Family carers’ perspectives on care for older people living with dementia: interactions and involvement with health services, and the role of health literacy

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Abstract

Background Care policies worldwide aim to control care expenses and provide more care in peoples' homes, increasing the importance of informal care and the role of family carers'. This Ph.D. project aims to better our understanding of family carers' perspectives on care provision to older people living with dementia, and how the interplay between health services and informal carers may be enhanced to improve care provision.

Method The study followed an exploratory sequential mixed method design: Substudy 1 was based on in-depth, semi-structured interviews of 23 family carers for older people living with dementia, to explore experiences with care provision. Transcribed interviews were coded and analyzed in four steps, informed by hermeneutics, phenomenology, and thematic analysis. Building on findings from Substudy 1, Substudy 2 comprised a quantitative survey in a larger sample of 188 family carers. Results were analyzed using descriptive statistics, and multiple linear regression models were used to test assumptions that health literacy could predict carer burden, health-related quality of life, and time spent on informal care.

Results Analysis of the interviews highlight how family carers may identify care needs unmet by health services, and indicate four preventive practices employed in their care, aiming to prevent physical, emotional, economic, and relational harm. In interactions with health services, family caregivers resort to two broad involvement strategies: (1) being "the hub in the wheel", through conciliatory co-ordination; and (2) "getting the wheel rolling", using purposeful and assertive acts to improve leverage. Both strategies have costs and benefits, and use depends on available personal resources. The survey participants displayed high levels of health literacy, a partially trainable personal resource. Regression analyses indicate that higher health literacy was associated with lower carer burden, higher health-related quality of life, and less time spent on informal care.

Conclusion Family cares can be valuable resources in care provision for older people living with dementia, adding important perspectives on safety and quality of care, and facilitating co-ordination and utilization of resources. Strong partnerships between formal and informal care may benefit from awareness of interaction challenges, including involvement strategies; differences in perspectives and motivations, including preventive practices; and differences in personal resources, such as different levels of health literacy.

Sammendrag

Bakgrunn Da mange land forsøker å begrense utgifter til helsetjenestene ved å tilby flere tjenester hjemmet, blir pårørende stadig viktigere for omsorgen som gis. Denne studiens formål var å komme til en bedre forståelse for pårørendes perspektiver på demensomsorgen og forstå hvordan helsetjenestene og pårørende, sammen, kan forbedre demensomsorgen.

Metode Utforskende, sekvensiell, blandet metode ble brukt, bestående av 23 dybdeintervjuer (delstudie 1), hvor resultatene ble brukt til å designe en spørreundersøkelse som ble sendt til en større gruppe pårørende (delstudie 2). En semistrukturert intervju-guide ble brukt i 23 intervjuer , på et utvalg bestående av maksimal variasjon av erfaringer, hvor pårørendes erfaringer med demensomsorgen ble utforsket. Fire stegs utforskende analyse, inspirert av hermeneutikk, fenomenologi og tematisk analyse ble gjennomført. Resultatene bidro til å identifisere variabler og generere hypoteser til spørreundersøkelsen som ble sendt ut til et større utvalg, bestående av 188 pårørende. Resultatene ble analysert med beskrivende statistikk og multippel lineær regresjon. Analysenes formål var å teste om helsekompetanse kunne predikere pårørendebyrde, helserelatert livskvalitet og tid brukt på uformell omsorg.

Resultater Funnene indikerer at pårørende kan påpeke omsorgsbehov som ikke blir tilstrekkelig møtt av helsetjenestene. Pårørendes bidrag kan forebygge fysisk, emosjonell, økonomisk og relasjonell skade på omsorgsmottakeren. Mange pårørende er involvert i omsorgsutøvelsen, og to strategier for involvering ble identifisert: 1) være «navet i hjulet», og 2) holde hjulet i gang. Strategiene ble brukt ulikt og medførte ulike kostander og gevinster. Ulikhetene var delvis som følge av ulike personlige ressurser. Utvalget i spørreundersøkelsen hadde et høyt nivå av helsekompetanse og regresjonsanalyser viste at høyt nivå av helsekompetanse, som er ansett som en personlig ressurs, var assosiert med lavere pårørendebyrde, høyere helserelatert livskvalitet og mindre tid brukt på omsorgsoppgaver.

Konklusjon Pårørende kan være verdifulle ressurser i demensomsorgen. De tilfører perspektiver på sikkerhet og kvalitet på omsorgen og kan bidra til bedre ressursutnyttelse. Et sterkt partnerskap mellom pårørende og helsetjenestene er nødvendig, men forutsetter en oppmerksomhet på utfordringer knyttet til interaksjon og ulikhet i perspektiver og ulike personlige ressurser hos ulike pårørende.

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Häikiö, K., Sagbakken, M., & Rugkåsa, J. (2019). Dementia and patient safety in the community: A qualitative study of family carers' protective practices and implications for services. *BMC Health Services Research, 19*, 635.
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Paper II

Häikiö, K., Sagbakken, M., & Rugkåsa, J. (2020). Family carers' involvement strategies in response to sub-optimal health services to older adults living with dementia – a qualitative study. *BMC Geriatrics, 20*(1), 290. DOI: **https://doi.org/10.1186/s12877-020-01663-z**.

Paper III

Häikiö K, Cloutier D, Rugkåsa J (2020) Is health literacy of family carers associated with carer burden, quality of life, and time spent on informal care for older persons living with dementia?. PLOS ONE 15(11): e0241982.
DOI: **https://doi.org/10.1371/journal.pone.0241982**

Glossary

Berger Dementia Scale (BDS): Berger dementia severity scale (Berger, 1980) is used to classify mild and severe dementia. See section 4.4.3.2.

Care provision: The totality of formal and informal care that is provided; wider than health services. See section 3.1.3.

Carer Burden: Generally, the physical, psychological, emotional, social, and financial strains experienced by family carers (L. George & Gwyther, 1986). In this thesis, carer burden refers to subjective elements, unless otherwise specified. See section 3.2.1.

Care-recipient: Person receiving care. In this study, older people living with dementia. See section 1.3.

Critical realism: Philosophical view, the basis for quantitative analyses in this study. See section 4.1.1.3.

Cultural Captial: Concept by Bourdieu (1986), encompassing social assets of a person, that promote social mobility. See section 3.2.4.

Cultural Health Capital (CHC): A concept based on cultural capital theories, to help account for how patient-provider interactions unfold in ways that may generate disparities in health care (Shim, 2010) See section 3.2.4.

Dementia: Organic brain disease that often occurs in old age, but which is not a normal part of aging (Cunningham, McGuinness, Herron, & Passmore, 2015; Fratiglioni et al., 2000). See section 2.1.

Descriptive statistics: Quantitive measures (statistics) that summarizes particular features of a set of data. See sections 4.4.5, 4.4.5.7, and 4.4.6.1.

Empiricism: Philosophical view, one of the basis for qualitative analysis See section 4.1.1.3.

EQ-5D-5L: Proper name of HRQoL-instrument developed and owned by the EuroQol Group. Describes health along five dimensions, resulting in a combined score (EQvalue); and a visual analogue scale (EQvas) See section 4.4.3.2.

Family carer: Not exclusive to family members: an unpaid individual (for example, a spouse, partner, family member, friend, or neighbor) involved in assisting others with activities of daily living and/or medical tasks (Family Caregiver Alliance, 2019, section 1). See section 2.3.1.

Formal care: Health services provided by professionals, both public and private. See section 3.1.2.

Health Literacy (HL): A person's capacity to obtain, process, and act on information about health and healthcare systems (Finbråten, 2018; Sørensen et al., 2012). See section 3.2.3.

Health Literacy Scale (HLS-N-Q12): 12-item version of the Health Literacy Scale (Finbraten et al., 2017). See section 4.3.1.

Health personnel: In accordance with the Norwegian Public Health Act (Norwegian Public Health Act (helsepersonelloven), 2019): Anyone working in health services, both trained and untrained, in health-related work. More detailed definition under section 3.1.6. See section 3.1.6.

Health services: Formal health services at primary- and specialist level. See section 3.1.3.

Health Services Research Unit (HØKH): Research unit at Akershus University Hospital. See section 1.1.

Health-Related Quality of Life (HRQoL): A concept that encompasses quality of life and health (Karimi & Brazier, 2016) See section 3.2.2.

High level of education: Also referred to as higher education. Operationalized as university-level education of more than 3 years. See section 4.4.5.1.

Imputation: Range of methods used in quantitative analyses to replace missing observations, typically by use of other observed data from the same respondent or from other respondents in the sample. See section 4.4.5.1.

Informal care: Unpaid care provided by e.g. family members. Contrast to formal care. See section 3.1.2.

Informal carer: See family carer. See section 2.3.1.

International Classification of Diseases, version 10 (ICD-10): WHO formal classification of diseases. See section .

Linear regression analysis: Class of statistical procedures for estimating linear relationships between predictors (independent variables) and variables to be predicted (dependent variable). See section 4.4.5.

Maximum variation sample: Sampling aimed at ensuring the widest practically possible range of diversity among participants (Patton, 2015). See section 4.2.4.

Objective carer burden: Quantities such as time and finances devoted to care. In contrast to subjective carer burden (referred to as just carer burden), which relates to experiences (Flyckt, Fatouros-Bergman, & Koernig, 2015; Hughes et al., 2014). See section 2.3.1.

Older person, older people: Adults aged 65 or older. See section 3.1.5.

Partnerships in care: Cooperation between formal and informal care, based on trust, equality, mutual understanding, shared goals, and shared accountability (WHO, 2017b) See section 2.7.

Pathways: Short title of umbrella project in which Ph.D. project was a part. Full title: "How Do We Provide Better, Safer and More Cost-Effective Care Pathways for Older People?" See section 1.1.

Person/people living with dementia: Positive language reference to individuals with dementia (Alzheimer's Society, 2018). In this study, the term is predominantly used to refer to people receiving care from study participants. See section 3.1.4.

Personal resources: In this study, resources that can be leveraged by the individual in order to improve access to and quality of healthcare. E.g. social skills, cultural capital, cultural health capital, social support network, and health literacy. See sections 4.2.9 and 4.3.1.

Primary care: Formal health services at primary level, such as community health services See section 2.5.2.

Quality of Life (QoL): Degree of satisfaction or dissatisfaction felt by people with various aspects of their lives. (Farquhar, 1995 p. 503) See section 3.2.2.

Realtive Stress Scale (RSS): 15-item questionnaire used to measure carer burden. See sections 4.3.2.1 and 4.4.3.2.

Resource Utilization in Dementia (RUD): Questionnaire used to measure time spent on care (Wimo et al., 2010; Wimo & Nordberg, 2007) See section 4.4.3.2.

Specialist care: Health care offered to individuals at particular need for highly specialized services; separately organized and financed from primary care. See section 2.5.1.

Substudy 1: Qualitative substudy centered around in-depth interviews of family carers to older persons with dementia. See section 4.1.2.

Substudy 2: Quantitative substudy, centered around survey targeting a larger group of family carers to older persons with dementia. See section 4.1.2.

Urban/rural residency: Classification of living location based on postal codes, categorized according to Rugkåsa et al. (2019) See section 4.4.3.3.

WHO: World Health Organization.

1 Introduction

In this chapter, I explain the context, the purpose, and aims of the project completed for this doctoral thesis.

1.1 Context of the project

This doctoral thesis is the result of a 3-year project, which itself was part of a larger project conducted in the Health Services Research Unit (HØKH) at Akershus University Hospital entitled “How Do We Provide Better, Safer and More Cost-Effective Care Pathways for Older People?”, and “Pathways” for short. The Pathways project was funded under the Norwegian Research Council’s HelseVel program, with the overall aim to generate knowledge about current trends in care for older persons and, in turn, facilitate evidence-based, high-quality, and patient-centered pathways of care for older people. Although many health services are provided to older people in the municipality, neither the Pathways project, nor this Ph.D. project were limited in scope to municipality care, but were rather concerned with formal and informal care pathways across health services, organizational levels, and institutions.

This Ph.D. project involved using an exploratory, sequential mixed method to arrive at a better understanding of family carers’ perspectives on care provision to older people living with dementia. Family carers’ perspectives on multiple health services stem from a range of such services, including specialist care, municipality care, and informal care.

Throughout the project, I sought council from HØKH’s user panel, which is composed of people from various professional backgrounds, with diverse experiences from different health services, organizations, and institutions. Their advices have informed my sample, my interview-style, and the information forms accompanying the two substudies.

Because many family carers to older people living with dementia are deeply involved with, and engaged in care, I believed they have unique knowledge about the provision of multiple health services and the overall care provision these care recipients. Consequently, they may contribute to highlight aspects of care that may contribute to the development of better, safer and more cost-effective care pathways to older people living with dementia. Research has also shown that family carers may represent barriers to utilization of services to older people living with dementia (Stephan et al., 2018), which emphasizes the need to improve understanding of care provision from the family carers’ point of view.

1.2 Overall purpose of the project

The overarching motivation and purpose of this Ph.D. was to make a contribution to the knowledge about how to provide better, safer, and more cost-effective health services to older people living with dementia. To reach that purpose, the aim of this Ph.D. project was to arrive at a better understanding of family carers’ perspectives on care provision to older people living with dementia. Such an understanding can be a precursor to better alignment of formal and informal care, and, ultimately, hold potential for improving health services for older people living with dementia. The aim will be reached by the following objectives, which, in turn are operationalized into two sub-studies. See Figure 1.

Figure 1. Objectives of the substudies

1. To explore how family carers experience healthcare provision to older people living with dementia, and how family carers contribute to the delivery of such care
2. To explore how family carers experience their interactions with, and contributions to, multiple health services
3. To explore family carers’ perceptions of, experiences with, and involvement in care provision to older people living with dementia.

Substudy 1

4. To further investigate the findings from Substudy 1 and test assumptions in a larger population

Substudy 2

1.3 Important presumptions

To understand this thesis, it is important to clarify a few presumptions that I bring to the project. First, my background as a nurse with almost 20 years of clinical experience has given me a perspective on health services from the "bottom up", meaning that I understand health services primarily from the perspectives of health personnel working in direct patient-related work. This perspective has formed my Ph.D. project, as I see the quality of health services as strongly conditioned by health personnel's knowledge, attitudes, and beliefs. This means that the overall purpose of this research effort is not exclusively aimed at informing policy makers. Rather, it has been conducted from a perspective that high quality of care can be supported by informing health personnel working clinically with older people living with dementia and their family carers, in addition to individuals involved in the framing of policy

Quality of care is also conditioned by the political, physical, and social context, such as prioritization of available resources, the physical environment, and the social constructs which form people's expectations and values. Awareness regarding the development of patients' autonomy in meetings with health services, but also their increased responsibility for own health and use of health services have affected the way I understand health services', and family carers', role. I have focused on how knowledge and awareness among health personnel may facilitate quality of care, but I have also sought to draw the lines to how a better understanding of family carers' experiences can inform policy, which subsequently may facilitate improved quality of services and care provision.

My nursing background has given me a holistic approach, meaning that I am concerned with all aspects of a care recipients' life, far beyond the boundaries of medical services. This is very much in line with "holistic nursing" as defined by PubMed database:

> *A philosophy of nursing practice that takes into account total patient care, considering the physical, emotional, social, economic, and spiritual needs of patients, their response to their illnesses, and the effect of illness on patients' abilities to meet self-care needs. (From Mosby's Medical, Nursing, and Allied Health Dictionary, 4th ed, p745)* (PubMed database, 2020 p. 1)

The holistic philosophy aligns well with how I understand patient-centeredness, meaning that I put the care-recipient and their families in the center for deciding which goals are most valuable, rather than clinicians deciding what is best.

My nursing background has also taught me to take patients' perspectives and advocate their interests in the meeting with health services. In my experience, this include asking questions on their behalf, seeking to ensure that the patient understands the information given to them, and help clarify at need. This background made me mindful of the vulnerability of subgroups of patients and informal caregivers when meeting with seemingly powerful health personnel or institutions.

These were the most important aspects of my preunderstanding that may be helpful to readers. I will elaborate on my preunderstanding in section 6.1.1.1.

2 Dementia and the provision of care to older people living with dementia

In this section, I will give an introduction to what dementia is, and introduce dementia as a global and national public health priority. I will then elaborate who the family carers are, what they do, and how they are affected by their carer role. Next is a chapter describing the national and international context in which family caring generally is performed. I then elaborate on the range of services for older people with dementia, provided through municipalities, primary care, and by informal carers. Finally, I briefly summarize what we know about family carers' experiences with health services, about supporting family carers, and future challenges for health services and care provision for older person living with dementia.

2.1 What is dementia?

Dementia is commonly understood as an organic brain disease that often occurs in old age, but which is not a normal part of aging (Cunningham, McGuinness, Herron, & Passmore, 2015; Fratiglioni et al., 2000). It has been suggested that dementia should be described as a syndrome rather than a specific disease, encompassing different types of dementia; Alzheimer's disease being the most prevalent, vascular dementia, dementia with Lewy bodies, and frontotemporal dementia (Oh & Rabins, 2019). Mixed dementia, which describes a combination of two or more types of dementia, is common (National Institute on Aging, 2017). Because dementia is usually manifested psychologically, dementia diagnoses are organized in the international classification of diseases version 10 (ICD-10) under the heading "organic, inclusive symptomatic, psychiatric disorders" (The Directorate for e-health (Direktoratet for e-helse), 2020). Dementia is variously described in terms of a disease, a disorder, or a syndrome in different literature. In this thesis, I will use the term dementia *disease* because I wish to emphasize that dementia is different from normal aging processes, and that it is characterized by degenerative and consistent changes in the brain (Center for Disease Control and Prevention, 2020; Lo, 2017; National Institute on Aging, 2020).

The symptoms of dementia arise when nerve cells in the brain lose connections with other brain cells and die on a far greater scale than they normally do as part of aging (S. Henderson, 2003; National Institute on Aging, 2017; WHO, 2017a). As a result, people living with dementia often lose cognitive functions such as memory, language, visual perception, problem solving, self-management, and the ability to focus and pay attention. Beyond that, some people living with dementia gradually lose control over their emotions, and exhibit changes in their behavior. Dementia varies not only in severity, but also in how the brain changes (National Health Service, 2017). Although the symptoms of dementia can fluctuate, they are usually progressive, currently irreversible, and result in behavioral inabilities that increasingly interfere with daily living and activities (Chertkow, Feldman, Jacova, & Massoud, 2013; A. S. Henderson & Jorm, 2000; National Institue on Aging, 2017; WHO, 2017a). Though symptoms in the early stages of dementia often go undetected (Alzheimer's Disease International, 2018; Prince et al., 2016; Wergeland, Selbaek, Hogset, Soderhamn, & Kirkevold, 2014), the progressive nature of the disease causes disability and dependency in later stages (WHO, 2018; WHO & Alzheimer's Disease International, 2012). In Norway, an estimated 80% of individuals living with dementia are diagnosed before progressing from mild dementia, and the mean time of living with dementia after diagnosis is 8.1 years, of which 2.1 years were living in institutions (Vossius et al., 2015).

The exact diagnostic criteria for dementia continue to be debated, and a diagnosis of dementia is usually determined only after careful consideration of several factors, including medical history, results on multiple dementia and neuropsychological tests, the narrative accounts of family, a range of biomarkers, and the results on radiological tests, to name a few (Chertkow et al., 2013). Dementia often goes undiagnosed for a long time; a study from the United Kingdom reports that only a third of people living with dementia were diagnosed with the condition, and that diagnosis was often set late in the dementia trajectory, and at a time of crisis (Ahmad, 2009). Of course, differences in opinion about the timeliness for diagnosing dementia abound, as well as about what *timeliness* means. In this context, many practitioners consider that timeliness needs to be collectively determined between the person affected, his or her family carers, and health professionals in light of various considerations, including treatment opportunities, ability to plan for the future, and personal preferences (Dubois, Padovian, Scheltens, Rossi, & Dell'Agnello, 2016; Kerpershoek et al., 2016). Medical treatment of dementia is only a small part of the treatment of dementia because the positive effects are small and uncertain, and side-effects, such as gastrointestinal symptoms with nausea, are common (Norwegian Health Informatics (Norsk Helseinformatikk), 2020). Due to the lack of effective cures for dementia, dementia care often focuses on disease-modifying treatment and modifiable risk factors (Livingston et al., 2017; Norwegian Health Informatics (Norsk Helseinformatikk), 2020), with symptomatic treatment made available primarily for people in early stages of dementia (Dyer, Harrison, Laver, Whitehead, & Crotty, 2018).

Research findings and accumulated clinical experiences also support initiatives and training aiming to maximize function and well-being for persons living with dementia. Attention is paid to the person's quality of life, and also to the education and support of the family carers (Oh & Rabins, 2019).

Though the number of people living with dementia worldwide was estimated to be 47 million in 2015 (Livingston et al., 2017), and a in Europe in 2018 the prevalence was estimated to 7.1% of the population (Bacigalupo et al., 2018). An exact figure is difficult to determine, particularly due to the often late diagnosis (Ahmad, 2009), to divergent criteria used for diagnosis, and varying inclusion criteria in studies on dementia (Bacigalupo et al., 2018; Ferri et al., 2005). For similar reasons, there are no reliable figures of how many people live with dementia in Norway, and estimates vary from 70,000 to 104,000 (Norwegian National Advisory Unit on Ageing and Health, 2017), although an ongoing study will provide updated estimates of prevalence in Norway, probably within the next year (G.Selbæk, personal communication, Feb 13 2020). More knowledge about the prevalence of dementia is necessary, especially in Norway where reliable numbers are lacking, to facilitate informed political decisions and successful planning of future healthcare to people living with dementia.

2.2 Dementia as a global and national public health priority

Worldwide, dementia has become a public health priority (Kaldy, 2020; WHO & Alzheimer's Disease International, 2012) . In 2017 WHO launched a global action plan on the public health response to dementia which provided a set of actions to increase prioritization and awareness of dementia, reduce the risk factors of dementia, improve care for persons living with dementia, improve support for dementia carers, and strengthening information systems for dementia among other areas (WHO, 2017b). Norway is now one of the leading countries in Europe in implementing dementia actions (WHO, 2017c). An international WHO guide towards a dementia plan was published in 2018, provided useful information for creating and operationalizing national dementia plans, strengthening existing dementia plans, or integrating dementia into already existing dementia-related plans (WHO, 2018). The guide is organized in three phases. First; preparing for the dementia plan, second; developing the dementia plan, and third; implementing the dementia plan. The *WHO global action plan*, and the *WHO guide towards a dementia plan* signals important steps forward to achieve physical, mental, and social wellbeing for people living with dementia and their family carers worldwide.

Norway was one of the first countries in the world to have a public national dementia plan, aiming to systematically improve the lives of people living with dementia, their families, and the people who care for them. The plan was published in 2007 (Ministry of Health and Care Services (Helse- og omsorgsdepartementet), 2007). The first Norwegian dementia plan was anchored in the health minister's vision of *the patient's healthcare*, meaning that health services should be patient-oriented rather than system-oriented, and the strategy led to a comprehensive awareness about dementia and health services to people living with dementia in Norway. The person-centered approach for caring, and the caring for the carer, have gained attention over the last decade. A new approach has emerged within dementia care, that addresses the relationship between the person living with dementia, their family carers, and healthcare professionals; also described as *the dementia care triads* (Adams & Gardiner, 2005*)*. The second Norwegian dementia strategy was published in 2015 and expanded the perspectives of care to encompass societal structures, facilitating a *dementia friendly society* (Ministry of Health and Care Services (Helse- og omsorgsdepartementet), 2015).

In 2019 WHO published guidelines on risk reduction of cognitive decline and dementia, providing evidence-based recommendations on lifestyle behaviors and interventions to delay onset of dementia (WHO, 2019c), followed by a support manual with skills and training program for carers of people living with dementia (WHO, 2019b). The latter two documents represent the main focus in the present paradigm in dementia healthcare: focusing on the dementia care triads, the delay or prevention of dementia, and on physical activity as an important constituent of well-being and quality of life. Physical activity is also emphasized as an important requisite for delaying onset of dementia and optimizing physical and mental resources and abilities, and the role of multi-morbidity and frailty is being investigated (Wallace et al., 2019).

2.3 Who are the family carers, what do they do, and how are they affected by the carer role?

2.3.1 Family carers in general

In this thesis I will focus on family carers to older people living with dementia. However, as some experiences are similar to those of other family carers for other groups, I also draw on research from family carers to older people in general, and to people with mental illnesses or other chronic diseases, when necessary.

In the following, a *family carer* refers to “an unpaid individual (for example, a spouse, partner, family member, friend, or neighbor) involved in assisting others with activieties of daily living and/or medical tasks” (Family Caregiver Alliance, 2019, section 1). Family carers are also referred to as *informal carers* (as opposed to health personnel who provide *formal* care).

In general, families have always provided care for children, parents, and sometimes other family members. As a result of medical advances, more people are living longer with their disabilities and chronic diseases, and family caregiving has become a more frequent, protracted, and complex responsibility (Zarit & Zarit, 2015). Changes in the population’s demographic represents new challenges, such as the majority of adults, women included, are attending the work-force and often working full-time (Zarit & Zarit, 2015).

Adult children and spouses are the most common family carers, and spouses are often the first in line to assume caregiving responsibilities to older people (Family Caregiver Alliance, 2019; NOU 2017: 16, 2017; Wolff & Kasper, 2006). Numbers from the United States (US) show that 75% of all caregivers are females, spending as much as 50% more time providing care than males (Family Caregiver Alliance, 2019). In Norway, the Family Caregiver Alliance found that 76% of the carers were females (Carer's Alliance (Pårørendealliansen), 2019) and a study of gender bias in public long-term care in Norway supports the finding that daughters of elderly women are more likely to provide informal care than sons. They also found that those for whom sons, rather than daughters, provide informal care receive 34% more formal care (Jakobsson, Kotsadam, Syse, & Øien, 2016). These are examples showing that health services are provided based on factors beyond the objective care needs of the care recipient. Several underlying beliefs, attitudes, and perceptions are influencing access to services.

Some studies report that the proportion of men providing care for older people has increased to such an extent that men may constitute nearly half of the primary caregivers of the elderly (Sharma, Chakrabarti, & Grover, 2016). Still, the majority of researches nationally and internationally are primarily focusing on female caregivers (Sharma et al., 2016). Discussion is ongoing as to whether caregiving is measured with “a female yardstick”, meaning that it is measured using female preferences, with the consequence of marginalizing and underestimating male caregiving (Lopez-Anuarbe & Kohli, 2019). Some international studies have found that male carers may not identify themselves as carers, but rather as a relative of the care recipient (Black, Schwartz, Caruso, & Hannum, 2009; Robinson, Bottorff, Pesut, Oliffe, & Tomlinson, 2014). This may be one explanation for the focusing on female caregivers in the majority of researches, and may serve as an example of how people are treated differently despite equal care needs.

Being a family carer is in many studies found to be associated with having poorer health than non-caregivers (Berglund, Lytsy, & Westerling, 2015; Pinquart & Sörensen, 2007), including both lower psychological wellbeing and poorer physical health. The term *carer burden* is often mentioned in association to the carer role. The term is usually used to describe carers subjective experiences of negative strains and stress (Chiao, Wu, & Hsiao, 2015), while the term *objective carer burden* refers to the quantities such as time and finances devoted to care (Flyckt, Fatouros-Bergman, & Koernig, 2015; Hughes et al., 2014). It is possible that reducing objective burdens may reduce subjective burdens (Hughes et al., 2014), but a systematic review on resilience in caregivers found that promoting a resilient coping style in family carers could reduce distress (Palacio, Krikorian, Gomez-Romero, & Limonero, 2019), meaning that subjective burden is affected by more than the measurable objective burden.

2.3.2 Family carers to older people living with dementia

According to the Norwegian Institute of Public Health, there are approximately 300.000 family carers caring for a person living with dementia in Norway (Norwegian Institute of Public Health (Folkehelseinstituttet), 2019), and caring for an older person living with dementia is different from other types of caring in some aspects.

As described, the risk of dementia increases with age (A. S. Henderson & Jorm, 2000; Piccirillo et al., 2008) and high age is associated with other chronic diseases. Consequently, dementia is associated with high care demands, and previous research have found that people living with dementia often become dependent on their family carers (WHO, 2015). For some, this occurs even at the early stages of dementia, which may result in family members playing a key role in accessing health services and interacting with health personnel on behalf of the person living with dementia (Bieber, Nguyen, Meyer, & Stephan, 2019). Family members are often the first to notice early symptoms of dementia (Social care institute for excellence, 2015), although subtle changes in behavior may not be interpreted as symptoms of dementia until later stages, and may be difficult to explain to others (Rasmussen, Hellzen, Stordal, & Enmarker, 2019).

During dementia’s progressive trajectory, many family carers spend a significant amount of time caring for their relatives living with dementia (Chiatti et al., 2018; Ory et al., 1999; Vossius et al., 2015; Wimo, Jonsson, Bond, Prince, & Winblad, 2013) and typically more time as the disease progresses.

A large share of the total care provided for older people living with dementia is provided by family carers (R. Schulz & Martire, 2004). Typical caregiving tasks for dementia caregivers involve helping with instrumental activities of daily living (ADL), such as household chores, shopping, meals, transportation, arranging appointments, managing finances, managing legal affairs, managing medication, and answering the phone. Other typical tasks include helping the person living with dementia adhere to treatment recommendations, assisting with bathing, dressing, grooming, feeding, walking, using the toilet, and managing incontinence (Alzheimer's Association, Thies, & Bleiler, 2013). Caring for a person living with dementia is in several studies associated with long care hours and physically and mentally demanding caregiving (Brodaty & Donkin, 2009), and family carers of people living with dementia report higher levels of burden than other caregivers (Ory et al., 1999). Behavioral and psychological symptoms of dementia, such as aggressive behavior, wandering, depressive mood, agitation, anxiety, repetitive activity, and nighttime disturbances are often experienced as stressful and demanding for the family carer to manage, and are often associated with negative impact on caregivers (Ornstein & Gaugler, 2012)

One study conducted in Norway, revealed that family carers provided approximately 160 hours per month of informal dementia care to their care recipients in the time before their admission to nursing homes (Vossius et al., 2015). Other studies have found considerably less time spent on informal care (Ulstein, Bruun, & Engedal, 2007), while a study from Sweden found considerably more time spent (Wimo, von Strauss, Nordberg, Sassi, & Johansson, 2002). The role of the family carers and the time they spend on informal care vary considerably, both between countries and through the dementia trajectory (Chiatti et al., 2018; Handels et al., 2018).

2.4 The political and legal context for family carers in Norway

In international and Norwegian health policy, family carers are attributed a role in enhancing the quality of care, utilize potential care resources and provide care tailored to individual needs (Ministry of Health and Care Services (Helse- og omsorgsdepartementet), 2018; WHO, 2018). This applies not only for those caring for older people living with dementia, but for family carers in general.

As in many other countries where informal care constitute a cornerstone of all care systems (Zigante, 2018), researchers in Norway have described the care provided by people outside formal services—that is, informal care—as the backbone of the Norwegian welfare state (Tønnessen, Kassah, & Tingvoll, 2016), meaning that family carers are carrying a large share of the responsibility for people with care-needs. However, according to the Norwegian National guide for family carers (Pårørendeveilederen), municipalities and hospitals are required to have systems for family carer involvement (The Norwegian Directorate of Health, 2017). This is anchored in the Regulation of Leadership and Quality Improvement in Health Services, to which hospitals and municipalities are committed to comply (Regulation for leadership and quality improvement in healht and care services, 2020; The Norwegian Directorate of Health, 2017). In a report from the government to Stortinget (white paper) called "Future Care" (Morgendagens Omsorg), it is specifically pointed out that no family carers should feel forced into a role as family carer or take on comprehensive care responsibilities because public services are unable to provide sufficient care (Ministry of Health and Care Services (Helse- og omsorgsdepartementet), 2013 p. 59). According to the Patient- and User Ombudsman in Buskerud, Norway, family carers have no formal obligations to provide care to sick or old family members (Amdahl, 2019).

Family carers often operate in complex contexts in which their rights and duties remain unclear (Tønnesen & Kassah, 2017). The rights of family carer in Norway are to a large degree conditioned by the care recipient's right to privacy and autonomy, and his or her given consent (Pettersen, 2018).

Researchers have found that a barrier to successful carer involvement may be the often challenging interaction and communication between family carers and health personnel (Bélanger, Bourbonnais, Bernier, & Benoit, 2017; Bunn et al., 2017). There is a need for better coordination of services and supports (Abdi, Spann, Borilovic, de Witte, & Hawley, 2019; McGilton et al., 2018), and also in Norway there is a lack of systematic procedures for service collaboration (Anker-Hansen, Skovdahl, McCormack, & Tønnessen, 2019).

2.4.1 Family carers' right to information

There has been a growing focus on the legal rights of family carers. One of these is family carers' right to general information, such as information about legal rights, available services, information about support-organizations, and general advices (The Norwegian Directorate of Health, 2017). If the person living with dementia opposes that information is given to family carers, family carers have no rights to specific information, such as their diagnosis, causes of disease, symptoms, or prognosis (The Norwegian Directorate of Health, 2017). On the other hand, information should be given to family carers if it is considered generally beneficial for the person living with dementia and for the carer (Norwegian Directorate of Health (Helsedirektoratet), 2019; Norwegian Public Health Act (helsepersonelloven), 2019; Patient and user's act (Pasient- og brukerrettighetsloven), 2020). A person living with dementia is often able to make decisions regarding own care (Miller, Whitlatch, & Lyons, 2016), and the family carers right to information about them is conditioned by the care recipient's consent to inform the family carer. However, in late stages, a person living with dementia's decision-making capacity is usually reduced, in which case family carers may have right to information on their behalf. According to the Act of Specialist Services (spesialisthelsetjenesteloven) the closest relative has the right to information about the person living with dementia if he/she is obviously unable to care for his/her own interests (Act of specialist services, 2020; The Norwegian Directorate of Health, 2017). Complex and ambiguous situations occur as the person living with dementia may reliably report on their care values, personal preferences, and well-being, even in moderate to severe stages of dementia (Miller et al., 2016), but their mental capacity may be fluctuating and their capacity to consent may vary. Consequently, patient confidentiality concerns may come in conflict with the family carers' need for, and right to, information when interacting with services.

2.4.2 Rights to training and support

It is important to emphasize that if the person living with dementia gives their consent to sharing information, health personnel are obligated to give information to the family carer in a manner suited to ensure that the carer can understand. Similarly, hospitals are required to give information and training to patients and their families (Patient and user's act, 2020). Persons with heavy care responsibilities are also entitled to support from the municipality in terms of guidance and training (Patient and user's act, 2020), and are also entitled counselling. In some cases family carers are entitled economic support, to prevent social consequences or to overcome and adjust to a difficult phase of life (Labour and social affairs act, 2020).

2.5 Care provision to older people living with dementia

There are around 50 million people are living with dementia worldwide(WHO, 2019a), and 70.000 -104.000 in Norway (Norwegian National Advisory Unit on Ageing and Health, 2017). Care provided to older people living with dementia, both nationally and internationally, usually involves a wide range of services. In Norway, as in several other countries, persons living with dementia often access mainstream services and specialist services through a referral by their family doctor or general practitioner (National Collaborating Centre for Mental Health (UK), 2007; The Directorate of Health (Helsedirektoratet), 2017). In Norway formal health services often include specialist care and municipality care, while informal care refers primarily to family care. Non-government organizations, such as voluntary dementia work organized by support groups, or interest groups nationally and internationally may consist of informal carers, formal carers, or both.

Everyone living in Norway is entitled to essential medical and care services (Patient and user's act, 2020). In the following sections I will describe these services as they are provided in Norway, and illustrate how this corresponds with dementia care internationally.

2.5.1 Specialist care for older people living with dementia

In Norway, specialist services are provided by reginal health trusts. Specialist dementia services in Norway are often organized as out-patient clinics, such as memory-clinics or geriatric outpatient clinics. Although dementia is described as an organic brain disease, the symptoms are often related to their mental and psychological capacity. Consequently, in Norway, specialist health services to people living with dementia are also offered in psychiatric out-patient clinics and sometimes in psychiatric- or geriatric hospital wards. International studies have shown that, like older people in general, those living with dementia are sometimes hospitalized related to other conditions, such as falls, or injuries (Rowe & Fehrenbach, 2004), infections (Naumova et al., 2009), or other acute or chronic conditions (Shepherd, Livingston, Chan, & Sommerlad, 2019). Also polypharmacy, high age, and comorbidity are common reasons why people living with dementia have higher hospital admission rates than the average population of older people (Shepherd et al., 2019). A person living with dementia may need more attention by hospital staff and more person-oriented attention while being hospitalized, and there is a considerable risk of deterioration in dementia symptoms while being hospitalized (J. George, Long, & Vincent, 2013). Change of environment may in itself cause disorientation, difficulties with following instructions, confusion, anxiety and other dementia-related issues. Furthermore, hospital staff may not be sufficiently aware of the dementia diagnosis (Watkin, Blanchard, Tookman, & Sampson, 2012).

2.5.2 Primary care

Primary care, in Norway, is the responsibility of the municipalities. In accordance with the principal of providing care at the lowest effective care level (Prinsippet for laveste effective omsorgsnivå, (*LEON-prinsippet)*) which was introduced in Norway in 1975 (Ministry of Social Affairs (sosialdepartementet), 1975), later also referred to as the principal of best effective care level (Beste effektive omsorgsnivå, (*BEON-prinsippet)*), care is commonly provided in persons home or in the municipality. It is estimated that 60% of people living with dementia in Norway are living in their own home in the municipality (Gjøra, Eek, & Kirkevold, 2015). In accordance with the *Coordination Reform* of 2009 (Norwegian Ministry of Health and Care Services (Helse- og omsorgsdepartementet), 2009) most health services are provided to people in the municipality, preferably in their homes. Primary care in Norway typically includes health services such as the general physician/family doctor, homecare, nursing homes, day activity centers, activity groups, and similar services. Most municipalities in Norway have a specialized dementia team, or similar, dedicated to support people who are living with dementia (or experiencing memory loss) and their families (Norwegian Directorate of Social- and Health Services (Sosial- og helsedirektoratet), 2007). The way these teams are organized, the kind of service they provide, and their relationships to the people they serve are not standardized, and consequently they vary between municipalities, allowing smaller and larger municipalities to organize services according to local needs. Respite care is another common service offered in the municipality, usually with the intention to temporarily relieve the family carer of their sometimes demanding care responsibilities. Adult day activity centers and outpatient social care centers are other common municipality services in Norway (WHO, 2017c) which offer customized activities for people living with dementia. Since January 2020 Norwegian municipalities are required to offer daily activities to older people living at home with dementia (Health and care act, 2020, § 3-2).

In Norway, nursing homes in the municipality are required for most people living with dementia in the late stages of the disease, and in many nursing homes there are specialized dementia units to offer more customized care in protective environments. The Directorate of Health estimates that 80% of those living in nursing homes are living with dementia (The Norwegian Directorate of Health, 2017), but only about 30% of those living with dementia in nursing homes are living in specialized units (Gjøra et al., 2015). Among those receiving home care, and not living in nursing homes or other care facilities, it is estimated that around 20 % are living with dementia (Ministry of Health and Care Services (Helse- og omsorgsdepartementet), 2015).

Because so many older people living with dementia are living in the municipalities, there is a need for training of healthcare personnel, both in understanding dementia and in caring for a person living with dementia. In Norway, the teaching- and training tools called “The ABC of care for persons living with dementia” (Demensomsorgens ABC), and “The ABC of care for older people” (Eldreomsorgens ABC), have been offered to around 32.000 employees and approximately 400 municipalities following dementia plan 2015 during the period 2015-2019. Furthermore, 81% of the Norwegian municipalities have received financial support to provide support groups and training for family carers to people living with dementia (Ministry of Health and Care Services (Helse- og omsorgsdepartementet), 2015; The Norwegian National Advisory Unit on Ageing and Health, 2020). Despite a comprehensive focus on dementia care nationally and internationally during the recent 5-10 years, there are still unmet needs and ongoing discussions about the access to and timeliness of health services (Abdi et al., 2019; Handels et al., 2018; Hughes et al., 2014; Janssen et al., 2018; Kerpershoek et al., 2016; McCabe, You, & Tatangelo, 2016).

