants with good experiences.

So how can FDCs as a setting provide good experiences for the participants? One avenue is the farm setting with its connection to nature. In paper 3 we found that being outdoors was positively associated with subjective well-being and quality of life. While we did not find the same clear association in Paper 2, the participants had in general a positive emotional well-being while doing activities outside. According to Markevych et al. (2017) one way green space can influence well-being is through restoration, that is in restoring the capacities of people. As described in section on theoretical and empirical framework this thesis uses stress reduction theory (SRT) to look at the effects of being and in a nature setting. According to SRT FDCs could influence the participants through eliciting a generalized affect response to the environment, be it in the form of liking it or disliking it. According to the theory FDCs would be more likely to elicit positive affect as the it contains different natural elements such as vegetations, trees and animals. Such positive affective responses would trigger a restorative process providing a reprieved from stress and negative feelings combined with positive feelings and an experience of liking something (Joye & van den Berg, 2013). Further, SRT focuses on that such responses happen without recognition and processing, meaning that the natural elements of the FDCs might elicit these responses from the participants regardless of cognitive decline. There is also a social aspect to the restoration process (von Lindern, Lymeus, & Hartig, 2017). Participants can help each other feel safe in a nature setting. In addition, they can explore and discover an environment together facilitating the restoration process (von Lindern et al., 2017). In addition to well-being, natural elements have also been linked to quality of life, with Holopainen et al. (2019) noting that the presence of animals was associated with improved quality of life. This means that the presence of animals at the FDCs could have a potential influence on the quality of life of the participants.

Another avenue is the activities provided at the FDCs. Firstly, the wide variety of activities could help the farms provide good experiences. Previous research has noted the variety in activities (Ibsen et al., 2018) and that activities at FDCs are more varied than at regular day care services (de Bruin et al., 2009). Such a variety could lead to less boredom and fatigue among the participants, in that there is a more constant shift between activities compared to a more limited selection. Secondly, the variety of activities provided at FDCs might help facilitate more individually tailored activities as there might be “something for everyone”. The activities at FDCs have been noted to be more individually tailored than regular day care services (de Bruin et al., 2009). The role of the service providers can also be viewed as an important part of the provision of activities and the individual tailoring of activities. The service providers role in facilitating activities has been noted both in FDCs (Sudmann & Børsheim, 2017) and in care farming in general (Ellingsen-Dalskau et al., 2016; Pedersen et al., 2012). There is evidence that such individually tailored activities could lead to good experiences. One review, based purely on randomized controlled trials, found some, if uncertain, evidence that individually tailored activities could impact affect and mood (Möhler, Renom, Renom,

& Meyer, 2018). Another review, with a wider scope, found that individualized social and leisure activities could have a positive impact through improving affect and engagement (Han, Radel, McDowd, & Sabata, 2016). While such individualized activities could also be present at regular day care services, a recent study, mentioned in Ch. 8.2.1, found that staff at regular day care services lacked knowledge on how to translate information on the participants into individualized activities (Strandenæs et al., 2019). As such, the variety of individually tailored activities can help explain the difference in emotional well-being between the participants from FDCs and participants from regular day care services. the variety of the activities offered at FDCs might be important in providing good experiences for the participants.

To summarize, the findings indicate that FDCs could provide good experiences, here defined as positive emotions and well-being, for the participants. For example, observed emotional well-being while at the service was generally positive and was higher for those attending FDCs compared with regular day care. With regards to quality of life there were no clear differences between the services, but the mean quality of life of those attending FDCs remained high throughout the study period.

8.4. Farm-based day care services for people with dementia and quality of care

The preceding discussion give some insights into the care provided for the participants at FDCs. One of the focuses for Campbell et al. (2000) idea of quality of care is clinical care, in this thesis viewed as provided care. As such the minimum is that the care is provided and then the effectiveness of it figures in. Based on the stated goals for day care services from the Norwegian Dementia Plans (Minsitry of Health and Care Services, 2007, 2015), I have discussed the provision of activities, stimulation and good experiences for people attending FDCs. Campbell et al. (2000) state that health measures can be used as quality of care outcomes for the care provided. The findings from paper 1, 2 and 3, using such health measures, indicate that not only do FDCs provide physical and social activities and stimulation together with good experiences, they seemingly provide these to such a degree that they can potentially promote physical health for the participants, promote social interaction and activity, and provide good experiences in the form of well-being.

The FDCs has this potential due to several reasons. Firstly, through the farm setting and the content within, with it both nature and activities naturally integrated in the setting, which can facilitate activities and engender good experiences. Secondly, the service provider can support, facilitate and guide the participants creating opportunities for physical and social activities and good experiences. And lastly, the wide varieties of activities present at FDCs can facilitate individual tailoring and engagement, potentially leading to more activity and enjoyment of the activities.

Therefore, based on the findings and the preceding discussion, FDCs has the potential to provide quality care for people with dementia in accordance with the stated goals of day care services in Norway as presented in the dementia plans.

8.5 Methodological and ethical considerations

In this section I will discuss some of the methodological and ethical challenges encounter throughout this PhD-project. To discuss the methodological considerations I will base myself on Shadish, Cook, and Campbell (2002) ideas on validity and threats to validity. I will use the four principles of ethics highlighted by Beauchamp and Childress (2013), autonomy, non-maleficence, beneficence and justice, to discuss the ethical considerations. I will focus the discussions on what I perceive to be the most important methodological and ethical considerations.

8.5.1 Methodological considerations

Shadish et al. (2002) uses the term validity to refer to the approximate truth of an inference or knowledge claim. In their validity typology they propose that validity comprises four different types: statistical conclusion validity, internal validity, construct validity and external validity (Shadish et al., 2002). According to Shadish et al. (2002) there are threats to all these types of validities, that is reasons why we could be partly or completely wrong about the inferences we make in our research. In the following sections I will present what I perceive to be the most important threats to validity in this PhD-projects for all of the four types of validity.

8.5.1.1 Statistical conclusion validity

According to Shadish et al. (2002) statistical conclusion validity deals with the validity of the inferences about the correlation/covariation between an exposure and the outcome. In this PhD, the exposure would be FDCs while the outcomes are the various measures. In this work there can be said to be several issues regarding the statistical conclusion validity. In my opinion, the two primary ones are: the statistical power and the use of repeated tests.

Statistical Power

In this project no power calculations were conducted. This was because the number of persons attending FDCs in Norway is relatively small compared to regular day care services and we aimed to include as many of these as possible. Thus, since the services are small potentially waiting for enough participants to satisfy a power calculation was deemed unfeasible. In addition, no primary outcome was designated and doing individual power calculations for each measure was also deemed unfeasible. This means that we cannot be certain that the we had the sufficient number of participants for our analyses.

However, based on the rule of thumbs for sample sizes were power calculations are not available, our data meets the requirements. VanVoorhis and Morgan (2007) recommend 30 per cell for group comparisons and a sample of 50 or more for relationships, such as regression. For our within-group analyses the increased number of observations per participants meant that they also adhere to these rules of thumbs.

Although we did not do a power calculation, we took certain steps to retain statistical power. As there were some missing values in the longitudinal data, we elected to impute the missing values under the assumption that they were missing at random. The imputation was conducted based on the criteria that the measure the value was missing from had to have less than 50% missing values in total. If more than 50% was missing, it would not be imputed. This means that we were able through the imputation to retain some power, although the imputed values might not accurately reflect what the respondent would have actually answered. While that is a drawback of the imputation process, we deemed imputation as necessary process to minimize data loss.

Repeated testing

In the process of analyses, we conducted some repeated testing. As this increases the risk of type one errors, that is detecting a relationship that is not present, one could potentially conduct Bonferroni’s correction or similar processes to counteract this. However, we did just a small number of such tests and the outcomes were often correlated with each other. The different levels of physical activity could for example be seen as correlated with each other and the subscales of QoL-AD were correlated with the main scale. We therefore elected not to do any form of adjustments or corrections in the analyses. This means that we cannot discount any potential effects of repeated testing, type one errors, in our findings, but we regard the risk of this as very low.

8.5.1.2 Internal validity

Internal validity deals with the validity of the inference about whether an observed covariation between two variables is a causal one (Shadish et al., 2002). There are several issues regarding the internal validity of this PhD-project and the primary ones are ambiguous temporal precedence, selection-bias and drop-out.

Ambiguous temporal precedence

In this PhD-project there are no data for the participants from before they started day care and paper 1 and 2 is based on cross-sectional data. This means that we cannot establish causal links between attending FDCs and the outcomes, but rather establish associations. Due to how the day care services in Norway are organized and due to time and logistical constraints, the inclusion of a pre-test in this project was deemed unfeasible. To get pre-test data one would have to include only participants new to day care services and this would have expanded the time frame beyond the scope of this project. Further, the idea of withholding day care service until a pre-test had been conducted was considered unethical as it would be depriving the person with dementia of a care service for a time.

Selection bias

Based on our inclusion criteria and recruitment procedure we introduced some selection bias. By limiting the participants to those who had regular contact with next-of-kin we excluded those that attended FDCs but did not have regular contact with next-of-kin. Based on an estimated 240 potential dyads, 71 participants were excluded due to not fulfilling the inclusion criteria. Out of the 169 dyads eligible for recruitment, 62 declined to participate in this study. Due to ethical considerations regarding participants right to data protection, no information was gathered on about those who were either not eligible or declined to participate. Therefore, we do not know whether those included in the study are differ from those who were not included or declined participation, or if this might have impacted the findings.

Further, we used intermediaries to recruit for us, meaning that they could potentially have used other criteria than just the inclusion criteria when they recruited the participants. The recruiters were usually forthright about this, without disclosing participants identity or other identifying information. Therefore, we could make an overview showing that out of the 169 eligible for recruitment, just 13 were not approached by the recruiter. This was generally due to health or family-issues. It is unlikely that by not approaching these any significant bias was introduced.

Another source of selection bias was the inclusion of data from external data sources in order to provide comparison groups, data from the ECOD-study and the actigraphy-data from people with dementia attending regular day care services. These had other inclusion criteria, meaning that there might be dissimilarities between the groups influencing the analyses. For example, the ECOD study only included those of 65 years or above, giving them a higher mean age than the FDC-group who had no age-related inclusion criteria. To account for this and other differences we included variables were the groups were dissimilar to adjust for these in our analyses. We cannot discount that an underlying difference between the groups might have influenced the findings, but we believe that we have taken measures to minimize the risk.

While randomization is a common route to avoid or minimize selection bias (Shadish et al., 2002), this route was not available to us. First of all, the comparison data used in this PhD-project was gathered before the FDC-project. Also, in Norway, there are few municipalities that have both regular day care and FDC, meaning that there are would be few opportunities for randomization. Making participants attend day care services in other municipalities, potentially far from their home, would have put undue strain on the participant. Lastly, randomization would have not been in line with the current focus on person-cantered dementia care.

Drop-out

Throughout the longitudinal study a number of participants dropped out. At baseline there were 94 dyads, at six months 65 dyads remained, and at 12 months there were 45 dyads remaining. The primary reason for dropping out were that they no longer attended FDCs. This was often due to a change in care level such as moving to a nursing home as a result of functional decline. A high number of drop-out was not unexpected given the progressive nature of dementia. We are unaware of any systematic differences between those who completed and those who dropped out and can therefore not discount that this could have impacted the findings.

8.5.1.3 Construct validity

Construct validity is about the inference from sampling particular of the study to the higher-order constructs they represent (Shadish et al., 2002). In other words, whether we measure what we say we measure. In this PhD-project several of the outcomes are based on constructs with disputed definitions. Neither quality of life, nor well-being has one decided upon definition for example. However, the measure used for measuring quality of life, QoL-AD, has direct links to Lawton's conceptualisation of quality of life for people with dementia indicating some type of congruence between the measure and that concept of quality of life. Lawton (1997) argued that no single measure could encompass quality of life, and that measures from different domains should be included. While QoL-AD is a single measure, factor analyses of the items indicate that it covers multiple domains (Gomez-Gallego, Gomez-Garcia, & Ato-Garcia, 2014; Revell et al., 2009). Revell et al. (2009) for example, found a physical, a social and a psychological subscale. As such it could be said to satisify Lawton's stipulation of the need to use many different domains to measure quality of life. For the measure for subjective well-being, WHO-5, the developers explicitly stated it as a measure of subjective well-being, signalling adherence to the concept. To signal the importance of positive well-being, each of the items is phrased in a positive manner (Topp et al., 2015). Further, analyses have confirmed that the five items constitute a unidimensional scale. Each of the items add unique information regarding the level of well-being of the respondents (Topp et al., 2015).

We have also used a number of proxy measures in this project. In the longitudinal study next-of-kin makes assessments on behalf of the participants. Examples of this were QoL-AD and NPI. This means that were measures where constructs were assessed as viewed by someone else. For NPI for example, this means that we get the intensity, frequency and burden as perceived by the next-of-kin, not as perceived by the person with dementia, or as perceived by other people. We included the use of proxy measures to ensure and to complement self-reported data. For example, were both proxy and self-reported data gathered on depression. In analyses, the self-reported measure was generally chosen over proxy-reported measures.

Further, in the observational study (Paper 2), the observing researchers rated the participants mood based on perceived signs of either negative, neutral or positive mood. The challenge here is although one can assume what mood a person has based on different cues, the observer cannot know for certain if the persons mood is really the same as rated. In addition, in the development of the observational tool, mood was seen as only one aspect, together with agitation, of emotional well-being (de Boer, Beerens, et al., 2016). In Paper 2 mood alone is used as an indication of emotional well-being. While this could be seen as a departure from how the construct emotional well-being was originally operationalized, this was based on the fact that no agitation had been observed among the participants. We therefore believe that using mood alone as an indicator for emotional well-being was an appropriate course of action given the circumstances.

8.5.1.4 External validity

External validity is the validity of the inferences of whether the relationship between the variables hold over variations in persons, settings, treatment variables and measurements variables (Shadish et al., 2002). For this project the primary question is the generalizability of the findings. Would other people with dementia would experience the same if they started at FDCs? This is what Shadish et al. (2002) calls the threat to external validity of the interaction of causal relationship with units, meaning that an effect found with certain kinds of units might not hold if other kinds of units had been studied.

So, would the findings be applicable to other people with dementia if they started at FDCs? We do not know how representative our participant is for the general population of people with dementia. Just as the number of people with dementia in Norway is uncertain, so are the characteristics of those with dementia. What we do know is that there is a large variety within the participants from FDCs, see Ibsen, Kirkevold, Patil, and Eriksen (2019), potentially indicating that they could be mirroring the variety in the general population of people with dementia. One could also potentially compare with all the participants in the ECOD-study, including those not attending day care services, to get a picture of how participants at FDCs compare to those. Based on the number presented in Ibsen et al. (2019) for those attending FDCs and Rokstad et al. (2018) for those in the ECOD-study, the participants at FDCs seem to have a lower mean age (75.8 vs. 81.5) and have a larger proportion of male participants (61.7% vs 34.6%). However, the ECOD-study did not recruit people under the age of 65 years, which could impact the mean age. Further, with a higher mean age, the increased average life span of women might impact the distribution of genders. In general, it would seem like there are a lot of overlap between the participants at FDCs and the all the participants on a wide range of variables, but a proper comparison between the groups would be predicated upon more substantial analyses including all the participants. Based on the available data it is difficult to quantify how representative our sample is, but I see no substantial evidence to suggest that the participants at FDCs are a special group or that they differ in a significant way from other people with dementia.

8.5.2 Ethical considerations

The PhD-project was conducted in accordance with the Helsinki-declaration. It emphasizes the importance of promoting and safeguarding the health, well-being and rights of the participants (World Medical Association, 2013). It further highlights the importance of taking into consideration the risks and burdens of participating in research, the protection of vulnerable groups, and the importance of privacy, confidentiality and informed consent (World Medical Association, 2013). As mentioned in the introduction to this section I will discuss the most important ethical considerations in this PhD-project using the four principles noted by Beauchamp and Childress (2013). These are respect for autonomy (the rights of the individual and their right to determine their lives), beneficence (a commitment to do actions that are of benefit), non-maleficence (do no harm) and justice (to act fairly when dealing with competing claims for rights or resources) (Beauchamp & Childress, 2013). Using these principles as a framework I will discuss the most important consideration concerning each principle.

8.5.2.1 Respect for autonomy

The principle of autonomy is particularly relevant to two aspects of the PhD-project, the capacity to consent and potential gate keepers. These two are both directly related to the rights of the individual and the right of the individual to make their own choices regarding their own lives.

The necessity of informed consent and the capacity to consent is an important aspect of dementia research (Sherratt, Soteriou, & Evans, 2007). Substantial attention was given to this in the FDC-project as we wanted the participants to be able to make informed choices and to respect their autonomy as human beings. The process of consenting to participation in the FDC-project happened in two stages. First, the intermediary recruiter informed, both orally and in writing, potential participants about the project and asked whether they would like to participate. If they expressed interest in participating, they were asked to give written consent to being approached by a researcher in the project. During this process, the service provider or municipal care staff, also assessed the participants capacity for consent based on the guidelines given by the project. It was decided that they would do it based on their prolonged contact with and knowledge of the participants. If they found that the potential participants did not have capacity to consent, they would confer with the next-of-kin. If they together concluded that participation would be in the interest of the person with dementia, next-of-kin could consent in their place. Secondly, at the start of the first visit from the researchers, participants were informed orally and in written form about the project. They were also informed about their rights, such as the right to withdraw at any time, and asked to provide written consent. In cases were the person with dementia was assumed to not have the capacity to give consent, three cases in total, next-of-kin could provide consent in their place. However, regardless of any consent and consent by proxy, if the person with dementia expressed that they did not want to take part in the research project then this took precedence. This was also practiced throughout the data collection period regardless of any consent given at the project start, if the person with dementia did not assent to data collection or expressed a desire to stop their participation, the researchers would consider this as withdrawing from the study and stop.

Another consideration regarding autonomy is the presence of gatekeepers. These are people who are in a position to facilitate or block a researcher's access to potential research participants (Sherratt et al., 2007). Because we used intermediaries to recruit for us, there were the potential for such gatekeepers to appear. Based on the previously mentioned overview, 13 potential participants were not approached by the recruiters due to different circumstances. While it can be argued that their right to determine for themselves whether they would like to participate in the research project or not, it could also be argued that we tried to shelter them from any undue burden. The reasons for not approaching them was often related to health and family-issues, and we did not want to add to that burden. This could be viewed as a case of conflicting choices between the principles of autonomy and non-maleficence. In the end we decided to err on the side of caution and weighted the principle of non-maleficence higher and trusted the judgment of the intermediaries that recruited for us. It is also possible that one or the other in the dyads might also have acted as gatekeepers, for example by withholding information about the possibility to participate in the project from one another. But based on the information we have available this is difficult to gauge.