2.5.3 Other contributors in care

In Norway, and in most other countries, a large amount of informal care is provided to older people living with dementia through voluntary work conducted by individuals and families (Brodaty & Donkin, 2009; Wimo, Jonsson, et al., 2013; Zigante, 2018). In addition to individual family carers, several non-governmental organizations and support-groups organize substantial informal care efforts. Internationally there are organizations like WHO, Alzheimer’s Society, and Alzheimer Europe who are important contributors of dementia awareness and dementia knowledge mobilization. In Norway, a network of dementia-unions (demensforeninger), based primarily on voluntary work, provide support to family carers and people living with dementia . Non-government organizations like *The Norwegian Health Association* (Nasjonalforeningen for folkehelsen) and *the Carer’s Alliance* (Pårørendealliansen) are important contributors to informal and formal care as they provide support to persons living with dementia and their families (Carer's Alliance (Pårørendealliansen), 2020; The Norwegian Health Association (Nasjonalforeningen for folkehelsen), 2020). These organizations and associations are contributing to care provision at many levels, including research; training of healthcare personnel and family carers; and collecting and providing information about dementia (among other conditions) and dementia-related topics. They also provide support through financial, and social, support to voluntary support groups around the country.

The Norwegian National Advisory Unit on Ageing and Health (Komeptansesenter for aldring og helse) has a unique position in addition to other formal and informal services. The advisory unit is not technically a non-governmental organization, as it is organized as a cooperation of institutions within specialist services. However, its role is similar to that of the non-governmental organizations; being responsible for securing national competency building and distribution of such knowledge on dementia and other conditions or disabilities commonly experienced among older people (Norwegian National Advisory Unit on Ageing and Health, 2020).

2.6 What we know about family carers' experiences with health services for people living with dementia

Family cares' experiences with health services are described in a large number of international studies. Their experiences vary considerably between different types of carers (e.g spouses, adult children) (Rigby, Ashwill, Johnson, & Galvin, 2019), between carers' gender (Xiong, Biscardi, Nalder, & Colantonio, 2018), stages of the dementia disease (Lethin, Hallberg, Karlsson, & Janlöv, 2016), types of dementia (Rasmussen et al., 2019), and between cultures (Sagbakken, Spilker, & Ingebretsen, 2017; Sagbakken, Spilker, & Nielsen, 2018). In this thesis I am including a broad variety of experiences.

Several international studies have investigated family carers' experiences with hospital admission or hospital discharges (Backman & Cho-Young, 2019; Bélanger et al., 2017) and family carers often report issues with communication, information, and carer involvement (Bunn et al., 2017; Mockford, 2015).

Regarding family carers for older people living with dementia, I have not been able to find other studies about family carers' experiences with hospital admissions in Norway. Reports of family carers' experiences with community services in Norway suggest that family carers often feel left out of decisions, and that they are often dissatisfied with information and communication (Jamieson, Grealish, Brown, & Draper, 2016; Rognstad, Sagbakken, &

Naden, 2015). In a survey from 2019, the Carer's Alliance (pårørendealliansen) found that 70% of family carers in Norway felt exploited or not listened to by healthcare personnel when providing care to a person living with dementia (Carer's Alliance (Pårørendealliansen), 2019).

International studies have shown that services for people living with dementia can assist in relieving carers' burden, but this may also produce unintended negative consequences (Laparidou, Middlemass, Karran, & Siriwardena, 2019; Lloyd & Stirling, 2011). Some family carers may experience a loss of independence and personal agency when medical procedures, tools, and routines similar to those found in institutions or hospitals are being performed in a person's home(Lloyd & Stirling, 2011). Studies have also reported of family carers who expected in-depth knowledge and understanding of dementia from healthcare personnel, but instead experienced lack of training among healthcare personnel, fragmentation of dementia care services, and lack of support (Laparidou et al., 2019).

As service provision may potentially come with some negative experiences along with positive (Prorok, Horgan, & Seitz, 2013), it is of importance to know whether services are actually meeting the needs of the person living with dementia, and whether it is supporting family carers or adding to their burdens. A scoping review, investigating if services meet the needs of people with dementia and carers living in the community, found that many experienced that their needs were not always effectively met (Morrisby, Joosten, & Ciccarelli, 2018). Conversely, a recent study from eight European countries, Norway included, reported from interviews with family carers and persons living with dementia, that they experienced having sufficient information about the disease and about available care, along with having a key contact person to guide them through the process of finding suitable care, and monitoring their needs were important (Kerpershoek et al., 2019).

Possible barriers towards services use for people living with dementia in Norway, and in other European countries, has been found to be related to family carers' beliefs about dementia; believes about health services, and individuals involved in the care; along with resistance from the person living with dementia to the use of services (Stephan et al., 2018).

International and Norwegian health policy documents emphasize the importance of family carers, and acknowledge that family carers are already carrying a considerable share of the care. At the same time surveys are still reporting heavy subjective carer burdens, and that family carers are feeling exploited despite their legal rights to support from formal services. This may seem like conflicting perspectives and represent a research gap. Consequently, it is important to better understand family carers' experiences with health services in combination with their informal carer role.

2.7 The necessity to support family carers and form partnerships in care

Many people living with dementia are capable of participating in making decisions about their care (Smebye, Kirkevold, & Engedal, 2012). Nevertheless, carer involvement in the decision-making process becomes increasingly important as care recipients' symptoms progress (Adams & Gardiner, 2005; Moye, Karel, Gurrera, & Azar, 2006). Family carers' approaches and interactions with health services are thus essential aspects of informal care in order to obtain information to make important decisions, as well as access services and equipment (Reinhard, Given, Petlick, & Bemis, 2008) and to fill gaps in the provision of care (Port et al., 2005; Williams et al., 2005).

Because the general direction of international healthcare policy is to provide more community-based care (Ministry of Health and Care Services (Helse- og omsorgsdepartementet), 2008; Peckham, Carbone, Poole, Allin, & Marchildon, 2019), most persons living with dementia receive services in primary care, in nursing homes, and in their own homes. Rapid demographic changes in age groups, family composition, participation in the workforce, and geographical mobility, along with economic restraints, challenge the future provision of home care services and the contributions of informal care (European Commission, 2016; Knapp, Comas-Herrera, Somani, & Banerjee, 2007). Although home care is less expensive than institutional care, many observers highlight that the rise of home care places increased financial, physical, and emotional responsibility upon informal carers (Etters, Goodall, & Harrison, 2008; Gautun, Werner, & Lurås, 2012; Lim & Zebrack, 2004; Noel, 2014; Shepperd et al., 2016). On top of that, many family carers are caring not only for their parents or other older persons in their households, but also their own children (Caregiver Action Network, 2020).In addition to their care responsibilities many family carers also struggle with their own health conditions.

Little is known about how those demographic changes affect carers and may affect society, but Gautun and Bratt (2016) have shown that family caregiving may indeed interfere with family carers' attendance at work. In response, they suggested that care services need to be expanded and to adjust to new demands if the welfare state is to remain able to combine work with informal care while avoiding institutional care. How this should be carried out is still unclear, and more research is needed: Some researchers are suggesting that intervention studies related to family caring are needed to test new interventions to support family carers (Ying et al., 2018). Several researchers have emphasized that stronger partnerships between family carers and formal carers are needed to improve care to older people living with dementia (Brodaty & Donkin, 2009; Hengelaar et al., 2018).

Researchers have found that family carers seek information about formal care services, and especially related to how to use services and available help (Soong, Au, Kyaw, Theng, & Car, 2019), but other researchers reveal important variation in people's ability to find, assess, and apply health information, which may constitute an equity challenge (Rostamzadeh et al., 2020; WHO, 2013). The concept of health literacy is frequently used to illuminate how differences in personal resources may result in inequalities in health outcomes (Demir Barutcu, 2019; S.-C. Lin, Chen, Yu, Lee, & Tsai, 2019; Zheng et al., 2018) and healthcare access (Rostamzadeh et al., 2020; Sudore et al., 2006) and underscores the need to support informal caregivers to reduce these risks of inequalities, such as for older people living with dementia who are dependent on their family carer. Health literacy is one of the areas where the Norwegian government is now focusing, aiming to facilitate increased health literacy in the Norwegian population (Ministry of Health and Care Services (Helse- og omsorgsdepartementet), 2019). Still, the equity challenge further emphasizes the need to better understand family carers perspectives related to health information, communication and interactions between family carers and health services that are important aspects of care provision to older people living with dementia.

As we have seen, caring for people living with dementia is an often a long-term responsibility with high care demands, which, due to a combination of changing demographics and general trends in health care, is expected to apply to a growing number of people in the population. Combined, this makes high demands on family carers and makes support to caregivers of older people living with dementia increasingly important (Hawken, Turner-Cobb, & Barnett, 2018; Jowsey, McRae, Gillespie, Banfield, & Yen, 2013; National Institute for Health and Care Excellence, 2006; Rosness, Haugen, Gausdal, Gjøra, & Engedal, 2012; Social care institute for excellence, 2015). In particular, family carers need support in order to prolong their capacity to provide care and be engaged in caregiving (Alzheimer Scotland. Action on Dementia, Convention of Scottish Local Authorities, & Healthier Scotland. Scottish

Government, 2013; WHO, 2018). Consequently, in many countries, dementia care strategies, and dementia care plans (Alzheimer Scotland. Action on Dementia et al., 2013; Carers Canada, 2015; Ministry of Health and Care Services (Helse- og omsorgsdepartementet), 2015; WHO, 2018), healthcare reforms for senior citizens (Canadian Medical Association, 2013; Ministry of Health and Care Services (Helse- og omsorgsdepartementet), 2018), and action plans to support family carers have highlighted supporting family carers and emphasized that partnerships with health personnel are needed to provide high-quality, sustainable care (Department of Helath & Social Care (UK), 2018; Hoff, 2015). Guidelines for family carer involvement have been developed in Norway (Norwegian Directorate of Health (Helsedirektoratet), 2019) and elsewhere (Alzheimer's Disease International, 2018; UK Government, 2015) to support and guide family carers in their roles as informal care providers.

In Norway, a study on older immigrants living with dementia revealed that many relatives of such immigrants may feel obliged to play the role of carer and engage in providing care at home (Sagbakken et al., 2017). The authors concluded that different models of care and collaboration between family carers and health personnel should be developed and applied in the future. Policy documents (Ministry of Health and Care Services (Helse- og omsorgsdepartementet), 2015, 2018), and research (Rugkåsa, 2015) highlight that new ways of organizing health service delivery in cooperation with family carers are necessary in order to meet future demands for dementia care in sustainable ways for all parties. In that regard, family caregivers have unique insight into interactions involved in the provision of care services and between such services and family carers.

Partnerships between family carers and health personnel are suggested as one way of involving family carers in the provision of care. According to the WHO partnerships in care between families and services should be based on trust, equality, mutual understanding, shared goals, and shared accountability (WHO, 2017b). By extension, such recommendations are reflected in policy documents such as the UK Strategy for Family Carers, which emphasizes that health personnel should consider family carers as partners in care and recognize their unique expertise (Department of Helath & Social Care (UK), 2018; Rugkåsa, 2015).

2.8 Future challenges for health services and care provision to older people living with dementia

Comparing data from 1994 and 2011, a study from the United Kingdom revealed that the prevalence of dementia had decreased among people more than 65 years old and that fewer had developed old-age dementia among those born in the later years before 2011; the age-adjusted risk of dementia appears to decline, while the number of individuals at risk is increasing (Matthews et al., 2013). Such trends may be explained by significant reductions in risk factors in higher-income countries (Capewell, Amp, Apos, & Flaherty, 2011; Hachinski et al., 2019). Despite a positive long-term trend in terms of age-adjusted risk, the risk of acquiring dementia increases with age and is estimated to double roughly every 5-6 years from around the age of 65 (Corrada, Brookmeyer, Paganini-Hill, Berlau, & Kawas, 2010) and the number of people living with dementia increases as a result of increased life expectancy (GBD 2013 Mortality and Causes of Death Collaborators, 2015).Worldwide, the total number of older people living with dementia is thus expected to increase considerably in the coming years (Cunningham et al., 2015; Naghavei et al., 2015).To illustrate the impact of dementia on society—that is, the societal costs of dementia—Alzheimer Disease International Alzheimer Disease International (2010) has shown that such costs related to dementia equal the combined costs of cancer, heart disease, and stroke.

In Norway, the number of people living with dementia is expected to more than double from 2015 to 2050 (Norwegian Institute of Public Health (Folkehelseinstituttet), 2019), while internationally, the number is expected to triple by 2050 (Livingston et al., 2017). In addition to the increased number of older people living with dementia, comorbidity is frequent in that population (Banerjee, 2014), which stresses the need for better service integration in order to meet the complex needs of such individuals (Alzheimer's Disease International, 2016; Holmøy, Kjelvik, & Strøm, 2014; Phelan, Borson, Grothaus, Balch, & Larson, 2012; Ydstebo et al., 2015).

Around the world, healthcare systems struggle to provide adequate coverage of diagnostic services to people living with dementia (Butler, Kowall, Lawler, Gaziano, & Driver, 2012). Beyond that, in today's globalized world, other challenges arise when people have different views on health and disease, different values and beliefs, and speak different languages (Sagbakken et al., 2018). In high-income countries, dementia care is often exceptionally specialized, with limited formal recognition of the role of primary care services, which is unlikely to be sustainable, when the demand for services increases (Alzheimer's Disease International, 2016; Butler et al., 2012; Kirson et al., 2016). At the same time, a future shortage in health personnel is expected both in Norway and worldwide (Clarc, Stewart, & Clarc, 2006; Holmøy et al., 2014). That likelihood especially concerns nurses, who traditionally care for the oldest people in society, including those living with dementia (Holmøy et al., 2014).

Formal health services have been criticized for not meeting actual needs of persons living with dementia (Granbo, Boulton, Saltvedt, Helbostad, & Taraldsen, 2019; Janssen et al., 2018). At the same time, regulations on dignity in care for older people (verdighetsgarantien) (The dignity guarantee (verdighetsgarantien), 2011) and on quality in healthcare services (kvalitetsforskriften) are emphasizing health services' duty to provide flexible and coordinated services, to facilitate shared decision-making, user involvement, and the service provision focusing on both social, physical, and emotional needs (Quality regulation for care services (Kvalitetsforskrift for pleie- og omsorgstjenestene), 2003)

Understanding care needs among older people living with dementia and their family carers (Abdi et al., 2019; Hughes et al., 2014; McCabe et al., 2016), identifying and understanding barriers to service use (Bieber et al., 2019; Kerpershoek et al., 2019; Mariani, Vernooij-Dassen, Koopmans, Engels, & Chattat, 2017; Mullins, Bliss, Rolnick, Henre, & Jackson, 2016; Stephan et al., 2018; Turi, Bals, Skre, & Kvernmo, 2009), the societal economic costs of dementia (Alzheimer's Disease International, 2016; Dodel et al., 2015; Grosse, Pike, Soelaeman, & Tilford, 2019; Janssen et al., 2018; Kirson et al., 2016; Nakabe et al., 2018; Shepherd et al., 2019; Weatherly, Faria, & Berg, 2014; Wimo, Jonsson, et al., 2013), and timeliness of services are important areas of ongoing research (Dubois et al., 2016; Janssen et al., 2018; Kerpershoek et al., 2016; Levy & Janke, 2016; Werner, Goldstein, Karpas, Chan, & Lai, 2014).

In the context of the described future challenges for healthcare provision, further research on health services and service provision is necessary, as are new innovations and the optimization of resources for formal as well as informal care. This Ph.D. thesis aims to learn from family carers how they experience health services and care provision to older people living with dementia. By better understanding family carers' experiences, new insight about potential gaps in existing health services and care provision may emerge. This may in turn provide new insight in how health services may improve care provision to older people living with dementia and their families and how health personnel may support family carers.

3 Definitions and theoretical framework

In this section, I will describe key terms and explain how they are understood and used in this thesis. I then move on to explain central theoretical concepts which are used in the development and interpretation of the findings.

3.1 Definitions of key terms

The following definitions explain how terms used in the thesis have been interpreted.

3.1.1 Family carer

A *family carer* refers to "an unpaid individual (for example, a spouse, partner, family member, friend, or neighbor) involved in assisting others with activieties of daily living and/or medical tasks" (Family Caregiver Alliance, 2019, section 1). Family carers typically help care recipients to manage a variety of tasks, including bathing, dressing, taking medication, cooking, shopping, cleaning, organizing daily activities, handling finances, and organizing appointments, interact with health personnel, all on top of regularly visiting the care recipient. In the thesis, I sometimes use *carer* in the same sense as *family carer*. Other synonyms for the term include *informal caregiver* or *family caregiver*, which are often used in the literature.

3.1.2 Informal care

As just mentioned, *informal care* refers to unpaid care provided by, among others, family carers. By contrast, *formal care* refers to formal health services and professional care.

3.1.3 Health services and care provision

The term *health services* is used about formal services at primary- and specialist level. The term *care provision* is a wider term used for the totality of care that is provided to older people living with dementia through a mix of formal and informal services, and is not limited to what is usually within the scope of health services.

3.1.4 Person living with dementia

The terms *person living with dementia* and *people living with dementia* refer below to all people receiving care from participants in the study, following the guidelines for the use of positive language in reference to dementia (Alzheimer's Society, 2018). As I explain in more detail below, I included family carers who had experience with caring for older people living with dementia symptoms, no matter the type or stage of the condition or whether formally diagnosed. Because dementia is often not diagnosed, using diagnosis as an inclusion criterion could have exclude individuals who care for older people living with early symptoms of dementia.

3.1.5 Older people

The terms *older person* and *older people* refer to adults aged 65 years or older.

3.1.6 Health personnel

The term *health personnel*, used in accordance with the Norwegian Public Health Act (Norwegian Public Health Act (helsepersonelloven), 2019), refers to everyone who works in health services, both trained and untrained, whether they engage in preventive or diagnostic work, and whether their work involves treatment, health preservation, rehabilitation, or healthcare in general

3.2 Central concepts

3.2.1 Carer burden

In this thesis we use the term *carer burden* as a reference to the *subjective burden* when nothing else is specified.

Many studies have reported heavy strains and burdens experienced by family carers in caring for others, including older persons living with dementia (Allen et al., 2017; Annerstedt, Elmstahl, Ingvad, & Samuelsson, 2000; Cheng, 2017; Rosness et al., 2012; Srivastava, Tripathi, Tiwari, Singh, & Tripathi, 2016; Sutcliffe et al., 2017; The Lancet, 2018; Vaingankar et al., 2016) . As a heterogeneous concept encapsulating subjective and objective elements, *carer burden* is commonly understood to mean the physical, psychological, emotional, social, and financial strains experienced by family carers (L. George & Gwyther, 1986). According to Montgomery, Gonyea, and Hooyman (1985), subjective elements of carer burden refers to the caregiver's perceptions of caregiving, such as depression, anxiety and guilt, while the objective element refers to concrete problems resulting from daily care, such as time spent on providing informal care per day. The term *objective carer burden* refers to the quantities such as time and finances devoted to care (Flyckt et al., 2015; Hughes et al., 2014).

Behavioral and psychological symptoms of dementia have been described to increase family carer's subjective burden (Baharudin, Din, Subramaniam, & Razali, 2019; Feast, Moniz-Cook, Stoner, Charlesworth, & Orrell, 2016) along with unmet care recipient's needs, and patient safety concerns (Allen et al., 2019; Hughes et al., 2014). Differences in personal characteristics among family carers, including gender (Xiong et al., 2018), personality (Dias et al., 2015; S. K. Kim et al., 2016), coping strategies (Hawken et al., 2018), and abilities in self-distraction, planning, and acceptance (Baharudin et al., 2019; Stensletten, Bruvik, Espehaug, & Drageset, 2016), may also affect how family carers perceive and manage their caregiving situations.

Family carers have an increased risk of experiencing the deterioration of their physical and mental health (Park & Park, 2015; R. Schulz & Martire, 2004; Stensletten et al., 2016; Ulstein, Wyller, & Engedal, 2007) and those who are older caregivers have a higher risk of mortality as well (R. Schulz & Beach, 1999). Negative health outcomes reported among family carers for older persons with dementia include sleep disturbances, depression, anxiety, poor physical status (S. Liu et al., 2017; Shaw et al., 1997), high blood pressure (King, Oka, & Young, 1994), and even slow wound healing (Kiecolt-Glaser, Marucha, Malarkey, Mercado, & Glaser, 1995).

Carer burden has been associated with reduced quality of life (Kuo, Lan, Chen, & Lan, 2010; Srivastava et al., 2016), and Settineri, Rizzo, Liotta, and Mento (2014) found that the association was stronger among carers who were motivated by a sense of duty instead of by love and affection (Settineri et al., 2014). Lopez-Anuarbe and Kohli (2019) found that male caregivers, in addition to female caregivers, do face caregiving burden, and that male caregivers often have weak support networks and are less likely to seek out support programs or help to cope with their burdens. Additionally, different cultural traditions may value family care differently and, as a result, impose different expectations upon family carers (Sagbakken et al., 2018). Given the potential for such diverse experiences with carer burden, a systematic review from 2017 called for increased research efforts on what promotes and hampers quality of life among family carers of older persons living with dementia (Farina et al., 2017).

Research in this field has mainly focused on reducing the carer burden, and less on promoting the positive outcomes from caring (Yu, Cheng, & Wang, 2018). The latter is found to include a sense of personal accomplishment and gratification, feelings of affirmation, role fulfillment, increased family cohesion, and personal growth (Stansfeld et al., 2017; Yu et al., 2018). Despite much research on the negative effects of caring, there is a scarcity of knowledge on how to support family carers and facilitate good care partnerships.

Researchers have shown that higher carer burden is associated with lower health literacy (see 3.2.3) and differences in service use, among other variables (Batterham, Hawkins, Collins, Buchbinder, & Osborne, 2016; Janssen et al., 2018; Lloyd & Stirling, 2011; Manafo & Wong, 2012). Community services can be of assistance in relieving carer burden to carers for people living with dementia (Lloyd & Stirling, 2011).

3.2.2 Health-related quality of life

The terms *health-related quality of life (HRQoL)*, *quality of life*, *health*, and *well-being* are sometimes difficult to differentiate (Shah, 2017), are often used inconsistently and interchangeably in the literature, and have been defined in various ways (Karimi & Brazier, 2016). For one, the term *quality of life*, which can be defined as "the degree of satisfaction or dissatisfaction felt by people with various aspects of their lives" (Farquhar, 1995 p. 503), became important in healthcare assessments when medical treatment began extending the length of life, sometimes at the expense of quality (Kaplan & Bush, 1982). As a result, the need to measure outcomes beyond death rates, morbidity, and biological functioning emerged (Karimi & Brazier, 2016).

Studies find strong associations between quality of life and depression, anxiety and satisfaction (Moreno et al., 2015). Family carers for older people in general, (Wolff, Spillman, Freedman, & Kasper, 2016) and family carers to older people living with dementia (Alltag, Conrad, & Riedel-Heller, 2019; de Oliveira, Vass, & Aubeeluck, 2015; Farina et al., 2017) are at risk of reduced quality of life. The term *HRQoL* is referring to a concept that encompasses quality of life and health (Karimi & Brazier, 2016). The concept of HRQoL has become important in public health monitoring, and is generally considered to be a valid indicator used in patient outcome research and indicator of health outcomes. HRQoL measures are often used to assess the quality of services, the need for health care, the effectiveness of interventions, and in cost utility analysis (Carr & Higginson, 2001). The attributes of the term *outcome* include a person's functional status, a person's safety (protected or unharmed), and satisfaction (Center for Disease Control and Prevention, 2018; Y. Liu, Avant, Aungsuroch, Zhang, & Jiang, 2014). It has also been described as a measure of morbidity burden and as a multidimensional concept that includes a person's subjective evaluation of positive and negative aspects of life (Brown et al., 2013). HRQoL has gained considerable attention in the past three decades, and can be measured with a variety of assessment tools, including the EQ-5D-5L instrument (Brown et al., 2013; Hickey, Barker, McGee, & O'Boyle, 2005). In this thesis, I use the term *HRQoL* to refer to "the impact of the health aspects of an individual's life on that person's quality of life, or overall well-being" (Brazier, Ratcliffe, Salomon, & Tsuchiya, 2007 p. 332.).

3.2.3 Health literacy

The concept of Health Literacy (HL) emerged from attempts to enhance the *literacy* of adults in the United States (US), i.e. their ability to read, write, and speak English, as well as compute and solve problems, at a level of proficiency necessary to function in a job and in society and, in turn, to achieve personal goals and develop personal knowledge and potential (Berkman, Sheridan, Donahue, Halpern, & Crotty, 2011). Later, the concept HL was developed in discussions about self-management and communication in healthcare, and it has since become a priority area in the management of chronic conditions in the US (Institute of Medicine Committee on Identifying Priority Areas for Quality, 2003). By extension, researchers have stressed the importance of measures of HL in enabling people to comprehend their health condition and treatment and to make the best decisions about their care (Nguyen, Paasche-Orlow, & McCormack, 2017; Nielsen-Bohlman, Panzer, & Kinding, 2004).

Several definitions and conceptual models of HL have been developed (Finbråten, 2018; Sørensen et al., 2012), and numerous studies have involved testing a wide range of HL measures (Finbråten, 2018; Nguyen et al., 2017; Sørensen et al., 2012). As a consequence, a major challenge in research on HL is the difficulty of comparing results across studies due to variability among conceptual models and definitions, as well as that HL has been measured with an array of tools (Nguyen et al., 2017). In this thesis, I use the term HL as described by Sørensen et al. (2012), measured across four cognitive domains (access, understand, appraise and apply health information) and three health domains (health care, disease prevention and health promotion):

> Health literacy is linked to literacy and entails people’s knowledge, motivation and competence to access, understand, appraise and apply health information in order to make judgments and take decisions in everyday life concerning healthcare, disease prevention and health promotion to maintain or improve quality of life during the life course. (Sørensen et al., 2012 p.3)

Sørensen et al., 2012 characterize that definition as “all-inclusive” as it was developed from 17 different definitions and 12 conceptual models of HL found in their systematic review.

Showing that HL is not equally distributed among individuals, Rudd (2007) found that adults without a high-school diploma, with health-related restrictions, with limited access to resources, who are members of minority populations, and who are immigrants have lower HL skills than others. Other researchers have confirmed that HL can be, at least partly, acquired from education and experience (Jacobs, Lou, Ownby, & Caballero, 2016; S.-C. Lin et al., 2019; Manafo & Wong, 2012; Nutbeam, McGill, & Premkumar, 2017).

HL can also be used to explain inequalities in healthcare and access to it (Batterham et al., 2016; Berkman et al., 2011). As a recent systematic scoping review of HL among caregivers of adult care recipients revealed, associations exist between low levels of caregiver HL and poorer care recipient self-management behaviors, increased care recipient use of acute health services, and increased caregiver burden (Yuen, Knight, Ricciardelli, & Burney, 2018). Researchers have also reported that a high level of HL is associated with improved access to better targeted health services (Batterham et al., 2016; Jansen et al., 2018; Manafo & Wong, 2012) the improved management of health (S.-C. Lin et al., 2019), and improved healthcare (S.-C. Lin et al., 2019).

3.2.4 Cultural health capital and cultural capital

Cultural health capital (CHC) is a concept related to HL, for it offers a perspective from which to understand inequalities in healthcare contexts. The concept's developer, Shim (2010), characterized CHC as a theoretical approach to understanding healthcare interactions and the dynamics of unequal treatment in healthcare settings (Shim, 2010). Shim (2010) based the concept of CHC on Pierre Bourdieu's theories of habitus and cultural capital, which describe a person's position in society and how cultural knowledge and skills represent capital that can be used to gain influence and social position (Bourdieu, 1986; Shim, 2010). Shim (2010) adapted that understanding to cultural capital, used specifically in healthcare contexts, often to leverage effective engagement with medical providers. The concept of CHC can thus help to account for how patient–provider interactions unfold in ways that may generate disparities in healthcare. As used in this thesis, *CHC* refers to "the repertoire of cultural skills, verbal and nonverbal competencies, attitudes and behaviors, and interaction styles, cultivated by patients and clinicians alike, that, when deployed, may result in more optimal healthcare relationships" (Shim, 2010 p. 1).

The kinds of skills or abilities that constitute CHC depend on the time, place, and context (Dubbin, Chang, & Shim, 2013; Shim, 2010). To that, Shim (2010) has added that the concept of CHC can complement other psychosocial, epidemiological, and sociological concepts and frameworks, including HL (Shim, Chang, & Dubbin, 2011), in addressing inequities in healthcare. Although Shim, Chang, and Dubbin (2011) chiefly describes the physician–patient relationship in applying the concept of CHC, in this thesis I suggest CHC might be helpful to illuminate the relationship between formal and informal carers (e.g., home care nurses and family carers).

3.2.5 Quality of healthcare and patient safety

The widely acknowledged prevalence of preventable patient harm and adverse outcomes in healthcare settings has prompted the use of the term *quality of healthcare* (Allen-Duck, Robinson, & Stewart, 2017), which can be defined as “the assessment and provision of effective and safe care, reflected in a culture of excellence, resulting in the attainment of optimal or desired health” (Allen-Duck et al., 2017 first paragraph). As indicated in that definition, quality of healthcare is linked to safe care and to *patient safety.* Although *quality of healthcare* and *patient safety* are often used interchangeably in the literature, they are nevertheless distinct concepts. Indeed, *patient safety* is commonly used as one of several descriptors of quality of healthcare (Allen-Duck et al., 2017). Other outcomes associated with quality of healthcare include effectiveness, patient-centeredness, timeliness, efficiency, and equitability (Institute of Medicine (US) Committee on Quality of Health Care in America, 2001), as described in Table 1. Elements of quality of healthcare

Table 1. Elements of quality of healthcare according to the Institute of Medicine (US) Committee on Quality of Health Care in America (2001)

Safe care	Avoiding injuries to patients from the care that is intended to help them
Effective care	Providing services based on scientific knowledge to all people who could benefit Refraining from providing services to people not likely to benefit from them (e.g., avoiding underuse and overuse)
Patient-centered care	Providing care that is respectful of and responsive to each patient’s preferences, needs, and values Ensuring that the patient’s values guide all clinical decisions
Timely care	Reducing wait times and sometimes harmful delays for caregivers and care recipients
Efficient care	Avoiding waste, particularly the waste of equipment, supplies, ideas, and energy
Equitable care	Providing care that does not vary in quality according to personal characteristics such as gender, ethnicity, geographic location, and socioeconomic status

Since the late 1990s, patient safety has been a pivotal area in health policy worldwide (Institute of Medicine (US) Committee on Quality of Health Care in America, 2001; Lark, Kirkpatrick, & Chung, 2018). In parallel, discussions about patient safety have moved beyond addressing concerns about medical errors and hospital mortality to focusing on broader themes, including how to maintain quality of life in healthcare and service delivery, in both hospital and community-based settings (Lark et al., 2018). In the context of community-based dementia care, typical topics concerning patient safety include falls, wandering around disoriented, food safety, traffic safety, and polypharmacy (Hays et al., 2017).

4 Methodology

In this section, I will present the philosophical underpinning of the research project and present the methods used in the two sub-studies, as well as how the two sub-studies are connected.

4.1 The research approach

Creswell (2014) suggests that a research approach consists of three elements; a philosophical worldview (in this case a pragmatic worldview); a research design (in this case an explanatory sequential mixed method design); and research methods (in this case interviews and surveys).

4.1.1 The philosophical worldview

There are multiple ways to understand and define what philosophy is (Edwards, 1997), but the term *philosophy* is derived from the Greek *philosophia*, meaning *the love of wisdom* (Kikuchi & Simmons, 1994). According to Kikuchi and Simmons (1994), philosophy seeks to illuminate values, beliefs, concepts, and principles that reflect ideas, convictions, and attitudes. This aligns with the view of other authors, such as Berlin, Hardy, MacIntyre, and Williams (2013) stating that “The goal of philosophy is always the same, to assist men to understand themselves and thus operate in the open, and not wildly, in the dark.” (Berlin et al., 2013 p. 14.).

Philosophy may consist of ontology (what is real), epistemology (how do we know what is real), methodology (how do we come to know what is real), and ethics/axiology (what are the values underpinning all of the above) (Sue, 2018; Varpio & MacLeod, 2020). Consequently, the philosophy which underpins the base of my methods illuminates how knowledge is found or constructed, and what kind of perceptions of the world and of knowledge the methods are based on. In the next sections, I will elaborate which philosophical worldview (ontology and epistemology) that forms the base for the methods that I have used. A thorough description of the methods I have used follows in sections 4.2 and 4.4. The ethics is discussed in chapter 5 and, as part of my preunderstanding, in 6.1.1.1.

4.1.1.1 The pragmatic worldview

Pragmatism was a reaction against philosophical idealism on one hand, and on the other hand it was a reaction to the dogmatic authority of cultural and religious elites who claimed to possess privileged knowledge of the world (Hellan, 1998). It has been described as an anti-theoretical philosophy, sticking as closely as possible to empirical reality (Alvesson &

Sköldberg, 2009). Pragmatisms arises out of actions, situations, and consequences, and is concerned about *what works* and *how to* (Creswell, 2014). The focus is on solving the problems at hand, and on the research question. Pragmatism employs all approaches available to understand the problem, rather than focusing on any one method (Creswell, 2014). Patton (2015) agrees with Creswell that mixed methods opens the door to different worldviews, and gives freedom of choices. However, pragmatism's fundamental principle was broader than just science. It includes all processes of human inquiry that occur within the domain of human experience as people struggle to cope with the world around, and language is how this struggle is expressed (Hellan, 1998).

From the philosophical basis, pragmatisms claims that truth is not based in a reality independent of the mind, or within the mind. Rather, pragmatists agree that research always occurs in social, historical, political, and other contexts (Creswell, 2014). These ideas bear resemblance to social constructivism, which emphasizes that people's subjective meanings are formed through interaction with others, and through historical and cultural norms that operate in their lives (Creswell, 2014). Social constructivists, similar to pragmatisms, do not start with a theory, and they are both concerned with what arises from dynamic situations and relations. However, while social constructivists are concerned primarily with disclosure of how social phenomena are socially constructed (Alvesson & Sköldberg, 2009), pragmatists are more concerned with actions to solve a problem, and the consequences of these actions (Creswell, 2014; Morgan, 2014).

Among mixed-method researchers, there is a strong tendency to emphasize the *how to* aspects, but stating pragmatism as a philosophy goes beyond problem solving and the focus on *how to*; according to Morgan (2014), researchers should place more importance on the question of *why to*. This puts greater emphasis on choices about both the goals to be pursued, and the means to meet those goals, which is in accordance with how pragmatism as a philosophy is described by Patton (2015). Patton emphasizes the consequences of actions, or consequences of methodological choices, such as making methods decisions based on the situation and opportunities that emerge, rather than adhering to any pure paradigm or fixed design. Morgan (2014) refers to Dewey, one of the writers from whom pragmatism derives, showing that pragmatism emphasizes human experience. The emphasis on experience is an active experience in a social, political or historical context, different from the phenomenological emphasis on describing the lifeworld. According to Morgan (2014), experience is built around two related questions: 1) what are the sources of our beliefs? and 2) what are the meanings of our actions? He then presents Dewey's model of experience as an ongoing dependency between reflecting on beliefs to choose actions, and reflecting on actions to choose beliefs. One question about practical consequences of design decisions is whether the design can be successfully carried out, within the constraints of available time, skills, or other resources. Another question is whether design tradeoffs are optimized, such as between depth of understanding and generalizability (Patton, 2015).

Patton (2015) explains that "methods can be separated from the epistemology out of which they have emerged" (Patton, 2015 p.154). He continues to explain that one can make interpretations without having studied hermeneutics, and can conduct interviews without reading phenomenology, so that "the methods of qualitative inquiry now stand on their own as reasonable ways to find out what is happening" (Patton, 2015 p.154). The logic of human inquiry in pragmatism comprises three stages: 1) abduction, the beginning of an idea; 2) induction, informed by specific instances; 3) deduction of logical consequences from general principles (Hellan, 1998).

In pragmatism, experience is not just a passive reception of the world. Rather, experience is active, structured by ideas, tested by actions, and aimed at broadening horizons by informing with new ideas (Hellan, 1998).

4.1.1.2 Pragmatism, hermeneutic and phenomenology

The broadening of horizons reminds us about Gadamer's fusion of horizons. That is Gadamer's description of how the text and the reader carry with them different views, values, and preunderstandings; and that these differences merge to form a new preunderstanding, which carries perspectives informed by the other part in addition to the original preunderstanding (Gadamer, 2006). In contrast to pragmatism, hermeneutics classically refers to questions of textual interpretation (Alvesson & Sköldberg, 2009), rather than the active experiences itself. Hermeneutic philosophy did not come from the quantitative sciences, but from the tradition of humanistic scholarship in scriptural studies, history, art, and related activities (Alvesson & Sköldberg, 2009). Pragmatism, like hermeneutic philosophy, focuses on the lived world of inquiry, and sees science as the creation not only of theoretical meanings, but also, more significantly, of cultural meanings (Hellan, 1998). In hermeneutic philosophy a main theme is that the meaning of a part can only be understood if it is related to the whole. Consequently, we are confronted with the objectivists hermeneutics' circle, the hermeneutic circle, between *parts* and the *whole* which was transforming into a spiral, emphasizing that when alternating between parts and whole, our understanding is developed further, and brings a progressively deeper understanding of both the parts and the whole (Alvesson & Sköldberg, 2009). The objective hermeneutic is based on a polarity between the subject and the object, while the alethic hermeneutics focused on the correspondence, the conceptions of an interpreting subject – the researcher, and consequently, we got a second hermeneutic circle, between *preunderstanding* and *understanding* (Alvesson & Sköldberg, 2009). The concept of the hermeneutic circle illustrates the reciprocal relationship between a preunderstanding and new understanding (Dowling, 2007) and illustrates the endeavoring of "uncovering of something hidden" (Alvesson & Sköldberg, 2009 p. 122). The understanding of how family carers' experienced, understood, and interpreted their experiences in relation to their context is in line with Hediegger's hermeneutics, focusing on the *meaning* of a phenomenon and the relation to the way people exist, act, or are involved in the world (Dowling, 2006).

Both pragmatism and hermeneutics are self-reflective, and focus on the role of perception. Although pragmatism and hermeneutic philosophy both treat science as a form of human culture, which approaches the world in the spirit of active inquiry, pragmatism tends to see the background, theory, and praxis as working together in solving problems and helping people to adapt to changes in the environment. This is in contrast to hermeneutic philosophy which seeks to take them apart to study the contribution each makes to the generation of meaning (Hellan, 1998). Hermeneutics are oriented towards meaning, not power; and towards the things that can be construed as having meaning, which is similar to pragmatism (Hellan, 1998). Hermeneutic philosophy however, seeks a level of understanding beyond pragmatism, and this difference in which level a phenomenon is understood is one of the main differences between hermeneutic philosophy and pragmatism. Pragmatism is more earthy abductive in its methods than hermeneutics are (Hellan, 1998).

In this research project, I chose an explorative and pragmatic approach, utilizing the variety of experiences of family carers willing to participate. I have focused on the research problem that is to arrive at a better understanding of family carers' experiences with health services for older people living with dementia. I decided how to research the phenomenon, based on the pragmatic assessment of benefits and consequences. For example, I weighed the benefit and consequences of using in-depth interviews compared to focus groups in the qualitative part.