8.5.2.2. Beneficence

In our research we aimed at following the principles of beneficence by investigating a care services to the betterment of the care services and their participants. For the individual participants this gave them an opportunity to share their experiences and potentially influence the service provided for them. On the other side, it could be argued that the participants themselves might not experience any benefits from participating in the research as they might not even be at a day care service anymore when the findings are published. As such the beneficence could be said to be more present for people with dementia as a group, more than the individual participants themselves. With this in mind it was important to ensure that we attempted to minimize the potential burden on the participants and attempt to facilitate their participation to the best of our abilities. The most important measures are discussed below under Non-maleficence

8.5.2.3 Non-maleficence

Participating in a research study can be a burden for the participants and we took steps in an attempt to potentially lessen these. This is especially important in research as people with dementia could be considered a vulnerable population. Vulnerable populations are groups of people who can be harmed, manipulated, coerced or deceived by researchers because of their diminished competence, powerlessness, or disadvantaged status (Sutton, Erlen, Glad, & Siminoff, 2003). To diminish any potential burden, we started by piloting our longitudinal study to ensure that the format was feasible and acceptable. Based on these experiences we decided that the data collection should take the form of parallel interviews, with one researcher interviewing the person with dementia and the other interviewing next-of-kin. Being interviewed apart could potentially make some participants unsecure as they were not together. At the same time this take less of the participants time, helped ensure that each of the participants in the dyad were given equal and adequate attention, and helped give them the opportunity to speak freely. To create a safe atmosphere and to make it easier for the participants, they chose were to conduct the data collection, often in their own home. Further, we started each data collection session all together so as to become more familiar with each other or following-up on what had happened since the last time we were there.

In conjunction with longitudinal data collection we also recruited a subsample to wear actigraphs to measure their physical activity (Paper 1). Having to wear an actigraph could potentially have been perceived as a burden by participants as they might view it as an irritant, feel that it’s in the way, forget why they are wearing it or believe that it is recording more than it actually is. In order to avoid this as much as possible we took great care to properly introduce the actigraph to both the participant and next-of-kin. We gave an oral presentation of the study and the device, how it worked and what it recorded. At the same time, we provided the participant with a written overview of both the actigraph and the study and gave our contact information in case they had any problems. As the actigraph only measured level of physical activity, and not type of activity, location or biometrics, we considered it to be a non-invasive measure to use.

We also collected observational data of the participants while they attended day care services (Paper 2). Such observation could have been perceived by the participants as obtrusive or burdensome. To alleviate any potential burden the observing researchers therefore greeted the participants as they arrived and participated in the beginning of the morning meals so as to be as unobtrusive as possible. These measures hopefully created some familiarity with the observer and lessened any potential burden of their presence and observation.

8.5.2.4 Justice

For this PhD-project, I believe the most important aspect of the principle of justice, with regards to the research ethics, must be the idea of fair treatment of all participants. As day care services for people with dementia is a service meant to be offered in all municipalities, it is important to include and cover as much of Norway as possible. In Norway FDCs, although few, are present in all parts of the country. Some lie in more central areas, while other lie in more rural areas. This often leads to some FDCs being more readily accessible than others, and the same goes for the participants. While this could further lead to an increase focus on the FDCs and participants that are more centrally located, we had in the FDC-project the opportunity to give equal focus to both participants in more central areas and in more rural areas. This meant that we met with the participants personally in conjunction with data collection whether it was a one-hour trip or a one-day trip, or more. As such the care and attention given during data collection did not depend on where one lived or ease of access, ensuring that in this regard they were given equal and fair treatment.

9.0 Conclusions and implications

In this section I will provide a summary of the findings in this thesis and draw a conclusion on the basis of these. I will also attempt to provide some implications for future research and some implications for practice.

9.1. Summary of the findings and conclusion

The findings in this thesis show that participants at FDCs have higher levels of physical activity than the participants from regular day care. In addition, the participants at FDCs were more active the days they were at the farm, compared with the days they were not at the farm. This manifested itself as less sedentary behaviour, more light and moderate activity and more steps taken. This indicates that FDCs could provide quality care through the provision of physical activities.

The findings also show that participants at day care services for people with dementia have high emotional well-being in general. Compared to regular day care services participants at FDCs had higher emotional well-being for the activities sitting, eating and drinking and reading, and for being engaged in the activity, sedentary activity, being indoors and for all types of social interaction. Further analyses adjusting for all factors showed that attending FDCs were associated with higher emotional well-being compared to regular day care services. In addition, the factor social interaction, and the activities exercise and dancing, and quiz, music and spiritual activities, were associated with emotional well-being regardless of day care service type. These findings indicate that FDCs can provide quality care through providing social activities and good experiences. They further indicate that FDCs can potentially provide better opportunities for good experiences compared to regular day care services.

Lastly, the findings also showed that participants at FDCs had a larger, but clinically insignificant, decrease in quality of life after 12 months compared with regular day care services. Further analyses indicated that changes in the social domain was the main contributor to the differences between the two groups. Within-analyses of the FDC-group showed that their subjective well-being remained stable throughout the 12-month period. They further showed that the service-related factors time spent outdoors, and number of participants was associated with quality of life, while time spent outdoors were associated with subjective well-being. These findings indicate that there is no clear difference between the two types of day care service with regards to quality of life. The findings also indicate that while FDCs might not impact quality of life, participants subjective well-being remain stable potentially indicating that the FDCs provide good experiences for their participants.

Based on these findings FDCs can provide quality care for its participants through the provision of physical and social activities, and the provision of good experiences. The findings indicate that the quality of care at FDCs are equal to those at regular day care services. They also indicate that for physical activity and good experiences the FDCs can potentially provide better quality of care than regular day care services.

9.2. Implications for future research

The research presented in this thesis give some implications for future research. Firstly, research should be conducted on disentangling how FDCs can promote physical activity among its participants and which activities are associated with increased physical activity. The activity data gathered only tell us that physical activity took place, not where and what. It would therefore be useful to explore this further.

Secondly, future research should further investigate the association between FDCs and emotional well-being. Even controlling for all the different observed aspects, we found that attending FDCs was associated with emotional well-being, suggesting some underlying mechanism not covered by the data collected.

Thirdly, future research should investigate how day care services can influence quality of life. In our research we found unclear differences between the day care services and future research should also investigate the feasibility of a single, albeit complex, interventions ability to influence global measures of quality of life.

Lastly, future research could look into how knowledge, content and activities can be transferred between different type of day care services. For example, activities that promote physical activity. This could potentially both aid in the provision of care and also create a diversity aiding in the provision of person-centred care.

9.3. Implications for practice

The findings presented in this thesis have some implications for practice. First of all, the differences between the different day care services might highlight areas of improvement. For example, can the difference in physical activity or emotional well-being indicate that there is untapped potential in the participants and that the day care services could implement measures realize this potential.

Secondly, the findings highlight the importance of social interaction with regards to the well-being of the participants. This association between social interaction and wellbeing was seen in both types of day care and a focus on facilitating and inviting to social interactions could as such help promote the well-being of the participants.

Thirdly, the findings indicate that spending time outdoors is positive for both for the quality of life of the participants and their subjective well-being. As the findings indicate that participants at FDCs are to a much larger extent outdoors than those at regular day care services, FDCs could benefit from continuing their implementation of this, while regular day care services could see if this could be implemented in their service.

Lastly, the differences between the services indicate that they could potentially learn from each other. Therefore, it could be to the benefit of both the services and the participants if avenues of interaction and cooperation were established between the different types of services and service providers.

9.4 Overall conclusion

As mentioned in the introduction (Ch. 1.0) the number of people with dementia are increasing, and there is a growing focus, both globally and nationally, on providing quality care for people with dementia. The findings in this thesis indicate that FDCs are day care services providing quality care in line with the national dementia plans and in accordance with recommendations from the WHO. FDCs can therefore be viewed an important part of the care pathway for people with dementia with the potential to help alleviate the increasing need in our society for such care services. The findings further show they are settings that can promote physical activity, social activity and foster good experiences among their participants. In short, they have the potential to promote health and well-being among people with dementia.

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11. Appendix

11.1 Measures for the participants with dementia in the FDC-project and ECOD

Table 11.1: Measures for the participants with dementia in the FDC-project and ECOD

Farm Based Dementia Care	ECOD
Demographic and background information	Demographic and background information
Prescribed medication	Prescribed medication
Resource Utilization in Dementia (RUD - Part 1)	Resource Utilization in Dementia (RUD Part 1)
Oslo Social Support Scale (OSS3)	
WHO-5 Well-being Index	
General Medical Health Rating (GMHR)	General Medical Health rating (GMHR)
Montreal Cognitive Assessment Scale (MoCA)	
Quality of Life – Alzheimer's Disease (QoL-AD)	Quality of Life – Alzheimer's Disease (QoL-AD)
Health Status - VAS	Health Status - VAS
	EQ-5D
Montgomery and Aasberg Depression Rating Scale (MADRS)	Montgomery and Aasberg Depression Rating Scale MADRS
Locus of Control	Locus of Control
Rating Anxiety in Dementia – Norwegian Version (RAID-N)	
Timed Up and Go-test (TUG)	
REED-scale (Anosognosia)	REED-scale (Anosognosia)
	Geriatric reading test
	MMSE-NR (Norwegian Revised Mini-Mental State Examination)
	CERAD 10-word test
	TMT-A (Trail making-test)
	Clock drawing
Neuropsychiatric Inventory (NPI)	Neuropsychiatric Inventory – Short (NPI-Q)
The Cornell Scale for Depression in Dementia (CSDD)	The Cornell Scale for Depression in Dementia (CSDD)
Personal Activities of Daily Life (P-ADL, also known as P-SMS)	P-SMS (Also known as Personal Activities of Daily Life, P-ADL)
Instrumental Activities of Daily Life (I-ADL)	Instrumental Activities of Daily Life (I-ADL)
Quality of Life – Alzheimer's Disease (QoL-AD)	Quality of Life – Alzheimer's Disease (QoL-AD)
	EQ-5D
Clinical Dementia Rating (CDR)	Clinical Dementia Rating (CDR)
Diagnosing of dementia	Diagnosing of dementia
Rating of Anxiety in Dementia (RAID-N)	

11.2 Approval of the FDC-project from the Norwegian Centre for Research Data

Grete Grindal Patil
Institutt for landskapsplanlegging Norges miljø- og biovitenskapelige universitet

1430 ÅS

Vår dato: 31.10.2016 Vår ref: 49799 / 3 / AGH Deres dato: Deres ref:

TILBAKEMELDING PÅ MELDING OM BEHANDLING AV PERSONOPPLYSNINGER

Vi viser til melding om behandling av personopplysninger, mottatt 06.09.2016. Meldingen gjelder prosjektet:

49799	*Demensomsorg på gård - betydning for bruker og pårørende*
Behandlingsansvarlig	*Norges miljø- og biovitenskapelige universitet, ved institusjonens øverste leder*
Daglig ansvarlig	*Grete Grindal Patil*

Personvernombudet har vurdert prosjektet, og finner at behandlingen av personopplysninger vil være regulert av § 7-27 i personopplysningsforskriften. Personvernombudet tilrår at prosjektet gjennomføres.

Personvernombudets tilråding forutsetter at prosjektet gjennomføres i tråd med opplysningene gitt i meldeskjemaet, korrespondanse med ombudet, ombudets kommentarer samt personopplysningsloven og helseregisterloven med forskrifter. Behandlingen av personopplysninger kan settes i gang.

Det gjøres oppmerksom på at det skal gis ny melding dersom behandlingen endres i forhold til de opplysninger som ligger til grunn for personvernombudets vurdering. Endringsmeldinger gis via et eget skjema, http://www.nsd.uib.no/personvern/meldeplikt/skjema.html. Det skal også gis melding etter tre år dersom prosjektet fortsatt pågår. Meldinger skal skje skriftlig til ombudet.

Personvernombudet har lagt ut opplysninger om prosjektet i en offentlig database, http://pvo.nsd.no/prosjekt.

Personvernombudet vil ved prosjektets avslutning, 31.12.2020, rette en henvendelse angående status for behandlingen av personopplysninger.

Dokumentet er elektronisk produsert og godkjent ved NSDs rutiner for elektronisk godkjenning.

Vennlig hilsen

Kjersti Haugstvedt

Agnete Hessevik

Kontaktperson: Agnete Hessevik tlf: 55 58 27 97
Vedlegg: Prosjektvurdering

Personvernombudet for forskning

Prosjektvurdering - Kommentar

Prosjektnr: 49799

SAMARBEIDSSTUDIE

Prosjektet er en nasjonal samarbeidsstudie. Norges miljø- og biovitenskapelige universitet er behandlingsansvarlig institusjon. Nasjonal kompetansetjeneste for aldring og helse er deltakende institusjon i prosjektet. Personvernombudet forutsetter at ansvaret for behandlingen av personopplysninger er avklart mellom institusjonene. Vi anbefaler at det inngås en avtale som omfatter ansvarsfordeling, ansvarsstruktur, hvem som initierer prosjektet, bruk av data og eventuelt eierskap.

FORMÅL

Formålet med prosjektet er kvalitetsutvikling av dagtilbud på gård som et komplimenterende dagaktivitetstilbud for personer med demens.

UTVALG OG REKRUTTERING

Utvalget består av ca. 150 personer med demens som er brukere av tilpasset dagaktivitetstilbud på gård og deres nærmeste pårørende (ca. 150 personer). Det vil også inkluderes ca. 25 personer med demens som er bruker av "vanlig" dagaktivitetstilbud. Personvernombudet forutsetter at frivillighet, taushetsplikt og konfidensialitet blir ivaretatt under rekruttering av utvalget.

Rekruttering foregår via leder av dagtilbudet, som foretar en samtykkevurdering og videre forespør brukeren om han/hun kan kontaktes av forskerne. Ved samtykke til dette, kontakter forskergruppen brukerne og innhenter skriftlig samtykke. Personvernombudet gjør oppmerksom på at brukerne/ de pårørende bør få full informasjon om studien på et tidlig tidspunkt, slik at de får tid til å ta avgjørelsen om de ønsker å delta i forskningsprosjektet eller ikke.

KONFIDENSIALITET

Per telefon 28.10.2016 har forsker forklart at gårdeier og helsepersonell er svært tett på deltakerne, og at disse vil kjenne til hvem som deltar i prosjektet og hvem som ikke deltar. Personvernombudet forstår at dette er vanskelig å unngå, særlig med tanke på at gårdeier/helsepersonell skal vurdere deltakernes samtykkekompetanse. Det må gjøres klart for deltakerne at gårdeier/helsepersonell vil vite hvem som deltar og ikke. Vi anbefaler å presisere dette i informasjonsskrivet til brukerne (vedlegg 2), samt å presisere at gårdeier/helsepersonell ikke vil få tilgang til datamaterialet.

DATAINNSAMLING

Alle deltakere vil kartlegges gjennom bruk av kartleggingsverktøyet (vedlegg 11 til meldeskjema). Dette betegnes som den longitudinelle delen av studien. I den longitudinelle delen av studien vil personer med demens og deres pårørende bli intervjuet av en forsker, og de vil fylle ut en rekke skjemaer. Denne kartleggingen gjennomføres ved prosjektstart, og 6 og 12 måneder etter oppstart.

Om personer med demens innhentes opplysninger om bakgrunn, helsetilstand og sykdommer, bruk av helsetjenester, livskvalitet, kognitiv funksjon, generell helsetilstand, nivå av angst og depresjon, generelle innstilling til tilværelsen og hukommelse. Personens bevegelsesfunksjonsevne testes. Opplysningene innhentes gjennom bruk av standardiserte tester og samtale med personen.

Fra pårørende innhentes opplysninger om personen med demens ved bruk av følgende standardiserte skjemaer/tester: nevropsykistrisk evalueringsguide (bl.a. vrangforestillinger, hallusinasjoner, depresjon, angst, nattlig atferd og spiseforstyrrelser), Cornell scala for depresjon ved demens, personlig ADL og instrumentell ADL (hvordan man klarer seg i hverdagen), QOL- AD (livskvalitet), EQ-5D (helsetilstand). På bakgrunn av disse opplysningene benytter forsker skjema for vurdering av demens.

Om pårørende innhentes opplysninger om bakgrunn, helsetilstand og sykdommer, bruk av helsetjenester, hvor mye omsorg pårørende yter overfor personen med demens, livskvalitet, nivå av depresjon og angst, opplevelse av belastning i hverdagen, funksjon i hverdagen, livskvalitet og generelle innstilling til tilværelsen.

I tillegg til den longitudinelle studien benyttes flere metoder i datainnsamlingen, men disse vil ikke inkludere alle deltakerne. I prosjektbeskrivelsen betegnes disse som sju delprosjekter (sub projects). Hver deltaker vil ikke bli spurt om å delta i mer enn to delprosjekter.

1) 8-10 personer med demens vil delta i dybdeintervju og observasjon på gården.
2) 30 deltakere (personer med demens) vil delta i en intervensjon ved bruk av Goal attainment scale (GAS). 3) 8-10 pårørende vil delta i dybdeintervjuer to ganger med 3-4 måneders mellomrom.
4) Pårørende til personer med demens som er i ferd med å avvikle dagtilbudet på gården vil bli intervjuet toganger med 3-4 måneders mellomrom.

5) 30 personer med demens vil bli observert gjennom en hel dag på gården der de deltar i gruppeaktiviteter. Detgjøres filmopptak eller benyttes standard kartleggingsverktøy (MEDLO) for observasjonen.
6) 25 personer med demens vil bli observert ved bruk av MEDLO ved et dagsenter.
7) 50 personer med demens vil ha på seg en aktivitetsmåler sammenhengende i sju dager.

I tillegg til det overnevnte, vil forskergruppen kontakte de pårørende dersom personen med demens dropper ut av dagtilbudet for å innhente opplysninger om hvorfor de sluttet. Dersom pårørende eller personen med demens trekker seg fra studien, vil forskerne også ta kontakt med den pårørende for å innhente opplysninger fra om hvorfor de besluttet å trekke seg fra prosjektet. Personvernombudet minner om at det i informasjonsskrivet står at man kan trekke seg uten å oppgi noen grunn, og det må derfor være frivillig å oppgi grunner til å trekke seg.

Forskerne vil innhente opplysninger om alder og kjønn for deltakerne som ikke samtykket til å delta i studien. Personvernombudet forutsetter at disse opplysningene utleveres anonymt. Det skal ikke være mulig å knytte disse opplysningene til enkeltpersoner, og alder må grovkategoriseres dersom nødvendig. Opplysninger som kan knyttes til enkeltpersoner kan ikke utleveres til forskerne uten samtykke. For utlevering av personidentifiserende opplysninger om personer som ikke samtykker til dette, kreves konsesjon fra Datatilsynet.

Opplysninger i studien skal sammenlignes med resultater fra studien "Effects and costs of a day care centre program designed for people with dementia and their next of kin (ECOD). I prosjektbeskrivelsen er det oppgitt at resultatene fra ECOD som benyttes til sammenligning er anonyme, og vi legger derfor dette til grunn.

SAMTYKKEKOMPETANSE

Siden utvalget består av personer med demens, vil en stor andel ha redusert eller manglende samtykkekompetanse. Personvernombudet minner om at det er forskers ansvar å innhente samtykke fra pårørende dersom deltageren ikke er i stand til å gi et frivillig og informert samtykke på egenhånd. Vi minner også om at deltagelse i forskning kan oppleves belastende, og at personer med kognitive funksjonsnedsettelser kan være mer autoritetstro enn andre og oppleve det vanskelig å trekke seg. Forsker vil derfor gjennom hele datainnsamlingen ha et selvstendig ansvar for å avbryte dersom noen av deltagerne viser tegn til ubehag/motvilje. Les gjerne mer om inkludering av personer med redusert samtykkekompetanse her:

http://www.etikkom.no/Forskningsetikk/Etiske-retningslinjer/Medisin-og-helse/Redusert-samtykkekompetanse/

INFORMASJON OG SAMTYKKE

Utvalget informeres skriftlig og muntlig og det innhentes samtykke fra personer med demens og deres pårørende til å delta i prosjektet. Det er utarbeidet gode rutiner for at helsepersonell vurderer samtykkekompetansen til personene med demens. Dersom disse ikke har full samtykkekompetanse, vil pårørende samtykke til at de kan delta. Det må likevel sørges for at personer med redusert eller manglende samtykkekompetanse får tilpasset informasjon om prosjektet og deltar frivillig.

Det inngår i samtykke til personen med demens at pårørende kan oppgi helseopplysninger om personen med demens.

Informasjonsskrivet til brukerne (vedlegg 2) og de pårørende (vedlegg 3) er hovedsakelig godt utformet. Vi anbefaler at det tilføyes informasjon om konfidensialitet og hvem som skal ha tilgang til datamaterialet (se KONFIDENSIALITET). Disse skrivene informerer også om delprosjekt 1, 3 og 4. Deltakerne må imidlertid få mer utfyllende informasjon muntlig eller skriftlig om delprosjektene når deltakelse bli aktuelt, må minnes på at deltakelse er frivillig, og det må innhentes et aktivt samtykke (muntlig eller skriftlig).

Informasjonsskrivet for delprosjekt 2 (vedlegg 5) er godt utformet, men bør inneholde informasjon om hvilke personopplysninger som innhentes til forskningsprosjektet.

Informasjonsskrivet for delprosjekt 5 (vedlegg 8) er godt utformet. Det bør informeres om at anonymisering ved prosjektslutt innebærer sletting/redigering av videomateriale.

Informasjonsskrivene for delprosjekt 6 (vedlegg 10) og 7 (vedlegg 9) er godt utformet.

Selv om det ikke skal registreres personopplysninger om deltakerne på dagtilbudene som ikke deltar i forskningsprosjektet, ber personvernombudet om at det gis informasjon i forkant til alle om at en forsker vil være til stede for å observere på et gitt tidspunkt. Det bør presiseres at forskeren ikke vil registrere noen opplysninger om de som ikke deltar i forskningsprosjektet.

Vær oppmerksom på at et avidentifisert datasett ikke skal inneholde indirekte identifiserende opplysninger.

Dersom datasettet uten koblingsnøkkel vil være indirekte identifiserbart, anbefaler vi at dere ikke kaller datasettet avidentifisert. Anonymisering av datasettet innebærer å også bearbeide datasettet slik at det ikke er indirekte identifiserbart.

TREDJEPERSONOPPLYSNINGER

Det kan framkomme enkelte opplysninger om tredjeperson (familiemedlemmer, venner, helsepersonell) i intervjuer med deltakerne. Det skal kun registreres opplysninger som er nødvendig for formålet med prosjektet. Opplysningene skal være av mindre omfang og ikke sensitive, og skal anonymiseres i publikasjon. Så fremt personvernulempen for tredjeperson reduseres på denne måten, kan prosjektleder unntas fra informasjonsplikten overfor tredjeperson, fordi det anses uforholdsmessig vanskelig å informere.

INNSYN I TAUSHETSPLIKTIGE OPPLYSNINGER

Personvernombudet forutsetter at forskerne ikke registrerer identifiserende opplysninger om (f.eks. ved bruk av MEDLO i observasjon) og ikke filmer personer (eller at personens stemmer kommer med på filmopptak på en måte som identifiserer vedkommende) som deltar i eller er ansatt ved dagaktivitetstilbud, og som ikke har samtykket til å delta i forskningsprosjektet.

Deltakere i forskergruppen som skal gjennomføre observasjon og videofilming vil likevel få innsyn i taushetsbelagte opplysninger om personer som ikke deltar i prosjektet, ved at disse er tilstede på dagaktivitetstilbudet. Ledelsen ved institusjonen dagaktivitetstilbudet tilhører må godkjenne prosjektet og forskers tilstedeværelse. Vi anbefaler at forskerne signerer en taushetserklæring.

SENSITIVE PERSONOPPLYSNINGER

Det behandles sensitive personopplysninger om helseforhold.

DATASIKKERHET

Personvernombudet legger til grunn at forsker etterfølger Norges miljø- og biovitenskapelige universitet sine interne rutiner for datasikkerhet. Dersom personopplysninger skal lagres på mobile enheter, må opplysningene krypteres tilstrekkelig.

Sykehuset Innlandet HF er databehandler for prosjektet. Grunnen er at de har en tjeneste for elektronisk innlesing av papirdokumenter. Norges miljø- og biovitenskapelige universitet skal inngå skriftlig avtale med Sykehuset Innlandet HF om hvordan personopplysninger skal behandles, jf. personopplysningsloven § 15. For råd om hva databehandleravtalen bør inneholde, se Datatilsynets veileder: http://www.datatilsynet.no/Sikkerhetinternkontroll/Databehandleravtale/.

PROSJEKTSLUTT

Forventet prosjektslutt er 31.12.2020. Ifølge prosjektmeldingen skal innsamlede opplysninger da anonymiseres. Anonymisering innebærer å bearbeide datamaterialet slik at ingen enkeltpersoner kan gjenkjennes. Det gjøres ved å:

- slette direkte personopplysninger (som navn/koblingsnøkkel)
- slette/omskrive indirekte personopplysninger (identifiserende sammenstilling av bakgrunnsopplysninger somf.eks. bosted/arbeidssted, alder og kjønn)
- slette/redigere digitale lyd-/bilde- og videoopptak

Vi gjør oppmerksom på at også databehandler (Sykehuset Innlandet HF) må slette personopplysninger tilknyttet prosjektet i sine systemer.

REK

Framleggingsvurdering for prosjektet er vurdert av REK sør-øst D til å være et kvalitetssikringsprosjekt og dermed falle utenfor virkeområdet til helseforskningsloven (ref. 2016/927).

VURDERING

Denne vurderingen er gjort på bakgrunn av det innsendte meldeskjemaet og vedleggene, samt epostkorrespondanse og telefonsamtaler med forsker. Vi har utformet et dokument hvor Personvernombudet har gjennomgått prosjektet, og forsker har bekreftet at vi har forstått prosjektet riktig.

I prosjektet samles det inn en stor mengde svært sensitiv informasjon, likevel vurderer vi at prosjektet er unntatt fra konsesjonsplikt grunnet at prosjektet er basert på samtykke fra informantene eller deres pårørende.

Prosjektet kan dermed hjemles i § 7-27 (unntatt fra konsesjonsplikt) i personopplysningsloven.

Personopplysninger i prosjektet som innhentes basert på informert samtykke fra de registrerte kan behandles med hjemmel i personopplysningslovens §§ 8 og 9 a).

Personvernombudet finner at opplysninger om personer med redusert eller manglende samtykkekompetanse, forutsatt samtykke fra pårørende, kan behandles med hjemmel i personopplysningslovens §§ 8 d) og 9 h).

Prosjektets potensielle samfunnsnytte ligger i at prosjektets formål er å bidra til å kvalitetssikre dagaktivitetstilbudet.

11.3 Approval of the merging of data between the FDC-project and the ECOD-study

REK
REGIONALE KOMITEER FOR MEDISINSK OG HELSEFAGLIG FORSKNINGSETIKK

Region:	**Saksbehandler:**	**Telefon:**	**Vår dato:**	**Vår referanse:**
REK sør-øst	Silje U. Lauvrak	22845520	19.04.2017	2013/1020/REK sør-øst D
			Deres dato:	**Deres referanse:**
			22.03.2017	

Vår referanse må oppgis ved alle henvendelser

Geir Selbæk
Nasjonalt kompetansesenter for aldring og helse

2013/1020 Effekt av dagsenteraktivitetstilbud for personer med demens

Forskningsansvarlig: Nasjonalt kompetansesenter for aldring og helse
Prosjektleder: Geir Selbæk

Vi viser til søknad om prosjektendring datert 22.03.2017 for ovennevnte forskningsprosjekt. Søknaden er behandlet av leder for REK sør-øst på fullmakt, med hjemmel i helseforskningsloven § 11.

Endringen innebærer:
- Anonymiserte, kvantitative data fra deltagerne (både personer med demens og pårørende) skal benyttes som kontrolldata i prosjektet "Demensomsorg på gård" (REK-ref.: 2016/927). Data fra gruppen personer med demens omfatter: sosiodemografiske data, kognitiv funksjon, livskvalitet, fysisk funksjon/ADL-funksjon, demensdiagnose, demenssymptomer, medisiner, psykisk helse, bruk av helseressurser. Data fra gruppen pårørende omfatter: sosiodemografiske data, livskvalitet, pårørendebelastning, psykiske helse, bruk av helseressurser.

Vurdering

REK har vurdert endringssøknaden og har ingen forskningsetiske innvendinger mot at anonymiserte data fra prosjektet benyttes som kontrolldata i prosjektet "Demensomsorg på gård". Begge prosjekter har som formål å undersøke betydningen av dagaktivitetstilbud for personer med demens, og en sammenligning vil gi bredere kunnskap om betydningen av tilbudene.

Vedtak

REK godkjenner prosjektet slik det nå foreligger, jfr. helseforskningsloven § 11, annet ledd.

Tillatelsen er gitt under forutsetning av at prosjektet gjennomføres slik det er beskrevet i søknaden, endringssøknad, oppdatert protokoll og de bestemmelser som følger av helseforskningsloven med forskrifter.

REKs vedtak kan påklages, jf. forvaltningslovens § 28 flg. Klagen sendes til REK sør-øst. Klagefristen er tre uker fra du mottar dette brevet. Dersom vedtaket opprettholdes av REK sør-øst, sendes klagen videre til Den nasjonale forskningsetiske komité for medisin og helsefag for endelig vurdering.

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Vennligst oppgi vårt referansenummer i korrespondansen.

Med vennlig hilsen

Finn Wisløff
Professor em. dr. med.
Leder

Silje U. Lauvrak
Rådgiver

Kopi til: arnfinn.eek@aldringoghelse.no
Nasjonalt kompetansesenter for aldring og helse ved øverste administrative ledelse: post@aldringoghelse.no

11. 4 Approval of the inclusion of activity data from participants from the Animal-assisted Care-project

From: post@helseforskning.etikkom.no [mailto:post@helseforskning.etikkom.no]
Sent: 6. november 2018 15:02
To: Camilla Martha Ihlebæk <camilla.ihlebak@nmbu.no>
Cc: torstein.steine@umb.no; Postmottak <postmottak@nmbu.no>
Subject: Sv: REK sør-øst 2012/1144 Dyreassisterte- og robotassisterte intervensjoner som helsefremmende tiltak for eldre med demens

Hei.
Det vises til søknad om prosjektendring mottatt 22.08.2018.

Når prosjektdata er anonymisert ved sletting av koblingsnøkkel, slik vi forstår er tilfellet her, kan data gjenbrukes uten at det er nødvendig med noen godkjenning fra REK.

Med vennlig hilsen

Claus H. Thorsen
rådgiver
sekretariatet
REK sør-øst

Physical activity in people with dementia attending farm-based dementia day care –

a comparative actigraphy study

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RESEARCH ARTICLE

Open Access

Physical activity in people with dementia attending farm-based dementia day care – a comparative actigraphy study

B. Finnanger Garshol*, L. H. Ellingsen-Dalskau and I. Pedersen

Abstract

Background: Despite public focus on the importance of physical activity and findings showing the benefits of such activity, research has shown that people with dementia are less physically active and have more sedentary behaviour compared to others in similar age groups. In Norway, there is a focus on day care services as a means to allow people with dementia to experience social, physical and cultural activities. Farm based services have been highlighted as an innovative and customized day care service, but little research has been done on physical activity and such services. This study therefor aims to investigate the potential of farm-based day care services as services that can promote physical activity for people with dementia.

Methods: Actigraphy data from people with dementia attending farm-based day care services ($n = 29$) and people with dementia attending regular day care services ($n = 107$) was used to assess levels of physical activity in each group and to compare the two groups.

Results: People attending farm-based day care had significantly higher levels of moderate activity, approximately 23 min each day, compared with persons attending ordinary day care ($p = 0.048$). Time spent in sedentary or light activity were similar for both groups. For the group attending farm-based day care services, days at the service, were significantly associated with less time spent in sedentary activity ($p = 0.012$) and more time spent in light ($p < 0.001$) and moderate activity ($p = 0.032$), and in taking more steps ($p = 0.005$) compared to days not at the service.

Conclusion: The findings indicate that participants in farm-based day care for people with dementia have higher levels of physical activity compared to ordinary day care and that farm-based day care increases levels of physical activity for its attendees. Farm based day care services has the potential to help their participants reach or maintain recommended levels of physical activity. Further research is needed to investigate what facilitates this increase in activity and how such knowledge could be used in all types of day care services.

Background

Physical activity and exercise can have many positive effects on people with dementia. It can improve physical functioning and basic activities of daily living [1, 2]; it can have a positive effect on cognitive function [3], and it can reduce levels of depression [4]. Additionally, both international and national guidelines highlight the importance of physical activity for older adults as a means to improve cardiorespiratory and muscular fitness, and functional health [5, 6]. Despite this, studies have found that people with dementia are less physically active, more sedentary and are more susceptible to physical decline than others in similar age groups [7–11], suggesting a need to promote physical activity among people with dementia.

Day care services for people with dementia are considered a setting that can help maintain physical function

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and provide opportunities for physical activity [12]. Day care services for people with dementia can be defined as adapted services, which aim to provide people with dementia the opportunity to experience social, physical and cultural experiences, and provide respite for caregivers [12]. In Norway, most day care services for people with dementia are located in conjunction with already existing institutions in the municipality (e.g. long-term care facilities, retirement homes) [13] and can be termed as regular day care services.

There is a call to innovate and create new services for people with dementia in Norway, and the Dementia Plan 2020 highlights farm-based dementia day care (FDC) as an example of varied and customized day care [12]. FDCs are structured similarly to regular day care, but base their activities on the farms resources and natural surroundings [14]. The farm as a care environment for people with dementia has been studied previously. Care farming can be defined as the use of commercial farms and agricultural landscapes as a base for promoting mental and physical health through normal farming activities [15]. Studies have observed that the participants at FDCs spend a large part of the day outdoors [14] and they are more actively involved in daily activities [16]. FDCs also stimulate dietary intake [17] and social participation [18], provide physical activity and contact with nature and animals [19], and the farm context enables activities and collaboration between participants and staff [20]. In addition, de Boer, Hamers, et al. [21] found in a study that people with dementia living in farm-based nursing homes had higher quality of life compared with residents of regular nursing homes.

There has been some research on day care services and physical activity. For regular day care services, van Alphen, Volkers, et al. [10] found that people with dementia attending these services were more active and less sedentary than people with dementia living in nursing homes, but less active and more sedentary than people without dementia living at home. Olsen, Pedersen, et al. [22] found similar results when comparing activity levels of people with dementia at regular day care with people with dementia in nursing homes. Strandenæs, Lund, et al. [23] found that participants reported that they felt attending regular day care helped them maintain physical functioning, and that it gave them opportunities for physical activity. At the same time, Strandenæs, Lund, et al. [24] found that while staff at regular day care centres highlighted the importance of physical activity, they tended not to offer specific training to strengthen the attendees.

There is seemingly little research on farm-based dementia care and physical activities and only De Bruin, Oosting, et al. [25] and de Boer, Hamers, et al. [26] seems to have investigated it. De Bruin, Oosting, et al. [25] found in an observational study that at FDCs activities (e.g. walking, crafts, watching animals etc.) were more frequent, more often outdoors, more aimed at individuals, and were of higher physical intensity than activities at regular day care facilities.de Boer, Hamers, et al. [26] found in their observational study of people with dementia living in different types of nursing homes, that participants living in farm-based nursing homes were more outside and more physically active. FDCs therefore seem to be an alternative day care service that could provide better opportunities for physical activity for people with dementia. However, little is still known about the level of physical activity at such services, and the difference between regular day care and FDC.

The present study therefore aims to investigate the potential of FDCs as services that can promote physical activity for people with dementia by comparing the levels of physical activity between attendees of regular day care and attendees of FDCs. In addition, it will compare levels of physical activity for people attending farm-based day care for the days they are at the farm and the days they are not. This may give a better understanding of what FDC can offer in relation to opportunities for physical activity. Based on existing research we expect to find that participants at FDCs have higher levels of physical activity than participants at regular day care services.

Methods

The data used in the analyses was collected in two separate studies. The first study was a longitudinal study, and we used data collected at the second data collection point 6 months after baseline. We collected activity data, demographic data and information about degree of dementia and degree of physical functioning from participants attending FDCs (Study 1, [27]). The second study was a cross-sectional study by Olsen, Pedersen, et al. [22] (Study 2). From Study 2 we got similar data as in the first study, but this was collected form participants attending regular day care services for people with dementia.