The benefits and consequences of this choice are discussed in section 4.2.2. I also decided the number of interviews based on a pragmatic assessment of benefits and consequences, and this is described in section 4.2.4.4. In interviews and surveys, I considered participants' experiences and their subjective meanings, as entry points for learning about their social worlds (Lucas, 2014) and lived experiences (Mapp, 2008; van Manen, 2016). Inspired by phenomenology, I used detailed and nuanced coding to describe what participants talked about, and pragmatically organized codes together. I condensed some of the codes to be able to organize codes together in higher-level codes. I used nuanced codes, mainly with descriptive codes, to create a distance to my initial understanding and to my initial interpretation of the text. All of this is elaborated further in section 4.2.7.2. In this sense, I have used techniques inspired by phenomenology in the third stage of my analysis (see section 4.2.7.3), to create a distance to my interpretation. However, I have also interpreted meanings from participants' experiences (see section 4.2.7.2 and section 4.2.7.4) by moving from parts to whole, and from whole to parts, and developed my preunderstanding to a new understanding of participants experiences, inspired by hermeneutics.

From a pragmatic worldview, I am not committed to any one system of philosophy (Alvesson & Sköldberg, 2009; Creswell, 2014). I took peoples' subjective constructions of meaning as a starting point for understanding social life (Alvesson & Sköldberg, 2018), and I have been drawing on the hermeneutic and the phenomenological philosophical traditions in my qualitative research methods as I have used a combination of different analytic techniques. These are outlined in section 4.2.7.

4.1.1.3 Empiricism and critical realism

I have considered participants experiences and subjective meanings as entry point for learning, in the quantitative part of this project as well as the qualitative. I used survey as my data collection method of their subjective experiences, and quantitative methods such as descriptive statistics, and regression analyses to analyze data. From an epistemological view, the procedures of regression analysis are conventionally considered to be examples of the positivistic empiric approaches and empiricist philosophy of science (Ron, 2002). Empiricism emphasizes that both natural and social sciences are describing, understanding, and explaining reality (Patton, 2015). Empiricism as philosophy is a version of positivism (Patton, 2015) which holds the view that experience, observation, or senses are the most important ways, or only way, to gain knowledge (Hjørland, 2005). Empiricism also claims that all controversies should be reduced to hypothesis that can be verified by observations (Hjørland, 2005). This means that there are a hypotheses that is tested against observations of the natural world, rather than solely on reasoning. In this sense, regression analysis seems to be based on empiricism since it is used after a reduction of the complex findings from interviews, and follows statistical and mathematical “laws” to test assumptions. In the sense that qualitative interviews also deals with in the data of experience, one may say that qualitative interviews are empirical, but the quantitative analysis is, by contrast, resting on empiricism as philosophy (Patton, 2015).

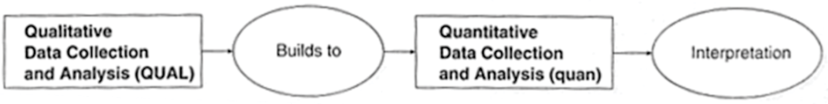
However, empiricism has been criticized by critical realists, who argue that experience is not the only source of knowledge. In critical realism, in contrast to empiricism, reality is consisting of three domains – the empirical, the actual, and the real (Alvesson & Sköldberg, 2009). Representing a critical realist’s view, Ron (2002)argue that the result of regression analysis is an estimated model which is based on, among other, the following two assumptions: 1) an ontological assumption that social relations are existing in ways that can be described as a mathematical function, 2) an epistemological assumption that it is possible to know the variables of this function. Ron then points out that whether or not one considers the first assumption to be true, is a matter of belief, not a matter empirical experiment alone. Consequently, it is not based on empirics. Next, Ron claims that even if one believes that social relations follow the laws of a mathematical function, social sciences provide few clues regarding the form of this function. This statement strengthens his point that regression analysis is not based on empiricism, but rather based on critical realism (Ron, 2002).

4.1.2 The research design

The sequential mixed-methods research design used in this study involves stages of qualitative and quantitative methods that build sequentially upon each other (Creswell, 2014; Schoonenboom & Johnson, 2017). I followed framework developed by Creswell (2014) and shown in Figure 2, which begins with a qualitative exploration followed with a quantitative investigation of elements identified during analysis. The design was to first explore the research objectives in a small sample and then to investigate subsets of the results in a larger population, leading to a better understanding the study phenomena.

There are different types of mixed method designs, and I chose a design that was sequential because I wanted to start with qualitative methods, with which I had previous experience. This allowed me to explore which variables of interest to include in Substudy 2. In accordance with the pragmatic philosophy, the choice to start with the qualitative part was made based on *what worked* and, *why to* do it this way. Consequently, I made choices regarding data construction and reflected on the consequences of those choices. The consequences of the choice to start with the qualitative part was that it allowed me to start Substudy 1 while learning more about quantitative methods and quantitative analysis, and subsequently to plan Substudy 2 while being close to the empirics and analysis of Substudy 1. Another consequence was that it allowed me to investigate findings from Substudy 1 in a larger sample, and identify variables suited for exploration in Substudy 2. On this basis, my research design involved an explanatory sequential mixed method, see Figure 2. An overview of the project design is also illustrated in Figure 3.

Figure 2. The exploratory sequential mixed-methods design



According to Patton (2015), a flexible and pragmatic design requires openness and high tolerance for ambiguity and uncertainty. Patton (2015) refers that the actual design can only be described retrospectively as opportunities are pursued during data generation and the study design evolves (Patton, 2015 p. 50). In section 4.2.4 I will show how this was applied in my Ph.D. project, as I pursued opportunities to recruit family carers with a wider range of experiences by using different recruitment strategies and travel to unplanned areas.

4.1.3 Choice of research methods

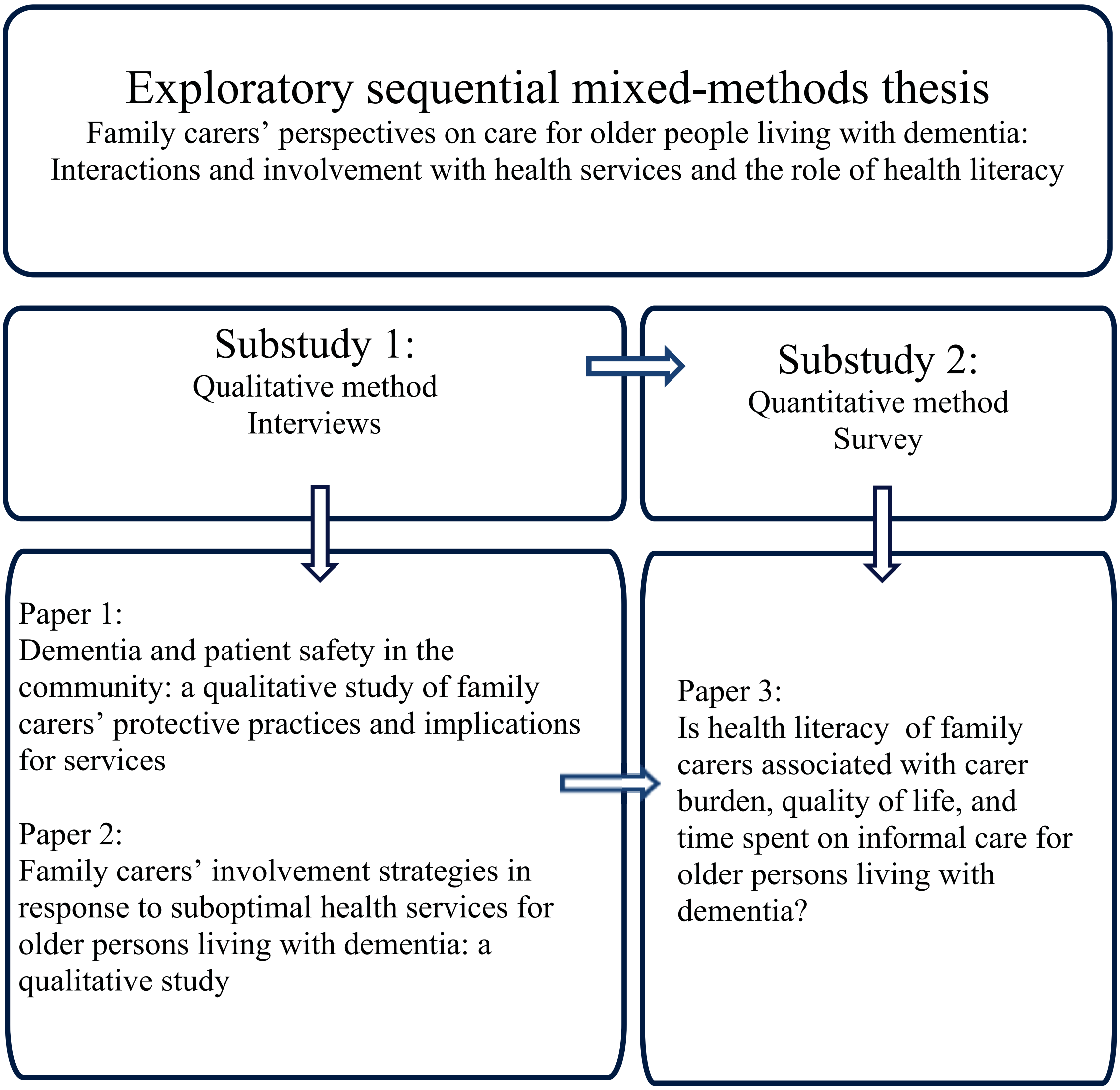
The pragmatic worldview is an epistemological stance that opens the door to multiple methods and different assumptions, as well as different forms of data generation and analysis (Creswell, 2014). Following a pragmatic worldview, I have used a pluralistic approach to generate knowledge about how family carers experienced health services to older people living with dementia, meaning that I have chosen a combinations of methods to investigate the phenomenon (Kaushik & Walsh, 2019). The research objectives were operationalized in two sub-studies using two different methods.

I wanted to explore the experiences from family carers' views in depth, and facilitate participation in the study for all kinds of family carers, including older persons and persons with extensive care responsibilities who may have difficulties leaving their homes at certain times. Therefore I chose to do individual interviews over group-based alternatives, with in-depth interviews as the method to generate data. To guide the conversation within relevant themes, and based on a pragmatic approach, I used a semi-structured interview guide as a framework to enable in-depth interviews as the method to address objectives 1-3 (see section 4.2.1). This allowed me to be flexible in terms of the time, place, and duration of the interviews, and to adjust to participant needs. The semi-structured interview-guide helped me guide the conversation within relevant aspects of their experiences, and the private setting allowed participants to talk about themes and subjects of personal character in a setting of privacy. The consequences of the choices to do semi-structured, in-depth, interviews are further elaborated on in section 4.2.2, 4.2.3, 4.2.4.4, and 4.2.7.

The analysis of data from the in-depth interviews was also pragmatically oriented. I used elements from phenomenological descriptive analysis as described by Giorgi (2009) and Malterud (2017), and hermeneutic interpretive analysis as described by Dowling (2007) and Fangen (2010). The process of identifying and describing themes were conducted using element of thematic analysis as described by Braun and Clarke (2006).

An overview of the project approach appears in Figure 3, and each Substudy is detailed in following subsections.

Figure 3. Overview of the project approach



4.2 Substudy 1: descriptions and interpretations of personal experiences

4.2.1 Research objectives of Substudy 1

Substudy 1 addressed the first three objectives:

1. To explore how family carers experience healthcare provision to older people living with dementia, and how family carers contribute to the delivery of such care

2. To explore how family carers experience their interactions with, and contributions to, multiple health services

3. To explore family carers' perceptions of, experiences with, and involvement in care provision to older people living with dementia.

As products of Substudy 1, Paper I in the thesis primarily addresses Objectives 1 and 2, whereas Paper II primarily addresses Objective 2 and 3.

4.2.2 Study design and selection of method

Family carers' experiences were explored using individual, in-depth, semi-structured interviews. This method allows research participants to freely describe their experiences, thus allowing for new perspectives and insights to emerge (Malterud, 2017; McGrath, Palmgren, & Liljedahl, 2019). The method accommodated adjustments to be made along the way as such new perspectives arose. The method allowed me to explore what participants experienced as important aspects of care provision in the context of their situation. More structured data generation methods, with predefined questions could have ensured that all participants were asked identical questions, and would have allowed more direct comparing of their answers. However, this would have limited the explorative potential to discover new perspectives and themes of which I was not aware in advance.

Semi-structured interviews allowed me to encourage participants to share their experiences with me in confidence (Kvale & Brinkmann, 2012), and allowed the time to go beneath the surface (Alvesson & Sköldberg, 2018). The method was thus suitable for gaining detailed, thorough descriptions of, and understanding of personal experiences prior to any scientific explanations (Kvale & Brinkmann, 2012; McGrath et al., 2019). The method was also suitable for practical reasons, because it could be adjusted to accommodate participants' schedules and restrictions in mobility and, as such, was more flexible than, for instance, focus groups. I expected in-depth interviews to better facilitate participation of family carers to the study, and especially family carers with great caring responsibilities. If focus groups were conducted, participants with similar experiences talking in a group could have created slightly different results. The dynamic nature of a group has the potential to stimulate ideas and memories, and would have allowed participants to comment or discuss each other experiences (Malterud, 2012). Focus groups allow less time for exploring individual experiences in depth (Malterud, 2012), and I would expect that fewer shared private and sensitive information.

To generate data about family carers' experiences I could also have used direct observation as a method. This would have given me information about what family carers did, which might be different from what they say they did, and could have given insight in situations that participants otherwise did not talk about (Fangen, 2010). However, observation would have limited my data to the activities conducted by the participant while under observation. Furthermore, observation would give limited information about previous experiences, which for some included more than a decade of caring (Fangen, 2010).

4.2.3 Development of the interview guide

Prior to the interviews, I developed a semi structured interview guide (Appendix 1, version 1) that contained an outline of categories, themes, subthemes, and examples of questions that could be asked during the interviews (Kvale & Brinkmann, 2012). Questions were open-ended because I wanted to encourage participants to guide me toward perspectives that were important to them (Alvesson & Sköldberg, 2018; Malterud, 2017). Thus, instead of asking questions that directly addressed the research objectives, I asked ones that aimed to prompt participants to answer in ways that expressed their values and experiences relevant to these objectives. The interview guide was developed in light of the aims of the project, and was informed by published research on dementia care, family caregiving, and health services. In line with the flexible design and pragmatic worldview (Patton, 2015), I modified the interview-guide twice (see appendix 1: version 2, and version 3) to be able to follow up on emerging themes in later interviews, and to remove themes that seemed to be of lesser interest among family carers, and thus provided less rich data.

All interview guides were based on, and facilitated explorative interviews and were not adjusted to pre-decided papers or preliminary analysis. The reason for adjusting the interview guide while interviews were ongoing was to follow a pragmatic, open-minded, explorative and inductive design, which could generate rich descriptions of their perspective on care provision to older people living with dementia.

I organized the first versions of the interview guide in four sections: introduction; contributions and interactions with health services; service integration and quality of services; and carer burdens and benefits along with economic costs and benefits. Each section consisted of themes, potential questions, and supporting questions. The subsequent versions of the interview guide followed the same structure, with minor changes which are described later (see Appendix I). All sections were covered in all interviews. However, with the exception of the introduction, the order in which the sections and themes were addressed during interviews varied. By virtue of the flexible design, participants were able to express varying interest in the different themes, and whereas some were asked several questions from the guide, others talked about relevant themes without being asked more than a few of the questions.

Each category included several themes that described what I was interested to know more about. Under each theme were examples of questions that could be used to gain knowledge about the theme. During interviews, those questions were typically used to introduce a new theme if I, as the interviewer, needed to redirect the conversation toward an objective or advance to another theme. From time to time, I also used supporting questions—that is, additional questions that helped me to remember what else to ask if participants did not discuss certain aspects of a themes. Because the consequences of being a family carer of older people living with dementia are often described in terms of heavy carer burden, reduced health, or reduced quality of life, I wanted to ask participants what they thought would improve their quality of life. I though their answer could reveal areas where health personnel or policy could improve services or facilitate better care provision. For that reason, in addition to the interview guide, I used a vertical visual analog scale ranging from 0 to 100, with the endpoints “Best imaginable quality of life” and “Worst imaginable quality of life,” as a tool to ask participants about their quality of life (see Appendix II). I presented the visual analog scale at the end of each interview, and asked the participant to indicate his or her quality of life now, and asked the participants to indicate what could be done to increase his or her quality of life by 20 units. In their responses, many participants provided a valuable summary of what they considered to be most important for their own well-being and quality of life.

A pilot interview was conducted with a member of HØKH’s user panel who had experience with being a family carer for a person living with dementia. As a result, the interview guide version 1 and interview approach were found to work well. The interview style of a private conversation was commended for being comfortable and open-minded.

Although the interviews provided rich data about most of the themes, some themes ended up with richer data than others, and a few seemed to be of generally low interest, or were easily misunderstood. For these reasons, in line with the pragmatic and flexible study design, I adjusted the interview-guide after 5 interviews.

In version 2 of the interview guide (Appendix I: Interview guide, version 2), I excluded questions about whether there were other family carers involved in the care situation. This information usually emerged during the interviews without me asking, and seemed to give information with less value to the research objectives. Rather, I chose to add a theme regarding how the person living with dementia and the family carer were supported by health services in the period after diagnosis was given. This theme was generated as some of the early participants discussed how they struggled to find information, support, and access health services at this stage. When planning the project, I was made aware of projects in different municipalities aimed at better supporting newly diagnosed people living with dementia, but it was not until family carers talked about this, that I included the theme in the interview-guide.

Participants also raised other themes that were not part of the interview guide version 1, but that nevertheless led me to new perspectives. Examples of such were themes about the use of welfare technology and supportive aids, and the (lack of) use of individual plans. A theme about openness and involvement of family carers in formal care was also added, as several family carers mentioned how they tried to contribute, but often did not feel included. A theme regarding advice for improved cooperation and coordination of services was taken out of the interview guide, as many family carers seemed to have few insights on this. Most family carers gave richer descriptions of their own experiences with cooperation between themselves and health services, than of their assessment of cooperation and coordination between different services.

After 11 interviews, I performed another review of the interview guide (Appendix I: Interview guide, version 3) in light of new themes and questions that caught my attention, and additional experiences with conducting the interviews. New questions were added, regarding experiences of negative feelings, and how participants coped with their own feelings and negative emotions from the person living with dementia. This was added as I became more aware of this aspect of being a family carer and understood more about the consequences, and how this affected the family carer, the care situation, and the need for support services. Narratives and descriptions regarding their negative feelings added valuable information about family carers' needs, and consequently gave hints on unmet needs and potentially what they needed from health services.

I conducted another search of the literature to understand more about which themes had already been thoroughly described, and which were new and thus needed further investigation. This informed the third version of the interview guide in terms of choosing to focus on the selected themes and leave out other themes (Appendix I).

Over the course of the interviews, I realized that some questions were not being understood as I intended. For example, a question about how family carers contributed to care provision seemed to prompt participants to defend their share of contributions, not discuss how they had experienced their contributions to the care provided. Consequently, this question was removed from the interview-guide. Instead I was aware of when participants talked about how they contributed to care provision and asked them to elaborate or talk more about this theme.

All interviews were completed before the main analytic phase started and papers 1 and 2 present results from analysis across all interviews.

4.2.4 Recruitment strategies

Eligible to participate in this study were all adults (18 years and above) who were helping a family member, friend, neighbor or similar, at the age of 65 or above, with symptoms of dementia.

I sought a maximum variation sample that reflected the greatest possible breadth and diversity of the population of family carers for older people living with dementia in Norway. I did this by recruiting in four stages, as described below.

4.2.4.1 Stage 1: Convenient, opportunistic recruitment in Eastern Norway

The first step in the recruitment process was to introduce the study to managers of services provided to older people living with dementia. That step was taken in order to facilitate rapport and trust with health personnel such that they would help to invite family carers to participate in the study. Because I depended upon their voluntary support of the study, I considered strong alliances with all health personnel to be pivotal to gaining access to family carers.

As part of that approach, I was invited to introduce the study at two regional meetings for dementia coordinators, as well as a regional meeting for leading nurses working in home care and nursing homes, all attended exclusively by health personnel working in rural and urban areas in Eastern Norway. After introducing the study, I asked the attendees for help with recruitment, provided my contact information, and distributed informative fliers about my research that could be further distributed to family carers encountered in the attendees' daily work. I also circulated information about the study on the study's Facebook page and encouraged friends, family, colleagues, and others to share the page on their own Facebook pages.

Two family carers contacted me after reading about the study on Facebook. As a result of inviting health personnel to support recruitment, several family carers approached me directly by phone or email to express their willingness to participate. Others gave health personnel permission to provide me with their contact information so that I could contact them and arrange interviews. The first 10 interviews, mostly with female family carers—spouses and daughters of people living with dementia—and all from Eastern Norway, were a result of this convenient and opportunistic recruitment strategy.

4.2.4.2 Stage 2: Purposeful recruitment in Eastern Norway

To broaden the range of experiences expressed by participants in the sample, I asked the same health personnel to specifically reach out to family carers who were men, non-spouse carers, carers born outside Norway, and carers of minority background. That strategy resulted in a few more men participants and one participant born outside Norway. I also reached out to more health personnel working in areas known to be the homes of many immigrants. One participant born outside of Norway was included as a result of this. To reach carers of minority backgrounds and to ask participants whether they would invite others to participate in the study, I also used snowball sampling in my social network (Bowling, 2014d), which resulted in the recruitment of one more participants born outside of Norway. Last, I contacted different religious organizations, nursing homes in areas known to be ethnically diverse, and a few organizations for people of ethnic minority backgrounds, all in the hope of recruiting more participants. However, such efforts did not generate any additional participants.

After completing 15 interviews I had accumulated a range of experiences from a variety of participants. Participants not only represented both genders and a wide range of ages but also had different relationships with their care recipients; different experiences due to living in big cities and rural areas; and different experiences due to providing care to people with dementia living in their own households, in nursing homes, or in other facilities. Family carers born abroad were also represented. At this point I started to experience what is sometimes described as a saturation point, meaning that I experienced new interviews bringing up mostly issues already familiar from previous interviews, so that less new knowledge was generated. The term saturation point is discussed in section 4.2.4.4.

4.2.4.3 Stage 3: Purposeful recruitment strategy in Northern Norway

After 15 completed interviews, with two more scheduled, and one withdrawn, the sample consisted of participants who collectively provided what I considered to be an acceptably diverse range of experiences, all from urban and rural areas in the Eastern Norway. However, I was ahead of schedule for the project, and used the opportunity to expand the sample further. By conducting additional interviews with people living in Northern Norway, I sought more diversity in the sample's range of experiences, including in terms of healthcare context, demographics, and religious and cultural background. After all, the organization and structure of health services vary between regions in Norway, with Northern Norway having longer distances to services and more rural areas than in Eastern Norway, which may affect peoples access to services and affect health outcomes (Statistics Norway, 2009) . Moreover, much of Northern Norway is also home to people of Sami background (Statistics Norway, 2018).

In the third stage of recruitment, I therefore contacted researchers from another research project being conducted among Sami people living with dementia in Northern Norway. The approach soon yielded contact information of members of a local dementia association in an area in Northern Norway with a high density of Sami people. Via snowballing, starting with one of the members of the mentioned research project, I was able to invite participants from one county in Northern Norway. Afterward, I contacted health personnel and dementia associations in nearby municipalities and managed to recruit seven more family carers to interviews, for a total of eight family carers from three municipalities in Northern Norway. Of these eight, two withdrew before the interviews were conducted, meaning that six interviews were completed in Northern Norway. Most participants from those municipalities related their experiences in communities mostly consisting of people of Sami background, several of whom speak Sami as their first language and live in small communities with long distances to specialized health services. Those characteristics of the participants ultimately contributed to the variety of experiences represented in the sample.

4.2.4.4 Considerations of the sample size

According to Patton (2015) there are no set rules for determining sample size in qualitative inquiry. Rather, the sample size depends on what I want to know, the purpose of the interviews, considerations of what will be useful, assessments of credibility, and what will be available within the frame of time and resources.

Because of the timeframe for the project, I originally planned to conduct approximately 20 interviews. As mentioned previously, I reached a saturation point while doing interviews in Eastern Norway. According to Patton (2015) a saturation point is reached when the information gained by more participants become redundant, meaning that no (or little) new information is given. However, data is generated in the social context (Kvale & Brinkmann, 2012) and I expected to find more new perspectives and experiences from family carers if I recruited family carers from more diverse social contexts, such as in the north of Norway.

When I purposefully included these family carers, I gained new perspectives and experiences, and this strengthened the sample because it broadened the breadth of experiences and perspectives that were represented. Since I had now reached the number of participants that I had planned for I reassessed the sample to decide whether to continue interviewing or not.

According to Malterud, Siersma, and Guassora (2016) suggest that instead of the term "saturation point", which is inconsistently applied, the concept "information power", might help to assess the adequacy of qualitative sample sizes. Different interviews generate different amount of information to illuminate the phenomenon under study. The authors argue that when rich information is given by participants, lower number of participants is needed. Consequently, the number needed in a sample is guided by the aim of the study, the sample specificity, the use of established theory, quality of dialogue and analysis strategy. With this in mind, I assessed the need for continued sampling after having completed 23 interviews.

The sample consisted of family carers with experience of caring for a person with dementia and they were all active family carers at the time of interview, meaning they all had recent experiences. Only one participant actively sought not to interact with health services. The rest of the sample was involved in care provision through informal care and through interactions with formal carers to a large extent. Consequently, the sample had experiences relevant to the study, and as explained above, participants provided rich descriptions about their experiences.

No established theory was used to form the interviews or used as a theoretical lens in the qualitative analysis, since the study was very much inductive and explorative. The theories used in this thesis were found as a result of the analysis and used to illuminate the results, not the analysis. This means the aim of the study was broad. According to Malterud et al. (2016), this required a larger sample than if the aim was of the study was narrower. I needed enough participants in my sample to reflect differences in experiences and a broad variety of experiences in the sample was necessary to make the findings transferable to other contexts. Including family carers from different places in Norway, different relationships to the care-recipient, and with different cultural backgrounds, facilitated transferable results and variety of experiences. Transferability of results is discussed further in section 6.1

The quality of the conversation was good for most interviews, in that participants seemed eager to talk and gave rich descriptions. Rich descriptions are explained in section 4.1.6. Several participants expressed that they felt good talking to me. My experience is that I gained participants trust and that many shared personal and sometimes vulnerable experiences with me. Also, most participants seemed to feel confident to share criticism towards health personnel (even though I am a nurse myself). Except for one interview, all participants talked willingly, often without me asking many questions. One participant explained that he did not want to be involved in health services and care provision to the care recipient, but volunteered to be interviewed in sympathy of the important work of research. This one interview added interesting perspectives regarding how some family carers may feel, but offered less knowledge on the phenomenon of health services to older people living with dementia. The other 22 interviews contained rich descriptions of experiences, and usually revealed their contributions and perspectives on care provision. Consequently fewer participants were needed. If I had more experience with interviews from the beginning, I could perhaps also have reduced the number in the sample further because I would be more effective in guiding the conversation to the types of questions that stimulated good conversations, especially during the first 10 interviews. However, since new information is always possible, the decision to be satisfied with 23 interviews is primarily based upon an assessment of the available resources and the expected benefit from more interviews.

The way I analyzed the transcripts, through four stages (described in section 4.2.7) was detailed and time consuming. It was important to have a sample size that allowed for time spent on rigorous analysis within the time frame of the project. A larger sample would have resulted in less time for thorough and detailed analysis. All in all, I assessed the sample to have include a sufficiently broad variation of important characteristics, as I discuss next, to be sufficiently large to explore the aim of the study and sufficiently small to allow for detailed analysis or rich data.

4.2.5 Description of the sample

Of the 26 family carers who agreed to participate in the study, three dropped out before the interviews—two due to acute illness, one for an unnamed reason—which left a sample of 23. Their characteristics are shown in Table 2.

Table 2. Characteristics of the sample (*n* = 23) at the time of interviews

Women, *n* (%)	17 (74)	
Men, *n* (%)	6 (26)	
Age in years, median (min–max)	62 (44–83)	
81–90 years, *n* (%)	1 (4)	
71–80 years, *n* (%)	9 (39)	
61–70 years, *n* (%)	3 (13)	
51–60 years, *n* (%)	4 (17)	
41–50 years, *n* (%)	6 (26)	
Relationship to care recipient living with dementia		
Spouse, *n* (%)	12 (52)	
Adult child, *n* (%)	9 (39)	
Adult sibling, *n* (%)	2 (9)	
Location, *n* (%):	Urban areas = 14 (61)	Rural areas = 9 (39)
Northern Norway, *n* = 6	0	6
Eastern Norway, *n* = 17	14	3
Living arrangement of care recipient		
Sharing a house with the family carer, *n* (%)	11 (48)	
Living in his or her own house, *n* (%)	6 (26)	
Living in a nursing home, *n* (%)	6 (26)	

Note. *Rural areas* were municipalities with fewer than 20,000 inhabitants, whereas *urban areas* were ones with more than 20,000 inhabitants. We classified participants' home municipalities as either rural or urban based on a combination of population density and proximity to regional centers and other towns/cities, as first calculated by Rugkåsa et al. (2019) and available upon request.

Collectively, the participants had experience with a variety of services for people living with dementia, such as memory clinics, hospital wards, geriatric outpatient clinics, nursing homes, home care nursing services, day activity centers, walking buddy services, volunteer visitors, food delivery services, personal assistants, and home help. These services were offered by a variety of people and groups, including dementia teams, general physicians, pharmacists, psychologists, physiotherapists, and nongovernmental organizations and interest groups.

Although I did not solicit information about the severity of dementia or comorbidity during interviews, such information was often provided as part of the context. Participants had a range of experiences with different symptoms, levels of functioning, diagnoses of dementia, and sometimes other additional health conditions such as chronic obstructive pulmonary disease, diabetes, muscle or skeletal pain, or stroke.

4.2.6 Interviews

The interviews were conducted between June and October 2017. Participants were allowed to choose the time and place of their interviews at their convenience. This was an important methodological decision made upon the assumptions that it could be difficult for some family carers to leave their home and responsibilities. Several family carers chose be interviewed at home, but to my surprise, many preferred to meet with me outside their home and everyday responsibilities. The interviews were thus conducted in participants' homes, at their workplaces, in one of the hospital's meeting rooms, or in a public cafeteria

During in-depth interviews, knowledge is generated in the interaction between researcher and study-participant (in this case family carer) (Kvale & Brinkmann, 2012). Consequently, my preunderstanding made me sensitive to certain themes and experiences which facilitated certain responses from the family carers who were interviewed. This made each interview unique in the generation of data (Kvale & Brinkmann, 2012). Being aware of this, I sought to facilitate interviews as a conversation where I could gain participants' trust.

According to Kvale and Brinkmann (2012), providing an introduction and briefing at the beginning of an interview can help set the scene and gain the trust of the interviewee. I sought to accomplish this by introducing myself as a researcher with a background in nursing and by explaining the aim and the structure of the interview to them. I repeated the information about confidentiality that was provided to them during recruitment, and reminded them of their right to not answer questions and to withdraw from the interview at any time. No participants availed themselves of either of those rights. On the contrary, most participants seemed eager to tell their stories and motivated to contribute to the study's objectives, which afforded me rich descriptions of their experiences. Participants were encouraged to ask questions if they had any, and they each signed an informed consent form before the interview commenced. Once the interview began, the audio recorder was turned on..

I wanted the interviews to have a relaxed atmosphere and the character of an informal conversation in which participants could speak freely. To that end, I offered or accepted cups of coffee, and I sought to show interest in understanding the participants' perspectives throughout the conversation (Brinkmann & Kvale, 2005). Instead of taking field notes, I sought to maintain eye contact with participants, mirror their body language, use paraphrasing, and be an active listener in other ways (Weger, Castle, & Emmett, 2010). According to Kvale and Brinkmann (2012). This was aimed at facilitating a positive atmosphere, facilitate the sharing of personal, and sometimes difficult experiences, thus providing rich descriptions. 'Rich' descriptions include detailed descriptions of specific situations or experiences, rather than general descriptions (Kvale & Brinkmann, 2012). When interesting themes were generated in the interview, I often followed up by asking the participant to elaborate or give examples. Often, it was necessary to interpret and show interest in what was expressed "between the lines", and then rephrase expressions and check with the participant whether I had understood them correctly. They would then be able to explain or confirm, and sometimes elaborate.

By virtue of the flexible design of the interviews, I was able to follow up on clues and new themes during interviews while also keeping the conversation directed toward achieving the aims of the study (Brinkmann & Kvale, 2005; McGrath, Palmgren, & Liljedahl, 2019). For the same reason, I often allowed participants to discuss experiences and issues that engaged them, after which I asked them to elaborate upon themes in the interview guide.

Most interviews lasted approximately 1.5 hours, and all were audio-recorded. The first 5 interviews were based on interview guide 1.0. During these first 5 interviews, I gradually became aware of new themes, and as several interviews confirmed the relevance of similar themes, I added these to the interview guide and continued the next 6 interviews with the interview guide version 2.0. Small adjustments were then made to the interview guide version 3.0, which was used for the remaining 12 interviews. How and why these adjustments were made in the interview guide is explained in relation to the development of the interview guide, Chapter 4.1.3.

Because all of the interviews were face-to-face, I observed participants' facial expressions and body language, which added important information to what was narrated (Mariampolski, 2001). Although nonverbal communication was not recorded, it was incorporated into my understanding and interpretations of the situations and expressions communicated during interviews (Denham & Onwuegbuzie, 2013). All interviews were conducted primarily with participant and me present. On a few occasions, another family member of the care recipient would enter the interview setting, at which point the interview would be paused and resumed once the person had left.

In addition to gathering information about the participants' experiences during interviews, I also collected some personal characteristics from participants, such as age, relation to care-recipient, income, education etc. (Appendix II). These were included because I wanted to describe the sample, and I included variables that I though could shed important light on the characteristics of the sample. I had in mind that I would later conduct a survey and I though perhaps some of these variables could be useful when discussing the differences in the two samples. However, it turned out that I only used some of these variables as I followed the qualitative tradition of which variables to describe and chose to present only those variables that seemed relevant for the results presented in the two papers.

4.2.7 Analysis

The analysis started during interviews and continued during the transcription of the interviews. The main phase of analysis (described in 4 stages), and the writing of the papers and, in turn, this thesis were all important parts of the analysis (Suter, 2012). In the main phase of analysis, the output from all interviews was collectively analyzed, and data from all interviews were analyzed for use in papers 1 and 2. The analytic phase has drawn on descriptions of the phenomena under study and interpretation of text and meanings (transcripts from interviews). According to Patton (2015) the goal of qualitative analysis is to uncover concepts, insights, emerging themes, patterns, and understandings. Some authors argue that to make research findings relevant for clinical practice we need more than qualitative descriptions, and consequently interpretation is important to conceptualize phenomenon and understand content (Andersen & Taule, 2020; Thorne, Brozyna, & Sandelowski, 2008). In the analytic process, I have described how family carers involved themselves in service provision, how they interact with health personnel, and how they experience health services. Further, I have interpreted the meaning of family carers' experiences, in relation to patient safety, involvement strategies, and their contribution to quality of care. In the analysis I have deliberately sought to combine my preunderstanding with a new understanding (Alvesson & Sköldberg, 2009), making analysis based on hermeneutics.

It is debated whether qualitative analysis should follow a rigorous methodological approach (epistemological purism) or if qualitative analysis should mix different approaches and draw of the strengths of different methods, enhancing a more creative analytic process (epistemological pluralism) (Andersen & Taule, 2020; Whittemore, Chase, & Mandle, 2001). In this thesis I have followed the latter approach and drawn on different analytic techniques, such as Malterud’s four step analysis (Malterud, 2017), Charmaz’ Grounded Theory (Charmaz, 2006), , Fangen’s three levels of interpretation (Fangen, 2010) and thematic analysis as described by Braun and Clarke (2006). Drawing on different methods and philosophies in this way is in line the methodological pluralism emphasizing that “knowledge accumulates from a variety of sources in a variety of ways” (Barker & Pistrang, 2005). Consequently, I have let different analytical techniques illuminate the data from different philosophical perspectives, such as from a creative and interpretive perspective (drawing on hermeneutics), and from a distant and descriptive perspective (drawing on phenomenology). Through that process I have allowed a combination of analytic techniques: transcription and first impressions (stage 1); interim analysis (stage 2); line-by-line inductive coding (stage 3); connecting codes and themes (stage 4). In these steps I have drawn on different techniques which in turn are based on different philosophy and epistemology. This is explained further in the following sections in this chapter. Following the pragmatic study design and pluralism I have used these different techniques to develop my preunderstanding, identify and integrate new perspectives, and merge my preunderstanding with new perspectives in each analytic step to a new understanding. In line with the view of other methodological pluralists, it is my opinion that drawing on different methodological techniques is a way of strengthening the analysis because it allows me to explore the data more creatively, but still drawing on rigorous techniques. In this process I have sought to make the analysis transparent so that readers are able to follow how data is analyzed and how results are based on the empirics.

Next, I provide a detailed description of the analysis, divided into four stages. All interviews were analyzed together, and the two qualitative papers are results of the same analysis, but focusing on different themes. There are pragmatic reasons for writing two papers based on the same analysis, such as the length of a paper and the wish to have a clear focus in each paper.

4.2.7.1 Stage 1: Transcription and first impressions

I transcribed all interviews verbatim, on the same day or the day after the interview if possibly, and usually before the next interview. Instances of nonverbal communication (e.g., crying and laughing) or tonal emphasis (e.g., sarcasm) were noted when I considered it of importance to the meaning of what was expressed. Interpreting such nonverbal communication—eye and facial movements, postures, and vocal cues such as crying and silence—contributes to understanding perspectives not easily expressed in interview transcripts (Dittmann & Wynne, 1961; Given, 2008).

The stage of listening and transcribing interviews afforded me an overview of each interview and of what participants had discussed overall. I concentrated on the participants' expressions and sought to understand their meanings without the distractions of planning the next question or guiding the conversation. This allowed me to reflect on, and sometimes adjust, immediate impressions from the interview situation—for example, I sometimes realized that I had misunderstood the content, or had not paid sufficient attention to fully comprehend what participants had tried to express.

4.2.7.2 Stage 2: Interim analysis

In interim analysis, I described and interpreted the transcripts by drawing on different analytic techniques that allowed me to blend perspectives and analytic methods without rigorously following only one model. This was a creative process, pluralistic in nature, and important for me to extend my perspectives and ability to understand and interpret the meaning of the texts. I will now explain how I did this.

First, I sought to identify how family carers described their experiences, interactions, and involvement in care provision. I made preliminary notes of impressions from each interview and other memos in the margins of the transcripts. That step was inspired by Charmaz' description of constant comparison (Charmaz, 2006). The technique allowed me to identify differences and similarities between the interviews and made me aware of different perspectives (Charmaz, 2006). I also wrote down immediate reflections on those comparisons and questions that emerged from them, allowing me to reflect on how different perspectives could change the way I understood their experiences.

In the process of interpreting the meaning of texts, I was informed by Fangen's (2010) three levels of interpretation. The first level of interpretation involved seeking to understand how participants understood their experiences from their own perspectives. Next, at the second level of interpretation, I sought to understand what participants' experiences could mean in an abstracted interpretation. Instead of describing similarities or differences, I attempted to understand what their experiences were expressions of, or what their described actions meant in their context. Last, at the third level of interpretation, I sought to identify potential underlying motives or hidden agendas (Fangen, 2010)

I was also guided by the recommendations of (Tjora, 2012) to ask myself what I immediately perceived from the transcripts, whether there were any recurring characteristics in the material, and what triggered me as a person and a professional when I read the transcripts. In that process, I identified potential themes and returned to the literature to pinpoint which themes could represent new findings, and which had already been widely described or studied. That method directed my attention to focus on new perspectives. It also allowed me to focus not only on the extraordinary but also the ordinary, everyday experiences related by the participants.

I have, in the analytic stage 2, interpreted the transcripts in light of participants' and my own understandings of the context, society, and healthcare, which afforded me a preunderstanding to apply later during analysis.