Participants and recruitment

In study 1, the municipality and the FDC were asked if they wanted to participate in the project. The day care service provider or a nurse in the municipality then conducted recruitment. Inclusion criteria for people with dementia were having attended a FDC for more than 3 weeks and seeing the same next of kin at least once a week. Age was not an inclusion criterion. In study 1, we recruited participant from late 2017 to late 2018. A total of 30 participants were recruited from 15 FDC services located all across Norway. In study 2, the development centres for dementia in three counties enrolled municipal day care centres. Data collection was conducted from early 2013 to mid-2014, and the staff at the enrolled centres conducted the recruitment of participants [22]. The inclusion criteria were 65 years or older and the person had to have either a dementia diagnosis or a score of < 25 on the Mini-Mental State Examination-test. A total of 115 participants from 23 day-care centres in the south-eastern part of Norway were included [22]. Figure 1 shows the inclusion of the participants from the two studies into the present study.

Measurements

Both studies collected the following demographic data: age, gender, level of education, and level of dementia using a questionnaire. In Study 1, participants filled in the questionnaire together with a person from the research team, while in Study 2 the participants filled in the questionnaire together with staff at the day care centre. In addition, both studies used a test of physical functioning to assess functional mobility and an actigraph to measure levels of physical activity.

Level of physical activity

We used actigraphs (Actisleep+, Actigraph, Pensacola, US) to measure the level of physical activity. Actisleep+ is a 3-axis accelerometer approximately the size of a wristwatch. It measures physical activity levels, light exposure and sleep patterns. Actisleep+ measures movement along three axes: Vertically (Up and down), laterally (side to side) and longitudinally (forward and backward). It also measures the frequency and intensity/force of these movements. Using software, this is translated into measures of physical activity. The Actisleep+ does not register type of activities, nor their location. Actigraphy is a validated method for monitoring sleep and activity levels in people with dementia [28] and Erickson, Barr, et al. [29] demonstrated the feasibility of using actigraphy to measure physical activity in people with dementia. Additionally, several studies have used actigraphy to study levels of physical activity in people with dementia [10, 22]. The researchers introduced the actigraph orally, visually and in written form in both studies, both to the person with dementia and to their caregivers/relatives. In both studies, the participants wore the actigraph on the left wrist continuously for 7 days, these days included both days while at the day care services and days while not at the day care services. The participants could remove the actigraph, but were encouraged not to do so. Caregivers and relatives were also instructed to encourage the participants to put it back on if it had been removed by mistake.

Level of dementia

Both studies used Clinical Dementia Rating (CDR) scale to assess level of dementia. The scale comprises six items: memory, orientation, judgment and problem solving, community affairs, home and hobbies, and personal care. Each item is scored on a five-point scale from 0 to 3. 0 is considered normal, 0,5 very mild dementia, 1 is mild dementia, 2 is moderate dementia, while 3 is considered severe dementia. One overall score, following the same scale, is set based on the six items, giving precedence to memory [30]. CDR is considered a valid substitute for a dementia assessment when rating dementia and the severity of it [31, 32].

Level of functional mobility

Both studies used the Timed Up and Go-test (TUG) [33] to assess functional mobility, as we consider this to impact levels of physical activity. The timed Up and Go-test is a physical test were the participant rises from a chair, walks three meters, turns, walks back and sits down, while the test-administrator takes the time. In both studies, the TUG was administered according to Botolfsen and Helbostad [34], i.e. the testers repeated the test up to two times and the final score was the mean of the time, in seconds, for the two attempts.

Statistical analysis

We processed the collected actigraphy data using the ActiLife-software, version 6.13.3 (ActiGraph, Pensacola, USA). To measure wear-time we subjected the data to a wear-time-validation. Wear-time validation allows the researcher to identify, based on a given set of parameters, invalid data. In this case, invalid data are periods when a participant has not worn the actigraph. We based the validation on the Troiano (2007) algorithm and excluded non-wear time from the subsequent analyses. We also applied a time filter between 08:00 and 20:00 to focus on day activity, as this is the timeframe where we believe the participants are the most active, and the timeframe in which day care centres could have an impact on the level of physical activity. We included days with more than 8 h recorded activity within that period as valid days. We decided that the participants would have to have at least three valid days to be included in the analyses, which is in accordance with findings from Hart, Swartz, et al. [35]. Of the 30 participants from study 1, only one participant was excluded from the analyses because of too few valid days, while in study 2, 8 participants were excluded because of too few valid days.

We processed the data further via the Scoring functions of the ActiLife-software. We calculated physical activity levels using the Freedson Adult Cut Points [36] in the ActiLife Software. ActiLife calculates activity levels based on the frequency and intensity of the registered movements. These constitute the measure counts and are specified as counts per minute (cpm). ActiLife

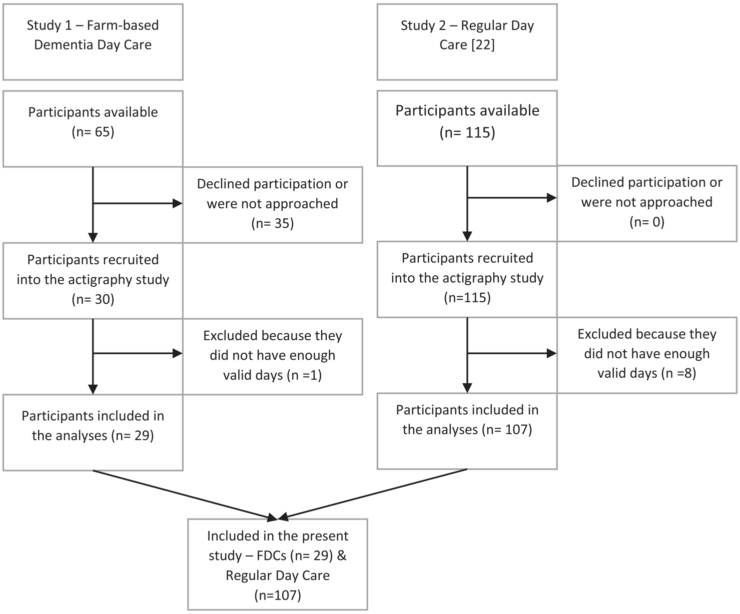

Fig. 1 Flowchart of the inclusion of participants – The Flow chart shows the process of including participants from Study 1 and Study 2 in the analyses of the present study

categorises activity into five levels: sedentary (0–99 cpm), light (100–1951 cpm), moderate (1952–5742 cpm), vigorous (5743–9498), and very vigorous (> 9498). Sedentary activity is for example sitting and watching TV or sitting and listening to a conversation; light activity is for example standing or household activities, while moderate activity is for example walking. The Actigraph recorded the time spent on the different activity levels in minutes. Figure 2 shows a 24-h activity graph for one of the participants at FDCs. The graph shows when and for how long the participant was at the different activity levels. Through processing, Actilife subsequently expressed these as a percentage of the overall monitoring time. ActiLife also converts the data for a given time period into steps taken, giving us an estimate for each day for each participant. For the data from regular day

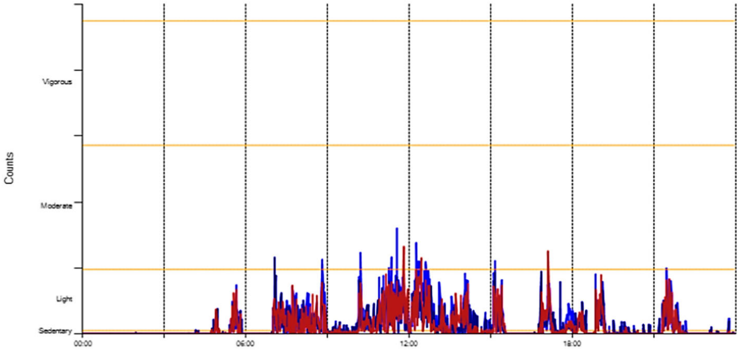

Fig. 2 A representation of the actigraphy data – 24 h for one participant. The graph shows activity levels (y-axis) throughout the day (24 h) for one participant. The different colours represent different axes of movement

care, only the percentages of activity levels were available for analysis.

We performed all statistical analyses using SPSS Statistics 25.0 (IBM Corp, Armonk, NY US) and we set the level of significance at 0.05. We used descriptive statistics to describe the two groups and an independent samples t-test to investigate differences between them. We used linear regression to further investigate the associations between type of day care and levels of physical activity, using data from both studies. We used the different levels of physical activity, based on the mean score for each participant, as the dependent variable and included type of day care service as an independent variable. Additionally, we included covariates that, based on previous research and existing differences between the two groups, could be confounders. Lastly, we used mixed model to investigate the difference in activity levels within group between days at the FDC and days without FDC, using only data from Study 1. In the linear mixed models, we used the levels of physical activity and steps taken each day as dependent variables, while attendance or non-attendance at the farm was included as an independent variable. As with the linear regression, we also included covariates that we considered as potential confounders. For both the linear regression analysis and mixed model analysis we analysed each of the levels of physical activity separately and built several models. Covariates were discarded from the models if they were not significant or did not significantly contribute to the model, for example as measured by r or Akaike information criterion (AIC). CDR and Living Alone were not included in the final analyses as they were not significant, and they did not contribute significantly to the model. In addition, despite there being a difference between the two groups on CDR, the group means were both in the "mild dementia"-category. The final models are presented in the tables in this paper.

Ethics

Study 1 was approved by the Norwegian Centre for Research Data (NSD). Study 2 was approved by the Regional Committees for Medical and Health Research Ethics (REK). For the present study, we submitted an application to REK for sharing of data from study 2 to Study 1. This was approved on the basis that the data was anonymized.

All participants gave informed written consent and were informed that they could at any time withdraw from the studies. Since the Actisleep+ did not register type of activity and location, we considered it a non-invasive measure.

Results

We present demographic data for the two groups and differences between the groups in Table 1. There were significantly more men among the participants attending FDC and they were significantly younger than those attending regular day care. In addition, among the participants attending FDC, fewer lived alone, more of them took prescription medication, and they had better TUG-mean time. The t-tests showed no group differences in time spent at different activity levels.

Given the group differences on several demographic variables, we conducted an adjusted linear regression analysis (Table 2). This showed a statistically significant association between FDC and increased time spent at moderate physical activity. Participants attending FDCs spent 3.33% more time in moderate activity level each day than those attending regular day care. The average time registered for each day among the participants of FDCs were 685.18 min. This gives a 3.33% of 685.18 min, meaning the participants spent 22.81 min more in moderate activity each day, amounting to 159.67 min more for the entire week than those at regular day care. We found no such association for sedentary and light activity levels (data not shown).

To investigate within-group differences among participants attending FDC we ran linear mixed models (Table 3). When comparing days attending FDC with days not attending FDC, we found that days spent at the FDC were statistically significant associated with less time spent in sedentary activity, more time spent in light and medium activity and walking more steps. On the days at the farm the participants spent 25.85 min less in sedentary activity ($p = 0.012$), 40.37 min more in light activity ($p < 0.001$), 12.53 min more in moderate activity ($p = 0.032$) and took 1043.36 more steps ($p = 0.005$).

Discussion

The aim of the present study was to investigate the association between FDCs and activity levels in order to shed light on their potential as environments for promoting physical activity in the target group for the services. We wanted to investigate this both in relation to regular day care and for the attendees compared with their everyday life.

As our results show, attending FDCs is significantly associated with more physical activity, and at higher levels than attending regular day care. For the group attending FDCs, days spent on the farms were significantly associated with less sedentary activity, more light and moderate activity, and with more steps taken compared to days not at the farm. This is in line with previous research on farms as care settings for people with dementia [25, 26].

The higher levels in physical activity at the FDCs compared with regular day care could potentially be

Table 1 Demographic data for participants attending farm-based dementia care or regular day care

Demographic	Farm-based dementia care ($n = 29$)	Regular Day Care ($n = 107$)	P-value[1]
Gender – man (%)	20 (69.0)	36 (34.0)	0.001
Age – mean (SD)	74.0 (7.22)	84.3 (8.10)	< 0.001
Education	$n = 29$	$n = 87$	0.189
- Primary (%)	4 (13.8)	40 (46.0)	
- Secondary (%)	19 (65.5)	20 (23.0)	
- College/University	6 (20.7)	25 (28.7)	
Living alone (%)	4 (13.8)	57 (54.3)	< 0.001
Clinical dementia rating (CDR)	$n = 29$	$N = 102$	
CDR – mean (SD)	1.22 (0.57)	1.52 (0.67)	0.021
CDR – groups			
- No (%)	0 (0)	4 (3.9)	
- Very mild (%)	3 (10.3)	3 (2.9)	
- Mild (%)	19 (65.5)	41 (40.2)	
- Moderate (%)	6 (20.7)	49 (48.0)	
- Severe (%)	1 (3.4)	5 (4.9)	
TUG – mean time in seconds (SD)	13.48 (5.61)	17.22 (8.02)	0.026
Activity levels			
Sedentary activity % - mean (SD)	39.70 (13.41)	43.51 (14.62)	0.209
Min – max[2]	11.75–66.19	10.67–73.41	
Light activity % - mean (SD)	50.53 (8.87)	50.19 (11.48)	0.864
Min-Max[2]	32.90–65.66	24.38–76.86	
Moderate activity % - mean (SD)	9.75 (9.34)	6.29 (5.97)	0,066
Min-Max[2]	0.17–38.43	0.03–28.35	

[1] $p < 0.05$ was considered significant
[2] Minimun and maximum values for the variable

explained by several factors. The same factors could also potentially explain why people attending FDC have higher levels of physical activity on days at the farm compared to days not at the farm. One factor could be that the farm setting, to a larger degree, invites to physical activity through supplying the space for such activity and by having tasks that necessitates physical activity (e.g. woodcutting, gardening, feeding animals). Ibsen, Eriksen, et al. [14] noted that, while organized similarly to regular day care, FDCs in Norway differed in type of care environment with a wide range of activities and available resources. This included activities such as working with plants, tending and harvesting crops, woodworking and animal-related activities. Further, they found that the service took place in several areas, both on and outside of the farms such as the yard, the barn, gardens, a greenhouse and the surrounding uncultivated areas like forests and trails [14]. De Bruin, Oosting, et al. [25] also noted on the difference in activities between regular day care and FDCs. They found that activities at the FDCs were more often outdoors or in another building than regular day care. Additionally, activities at regular day care more often involved sitting, while activities at the FDCs more often involved standing or walking. de Boer, Hamers, et al. [26] observed similar results, but then in farm-based nursing homes. They found that the residents of farm-based nursing homes were more physically active, spent less time in passive activities, and were more engaged in their activities. Sudmann and Børsheim [19] found that the participants perceived the tasks at the FDCs as useful and meaningful, which could potentially increase their engagement in the task and the

Table 2 Linear regression for the association between type of day care, gender, age and TUG-sum on percentage of the time spent in moderate activity[1]

Variable	B (SE)	Beta	p-value[2]
Farm-based day care	3.33 (1.66)	0.20	0.048
Gender[3]	−5.01 (1.28)	−0.35	< 0.001
Age	−0.148 (0.08)	−0.18	0.073
TUG	−0.228 (0.079)	−0.24	0.005

[1] $r^2 = 0.250$
[2] $p < 0.05$ was considered significant
[3] Women = 0, men = 1

Table 3 Linear mixed models for the difference between days attending FDC and days not attending FDC with differing levels of physical activity or steps taken as dependent variable

Minutes in sedentary activity			
Variable	Estimate of fixed effects	95% CI	*p*-value[1]
Farm-based[2]	−25.84	(−45.81, − 5.88)	0.012
Gender	27.13	(−33.82, 88.09)	0.37
Age	−1.88	(−6.44, 2.66)	0.40
TUG	4.40	(−1.47, 10.28)	0.13
Minutes in light activity			
Farm-based	40.37	(24.69, 56.05)	< 0.001
Gender	36.96	(−11.85, 85.78)	0.132
Age	3.95	(0.30, 7.59)	0.035
TUG	−1.24	(−5.95, 3.46)	0.593
Minutes in medium activity			
Farm-based	12.53	(1.12, 23.95)	0.032
Gender	−44.85	(− 83.21, −6.48)	0.023
Age	−1.21	(−4.18, 1.55)	0.357
TUG	−3.11	(−6.81, 0.58)	0.096
Number of steps per day			
Farm-based	1043.36	(327.03, 1759.68)	0.005
Gender	− 467.62	(− 2771.26, 1836.02)	0.682
Age	−27.47	(−199.59, 144.64)	0.747
TUG	−38.59	(− 260.64, 183.45)	0.726

[1] $p < 0.05$ was considered significant

[2] Days on the farm = 1, days not on the farm = 0

intensity. Further, Hassink, De Bruin, et al. [37] found that working with animals at care farms implicitly stimulated to physical activity. Lastly, de Bruin, de Boer, et al. [38] note that at FDCs activities are naturally incorporated into the environment and care provisions and are as such continuously present. Based on this previous research, activities at the FDCs, and especially the farm activities, seem to encourage higher levels of physical activity, than activities found at regular day care. The activities at, and inherent to, the FDCs can as such explain the higher levels of physical activity we found in our analyses. One avenue for future research could be to investigate if and how aspects of the farm setting could be transferred to other care settings for people with dementia.

Another factor explaining our findings could be the importance of the service providers as they are generally the ones who structure the day, and it is in many ways up to them how much focus there are on physical activity. While this is true for all types of day care services, the farmer has the added benefit of the farm resources and surroundings, and the knowhow that allows for their inclusion in the service. Sudmann and Børsheim [19] highlights the importance of the service provider as a facilitator for activities for the participants of FDCs, noting their roles as “work leader” and “host”. Within care farming in general the importance of the service provider has also been noted. Hassink, Elings, et al. [39] found that the personal and involved attitude of the farmer was considered a defining characteristic of care farms in general, and this is echoed in Steigen, Kogstad, et al. [40] which highlights the farmer as a significant important other to the participants. Pedersen, Ihlebaek, et al. [41] found that the participants, here people with clinical depression, reported that the farmers gave them tasks they could accomplish, leading to increased self-confidence and independence. Ellingsen-Dalskau, Morken, et al. [42] also note the positive effect of the involved farmer. In their study, the participants of a farm-based prevocational program reported that the farmers provided guidance, positive feedback and encouraged them to try new activities. The service provider’s engagement at the FDCs might facilitate increased physical activity through support, encouragement and the creating opportunities for the participants to experience coping. Low self-efficacy for going outdoors have for example been linked with restricting activities [43], and support from the service-provider could potentially alleviate this. Additionally, the service providers at farms could use their knowledge to facilitate and tailor activities more to the individual. De Bruin, Oosting, et al. [25] noted that activities at the FDCs were more often aimed at the individuals than at regular day care services, and that the regular day cares often had activities that included the entire group. Individualized activities have been noted as a facilitator for physical activity for people with dementia [44]. While there is a focus on tailoring activities to the individual at regular day care services, Strandenæs, Lund, et al. [24] found that staff at regular day care would state that they gathered individual knowledge about the attendees and tried to offer individualized services. At the same time, observations showed that the staff seemed to have insufficient knowledge about how to translate the information on the individuals into individually tailored and structured meaningful activities for the attendees. Additionally, the study found that there was a potential to include the attendees more in ongoing activities. This is mirrored in Myren, Enmarker, et al. [20] which found that participants at an FDC were more included in the daily activities at the FDC, like preparing meals, while participants at the regular day care centre were more passive in the daily activities. Therefore, the reason why we see differences, both between types of day care services, and days on and off the FDCs might be because the service providers promote physical activity both through providing organized activities to promote physical activity, such as taking walks or labour-intensive tasks, but also through support guidance, and individualization so that the participants try out farm activities which they might enjoy and exert themselves.