An important aspect of the second stage of analysis was acknowledging that the data reflected what particular participants had said, which was not necessarily "the truth" or even consistent with what they had in fact done, or said at different point in the interview. Although that difference is recognized well in qualitative research, it was nevertheless an important aspect to bear in mind during analysis.

Owing to the analytic techniques described above, themes began to emerge. For example, I became aware of differences in how family carers involved themselves in providing care and differences in the ease or difficulty with which family carers described the process of accessing services for the people living with dementia. Later, this would lead to the concepts of Health Literacy and Cultural Health Capital. These were concepts that I learned about after having started on the analysis, and I found them to illuminate my findings in line with my initial interpretation. The concepts of carer burden, quality of healthcare, and patient safety were concepts that I was familiar with before analysis. Still, these concepts were not used applied to the data until after the main analytic phase..

4.2.7.3 Stage 3: Line-by-line inductive coding

In the next stage of analysis, I drew on Giorgi's phenomenology and Malterud's methods of analysis, when I performed line-by-line inductive coding of all transcripts, using the software NVivo version 11. I sought to make the codes as descriptive as possible and consequently the codes described family carers' experiences, and what family carers said they did, with as little interpretation as possible. As a result, I generated 1,383 codes, organized pragmatically and hierarchically into 53 main codes and hundreds of subcodes. The initial coding was conducted by reading each line or a couple of lines, and condensing the meaning of that unit of text in a short description of the content – a code (Malterud, 2017). The code was sought to be descriptive, but by condensing and rephrasing a text it will always be a certain level of interpretation, as it contains an interpretation of what is meaningful and valuable (Thornquist, 2003). Next, I copied the piece of text used to create the code, and pasted it into the code in NVivo. In coding the transcripts line by line, I generated new codes whenever the text did not align with existing codes and sorted all text into one or more codes that described the content. This stage followed a rigorous, and less creative analytic approach compared to stage two. It allowed me to study each parts of the whole, with less focus on the overall meaning.

According to Fangen (2010) this kind of "network" of codes is useful to organize data, but it also draws the attention away from activities and aspects which are not coded and categorized. This is the reason why I chose to combine this technique with other analytic techniques used in the other stages.

At the same time, the pragmatic and hierarchical organizing of codes made clusters of codes that made me aware of other relationships between codes and themes in the transcripts. When I reached a number of codes that made it difficult to keep an overview, I started to pragmatically organize coded hierarchically. I then condensed the meaning of similar codes to a higher level code and organized the codes as sub-codes to the new condensed code. One example is that I had multiple codes describing what family carers said about their caregiving activities. As the number of codes grew, I organized all these codes together under the code "care tasks". When seeing this condensed code with all sub-codes it made me aware of the breadth and variety of these activities.

For these reasons, this step was important in two ways: 1) to create a distance to my immediate understanding, 2) to use this new awareness of the content of codes in combination with previous interpretations, to create awareness about a range of aspects in the data.

As a result of inductive coding, all initial codes came from the transcripts, not from theory. The detailed coding approach resulted in a large number of codes. When the number of codes exceeded my practical overview, I sorted the codes together pragmatically in order to maintain a clear overview. By applying that technique, I dismantled entire transcripts into meaningful units and sorted all text into codes and subcodes. This rigorous analytic stage, informed by phenomenology, and phenomenological reduction, allowed me to view the text from a different viewpoint, because of the distance from the earlier creative analytic process.

Although, utilizing my own preunderstanding in the analysis of the text is traditionally an important aspect of qualitative methods (see 4.1.1.2), I used this analytic stage 3, to gain new insight in the data generated, and move beyond my initial understanding. Although it was informed by descriptive phenomenology, I used the results from this analytic stage three together with my previous analysis to form a new preunderstanding in stage four.

4.2.7.4 Stage 4: Connecting codes and themes

In the final stage of analysis, I used the descriptive codes from stage 3 along with the preliminary themes from stage two, to identify themes. I drew mind maps in NVivo to practically and pragmatically visualize how I identified and connected codes and themes (an example of a work-in-progress mind map from the work in Stage four is shown in Figure 5). This is coinciding with what Braun and Clarke (2006) describes as thematic analysis, which is not wedded to any pre-existing theoretical framework. Braun and Clarke's thematic analysis seeks to make the role of the researcher transparent, as the researcher's own theoretical position and values are acknowledged as tools to interpret and understand data and generate findings (Braun & Clarke, 2006).

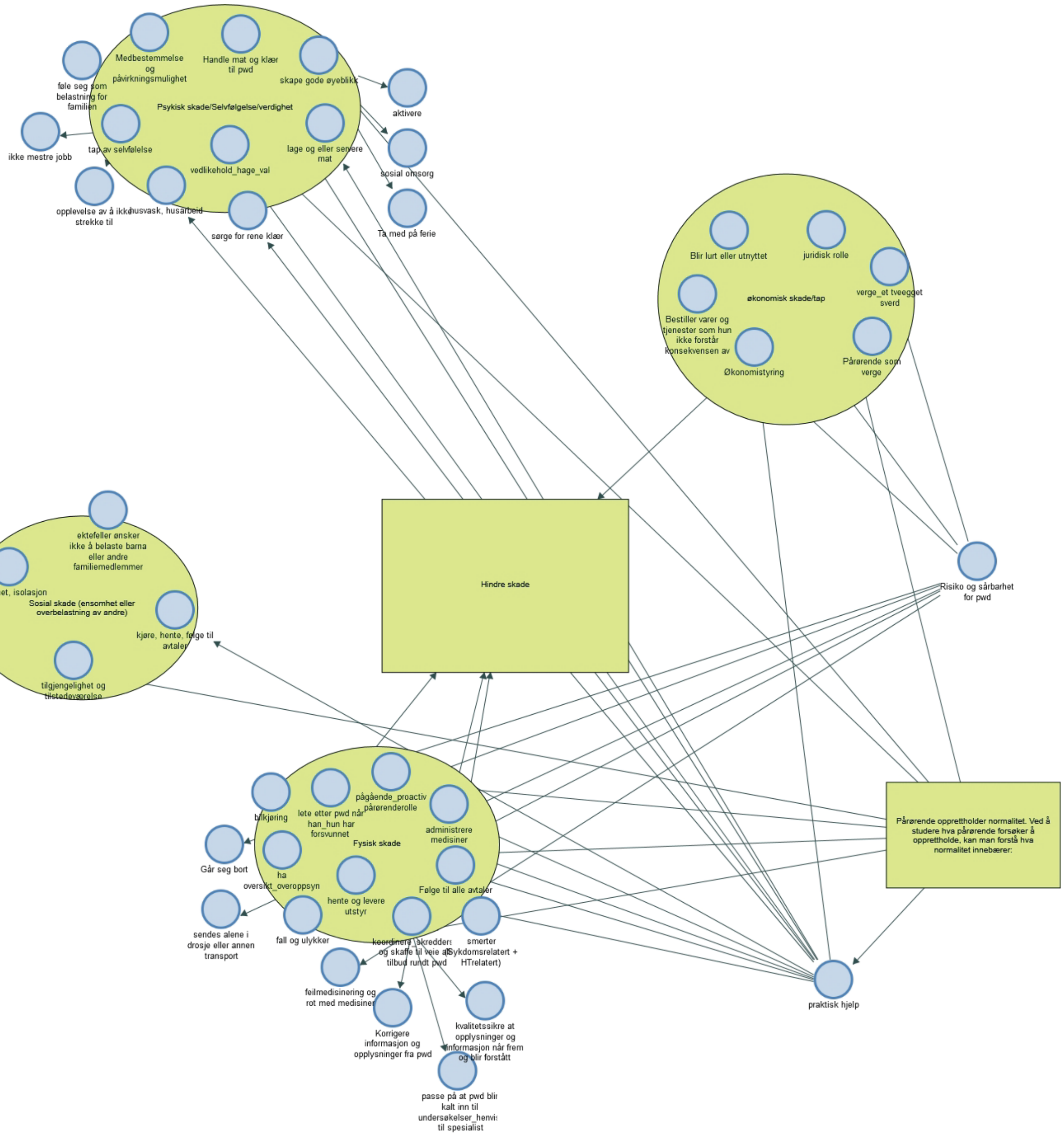
In stage four, I started to analyze the codes by gathering similar codes into code groups, and abstracting code groups to form themes. For example, I grouped codes related to what tasks family carers had said they did when providing informal care. In light of my understanding developed during earlier stages of analysis, I used those codes to form high-level themes such as "Preventing harm to the person living with dementia" and "Involvement strategies". These themes were constructed in line with elements from the second stage of analysis, when I identified that family carers involved themselves in providing care in different ways and with different results, and also my interpretation of this as a patient safety aspect. All high-level themes are presented with subthemes in sections 4.1.8 and 4.1.9.

Once a high-level theme, such as "Preventing harm to the person living with dementia" was identified, I revisited all codes and connected more relevant ones to that theme. I then organized the codes within the higher-level themes and condensed the new code groups to form new lower-level themes (e.g., "Physical harm" and "Emotional harm"). In this way, the high-level themes that ended up as the themes for papers 1 and 2 emerged.

In the process of connecting codes to themes, I was able to reassemble the pieces for the full picture such that parts could be understood in relation to the whole, inspired by the hermeneutic philosophy (Alvesson & Sköldberg, 2009). As a result, I merged my new understanding with my previous understanding, for what is commonly described as a hermeneutic way of analyzing texts (Alvesson & Sköldberg, 2018).

When presenting the results, findings were illustrated and validated with quotations from the transcripts (Smart, 2007) and, unless otherwise specified, represented common views in the sample. Findings were discussed among the authors of the papers in which they were presented (i.e., Paper s I and II), and supplemental feedback was provided by a wider research group but not by participants. No participants were asked to contribute to the analysis.

Figure 4. Example of a work-in-progress mind map made in NVivo



Note. The green squares and circles represent themes found during analysis stage 4, whereas the small blue circles represent codes from NVivo. All arrows and lines indicate how I interpreted the relationship between codes and themes. The green square to the right was an interpretation and preliminary theme that I chose not to follow because the data indicated stronger support for the “prevention of harm” theme.

4.2.8 Results: Paper I

From the analysis, the high-level theme "Protecting the person living with dementia from harm" reflected that family carers contributed to care for older people living with dementia by preventing or reducing their risk of harm, or by mitigating damage from harm that had occurred in their lives. The way in which the family carers discussed their contributions to care and interactions with health personnel revealed that they actively addressed risks and issue of safety in what can be understood to constitute four *protective practices* related to four areas of potential harm: "Preventing physical harm," "Preventing economic harm," "Preventing emotional harm," and "Preventing relational harm." Each of those protective practices was presented as a lower-level theme with subthemes, as shown in Table 3.

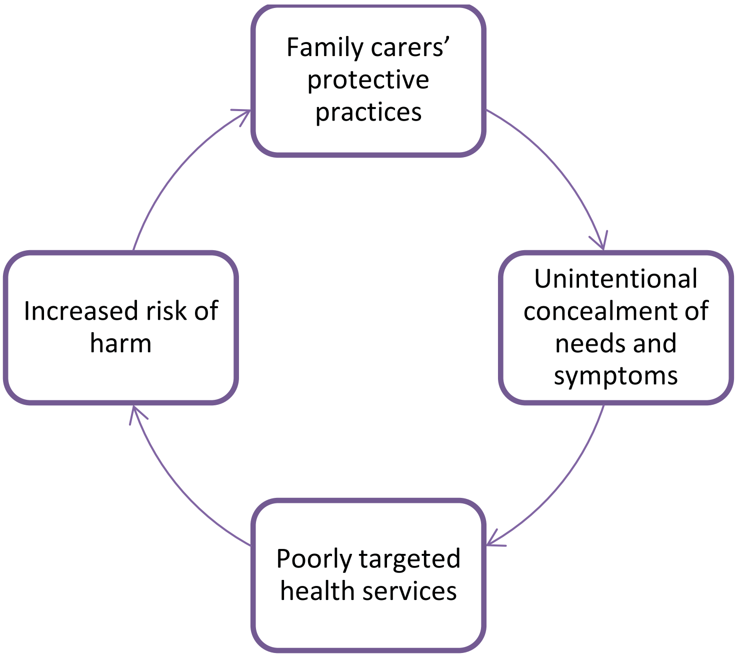
Table 3. Themes and subthemes related to the four protective practices

High-level theme	Lower-level theme		Subtheme
Protecting the person living with dementia from harm	*Four protective practices*	Preventing physical harm	• Preventing harm by being present • Tailoring the use of protective aids • Monitoring health professionals' work
		Preventing economic harm	• Assisting with practical tasks • Monitoring and preventing unnecessary economic spending • Taking full responsibility as legal guardians
		Preventing emotional harm	• Aiming to maintain respect and dignity for the person with dementia • Preventing loneliness and other negative feelings • Creating good moments and positive feelings through activity
		Preventing relational harm	• Preventing harm to other relationships

The four types of protective practices were connected and interlinked, and family carers sometimes prioritized one over another. For example, in an instance where health personnel placed a commode chair in the living room, where it could be accessed easily, and thus reduced the risk of physical harm, the family carer moved it to the bedroom where it was more difficult to access, but reduced the risk of social harm by keeping it out of sight to visitors. Different perspectives could lead to different views of what was taking priority, and could explain misunderstandings between people with different views or disagreements (e.g., between formal carers and family carers or between different family members).

The application of the protective practices may be invisible to health personnel, who were not party to family practices or the care recipient's everyday life. For that reason, family carers' contributions to preventing harm may also inadvertently conceal symptoms or care needs, and thus complicate interactions with health professionals. Where health personnel cannot grasp the totality of care needs, a consequence may be poorly targeted health services, and an increase in risk of harm that family carers aim to prevent. In this dynamic, the interaction between family carers and health personnel risks falling into a negative feedback loop, as illustrated in Figure 5.

Figure 5. Potential negative feedback loop



For health personnel to be able to provide safe, person-centered care to older people living with dementia, as well as to use the resources from family carers in a sustainable way, they need to be aware of such potential negative feedback loops. They also need to understand that many family carers contribute extensively to areas of care recipients' lives not visible to them. Stronger partnerships between family carers and health personnel could facilitate better communication about such safety- and care-related needs and make the use of available resources more efficient.

4.2.9 Results: Paper II

In paper II, I reported the high-level theme "Involvement strategies". This include how family carers discussed responding when they experienced services to be inadequate or disagreed with health personnel about care and service provision. I described, and interpreted lower-level themes in terms of two involvement strategies: "Being the hub in the wheel" and "Getting the wheel rolling." Each strategy consisted of a cluster of approaches (i.e., subthemes) used by family carers, as shown in Table 4. The first strategy was a cluster of approaches interpreted as being supportive and complementary to health services, whereas the second strategy was a cluster of more assertive approaches used to increase the family carers' influence in relation to health personnel.

Table 4. Themes and subthemes related to involvement strategies

High-level theme	Lower-level themes	Subthemes
Family carers' involvement strategies	Being the hub in the wheel	Rectifying incomplete information flows between families and services
		Connecting disjointed services
		Filling care gaps
	Getting the wheel rolling	Keeping health personnel on alert
		Using relationships to gain leverage
		Filing formal complaints

The first strategy contained a cluster of everyday approaches often not emphasized by participants but nevertheless commonly described when they discussed their day-to-day challenges and how they negotiated disagreements and poorly targeted services. From the perspective of the family carers, the so-called "hub-in-the-wheel" strategy played a central role in personalizing the overall care of the people living with dementia and ensuring quality of care and by filling care gaps. Several participants described experiencing difficulties with finding ways to become more involved and have more influence on health services. Several family carers had invested extensively into the role of being "the hub in the wheel" before using the second strategy.

Whereas the first strategy represented common, everyday approaches, the second strategy was a cluster of assertive approaches used to gain leverage in arguments or processes when needed. Such approaches were often used in response to experiences that were obviously negative to the carers, and several carers described emotive and dramatic experiences. However, the second strategy also seemed to be deployed to supplement the first strategy and most often when care was not perceived to be sufficient despite the extended use of the first strategy.

The two strategies posed different potential costs and benefits. Several participants seemed to weigh these potential effects for the care recipient, themselves, and health personnel. The first strategy was repeatedly described as being beneficial to developing or maintaining good relationships with health personnel, who were perceived to appreciate it when family carers' relieved them of their duties by assisting the person during meals etc. However, when family carers filled gaps in care or complemented care, the personal cost to them could be considerable in terms of time spent on informal care, and of the negative stress that shouldering such responsibilities caused for them.

In contrast, the second strategy was characterized as having the potential benefit of enforcing more person-oriented support and enforcing improved quality or increased quantity of care of the person living with dementia. The potential costs of this second strategy were described as increased time spent on organizing or improving care, energy used to argue with health managers or health personnel, increased carer burden, and the risk of being viewed as a so-called "difficult" family carer, or straining relationships with the formal carers whose support they needed.

Differences in personal resources among family carers, such as social skills, cultural capital, social support networks, knowledge about health services, or experience from working in health services, motivation to provide care, and ability to communicate effectively—may have contributed to the different perceived costs and benefits of their approaches. Such personal resources can be interpreted in light of the concepts of cultural capital, CHC, and HL.

4.3 From interviews to surveys

As the findings from the in-depth interviews emerged, I planned sub-study 2, which involved a quantitative approach to further investigate family carers' experiences in a larger sample, and statistical tests of assumptions.

The results in Sub-study 1 indicated that some carers' experienced difficulties in communicating and interacting with health personnel, as exemplified by the potential negative feedback loop (Paper I). Results also showed that family carers experienced difficulties in their involvement in care provision, as demonstrated in the two involvement strategies (Paper II). Family carers seemed to weigh conflicting concerns and interests in terms of balancing their personal resources against the potential cost in terms of negative feelings, time spent on care, impaired relationships with health personnel, and worry about the risk of harm. The ways in which those conflicting concerns were assessed by family carers and how they chose to react differed, and Paper II suggests how differences in cultural capital, CHC, and HL might explain difference in outcomes.

Previous research report associations between higher carer burden and lower quality of life among family carers of older people living with dementia (Etters et al., 2008; S. K. Kim et al., 2016; Srivastava et al., 2016) were consistent with what underpinned participants' accounts in Substudy 1. Moreover, carer burden and quality of life are commonly used outcome measures in healthcare (Brown et al., 2013) and for caregivers in various settings (Igarashi et al., 2020; Shilling, Matthews, Jenkins, & Fallowfield, 2016) For those reasons, I wanted to further investigate how family carers' personal resources were associated with experienced costs and outcomes of providing care.

4.3.1 Measuring personal resources

Over the course of conducting interviews and analyzing their content, I reflected upon how participants had experienced accessing health services for the people living with dementia with varying degrees of ease or difficulty. As discussed in Paper II, participants gained leverage for their arguments and processes by using personal resources, and some additionally drew on their past experiences and knowledge about health services. On top of that, some used their social skills, cultural capital, and CHC when seeking to access services on behalf of their care recipients and when involving themselves in the provision of services. In those ways, the family carers sought to influence quality of care, albeit often at a personal cost to themselves.

I became familiar with the concept of CHC while reviewing literature after completing inductive coding in Substudy 1. I found that CHC added to my understanding of personal resources, including knowledge of medical language or the ability to communicate needs in ways that health personnel understand, and how differences in such resources can affect healthcare interactions (Shim, 2010). CHC seemed to be a promising concept for seeking explanations to differences in people's access to healthcare and in family carers' outcomes as a consequence of those differences. At the same time, because no quantitative research had been performed on CHC, at least to my knowledge, and because I wanted to use validated questions whenever possible for the sake of the project's validity, I looked for related concept with validated instruments in order to identify and measure differences in personal resources.

I came across Health Literacy (HL) which I found to be a promising concept. As explained earlier, CHC can complement HL, which principally focuses on personal resources as a possible explanation for differences in access to healthcare (see Section 3.2.3). The concept of HL also captures differences in personal resources, including skills, knowledge, motivations, and competencies used to access healthcare, for example, and maintain or improve quality of life (Sørensen et al., 2012). Bieber et al. (2019) have demonstrated that the access to and use of formal community-based care services for dementia can be partly explained by individual-level factors, including experiences with such services, attitudes toward them, and the recommendations of healthcare professionals. Because those findings confirmed my impressions from Substudy 1 about differences in personal resources and personal costs, I chose to further investigate the relationship between personal resources and personal costs or outcome in a larger sample in Substudy 2.

To that end, I chose to use HL as the measure of personal resources. HL seemed relevant to further investigate the personal resources that factor into interactions of family carers and health services. As an added benefit, the validated instrument, Health Literacy Scale (HLS-N-Q12), was available in Norwegian. Thus, I designed Substudy 2 under the assumption that differences in personal resources measured with HL were associated with the participants' perceived personal costs and benefits.

4.3.2 Measuring personal costs and benefits

4.3.2.1 Carer burden

Despite extensive research on carer burden, there is still ongoing research to understand what characteristics of carers and care recipients that contribute to various aspects of carer burden remain unknown (Allen et al., 2019; Allen et al., 2017). In Substudy 1, some participants expressed exhaustion and negative emotions related to overload of care responsibilities, difficulties with accessing services, and problems communicating their needs. Such negative feelings related to caring for a family member can be understood as part of carer burden (see Section 3.2.1), which can be regarded as a personal cost (R. Schulz & Beach, 1999; R. Schulz & Martire, 2004)). Thus, carer burden was chosen a suitable outcome measure and, in turn, as an outcome variable in Substudy 2. In short, I wanted to test whether HL could predict carer burden. Carer burden has been be measured with various questionnaires (Deeken, Taylor, Mangan, Yabroff, & Ingham, 2003; Etters et al., 2008). Instruments commonly used to measure carer burden among family carer of people living with dementia include the Zarit

Burden Interview (ZBI), Caregiver Strain Index (CSI), and the Screen for Caregiver Burden (SCB)(Etters et al., 2008). I decided to use the Relative Stress Scale (RSS), which is used and validated in Norwegian with family carers of people living with dementia (Ulstein, Bruun, et al., 2007; Ulstein, Wyller, et al., 2007), because it is used in Norway on a similar sample, it is validated in Norwegian, and it is a short questionnaire that I considered easy to complete for family carers. The questions in RSS fit well with what many participants had been talking about in the interviews. Consequently, I found it well suited to my purposes, despite its limited use internationally.

4.3.2.2 Health-related quality of life (HRQoL)

In Substudy 1, I asked participants what it would take to increase their quality of life. That question was not meant to measure their QoL, but rather to focus on the follow-up question about what it would take to increase their QoL. Regardless, the family carers' answers indicated great differences in their quality of life and recurring experiences with reduced health and well-being. Family carers' QoL or HRQoL are commonly used as outcomes in studies on informal care (de Oliveira et al., 2015). It fits well with the definition of HL adopted in this thesis. For all of those reasons, health-related quality of life was chosen as an outcome measure in Substudy 2, where I wanted to test whether HL could predict HRQoL.

As with carer burden, there are several instruments to choose from. A systematic review of studies measuring HRQoL of general injury populations found 14 different generic instruments, the most commonly used was EQ-5D and two versions of Short Form Health Survey (SF12 and SF36) (Geraerds, Richardson, Haagsma, Derrett, & Polinder, 2020). In addition there are numerous disease specific instruments, including dementia specific, but since I was asking family carers, these instruments were not considered. A systematic review of instruments measuring the disease-specific quality of life of family carers of people with neurodegenerative diseases (including dementia), found seven disease-specific carer QoL measures (Page et al., 2017), but none of the two relevant for dementia were translated to Norwegian.

After considering the issues above, I wanted to measure HRQoL which focused more on the health perspectives, than on the subjective psychological aspects, compared to many of the QoL instruments. I then decided to use the official Norwegian translation of the EQ-5D-5L (EuroQol Group, 2011), mainly because it is well validated, commonly used, brief, and easy for family carers to complete, and easy to interpret during analyzis (Rabin R. & De Charro F., 2001). EQ-5D-5L offered the benefit of capturing differences in health and their effects on quality of life and has been tested and recommended also for use with older adults (Haywood, Garratt, & Fitzpatrick, 2005).

4.3.2.3 Time spent on informal care

As explained in Paper II, I found that in response to suboptimal care, participants tended to cite the use and misuse of time. Time spent on informal care can be regarded as a burden, often referred to as objective burden, which may have societal consequences, such as reduced health, increased sick leave, or reduced participation in paid work (Grosse et al., 2019). I assumed that time spent on informal care could be reduced if participants were able to easily access targeted health services on behalf of the people living with dementia and receiving more formal care. By extension, I also assumed that HL skills could contribute to more person-oriented care such that carers could reduce their time spent on providing informal care. Consequently, I wanted to test whether HL could predict time spent on informal care.

How best to measure time spent on informal care has been discussed widely because it is complex and difficult to substantiate (Cès et al., 2017; Grosse et al., 2019; Wimo, Jonsson, et al., 2013). A wide variety of questions have been used in previous studies to measure time spent on informal care (Cès et al., 2017). Results therefore vary between studies (Oliva-Moreno et al., 2019), and few studies have been conducted in the Norwegian setting (Vossius et al., 2015). I chose to base my measurement of time on the Resource Utilization in Dementia (RUD) questionnaire, which has been validated and made available in Norwegian (Wimo, Jonsson, & Zbrozek, 2010; Wimo & Nordberg, 2007) and is the most widely used instrument for collecting data about use of resources in dementia care (Cès et al., 2017; Wimo, Gustavsson, et al., 2013; Wimo, Jonsson, et al., 2013). Adjustments were made based on findings from Substudy 1. This included adding questions on time spent talking to the care recipient on the phone, seeking information about dementia and available services, and on coordinating their formal care. This aligned my measurement with items identified in a systematic review of questionnaires used to measure time spent on family care for frail older adults (Cès et al., 2017). I also added a few more examples to the information about items. Some chores were in the interviews often talked about by male participants, such as changing the bulbs, and painting the garden fence. I aimed to capture such chores by adding this to the RUD questionnaire. These aspects of informal care have often been excluded from standardized questionnaires about informal care, making them less suitable to capture this dimension of time spent on care. By adding these tasks to the RUD questionnaire I hoped to capture broader aspects of family care and perhaps chores that were not typically included when measuring time spent on informal care. More discussions about methodological considerations related to this variable are found in section 6.0.

4.3.3 Individual characteristics

Based on data from the interviews and earlier research (Carvalho & Neri, 2019; Vossius et al., 2015) it seemed reasonable to assume that many of the mentioned variables would be affected by care recipients' severity of dementia. Consequently, I collected data about the severity of their dementia, as described in Section 4.4.3.3.

Work attendance has been positively associated with quality of life (Sörensen et al., 2008). Howver, studies have shown that many informal carers reduce their hours spent at work or leave the workforce earlier than expected in order to make time for their work as carers (Gautun & Bratt, 2016). Nonetheless, a few participants in Substudy 1 reported that they had increased their hours at work in order to gain some relief from being at home. To capture this aspect of relevance to quality of life, I added items to the survey about the participants' current work status and changes to their working lives made to accommodate their role as carers. I also added an item asking whether the participants had ever worked as health personnel, because several participants in Substudy 1 had indicated that they benefitted from their health care experiences in their role as family carers, and this might be related to their level of HL. The full list of individual characteristics queried appears in Section 4.4.3.3.

4.4 Quantitative research: Substudy 2

4.4.1 The aim and research questions of Substudy 2

The objective for Substudy 2 was to further investigate the findings from Substudy 1 and test assumptions in a larger population.

To that end, because I chose HL to measure personal resources, the aim of Substudy 2 became to investigate HL among family carers of older people living with dementia in Norway, as well as the association between HL and family carers' outcomes in terms of carer burden, HRQoL, and time spent on informal care. That aim was pursued by formulating two research questions:

1. How is HL distributed among family carers of older people living with dementia in Norway?
2. Is HL a predictor of CB, HRQoL, and time spent on informal care?

Substudy 2 is reported in Paper III.

4.4.2 Study design and choice of method

To investigate the research questions for Substudy 2 within the constraints of time and available resources, I chose to deploy self-administered surveys to a nonprobability sample of family carers of older people living with dementia in Norway. The methodological issues regarding the nonprobability sample are elaborated in section 6.2.3. As explained, the survey was developed to investigate HL, and the prediction of HL on carer burden, HRQoL, and time spent on informal care, mainly by using previously validated questions. The content of the survey (Appendix VIII) is explained in Section 4.4.3, whereas further strength and limitations of each instrument are discussed in section 6.2.2.

To answer the first objective, I used descriptive statistics to describe individual characteristics, the level of HL, and the other outcome variables. Bivariate and multiple linear regression analyses were used to investigate associations between the independent variables and outcome variables. HL was used as the primary independent variable (IV) to predict carer burden, HRQoL, and time spent on informal care (outcome variables), and selected individual characteristics were used as additional explanatory independent variables. The selected individual characteristics were based on correlation analysis, theory, and the number of cases in the study. The statistical analyses are explained in full in Section 4.3.5.

According to Pallant (2020) regular linear regression analysis is based on the following assumptions:

Sample size: To have reliable results from multiple regression analysis it is necessary to have a big enough sample size. In simple terms, the larger the sample, the better: larger samples reduce the risk of unusual observations overly influencing results, and the precision of estimates improves with sample size. More to the point, the level of statistical model complexity, usually in terms of number of IV's, that is "safe" to include depends on sample size. A rule of thumb is to have at least 50 + 8m (m=number of IV). Given this rule and my 7 IV, I needed a sample of at least 106 cases.

Avoiding multicollinearity: multicollinearity refers to problems occurring as a consequence of high correlation between different IV, which makes it difficult to separate the unique contribution of each IV, and may result in errors of attribution, or otherwise suitable predictors being reported as not statistically significant.

Checking for outlies: extreme values should be checked because they have the potential to significantly impact the results of analysis.

Normality: the residuals of the outcome variables should be normally distributed.

Linearity: there is a linear relationship between IV and outcome variables.

Homoscedasticity: the variance of the residuals should be the same for the range of values of the outcome variable.

4.4.3 Survey

According to Bowling (2014), planning and piloting are important procedures when constructing a questionnaire. In planning the survey, I designed a six-page survey consisting of items about HL, carer burden, HRQoL, and time spent on informal care, in addition to relevant individual background characteristics. In the process, I prioritized brevity in order to prevent survey fatigue (Bowling, 2014). Next, the survey was pilot-tested in HØKH's user panel, and with five colleagues and friends. This generated helpful feedback on the importance of including time spent talking to care recipients on the phone, and on the visual design of the survey, such as how I could make it more user friendly with a larger font size and an improved introduction. Other feedback concerned how the information sheet could be improved to clarify the aim of the study, and how to best order the questions. After pilot-testing and feedback, the design, content, and order of the variables in the survey were discussed among supervisors and colleagues. Next, I will present the variables, in the order they were applied during multiple regression analysis..

4.4.3.1 Primary independent variable

HL was measured with the Health Literacy Scale, Norwegian translation (HLS-N-Q12), a validated 12-item scale (Finbraten et al., 2017) based on the European Health Literacy Survey Questionnaire (HLS-EU-Q47; (Finbråten, Guttersrud, & Nordström, 2018). Each item is scored on a 6-point Likert scale (1 = *very difficult*, 6 = *very easy*) and total scores range from 12 to 72, in which higher scores indicate a higher level of HL (Finbraten et al., 2018; Sørensen et al., 2012). However, the order of presentation, from *difficult* to *easy*, was in the opposite direction of the majority of questions included in the survey. To avoid confusion among respondents, the order of presentation for HLS-N-Q12 was reversed in the survey (1 = *very easy*, 6 = *very difficult*) so that all scales for items progressed from very *easy/never problematic* to very *difficult/very problematic*.

4.4.3.2 Outcome variables

Carer burden was measured with the RSS (Ulstein, Bruun, et al., 2007), because it was short, easy to use, and validated for the Norwegian population of carers of people living with dementia (Ulstein, Bruun, et al., 2007). The RSS measured three aspects related to carer burden: emotional distress, social distress, and negative feelings. Each of the RSS's 15 items was scored on a 5-point Likert scale (0 = *never*, 4 = *always*), and total scores ranged from 0 to 60, with higher scores indicating higher levels of carer burden (Ulstein, Bruun, et al., 2007).

I wanted to measure HRQoL with the official Norwegian translation of the EQ-5D-5L (EuroQol Group, 2011). The questionnaire has two parts: a health profile (EQvalue) and a visual analog scale (EQvas). The health profile comprised five dimensions of health: mobility, self-care, usual activities, pain and discomfort, and anxiety and depression. Each dimension is rated on a 5-point scale, with each point indicating the level of problems experienced (1 = *none*, 2 = *slight*, 3 = *moderate*, 4 = *severe*, 5 = *extreme*; (EuroQol Group, 2017; EuroQol Research Foundation, 2019a). Each of the 3,125 possible combinations of responses (i.e., EQ-5D health states) is assigned a value reflecting population preferences for the various health states, presented on a scale anchored in 1, equaled being in full health, and 0, equaled being dead (EuroQol Research Foundation, 2019a). Consequently, the EQvalue reflects how good or bad the state of health is according to the preferences of the general population.

The second part of EQ-5D-5L, the EQvas, offered an alternative way for participants to provide their subjective ratings of their current overall health (EuroQol Research Foundation, 2019a) on a vertical visual analog scale, with the endpoints "Best health you can imagine" (=100) and "Worst health you can imagine" (=0) (EuroQol Reserach Foundation, 2017).

The variable of time spent on informal care, usually abbreviated as "Time" hereafter, was measured with items informed by the Resource Utilization in Dementia (RUD) questionnaire, version 3.0 (Wimo et al., 2010; Wimo & Nordberg, 2007). In addition to the questions in the original RUD, I added items on time spent talking on the phone with the care recipient with dementia, on contacting health personnel, searching for information, gardening, and house maintenance. The reason for adding these tasks were that these were often mentioned in the interviews in Substudy 1, were presented as time-consuming, and were not captured by the RUD questionnaire.

Participants were asked to indicate how many hours they spent on performing a range of informal care tasks on an average care day (hours per day), and then how many such care days there had been over the past 30 days (days per month). Different tasks were grouped in five task clusters:

a) Personal care
b) Gardening, housework, shopping, medication, and managing banking and finances
c) Taking with the care recipient on the phone
d) Attending appointments with the care recipient
e) Interacting with health personnel or searching for information about services on behalf of the care recipient

The variable of time was the total time spent on tasks in all five task clusters.

4.4.3.3 Variables of individual characteristics

Relevant individual characteristics were collected based on findings from Substudy 1 (as outlined in Section 4.3.3), and earlier research. Findings from earlier research suggest that socioeconomic and sociodemographic variables can affect the selected outcomes (Darin-Mattsson, Fors, & Kåreholt, 2017; Koukouli, Vlachonikolis, & Philalithis, 2002). For these reasons, I chose to include the following individual characteristics:

Age (year of birth) and *gender* (0 = *woman*, 1 = *man*) were collected, because they are considered standard background variables in research.

Carer born abroad (0 = *no*, 1 = *yes*), indicating whether the carer was born outside Norway, was included on the basis of earlier findings have found that many immigrants in Norway experienced challenges in assessing dementia because of language barriers, and that strong norms related to family care could lead to a delay or lack of diagnosis among older immigrants living with dementia (Sagbakken et al., 2018). These difficulties may have implications for access to health services, carer burden, and quality of life.

Person living with dementia born abroad (0 = *no*, 1 = *yes*), indicating whether the care recipient was born outside Norway, was included for the same reason as above.

Urban residency (0 = *rural*, 1 = *urban*) was a binary variable determined with reference to participants' postal codes, based on a categorization used in Rugkåsa et al. (2019). The variable was included because health services in Norway vary between urban and rural areas, which can affect their accessibility. In addition, other researchers have detected associations between rural versus urban living and quality of life (Shucksmith, Cameron, Merridew, & Pichler, 2009).

Shared household (0 = *no*, 1 = *yes*) was a binary variable from the item concerning whether care recipients lived in their own housing, in an institution, or in the participant's house. The variable was included because some outcomes, including carer burden and time spent on informal care, might be affected by such living arrangements (S. Liu et al., 2017).

Spouse (0 = *no*, 1 = *yes*) was used as a binary variable of participants' relationships with their care recipients. The variable was included because different relationships are known to affect the experiences of carers differently (Rigby et al., 2019).

High level of education (0 = *no*, 1 = *yes*) Education is strongly associated with socio-economic differences which might affect quality of life in Norway (Norwegian Institute of Public Health, 2016). The scale for level of education had four response options: primary school (i.e., 9 years in Norway); secondary school (i.e., an additional 3 years); up to 3 years of university education; and more than 3 years of university education. Due to very few respondents reporting primary or secondary education, the variable was dichotomized such that 1 indicated more than 3 years of university-level education, and 0 any other level. Level of education has also been found to be associated with levels of HL, as HL can improve as a result of learning programs (S.-C. Lin et al., 2019; Lundetrae & Gabrielsen, 2016; Manafo & Wong, 2012; van der Heide et al., 2013; Yamashita & Kunkel, 2015). See section 4.4.5.6 for results of partial correlation analysis to explore the effect of the potential confounding variable.

Health personnel (0 = *no*, 1 = *yes*) was based on participants' responses regarding whether they had ever worked as health personnel. No further definition or explanation was provided in the questionnaire.

Work status (0 = *unemployed*, 1 = *employed*) was used to indicate whether participants were in paid employment; pensioned, or in receipt of disability benefits. For analyses, I dichotomized the responses such that employed was coded as 1, otherwise zero. Those in employment were asked how many hours they work per week. Those not in employment were asked whether this was because they were pensioned, disabled, or for other reasons.

Changes of work, indicated whether participants' role as carers had caused changes in their working lives. If yes, then they could select one of three reasons: a) worked more hours or worked for more years than otherwise expected, b) withdrew from work early, or c) worked fewer hours or began working at a lower salary.

Dementia severity was measured with a Norwegian translation of the Berger Dementia Scale (BDS)(Berger, 1980; Engedal, Haugen, & Nasjonalt kompetansesenter for aldersdemens, 2004) and was used to distinguish participants according to whether they cared for people living with severe or mild dementia (Berger, 1980). On the BDS, family carers indicated their assessment of their care recipients' daily function related to dementia. The BDS is brief, can be completed by family carers, and does not require any medical information. The latter was important, as the application for ethical approval did not include medical information. It does not provide a clinical evaluation of dementia symptoms. The BDS consists of six statements with an ordinal ranking between statements, and participants indicate which statement they considered to be most consistent with the daily function of their care recipients. Affirmative responses to the first three items on the BDS indicate mild dementia, whereas affirmative responses to the last three items indicate severe dementia (Berger, 1980).

4.4.4 Recruitment strategy and data collection

I realized early in the planning of Substudy 2 that I would not be able to gain a representative sample within the time-frame and resources available for this Ph.D.project. I was however, aiming to investigate findings from Substudy 1 further in a sufficiently large sample of family carers, so that I could test associations between variables that were generated from the interviews. With this aim, we planned a survey with enough respondents to conduct multiple linear regression analysis. A preliminary model of four multiple regression analyses indicated that we would need at least 150 respondents to complete and return the questionnaire for the analysis to be viable. Expecting a low completion rate around 20-30%, which is common in this kind of studies, (Lindemann, 2019) we planned to distribute the survey to at least 800 potential participants.

From January to May 2019, I recruited a non-probability sample using opportunistic and convenience sampling methods. I contacted the same health personnel as in Substudy 1, but increased the number of people and services to include members of municipal dementia teams, outpatient clinics, nursing homes, and home care services.

Health personnel working with people affected by dementia in different parts of Norway, working in primary and specialist care, in rural and urban areas, and in various districts, helped to distribute survey according to three strategies. First, paper-based print surveys were distributed to potential participants. Second, links to an online version of the survey were distributed via email and on dementia-related webpages. Health personnel were also asked to share a link to the online survey on their webpages or in their social media groups. Interest groups, home care services, and dementia teams additionally agreed to publish the link on their webpages and Facebook pages. Beyond that, I distributed an open link via my personal Facebook page, and encouraged friends and family to share the link. Third, single-page information sheets with a quick response (QR) code and a link to the online version of the survey were sent to health personnel and, through them, made available to family carers in outpatient clinics, in general physicians' waiting areas, and in dementia carer group meetings. By scanning the QR code, participants could complete the online survey on their phones.