Both WHOs “Global Recommendations on Physical Activity for Health” [5] and Norwegian National Guidelines for physical activity for older people [45] gives recommendations on how much physical activity is necessary to maintain physical function and health. Additionally, the Norwegian guidelines recommend regular walks in varying terrain to maintain balance, range of motion and walking ability. Our findings indicate that attending FDCs could facilitate following these recommendations more so than attending regular day care. Further, our findings indicate that for those attending FDCs, the days on the farm are significantly more active and less sedentary. Given the high amounts of sedentary behaviour among people with dementia reported in previous research [7–10], the increased levels of physical activity on days with FDCs would seemingly be a valuable contribution towards less sedentary behaviour. That the participants are less sedentary are also in line with the WHO recommendations, as they highlight the need to avoid physical inactivity, as this has been identified as the fourth leading risk factor for global mortality [5]. Breaking up sedentary behaviour can also be important to maintain physical function in elderly people as Fujita, Fujiwara, et al. [46] and Shimada, Ishizaki, et al. [43] found when looking at the association between frequency of leaving the home and instrumental and basic activities of daily living. On the other hand, de Bruin, Oosting, et al. [47] found no significant difference between regular day care and FDCs in maintaining functional performance. Still, Blankevoort, van Heuvelen, et al. [1] found that physical activity improved physical functioning and basic activities of daily living among people with dementia. Additionally, they noted that higher levels of physical activity seemingly led to higher impact on physical functioning and activities of daily living. Based on current recommendations and previous research, our findings indicate that FDCs can potentially facilitate adherence to the recommendations and improve physical functioning.

Strengths and weaknesses

The data for the present study were taken from two different projects, both with several data collectors, meaning we cannot discount inter-rater discrepancies with some of the measurements. However, the CDR [33, 34] and TUG [36] are both validated instruments with clear instructions. Also, the main measurement, the actigraphy, was assessed using the same software in both projects and data included in analyses based on the same guidelines, minimizing any discrepancies.

Further, the participants were not randomly select from among the relevant population. Recruitment was conducted by intermediaries, service providers and staff, in both studies. They might have screened their participants based on other criteria than the inclusion criteria, such as social or health status. This means that we might have a sample who are not representable for the whole population, potentially limiting the generalisability of the findings. The group attending regular day care and the group attending FDCs differed across several variables, such as gender, age, level of dementia and physical functioning. Additionally, it could be that participants attending FDCs are more physically active or have higher physical functioning, than people attending regular day care. To account for some of these differences we included age, gender and assessment of physical functioning in the statistical models as covariates as we believed these could influence levels of physical activity.

Last, one drawback with actigraphy, is that it does not give any information on the types of activity being conducted. As such, we do not know exactly what types of activities they are doing at the different types of day care services and which ones that contribute to physical activity. This means that we cannot preclude that the activities that contribute to physical activity at the FDCs are not specifically farm-related. Additionally, the way the actigraph measures activity means some forms of activity might be physically demanding, but not show up as physical activity with higher intensity [48]. This might be applicable for both groups, but more so for the ones attending FDCs due to the nature of the activities at the farms, for example carrying fodder for farm animals. However, a strength of using actigraphy is that it gives objective data on the participants physical activity and has been shown to be feasible for people with dementia [29], as relying on self-reported data alone has been shown to be unreliable [49, 50]. Non-wear can also be a challenge with actigraphy, but we conducted wear-time analyses and included requirements for what constituted a valid day to be included in the further analyses (minimum 8 h recorded activity in a 12-h time span), effectively minimizing the potential impact of non-wear.

The present study is cross-sectional, as such we do not have data about the participants baseline activity levels before attending day care, nor about the progression over time. This means we cannot infer causality based on the present study, but the results from the linear mix-model supports the assumption that attending FDCs is a main contributor to the higher levels of physical activity among their participants.

Conclusions

As hypothesized the results of the present study indicate that participants attending FDCs have higher levels of physical activity compared to regular day care services and that FDCs increases physical activity levels for their attendees. FDCs has the potential to help their participants to reach or maintain the recommended amounts of physical activity stipulated in international and national guidelines. Further, previous research has shown that higher levels of physical activity can lead to health benefits for the participants. It can also aid them in maintaining physical function, and thereby maintain their activities of daily living. Based on previous studies, the farm setting and the service provider as a support for the participants and facilitator of individually tailored activities could explain the higher levels of physical activity at FDCs. Further research is needed to investigate what facilitates this increase in activity and which aspects promote physical activity and how such knowledge could be transferred between and used in all types of day care services.

Abbreviations

FDC: Farm-based dementia day care; CDR: Clinical dementia rating scale; TUG: The timed up and go-test

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Authors' contributions

BFG participated in data collection, performed the data analyses, participated in data interpretation, and wrote the paper. IP designed the study, participated in data collection, data analyses and interpretation, and contributed to the drafting and revising of the paper. LED participated in the design of the study, the data collection, data analysis and interpretation, and contributed to the drafting and revising of the paper. All authors read and approved the final manuscript.

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Availability of data and materials

The datasets generated and/or analyzed during the current study are not publicly available due to them still being used for analyses but are available from the corresponding author on reasonable request.

Ethics approval and consent to participate

The present study, together with study 1, was approved by Norwegian Centre for Research Data (NSD) and inclusion of data from Study 2 was approved by the Regional Committees for Medical and Health Research Ethics (REK). All participants gave informed, written consent.

Consent for publication

Not applicable.

Competing interests

The authors declare that they have no competing interests.

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Publisher's Note

Emotional well-being in day care services for people with dementia – a comparative study between farm-based day care and regular day care

Finnanger-Garshol, B., Pedersen, I., Patil, G., Eriksen, S. & Ellingsen-Dalskau, L.

Manuscript

Paper II

Emotional well-being in day care services for people with dementia – a comparative study between farm-based day care and regular day care

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Abstract

Background and aim: There is a focus on how to provide care for the increasing number of people with dementia, and day care services have been highlighted as an important service. The present study aims to investigate potential differences between two types of day care settings, farm-based day care and regular day care, with regards to the emotional well-being of the participants. Additionally, it aims to investigate the different aspects of the day care settings association with emotional well-being.

Method: We used The Maastricht Electronic Daily Life Observation-tool (MEDLO) to observe and register different aspects of daily life at day care services. Observations took place at 10 FDCs, with 42 participants, and 7 regular day care centres, with 46 participants. Observed mood was seen as an indicator for the emotional wellbeing of the participants and used as the primary outcome.

Results: The analyses showed a general positive mood for all participants, regardless of day care service. The unadjusted analyses showed more positive mood for the participants at FDCs across a range of factors compared to regular day care. The linear mixed model showed an association between attending FDCs and positive mood ($p= 0.002$). Regardless of service type the activities exercise and dancing ($p= 0.003$), and quiz, music and spiritual activities ($p< 0.001$) were associated with positive mood. Social interaction, either with one ($p< 0.001$) or two or more ($p< 0.001$), were also associated with positive mood regardless of service type.

Conclusion: We found a positive association between FDCs and emotional well-being, potentially a reflection of the positive influences of the farm setting and the service providers at FDCs. Regardless of setting, social interaction was positively associated with emotional wellbeing. The same was true for the activities quiz, music and spiritual activities and exercise and dancing, all of which could be considered social activities. This highlights the importance of the social aspect of the day care services and future research should investigate how one can facilitate good social interactions at day care services.

Introduction

Dementia is one of the major causes of disability and dependency among older people worldwide, and affects not only the people who have it, but also their next-of-kin and informal caregivers (World Health Organization, 2012). The number of people with dementia is expected to rise in the coming years (Prince et al., 2013) and the WHO as issued a "Global action plan on the public health response to dementia" towards achieving physical, mental and social well-being for people with dementia. This action plan states that people with dementia should a receive care according to their wishes and preferences and be empowered to live in the community (World Health Organization, 2017). Day care services for people with dementia have been suggested as a setting to ensure socializing, meaningful activities and well-being for home-dwelling people with dementia and respite for their caregivers and family (Ministry of Health and Care Services, 2007, 2015; World Health Organization, 2012). Given this focus, it is therefore important to investigate whether the stated goals of day care services for people with dementia are achieved, such as if the participants experience well-being while at the services.

In Norway, there are different types of day care services for people with dementia. The most common one is so-called regular day care centers located at already existing services, often long-term care facilities or retirement homes, in the municipality (Gjøra, Eek, & Kirkevold, 2015). Another complementary type is the farm-based day care services (FDCs), which are day care centers located at farms. FDCs in Norway are structured and organized similarly to the regular day care centers but differ in the type of care setting. FDCs use the farm setting og farm resources actively in the day care service, for example through using farm activities as a part of the service (Ibsen, Eriksen, & Patil, 2018). FDCs are a type of care farm, and as such fall under the umbrella term nature-based interventions (Shanahan et al., 2019). A few studies have compared the two care settings. Studies have found that the environment at FDCs were more homelike compared to the more institutional environment at regular day-care services, and that the farm setting enabled activities and collaboration between participants and staff (Myren, Enmarker, Hellzen, & Saur, 2017), and participants at farm-based day care were more actively involved in daily activities compared to those at regular day care (Schols & van der Schriek-van Meel, 2006). De Bruin et al. (2009) found that activities at FDCs were more varied, took place outside more often and required higher levels of physical effort than activities at regular day care. Similarly, Finnanger-Garshol, Ellingsen-Dalskau, and Pedersen (2020) found increased levels of physical activity at FDCs compared with regular day care. Lastly, Ellingsen-Dalskau, de Boer and Pedersen (In press), a study from the same project as the present study, found that attending FDCs lead to more physical effort, more time spent outdoors, and more social interaction and they observed more positive emotions among the participants.

Well-being has been described as multi-dimensional construct, and is often divided into subjective and objective well-being (Linton, Dieppe, & Medina-Lara, 2016). One noted component of subjective well-being is the affective component, the one related to emotions and how one is feeling, such as happiness (Linton et al., 2016). In the current paper we refer to this part of the well-being construct as emotional well-being, and we view it both as a goal in itself, and as an important part of a broader concept of quality of life. This is in line with Lawton (1991), and his concept of psychological well-being as an important domain of quality of life. While little research has been conducted on subjective-wellbeing and people with dementia specifically (Martyr et al., 2018), there has been some research looking at what influences mood and affect in people with dementia, primarily in nursing homes. Social interaction has been found to be linked to positive affect (Jao, Loken, MacAndrew, Van Haitsma, & Kolanowski, 2018) and better mood (Beerens et al., 2018). There is also evidence for an impact of individually tailored activities (Han, Radel, McDowd, & Sabata, 2016; Möhler, Renom, Renom, & Meyer, 2018) and physical activity (Brett, Traynor, & Stapley, 2016) on mood and affect.

Across the different settings, previous research on day-care services has predominantly focused on cognitive function, activities of daily life and neuropsychiatric symptoms, and a review (Reinar, Fure, Kirkehei, Dahm, & Landmark, 2011) found only two studies that focused on the participants wellbeing. The first (Droes, Breebaart, Ettema, van Tilburg, & Mellenbergh, 2000) found no difference in negative emotions between participants at day care services and those participating in an integrated family support program. The other study (Zank & Schacke, 2002) found a positive effect on life satisfaction for participants attending day care services compared with not attending any day care services. Later research investigating quality of life for people with dementia attending day care services have found improved quality of life compared to other groups (Olsen et al., 2016; Rokstad et al., 2017). De Bruin, Buist, Hassink, and Vaandrager (2019) found that participants at nature-based day care services for people with dementia felt that attending these services contributed to their well-being. While the participants well-being and quality of life is a very important outcome, none of the presented studies took into account the well-being of the participants while at the services and overall there is little research on this in the available literature, with the exception of Ellingsen-Dalskau et al. (in press).

The present study therefore aims to build on the observations by Ellingsen-Dalskau et al. (in press) to investigate the association between the different aspects of the day care services and the activities provided with emotional well-being, and to investigate if there are any potential differences between farm-based day care services and regular day care services.

Material and Methods

This study is a part of a larger project investigating FDCs in Norway consisting of several work packages. A protocol for parts of the project has been published (Eriksen et al., 2019).

Design

The current study is an observational study based on ecological momentary assessments of participants from two different types of day care, FDCs and regular day care services. Momentary assessments enabled us to observe and compare the potential differences regarding aspects of daily life related to engagement, affect, social interaction, physical effort and physical location. This provided insights into the content of the day care services and the participants response to the contents.

Recruitment

Care farms offering day care services for people with dementia were approached to participate in the study. These were located in different regions of Norway. Simultaneously, regular day care centers were recruited from the same geographical area. Recruitment was conducted from November 2017 to May 2018. As the included FDCs had generally smaller groups, more FDCs than regular day care centers were recruited so as to have approximately the same number of participants in each group of day care service. In the end 10 FDCs with 42 participants and 7 regular day-care centers with 46 participants were recruited, totaling 17 day-care centers and 88 participants. As the current study was conducted anonymously, no demographic information is available for the participants.

Setting

The recruited FDCs were situated at ordinary farms and most often had their own building. The farms had varying degrees of conventional farming activities, and the activities at the FDCs could include some or none of these. All the recruited FDCs had access to different outdoor areas, for example courtyards, gardens, fields and walking trails. They also had access to other farm buildings, such as barns, workshops or woodsheds (Ellingsen-Dalskau et al., in press).

The recruited regular day care centers were situated at or near residential nursing homes but had their own staff. The regular day care centers often had access to additional services located at the nursing homes, such as hairdressers, doctors' offices, gyms and cafeterias. In addition, all regular day care centers had access to outdoor areas, with several having patios, walking trails or gardens (Ellingsen-Dalskau et al., in press).

Data Collection

We conducted data collection between March and June 2018. We spread the observations at FDCs and at regular day care centers evenly within this period to account for any seasonal variations. The observations were conducted by three researchers working in alternating pairs. Observations started in the morning with a meeting with the staff at the day care center to plan the day. Staff were informed that they could at any time stop the observations if any of the participants did not feel comfortable with the situation. The ensure that the observations were as unobtrusive as possible, the observers greeted the participants when they arrived and often participated in half of the morning meal before starting their observations. An ordinary day often consisted of breakfast in the morning, a period of activities or relaxation, then a coffee break in the middle of the day, followed by another period of activities or relaxation, before ending with dinner in the afternoon. The observers did two hours of observations in the morning, followed by a 30 minutes break, and then two hours of observations in the afternoon. This observational pattern meshed well with the opening hours of most day care centers. Participants were observed in random order for one minute, three times an hour, for a total of 4 hours. This resulted in 12 observations for each participant leading to a total of 1056 observations, 504 from the FDCs and 552 from regular day care centers.

Measures

We used the Maastricht Electronic Daily Life Observation-tool (MEDLO) (de Boer, Beerens, et al., 2016) to observe and register the different aspects of daily life at the day care services. MEDLO has been shown to be both valid and reliable (de Boer, Beerens, et al., 2016). Additionally, we piloted the tool at one FDC and one regular day care center to ensure inter-rater reliability. Observed aspects of the daily life at the day care centers included: Mood, activity, engagement, physical effort, location and social interaction (Table 1).

Table 1: Categories of mood, activities, engagement, physical effort, social interaction and location as used during analyses and observation

Aspects of daily life	Categories used in analysis	Categories registered during observation
Mood	1: Great signs of negative mood	Great signs of negative mood
	2: Considerable signs of negative mood	Considerable signs of negative mood
	3: Small signs of negative mood	Small signs of negative mood
	4: Neutral mood	Neutral mood
	5: Small signs of positive mood	Small signs of positive mood
	6: Considerable signs of positive mood	Considerable signs of positive mood
	7: Great signs of positive mood	Great signs of positive mood
Activity	Sitting	Sitting
	Eating/drinking	Eating and drinking
	Quiz/music/spiritual	Playing cards, playing a game, doing a puzzle; Music and singing; Handcrafts/arts; Spiritual or religious activity
	Walking outdoors	Walking outdoors
	Exercise and dancing	Chair exercise/sports; Dancing; Walking indoors (does not include pacing)
	Reading	Reading (being read to), writing, crossword puzzle; Watching television or listening to the radio
	Farming and animal activities	Gardening, taking care of plants; Maintaining the farm; Working with firewood; Cultivation of grains, fruits, berries etc.; Interacting with pets; Working with animals (physical contact); Working with animals (no physical contact); Interaction with farm animal (including observing animals)
	Domestic and cooking	Domestic activities Cooking and preparing food
	Self-care	
	Social activities	
	Unobservable/other	Unobservable; Other

Engagement	0: Not engaged in activity	Sleeping; Gazing in the air; Focus on something else than activity
	1: Engaged in activity	Focus on activity taking place Active participation in activity
Physical effort	1: Sedentary	Lying or sitting without movements; Sitting quietly (awake)
	2: Light activity	Light-to-moderate sitting activities; Standing or light-standing activity
	3: Moderate activity	Standing activity or walking; Walking activity or cycling; Whole-body movements
Location	0: Indoors	Indoors at the unit; Indoors outside the unit
	1: Outdoors	Being outdoors
Social Interaction	0: No social interaction	No social interaction; Participant attempts to interact, but gets no response; Environment attempts to interact, participant do not respond
	1: Social interaction with someone else	Social interaction with one other person
	2: Social interaction with two or more	Social interaction with two or more

In the development of the MEDLO-tool, de Boer, Beerens, et al. (2016) considered mood and agitation the most relevant aspects of emotional wellbeing in daily life. There was no observed agitation among our participants, and because of this we consider the observed mood the sole indicator of the emotional wellbeing of the participants (See table 1). Negative mood could be characterized by crying, groaning, moaning, shouting, screaming and/or tensed facial expression (e.g. frowning) or tensed body language. Positive mood could be characterized by smiling, chuckling, laughing, relaxed facial expression and body language and/or humming a tune. For both types content and tone of verbal and non-verbal interactions gave added information about the mood. Mood was considered as neutral when no negative or positive mood was observable (de Boer, Hamers, Zwakhalen, Beerens, & Verbeek, 2016).

Activity was rated based on the activities the participants engaged in (see table 1). This consisted of 32 different categories in the original MEDLO (de Boer, Hamers, et al., 2016), but version used in the present study was based on further development (Ellingsen-Dalskau et al., in press) which included expanding the farm work category. Based on the different rated activity categories, eleven main categories were established: sitting, eating and drinking, quiz, music and spiritual, walking outdoors, exercise and dancing, reading, farming and animal activities, domestic and cooking, self-care, social activities and unobservable/other.

Engagement was rated based on the participants engagement in the observed activities (See table 1). In the present study this was dichotomized into not engaged in the activity and engaged in the activity. Those not engaged were observed to be sleeping, gazing or focusing on something else than the activity. Those engaged were observed to either actively participate in the activity or focus on the activity taking place.

Physical effort was rated on a seven-point scale based on the participants observed effort. These were afterwards incorporated into three categories (See table 1). The category sedentary activity included lying or sitting without movements and sitting quietly (awake). The category light activity included light-to-moderate sitting activities and standing or light-standing activity. Lastly, the category moderate activity included standing activity or walking, walking activity or cycling, and whole-body movements

Location was rated based on were the participant was located at the time of observation (See table 1). In the present study this is based on whether the observed participant was outside or not, with indoors including both being indoors at the unit and indoors outside the unit.

Social interaction was rated based on the observable social interaction of the participants. In the present study the observed interactions were group into three categories: no social interaction, social interaction with someone else or social interaction with two or more (See table 1). No social interaction was when there was no observed social interaction, when the participants attempted to interact and got no response, or when the environment tried to interact with the participant but got no response.

Statistical analyses

All statistical analyses in the present study were made using SPSS Statistics 25.0 (IBM Corp, Armonk, NY, US). P-values ≤ 0.05 were considered statistically significant. We used descriptive statistics to describe the distribution of observed variables and the mean mood scores for variables of interest. We used t-tests to investigate differences in mean mood-scores between farm-based dementia day care and regular day care for the different activities and other aspects. We used linear mixed models to further investigate the association between mood scores, type of day care services and the other factors activity, engagement, physical effort, location and social interaction. In these models the mood score was set as the dependent variable and the participants were nested within their respective day care centers to account for potential clustering. For activities, eating and drinking was set as the reference activity. Some variables were not included in the analyses because there were few observations (Social and self-care activities) or because they were present at almost all observations (Engagement). The linear mixed models were evaluated based on Akaike's information criteria (AIC), where lower score is better (Fitzmaurice, Laird, & Ware, 2012). We also looked at interaction for some variables of interest, such as mood when sitting outside, but these were not significant and not included in the final model.

Ethics

The present study was approved by the NSD. We informed both participants and their next of kin about the purpose of the study, the anonymity of the participants and the participants right to decline participation. We obtained oral or written consent from all participants.

Table 2: Descriptive statistics for the observed variables for all participants, for those attending FDCs and those attending regular day care services.

	All (n=1056)	FDC (n=504)	Regular (n= 552)
Mood (%)	5.39 (SD= 0.84)[1]	5.60 (SD= 0.78)[1]	5.19 (SD= 0.84)[1]
- Great signs of negative mood	0 (0.0)	0 (0.0)	0 (0.0)
- Considerable signs of negative mood	0 (0.0)	0 (0.0)	0 (0.0)
- Small signs of negative mood	4 (0.4)	1 (0.2)	3 (0.6)
- Neutral	127 (12.8)	28 (5.6)	99 (20.0)
- Contentment	426 (42.9)	199 (40.1)	227 (45.8)
- Considerable positive mood	344 (34.7)	207 (41.7)	137 (27.6)
- Very high positive mood	91 (9.2)	61 (12.3)	30 (6.0)
Engagement (%)			
- Engaged in activity	981 (98.4)	493 (99.4)	488 (97.4)
- Not engaged in activity	16 (1.6)	3 (0.6)	13 (2.6)
Activities (%)			
- Sitting	245 (23.2)	124 (24.6)	121 (21.9)
- Eating/drinking	231 (21.9)	109 (21.6)	122 (22.1)
- Quiz/music/spiritual	126 (11.9)	31 (6.2)	95 (17.2)
- Farming/animal activities	87 (8.2)	87 (17.3)	0 (0.0)
- Walking outside	86 (8.1)	77 (15.3)	9 (1.6)
- Exercise/dancing	71 (6.7)	6 (1.2)	65 (11.8)
- Reading	70 (6.6)	10 (2.0)	60 (10.9)
- Domestic/cooking	54 (5.1)	45 (8.9)	9 (1.6)
- Social activity	16 (1.5)	5 (1.0)	11 (2.0)
- Self-care	10 (0.9)	2 (0.4)	8 (1.4)
- Unobservable/other	60 (5.7)	8 (1.6)	52 (9.4)
Physical effort (%)	2.89 (SD= 1.45)[1]	3.31 (SD= 1.67)[1]	2.41 (SD= 0.99)[1]
- Sedentary	686 (69.2)	288 (58.1)	398 (80.4)
- Light activity	100 (10.1)	48 (9.7)	52 (10.5)
- Moderate activity	205 (20.7)	160 (32.3)	45 (9.1)
Social Interaction (%)			
- No social interaction	279 (28.0)	93 (18.8)	186 (37.2)
- Interaction with someone else	372 (37.4)	179 (36.2)	193 (38.6)
- Interaction with two or more people	344 (34.6)	223 (45.1)	121 (24.2)
Location (%)			
- Inside	776 (77.7)	285 (57.5)	491 (97.6)
- Outside	223 (22.3)	211 (42.5)	12 (2.4)
Agitation (%)			
- Not present	993 (100.0)	496 (100.0)	497 (100.0)

[1] Mean score and standard deviation

Percentages are given as valid percent

Results

Table 2 shows the distribution of observed variables. The participants at both FDCs and regular day care services were generally in positive mood and negative mood was rarely observed. The level of engagement was high in both groups and only rarely were participants not engaged. For the FDC-group the three most common activities were sitting, eating and drinking and farming and animal activities, while it for the group at regular day care were sitting, eating and drinking and quiz, music and spiritual activities. For physical effort regular day care centers has a higher percentage of sedentary activity, while FDCs have a higher percentage of moderate activity. The percentages of light activity were quite similar for both groups. Regular day care centers had a higher percentage of observed no social interaction, while FDC had a higher percentage of social interaction with two or more. For social interaction with one other person the groups had similar percentages of the observations. For the FDC-group a higher percentage of the observation were outdoors compared to the regular day care.

Table 3: Mean mood scores for various aspects of the day care services, split into participants of FDCs and participants of regular day care, and differences between services

	FDC	Regular	p-value[1]
Engagement			
- Engaged in activity	5.61 (0.77)	5.21 (0.83)	**<0.001**
- Not engaged in activity	4.00 (0.00)	4.00 (0.00)	---
Activities			
- Sitting	5.56 (0.84)	4.99 (0.78)	**<0.001**
- Eating/drinking	5.53 (0.72)	5.07 (0.72)	**<0.001**
- Quiz/music/spiritual	5.68 (0.79)	5.43 (0.90)	0.179
- Farming/animal activities	5.74 (0.75)	---	---
- Walking outside	5.58 (0.84)	5.56 (0.52)	0.921
- Exercise/dancing	5.17 (0.98)	5.60 (0.93)	0.282
- Reading	5.40 (0.51)	4.72 (0.64)	**0.002**
- Domestic/cooking	5.71 (0.66)	5.44 (0.72)	0.282
- Social activity	5.60 (0.89)	5.91 (0.94)	0.548
- Self-care	5.50 (0.70)	5.13 (0.35)	0.286
- Unobservable/other	---	---	---
Physical effort			
- Sedentary	5.56 (0.78)	5.10 (0.81)	**<0.001**
- Light activity	5.67 (0.59)	5.69 (0.85)	0.861
- Moderate activity	5.67 (0.83)	5.47 (0.81)	0.149
Social Interaction			
- No social interaction	4.88 (0.60)	4.71 (0.72)	**0.040**
- Interaction with someone else	5.53 (0.71)	5.30 (0.73)	**0.004**
- Interaction with two or more people	5.97 (0.66)	5.72 (0.78)	**0.003**

Location			
- Inside	5.62 (0.79)	5.18 (0.84)	**<0.001**
- Outside	5.58 (0.77)	5.50 (0.52)	0.730

Table 3 shows mean mood scores for the other observed variables. For the FDC-group all activities had a mean score above 5, while for the group attending regular day care, all activities except sitting and reading had a score above 5. For the other variables, only no social interaction and not being engaged in the activity had a score below 5, and this was both groups. There was a statistically significant difference in mood-scores between the groups on the activities sitting, eating/drinking and reading, with the FDC-group having higher scores. There were also significant differences between the two groups in mean mood-scores for sedentary physical effort, no social interaction, interaction with someone else, interaction with two or more people, being inside and being engaged in activity. The group attending FDC had higher mean mood scores for these variables than the group attending regular day care.

Table 4. Linear mixed model for the association between type of day care service and aspects of the day care services with emotional well-being

Variables	Estimate	95% CI	p-value
FDC[1]	0.27	0.10, 0.44	**0.002**
Sitting[2]	0.01	-0.10, 0.14	0.771
Farm and animal activities[2]	0.16	-0.09, 0.42	0.225
Domestic and cooking activities[2]	0.04	-0,17, 0.26	0.671
Exercise[2]	0.37	0.12, 0.62	**0.003**
Quiz, music and spiritual activities[2]	0.31	0.16, 0.47	**<0.001**
Reading[2]	-0.15	-0.34, 0.02	0.096
Walking outside[2]	0.04	-0.25, 0.34	0.787
Physical effort	0.01	-0.10, 0.12	0.851
Interaction with someone[3]	0.55	0.44, 0.65	**<0.001**
Interaction with two or more[3]	0.89	0.77, 1.00	**<0.001**
Being outside	0.02	-0.28, 0.08	0.703

[1] Reference: regular day care

[2] Reference activity: eating and drinking

[3] Reference: no social interaction

To further investigate the potential differences between type of day care and emotional well-being we conducted a linear mixed model (Table 4) using mood-scores as the dependent variable and adjusting for all of the observed variables. This also let us investigate which of the observed variables were associated with emotional well-being. Type of day care was statistically significantly associated with emotional well-being and attending farm-based day care was associated with higher emotional well-being than attending regular day care. Among the activities exercise/dancing and quiz/music/spiritual were both positively significantly associated with emotional well-being, while this was not the case for any of the other activities. Social interaction was also significantly associated with emotional well-being, with both interaction with someone and interaction with two or more being associated with higher emotional well-being. Neither the location, whether indoors or outdoors, nor physical effort were not significantly associated with emotional well-being.

Discussion

The present study aimed to investigate the association between the different aspects of the day care services and the activities provided with emotional well-being, and to investigate if there are any potential differences between farm-based day care services and regular day care services.

In the mixed model, we found that attending FDCs was positively associated with emotional well-being. This echoes the findings from unadjusted analyses. For while the participants emotional well-being was generally positive at both types of day care services, participants at FDCs had more positive emotional well-being for sitting, eating and drinking, reading, when they were sedentary, for all types of social interaction and for when they were inside. For all other factors there were no significant difference between FDCs and regular day care.

That FDCs provide activities in a nature setting can be one the reasons why locating day care services for people with dementia in a farm context is positively associated with emotional well-being. As a type of NBI, FDCs share this type of setting with other interventions aimed at promoting health and well-being (Shanahan et al., 2019). Markevych et al. (2017) notes different pathways that nature can influence health and well-being in people. One pathway relevant to mood can be restoration, the restoring of mental capacities through exposure to nature and green space. This pathway bases itself on the nature's potential to evoke positive emotions in people, which is linked to nature's stress-reducing effect (Markevych et al., 2017), and is grounded in restorative theories, such as the stress reduction theory (Ulrich et al., 1991). FDCs could be viewed as having a more immediate access to nature and green-space and this could positively influence the well-being of the participants. The farm setting also includes farm and animal activities. While these activities were not significant in the analyses, they were only present at the FDCs and as such might still help explain the difference between the two services. Soga, Gaston, and Yamaura (2017) for example, found that gardening has a positive impact on life satisfaction, mood and positive affect. Further, animal interactions have been found to have a positive effect on social behavior, agitation/aggression and quality of life (Yakimicki, Edwards, Richards, & Beck, 2019).

The variety of activities at the FDCs could also explain the association with emotional well-being. Previous research (De Bruin et al., 2009) has noted that activities at FDCs were more varied than at regular day care centers. This variation might lead to less boredom and fatigue, in that there is a more constant shift between activities instead of a limited selection that is just repeated. In addition, the variety of activities available might facilitate tailoring the activities to the individual. Research has found that activities at FDCs tended to be more individually tailored than the activities at regular day care services (De Bruin et al., 2009). Here the role of the service provider is also important, and within research on care farming in general, several studies have noted the importance of the service provider, both as a involved and important other (Hassink, Elings, Zweekhorst, van den Nieuwenhuizen, & Smit, 2010; Steigen, Kogstad, & Hummelvoll, 2016) and as a supporter of and facilitator for the participants (Ellingsen-Dalskau, Morken, Berget, & Pedersen, 2016; Pedersen, Ihlebaek, & Kirkevold, 2012; Sudmann & Børsheim, 2017). Through this, and based on their knowledge of the farm context and the activities, the service providers at FDCs can facilitate individually tailored activities. While regular day care service might also focus on individually tailored activities, Strandenæs, Lund, and Rokstad (2019) found that staff at regular day care seemed to have insufficient knowledge on how to offer individually tailored and structured activities. Such individually tailored activities could result in better mood while performing said activities. A review based on only randomized controlled trials or clinical trials conducted within long-term care for people with dementia found some, if uncertain, evidence that individually tailored activities could influence affect and mood (Möhler et al., 2018). Han et al. (2016) included a wider selection of studies in their review and found that individualized social and leisure activities could have a positive impact through improving engagement and affect, and by reducing agitation and withdrawn behaviour.

In the mixed models we found that among the activities exercise and dancing and quiz, music and spiritual activities were both positively associated with emotional wellbeing. Social interaction, both with someone and two or more, were also positively associated with emotional well-being. The social aspect can help explain a large part of the association between the activities and social interaction with emotional well-being. Helliwell and Putnam (2004) introduced something they called the social context of well-being. In their research they found that, in the general population, social capital, e.g. work-place ties and friendships, were linked with subjective well-being. There is a seemingly clear connection between social interaction and developing social ties, and research has found that people with dementia appreciate the opportunity to be together with their peers (Eriksen et al., 2016). Among people with dementia in long-term care social interaction has been linked with better mood (Beerens et al., 2018) and positive affect (Jao et al., 2018). In addition, the activities exercise and dancing, and quiz, music and spiritual activities could also foster such social ties through shared experiences between the participants, and by giving them someone to interact with and something to interact about. Further, the activities might influence emotional well-being more directly. As mentioned, we view emotional well-being as also being a part of quality of life and the activities found to be associated with emotional well-being in this study, can also be linked with quality of life. Holopainen, Siltanen, Pohjanvuori, Makisalo-Ropponen, and Okkonen (2019) found in their review that cognitive stimulating activities, music, exercise and spirituality could have a positive effect on quality of life.

Methodological considerations

One major strength of the present study is the use of momentary assessments as these allows us to gather information about different aspects of the participants daily life at the services in real time, instead of depending on data based on proxy-assessments or retrospective thinking. However, due to the momentary nature of the assessments, we do not know if any positive mood persisted after leaving the day care services or its impact on their quality of life. Further, we cannot know exactly what the person was feeling, only their external communication of this. As such, activities could have given the participants a sense of well-being without it necessarily translating into observable cues. A limitation of the study is the lack of demographic data on the participants of the study. Previous research has indicated that there might be differences between the groups (Ibsen, Kirkevold, Patil, & Eriksen, 2019) which we were not able to account for. The inclusion of such demographic data was planned, but due to practical and logistical reasons this was deemed impossible. Further, the way day care services are organized precluded any form of randomization of the participants. Lastly, the nature of the data lets us say something about associations between different factors and mood, but not anything about the causality of the relationships.

Conclusion

The present study found a positive association between FDCs and emotional well-being, reflected by higher emotional well-being across a variety of activities and factors when compared to regular day care services. This is potentially a reflection of the positive influences of the farm setting, and the activities and service providers at FDCs. Across both settings, social interaction was positively associated with mood. The same was true for the activities quiz, music and spiritual activities and exercise and dancing, all of which could be considered social activities. This highlights the importance of the social aspect of the day care services and future research should investigate how one can facilitate good social interactions at day care services.

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Quality of life in people with dementia attending farm-based dementia day care – A comparative, longitudinal study

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Submitted

Paper III

Quality of life in people with dementia attending farm-based dementia day care – A comparative, longitudinal study

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Abstract

Background and objective: The adherent symptoms of dementia can profoundly affect the quality of life of people with dementia. Day care services for people with dementia have been suggested as settings with the potential to improve quality of life. We aimed to explore the association between farm-based dementia day care and quality of life, and the individual and contextual factors associated with quality of life.

Research design and method: A longitudinal study including pairs of attendees and next-of-kin from farm-based dementia care (n=45) and regular dementia day care (n=100) in Norway. Participants completed standardized measures for quality of life, wellbeing and other relevant outcomes at different time points over one year. We used linear regression and linear mixed models to analyses the relationships between these and the two types of day care.

Results: We found a larger, but not clinically significant, decrease in quality of life after 12 months among participants of farm-based dementia day care compared to those at regular day care. Both groups had high self-reported quality of life, which stayed high across the 12 months. Further analyses suggested that changes in the social domain of quality of life was the main contributor to the difference between the two groups. Additionally, in with-in group analyses we found that the service-related factors, time spent outdoors at the service and number of participants at the service, were associated with quality of life for the participants at farm-based day care.

Discussion and implications: There are seemingly no clear difference in the association between type of day care and quality of life. Time spent outdoors and number of participants at the service were positively associated with quality of life among those attending farm-based dementia care suggesting that the influence of these factors should be further explored.

Introduction

A common complication in dementia is the occurrence of neuropsychiatric symptoms (Lyketsos et al., 2002; Savva et al., 2009), which profoundly affect the quality of life(QOL) of people with dementia (World Health Organization, 2012). Internationally (Merkuri et al., 2017; World Health Organization, 2012) there has been an increased focus on ensuring QOL for people with dementia and QOL has also been noted as an important outcome measure in dementia care research (Moniz-Cook et al., 2008).