Although I cannot know exactly how many family carers received an invitation to participate in the study, because most participants were invited by health personnel on my behalf, I distributed 410 print versions of the questionnaire and 235 single-page fliers to health personnel, as well as registering more than 250 clicks on links to the online survey posted on Facebook. In total, 188 completed surveys were received.

4.4.5 Analysis

In the following subsections, I present how I processed and analysed the data from the 188 completed surveys, including how I treated missing values and which statistical assumptions I checked to prepare the data for the statistical analysis. After that, I describe how I used descriptive statistics, linear regression, and multiple regressions to answer the research questions. All analyses were performed in the Statistical Package for the Social Sciences (SPSS) version 25.

4.4.5.1 Data handling, error checks, and use of imputation

Of the 188 completed surveys, 87 returned the print version, and 101 submitted electronically. We have no information on those family carers who declined to participate. Neither do we have information about how many surveys that were distributed to family carers, nor how many were exposed to the online link. This raises methodological challenges and issues which are discussed further below (section 6.2.1).

The electronic responses were automatically transferred to an SPSS file, which two members of the research team manually checked for errors. The print version responses were manually entered in the same SPSS database by me or a research coordinator. To reduce the risk of errors, all values were controlled by us both, and the few errors found were compared to the relevant survey and corrected.

In the cases in which participants had answered items ambiguously, I chose to record the least positive value in order to interpret all ambiguously answers in the same direction. Doing that allowed me to know in which direction I have interpreted ambiguous data. For example, if a participant had answered that he or she spent 1 to 2 hours on informal care per week, then I recorded the least positive value—that is, 2 hours. Similarly, if a participant had indicated two choices on the BDS, then I recorded the lowest functional level.

HL is calculated from each answer on the 12 items of the Health Literacy Scale (HLS-N-Q12), each item being on a 6 level scale. Because the HLS-N-Q12 needed to be reversed in the survey such that all scales progressed in the same direction, I changed the direction of the scale in the SPSS file so that higher scores indicated higher levels of HL, as intended by the scale's developers (Finbraten et al., 2018).The new variable was checked and no errors were found.

An error in the electronical version of the questionnaire meant that the second item on the HL scale was omitted for the first 97 participants, before we discovered and resolved the issue. Because a total HL score cannot be calculated without values from all 12 items, I needed to use imputation of missing values. If fewer than six of the 12 values for the same participant were missing, I used imputation of mean value for the case (Cokluk & Kayri, 2011; Lewis-Beck, Bryman, & Liao, 2003; W.-C. Lin & Tsai, 2020). This was done for five cases, in addition to the 97 participants who were presented with only 11 items. Eight cases had more than 6 missing values, and were recorded as missing for HL. The rest of the participants had a maximum of 2 missing values in the HL scale. Methodological issues regarding the use of imputation are discussed in section 6.2.2.

To compare the results for HL from our study with results from other studies that used other instruments to measure HL, cutoff values in the data were calculated to present descriptive categories of HL. This was done according to the procedure described by the developers (Guttersrud, Le, Pettersen, Helseth, & Finbråten, in review). To calculate cutoff values for HL accordingly, the 6-point scale was converted to a 4-point scale (1 = *very difficult*, 4 = *very easy*) following the formula 1 = 1, 2 = 2, 3 = 2, 4 = 3, 5 = 3, and 6 = 4. Using the sum of the 4-point scale, the four descriptive categories were: inadequate HL (i.e., 12–26), marginal HL (i.e., 27–32), intermediate HL (i.e., 33–38), and advanced HL (i.e., 39–48).

To generate a total score on RSS for each participant I summarized the values across the items. Higher score indicated higher carer burden. There were no established cut-off values or procedures available. For missing values, I used the same type of imputation as for HL, and no other changes or adjustments were made to that variable.

For HRQoL, I analyzed EQvalue and EQvas as two separate measures. No imputation was made for any of these values. For EQvalue, no imputation was used, and five participants with incomplete EQ-5D-5L responses were recorded as missing. There were no missing values on the EQvas variable. The responses in the five mentioned dimensions were converted to an index value between 0 and 1. In the absence of a Norwegian value set for the EQ-5D-5L, I followed the convention of using values derived in the United Kingdom (EuroQol Research Foundation, 2019).

Time spent on informal care was the total time each participant spent on completing a number of tasks (categorized in five clusters, see section 4.4.3.2) during the past 30 days (i.e., "hours spent on a typical care day" multiplied by "days per month"). For five participants, the time spent on these tasks in all clusters combined exceeded the maximum possible hours per month (>720 hours). Expecting that problem, I opted to use the sum of time as indicated by respondents, even when exceeding maximum possible hours per month because such values were believed to indicate overlapping tasks conducted during the period. I discuss the implication of this below. Rather than the interpretation of the Time variable as an absolute number of hours spent on informal care I have interpreted the variable as an objective measure of burden. This is a common interpretation of the time variable used in other studies (Flyckt et al., 2015; Wolfs et al., 2011),

Because the variable of time was indicated by participants as text (a string, in SPSS) rather than numbers, I changed responses to numerical values manually. The changes were checked by another member of the research team: three errors were found and corrected.

The Time variable was calculated for each participant by multiplying the hours spent on a typical care day by the number of days during the last 30 days. That step was performed for each cluster of tasks and summarized across all clusters for each participant. We used imputation of missing values to avoid reduction of the dataset and reduced statistical power which is a serious threat to validity and reliability (Mackinnon, 2010). Imputation was used as follows:

1) If the number of hours spent on a typical care day (hours per day) *and* the number of care days during the last 30 days (days per month) were missing, then I used the values of 0 hours and 0 days. Such steps were necessary for one or more of the task clusters in 32 cases. The result is either correct, where participants actually did not spend any time on the task cluster in question, or an underestimate of time spent.
2) In the few cases where only one of the two values (hours per day, or days per month) were indicated, I imputed the mean value from the remainder of the sample.

Because the Time variable tended to be exponentially distributed, I converted the variable to the natural logarithm (Ln) of Time to better meet the assumptions of linearity in the regression analysis (C. Feng et al., 2014). A minute was added to the value in order to avoid logarithms of 0, which is not defined (there is no x such that $b^x=0$). In regression analysis, the natural logarithm (Ln) of time spent on informal care was used as an independent variable.

For all other variables, missing values were recorded as missing, and no further changes were made. The age variable was kept as a continuous variable. Gender male was coded female=0/male=1. For the education variable, I created dummy variables to use a binary variable in the regression analysis. I defined higher education as > 3 years of university education and used all education up to 3 years of university education as reference. Higher education was coded as 1, all other coded as 0. Urban residency was categorized from participants' postal code. The variable was made a binary variable (rural = 0/urban = 1,) by using a classification used by (Rugkåsa et al., 2019), based on a combination of population density, proximity to regional centers and other cities. Whether participants had experience as health personnel was a binary variable (yes/no). If participants had not worked as a health personnel they were coded as 0. If they had ever work as health personnel (no matter for how long or what kind of health personnel) they were coded as 1.

Dementia severity (mild dementia=0/severe dementia=1) was transformed to a binary variable following the guide described in (Berger, 1980) to classify the three mildest categories of function loss in BDS as mild dementia and the three categories with severe function loss in BDS as severe dementia.

4.4.5.2 Distribution of variables

Distributions of HL and the outcome variables were assessed during a visual inspection of histograms. Histograms (Figure 6) showed that carer burden was symmetrically distributed, whereas HL, EQvalue, EQvas, and Time were skewed. The median value is the value representing the "person in the middle" of the distribution, and I have considered the median as a better representation of a typical value for the sample than the mean, because mean values are more affected by extreme values and skewness. I therefore present the variables in terms of their median, minimum, and maximum, rather than mean and standard deviation.

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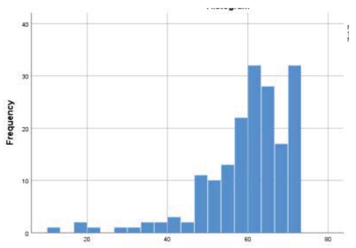
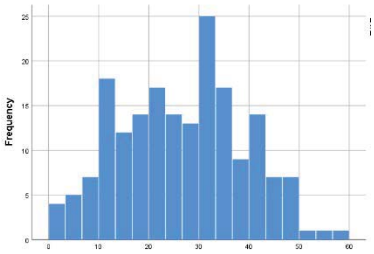
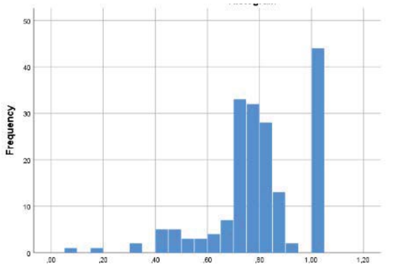
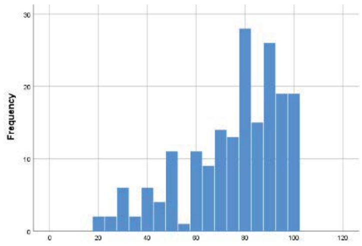
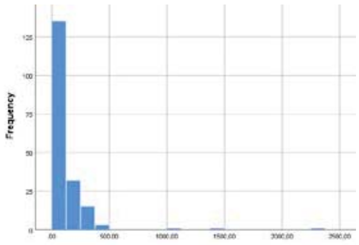
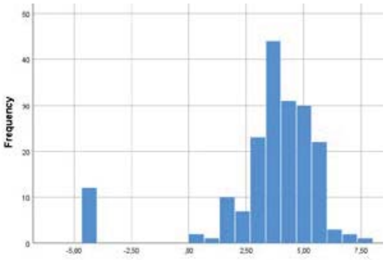
Figure 6. Histograms showing the distribution of variables

		
Health literacy	Carer burden	Health-related quality of life (EQvalue)
		
Health-related quality of life (EQvas)	Time spent on informal care	Time (Ln)

Boxplots were used to check for outliers in the continuous variables, and the outliers identified were further explored to determine whether they were errors in the data or actual values. All outliers determined to be actual values, not errors, were kept in the analysis.

4.4.5.3 Linearity

Because linearity is an assumption in the regression analyses, I investigated the relationship between HL and outcome variables. Scatterplots revealed weak linear relationships between HL and the outcome variables but no other associations (Appendix III). Because the linearity was weak, the relationships between HL and outcome variables were further investigated using boxplots, in which I inspected quartiles of HL and each outcome variable (Appendix

III). The direction of the relationships was consistent with the direction of the regression lines in the scatterplots, and no other relationship was found.

Pearson correlations were calculated among all variables considered for regression analysis in order to investigate relationships between the variables (Appendix IV). Together with theory and the research objectives, such correlations helped to determine which individual characteristics should be included in the multiple regression analysis as exploratory independent variables. With a sample of 188, I wanted to limit the number of variables in the regression analysis to maintain at least 10–20 cases per variable (Harris, 2013). Accordingly, when individual characteristics strongly correlated to each other, I chose only one of them for use in the regression analysis in order to avoid multicollinearity, and prioritize variables capturing other characteristics. What is considered to be a strong, moderate, or weak correlation varies between authors and fields (Pallant, 2020; Samuel & Okey, 2015). I used the guidelines (Pallant, 2020) for Pearson's r; *weak* (0.10–0.29), *moderate* (0.30 to 0.49), and *strong* (0.50–1.0).

Correlation analysis was performed with the variables carer burden, EQvalue, EQvas, Time, HL, dementia severity, age, gender, urban residency, health personnel, carer born abroad, care recipient born abroad, no university education, up to 3 years of university education, more than 3 years of university education, being a spouse, sharing household, and working (Appendix IV).

The correlation analysis revealed that age was strongly correlated (Pearson's $r > 0.5$) with spouse, work status, and shared household. Because age is one of the most commonly used background variables in research, it was kept in the regression analysis, whereas being a spouse, working, and sharing household were excluded variables.

Based on the results of correlation analyses, the research questions, and the general rule of thumb to have no less than 10–20 cases per independent variable (Harris, 2013), I included seven explanatory independent variables in the multiple linear regression analyses: age, gender, high level of education, urban residency, health personnel, dementia severity, and carer born abroad.

4.4.5.4 Multicollinearity

Multicollinearity is an undesirable statistical situation in which independent variables in the regression model are highly correlated (Bjørndal, 2012). Multicollinearity is investigated in terms of the variance inflation factor, which should be less than 10 and preferably less than 5 to be acceptable (Pallant, 2020). Among the independent variables, I found no variance inflation factor greater than 1.2, which was far below any critical values and means that my analyses were not notably affected by multicollinearity.

4.4.5.5 Homoscedasticity

Homoscedasticity means that the variance of residuals is the same for all values of the predicted outcome variable (Bjørndal, 2012). Homoscedasticity was checked with a scatterplot of residuals (Pallant, 2020) and no substantial deviations were found for any of the four outcome variables. Because regular linear regression analysis presumes a normal distribution of residuals (not of the included variables), I was able to use regression analysis even if the variables were skewed, because the residuals were normally distributed for all variables, after log-transformation of the Time variable.

4.4.5.6 Possible confounders

Because education was identified as a potential confounder, meaning that the variable could affect both the main independent variable (HL) and the outcome variables, I conduced a partial correlation analysis (Pallant, 2020) to explore if this was an issue in my analysis. The results indicate that education is not a confounder in this case (see section 4.4.6.1 for further details).

4.4.5.7 Descriptive statistics

I described the sample in terms of the number and percentage of valid cases, along with the number of missing values for categorical variables. For continuous variables, I described the sample in terms of median, minimum, and maximum values. As explained above, I report the median rather than mean because the distribution were skewed for most variables and the median as a central value is less affected by outliers. Not all variables were presented in Paper III, such as the variables related to work. The reason for this is that I chose to focus on the role of HL to predict carer burden, HRQoL, and Time. Doing so, correlation analysis, theory and the number of cases in my study made it necessary to exclude some of the variables that were collected. Consequently, I presented only the relevant variables in the paper. However, in this thesis, the variable regarding work is presented in the table showing participants characteristics.

4.4.5.8 Regression analyses

Bivariate regression models were estimated for HL and each of the outcome variable in order to assess unadjusted associations. Four multiple regressions models were developed to investigate the associations between HL and each outcome variable.

- Model 1: Relationship between HL and carer burden
- Model 2: Relationship between HL and EQvalue
- Model 3: Relationship between HL and EQvas
- Model 4: Relationship between HL and Time (Ln)

4.4.6 Results: Paper III

4.4.6.1 Descriptive statistics

The characteristics of the sample (*n* = 188) appear in Table 5. Of all participants, 71% (*n* = 134) were women, and the median age was 60 (25–84) years. Most participants were born in Norway; in fact, only 9% (*n* = 17) were born abroad. The majority had at least some university education (68%, *n* = 128) and were employed in paid positions (55%, *n* = 103). By relationship to the care recipient, 35% (*n* = 66) were spouses, the majority, 60% (*n* = 113), were other family members, with the remainder (*n* = 6) not being family members. The majority of the care recipients (53%, *n* = 99) were living in their own homes, and 64% (*n* = 120) were classified as having mild dementia.

Table 5. Characteristics of the sample

	Valid ***n* = 188**	**Missing**
Women, *n* (%)	134 (71)	1
Age in years, median (min–max)	60 (25–84)	0
Carer born outside Norway, *n* (%)	17 (9)	2
Level of education		2
Primary school (9 years), *n* (%)	11 (6)	
Secondary school (3 years), *n* (%)	47 (25)	
Some university education (1–3 years), *n* (%)	45 (24)	
University education (>3 years), *n* (%)	83 (44)	
Work		7
Worked as health personnel in the past, *n* (%)	59 (31)	7

Employed in paid position, *n* (%)	103 (55)	
Retired, *n* (%)	84 (45)	
Changes at work		19
Changed work schedule due to carer role, *n* (%)	46 (25)	13
Increased or prolonged work, *n* (%)	9 (5)	25
Reduced or quit work, *n* (%)	38 (20)	19
Reduced salary or work, *n* (%)	23 (12)	29
Relationship to care recipient		3
Spouse or partner, *n* (%)	66 (35)	
Other family member, *n* (%)	113 (60)	
Other (e.g., friend or neighbor), *n* (%)	6 (3)	
Living arrangement of care recipient		1
Living independently, *n* (%)	99 (53)	
Living in participant's house, *n* (%)	54 (29)	
Living in institution, *n* (%)	34 (18)	
Care recipient with mild dementia, *n* (%)	120 (64)	1
Care recipient born outside Norway, *n* (%)	11 (6)	7
Health literacy (HL), 6-point scale, median (min–max)	61 (12–72)	8
HL, 4-point scale, median (min–max)	41 (12–48)	8
Advanced HL, *n* (%)	104 (58)	
Intermediate HL, *n* (%)	59 (33)	
Marginal HL, *n* (%)	9 (5)	
Inadequate HL, *n* (%)	8 (4)	
Carer burden, median (min–max)	27 (0–60)	2
EQvalue, median (min–max)	0.79 (0.09–1)	5
EQvas, median (min–max)	80 (20–100)	0
Hours spent on informal care per month, median (min–max)	52.1 (0–1520)*	0

* For five participants, the time exceeded the maximum number of hours in a month (<720 hours).

The median level of HL in the sample was 61 (12–72), and the median carer burden was 27 (0–60). The median EQvalue was 0.79 (0.09–1), the median EQvas was 80 (20–100), and the median time (hours) spent on informal care during the last month was 52.1 hours (0–1520). Because there are 720 hours in 30 days, in a sensitivity analysis I excluded the five cases exceeding 720 hours per month, in which case the median value of time spent on informal care was 50 hours per month (0–493). Also, inspection of zero-order correlation coefficient (exploring potential confounding) suggested that controlling for education had very little effect on the strength of the relationship between HL and the outcome variables (Pallant, 2020). The only effect identified was between HL and Time, changing from r = -0.131 to r = -0.132.

4.4.6.2 Bivariate regression analysis: Outcome variables and health literacy

Bivariate regression analysis between HL and the outcome variables (carer burden, EQvalue, EQvas, and LnTime) showed a significant linear relationship between increased HL and reduced carer burden (B = -0.21, 95% CI [-0.37, 0.34], *p* = .01), and between increased HL and increased EQvalue (B = 0.003, 95% CI [0.001, -0.005], *p* = .01), as shown inTable 6.

Table 6. Results of bivariate regression analysis between health literacy and outcome variables

	B (95% CI)	Sig	N	R^2
Carer burden	-0.21 (-0.37, 0.04)	0.01*	179	0.03
EQvalue	0.003 (0.001,0.005)	0.01*	177	0.04
EQvas	0.21 (-0.06,0.47)	0.13	179	0.01
LnTime	-0.03 (-0.05, 0.003)	0.08	179	0.02

* $p < .05$.

The multiple linear regression analysis revealed that statistically significant associations were found after adjusting for the effects of age, gender, higher education, urban residency, having worked as health personnel, caring for someone with severe dementia, and being born abroad. Findings indicate that higher HL was associated with lower carer burden (B = -0.18, 95% CI [-0.33, -0.02], *p* = .02); higher HL was associated with higher HRQoL when measured with EQvalue (B = 0.003, 95% CI [0.001, 0.006], *p* = .004), and; higher HL was associated with less time spent on informal care (LnTime) (B = -0.03, 95% CI [-0.58, 0.000], p = 0.046). This is detailed in Table 7.

Table 7 Results of the multiple regression analyses with the four models

	Model 1, n=168 Carer burden R^2= 0.224		Model 2, n=167 Health-related quality of life (EQvalue) R^2 =0.146		Model 3, n=168 Health-related quality of life (EQvas) R^2 =0.121		Model 4, n=168 Time^a R^2= 0.075	
	B (95% CI)	**Sig**	**B (95% CI)**	**Sig**	**B (95% CI)**	**Sig**	**B (95% CI)**	**Sig**
(Constant)	33.39 (20.91,45.87)	0.00	0.51 (0.32, 0.69)	0.00	51.89 (30.49,73.29)	0.00	4.68 (2.34,7.04)	0.00
Health literacy	-0.18 (-0.33,-0.02)	0.02*	0.003 (0.001,0.006)	0.04*	0.20 (-0.06, 0.46)	0.13	-0.03 (-0.58, 0.000)	0.046*

Age	0.09 (-0.04, 0.22)	0.18	-0.001 (-0.002,0.001)	0.59	-0.05(-0.27, 0.17)	0.65	0.03 (0.001, 0.05)	0.04*
Gender, male[b]	-8.93 (-12.88, -4.98)	0.00*	0.11 (0.05, 0.16)	0.000*	8.36 (1.58, 15.13)	0.02*	-0.92 (-1.67, -0.18)	0.02*
Higher education[b]	-4.76 (-8.37,-1.16)	0.01*	0.03 (-0.03, 0.08)	0.31	6.69 (0.51, 12.87)	0.03*	-0.17 (-0.85, 0.51)	0.63
Urban residency[b]	1.42 (-3.73,6.56)	0.59	0.08 (0.01, 0.15)	0.048*	8.35 (-0.47, 17.17)	0.06	-0.33 (-1.30, 0.64)	0.50
Health personnel[b]	-1.66 (-5.53 ,2.20)	0.40	0.03 (-0.03, 0.09)	0.26	5.56 (-1.06, 12.19)	0.10	-0.30 (-1.03, 0.42)	0.41
Dementia, severity[c]	5.47 (1.83,9.11)	0.003*	-0.004 (-0.06, 0.05)	0.90	-1.00 (-7.25, 5.24)	0.75	-0.07 (-0.76, 0.62)	0.84
Carer born abroad[b]	6.95 (0.71,13.19)	0.03*	-0.002 (-0.09, 0.09)	0.96	-4.34 (-15.05,6.37)	0.43	0.04 (-1.14, 1.21)	0.95

,*$p<0.05$; ¶ Note: The 6-level scale of HL is used in the regression; [a] The Time variable is the log transformed variable; [b] Variables are binary and coded no=0/yes=1; [c] The variable Dementia severity is coded mild dementia=0/severe dementia=1.

Of the explanatory independent variables affecting carer burden, being a female, caring for someone with severe dementia, and being born abroad were statistically significantly associated with higher carer burden; while being male and having higher education were significantly associated with lower carer burden. See Table 3.

Of the explanatory independent variables affecting EQvalue and EQvas, being male was statistically significantly associated with both, indicating that being male was associated with higher HRQoL compared to being female. Living in urban areas was statistically significantly associated with higher HRQoL, but only when measured with EQvalue. Having higher education (>3 years or higher university education) was statistically significantly associated with higher HRQoL only when measured with EQvas. See Table 3.

Of the explanatory independent variable affecting Time spent on informal care; higher age and being female were statistically significantly associated with more time spent on informal care.. See Table 7.

5 Ethics approvals and ethical considerations

In addition to ontology, epistemology, and methods; ethics may also be considered part of the philosophy (Sue, 2018; Varpio & MacLeod, 2020). Methodological choices are also based on values, such as what kind of research is useful, who's perspectives are given priority, what kind of harm is acceptable, etc.

Both substudies took the perspective of people caring for an older person with dementia. From a philosophical view, this shows that family carers are valued when it comes to understand their perspectives, and they are considered valuable contributors to the overall care.

Both Substudy 1 and Substudy 2 were deemed to fall outside the scope of the Norwegian Health Research Act by the Norwegian Regional Research Ethics Committees (REK sør-øst) (ref. no.: 2017/756 B, Appendix V; ref. no.: 2017/756 B, Appendix V). Approvals to conduct the substudies were provided by Akershus University Hospital's privacy ombudsman based on my description of aims, methods, ethical considerations, and data protection routines (ref. no.: 17-128, Appendix VI; ref. no.: 2018-126, Appendix VI). These approvals confirm the value of the results and that the values of these results are considered more important than the potential harm to participants.

All participants were given written information about the substudy in which they participated (Appendix VII). They were also informed about the aims of the studies, the potential disadvantages of participating, that participation was voluntary, and that they could withdraw from the study at any time for any or no reason. Their right to be informed and the main rule that participants may participant after following an informed and voluntary consent (Act of health reserach (helseforskningsloven), 2018)also demonstrate that each individual have value and that the principal of autonomy is strong in our society.

Dementia coordinators and other health personnel working in dementia care emphasized the considerable stigma persistently attached to living with dementia. They also made me aware that many people living with dementia and their carers have not fully acknowledged or come to terms with the dementia disease. Indeed, some family carers continue to avoid using the term *dementia*. For those reasons, I wanted to be careful not to offend people by inviting to participate in a study on dementia caregivers. Because health personnel who work closely with people living with dementia and their caregivers are typically aware of the need to be sensitive about those issues, I concluded that approaching family carers through health personnel who work with people living with dementia would ensure a sensitive recruitment process.

Consideration for family carers who were already experiencing heavy burdens from caring was also a concern among many healthcare workers who helped to invite prospective participants. Because I depended upon the help of health personnel and trusted their ability to be considerate and respectful, I encouraged them to use their best judgment when inviting people to participate in the study. The implications this had for the sample is discussed in section 6.1.1.2.

5.1 Ethical considerations: Substudy 1

Written informed consent was received from all participants before their interviews commenced. The audio-recorded interviews were immediately transferred in encrypted files to a password-protected computer without any internet access, and the recordings were deleted from the recording device immediately afterward.

In the transcripts, the names of individuals, the names of places, and other directly identifiable information was removed or replaced with a fictive name/description. Although I did not ask participants for information about their health, ethnicity, or religion, information about those aspects was often emerged during interviews. Such information was considered to be sensitive data and accordingly de-identified and saved on a secure research server. The de-identified transcripts were saved on the hospital's research server with password-restricted access. The consent forms with participants' names were kept in a locked drawer in a locked office with limited access.

During interviews, some participants asked me for advice based on my nursing background. Some of them may have perceived me as a clinical expert in the field, which I am not. It was important for me not to assume the role of helper in the interview context. At the same time, a couple of participants seemed to lack knowledge about services or options that were obviously available and potentially of use to them. In those cases, I opted to provide them with examples of how other participants had resolved problems using similar services and options. Although it was important for me to balance my role between not being a helper or an expert, I also wanted to share knowledge with participants when it would clearly be helpful to them. Going too far in either direction would have been unethical, and I was careful to always consider that balance.

Some participants expressed their hope that I would achieve immediate improvements in health services for older people with dementia. While contributing to the improvement of such services was indeed a purpose of the study, research is a meticulous, time consuming process, and participants' expectations might have been unrealistic. In retrospect, this could have been expressed more clearly to them, as it is always important for research to be conducted in a way that does not violate trust in research in general.

5.2 Ethical considerations: Substudy 2

The information sheet enclosed with the printed surveys stated that I considered the return of a completed form as their consent to participate. For the online survey, an information sheet was displayed to participants before starting the survey. To access the rest of the items in the online survey, all participants had to state that they had read the information and agreed to participate.

Although information about directly identifying characteristics was not collected, indirectly identifiable information nevertheless constituted a risk of identification. For that reason, the submitted and returned forms were treated as potentially identifiable. The print surveys were returned directly to the research team in closed, prepaid envelopes. They were kept in a locked drawer in a locked office with limited access. Electronic surveys were submitted to the research team via an encrypted data server. The SPSS-files used to analyze data were stored on the hospital's secure research server with limited access.

To enable participants to withdraw from the study after having submitted their answers, each of the print surveys had a serial number. Participants who answered online were asked to create a personal code. This made it possible for respondents to withdraw by contacting the research team and provide their personal code or serial number. No respondents made use of this opportunity.

Health personnel distributed surveys to family carers under with the same ethical considerations observed in Substudy 1. The online surveys, by contrast, were distributed widely and made open to anyone via Facebook and other webpages. When sharing an open link, I expected that individuals who did not identify themselves as family carers for an older person living with dementia would not consider themselves eligible to participate.

One participant expressed negative experiences after having answered or tried to answer the questionnaire. A few others typed negative comments the survey on Facebook. A typical negative reaction was that the items were too narrow to capture how they felt about being a family carer and would not give a true picture of the complexity their situations. One participant even wrote a letter to me explaining her experience with being a family carer and the reasons why the questionnaire had failed to capture that experience. I replied only to the one writing the letter. My response was to validate their feelings, and then refer to the overall research design by which I first investigated such complexities through in-depth interview, and that the survey was designed to investigate this by statistical means.

6 Methodological considerations

In this section, I will address methodological considerations that I have not elaborated earlier.

6.1 Methodological considerations: Substudy 1

Where the quality of quantitative studies is often assessed in terms of generalizability, validity, and reliability, it has been extensively debated whether qualitative and quantitative methods can or should be assessed according to the same quality criteria (Mays & Pope, 2000). I follow the advice of Malterud (2017) and Mays and Pope (2000) and assess the quality of the qualitative substudy by discussing its reflexivity, relevance, transferability, and transparency (Malterud, 2017; Mays & Pope, 2000).

6.1.1 Reflexivity

By *reflexivity*, I refer to not only a critical awareness of how data have been constructed, but also sensitivity to the ways in which the research process and the researcher's preunderstanding may have shaped the generation and analysis of data (Dowling, 2006; Mays & Pope, 2000). By reflecting upon and describing the strengths and weaknesses of the study, I endeavor to make the reader able to consider those factors when assessing the process and the results (Bowling, 2014; Creswell, 2014; Kvale & Brinkmann, 2012)

6.1.1.1 My preunderstanding

According to Alvesson and Sköldberg (2009), a reflexive approach to the research process involves interpreting data carefully. This requires reflecting on one's interpretations, and being critical about self-exploration in those interpretations. According to Malterud (2017), a researcher's preunderstanding may cause those interpretations to be affected by personal experiences without him or her necessarily realizing it. In chapter 1.3 I explained important presumptions that I brought to the project. Here, I further describe how my preunderstanding may have affected the project and the study result, so that the reader can be informed about the conditions under which the knowledge generated by the study was developed (Alvesson & Sköldberg, 2018).

My background as a Norwegian-born female, professionally trained nurse, with more than 15 years of experience with working in health services in urban areas of Norway, mainly in hospitals, formed my preunderstanding of how health services are provided. In addition to my clinical experience, I previously studied the role of nurses in emergency departments. Thus, my preunderstanding stems from a perspective backed by relatively extensive knowledge of how healthcare professionals think, talk, and experience their roles. At the same time, my health service background might have aided me in understanding the context of many of the participants' experiences. Altogether, I applied my experience and knowledge to identify how perspectives of family carers and health personnel differed, and as a result, I sometimes understood why misunderstandings had occurred due to my experience of hospital cultures. As described in section 1.3, I hold a holistic view, in line with how patient-centeredness is commonly understood. According to Latimer, Roscamp, and Papanikitas (2017) patient-centeredness is

> "achieved by adopting a holistic approach; examining all part of the patient's life and widening the gaze from a purely biomedical viewpoint to allow the practitioner to understand the patient's values and life narrative, and to adapt therapy accordingly" (Latimer et al., 2017 p.1)

The definition by Latimer et al. (2017), matches well with the preunderstanding that I bring into this project. This view has made me sensitive to family carers' needs beyond the scope of health services, and I have consciously utilized this perspective to identify how family carers experiences may be useful to understand what they need, and consequently, how health services can improve to facilitate better care provision to older people living with dementia.

According to Malterud (2017), my proximity to formal health services may have impacted my reflexivity. It may have also have resulted in interviews being more targeted and relevant as well, because I have many years of experience with meeting family carers within health services, although in a different healthcare context . I have described how I used open-ended questions and a flexible, semi structured interview guide. This allowed new perspectives to emerge, and be added into subsequent data generation as I did not want my preunderstanding to be a barrier against perspectives that were deemed important by the participants.

I actively sought to move beyond my initial understanding during analysis, drawing on different analyzing techniques, and using a creative and interpretive approach in combination with rigorous coding. I sought to establish a degree of distance between my preunderstanding and the material when performing line-by-line coding by focusing on the meaning of each part of the text. I discussed possible themes and interpretations of transcripts with researchers with other backgrounds, which also helped reflections on my own preunderstanding.

I have limited experience with health services in contexts other than hospitals in urban areas of Norway (e.g., community-based services), and I have never been the primary family carer for an older person. Neither do I have any extensive experience in working with older people living with dementia, although I have met people living with the condition and their family carers during my work in hospitals. Consequently, I embarked on the project without strong personal experience, or organizational/political loyalty, regarding dementia care for older people.

According to Kvale and Brinkmann (2012), participants typically want to have some idea of whom they are talking to before they open up about their experiences and feelings during interviews. I informed participants of my nursing background to provide them with some knowledge about me. Openness and clarification about my role in the interview (as a researcher and not a nurse) was aimed to enhance a sense of trust or confidence and, ideally, a feeling of control in the interview situation. This was important both as an ethical approach to asking people to talk about their lives, and to generating rich data.

6.1.1.2 Reflexive considerations of the sample

I sought a sample that reflected the breadth and diversity of the population of family carers for older people living with dementia in Norway. Accessing health personnel was a primary means to recruiting family carers, meaning that such personnel issued judgment about whether a family carer was suitable to be interviewed based on the inclusion criteria. It is likely that some family carers who would have wanted to report their experiences might not have been invited to enroll. It is also possible that family carers perceived to have extensive challenges were not invited because health personnel wanted to protect them, and not add any pressure.

There was also a risk that participants were among the carers most eager to contribute to care, whereas family carers with less interest in health services or with a more withdrawn attitude toward health personnel or health services might have been less likely to volunteer. To address this weakness I used snowball sampling where I asked family carers to invite other family members or others. Some families were therefore represented by more than one carer in this sample. This could potentially have reduced the variation of experiences in the sample given that the care-recipient was identical, but I found that the perspectives and experiences of different members of the same family varied distinctly. I believe this is demonstrative of knowledge being generated in relation to the social context, and the lens through which you view it, both for the participant and the researcher.

Despite those possible limitations, the purposive sampling method allowed me to seek participants with different characteristics and afforded me some degree of control over the sample (Barbour, 2001). I have described earlier how I particularly sought men and foreign-born participants to balance the sample.

Ultimately, the sample captured a broad spectrum of experiences, with variation in age, gender, relationships to care recipients, urban versus rural residency, and being born in versus outside of Norway. An important choice in the third stage of sampling was to recruit participants from Northern Norway, where the healthcare context and culture differ somewhat from Eastern Norway's. Thus, seeking participants that increased the variation in the sample contributed new aspects, and, in turn, increased the quality of the study (Barbour, 2001).

There was a risk that family carers with less confidence in their own role as carers may have declined the invitation to participate because they did not want their perceived inability to come to light. Although some participants talked about their strained relationships and negative feelings toward the person with dementia under their care, they all seemed to care deeply for the care recipients. However, not all families have good, loving internal relationships, and frail older adults are vulnerable to physical, economic, and sexual abuse, even at the hands of family carers (Friedman, Avila, Rizvi, Partida, & Friedman, 2017; Giurani & Hasan, 2000; Lino, Rodriques, de Lima, Athie, & de Souza, 2019). As far as I know, no such relationships were represented in the study.

I purposely invited family carers from minority groups via people who spoke their language, but few accepted the invitation. The participants who were born outside Norway or identified themselves as belonging to a minority group were usually found by way of targeted snowball sampling. The lack of participants who would have needed an interpreter for the interviews, in addition to the difficulties with recruiting participants from minority groups, indicate that families of minority ethnic, religious, or cultural backgrounds were not well represented in the sample. Some minority groups have low confidence in formal authorities (The Ministry of Local Government and Modernisation (NOU 2015:7, 2015; Turi et al., 2009), and as a native Norwegian representing a public institution, I may have embodied reasons for difficulties in recruiting people from minority groups.

Given the overall aim of the study, it was important that participants had some experience with the health services of the care recipients. Male participants seemed less involved in personal care tasks, such as grooming, dressing, bathing, and similar tasks typical of healthcare provided by e.g homecare nurses. Nevertheless, they were invested in other tasks such as gardening, home maintenance, carrying heavy bags, changing lightbulbs, helping with banking, paying bills, taking care of insurance needs, and providing transportation. Some of those tasks fell beyond the remit of health services but were deemed as important parts of caring for an older adult living with dementia nonetheless. The fact that these tasks are often not considered healthcare may be one of the reasons why the majority of people who volunteered to participate in interviews about health services were women. As mentioned earlier, it is discussed in research whether caregiving is measured with "a female yardstick", meaning that it is measured using female preferences (Lopez-Anuarbe & Kohli, 2019).

Snowball sampling is a way to maximize the potential of social relationships for recruitment. Berg (2006) has claimed that snowball sampling gives socially connected people higher odds of being selected for participation and prevents others from being included. I used snowball sampling for specific purposes, which resulted in a small number of recruits, namely to target carers with characteristics that could balance the sample. As such, it helped to supplement other recruitment strategies to reach a broader variety of participants than I would have otherwise been able to reach.

Despite the above considerations, the final sample in Substudy 1 included participants with a wide variety of characteristics, representing a diversity of experiences, perspectives, and roles. Even though a dementia diagnosis was not a criterion, most participants reported that their care recipients had indeed been diagnosed with dementia, and the few who were not, were in the process of medical investigation for dementia. As such, I achieved a sample with a great deal of breadth in their backgrounds, although it is always possible to extend the breath of experiences. See reflections regarding sample size and "saturation point" in section 4.2.4.4.

6.1.1.3 Data generation

As the method of generating data, in-depth qualitative interviews were suitable for the purpose of exploring participants' perspectives and experiences. Most interviews yielded rich data, and flexibility in scheduling the time and place of interviews was helpful because several participants were often obliged to fulfill care responsibilities while others was glad to have a reason to leave home, and meet other people. Also, by recruiting through health personnel who worked with the care recipients and knew the family carers, I allowed them to use their best judgement regarding who, how and when to approach the carers.

Before each interview, I followed Kvale and Brinkmann (2012) recommendation to host a briefing in which I repeated information from the information sheet. Participants seemed quick to understand what was expected of them, and several had even prepared themselves for the interview by thinking through certain aspects of their experiences that they considered particularly important. I sometimes did not even have to ask my first question before participants spontaneously talked about their experiences. In short, most participants seemed eager to share their experiences with me.

During interviews, I routinely picked up clues and asked questions to clarify what participants meant (Kvale & Brinkmann, 2012). In some cases, however, I did not realize until after the interview that it would have been interesting to hear more about certain themes.

I tried to ask simple, brief, open-ended questions so that it would be easy for participants to understand what I was asking and provide rich answers without being interrupted unnecessarily. To the same purpose, I tried to use clear, everyday language and to avoid asking leading questions. I endeavored to listen actively, and to allow pauses and silence that often prompted participants to continue talking without me re-directing the conversation prematurely (Kvale & Brinkmann, 2012).

One participant stood out from the others by expressing discomfort in the interview. When I asked him about his concern, he replied that he was struggling to accept that the care recipient was ageing and that one day he would lose her. He preferred not to think about it, and for that reason, he did not engage much in the tasks related to her health or health services. His interview was far shorter than the others and not as rich in information, but it nevertheless was a useful reminder about how some family carers provided care in ways other than being involved in health services or tasks related to their health.

6.1.1.4 Data quality

Interpreting spoken language in written form raises questions about how the different characteristics between those two modes of language might impact interpretation (Kvale & Brinkmann, 2012). I transcribed each interview verbatim, usually immediately after it was conducted, which made it easy to remember, and incorporate, details such as body language and nonverbal expressions not captured on audio recordings. I thus added contextual notes in the transcripts, including about whether a person had cried, laughed, used irony, or made facial expressions, among other things. A benefit of both conducting and transcribing interviews myself was that I could use these notes, and go back to the audio recordings if needed, to interpret the meaning of the text in the context of the spoken words (Denham & Onwuegbuzie, 2013).