QOL is defined by the WHO 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, standards and concerns” (WHOQOL Group, 1995). QOL is considered a complex concept (Haraldstad et al., 2019), and there is no current consensus on the meaning of QOL for people with dementia (O'Rourke, Fraser, & Duggleby, 2015). One attempt at describing QOL for people with dementia is Lawton (1983, 1997), who argued that QOL for older people is composed of the domains: behavioural competence, perceived QOL, psychological well-being and the objective environment. Another way of describing QOL is as emotional wellbeing, as positive affect and enjoyment of activities (Albert et al., 1996).

Concurrently with the discussion of what constitutes QOL for people with dementia, researchers have investigated which factors influence QOL and what interventions can impact QOL. In a review Martyr et al. (2018) found that factors related to relationships, social engagement and functional abilities were associated with higher QOL, while factors associated with poor physical and mental health, for example depression, and poor carer well-being were associated with lower QOL. Another recent review came to similar conclusions (Holopainen, Siltanen, Pohjanvuori, Makisalo-Ropponen, & Okkonen, 2019). They also found that activation of people with dementia, group-based physical activity, music, social support and interaction with animals were interventions associated with improved QOL (Holopainen et al., 2019).

One potential way of providing such activities for people with dementia is day care services. In the Norwegian context, day care services are considered settings where the participants can do meaningful activities, and experience coping and wellbeing (Ministry of Health and Care Services, 2015). Day care services for people with dementia in Norway are generally located at already existing institutions in the municipalities, e.g. long-term care facilities, (Gjøra, Eek, & Kirkevold, 2015). In this paper, these are referred to as regular day care services for people with dementia. The Dementia Plan 2020 highlights the need for diversifying day care services for people with dementia and notes farm-based dementia day care services (FDCs) as an innovative service for people with dementia. In Norway, FDCs are organized similarly to regular day care services, but use the farm setting and farm resources as an integrated part of the service (Ibsen, Eriksen, & Patil, 2018). Farms are also being used as a care setting for people with dementia elsewhere in Europe, such as in the Netherlands, and in the US and Japan (Buist, Verbeek, de Boer, & de Bruin, 2018). Sempik, Hine, and Wilcox (2010) defines care farming as the use of commercial farms and agricultural landscapes as a base for promoting mental and physical health, through normal farm activities, for example horticulture, animal husbandry and harvesting crops. Studies investigating farms as a care setting for people with dementia have found that they provide contact with nature and animals (Sudmann & Børsheim, 2017), stimulate social participation (de Boer, Hamers, Zwakhalen, Tan, Beerens, et al., 2017; de Bruin et al., 2015), dietary intake (de Bruin et al., 2010), and physical activity (de Boer, Hamers, Zwakhalen, Tan, Beerens, et al., 2017; de Bruin et al., 2009; Garshol et al., Submitted). Several of these factors have been noted to improve QOL in people with dementia in general (Holopainen et al., 2019).

Studies have investigated the effects of day care services on QOL for people with dementia. A review (Reinar, Fure, Kirkehei, Dahm, & Landmark, 2011) did not find sufficient evidence to for an effect on QOL, nor did they find evidence for an effect on physical activity. The review did find some evidence signifying that attending such services could potentially lead to lower incidence of behavioural problems, less use of psychiatric medication and less burden for carers. Studies have found that people with dementia attending day care services have higher QOL than people with dementia living in nursing homes (Olsen et al., 2016) and home-dwelling people with dementia who did not attend any services (Rokstad et al., 2017). Additionally, participants at nature-based day care services for people with dementia indicated that attendance positively influenced their wellbeing (de Bruin, Buist, Hassink, & Vaandrager, 2019). For farm-based services, one study found that participants at FDCs showed more positive mood while at the service than participants at regular day care (Ellingsen-Dalskau et al., submitted). Another study investigated QOL in farm-based nursing homes for people with dementia and found that they scored higher on QOL than those living in traditional nursing homes (de Boer, Hamers, Zwakhalen, Tan, & Verbeek, 2017). Lastly, one study found an association between time spent outdoors and higher QOL among those attending FDCs, but it also noted the need for longitudinal studies to further investigate which factors are associated with QOL

(Ibsen, Kirkevold, Patil, & Eriksen, 2019). Overall there is little research on day care services and their impact on QOL, and even less on the impact of FDCs on QOL.

Based on the available research on factors affecting QOL and on the farm as a care setting, we assume a positive association between QOL and attending FDCs. The present study therefore aims to investigate this potential association by comparing QOL over time for attendees of FDCs with attendees of regular day care. Additionally, the study will look at QOL over time within the FDC-group and which individual and contextual factors are associated with it.

Materials and methods

Design

The present study is an observational study conducted between 2017-2019. It is based on longitudinal data collected from participants of FDCs over a one-year period as a part of the Farm-based Dementia Care-project (FDC-project) (Eriksen et al., 2019). We also included comparable data from participants attending regular day care from the Effects and Costs of a Day Care Centre Program Designed for People with Dementia-A 24 Month Controlled Study (ECOD) (Rokstad et al., 2014). We availed ourselves of ECOD-data as these were readily available, from a similar group and used similar measures.

Participants and recruitment

In the FDC-project we invited municipalities with FDCs and the FDCs themselves to participate in the project. If both consented to participate, either the service providers or a representative from the municipality approached potential participants. The inclusion criteria were: attended FDCs for at least three weeks prior to inclusion, able to express themselves verbally and have the cognitive capacity to participate, lived with next of kin or saw them at least once a week, and had a next-of-kin (18 years or older) who were willing to participate and saw the person with dementia at least once per week (Eriksen et al., 2019). If these participants then consented to be contacted, the project researchers would schedule the first round of interviews/data collection. The recruitment period lasted from early 2017 to early 2018, while the data collection period lasted from early 2017 to early 2019. 94 dyads of people with dementia and next-of-kin were included at start-up, of these 45 dyads remained when data collection was completed.

In ECOD, participants were recruited through invited day care centres. The inclusion criteria were: 65 years or older, had an existing dementia diagnosis, a mini-mental state examination (MMSE) score equal to or more than 15, had the capacity to give informed consent, attended a day care centre at least twice a week, not attended a day care centre for more than one year, and had a carer willing to participate and who saw the person with dementia at least once a week (Rokstad et al., 2014). The recruitment period lasted from late 2013 to mid-2015, and data collection from late 2013 to mid-2017. 183 dyads were recruited (Rokstad et al., 2017), of which 100 were still in the project at 12 months.

Data collection

In the FDC-project we conducted data collection at “baseline”, after 6 months and after 12 months. In ECOD data collection took place at “baseline”, after 12 months and after 24 months. In the comparison between service types, data from baseline and 12 months from the two projects are included. In both projects, researchers and research assistants collected the data. All data collectors attended a training day on the use of the different measures before data collection began. Data collection was conducted as interviews with the dyads using standardized assessment forms. The interviews usually took place in the home of the person with dementia and lasted approximately one hour, with one researcher interviewing the person with dementia, and the other interviewing next-of-kin. In addition, next-of-kin also filled out some of the forms by themselves.

Measures

Both projects collected demographic information such as age, gender, education level, previous illness, living situation etc. Further, they included several standardized measures to gather data on variables of interest, both to include as potential confounders and as factors that could be associated with QOL. We based the inclusion of these in the present paper on the available literature on QOL.

QOL

We used QOL in Alzheimer’s Disease (QoL-AD) to measure QOL in both the persons with dementia and their next-of-kin (Logsdon, Gibbons, McCurry, & Teri, 1999). The domains proposed by Lawton were used in the development of this measure (Logsdon et al., 1999; Logsdon, Gibbons, McCurry, & Teri, 2002). For the persons with dementia we collected both self-reported and proxy-reported data. The QoL-AD is a 13-item questionnaire where each item is rated from 1 to 4 (1 is “Poor”, 2 is “Fair”, 3 is “Good” and 4 is “Excellent”). The ratings on the different items are summed up in a score ranging from 13 to 52 points (Logsdon et al., 1999). Cut-offs for the QoL-AD score have been suggested, with a score of less than 33 being low QOL, 33 to 37 being moderate QOL and more than 37 being high QOL (Conde-Sala et al., 2016). Additionally, several studies have used a change equal to or greater than 3 points as clinically significant (Beerens et al., 2015; Clare et al., 2014; Conde-Sala et al., 2016; Hoe et al., 2009; Selwood, Thorgrimsen, & Orrell, 2005). In order to further explore the aspects of QoL-AD we elected to include subscales from Revell, Caskie, Willis, and Schaie (2009). These were Physical QoL-AD (Physical health, Energy, Ability to do chores and Ability to do things for fun), Social QoL-AD (Living situation, Family, Marriage, Friends, Money) and Psychological QoL-AD (Mood, Memory, Self as a whole, Life as a whole).

Physical activity

To measure physical activity levels, we asked the average number of times the participants were physically active in a week. Physical activity was defined as a period of activity with a duration of at least 30 minutes where the participant had felt out of breath and/or increased body temperature.

Depressive symptoms

We used the Montgomery and Asberg Depression Rating Scale (MADRS) to measure depressive symptoms. MADRS consists of 10 items, rated 1 to 6, resulting in a score of 0 to 60. A higher score indicates more severe depressive symptoms (Montgomery & Asberg, 1979).

Neuropsychiatric symptoms

To measure neuropsychiatric symptoms among the participants we used the Neuropsychiatric Inventory (NPI-Q). NPI-Q was rated based on interviews with next-of-kin. It consists of 12 items which are rated as present or not present and further rated based on severity (1-3) giving a sum between 0-36. Higher scores indicate a higher degree of neuropsychiatric symptoms (Kaufer et al., 2000).

Medical comorbidity

We used the General Medical Health Rating (GMHR) to measure medical comorbidity. This is a rapid global rating scale of medical comorbidity in people with dementia and is rated on a scale from 1 to 4, with 1 being "Poor" and 4 being "Excellent" (Lyketsos et al., 1999).

Degree of dementia

To measure degree of dementia we used the Clinical Dementia Rating (CDR). This is a 6-item scale, each rated from 0 to 3, were 0 is no dementia, 0.5 is possible dementia, 1 is mild dementia, 2 is moderate dementia and 3 is severe dementia (Hughes, Berg, Danziger, Coben, & Martin, 1982). The ratings are then translated into an overall score, giving precedence to memory. This score is based on the same 0 to 3 scale. Alternatively, the ratings can be summed up in a sum-of-boxes, ranging from 0 to 18 (O'Bryant et al., 2008). This study uses the sum-of-boxes in the analyses.

We also gathered data based on additional measures for the group attending FDCs, which are presented below. These were only available for the FDC-group and are therefore were not included in the comparative analyses between FDC and ECOD.

Well-being

We used the World Health Organizations Well-being Index (WHO5) to measure well-being. It is a short generic global rating scale that measures subjective wellbeing (Topp, Ostergaard, Sondergaard, & Bech, 2015) and is considered to give an insight into people's positive psychological health and more specifically their positive affect (Nes, Barstad, & Hansen, 2018). It was included in the present study to measure QOL from a different perspective than QoL-AD. The WHO5 consists of 5 items/statements, rated from 0-5, with 0 being "At no time" and 5 being "All the time". The ratings are summed up to give a score between 0-25. The score is multiplied by 4 to give a percentage scale from 0 to 100. A change of 10% is considered a significant change (Topp et al., 2015). WHO-5 has not been validated for use with people with dementia, but it has been validated for older people (Heun, Burkart, Maier, & Bech, 1999), and it has been used previously in dementia-related research (Jha, Jan, Gale, & Newman, 2013; Rippon et al., 2019).

Social support

To measure perceived social support, we used the Oslo Social Support Scale (OSS3). This scale consists of three items. One item on how many people one feels one can rely on (given as number of people); one item on how much concern people show (rated from none to a lot); one item on how easy it is to get help from the neighbours (rated from very easy to very difficult) (Dalgard et al., 2006). The responses are scored and gives a sum ranging from 3 to 14. 3-8 constitutes "poor support", 9-11 constitutes "moderate support, while 12-14 constitutes "strong support" (Bøen, Dalgard, & Bjertness, 2012). OSS3 is not validated for people with dementia but has previously been used in research with older people (Bøen et al., 2012).

Service-related variables

We also collected data related to FDC-participation, such as average time spent outdoors per week at the FDC, hours at the FDC per week, number of participants each day and group size, and the presence of animals. These were gathered for another study in FDC-project by Ibsen et al. (2018). Average time spent outdoors and hours at the FDC per week were constructed using longitudinal data on attendance from each participant and information from the farmers on average time spent outdoors for the group at baseline. The other variables were based on information gathered from farmers around baseline and assumed to be constant. Only one participant did not have access to animals, and the variable was therefore not included in the analyses.

Other measures

Both the FDC-project and ECOD included measures for personal activity of daily living (PADL) and instrumental activities of daily living (IADL) (Lawton & Brody, 1970), awareness of memory loss (REED) (Reed, Jagust, & Coulter, 1993) and proxy-reported depression (Cornell Scale for Depression in Dementia) (Alexopoulos, Abrams, Young, & Shamoian, 1988). None of these were included in the final analyses and are therefore not described in length.

Statistical analysis

All imputation and statistical analyses in the present study were made using SPSS Statistics 25.0 (IBM Corp, Armonk, NY, US). P-values ≤ 0.05 were considered statistically significant. We assumed missing values from the measures were missing at random and did the imputation at the item level. We performed imputations only in cases were the respondent had answered at least 50% of the items in the measurement in question. Imputed values were random numbers drawn from the observed distribution in the dataset. The data from ECOD were imputed along the same guidelines and in a similar fashion (Rokstad et al., 2017). We used descriptive statistics to describe the people attending FDC and people attending regular day care. We used independent samples t-tests to investigate potential differences between them. To further investigate the association between type of day care and QOL over time at 12 months we used linear regression and controlled for baseline QOL. ANOVA was used to see differences between the three time points for the group attending FDCs. Lastly, we used linear mixed models to investigate factors associated with QOL among people attending FDCs. Linear mixed models were chosen because of their ability to incorporate all three data collection points. In both the linear regression analyses and the linear mixed models, we built several models. These were founded on logical assumptions based on previous research and bivariate analyses of QoL-AD and other variables in the dataset. Covariates were discarded from the models based on whether they significantly contributed to the model, as measured by r (Field, 2013), for the linear regression, and Akaike's information criterion (AIC) (Fitzmaurice, Laird, & Ware, 2012), for the linear mixed models. Significant covariates were not discarded. For bivariate correlation between independent variables a recommended cut-off is 0.7 (Pallant, 2013), but due to limitations based on the size of the data set, we also discarded some variables with moderately high correlation (more than 0.5, but less than 0.7). Data is only shown for the final models.

Ethics

The FDC-project was approved by the Norwegian Centre for Research Data (No. 49,799) (Eriksen et al., 2019), and ECOD was approved by the Regional Committee for Medical and Health Research Ethics in South-East Norway and registered in Clinical Trials (NCT01943071) (Rokstad et al., 2014). The inclusion of data from ECOD in the FDC-project was approved by the Regional Committee for Medical and Health Research Ethics. All participants gave informed written consent and were informed that they could at any time withdraw from the studies.

Table 1. Descriptives of participants attending FDCs and participants attending regular day care.

Variable	Farm-based Dementia Care (n= 45)	Regular day care centers (n= 100)	p-value for difference[1]
Gender (%)			0.013
Women	17 (37,8%)	60 (60,0%)	
Men	28 (62,2%)	40 (40,0%)	
Age (SD)	74.73 (8.17)	81.47 (6.48)	<0.001
Education level (%)			0.331
Primary school	17 (37,8%)	48 (48,0%)	
High School	19 (42,2%)	30 (30,0%)	
University College/University	9 (20,0%)	18 (18,0%)	
Missing	0 (0,0%)	4 (4,0%)	
Times active per week (SD)	3.20 (2.86)	1.20 (2.48)	<0.001
Time (weeks) in service before first interview (SD)	87.60 (81.31)	29.88 (21.17)	<0.001
QoL-AD Self-reported (baseline) – Sum (SD)	39.33 (4.26)	38.75 (5.25)	0.514
QoL-AD Self-reported (12 months) – Sum (SD)	38.00 (5.59)	38.79 (5.17)	0.423
QoL-AD Proxy-reported (baseline) – Sum (SD)	35.77 (4.25)	33.57 (5.23)	0.008
QoL-AD Proxy-reported (12 months) – Sum (SD)	34.80 (5.07)	32.85 (5.41)	0.045
QoL-AD (12 months) Next-of-kin – Sum	40.35 (5.69)	41.45 (5.29)	0.269
MADRS – Sum (SD)	3.29 (3.52)	4.41 (5.86)	0.256
NPI – Sum (SD)	5.00 (4.47)	6.02 (4.82)	0.259
CDR – Sum (SD)	7.72 (3.40)	8.30 (2.81)	0.292
GMHR – Sum (SD)	3.04 (0.71)	2.96 (0.71)	0.549

[1] p-values ≤0.05 were considered significant

QoL-AD: QOL in Alzheimer’s Disease, MADRS: Montgomery and Asberg Depression Rating Scale, NPI: Neuropsychatric Inventory, CDR: Clinical Dementia Rating, GMHR: General Medical Health Rating, SD: Standard deviation

Results

We present demographic variables for the FDC-group and the group attending regular day care in Table 1, along with the results of the t-test for differences. There were only significant differences for proxy-reported QoL-AD at baseline and 12 months, while no such difference was found for self-reported QoL-AD. Additionally, there were no significant differences between the two groups at 12 months for education level, MADRS, NPI, CDR, GMHR and QoL-AD for next-of-kin. We found group differences on age, gender, physical activity level and attendance time before enrolment in the project.

Table 2: Linear regression for the association between type of day care service and self-reported QoL-AD, adjusted for baseline QoL-AD

Variables	QoL-AD Sum		QoL-AD Physical		QoL-AD Social		QoL-AD Psychological	
	B	p-value[1]	B	p-value[1]	B	p-value[1]	B	p-value[1]
Day Care Service	-2.359	0.009	-0.338	0.454	-1.455	0.006	-0.616	0.089
Time in service	-0.008	0.265	-0.004	0.248	0.001	0.897	-0.003	0.270
Gender	-0.629	0.411	-0.082	0.742	-0.145	0.740	-0.281	0.368
Age	0.034	0.549	0.010	0.742	-0.002	0.956	0.018	0.430
Education level	0.486	0.339	0.364	0.161	-0.047	0.873	0.123	0.544
Times active in a week	0.324	0.040	0.129	0.108	0.071	0.430	0.096	0.135
MADRS – Sum	-0.348	0.000	-0.118	0.001	-0.114	0.004	-0.150	0.000
NPI – Sum	-0.166	0.031	-0.051	0.189	-0.033	0.452	-0.069	0.027
CDR – Sum	-0.281	0.037	-0.134	0.050	-0.155	0.048	0.014	0.801
GMHR	1.398	0.017	0.953	0.001	-0.299	0.362	0.811	0.001
QoL-AD Baseline	0.357	0.000	0.337	0.000	0.423	0.000	0.170	0.058

[1] p-values ≤0.05 were considered significant

QoL-AD: QOL in Alzheimer's Disease, MADRS: Montgomery and Asberg Depression Rating Scale, NPI: Neuropsychiatric Inventory, CDR: Clinical Dementia Rating, GMHR: General Medical Health Rating.