Data were generated in my social interaction with participants in the context of the interview, in which I functioned as the interviewer (Kvale & Brinkmann, 2012; Patton, 2015). One of the main criteria for a high-quality interview is that participants receive the opportunity to give rich, spontaneous, specific, relevant answers (Kvale & Brinkmann, 2012). I believed that the best way to achieve this was through individual, face-to-face interviews conducted in the way described above. I endeavored to use the interview guide flexibly, phrase questions in an open-ended manner, and to be sensitive to emerging themes that could be pursued. Other methods of data generation, such as group interviews, telephone interviews, or more structured interviews would most likely have yielded different data and additional insights. Rather that presenting my results as the “truth” about family carers’ experiences, I consider them as representations of reality (Mays & Pope, 2000), following the phenomenological and hermeneutical epistemologic stance where data is representing participants’ lifeworld, as they are experiencing the phenomenon.

The data from interviews were based on conversations with others and almost entirely dependent upon language (Kvale & Brinkmann, 2012). A few participants were not fluent in Norwegian, and during their interviews, I often had to ask them to explain what they meant or contextualize their choice of words or expressions in order to understand their experiences in their social contexts.

6.1.1.5 Quality of the analysis

Systematic analysis is a criterion for high-quality analysis in qualitative research (Malterud, 2017). My analysis combined different analytic techniques rather than following a single model. Nevertheless, I followed the four stages systematically. In that way, I was able to view the data from different perspectives: one perspective, where I used my creative interpretation, meaning that I explored and interpreted the meanings of experiences, similarities and differences between experiences, sought different interpretations etc. (analytic stage 1 and 2); and a second perspective, where I gained a distance from my preliminary interpretations as I conducted nuanced and rigorous line-by-line coding (analytic stage 3). In the analytic stage 4, I used the merged perspectives that had become a new horizon of knowledge as I identified themes to follow and connected codes and themes.

In qualitative research, elements of analysis begin during interviews. I sought to verify interpretations during interviews by asking clarifying questions such as, “When you say you got ‘help with cleaning’, you mean that you got help with cleaning the apartment, or your wife’s personal hygiene?” The participant could then clarify and elaborate as appropriate. I also sometimes tried to summarize what participants had reported in order to give them an opportunity to correct my understanding of what they had said. However, at times, I interpreted irony and sarcasm from the tone of voice or body language without verifying the intentions of the participants.

I sought different perspectives on my data by having my coauthors and members of my research team read sections of the interview transcripts and discuss potential themes or codes. Furthermore, the use of constant comparison (Charmaz, 2006) between interviews made it easier to identify how participants sometimes perceived similar experiences differently, and I then sought to understand, inspired by the three levels of interpretation by Fangen (2010), what had made them evaluate or express similar experiences differently. The principal purpose of that process was to widen my own perspectives to more incisively interpret the data and move beyond my immediate understandings.

In the preliminary phase of analysis, I accessed literature to investigate whether interesting themes or codes were already described therein. That step helped me to identify what represented new perspectives and new connections between themes, which guided me toward themes to be followed up during later stages. It is important to underscore that the use of literature was not used to guide my analysis, but only to guide which themes to follow based on what themes that were already commonly described.

In the second phase of analysis, I deconstructed the transcripts by performing line-by-line coding independent of the former stages of analysis. Focusing on each small piece of the transcripts one at a time allowed valuable distance from my preliminary interpretations.

In the fourth stage of analysis, I merged the different impressions, reflections, perspectives, codes, and themes from the previous phases to form high-level themes, which were presented as results in Papers I, and Paper II. Done in collaboration with my coauthors and in light of the literature, the process granted additional insights and suggested ways of refining codes and themes (Barbour, 2001).

When writing the papers based on those themes, I continued to engage in analysis. Codes and themes were understood better when presented as words with quotations, and the structure of the papers ended up slightly different from the original codes and themes, because articulating the results made me aware of the nuances and relationships between codes and themes.

6.1.2 Relevance and transferability of results

The transferability of results is a prerequisite for sharing results with others (Malterud, 2017). *Transferability* expresses a reflexive consideration of the applicability of results to other similar situations or contexts (Malterud, 2017). In contrast to the strive for numeric generalization in quantitative studies, qualitative research aims to present results that have relevance to similar populations, contexts or processes (Malterud, 2017). As I was commencing the interviews, I was advised by health personnel working in municipality dementia teams to view “health services” in a very broad perspective. What they meant was that because dementia affected people’s lives in so many complex ways, far beyond what can be addressed by the formal care sector, a broader perspective is needed to capture the totality of care needs, and to understand how health services can meet these needs and increase the quality of care provision. For that reason, the data generated in this study may for some seem as peripheral to formal care, but for those working close with people living with dementia, this was one of the perspectives that they thought needed more attention. As such, it should be of relevance to the wider Norwegian context of dementia care.

The findings might be of some interest internationally, as it provides knowledge that can inform solutions to future challenges faced by welfare states. In particular, how to provide care for the increasing number of older people living with dementia in most welfare states is a growing concern, as is the support for family carers, and sustainability of informal care. The findings may also be of value for understanding the relationship between formal and informal care beyond the population of carers for older people with dementia.

6.1.3 Transparency

By presenting the strengths and weaknesses of the study, I have worked to make the research processes transparent (Symon, 2012) and enabled readers to consider the shortcomings of those processes when assessing the results (Bowling, 2014; Creswell, 2014; Kvale & Brinkmann, 2012). By reflecting and describing data collection, the sample, and the analysis in enough detail for readers to judge whether the interpretation proffered is adequately supported by the data, as well as by showing the range of different perspectives, not only the viewpoint of one group as the sole truth, I have increased the research's transparency and thus quality (Mays & Pope, 2000).

6.2 Methodological considerations: Quantitative study

6.2.1 Representativeness and generalizability of the sample

In the planning face of Substudy 2, I explored the possibility of accessing data about family carers from a national registry of cognitive data, which is based on data from people being investigated by specialist services regarding cognitive symptoms. This could have facilitated a representative sample, but it turned out that the registry did not have systematic information on informal carers, nor consent to distribute such information. I also sought collaboration with existing studies to see if I could use their databases as a sampling frame, but this turned out to be outside the scope of their ethical approval and consent by participants. Consequently, Substudy 2 was based on a nonprobability sample.

The number of respondents were approximately as expected, as it is common for printed or electronical surveys with no follow-up have a response rate around 20-30% (Lindemann, 2019; Yun & Trumbo, 2000). Increasing the response rate among those invited to participate could in theory have been done by e.g. use of reminders. However, this was not part of the selected recruitment strategy, due to both ethical and practical constraints. For ethical reasons, we wanted to avoid pressuring family carers to participate. For practical reasons, such reminders would have been problematic given the available resources and the time-limitations of the Ph.D. The reliability and validity of the study results would have benefited both from a larger and a more representative sample of respondents. However, the efforts required to move in the direction of either were considered greater than the potential benefits.

The distribution of information about the study depended, to a large extent, on the willingness of individual health personnel. Personal engagement among a few individual dementia coordinators and other health personnel contributed to more participants from certain areas. My personal relationships with some of the health personnel seemed vital to gain their trust and support, which is why most participants were recruited from Eastern Norway, where I was situated and had gained clinical experience. In Northern Norway, I was able to establish a few relationships with health personnel and service managers who were supportive of the study and willing to participate. These factors result in the uneven geographical sampling of respondents.

Given the selected sampling strategy, I have no information about the characteristics of individuals who chose not to reply to the survey, or why some carers declined while others responded. Nor do I know if all my distributed questionnaires were forwarded from healthcare personnel to family carers, or how health personnel promoted the study among the family carers. In the online questionnaire, the initial attempt to share the link resulted in feedback that the "Link was not secure", an error caused by problems with the Secure Socket Layer certificate on the web server housing the questionnaire. Although I was able to correct the problem within days, some potential participants may have been deterred from answering. Because I am not able to decide how the sample is skewed, this represents a limitation of the study. Consequently, my ability to assess the representativeness and generalizability of the sample is limited.

There may be a selection bias in the participants in this study, and we have no information about who was exposed to the study or who declined to participate. This is a methodological limitation, as it is likely that the combination of a non-probability sampling method, voluntarily participation of family carers, and self-administration of the survey, have together contributed to oversampling of participants with higher levels of HL. A self-administered survey makes cognitive demands on participants (Bowling, 2014), which may have impacted who volunteered to take part (Marcus & Schutz, 2005). Those who chose to participate had higher levels of HL than the general population [45-46], which could indicate a selection bias in the sample.

The nature of a nonprobability sample makes generalization of results more challenging, as the sample is most likely not representative of the population of family caregivers in Norway. Rather, we expect that the sample consist of family carers with access to the survey, with interest in participating, and perhaps with spare energy to complete a survey. This sample may have other characteristics, and generate different results, than would a representative sample. For this reason, I have interpreted the results in consideration of this issue, focusing on describing my sample and pointed out which characteristics differed from what we would expect in a representative sample. Rather than describing our results as representative for the family carer population, we have discussed and described how the results may be useful, and to whom.

The survey included limited information about the care recipients, and I cannot rule out that participants completed the survey without actually being carers of anyone living with dementia. However, I consider it unlikely that this has affected the results. Since closing the survey, I have met a handful of people who have informed me that they did not complete the questionnaire because they believed they were not in the target group. However, after talking with them, I considered them eligible. This indicates that the invitation and provided information may have given an impression that the intended audience was more restricted than I wished to communicate.

It was a challenge to strike the optimal balance between overly wide and overly narrow inclusion criteria. A separate methodological challenge was that dementia remains stigmatized in various ways, and before health personnel acted to invite family carers to contribute, they typically wanted assurance that the family carer was indeed comfortable with being "labeled" as a family carer for an older person with dementia.

The descriptor *family carer* was not limited to primary caregivers, nor did I include only the closest family members. Consequently, the findings represent views and experiences from a range of people who care for older people living with dementia.

6.2.2 Validity and reliability of the data in Substudy 2

Important indicators of the quality of data from the survey are the results of the assessment of the validity and reliability of the instruments used. Because carer burden, HRQoL, and HL are abstract concepts, I sought to use instruments that are considered valid and reliable (Kimberlin & Winterstein, 2008). Validity is understood as the accuracy of measures, the extent to which one can draw useful and meaningful conclusions with the instruments used, and whether the instruments actually measured what they were intended to measure (Bowling, 2014; Creswell, 2014). By contrast, reliability is related to consistency in responses and to which degree items used in a survey elicit the same kind of information each time that they were asked (Salkind, 2010). I also prioritized short scales, which were easy to use, to avoid survey fatigue among participants, and reduce the risk of incomplete responses.

HL was measured with a scale, recently validated on a Norwegian population (Finbraten et al., 2017; Finbraten et al., 2018; Finbråten, 2018; Finbråten, Guttersrud, & Nordström, 2018). Nevertheless, there may be aspects of HL that are not captured by the scale, including online HL, or e-HL. E-HL is gaining interest among researchers interested in HL, primarily because so much health information is online, and participation in modern society presupposes online understanding, knowledge, and competencies (H. Kim & Xie, 2017).

HL was treated as a continuous variable. I do not know whether the intervals between values were equal, and consequently, the variable should be considered to be ordinal. However, the residuals for HL were normally distributed, and for that reason, I treated HL as a continuous variable in the regression analysis.

When the online survey was first live, the second item in HLS-N-Q12 was omitted by mistake, which resulted in missing values for this item for the first 97 online participants. The pattern of how each participant answered the items on the HLS-N-Q12 usually demonstrated little variance; most participants answered all such items with the same one or two numbers on the 6-point Likert scale. Consequently, I imputed the missing values by taking the mean for the available HLS-N-Q12 items for each individual respondent. This technique is considered to be the best way of estimating missing values when researchers do not have enough prior knowledge to make predictions of the missing values (Cokluk & Kayri, 2011). Due to that pattern of low within-respondent variation, I suspect that the imputed values do not deviate much from what would have been their actual answers. However, there is uncertainty attached to the use of imputed values that makes the data less reliable than if participants' actual answers had been collected. As an additional precaution, we discussed alternative imputation methods with other researchers and statisticians.

On the survey, I added three items concerning the concept of CHC. However, in retrospect, with the knowledge that I accumulated through the process, I acknowledge that those items did not add valuable information in any statistically reliable way, which is why these items are not mentioned earlier in this thesis.

Carer burden was measured with the RSS, one of several scales that aim to measure the concept. While used in a number of studies in Norway, the RSS has not been frequently used internationally, nor is it well-validated. Although carer burden is a heterogeneous concept that encapsulates subjective and objective elements, the RSS measures only the subjective ones (L. George & Gwyther, 1986; Ulstein, Wyller, et al., 2007). In one study, the RSS was validated to measure carer burden in terms of emotional and social distress, as well as negative feelings (Ulstein, Bruun, et al., 2007). The RSS does not capture all aspects of carer burden; however, based on research on the validity of the RSS with caregivers of people living with dementia in Norway (Ulstein, Bruun, et al., 2007; Ulstein, Wyller, et al., 2007), I found carer burden measured with RSS to be a useful measure, even though it captures only a subset of what constitutes total carer burden.

The EQ-5D-5L is considered to have high reliability for measuring HRQoL. The use of the EQ-5D-5L instrument has shown good responsiveness, good validity, and short completion time (Hounsome, Orrell, & Edwards, 2011), even among older adults (Haywood et al., 2005). On basis of a literature review and expert consensus, EQ-5D is suggested as a one of the suitable generic instruments to measure HRQoL among family carers of older people living with dementia (Moniz-Cook et al., 2008). Instruments commonly used to measure the concepts of carer burden and HRQoL often have overlapping domains (Deeken et al., 2003). I considered using the dementia specific questionnaire CarerQol-7D for measuring QoL (Brouwer, van Exel, van Gorp, & Redekop, 2006). This instrument is translated into Norwegian. The reason I decided not to use the instrument, was that the CarerQol asked several questions which were overlapping with those in the RSS questionnaire. For these reasons, I considered the EQ-5D-5L to be a better fit for use among family carers of older people living with dementia to measure HRQoL in conjunction with RSS. The two variables derived from the EQ-5D-5L instrument, EQvalue and EQvas, measure slightly different aspects of HRQoL. While the EQvalue describes the average value of a sample for each combination of the five descriptive dimensions (e.g. mobility=1, self-care = 2. usual activities=1. pain/discomfort=3, anxiety/depression=4), EQvas indicates how participants assess their current health on a single scale. The two measures are not intended to be combined to one HRQoL-scale, so the two values need to be assessed as two independently measures of HRQoL which measure slightly different aspect. It is a known methodological issue that the EQvas seems to face a ceiling effect, and it is suggested in research that the general well-being may cause EQvas to be high despite lower scores on the EQvalue. It is also argued that EQvas measures a broader underlying construct of health that summarizes health in a way closer to people's perspectives (Feng, Parkin, & Devlin, 2014), or that EQvas may capture aspects of peoples' HRQoL which is not captured by the EQvalue (Murasawa et al., 2020).

The Time variable was measured with questions informed by items from the RUD questionnaire, although items were modified to capture findings from Substudy 1. The RUD questionnaire has been found to be a valid and reliable measure for assessing time spent on informal care when compared to actual observation (Wimo & Nordberg, 2007) and for use with people living with dementia in community-based care settings (Wimo et al., 2010).

However, the number of missing values indicates that this question was difficult for participants to answer. Consequently this may represent a methodological limitation. Even though imputation is used extensively in the research literature (Mackinnon, 2010), missing values in our dataset may have reduced the validity of this variable and of the results.

To handle missing values, I chose to use imputation (mean value when appropriate, otherwise with zero (See section 4.4.5) in order to reduce the risk of Type II errors in a small sample. A complete case analysis (CCA) would have reduced power substantially (Mackinnon, 2010) and imputation of mean for all missing values would most likely be an overestimation; it seems likely that carers who did not spend time on a task may have skipped it, meaning that the missing responses likely would not equal the mean of the observed responses. By imputing zero instead of mean values when both values in a task cluster was missing, I have decreased the risk of false positive answers in the regression analysis, while maintaining the statistical power in the analysis. Also, we know that our Time variable is most likely underestimated rather than overestimated. The underestimation of the Time increased the risk of false negative results (Mackinnon, 2010), but it reduced the threat to the reliability of the positive findings.

The Time variable was by far the item with most missing values. I considered it likely that some of these family carers were not spending much time on the described carer tasks. The inclusion criteria opened for people to take part even if they lived far away, or were not involved in many care tasks on a regular basis. For this reason, and because it allowed us to be certain that the variable was underestimated rather than overestimated, I used the value zero for imputation when both values (hours and days) were missing on a task.

When the participant had indicated only one of the two values (hours per day or days per month) for a task, I used imputation of mean value for the task in the sample. The reason was that when one of the two values was scored, this indicated that some time was spent by the family carer on that task, and imputing zero would not reflect this. I therefore applied predicted imputation (Cokluk & Kayri, 2011), based on mean scores for the corresponding items in the remainder of the sample.

Sensitivity analyses were conducted on the Time variable to investigate whether the association between Time and HL changed if I imputed with only the value zero instead of a combination of zero and mean, as described earlier. This showed that higher level of HL remained statistically significantly associated with less time spent on informal care (B -0.33

with 95% CI: -0.07, 0.000, p=0.049). We also tested whether results changed significantly if we excluded the 5 participants who had indicated >720 hours in the last 30 days: they did not. HL was still statistically significantly associated with Time (B -0.29 with 95% CI: -0.06, 0.000, p=0.049).

In the process of publishing Paper III, one of the reviewers commented that the analysis of time spent on care should have been adjusted to whether the participant was caring for someone who lived in an institution. We therefore conducted a sensitivity analysis using independent sample T-test to investigate differences of mean between the group of family carers who cared for a person living in nursing home (mean 3.6 hours, SD 2.3) compared to the remainder of the sample (mean 3.2 hours, SD 2.6). There were no statistically significant differences in time spent between these groups (p = 0.31). Furthermore, the correlation analysis conducted to prepare the regression analyses found only a weak correlation between the time variable and caring for a person living in a nursing home (Pearson's R = -0.14, p=0.051).

The BDS was used to distinguish participants who cared for people living with mild versus severe dementia. While the BDS was developed for that purpose (Berger, 1980), it has not been extensively validated. As many older adults suffer multi-morbidity (Ofori-Asenso et al., 2019), a decline in functioning could stem from other diseases than the dementia, and this could be picked up by the BDS, despite the effort to make BDS dementia specific. Some participants might therefore have been incorrectly categorized if compared to a full medical assessment. I do not know to what extent the severity categories from BDS would be consistent with a medical evaluation of dementia severity. I consider the validity of the BDS to be uncertain, and potentially limited. However, it was the best option available within the legal, ethical, and practical limits of the study.

I wanted to be able to adjust for the effect of not being born in Norway, and used the variable of carer born abroad, which I assumed would identify those who did not speak Norwegian as their first language, and perhaps were not as familiar with the Norwegian culture and healthcare traditions as other carers. One participant wrote to me and explained that she answered affirmatively to this question because she was born in Sweden, albeit to two Norwegian parents and she had lived in Norway since she was 2 years old. This shows the question might have failed to capture what it was intended to.

Regarding the variable of having worked as health personnel at any point, it might have been that the simple yes-or-no question was not sufficiently specific or sensitive to reveal differences between groups. For example, the question did not discriminate between having worked as health personnel for shorter or longer periods or what type of work it involved. Thus, the term *health personnel* could have been better defined for the variable to serve its intended function.

By making the survey available in print and online versions, I utilized two data collection methods in order to increase the response rate. This assumption is supported by Yun and Trumbo (2000) who found in their literature review that respondents may prefer one type of questionnaire (such as paper print or online versions) more than another, and that response rates may increase if methods are combined (Converse, Wolfe, Huang, & Oswald, 2008; Fincham, 2008). However, I do not have information on how many family carers were presented with either option, let alone the choice between the two. Because distribution of questionnaires was made primarily through healthcare personnel, it was also important that the distribution was convenient in their daily work. If the distribution method was perceived as demanding, I would expect healthcare personnel not to prioritize it within a busy work schedule, which would also lead to low number of respondents. They were for that reason asked to distribute paper prints and/or online versions, depending on what was most convenient, and depending on their assessment of what was most likely to generate participating family carers. The low number of responses and the non-probability sampling method constitute methodological weaknesses that decrease the validity of the study, because we have little information on how the characteristics of carers in the sample were skewed. Consequently, results should be interpreted with care, and there may be call for investigation of the issues raised here in more representative samples of family carers to older people living with dementia.

A high level of HL may make it less demanding to answer a questionnaire about HL. The use of a nonprobability-based method of data collection combined with voluntary participation and the use of a self-administered survey seemed to have made the sample over-representative of family carers with high levels of HL and education. This is one of the characteristics of the sample which I have considered when interpreting the data, and I have discussed this skewness in relation to the relevance and generalizability of results.

6.2.3 Considerations of the quantitative analysis

In light of the number of distributed printed surveys to health personnel, and the number of clicks registered on electronical links, the number of respondents in Substudy 2 was low (even though we do not know the exact rate), but approximately as expected.

Nevertheless, a strength of the study is that it is, to my knowledge, the first test for associations between HL as the dependent variables in a sample of family carers for older people living with dementia. Research is about building accumulatively on previous work, and I do consider my findings, based on an explorative design, to introduce hypothesis for further investigation, such as testing associations in a representative samples of family carers to older people living with dementia to confirm or reject my results.

The linear relationships between HL and the outcome variables were weak, and in multiple linear regressions, the low R^2 values confirmed that that the models were weak as well. HL explained only a fraction of the effect on the outcome variables, meaning that most of the in carer burden, HRQoL, and time spent on informal care remains unexplained.

It is common in the social sciences to yield low R^2 values, because a wide range of factors typically affect the variables in question, and thus there is usually not a very strong linear relationship between concepts. The rationale behind the regression analysis performed for this thesis was *not* to identify the main predictors of carer burden, HRQoL, or time spent on informal care, but to gauge whether there was a reliable relationship between HL and the outcome variables. The R^2 values indicated that little of the variation in HL was explained by the models, meaning that HL was a small part of the explanation for CB, HRQoL, and time spent on informal care. However, a low R^2 value does not change the fact that significant findings can be reliable and valid, meaning that higher HL appears to be associated with lower CB, higher HRQoL, and less time spent on informal care tasks. Given that the measures were reliable and valid, the statistically significant findings remain reliable and valid; indicating a linear relationship between the variables (Lewis-Beck et al., 2003).

Among the exploratory independent variables used in the multiple linear regression analysis, several were statistically significant, meaning that they were important to include in the model because they affected the outcome variables.

6.3 Methodological considerations: Mixed-methods study

The strength of my exploratory sequential mixed-method design was that Substudy 1 provided rich, complex data, which enabled me to generate assumptions which could be tested in Substudy 2 (Schoonenboom & Johnson, 2017; Wisdom, Cavaleri, Onwuegbuzie, & Green, 2012).

To assess the quality of a mixed-methods study, it is necessary to assess the validity and reliability of each method (Wisdom et al., 2012), as I have reported in the previous sections. If validity or reliability is threatened in any of the methods, then it is also threatened in the overall mixed-methods design.

Validity may also be threatened in mixed methods by an uneven emphasis upon the different methods, including if quantitative results are not used with any consideration of the nuances, variety, and complexity of the qualitative ones (Creswell, 2014). Chapter 4.2 elaborates how Substudy 1 indeed informed Substudy 2, facilitating valid findings of the mixed method. In Chapter 7, I discuss the results from both studies in the context of each other (Schoonenboom & Johnson, 2017).

Using qualitative, quantitative, and mixed methods in one doctoral study, demand skills in using and balancing three methodologies. The timeframe of my research project made it challenging to sufficiently master all three. Given the limited time available to execute the doctoral project, designing Substudy 2 began before all analyses in Substudy 1 had been completed. With more time available, the final design could have benefitted from my increased understanding of quantitative methods, and I might have made small adjustments to improve Substudy 2 as a result.

7 Discussions of study results

This study has focused on family carers’ experiences with health services and their perspectives regarding care provision to older people living with dementia. In this chapter, I will discuss the findings from all three papers in relation to each other. First, I discuss the results related to family carers’ position in care provision. Second, I discuss interactions and communicative challenges. Third, I discuss findings related to family carers’ personal costs and resources. Fourth, I suggest how this might relate to inequality in access to healthcare. Fifth, I discuss the role of health literacy. Finally, I discuss the findings related to quality in healthcare more generally, and use the findings in this study to point out areas for future research before I set out some overall conclusions.

7.1 Family carers’ position in care provision to older people living with dementia

I have shown how family carers are often placed in a position of multiple, and sometimes conflicting, demands and responsibilities, and that they hold different views and values. The way the carers described themselves as being a “hub in the wheel” in terms of being a messenger, coordinator, or tailor of the overall care, illustrates this. Consequently it mirrors care provision as it is facilitated by formal care through health services. Family carers were also often the ones communicating and interacting with health personnel on behalf of the care recipient, trying to adjust health services to the individual needs, or compensate for services not targeted to the needs. Although family carers are recognized as important contributors to care for older people living with dementia, and are recognized as such in the policy documents of many countries, their right to information and be parts of decision are often ambiguous. In Norway, this especially applies when the care recipient is competent to give consent (Tønnesen & Kassah, 2017). In our study, few carers were caring for a person who was not competent to give consent, but most family carers expressed that their care-recipient was more or less dependent on them to assist with daily activities, prevent physical, emotional, relational, or economic harm, and to tailor care provision to individual needs. Family carers and health personnel usually interacted and communicated about care and care needs in a blurry area between ethical and legal rights and demands.

Two areas in which differences between family carers and health personnel emerged regarding care provision were in relation to person-centeredness; and in relation to the overview across multiple health services and across formal and informal care. To tailor the overall care provision in a way that ensures good information flow and appropriate use of formal and informal resources were important for most participants. Family carers pointed out that they were often the only one with the total overview across services and beyond the scope of established health services. Most participants were involved in providing safe and person-centered care, from a holistic view, with the care recipient and themselves in the center, and several family carers spent extensive time and energy informing services, communicating care needs, and contributing to improving the care provided by health services. Most family carers in this study expressed that they had a good overview of both the care needs of the person living with dementia and the services involved in their care. Many described themselves as being the only ones with the necessary overview. Some family carers expressed a wish for someone else to have this overview.

The European Network of National Human Rights Institutions (ENNHRI) emphasizes that there is a failure by many governments to protect and promote informal carers' human rights, and highlights family carers right to health, right to private and family life, right to work, and right to participation, to mention some (European Network of National Human Rights Institutions, 2020). The failure of governments to protect and support family carers in these areas may be even greater in low-income countries, and in countries without less comprehensive welfare systems than we have in Norway. Still, there are examples in my project showing that family carers did retire from paid work earlier than planned or reduced work because of their carer responsibilities. It is also, as explained earlier, well known that family carers are at risk of reduced health. These examples are reminders that there remains potential for improvement in care provision to older people living with dementia, including how to prevent exploitation of family carers, and rather support family carers as long-term resources in care provision.

7.2 Interaction and communication challenges between formal and informal carers

While formal health services are required to provide health services to people who have care needs (Patient and user's act, 2020), family carers are not required to do so (Ministry of Health and Care Services, 2013 p. 59). Differences in legal responsibilities, values (such as which need to prioritize), and differences in perspective between family carers and health personnel contributed to difficulties in communication and interaction with health personnel for many participants. Several expressed that their contribution, insight, and expertise in the specific situation of the person living with dementia were inadequately recognized or made use of. Communication barriers between family carers and health personnel are described in earlier international research (Mullins et al., 2016; Reid & Chappell, 2017), and in Norway (Nordhagen & Sörlie, 2016). Differences in values, beliefs, and language have been found to complicate interactions between family carers and health personnel. Some studies have found that this might particularly be the case for people born outside of Norway (Sagbakken et al., 2017) and between non-Sami health personnel and the Sami population (Blix & Hamran, 2017; Ness, Söderberg, & Hellzèn, 2019). Schulz and Martire (2004) point out that while there are guidelines to assist health personnel in the communication with family carers, these are often not applied. They also point to health personnel's responsibility to facilitate communication and partnerships with family carers. Caswell, Pollock, Harwood, and Porock (2015) found in a study about end-of-life care in acute hospital settings that there are individual differences regarding how health personnel are able to include and communicate with family carers. Similar findings are reported from a study of homecare services in Norway (Nordhagen & Sörlie, 2016). Peoples' expectations of health services, the resources available in these services, and the differences in scope and priority between organizations, government, and specific services, are conditions that are typically difficult to unite (Vike, Bakken, Brinchmann, Haukelien, & Kroken, 2002), and can influence interactions between family carers and health personnel, and consequently affect how healthcare is provided.

Our study is not the first to point out that services can be poorly targeted to the needs of older persons living with dementia as perceived by their family carer (Ceci, Symonds Brown, & Purkis, 2018; Granbo et al., 2019; Tretteteig & Thorsen, 2019). In Paper I, we found that family carers contributed to fulfilling care needs and preventing harm, but their contribution could unintentionally conceal care needs and thereby potentially lead to a continuation of poorly targeted services. This may lead to further increased risks of harm, more use of protective practices, and so on. Unintentionally, therefore, in situations of suboptimal communication, the potential concealment of needs could result from family carers' contribution to preventing harm, despite family carers' and health personnel's intentions to prevent this.

To better understand how family carers responded to such interactions and illuminate why care needs sometimes became invisible despite family carers' efforts to communicate them to health personnel, I investigated what family carers said they did when they experienced insufficient care. By doing so, I identified two involvement strategies, as presented in Paper II. I found that some family carers expressed that they occasionally needed to use assertive approaches, which added leverage to their arguments. However, such approaches could come at cost to their working relationship as partners in care, which was why they usually preferred the supportive and complementing strategy. In some cases, family carers avoided the assertive strategy, and preferred to accept the personal costs of the complementary strategy – taking on the sometimes demanding role of the hub in the wheel. In contrast to previous research about internal coping strategies (Hawken et al., 2018) in response to substandard care provision, paper II was seeking to describe and interpret what actions carers said they took in response to suboptimal care to involve themselves and contribute to care provision.

The carers described different experiences and approaches to communication and involvement in care provision, which were partly dependent on how they believed their actions were interpreted by health personnel. The perception that information disappeared between work-shifts or between services reflects findings in earlier studies (Nordhagen & Sörlie, 2016). Some family carers used the assertive strategy, in which they employed various resources to add leverage to their arguments or positions, and chose approaches such as deliberately keeping health personnel on the alert, to ensure quality standards were met. Such assertive action may reflect the portrayal of *the difficult family carer*, as described in the literature. This entails a family carer who is typically engaged in the care, and may have reasonable and appropriate questions and requests, but are perceived by health professionals to act inappropriately, intimidating, or threatening towards health personnel (Bourdreaux, 2010). As Bourdreaux (2010) points out, many family carers may be valuable assets to the care team if they are listened to, and their fears are addressed. The findings in our study support those of Bourdreaux (2010) that many of the family carers' requests may be reasonable and appropriate, even when presented in an assertive manner.

7.3 The potential for differences in personal costs and personal resources to affect care provision

Different involvement strategies appeared together with deliberations over associated costs and benefits, and differences in people's repertoire of available personal resources contributed to the perspective of inequalities and discrepancies in healthcare and access to health services on behalf of their care recipient.

The use of the strategy of "the hub in the wheel", along with many other tasks participants described, meant family carers spent considerable time on informal care. Time spent on informal care, and other factors such as reduced quality of life, can be seen as constituting personal costs of being a family carer, often conceptualized as "carer burden" (Abdollahpour, Nedjat, Salimi, Noroozian, & Majdzadeh, 2015). A study from Australia found that caregivers worried about harm and accidents (Dow, Meyer, Moore, & Hill, 2013). They also found that carer burden increased in perceived risky situations, while quality of life decreased (Dow et al., 2013). This resonates with the four preventive practices described in Paper I, and suggests that constant worry over potential or actual physical, emotional, economic, and relational harm can contribute to increased carer burden, in this context understood as a personal cost for family carers. Some also suggested that health services, while usually considered valuable, could also add responsibilities, worries, or stress; such as when the family carer considered services not being sensitive enough to individual needs, and they needed to leverage their arguments despite additional personal costs. As such, inadequate services and challenging communication and interaction with health personnel may add to the carer burden. As shown in Paper II, additional potential costs are also associated with family carers' interactions with health services and consequently affecting experienced quality of care.

Findings indicated that carers weighed potential costs against benefits when choosing approaches to involve themselves in the care provision. Such differences in personal costs or outcomes are also described in other studies (Janssen et al., 2018; Kerpershoek et al., 2016). The narratives from the family carers in this Ph.D. project seemed to display varying abilities, knowledge, expectations, motivations, social skills, or social support. These aspects can be seen as constituting valuable personal resources for navigating between concerns, needs, costs and benefits, and for tailoring formal and informal care provision.

7.4 Potential implications of study findings for equality in healthcare

Inequalities in healthcare is a considerable concern (Watson, Giebel, Green, Darlington-Pollock, & Akpan, 2020), and several theoretical concepts have aimed to explain the role of personal resources in creating or maintaining such inequalities. These include social capital (Bhandari & Yasunobu, 2009), cultural capital (Bourdieu, 1986), and the broader concept of cultural health capital (Dubbin, Chang, & Shim, 2013; Shim, 2010; Shim, Chang, & Dubbin, 2011). While Bourdieu's concept of cultural capital is well known, and useful to explain how personal knowledge, expertise, or skills are accumulated and utilized in social contexts (Bourdieu, 1986), the theoretical concept of cultural health capital takes the concept specifically into the healthcare context. The concepts are useful tools to understand mechanisms that might be underlying differences in care provision and access to services.

Shim (2010) suggests that knowledge of medical topics and vocabulary, knowledge of what information is relevant to health personnel, and skills to communicate health-related information in a medically intelligible and efficient manner, are all examples of what is called Cultural Health Capital. The concept of cultural health capital might offer a perspective to illuminate how differences in personal resources operate in the interaction between healthcare providers and healthcare receivers (or family carers) (Shim, 2010) and how these differences may lead to, or mitigate inequalities in healthcare. Applied to the context of our study, the receivers of services are family carers, because family carers are often the ones communicating and interacting with health personnel and accessing health services on behalf of older people living with dementia.

The concept of CHC focuses on the two-way interaction. It is not solely the personal resources of the family carers that play a role, but also the actions and reactions of health personnel. The two-way interaction between health personnel and family carers is emphasized, as the use of cultural health capital provides a presentation of the family carers' personal resources, which may prompt health personnel to react differently. This may consequently lead to differences in care provision and access to services (Dubbin et al., 2013; Shim, 2010). Individual differences among health personnel, as well as organizational, or structural differences in the healthcare contexts are framing the interactions, and may facilitate or compromise good interactions and strong partnerships between health personnel and family carers.

The model of the potential negative feedback loop (presented in Paper I) indicated that some aspects of care are occasionally misunderstood, unintentionally concealed, or perceived differently between family carers and health personnel. This two-way perspective of how personal resources interfere with access to health services is a valuable lens to interpret the findings. The differences in how similar situations are perceived and responded to can be explained by differences in particular repertoires of cultural skills, verbal and nonverbal competencies, and interactional styles (Shim, 2010), and might be used to illuminate dynamics and interactions that contribute to differences in care provision and access to services.

Underpinning my interpretation of family carers' interaction with health personnel as related to personal resources is an acknowledgment of social differences in healthcare access (Levy & Janke, 2016), and the need to better support family carers, who often experience extensive carer burdens. The interpretation is underpinned by what is sometimes referred to as consumerism – the idea of a shift of power in the direction of more power to the users of public services (Jung, 2010). Patient empowerment has also assumed a prominent place in healthcare (P. J. Schulz & Nakamoto, 2013), and empowerment in health can be understood as *a process through which people gain greater control over decisions and actions affecting their health* (World Health Organization, 1998 p. 16). According to R. Schulz and Martire (2004), patient (and family carer) empowerment is based on three appeals: individuals' right to be involved in decision-making regarding their own health, the responsibility for one's own healthcare, and empowerment is advocated as improving health outcomes. Extrapolated to the family carer on behalf of their care recipient, these appeals apply both in terms of the carer's right to involvement; and family carers' responsibility for care recipient's health and healthcare. Following these concepts, the role of health personnel needs to develop further to facilitate individuals' ability to manage of health. In 2019 the Norwegian government launched a plan for improving HL in the Norwegian population (Ministry of Health and Care Services (Helse- og omsorgsdepartementet), 2019). This can be considered a first step, by policy, to facilitate a stronger focus on HL in Norway. Anchored in this plan, health personnel may integrate knowledge and awareness of differences in personal resources, such as HL, when developing health services to older persons living with dementia, and seek to improve quality of services by adjusting services to individual needs. Of course, in this context, HL of family carers must be considered together with HL of care recipients, when concerned with differences in available personal resources.

7.5 Health literacy as a measure of personal resources

As just discussed, personal resources, such as cultural health capital, cultural capital, and social capital may all be important for how family carers navigate the health care system. Due to lack of suitable tools for measuring these concepts quantitatively, we used the concept of HL.

HL refers to a person's capacity to obtain, process, and act on information about health and healthcare systems (Finbråten, 2018; Sørensen et al., 2012). Unlike the focus on the interaction in the concept of cultural health capital, HL focuses on individual abilities, such as the persons' motivation, knowledge, and competency (Sørensen et al., 2012). Statistical associations between personal recourses and personal costs for family carers of older people living with dementia are underexplored before our study, with the exception of associations with quality of life (Demir Barutcu, 2019; Zheng et al., 2018). In Paper III, we investigated the level of HL among family carers of older persons living with dementia, and found that the level was higher than in previous studies, such as in a population of people living with diabetes in Norway (Finbråten et al., 2020). I also tested our assumption that HL could predict family carers' personal costs, and found that HL was a significant predictor of carer burden and time spent on informal care. HL was also a significant predictor of one of the two measures for health-related quality of life.

Although HL is used as a measure of personal resources in this study, Schulz and Martire (2004) point out that HL needs to be considered in conjunction with people's confidence in their ability to assess and use health information in a constructive way. High HL combined with high self-confidence can be beneficial, while low HL in combination with high self-confidence can be disadvantageous. These perspectives should be investigated further in future research to gain a better understanding how health services may support family carers in their role in order to improve care provision.

According to Batterham et al. (2016), a degree of HL is required for interacting with health providers and participating in health decision-making, but the concept also focuses on the individual’s abilities to manage these interactions. In our study, there is a sample of family carers with a higher median value of HL than in other studies, which suggests that the sample participants wield above-average personal resources. Our assumptions that HL was associated with the outcome variables (carer burden, health-related quality of life, and time spent on informal care) were confirmed in three of the four multiple linear regression models. Despite this association and the high levels of HL in our sample, the levels of carer burden were higher than in a previous study on family carers of persons living with dementia in Norway, and time spent on informal care differed slightly from my findings (Ulstein, Bruun, et al., 2007). The estimate of time spent on informal care was slightly higher in my study than in the study by Ulstein, Bruun, et al. (2007), but as previously mentioned, my estimates of the time spent on informal care must be understood as an expression of objective carer burden rather than the absolute time spent on care. In a Swedish study, the time spent on informal care greatly exceeded the time spent on informal care in our study (Wimo et al., 2002). However, the way informal care is measured differs between studies, but the measurement of time spent on informal care is becoming a part of health economic evaluations and is acknowledged as a considerable part of the total care (Grosse et al., 2019). The level of health-related quality of life in our study was significantly lower than in the Norwegian norm data retrieved from Stavem, Augestad, Kristiansen, and Rand (2018). This indicates that even among a sample of family carers with high levels of personal resources, being a family carer is associated with negative influence on their HRQoL.

In line with these perspectives and based on the findings in Paper III, there might be reason to believe that initiatives that contribute to increasing family carers’ HL could combat some negative outcomes of family caregiving, such as carer burden, reduced quality of life, extensive time spent on informal care, and the potential effect of inequality of access to health services for older people living with dementia (Levy &

Janke, 2016). However, HL is only one of several predictors for family carers' outcomes, and not one of the main predictors.

In this era of being informed users of health services, having responsibility for own health choices, and increased responsibility placed on family carers, health personnel should perhaps focus on facilitating good care through increasing the health literacy of family carers as one of several measures to support family carers. Health services and health personnel also need to adjust to differences in HL and other personal resources when interacting with, and supporting family carers in providing care. Family carers' initiatives to involve and engage in care provision should be seen as potential resources, rather than a sign of being a "difficult carer". Studies have found that the level of HL can improve from theoretically and/or practically traning (Cianfrocca et al., 2018; Jiang, Sereika, Lingler, Tamres, & Erlen, 2018; Nutbeam, 2000) and consequently I have interpreted the results of this Ph.D. project in the direction that increasing of HL is one potential way of improving care provision, and supporting family carers to older people living with dementia. As HL may be taught and trained (Nutbeam et al., 2017), it may be possible to provide family carers with the skills to better align formal and informal care, increase self-efficacy, and help them maintain a level of care that is sustainable for a longer duration of time. This could serve multiple purposes: to improve the position of family carers, to improve care provision to older people living with dementia, and to reduce inequities in access to care.

7.6 The potential role of partnerships in improving quality in healthcare

The role of family carers is described in international and Norwegian health policy documents as a means to enhance quality of care, utilize potential care resources, and provide care tailored to individual needs. It is envisaged to help achieve the political goals of community-based care and postponement of institutionalization (Ministry of Health and Care Services (Helse- og omsorgsdepartementet), 2018; WHO, 2018). Norwegian and international policies have pointed out the need for stronger partnerships between formal care and family care to maintain current standards of care (Ministry of Health and Care Services (Helse- og omsorgsdepartementet), 2008, 2013; Pettersen, 2018; WHO, 2017b). If these policies are to be realistic, however, we need to better understand family carers perceives, how they carry out their role, and how they contribute to care within, between, and beyond services. Health personnel and health policy need to ensure complementarity of formal and informal care.

This study has shown how family carers discussed the way in which they prevented harm and sought to contribute to safer care for the care recipient. The perspective from the preventive practices, the four areas of protective practices, and the potential negative feedback loop are novel additions to the literature on patient safety in the community, as it provides awareness about potential harm and risks of harm that are not acknowledged and consequently illuminate how health services may improve their care provision.

Safety is one of six constituent parts of *quality in healthcare*, along with effectiveness, patient-centeredness, timely help, efficient use of resources, and equitable care (Institute of Medicine (US) Committee on Quality of Health Care in America, 2001). Many participants sought to improve services, or found that they needed to contribute to ensure patient safety. They did so by filling care gaps, sharing information between services, maintaining an overview, speeding up processes between and across different services, and preventing different types of harm to the person living with dementia.

Family carers have the potential to play a role on the improvement of quality of care beyond the safety aspect. As they connect services, they contribute to the efficient use of resources, and by contributing with information about the care recipient or rectifying incomplete information flow, they facilitate person-centered care (patient-centeredness) and information flow between services. They also often took on tasks that fell outside the scope of health services, but which they considered to be additional care needs. By pinpointing what they perceived as insufficient services, failure of services to meet needs, or difficulties accessing services, family carers provided clues about how to improve the quality of services.

Modern healthcare has developed towards an approach where patients are expected to take more responsibility for their own health. Information is available and accessible through the internet and databases, and patients and families are invited to take part in decisions (Mariani et al., 2017). While this sharing of knowledge and decisions gives individuals more control over their lives, it also gives with more responsibility (P. J. Schulz & Nakamoto, 2013). Moreover, it means people’s ability to orient themselves in the health field might be decisive to the services they access on behalf of themselves or others, and their communication with health professionals. This may be seen as a threat to equitable care, and health service providers who want to increase quality of care need to take this into consideration. Different people may need to be treated differently in order to have the same access to services. Consequently, differences in personal resources should be considered when aiming to provide high-quality services to people with various prerequisites to access services and different abilities to argue for their rights. HL is one of the concepts that can be used to facilitate better quality of care because it is associated with access to, and use of, health services (Levy & Janke, 2016; Sudore et al., 2006) and has, in former studies, shown that interventions might increase family carers' health literacy (S.-C. Lin et al., 2019).

Family carers identified several areas where quality of care has the potential to improve. They also talked about how they sought to influence or involve themselves in the safety and quality of care in general. Several carers expressed that they lacked someone other than themselves who had an overview and ability to coordinate care that met all needs, which leads us back to the benefits of improved partnerships between formal and informal care.

From the interviews, I have shown how health services given to the care recipient may give release to some carer burdens, but add others. Examples of added carer burdens are the time-consuming role of being the hub in the wheel, or the cost (in terms of increased negative feelings) related to fear of being unpopular when adding leverage to their arguments, as described in our two involvement strategies. Through improved communication and stronger partnerships between family carers and health personnel, the resources of both could be better utilized.

7.7 Areas for future research

Some participants in this study have expressed the need for someone else than themselves to coordinate and organize the care across services, and their experiences have indicated a lack of continuity between services. Better integrated care models with a systematic approach to ensure information flow between services should be of interest for future studies. The perspectives of family carers can help us gain an overall view of individuals' care needs and service use, and facilitate more efficient use of resources and timely help, along with individual knowledge about care needs and risks of harm. Better integration of formal and informal care may also facilitate more person-centered and effective care. These perspectives from family carers may complement or guide the provision of formal healthcare to older people living with dementia, and improve quality of services. Models for partnerships in care between family carers and health personnel should be tested in intervention studies to facilitate stronger and more transparent partnerships, and studies should investigate how partnerships in care can be operationalized. It is necessary to take into account that family carers have different personal resources and experience personal costs in different ways. The way in which these differences impact inequalities in healthcare access for older persons living with dementia needs further investigation. Also, future studies should aim to develop and test interventions among health personnel with the objective of enabling health personnel to acknowledge and make use of involvement by family carers

This study has given a clear indication that communication issues and high carer burden remain frequent among informal caregivers for older persons living with dementia. Efforts have been made to understand how society or health services can better support family carers to avoid negative outcomes for family carers (Ceci et al., 2018; Lilly, Robinson, Holtzman, & Bottorff, 2012; Roberts & Struckmeyer, 2018). Health literacy is identified as one area where differences may affect access to services, but the net effect of formal services (to the person living with dementia) on the perceived carer burden for the family carer seems not evident, and this relationship could benefit from more research.

Little is known about how patient safety is practiced in a community care setting (Morrisby, Joosten, & Ciccarelli, 2018; Panesar et al., 2016; Tudor et al., 2017), and even less is known about the role of family carers. There is a paucity of research from the perspective of family carers regarding what constitutes a risk of harm to persons living with dementia and how family carers contribute to addressing and preventing these risks (Jennings et al., 2017; Panesar et al., 2016; Tudor et al., 2017). Given the increased role of carers in health service delivery, this lack of knowledge is a concern, not least because family carers, care recipients, and health professionals may have different perspectives on these issues, and stronger partnerships are needed to increase safety and quality of care in general.

HL should be further investigated as a personal resource to reduce negative outcomes among family carers, and interventions to increase HL among family carers of older people living with dementia should be tested. Unlike the broader concept of cultural health capital, HL measures only an individual set of capabilities, skills or motivation. The broader concept of cultural health capital emphasizes the two-way dynamic in the interaction between healthcare providers and healthcare consumers, and the development of tools to measure this would have the potential to add useful perspectives that could complement studies of HL (Shim, 2010). The concept of cultural health capital might be a useful lens for future research to explore differences in personal resources. A tool to measure cultural health capital quantitatively could also be a valuable addition to the field.

7.8 Conclusion

In this Ph.D. project, I have investigated family carers' perspectives on care provision to older people living with dementia, with the purpose to use their experiences to understand how health services can improve their services and better facilitate high quality care provision to older people living with dementia. I have described family carers experiences and interpreted family carers' perspectives on how they prevent different forms of harm to older people living with dementia while receiving community-based services, and how family carers' efforts to alleviate risks might affect and interact with health professionals' activities. I have then interpreted these findings to illuminate how health services can improve care provision through a better understanding of and alignment with informal care provided by family carers.

This study has shown that family carers play an important and complementary role in the provision of care to older persons living with dementia, and that their perspectives on care provision are valuable contributions to improve care provision to this population group. It has shown that while many carers endeavor to be involved in the care provision, many also struggle with communication and interaction with health personnel. Differences in perspectives, values, or family practices sometimes led to different responses to care needs, and various involvement approaches were commonly used to influence on health services. Most commonly, family carers used a supportive and complementary involvement strategy to influence health services, but for some, this involvement strategy did not lead to what they perceived as sufficient care.

Some study participants perceived that it was difficult to be involved in care provision and access what they perceived to be adequate care on behalf of the person living with dementia.

Differences in personal resources among family carers and their repertoire of personal resources, such as HL, social capital, cultural capital, or cultural health capital, may play a role in the access to services and in how care needs are understood, communicated, and advocated. Differences also seemed to be present regarding personal costs, such as carer burden, quality of life, time spent on care, social relationship or negative emotions. Although the concept of HL does not capture all aspects of personal resources, this study indicates an association between the level of HL and the level of personal costs when measured as carer burden, HRQoL, and time spent on informal care among family carers of older people living with dementia.

By integrating the perspectives of family carers with the perspective of health personnel, family carers' involvement in, and contribution to care provision may facilitate better utilization of resources and contribute to better-targeted health services. By doing so, resources may be used more efficiently, but this presupposes that healthcare planners and policymakers recognize this effect and facilitate partnerships between family carers and health personnel.

There is an urgent need, both nationally and internationally, to better utilize formal and informal resources and improve healthcare quality for older persons living with dementia. To avoid a future situation with seriously underserved areas of healthcare to the older people living with dementia, stronger and more transparent partnerships between health personnel and family carers are needed. Such partnerships must be facilitated from all levels in society – from research, to politics, and to formal and informal healthcare providers.

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Appendix I

Interview guides used in Paper I and Paper II

1. Interview guide, version 1
2. Interview guide, version 2
3. Interview guide, version 3

Versjon 1.0

INNLEDNING		
TEMA	**SPØRSMÅL**	**UNDERPUNKTER**
Hvordan det startet	**Når begynte det?**	• Når kontakt med helsevesenet pga demens?
	Hvordan opplevde du tiden før han/hun fikk en diagnose?	• Utfordringer • Motivasjon/styrke • Kontakt med helsevesenet (praktisk, emosjonelt)
Nettverk av pårørende	**Er det flere pårørende som bistår i omsorgen for XX?**	• Hvem og hvordan? • Hvem tar avgjørelser og hvordan?

BIDRAG TIL OG INTERAKSJON MED HELSETJENESTENE:		
TEMA	**SPØRSMÅL**	**UNDERPUNKTER**
Spekter av tjenester	**Hvilke tjenester mottar dere i forbindelse med demenssykdommen?**	fastlege, dagsenter, hjemmesykepleie, hjemmehjelp, sykehjem, fysioterapeut, fotpleier, frisør, tannlege, ergoterapeut, aktivitetssentra, hjelpemiddelsentral, frivillighetssentral
Utførelse av tjenester	**Kan du fortelle mer om hvordan disse tjenestene)utføres?**	• Eksempler på gode tjenester • Eksempler på tjenester som ikke fungerer. • Kommune + sykehus
Hva helsepersonell snakker om	**Hva snakker helsepersonell med deg om?**	Hvordan merker du om de lytter?
Involvering & Samarbeid	**Hvordan involverer og samarbeider helsepersonell med deg som pårørende?**	• Gi eksempler • Hva er viktig for deg? • Hva er ikke viktig eller ikke ønskelig?
Pårørendes bidrag	**Hvilke erfaringer, kunnskaper eller bidrag opplever du at du har som er nyttig for helsetjenesten til personen med demens?**	• Har du eksempler som viser hvordan du har forsøkt å samarbeide? • Hvordan opplevde du at dine innspill/initiativ ble møtt? • Hva ble resultatet av ditt initiativ/innspill?
Hinder for samarbeid	**Hva tror du er de viktigste hindringene for godt samarbeid med mellom helsepersonell og pårørende?**	Tro du at de som jobber i tjenestene vil være enige med deg?

TJENESTEINTEGRASJON OG KVALITET PÅ TJENESTER		
TEMA	**SPØRSMÅL**	**UNDERPUNKTER**
Møte med helsevesenet	**Kan du fortelle om en god opplevelse dere har hatt i møte med helsevesenet?**	• og en utfordrende
Gode tjenester	**Hva gjør en tjeneste god?**	• Eksempler • Hva er utfordringer? • Oppgaver du ønsker mer hjelp til?
Koordinasjon av tjenester	**Hvordan opplever du at de ulike tjeneste-tilbudene til X samarbeider?**	• Eksempler på gode og dårlige • Kolliderende avtaler? • Eksempler på hvordan det løses? • Hva blir din rolle som pårørende?
Dekker tjenestene behovet	**I hvilken grad dekker disse tjenestene de behovene dere har?**	• Hva dekkes ikke? • Og løses dette? • Hva gjør dette med deg? (praktisk, følelsesmessig, alene, i kontakt med andre)
Unødvendige tjenester	**Får du tilbud om tjenester som du av ulike årsaker ikke ønsker eller ikke kan benytte deg av?**	• Hvordan fungerer disse tjenestene? • Kunne de vært organisert eller gjort annerledes på en måte som gjorde at du ville motta dem? • (kostnad, tilgjengelighet, avstand)
Tips til bedre samarbeid & koordinering	**Utfra dine erfaringer, hva tror du skal til for at samarbeidet og koordinering av tjenester kan gjøres bedre?**	

PÅRØRENDEBYRDER/-GEVINSTER OG ØKONOMISKE KOSTNADER/GODER:		
TEMA	**SPØRSMÅL**	**UNDERPUNKTER**
Effekt på pårørende	**Hvordan preger det livet ditt, at du er pårørende til den demente?**	• Positivt og negativt • Livskvalitet, helse, økonomi, sosialt, psykisk, åndelig (Gi eksempler)
Livskvalitet pårørende	**Hvordan vil du beskrive din livskvalitet på en skala mellom 0-100 (VAS)?**	• Hvordan øke din livskvalitet – 20 poeng? • Hva gir styrke/tar styrke? (Gi eksempler)
Bekostninger for pårørende	**Hva har du tapt eller gått glipp av?**	• Økonomisk • Personlig • Helse Gi eksempler
Gevinster for pårørende	**Hvilke positive aspekter opplever du ved å være pårørende til den demente?**	• Eksempler & utdyping
Motivasjon	**Hva motiverer deg til å gjøre den innsatsen du gjør for den demente?**	
Råd til andre	**Hva vil være dine råd til andre pårørende?**	• Personlig • Mtp helsevesenet
Ressurser over tid	**Opplever du at du har nok tid, ressurser og overskudd til å håndtere rollen som pårørende så lenge det er nødvendig?**	• Forklare, gi eksempler? • Hva trenger du? • Hva er viktig for å føle mestring? • Hva gjør det vanskelig?
Håndterbarhet	**Hva synes du er mest vanskelig å håndtere som pårørende?**	Dersom bekymring nevnes: • Hvordan kunne de vært løst?
Tidsbruk	**Hva ville du brukt mer tid på dersom du ikke hadde ansvar for en som var dement?**	• Fritid • Jobb • Sosialt

INNLEDNING		
TEMA	**SPØRSMÅL**	**UNDERPUNKTER**
Hvordan det startet	**Når begynte det?**	• Hvordan begynte du å merke at noe var galt? • Hvor henvendte du deg først?
Oppfølging etter diagnose	**Hvordan ble dere fulgt opp?**	• Hva fikk dere informasjon om? • Hvilke andre helsetjenester ble involvert?

BIDRAG TIL OG INTERAKSJON MED HELSETJENESTENE:		
TEMA	**SPØRSMÅL**	**UNDERPUNKTER**
Spekter av tjenester	**Hvordan kom dere i kontakt med de tjenestene dere bruker nå?**	fastlege, dagsenter, hjemmesykepleie, hjemmehjelp, sykehjem, fysioterapeut, fotpleier, frisør, tannlege, ergoterapeut, aktivitetssentra, hjelpemiddelsentral, frivillighetssentral, NAV
Samhandling formell og uformell omsorg	**På hvilken måte baserer det offentlige seg på deg som pårørende?**	• Hvordan påvirker du hjelpen fra det offentlige? • Hvordan anerkjenner det offentlige ditt bidrag i omsorgen? • Hvordan avlaster det offentlige den pårørendes innsats?
Sammenheng i tjenestene	**Kan du fortelle mer om hvordan disse tjenestene)utføres?**	• Eksempler på gode tjenester • Eksempler på tjenester som ikke fungerer. • Kommune + sykehus
Hva helsepersonell snakker om	**Hva snakker helsepersonell med deg om?**	Hvordan merker du om de lytter?
	På hvilke måter blir du invitert til å bidra i planleggingen av omsorgen til PWD?	• Innkalt til møter? • Spurt om PWD sin livshistorie osv?
Åpenhet og involvering	**Hva tenker du at helsepersonell dokumenterer i**	• Sykepleie – dokumentasjonsplikt

	journalene?	- Lege - Andre
	Føler du at HP er åpne om hvordan de vurderer PWD?	- Hemmelighold - Svarer på spørsmål - Forteller for mye - Forteller ingenting
Tverrfaglige team	**Har det vært tverrfaglige team involvert?**	- Har du eksempler som viser hvordan du har forsøkt å samarbeide? - Hvordan opplevde du at dine innspill/initiativ ble møtt? - Hva ble resultatet av ditt initiativ/innspill?
Hinder for samarbeid	**Hva tror du er de viktigste hindringene for godt samarbeid med mellom helsepersonell og pårørende?**	Tro du at de som jobber i tjenestene vil være enige med deg?

TJENESTEINTEGRASJON OG KVALITET PÅ TJENESTER

TEMA	**SPØRSMÅL**	**UNDERPUNKTER**
Møte med helsevesenet	**Kan du fortelle om en god opplevelse dere har hatt i møte med helsevesenet?**	- og en utfordrende
Gode tjenester	**Hva gjør en tjeneste god?**	- Eksempler - Hva er utfordringer? - Oppgaver du ønsker mer hjelp til?
Koordinasjon av tjenester	**Hvordan opplever du at de ulike tjeneste-tilbudene til X samarbeider?**	- Eksempler på gode og dårlige - Kolliderende avtaler? - Eksempler på hvordan det løses? - Hva blir din rolle som pårørende?
Dekker tjenestene behovet	**I hvilken grad dekker disse tjenestene de behovene dere har?**	- Hva dekkes ikke? - Og løses dette? - Hva gjør dette med deg? (praktisk, følelsesmessig, alene, i kontakt med andre)
Individuell plan	**Benytter dere individuell plan?**	- På hvilken måte? - Hva fungerer godt/mindre godt?
Unødvendige tjenester	**Får du tilbud om tjenester som du av ulike årsaker ikke ønsker**	- Hvordan fungerer disse tjenestene?

	eller ikke kan benytte deg av?	- Ville du benyttet dem dersom de fungerte annerledes?
Velferdsteknologi	**Finnes det teknologi som kan hjelpe?**	- Hva kunne du ha nytte av?

PÅRØRENDEBYRDER/-GEVINSTER OG ØKONOMISKE KOSTNADER/GODER:		
TEMA	**SPØRSMÅL**	**UNDERPUNKTER**
Effekt på pårørende	**Hvordan preger det livet ditt, at du er pårørende til den demente?**	• Positivt og negativt • Livskvalitet, helse, økonomi, sosialt, psykisk, åndelig (Gi eksempler)
Livskvalitet pårørende	**Hvordan vil du beskrive din livskvalitet på en skala mellom 0-100 (VAS)?**	• Hvordan øke din livskvalitet – 20 poeng? • Hva gir styrke/tar styrke? (Gi eksempler)
Bekostninger for pårørende	**Hva har du tapt eller gått glipp av?**	• Økonomisk • Personlig • Helse Gi eksempler
Gevinster for pårørende	**Hvilke positive aspekter opplever du ved å være pårørende til den demente?**	• Eksempler & utdyping
Motivasjon	**Hva motiverer deg til å gjøre den innsatsen du gjør for den demente?**	
Råd til andre	**Hva vil være dine råd til andre pårørende?**	• Personlig • Mtp helsevesenet
Ressurser over tid	**Opplever du at du har nok tid, ressurser og overskudd til å håndtere rollen som pårørende så lenge det er nødvendig?**	• Forklare, gi eksempler? • Hva trenger du? • Hva er viktig for å føle mestring? • Hva gjør det vanskelig?
Håndterbarhet	**Hva synes du er mest vanskelig å håndtere som pårørende?**	Dersom bekymring nevnes: • Hvordan kunne de vært løst?
Tidsbruk	**Hva ville du brukt mer tid på dersom du ikke hadde ansvar for en som var dement?**	• Fritid • Jobb • Sosialt

Versjon 3.0

INNLEDNING		
TEMA	**SPØRSMÅL**	**UNDERPUNKTER**
Hvordan det startet	**Når begynte det?**	• Hvordan begynte du å merke at noe var galt? • Hvor henvendte du deg først?
Oppfølging etter diagnose	**Hvordan ble dere fulgt opp?**	• Hva fikk dere informasjon om? • Hvilke andre helsetjenester ble involvert?

BIDRAG TIL OG INTERAKSJON MED HELSETJENESTENE:		
TEMA	**SPØRSMÅL**	**UNDERPUNKTER**
Spekter av tjenester	**Hvordan kom dere i kontakt med de tjenestene dere bruker nå?**	fastlege, dagsenter, hjemmesykepleie, hjemmehjelp, sykehjem, fysioterapeut, fotpleier, frisør, tannlege, ergoterapeut, aktivitetssentra, hjelpemiddelsentral, frivillighetssentral, NAV
Samhandling formell og uformell omsorg	**På hvilken måte baserer det offentlige seg på deg som pårørende?**	• Hvordan påvirker du hjelpen fra det offentlige? • Hvordan anerkjenner det offentlige ditt bidrag i omsorgen? • Hvordan avlaster det offentlige den pårørendes innsats?
Sammenheng i tjenestene	**Kan du fortelle mer om hvordan disse tjenestene)utføres?**	• Eksempler på gode tjenester • Eksempler på tjenester som ikke fungerer. • Kommune + sykehus
Hva helsepersonell snakker om	**Hva snakker helsepersonell med deg om?**	Hvordan merker du om de lytter?
	På hvilke måter blir du invitert til å bidra i planleggingen av omsorgen til PWD?	• Innkalt til møter? • Spurt om PWD sin livshistorie osv?
Åpenhet og involvering	**Hva tenker du at helsepersonell dokumenterer i**	• Sykepleie – dokumentasjonsplikt

	journalene?	• Lege • Andre
	Føler du at HP er åpne om hvordan de vurderer PWD?	• Hemmelighold • Svarer på spørsmål • Forteller for mye • Forteller ingenting
Tverrfaglige team	**Har det vært tverrfaglige team involvert?**	• Har du eksempler som viser hvordan du har forsøkt å samarbeide? • Hvordan opplevde du at dine innspill/initiativ ble møtt? • Hva ble resultatet av ditt initiativ/innspill?
Hinder for samarbeid	**Hva tror du er de viktigste hindringene for godt samarbeid med mellom helsepersonell og pårørende?**	Tro du at de som jobber i tjenestene vil være enige med deg?

TJENESTEINTEGRASJON OG KVALITET PÅ TJENESTER		
TEMA	**SPØRSMÅL**	**UNDERPUNKTER**
Møte med helsevesenet	**Kan du fortelle om en god opplevelse dere har hatt i møte med helsevesenet?**	• og en utfordrende
Gode tjenester	**Hva gjør en tjeneste god?**	• Eksempler • Hva er utfordringer? • Oppgaver du ønsker mer hjelp til?
Koordinasjon av tjenester	**Hvordan opplever du at de ulike tjeneste-tilbudene til PWD samarbeider?**	• Eksempler på gode og dårlige • Kolliderende avtaler? • Eksempler på hvordan det løses? • Hva blir din rolle som pårørende?
Dekker tjenestene behovet	**I hvilken grad dekker disse tjenestene de behovene dere har?**	• Hva dekkes ikke? • Og løses dette? • Hva gjør dette med deg? (praktisk, følelsesmessig, alene, i kontakt med andre)
Individuell plan	**Benytter dere individuell plan?**	• På hvilken måte? • Hva fungerer godt/mindre godt?
Unødvendige tjenester	**Får du tilbud om tjenester som du av ulike årsaker ikke ønsker**	• Hvordan fungerer disse tjenestene?

	eller ikke kan benytte deg av?	• Ville du benyttet dem dersom de fungerte annerledes?
Velferdsteknologi	**Finnes det teknologi som kan hjelpe?**	• Hva kunne du ha nytte av?

PÅRØRENDEBYRDER/-GEVINSTER OG ØKONOMISKE KOSTNADER/GODER:		
TEMA	**SPØRSMÅL**	**UNDERPUNKTER**
Effekt på pårørende	**Hvordan preger det livet ditt, at du er pårørende til den demente?**	• Positivt og negativt • Livskvalitet, helse, økonomi, sosialt, psykisk, åndelig (Gi eksempler)
	Hender det at du opplever å bli sint, frustrert, irritert?	• Hvordan håndterer du dette? • Opplever du at HP kan være til hjelp eller støtte rundt dette? •
	Hender det at PWD blir sint, voldelig eller påtrengende?	• Hvordan håndterer du dette? • Er dette noe du ville ha ønsket å snakke med HP om? • Finnes det gode løsninger eller tiltak som kan være til hjelp?
Bekostninger for pårørende	**Hva har du tapt eller gått glipp av?**	• Økonomisk • Personlig • Helse Gi eksempler
Gevinster for pårørende	**Hvilke positive aspekter opplever du ved å være pårørende til den demente?**	• Eksempler & utdyping
Motivasjon	**Hva motiverer deg til å gjøre den innsatsen du gjør for den demente?**	
Råd til andre	**Hva vil være dine råd til andre pårørende?**	• Personlig • Mtp helsevesenet
Ressurser over tid	**Opplever du at du har nok tid, ressurser og overskudd til å håndtere rollen som pårørende så lenge det er nødvendig?**	• Forklare, gi eksempler? • Hva trenger du? • Hva er viktig for å føle mestring? • Hva gjør det vanskelig?

Håndterbarhet	**Hva synes du er mest vanskelig å håndtere som pårørende?**	Dersom bekymring nevnes: • Hvordan kunne de vært løst?
Tidsbruk	**Hva ville du brukt mer tid på dersom du ikke hadde ansvar for en som var dement?**	• Fritid • Jobb • Sosialt
Livskvalitet pårørende	**Hvordan vil du beskrive din livskvalitet på en skala mellom 0-100 (VAS)?**	• Hvordan øke din livskvalitet – 20 poeng? • Hva gir styrke/tar styrke? (Gi eksempler)

Appendix II

Additional tools used in Paper I and Paper II

1. Individual characteristics collected in Substudy 1
2. Quality of life visual analogue scale

VARIABLER TIL CROSS-CUTTING ANALYSER

Personen med demens

fødselsår **Hvilket år er vedkommende født?** _ _ _ _

kjonn **Kjønn?**

1. Kvinne
2. Mann
3. Ønsker ikke å oppgi

norsk **Er vedkommende født i Norge?**

1. Ja
2. Nei -> Hvor er du født? (Åpent felt)

bolig **Bor vedkommende i**

1. Egen bolig
2. Omsorgsbolig
3. Institusjon (sykehjem/aldershjem eller annet)
4. Annet

postnr **Hva er postnummeret til vedkommende?** _ _ _ _

siv_status **Hva er sivilstatusen?**

1. Ugift
2. Gift eller samboer
3. Enke/enkemann eller gjenlevende samboer
4. Skilt eller separert
5. Vil ikke svare

antall_bolig **Hvor mange bor i husholdet til vedkommende?** _ _

utdanning **Hva er den høyeste utdanningen vedkommende har fullført?**

1. Grunnskole
2. Videregående skole/fagbrev/mesterbrev
3. 3 år på høyskole eller universitet
4. Mer enn 3 år på høyskole eller universitet
5. Vil ikke svare

yrke **Hva er/var yrket til vedkommende?**

-> fyll inn (åpent felt)

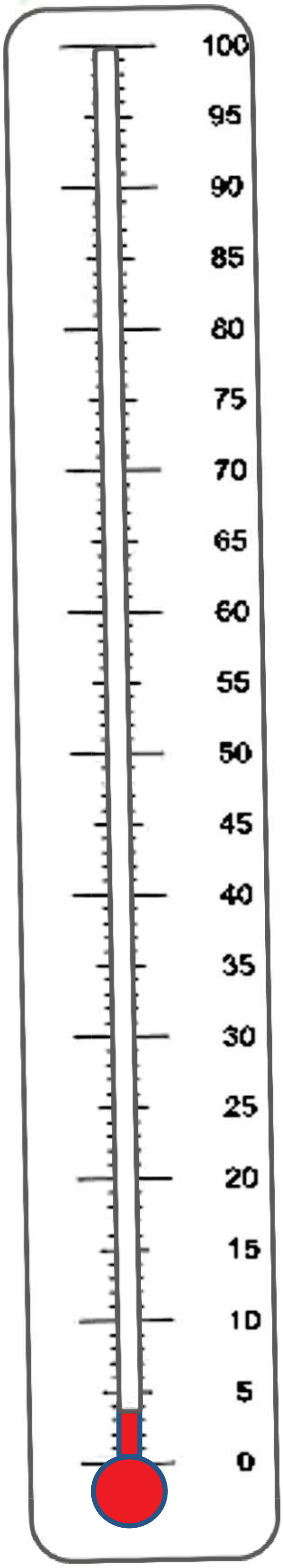
yrkesaktiv **Er vedkommende yrkesaktiv nå?**

1. Ja arbeider heltid
2. Ja, arbeider deltid
3. Nei, er langtidssykemeldt (8 uker eller mer)
4. Nei, er på arbeidsavklaring
5. Nei, er uføretrygdet
6. Nei, er pensjonert
7. Nei, er hjemmearbeidende
8. Annet

inntekt **Hva er husholdnings samlede inntekt før skatt (inkludert eventuelle trygdeytelser og sosiale stønader) i 2016?** ***(evt siste hele år)***

1. Under 200 000 kr
2. 200 000 – 349 000 kr
3. 350 000 – 749 000 kr
4. 750 000 – 999 000 kr
5. 1 million kr eller mer

Best tenkelig
livskvalitet



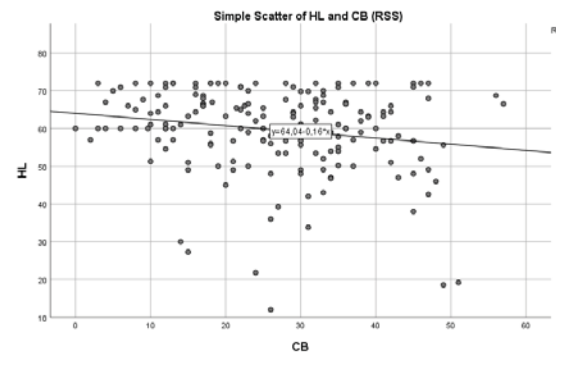
Verst tenkelig
livskvalitet

Appendix III

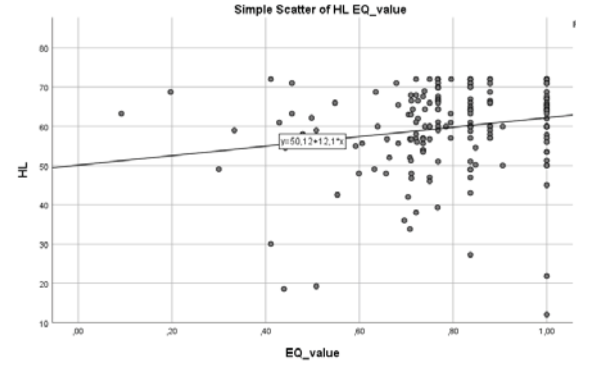
Scatterplots and boxplots of health literacy and outcome variables

Appendix III

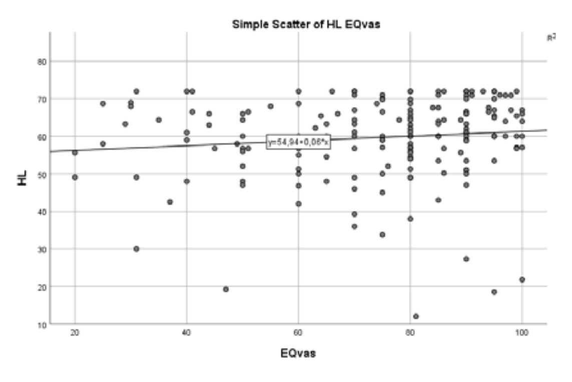
Figure 1 Scatterplot with regression line for HL and each of the outcome variables



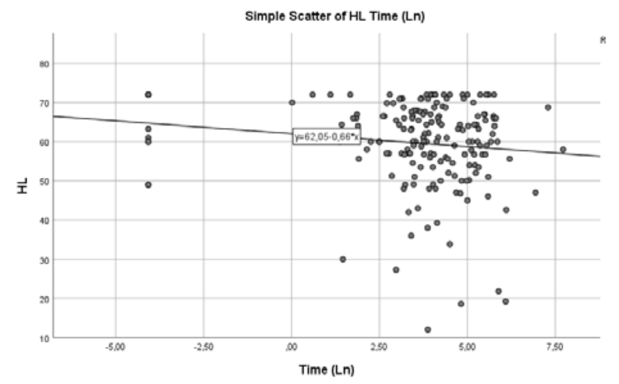
Scatterplot of HL and CB, n=186



Scatterplot of HL and EQvalue, n=183

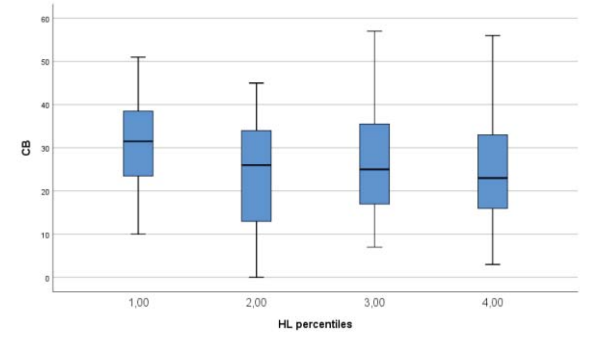


Scatterplot of HL and EQvas, n=188

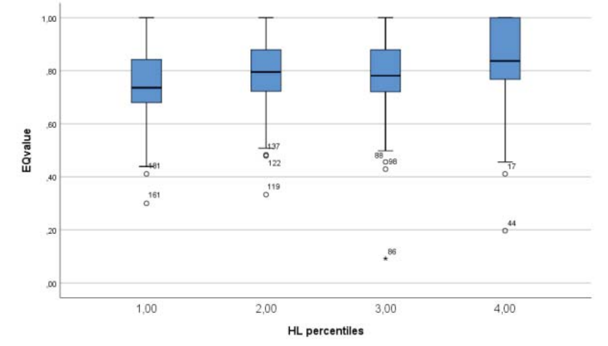


Scatterplot of HL and Time (Ln), n=180

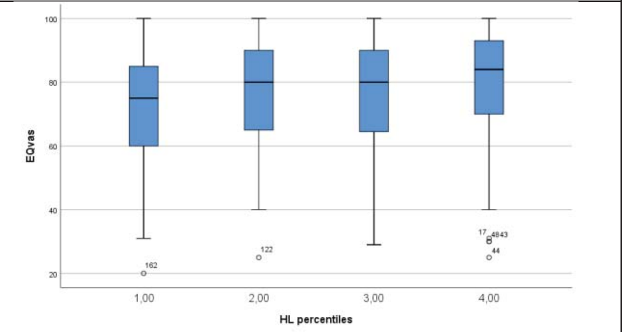
Figure 2 Boxplot of percentiles of HL and each outcome variable



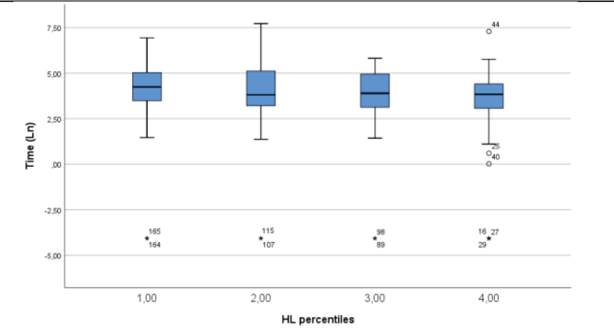
Scatterplot of HL and CB, n=186



Scatterplot of HL and EQvalue, n=183



Scatterplot of HL and EQvas, n=188



Scatterplot of HL and Time, n=180

Appendix IV

Correlation analysis

		EQvalue	EQ vas	Time	CB	HL	Dementia severity	HL_inadequate	HL_marginal	HL_intermediate	HL_advanced	age	gender	Urban residency	Health personnel	car_born_abroad	pwd_born_abroad	No university education	Up to 3 years of university education	> 3 years of university education	Spouse	Shared household	work status
EQ value	Pearson	1	**,663**	-,135	-,286	,188	-,035	,024	,023	,021	,028	-,029	,184	,141	,043	-,044	-,014	,104	,034	,124	-,005	-,049	-,287
	Sig.		,000	,069	,000	,012	,635	,751	,762	,773	,705	,697	,013	,058	,571	,552	,856	,163	,652	,097	,945	,508	,000
	N	183	183	183	178	178	183	183	183	183	183	179	183	180	179	182	177	182	182	182	181	183	183
EQvas	Pearson	**,663**	**1**	-,145	-,280	,115	-,061	,149	,148	,147	,153	-,026	,080	,146	,137	-,097	-,094	,122	,114	,210	-,011	-,111	-,291
	Sig.	,000		,047	,000	,126	,406	,041	,042	,044	,037	,731	,279	,048	,067	,187	,208	,096	,120	,004	,881	,131	,000
	N	183	188	188	181	180	187	188	188	188	188	183	187	184	181	186	181	186	186	186	185	187	187
Time	Pearson	-,135	-,145	**1**	**,514**	-,133	-,034	-,159	-,159	-,160	-,160	,138	-,114	-,032	-,026	,047	-,062	,006	,032	-,009	,178	,197	,119
	Sig.	,069	,047		,000	,076	,642	,029	,030	,029	,028	,063	,119	,668	,729	,521	,405	,932	,663	,905	,016	,007	,105
	N	183	188	188	181	180	187	188	188	188	188	183	187	184	181	186	181	186	186	186	185	187	187
CB	Pearson	-,286	-,280	,514	**1**	-,139	,227	-,023	-,021	-,022	-,026	,100	-,239	,032	-,035	,097	-,007	-,096	-,097	-,129	,205	,190	,250
	Sig.	,000	,000	,000		,066	,002	,754	,778	,764	,725	,186	,001	,671	,645	,194	,931	,202	,194	,085	,006	,011	,001
	N	178	181	181	181	175	181	181	181	181	181	177	181	178	175	180	175	180	180	180	179	181	181
HL	Pearson	,188	,115	-,133	-,139	**1**	-,125	.	-,359	-,331	,735	,007	-,098	-,020	,038	-,039	-,088	,034	,003	,041	-,061	-,064	-,066
	Sig.	,012	,126	,076	,066		,095	,000	,000	,000	,000	,927	,189	,794	,615	,606	,250	,648	,964	,587	,419	,396	,377
	N	178	180	180	175	180	180	180	180	180	180	177	180	178	175	179	174	179	179	179	178	180	180
Dementia	Pearson	-,035	-,061	-,034	,227	-,125	**1**	,029	,031	,030	,026	,035	,050	-,047	,044	,112	,105	-,049	,070	,137	,002	-,033	,043
	Sig	,635	,406	,642	,002	,095		,695	,678	,684	,719	,633	,499	,528	,552	,129	,158	,504	,343	,061	,975	,652	,562
	N	183	187	187	181	180	187	187	187	187	187	183	187	184	181	186	181	186	186	186	185	187	187
HL_inadequate	Pearson	,024	,149	-,159	-,023	.	,029	**1**	**1**	**1**	**1**	-,003	-,124	,071	,003	-,063	-,051	,050	,133	,163	,030	,061	-,008
	Sig.	,751	,041	,029	,754	,000	,695		,000	,000	,000	,973	,091	,337	,969	,395	,495	,502	,070	,026	,688	,408	,912
	N	183	188	188	181	180	187	188	188	188	188	183	187	184	181	186	181	186	186	186	185	187	187
HL_marginal	Pearson	,023	,148	-,159	-,021	-,359	,031	**1**	**1**	**1**	**1**	-,002	-,124	,070	,002	-,063	-,049	,049	,132	,162	,030	,062	-,007
	Sig.	,762	,042	,030	,778	,000	,678	,000		,000	,000	,975	,091	,342	,976	,396	,511	,506	,073	,027	,683	,401	,924
	N	183	188	188	181	180	187	188	188	188	188	183	187	184	181	186	181	186	186	186	185	187	187
HL_intermediate	Pearson	,021	,147	-,160	-,022	-,331	,030	**1**	**1**	**1**	**,999**	-,003	-,121	,070	,002	-,064	-,051	,046	,132	,162	,030	,063	-,008
	Sig.	,773	,044	,029	,764	,000	,684	,000	,000		,000	,964	,098	,343	,983	,387	,492	,530	,074	,028	,687	,395	,916
	N	183	188	188	181	180	187	188	188	188	188	183	187	184	181	186	181	186	186	186	185	187	187
HL_advanced	Pearson	,028	,153	-,160	-,026	**,735**	,026	**1**	**1**	**,999**	**1**	-,001	-,127	,072	,004	-,062	-,053	,053	,135	,166	,029	,058	-,010
	Sig.	,705	,037	,028	,725	,000	,719	,000	,000	,000		,985	,084	,333	,954	,400	,477	,474	,066	,024	,697	,429	,896
	N	183	188	188	181	180	187	188	188	188	188	183	187	184	181	186	181	186	186	186	185	187	187
age	Pearson	-,029	-,026	,138	,100	,007	,035	-,003	-,002	-,003	-,001	**1**	,191	,154	-,008	,138	-,111	-,109	,084	,003	**,726**	,414	**,610**
	Sig.	,697	,731	,063	,186	,927	,633	,973	,975	,964	,985		,010	,038	,917	,064	,142	,144	,261	,971	,000	,000	,000