Comparison of self-reported and proxy-reported QoL-AD between FDCs and regular day care

Due to the group differences, we conducted an adjusted linear regression for self-reported QoL-AD at 12 months where we adjusted for QoL-AD at baseline (Table 2). This showed a significant association between type of day care and QoL-AD at 12 months. Those attending regular day care scored 2.36 points higher than those attending FDCs. We also conducted the same adjusted linear regression on the three subscales for QoL-AD. There were no significant associations between type of day care service and the score on the physical and psychological subscales. There was a statistically significant difference between the groups on the social subscale where those attending regular day care scored 1.46 points higher than those attending FDCs.

Table 3: Linear regression for the association between type of day care service and proxy-reported QoL-AD, adjusted for baseline QoL-AD

Variables	QoL-AD Sum		QoL-AD Physical		QoL-AD Social		QoL-AD Psychological	
	B	p-value[1]	B	p-value[1]	B	p-value[1]	B	p-value[1]
Day Care Service	-1.572	0.071	0.010	0.980	-1.055	0.023	-0.387	0.336
Time in service	-0.001	0.833	0.002	0.457	-0.004	0.271	0.000	0.979
Gender	0.650	0.374	0.220	0.509	0.332	0.382	0.072	0.837
Age	-0.066	0.223	-0.035	0.153	-0.040	0.166	0.001	0.957
Education level	-0.838	0.083	-0.335	0.127	-0.353	0.158	-0.099	0.666
Times active in a week	0.094	0.527	0.152	0.029	-0.066	0.389	0.048	0.490
MADRS – Sum	-0.131	0.045	-0.064	0.026	-0.010	0.762	-0.081	0.013
NPI – Sum	-0.277	0.002	-0.109	0.006	-0.093	0.037	-0.098	0.020
CDR – Sum	-0.241	0.060	-0.131	0.032	-0.075	0.254	-0.67	0.276
GMHR	1.291	0.015	1.030	0.000	-0.021	0.938	0.353	0.162
QoL-AD Next-of-kin	0.167	0.013	-0.005	0.870	0.130	0.000	0.039	0.218
QoL-AD Baseline	0.625	0.000	0.415	0.000	0.674	0.000	0.394	0.000

[1] p-values ≤0.05 were considered significant

QoL-AD: QOL in Alzheimer's Disease, MADRS: Montgomery and Asberg Depression Rating Scale, NPI: Neuropsychiatric Inventory, CDR: Clinical Dementia Rating, GMHR: General Medical Health Rating.

We also conducted an adjusted linear regression for proxy-reported QoL-AD at 12 months, adjusting for baseline QoL-AD (Table 3), and found no statistically significant association with type of day care service. Further, we found no statistically significant association between type of day care and the physical and psychological subscales. However. we did find a statistically significant association for the social subscale were the participants of regular day care scored 1.06 points higher than those attending FDCs.

Table 4: Descriptives for FDC within-group variables

Variables	Baseline	6 months	12 months	p-value[1]
QoL-AD self-reported (SD)	39.33 (4.26)	38.57 (5.13)	38.00 (5.59)	0.465
QoL-AD proxy-reported (SD)	35.77 (4.25)	35.26 (4.39)	34.80 (5.07)	0.601
WHO-5 (SD)	74.23 (16.12)	70.70 (16.53)	74.90 (17.81)	0.487
OSS3 (%)				0.437
- Poor support	4 (8.9)	4 (8.9)	4 (8.9)	
- Moderate support	19 (42.2)	17 (37.8)	22 (48.9)	
- Strong support	22 (48.9)	22 (48.9)	14 (31.1)	
- Missing	0 (0.0)	2 (4.4)	5 (11.1)	
-				
Average time spent outdoors in a week (SD)	5.09 (2.64)	5.21 (2.79)	5.40 (2.81)	0.869

[1] p-values ≤0.05 were considered significant

QoL-AD: QOL in Alzheimer's Disease, WHO-5: World Health Organization's Wellbeing Index, OSS3: Oslo Social Support Scale, SD: Standard deviation

FDC - within-group analyses

FDC-project specific variables are presented in Table 4. There were no statistically significant changes across the 12-month period for self-reported QoL-AD, proxy-reported QoL-AD, WHO-5, OSS-3 and time spent outdoors while at the farm.

We conducted a linear mixed model analysis for factors related to self-reported QoL-AD and WHO-5 over time (Table 5). For the service-related variables, more time spent outdoors and higher numbers of participants each day were significantly associated with higher QoL-AD-Sum and higher score on the WHO5. For all three QoL-AD subscales more time spent outdoors were significantly associated with higher scores on the subscale. For the psychological subscale higher numbers of participants were also significantly associated with higher scores on the subscale. For the non-service-related factors, we found that high social support (OSS3) was significantly associated with higher scores on the social subscale.

Table 5: Linear mixed model for the association between different factors and self-reported QoL-AD

Variables	QoL-AD Sum		QoL-AD Physical		QoL-AD Social		QoL-AD Psychological		WHO-5	
	B	p-value[1]	B	p-value[1]	B	p-value[1]	B	p-value[1]	B	p-value[1]
Age	0.08	0.169	0.008	0.802	0.06	0.043	0.005	0.810	-0.20	0.343
Gender	-0.21	0.836	-0.54	0.306	0.24	0.658	0.04	0.899	-4.66	0.192
Time										
2	-0.54	0.422	-0.005	0.986	-0.22	0.462	-0.32	0.252	-0.59	0.836
3	-1.32	0.117	-0.28	0.467	-0.52	0.178	-0.53	0.112	-3.92	0.099
CDR	-0.45	0.008	-0.21	0.009	-0.17	0.033	-0.02	0.699	-0.85	0.149
MADRS	-0.28	0.006	-0.01	0.830	-0.07	0.099	-0.19	<0.001	-1.38	<0.001
OSS3										
2	2.35	0.079	0.63	0.303	1.78	0.005	-0.29	0.566	2.43	0.595
3	2.02	0.137	0.20	0.745	8.06	0.001	-0.40	0.440	-4.79	0.301
Time outdoors	0.64	0.001	0.17	0.045	0.18	0.045	0.24	<0.001	1.26	0.039
Number of participants	0.86	0.019	0.33	0.072	0.24	0.199	0.30	0.016	2.41	0.052

[1] p-values ≤0.05 were considered significant

QoL-AD: QOL in Alzheimer's Disease, WHO-5: World Health Organization's Wellbeing Index, MADRS: Montgomery and Asberg Depression Rating Scale, CDR: Clinical Dementia Rating, OSS3: Oslo Social Support Scale

We conducted the same analysis for proxy-reported QoL-AD (Data not shown). None of the service-related variables were significantly associated with proxy-reported QoL-AD-Sum score or the subscales. For OSS3 we found similar results as for self-reported, and additionally, carers QoL-AD Sum was significantly associated with the proxy-reported social subscale.

Discussion

The aims of the present study were to investigate the influence of farm-based dementia day care services on QOL over time and compare it with regular day care services. Additionally, the present study wanted to investigate factors relating to different aspects of QOL, as measured by QoL-AD and WHO-5, including aspects of the FDC.

We found a statistically significant association between type of day care and self-reported QoL-AD over time, with those attending regular day care having higher scores. Previous research on farm-based dementia care has found a different association, with people at farm-based nursing homes having higher QOL than people in other types of nursing homes (de Boer, Hamers, Zwakhalen, Tan, & Verbeek, 2017). Although we found a statistically significant difference between the groups, the difference in self-reported QoL-AD (2.36 points) at twelve months was not clinically significant (≥3 points). The changes within the groups was also not clinically significant and both groups had, according to self-reported QoL-AD, high QOL (>37 points) at the beginning of the study and at 12 months. As such, there does not seem to be a substantial difference between the two day-care services when it comes to QOL as measured by QoL-AD.

For proxy-reported QoL-AD, we did not find any statistically significant associations with type of day care. For proxy-reported QoL-AD the FDC group average remained at moderate QOL (33-37 points), while the group average for those attending regular day care went from moderate to low (<33 points) QOL. Based on the cut-offs for high and moderate QOL per QoL-AD (Conde-Sala et al., 2016), differences between self-reported and proxy-reported QoL-AD were present in both groups. Differences in the rating of QoL-AD between self-report and proxy have been noted by the researchers behind the measure and they attribute it to a difference in the perception of QoL (Logsdon et al., 2002). Subsequent research has found proxy-reported QoL-AD to be consistently lower than self-reported QoL-AD (Banerjee et al., 2009; Römhild et al., 2018). Several factors have been suggested as impacting proxy-reported QoL-AD, such as carer depression (Logsdon et al., 1999, 2002) and carer burden (Logsdon et al., 2002; Sands, Ferreira, Stewart, Brod, & Yaffe, 2004). Based on current research there is no clear service-related factor to attribute the difference between self-reported and proxy-reported QoL-AD to.

For the subscales we found no statistically significant association between the physical and psychological subscales and type of day care service, neither on self-reported nor proxy-reported. This seems to indicate a similar impact of both types of day care services on these two subscales despite the different settings. Based on previous research showing higher levels of physical activity at care farms (de Boer, Hamers, Zwakhalen, Tan, Beerens, et al., 2017; de Bruin et al., 2009; Garshol et al., submitted) one would expect attending FDCs to translate into a higher score on the physical subscale, but the present results do not indicate this. This could be because the difference in physical activity levels is not large enough to translate into a difference on the subscale or because increased physical activity alone is not enough to change the score on the subscale. Another explanation could be that the subscales might not be sensitive enough to change to capture changes over time. Similar explanations could account for the lack of difference on the psychological subscale. One aspect of the subscale is mood, and a recent study (Ellingsen-Dalskau et al., submitted) found that participants at FDCs exhibited more positive mood when at the service than participants at regular day care services. Still this difference is not present in the current results. This could, similarly to the physical subscale, be because the difference is not large enough to translate into a difference on the subscale or because the difference in mood alone is not enough to change the score on the subscale.

For both groups there was a statistically significant association between type of day care service and the social subscale of QoL-AD, with those attending regular day care having a higher score. Based on our QoL-AD subscales analyses the differences between the two groups therefore seem to be rooted in the difference in the social subscale as this was the only one of the subscales that was statistically significant in both self- and proxy-reported analyses. The social subscale includes items on “Living conditions”, “Family”, “Marriage”, “Friends” and “Money”, several of which, particularly living conditions and money, day care services would not be able to influence in any noticeable degree. Previous studies on farm-based dementia care have highlighted increased social interaction among its participants compared to regular care settings (de Boer, Hamers, Zwakhalen, Tan, Beerens, et al., 2017; de Bruin et al., 2015; Ellingsen-Dalskau et al., submitted). This indicates that it is not a lack of social interaction at care farms causing the difference between the FDCs and regular day care, but rather that the main impacts on the social subscale come from factors outside the day care setting, factors we either have not measured or been able to account for.

For the FDC-group, we found no statistically significant changes between start-up, 6 months and 12 months for either QoL-AD or WHO5. The QoL-AD went slightly down for both self-reported and proxy-reported, while the WHO-5 remained stable. The stability of the WHO-5 scores over time contrasts with the relative decrease in QoL-AD scores and seems to indicate that they tap into slightly different aspects of QOL. The QoL-AD is a condition specific QOL measure measuring different domains in life (Logsdon et al., 1999), while the WHO-5 is a more generic QOL measure focusing on subjective wellbeing (Topp et al., 2015). At the same time neither had any clinically significant changes over the one-year period. This might be because the day care services have little impact on QOL, either because they do not affect QOL, or because the way QOL is measured encompasses too much for the service to make a noticeable impact. Factor analyses of QoL-AD have revealed multiple domains within the measure (Revell et al., 2009; Torisson, Stavenow, Minthon, & Londos, 2016), domains that day care services might not necessarily influence in any significant degree. The lack of changes might also be because, as has been noted for QoL-AD, QOL stays stable in people with dementia (Clare et al., 2014; Selwood et al., 2005). An alternative interpretation could be that attending day care contributes to the stability of the QOL over time.

We found several factors associated with QoL-AD and WHO-5. Among the FDC-related factors, average time spent outdoors were related to higher score on self-reported QoL-AD, including subscales, and WHO-5. Higher numbers of participants were associated with higher self-reported QoL-AD, including the psychological subscale, and higher score on the WHO-5. None of the service-related variables were associated with proxy-reported QoL-AD.

Being outdoors has been reported as beneficial for people with dementia, for example as important for their emotional wellbeing (Duggan, Blackman, Martyr, & Van Schaik, 2008; Førsund et al., 2018; Olsson, Lampic, Skovdahl, & Engstrom, 2013). More generally, Markevych et al. (2017) suggested that being outdoors in green space could affect health and wellbeing through several pathways. One relevant pathway for the farm context is instoration. Instoration is about impacting wellbeing through building capacities, for example through encouraging physical activity and promoting social cohesion (Markevych et al., 2017). Tasks at the farm could be viewed as naturally facilitating physical activity, as woodworking or harvesting for example necessitates a certain level of physical effort. Another relevant pathway is restoration. This pathway is about the restoring capacities of greenspace and bases itself on the potential stress-reducing effect of being in or viewing nature, and nature’s potential to evoke positive emotions (Markevych et al., 2017). The immediate access to green space found at farms could therefore positively influence the wellbeing of the participants at FDCs. The association between being outdoors and QoL-AD and WHO-5 might also be related to the activities conducted outdoors. Soga, Gaston, and Yamaura (2017) found a positive impact of gardening on several outcomes, including life satisfaction, mood and positive affect. The outdoors is also an environment for interactions with animals and animal assisted activities/interventions have been found to have a positive effect on QOL for people with dementia (Holopainen et al., 2019; Yakimicki, Edwards, Richards, & Beck, 2019). Since all participants, bar one, had access to animals, we were not able to investigate the direct association between access to animals and QOL. As shown, there are many potential pathways and the consistent association of time spent outdoors with the outcomes might be due to the outdoors containing all these possible influences on QOL and well-being.

The number of participants at the farm was positively associated with the psychological subscale of QoL-AD and WHO5. This association could be explained by what Helliwell and Putnam (2004) called the social context of well-being. They found that social capital, for example in the form of friendships or work-place ties, were linked with subjective well-being in the general population. De Bruin et al. (2015) noted that attending FDCs made the participants feel like a part of society and that it increased social interactions. Additionally, the participants at FDCs mentioned social participation in the form of employment or volunteer work (de Bruin et al., 2015), which could indicate that the FDCs might fill the social space formerly held by the workplace. Higher numbers of participants could mean increased opportunities for social interaction, and social interactions have been linked with positive affect (Jao, Loken, MacAndrew, Van Haitsma, & Kolanowski, 2018) and better mood (Beerens et al., 2018) among people with dementia in long term care. Additionally, people with dementia also appreciate the opportunity to be together with their peers (Eriksen et al., 2016). Martyr et al. (2018) found that factors relating to relationships and social engagement were associated with higher QOL, which is echoed in other studies that also found that the quality of relationships were related to QOL (Moyle et al., 2011; O'Rourke, Duggleby, Fraser, & Jerke, 2015). Holopainen et al. (2019) notes that studies have shown that relationships and participation improve QOL, while loneliness, a lack of interest and a feeling of not belonging decreases QOL.

For the non-service-related factors we found that perceived social support, OSS3, was significantly associated with the social-subscale of both self-reported and proxy-reported QoL-AD. OSS3 was not significantly associated with any other aspect of QoL-AD or WHO-5. This can be linked to possible the explanations for the impact of number of participants at the farm mentioned above. Further, social support has been linked with mood and well-being among older adults (Golden et al., 2009) and a lack of social support has been linked to psychological distress among older adults living at home (Bøen et al., 2012). Social support interventions can also potentially improve QOL in early stages of dementia (Holopainen et al., 2019). The fellow participants at the farm could be viewed as people willing to help or as showing interest in the person's life, which could explain the association between perceived social support and the social subscale of the QoL-AD.

Methodological Considerations

The main strength of the present study is its longitudinal and comparative perspective, based on the best available data, from a setting were practical and ethical considerations makes randomized controlled trials difficult and unfeasible. At the same time the present study has some limitations. Firstly, the data is from two different projects, both with their own inclusion criteria. The differences in inclusion criteria might suggest that the FDC-group and regular day care group are less comparable, for example when it comes to age. However, we included several covariates in our analyses to account for these differences. Neither of the groups were randomized, and recruitment was conducted through intermediaries, who might have screened the participants based on different criteria than just the inclusion criteria. This might influence how representative the samples are and the generalizability of our findings. However, based on the organization of the services in Norway, time constraint and ethical considerations, this was deemed the only option.

The two projects had for the most part different data collectors, meaning that we cannot discount inter-rater discrepancies. However, in both projects data collectors were trained along similar guidelines and both projects used the same standardized and validated instruments, potentially minimizing such discrepancies. We also do not have any pre-day care assessments for any of the groups, meaning that we cannot say anything with regards to causality. As with randomization such a pre-day care assessment would have been difficult both with regards to the organization of welfare services in Norway, and to logistical and ethical considerations. The QoL-AD subscales used in the present study are based on a different study with community-dwelling older adults (Revell et al., 2009) and this might impact its applicableness. At the same time other studies have found similar subscales with just minor differences (Torisson et al., 2016) and the subscales have been used in other studies of people with dementia (Larsson et al., 2011; Ydstebø et al., 2018)

Conclusion

The present study found no clear difference between type of day care services and their association with QoL-AD over time, with both attendees of farm-based and regular day care services retaining high self-reported QoL-AD over the one-year period. Future research should consider along which pathways day care services can be expected to influence QOL. And further, if global measures of QOL are too encompassing to be influenced sufficiently by one single intervention.

The present study further found that among participants at FDCs time spent outdoors and number of participants were factors positively associated with QOL and wellbeing, highlighting the potential positive effects of being in nature and of social interactions. Such factors could be considered and implemented across different types of day care service, but further research is needed to assess its applicability in different settings.

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