	N	179	183	183	177	177	183	183	183	183	183	183	183	181	177	182	177	182	182	182	181	183	183
		EQvalue	EQ vas	Time	CB	HL	Dementia	HL_inadequate	HL_marginal	HL_intermediate	HL_advanced	age	gender	urban	HP	car_born_abroad	pwd_born_abroad	edu_2	edu_3	edu_4	Spouse	Living with pwd	work status
gender	Pearson	,184	,080	-,114	-,239	-,098	,050	-,124	-,124	-,121	-,127	,191	**1**	,104	-,226	,130	,149	,004	,006	-,029	,152	,018	,052
	Sig	,013	,279	,119	,001	,189	,499	,091	,091	,098	,084	,010		,161	,002	,076	,045	,959	,940	,694	,039	,805	,477
	N	183	187	187	181	180	187	187	187	187	187	183	187	184	181	186	181	186	186	186	185	187	187
Urban	Pearson	,141	,146	-,032	,032	-,020	-,047	,071	,070	,070	,072	,154	,104	**1**	-,141	,065	,029	,038	,153	,183	,155	,104	,027
	Sig.	,058	,048	,668	,671	,794	,528	,337	,342	,343	,333	,038	,161		,060	,385	,698	,610	,039	,013	,037	,161	,718
	N	180	184	184	178	178	184	184	184	184	184	181	184	184	178	183	178	183	183	183	182	184	184
HP	Pearson	,043	,137	-,026	-,035	,038	,044	,003	,002	,002	,004	-,008	-,226	-,141	**1**	-,090	-,073	,014	,060	,177	-,078	-,181	-,042
	Sig	,571	,067	,729	,645	,615	,552	,969	,976	,983	,954	,917	,002	,060		,229	,337	,848	,422	,017	,302	,015	,578
	N	179	181	181	175	175	181	181	181	181	181	177	181	178	181	180	176	180	180	180	179	181	181
car_born_abroad	Pearson	-,044	-,097	,047	,097	-,039	,112	-,063	-,063	-,064	-,062	,138	,130	,065	-,090	**1**	,314	-,004	-,003	-,007	,192	,044	,200
	Sig	,552	,187	,521	,194	,606	,129	,395	,396	,387	,400	,064	,076	,385	,229		,000	,957	,968	,926	,009	,553	,006
	N	182	186	186	180	179	186	186	186	186	186	182	186	183	180	186	181	185	185	185	184	186	186
pwd_born_abroad	Pearson	-,051	-,049	-,051	-,053	-,111	,149	,029	-,073	,314	**1**	-,032	-,035	,043	-,091	-,008	,004	-,051	-,049	-,051	-,053	-,111	,149
	Sig.	,495	,511	,492	,477	,142	,045	,698	,337	,000		,672	,637	,565	,225	,913	,962	,495	,511	,492	,477	,142	,045
	N	181	181	181	181	177	181	178	176	181	181	180	180	180	179	181	181	181	181	181	181	177	181
edu_2	Pearson	,050	,049	,046	,053	-,109	,004	,038	,014	-,004	-,032	**1**	,372	,225	-,197	-,040	-,096	,050	,049	,046	,053	-,109	,004
	Sig.	,502	,506	,530	,474	,144	,959	,610	,848	,957	,672		,000	,002	,007	,583	,193	,502	,506	,530	,474	,144	,959
	N	186	186	186	186	182	186	183	180	185	180	186	186	186	184	186	186	186	186	186	186	182	186
edu_3	Pearson	,133	,132	,132	,135	,084	,006	,153	,060	-,003	-,035	,372	**1**	**,604**	-,005	-,004	-,073	,133	,132	,132	,135	,084	,006
	Sig.	,070	,073	,074	,066	,261	,940	,039	,422	,968	,637	,000		,000	,942	,955	,323	,070	,073	,074	,066	,261	,940
	N	186	186	186	186	182	186	183	180	185	180	186	186	186	184	186	186	186	186	186	186	182	186
edu_4	Pearson	,163	,162	,162	,166	,003	-,029	,183	,177	-,007	,043	,225	**,604**	**1**	-,053	-,026	-,110	,163	,162	,162	,166	,003	-,029
	Sig.	,026	,027	,028	,024	,971	,694	,013	,017	,926	,565	,002	,000		,475	,723	,136	,026	,027	,028	,024	,971	,694
	N	186	186	186	186	182	186	183	180	185	180	186	186	186	184	186	186	186	186	186	186	182	186
Spouse	Pearson	,030	,030	,030	,029	**,726**	,152	,155	-,078	,192	-,091	-,197	-,005	-,053	1	**,651**	**,590**	,030	,030	,030	,029	**,726**	,152
	Sig.	,688	,683	,687	,697	,000	,039	,037	,302	,009	,225	,007	,942	,475		,000	,000	,688	,683	,687	,697	,000	,039
	N	185	185	185	185	181	185	182	179	184	179	184	184	184	185	185	185	185	185	185	185	181	185
Living with pwd	Pearson	,061	,062	,063	,058	,414	,018	,104	-,181	,044	-,008	-,040	-,004	-,026	**,651**	**1**	,350	,061	,062	,063	,058	,414	,018
	Sig.	,408	,401	,395	,429	,000	,805	,161	,015	,553	,913	,583	,955	,723	,000		,000	,408	,401	,395	,429	,000	,805
	N	187	187	187	187	183	187	184	181	186	181	186	186	186	185	187	187	187	187	187	187	183	187

work status	Pearson	-,008	-,007	-,008	-,010	**,610**	,052	,027	-,042	,200	,004	-,096	-,073	-,110	,590	,350	**1**	-,008	-,007	-,008	-,010	,610	,052
	Sig.	,912	,924	,916	,896	,000	,477	,718	,578	,006	,962	,193	,323	,136	,000	,000		,912	,924	,916	,896	,000	,477
	N	187	187	187	187	183	187	184	181	186	181	186	186	186	185	187	187	187	187	187	187	183	187

		EQ_value	EQvas	Time	CB	HL	Dementia	HL_inadequate	HL_marginal	HL_intermediate	HL_advanced	age	gender	urban	HP	car_born_abroad	pwd_born_abroad	edu_2	edu_3	edu_4	Spouse	Living with pwd	work status
EQ_value	Pearson	1	,678**	-,091	-,262**	,142	-,011	,099	-,099	-,134	,175*	,022	,228**	,152	,007	,070	,045	,134	,077	,127	,067	-,033	-,285**
	Sig.		,000	,257	,001	,077	,892	,218	,218	,096	,029	,782	,004	,058	,934	,386	,579	,095	,338	,114	,408	,681	,000
	N	156	156	156	156	156	156	156	156	156	156	156	156	156	156	156	156	156	156	156	156	156	156
EQvas	Pearson	,678**	1	-,107	-,250**	,136	,011	,122	-,122	-,113	,159*	-,028	,139	,154	,099	,056	,001	,179*	,177*	,236**	-,016	-,098	-,329**
	Sig.	,000		,184	,002	,092	,895	,128	,128	,161	,048	,732	,084	,055	,217	,484	,995	,025	,028	,003	,842	,226	,000
	N	156	156	156	156	156	156	156	156	156	156	156	156	156	156	156	156	156	156	156	156	156	156
Time	Pearson	-,091	-,107	1	,491**	-,117	,025	-,058	,058	,000	-,029	,149	-,079	-,026	-,022	-,047	-,131	,013	,040	-,016	,172*	,148	,109
	Sig.	,257	,184		,000	,145	,761	,470	,470	,998	,717	,063	,330	,747	,787	,559	,104	,870	,624	,842	,032	,065	,174
	N	156	156	156	156	156	156	156	156	156	156	156	156	156	156	156	156	156	156	156	156	156	156
CB	Pearson	-,262**	-,250**	,491**	1	-,091	,247**	-,134	,134	,046	-,080	,028	-,217**	-,004	-,056	,093	-,002	-,088	-,114	-,157	,143	,116	,227**
	Sig.	,001	,002	,000		,258	,002	,095	,095	,566	,324	,732	,006	,958	,490	,246	,982	,273	,155	,050	,076	,151	,004
	N	156	156	156	156	156	156	156	156	156	156	156	156	156	156	156	156	156	156	156	156	156	156
HL	Pearson	,142	,136	-,117	-,091	1	-,136	,364**	-,364**	-,388**	,745**	,020	-,122	,022	,027	-,013	,003	,045	,047	,055	-,025	-,046	-,025
	Sig.	,077	,092	,145	,258		,091	,000	,000	,000	,000	,804	,128	,781	,737	,871	,967	,581	,557	,495	,759	,572	,757
	N	156	156	156	156	156	156	156	156	156	156	156	156	156	156	156	156	156	156	156	156	156	156
Dementia	Pearson	-,011	,011	,025	,247**	-,136	1	-,103	,103	,011	-,062	,009	,032	-,054	,078	,168*	,109	-,051	,037	,137	-,010	-,067	,030
	Sig	,892	,895	,761	,002	,091		,202	,202	,889	,444	,914	,693	,506	,335	,036	,176	,526	,644	,088	,903	,407	,708
	N	156	156	156	156	156	156	156	156	156	156	156	156	156	156	156	156	156	156	156	156	156	156
HL_inadequate	Pearson	,099	,122	-,058	-,134	,364**	-,103	1	-1**	,144	,274**	,052	-,064	,090	,149	-,061	-,212**	,079	,128	,076	,025	-,002	-,056
	Sig.	,218	,128	,470	,095	,000	,202		,000	,072	,001	,516	,431	,263	,064	,448	,008	,326	,112	,343	,759	,983	,485
	N	156	156	156	156	156	156	156	156	156	156	156	156	156	156	156	156	156	156	156	156	156	156
HL_marginal	Pearson	-,099	-,122	,058	,134	-,364**	,103	-1**	1	-,144	-,274**	-,052	,064	-,090	-,149	,061	,212**	-,079	-,128	-,076	-,025	,002	,056
	Sig.	,218	,128	,470	,095	,000	,202	,000		,072	,001	,516	,431	,263	,064	,448	,008	,326	,112	,343	,759	,983	,485
	N	156	156	156	156	156	156	156	156	156	156	156	156	156	156	156	156	156	156	156	156	156	156
HL_intermediate	Pearson	-,134	-,113	,000	,046	-,388**	,011	,144	-,144	1	-,843**	-,027	,117	-,049	-,011	-,021	-,046	-,133	-,077	-,116	,020	,045	-,006
	Sig.	,096	,161	,998	,566	,000	,889	,072	,072		,000	,742	,145	,543	,887	,796	,570	,098	,340	,150	,801	,576	,936
	N	156	156	156	156	156	156	156	156	156	156	156	156	156	156	156	156	156	156	156	156	156	156

HL_advanced	Pearson	,175*	,159*	-,029	-,080	,745**	-,062	,274**	-,274**	-,843**	1	,052	-,124	,058	,035	,012	-,030	,143	,113	,124	-,017	-,061	-,012
	Sig.	,029	,048	,717	,324	,000	,444	,001	,001	,000		,521	,122	,470	,667	,883	,706	,074	,161	,123	,832	,451	,879
	N	156	156	156	156	156	156	156	156	156	156	156	156	156	156	156	156	156	156	156	156	156	156
age	Pearson	,022	-,028	,149	,028	,020	,009	,052	-,052	-,027	,052	1	,248**	,131	-,030	,162*	-,055	-,076	,123	-,010	,719**	,412**	,565**
	Sig.	,782	,732	,063	,732	,804	,914	,516	,516	,742	,521		,002	,103	,707	,043	,497	,345	,127	,899	,000	,000	,000
	N	156	156	156	156	156	156	156	156	156	156	156	156	156	156	156	156	156	156	156	156	156	156
gender	Pearson	,228**	,139	-,079	-,217**	-,122	,032	-,064	,064	,117	-,124	,248**	1	,100	-,233**	,096	,141	-,021	-,004	-,035	,189*	,095	,075
	Sig	,004	,084	,330	,006	,128	,693	,431	,431	,145	,122	,002		,212	,003	,231	,078	,796	,957	,667	,018	,241	,351
	N	156	156	156	156	156	156	156	156	156	156	156	156	156	156	156	156	156	156	156	156	156	156
Urban	Pearson	,152	,154	-,026	-,004	,022	-,054	,090	-,090	-,049	,058	,131	,100	1	-,156	,040	,021	,058	,175*	,190*	,135	,090	-,010
	Sig.	,058	,055	,747	,958	,781	,506	,263	,263	,543	,470	,103	,212		,052	,623	,792	,474	,028	,017	,093	,263	,902
	N	156	156	156	156	156	156	156	156	156	156	156	156	156	156	156	156	156	156	156	156	156	156
HP	Pearson	,007	,099	-,022	-,056	,027	,078	,149	-,149	-,011	,035	-,030	-,233**	-,156	1	-,028	-,052	,052	,152	,273**	-,087	-,186*	-,059
	Sig	,934	,217	,787	,490	,737	,335	,064	,064	,887	,667	,707	,003	,052		,727	,518	,518	,059	,001	,282	,020	,468
	N	156	156	156	156	156	156	156	156	156	156	156	156	156	156	156	156	156	156	156	156	156	156
car_born_abroad	Pearson	,070	,056	-,047	,093	-,013	,168*	-,061	,061	-,021	,012	,162*	,096	,040	-,028	1	,254**	-,039	,017	-,004	,225**	-,006	,208**
	Sig	,386	,484	,559	,246	,871	,036	,448	,448	,796	,883	,043	,231	,623	,727		,001	,627	,832	,962	,005	,944	,009
	N	156	156	156	156	156	156	156	156	156	156	156	156	156	156	156	156	156	156	156	156	156	156
pwd_born_abroad	Pearson	,045	,001	-,131	-,002	,003	,109	-,212**	,212**	-,046	-,030	-,055	,141	,021	-,052	,254**	1	-,057	-,077	,047	-,061	-,033	,001
	Sig.	,579	,995	,104	,982	,967	,176	,008	,008	,570	,706	,497	,078	,792	,518	,001		,482	,338	,563	,446	,683	,989
	N	156	156	156	156	156	156	156	156	156	156	156	156	156	156	156	156	156	156	156	156	156	156
edu_2	Pearson	,134	,179*	,013	-,088	,045	-,051	,079	-,079	-,133	,143	-,076	-,021	,058	,052	-,039	-,057	1	,377**	,229**	-,229**	-,089	-,056
	Sig.	,095	,025	,870	,273	,581	,526	,326	,326	,098	,074	,345	,796	,474	,518	,627	,482		,000	,004	,004	,268	,484
	N	156	156	156	156	156	156	156	156	156	156	156	156	156	156	156	156	156	156	156	156	156	156
edu_3	Pearson	,077	,177*	,040	-,114	,047	,037	,128	-,128	-,077	,113	,123	-,004	,175*	,152	,017	-,077	,377**	1	,608**	-,001	,008	-,090
	Sig.	,338	,028	,624	,155	,557	,644	,112	,112	,340	,161	,127	,957	,028	,059	,832	,338	,000		,000	,991	,921	,262
	N	156	156	156	156	156	156	156	156	156	156	156	156	156	156	156	156	156	156	156	156	156	156
edu_4	Pearson	,127	,236**	-,016	-,157	,055	,137	,076	-,076	-,116	,124	-,010	-,035	,190*	,273**	-,004	,047	,229**	,608**	1	-,067	-,037	-,151
	Sig.	,114	,003	,842	,050	,495	,088	,343	,343	,150	,123	,899	,667	,017	,001	,962	,563	,004	,000		,407	,643	,059

	N	156	156	156	156	156	156	156	156	156	156	156	156	156	156	156	156	156	156	156	156	156	156
Spouse	Pearson	,067	-,016	,172*	,143	-,025	-,010	,025	-,025	,020	-,017	**,719****	,189*	,135	-,087	,225**	-,061	-,229**	-,001	-,067	1	**,663****	**,560****
	Sig.	,408	,842	,032	,076	,759	,903	,759	,759	,801	,832	,000	,018	,093	,282	,005	,446	,004	,991	,407		,000	,000
	N	156	156	156	156	156	156	156	156	156	156	156	156	156	156	156	156	156	156	156	156	156	156
Living with pwd	Pearson	-,033	-,098	,148	,116	-,046	-,067	-,002	,002	,045	-,061	,412**	,095	,090	-,186*	-,006	-,033	-,089	,008	-,037	**,663****	**1**	,331**
	Sig.	,681	,226	,065	,151	,572	,407	,983	,983	,576	,451	,000	,241	,263	,020	,944	,683	,268	,921	,643	,000		,000
	N	156	156	156	156	156	156	156	156	156	156	156	156	156	156	156	156	156	156	156	156	156	156
work status	Pearson	-,285**	-,329**	,109	,227**	-,025	,030	-,056	,056	-,006	-,012	**,565****	,075	-,010	-,059	,208**	,001	-,056	-,090	-,151	**,560****	,331**	**1**
	Sig.	,000	,000	,174	,004	,757	,708	,485	,485	,936	,879	,000	,351	,902	,468	,009	,989	,484	,262	,059	,000	,000	
	N	156	156	156	156	156	156	156	156	156	156	156	156	156	156	156	156	156	156	156	156	156	156

Appendix V

Ethical approvals

1. Reginal Committees for medical and health research ethics. Substudy1
2. Reginal Committees for medical and health research ethics. Substudy 2

Emne: Sv: Helsetjenester til eldre personer med demens fra et pårørendeperspektiv.
Fra: post@helseforskning.etikkom.no
Dato: 04.05.2017 11:04
Til: jorun.rugkasa@ahus.no
Kopi:

Vår ref.nr.: 2017/756 B

Hei,

Vi viser til fremleggingsvurdering for prosjektet, «*Helsetjenester til eldre personer med demens fra et pårørendeperspektiv*», mottatt 04.04.2017.

I skjema og vedlagt prosjektbeskrivelse fremkommer det at formål med oppgaven vil være «*å belyse pårørendes perspektiv på og deltagelse i, helsetjenester til eldre personer med demens. Pårørende kan gi et unikt perspektiv på samhandling og tjenesteintegrasjon som er nyttig i fremtidig tjenesteutvikling for en stadig økende gruppe eldre."*

Det er altså ikke direkte ny kunnskap om helse eller sykdom per se som er formålet. Prosjektet faller dermed utenfor bestemmelsene i helseforskningsloven, jf. helseforskningslovens § 4. Prosjektet er ikke fremleggelsespliktig for REK.

Komiteen antar for øvrig at prosjektet kommer inn under de interne regler for behandling av opplysninger som gjelder ved ansvarlig virksomhet. Søker bør derfor ta kontakt med enten forskerstøtteavdeling eller personvernombud for å avklare hvilke retningslinjer som er gjeldende.

Vi gjør videre oppmerksom på at konklusjonen er å anse som veiledende**,** jfr. forvaltningsloven § 11.

Dersom dere likevel ønsker å søke REK vil søknaden bli behandlet i komitémøte, og det vil bli fattet et enkeltvedtak etter forvaltningsloven.

Med vennlig hilsen

Mariann Glenna Davidsen

rådgiver
post@helseforskning.etikkom.no
T: 22845526

Regional komité for medisinsk og helsefaglig
forskningsetikk REK sør-øst-Norge (REK sør-øst)
http://helseforskning.etikkom.no

-------- Original message --------
From: post@helseforskning.etikkom.no
Date: 24/09/2018 09:50 (GMT+01:00)
To: Jorun Rugkåsa <Jorun.Rugkasa@ahus.no>
Subject: Sv: REK sør-øst 2018/1725 Helsetjenester til eldre personer med demens fra et pårørendeperspektiv, del 2

Vår ref.nr.: 2018/1725 C

Hei.

Vi viser til innsendt skjema for fremleggingsvurdering av ovennevnte prosjekt, mottatt 12.09.18.

I henvendelsen angis følgende om prosjektet:
Health Literacy innebærer det å finne, forstå, vurdere og bruke helserelatert informasjon til å ta valg
som fremmer god helse. Hvor tilgjengelighet tjenestene oppleves å være er forbundet med begrepet.
Funn fra studiens del 1 antyder at det er stor variasjon i hvilke helsetjenester som benyttes i forbindelse demens, og hvor lett tilgjengelig disse tjenestene oppfattes å være. Vi ønsker derfor, i del 2, å undersøke om nivået av Health Literacy hos pårørende kan forklare noen av disse ulikhetene.

Studiens del 1 er tidligere vurdert å ligge utenfor helseforskningslovens virkeområde.

I forhold til fremleggingsplikten for del 2 av prosjektet, anfører søker:
Vi vurderer at prosjektet ligger i grenselandet mellom kvalitetssikring og helsetjenesteforskning og
ikke omfattes av helseforkningsoven. Det er viktig for oss å få REKs vurdering av dette spørsmålet
slik at prosjektet kan gjennomføres uten usikkerhet om lovligheten.

Vi deler søkers vurdering av prosjektet, som dermed ikke er avhengig av REK-godkjenning, jf. helseforskningslovens §§ 2 og 4.

Vi antar for øvrig at prosjektet kommer inn under de interne regler for behandling av pasient-/helseopplysninger som gjelder ved ansvarlig virksomhet. Søker bør derfor ta kontakt med enten forskerstøtteavdeling eller personvernombud for å avklare hvilke retningslinjer som er gjeldende.

Vi gjør videre oppmerksom på at konklusjonen er å anse som veiledende jfr. forvaltningsloven § 11.

Dersom dere likevel ønsker å søke REK, vil søknaden bli behandlet i komitémøte, og det vil bli fattet et enkeltvedtak etter forvaltningsloven.

Med vennlig hilsen
Tor Even Marthinsen

seniorrådgiver
post@helseforskning.etikkom.no
T: 22845521

Regional komité for medisinsk og helsefaglig forskningsetikk REK sør-øst-Norge (REK sør-øst)
http://helseforskning.etikkom.no

REK
REGIONALE KOMITEER FOR MEDISINSK OG HELSEFAGLIG FORSKNINGSETIKK

Appendix VI

Approvals from the Privacy Ombudsman

1. Privacy Ombudsman, Substudy 1
2. Privacy Ombudsman, Substudy 2
3. Data Protection Impact Assessment - DPIA, Substudy 2

Personvernombudet
Akershus universitetssykehus HF

AKERSHUS UNIVERSITETSSYKEHUS

PERSONVERNOMBUDETS TILRÅDING ANNEN FORSKNING – IKKE HELSEOPPLYSNINGER KNYTTET TIL ENKELTPERSONER

Til:	Kristin Häikiö, forsker / stipendiat Jorun Rugkåsa, prosjektleder, iflg infoskriv
Kopi:	Hilde Lurås, avdelingsleder, HØKH
Fra:	Personvernombudet for forskning og kvalitetssikring
Saksbehandler:	Marianne B Blair
Dato:	30.05.2017
Offentlighet:	Ikke unntatt offentlighet
Sak:	Personvernombudets tilråding til innsamling og behandling av personopplysninger
Saksnummer/ Personvernnummer:	17/128

Personvernombudets tilråding til innsamling og behandling av personopplysninger for prosjektet "Helsetjenester til eldre personer med demens fra et pårørendeperspektiv.»

Prosjektbeskrivelse, erfarings-intervju av pårørende uten personopplysninger verken personopplysninger om pårørende eller pasienter legges inn i noen datafil eller elektronisk system.

Formål:
Dette prosjektet søker å belyse pårørendes perspektiv på og deltagelse i, helsetjenester til eldre personer med demens. Pårørende kan gi et unikt perspektiv på samhandling og tjenesteintegrasjon som er nyttig i fremtidig tjenesteutvikling for en stadig økende gruppe eldre.

Delmål:
- Å kartlegge de ulike måtene pårørende til demente observerer og interagerer med helsetjenestene.
- Å kartlegge pårørendes observasjoner av tjenesteintegrasjon og hva de mener er vellykkede tjenester.

- Å undersøke hva pårørende oppfatter som materielle og ikke-materielle kostnader, byrder, besparelser eller fordeler av pårørenderollen.

PVO viser til innsendt melding om innhenting av erfaringsbaserte opplysninger om opplevelse av eller erfaring med oppfølgning av pasienter og fra deres pårørende knyttet til dement, og uten nærmere diagnoseangivelse som kan tilbakeføres til enkeltpasienter. Det følgende er personvernombudets tilråding av prosjektet.

Med hjemmel i personopplysningsloven § 31, jf personopplysningsforskriftens § 7-12 jf, har Datatilsynet, ved oppnevning av personvernombud, fritatt sykehuset fra meldeplikten til Datatilsynet. Behandling og utlevering av personopplysninger meldes derfor til sykehusets personvernombud.

Databehandlingen tilfredsstiller forutsetningene for melding gitt i personopplysningsforskriften § 7-27, og er derfor unntatt søknad om konsesjon.

Personvernombudet tilrår at prosjektet gjennomføres under forutsetning av følgende:

1. Databehandlingsansvarlig er Ahus ved adm. dir.
2. Avdelingsleder og forskningsansvarlig i divisjonen/klinikken har godkjent gjennomføringen av prosjektet.
3. Data lagres som oppgitt i meldingen (vedlagt)
4. Innsamling og behandling av opplysningene i prosjektet skjer i samsvar med, og innenfor det formål som er oppgitt i meldingen.
5. Stemmen til ansatte/informanter er personlig og gjenkjennelig på individnivå, og lydopptak må derfor vernes og ikke tilgjengeliggjøres for andre enn prosjektets medarbeidere og legges på et tilgangsstyrt PC som beskrevet i meldingen. Dersom lydfilen ikke tas opp direkte på PC-en må den legges over på PC umiddelbart og slettes fra opptaksutstyret (device) f eks mobiltelefon. Pårørende som intervjues må informeres og godta dette i hht informasjonsskrivet som er fremlagt.
6. Kodeliste som kobler avidentifiserte data med personopplysninger lagres som angitt i meldingen og oppbevares separat nedlåst på adgangsbegrenset rom på sykehuset eller elektronisk som separat fil.
7. Hensynet til den pårørendes / informantenes og pasientenes integritet og konfidensialitet synes tilfredsstillende ivaretatt i fremlagt dokumentasjon. Eventuelle fremtidige endringer som berører formålet, utvalget inkluderte eller databehandlingen må forevises personvernombudet som eventuelt tilrår endringene, før de tas i bruk.
8. Data slettes eller anonymiseres ved prosjektslutt 1.7.2022 ved at kodeliste slettes samme dator, og eventuelle andre identifikasjonsmuligheter i databasen fjernes. Dersom det er nødvendig å oppbevare lydfil og eller kodeliste utover 3 år må personvernombudet forespørres hurtigst mulig og før fristen løper ut. Dette kan i så fall gjøres på email til ombudets postkasse og merket med prosjektnummer 17-128. Når formålet med registeret er oppfylt sendes melding om bekreftet sletting til personvernombudet.

Prosjektet er registrert i oversikten over tilrådinger og uttalelser til forskning og kvalitetsprosjekter som Personvernombudet fører for sykehuset. Oversikten er offentlig tilgjengelig.

Lykke til med prosjektet!

Med vennlig hilsen
for Personvernombudet for forskning og kvalitetssikring

Marianne B Blair
Spesialrådgiver – Helsejus/personvern

Akershus universitetssykehus HF
sekretariatet
1478 LØRENSKOG

Tlf: +47 02900 (sentralbord)
Mobil: +47 482 15 245
E-Post: marianne.b.blair@ahus.no
Web: www.ahus.no

□ Tenk miljø – ikke skriv ut denne om det ikke er absolutt nødvendig!
Dokumentet er signert elektronisk

Personvernombudet
Akershus universitetssykehus HF

AKERSHUS UNIVERSITETSSYKEHUS

PERSONVERNOMBUDETS TILRÅDING ANNEN FORSKNING

Til:	Jorun Rugkåsa, Avdeling for helseforskning, Ahus
Kopi:	Hilde Lurås, Avdeling for helseforskning, Ahus
Fra:	Personvernombudet for forskning og kvalitetssikring
Dato:	07.01.2019
Offentlighet:	Ikke unntatt offentlighet
Sak:	Personvernombudets tilråding til innsamling og behandling av personopplysninger
Saksnummer/ Personvernnummer:	2018_126

Personvernombudets tilråding til innsamling og behandling av personopplysninger for prosjektet "Helsetjenester til eldre personer med demens – fra et pårørendeperspektiv de 2"

Prosjektbeskrivelse:
Dette prosjektet er en videreføring av et allerede godkjent prosjekt med ref.nr 17/128 versjon 3.0.

Dette godkjente prosjektet kalles heretter del 1. Det som nå søkes om er å gjøre en del 2 som bygger på funnene i del 1.
Både del 1 og del 2 søker å belyse pårørendes perspektiv på og deltagelse i, helsetjenester til eldre personer med demens. Pårørende kan gi et unikt perspektiv på samhandling og tjenesteintegrasjon som er nyttig i fremtidig tjenesteutvikling for en stadig økende gruppe eldre. Formålet med del 2 er å undersøke nivået av Health Literacy og om ulikheter i Health Literacy har sammenheng med pårørendes opplevelse av belastning, livskvalitet og tid brukt på omsorgsarbeid, samt undersøke om bakgrunnsvariabler som yrke, arbeid, kjønn osv påvirker resultatet.*
Forskningsspørsmål del 2
- *Hvor høyt er nivået på Health Literacy i populasjonen til pårørende til eldre personer med demens i Norge?*
- *Er det sammenheng mellom nivået av Health Literacy og subjektiv pårørendebelastning?*
- *Er det sammenheng mellom nivået av Health Literacy og Helserelatert livskvalitet*
- *Er det sammenheng mellom Health Literacy og hvor mye tid man benytter på omsorgsoppgaver?*
- *Er det sammenheng mellom Health Literacy og hvor lenge pårørende står i lønnet arbeid?*
- *Er det sammenheng mellom Health Literacy og noen av bakgrunnsvariablene?*

** Health Literacy er knyttet til det å finne, forstå, vurdere og bruke helseinformasjon til fordel for egen helse.*

Viser til innsendt melding om behandling av personopplysninger / helseopplysninger. Det følgende er personvernombudets tilråding av prosjektet.

Med hjemmel i forordning (EU) nr. 2016/679 (generell personvernforordning) artikkel 37, er det oppnevnt personvernombud ved Akershus Universitetssykehus (Ahus).

Den behandlingsansvarlige skal sikre at personvernombudet på riktig måte og i rett tid involveres i alle spørsmål som gjelder vern av personopplysninger, jf. artikkel 38. Artikkel 30 pålegger Ahus å føre oversikt over hvilke behandlinger av personopplysninger virksomheten har. Behandling av personopplysninger meldes derfor til sykehusets personvernombud.

Før det foretas behandling av helseopplysninger, skal dataansvarlig rådføre seg med personvernombudet, jf. personopplysningsloven §§ 9 eller 10. Ved rådføringen skal det vurderes om behandling oppfyller kravene i personvernforordningen og øvrige bestemmelser fastsatt i eller med hjemmel i loven her.

Personvernombudet tilrår at prosjektet gjennomføres under forutsetning av følgende:

1. Databehandlingsansvarlig er Ahus ved adm. dir.
2. Avdelingsleder og forskningsansvarlig i divisjonen/klinikken har godkjent gjennomføringen av prosjektet.
3. Behandling av personopplysningene / helseopplysninger i prosjektet skjer i samsvar med og innenfor det formål som er oppgitt i meldingen.
4. Data lagres som oppgitt i meldingen og det er i samsvar med sykehusets retningslinjer.
5. Kodeliste som kobler avidentifiserte data med personopplysninger lagres som angitt i meldingen og oppbevares separat nedlåst på adgangsbegrenset rom på sykehuset eller elektronisk som separat fil på tilgangsstyrt prosjektområde på forskningsserver i sikker sone. Kontakt datafangstgruppen for opprettelse av prosjektområde på forskningsserver på datafangst@ahus.no
6. Hensynet til pasientens integritet og konfidensialitet synes tilfredsstillende ivaretatt.
7. Det rettslige grunnlaget for databehandlingen er personvernforordningen artikkel 9 punkt 2 a) - studien er frivillig og samtykkebasert.
8. Vedlagte samtykke benyttes, inklusive markerte tillegg og endringer foretatt av personvernombudet. Eventuelle fremtidige endringer som berører formålet, utvalget inkluderte eller databehandlingen må forevises personvernombudet før de tas i bruk.
9. Den behandlingsansvarlige har rådført seg med personvernombudet, jf. personopplysningsloven § 10.
10. Det er gjennomført en personvernkonsekvensvurdering, jf. forordningens artikkel 35, hvor risikoen for personvernskonsekvenser er vurdert til å være på et akseptabelt nivå.
11. Dersom formålet eller databehandlingen endres må personvernombudet informeres om dette.
12. Kontaktperson for prosjektet skal hvert tredje år sende personvernombudet ny melding som bekrefter at databehandlingen skjer i overensstemmelse med opprinnelig formål og helseregisterlovens regler.
13. Data slettes eller anonymiseres ved prosjektslutt 01.07.2025. Når formålet med registeret er oppfylt sendes melding om bekreftet sletting til personvernombudet.

Prosjektet er registrert i oversikten over tilrådinger og uttalelser til forskning og kvalitetsprosjekter som Personvernombudet fører for sykehuset. Oversikten er offentlig tilgjengelig.

Lykke til med prosjektet!

Med vennlig hilsen
for Personvernombudet for forskning og kvalitetssikring

Line Mostad Samuelsen
Jurist/ personvernrådgiver

Akershus universitetssykehus HF

Epost: fellesmail.personvernombud@ahus.no
Web: www.ahus.no

Dokumentet er signert elektronisk

PERSONVERNKONSEKVENSVURDERING

Prosjektopplysninger

Prosjekttittel: Helsetjenester til eldre personer med demens – fra et pårørendperspektiv del 2 (pvo-nr. 2018-126)
Prosjektleder: Jorun Rugkåsa
Prosjektets tilhørighet (avdeling): HØKH
Arkivnummer (P-360): 16/10997

Behov for personvernkonsekvensvurdering:

Når må DPIA gjennomføres?

> *«Dersom det er sannsynlig at en **type behandling**, særlig ved bruk av ny teknologi og idet det tas hensyn til behandlingens **art, omfang, formål og sammenhengen den utføres i**, vil medføre en **høy risiko** for fysiske personers **rettigheter og friheter**, skal den behandlingsansvarlige før behandlingen foreta en vurdering av hvilke konsekvenser den planlagte behandlingen vil ha for vernet av personopplysninger.»* (GDPR art.35.1)

Kriterier når DPIA *kan* bli et krav når to eller flere av følgende kriterier er oppfylt:

1. **Evaluering eller scoring**, spesielt knyttet til arbeidsresultater, økonomisk situasjon, helse, personlige preferanser eller interesser, oppførsel og adferd, lokasjon og bevegelser osv.
2. **Automatiserte beslutninger** med juridisk eller tilsvarende betydning.
3. **Systematisk overvåking** av registrerte.
4. **Særlige kategorier personopplysninger** eller **andre sensitive personopplysninger av høy personlig karakter** (sistnevnte spesielt knyttet de enkeltes «friheter», men kan også omfatte f.eks. økonomiske og finansielle opplysninger).
5. **Databehandling i stort omfang**, som at det er et stort antall registrerte involvert, store mengder data, mange ulike typer data, lang varighet av behandlingen, stor geografisk utbredelse av behandlingen osv.
6. **Kombinering eller sammenstilling av datasett**.
7. Personopplysninger vedrørende **spesielt sårbare registrerte** (som barn, ansatte, psykisk syke, asylsøkere, eldre, pasienter mv.).
8. **Innovativ eller nyskapende bruk av personopplysninger,** som f.eks. bruk av biometriske data for tilgangskontroll, Internet of Things-løsninger, velferdsteknologi osv.
9. Når behandlingen i seg selv **forhindrer eller begrenser de registrertes mulighet til å utøve sine rettigheter** etter loven eller avtale, eller **bruke tjenester**.

Vurderingsspørsmål:

Nr.	Vurderingsspørsmål	Ja/Nei
1.	Er dette et nytt prosjekt eller prosess?	Ja
2.	Vil prosjektet innebære innsamling av ny informasjon om enkeltpersoner?	Ja
3.	Vil prosjektet be enkeltpersoner om å gi informasjon om seg selv?	Ja
4.	Vil informasjon om enkeltpersoner bli delt med organisasjoner eller personer som ikke tidligere har hatt rutinemessig tilgang til informasjonen?	Nei
5.	Skal du bruke informasjon om enkeltpersoner som er innsamlet for et formål, men der opplysningene for tiden ikke er eller ikke lenger er i bruk (ikke behandles utover lagring)?	Nei
6.	Innebærer prosjektet at du bruker ny teknologi som kan oppfattes som inngripende for personvernet? For eksempel, bruk av biometri eller ansiktsgjenkjenning?	Nei
7.	Vil prosjektet resultere i at du tar beslutninger eller gjennomfører tiltak mot enkeltpersoner på måter som kan ha en betydelig innvirkning på dem?	Nei
8.	Basert på typen informasjon om enkeltpersoner, er det spesielt sannsynlig at bekymringen for eller forventninger til personvernet vil øke?	Ja
9.	Vil prosjektet kreve at du kontakter personer på måter som de kan finne inngripende?	Nei
10	Vil prosjektet innebære databehandling i stort omfang, som at det er et stort antall registrerte involvert, store mengder data, mange ulike typer data, lang varighet av behandlingen, stor geografisk utbredelse av behandlingen osv?	Nei

Dersom svaret er "ja" på ett eller flere av spørsmålene ovenfor, kan det bety at det er behov for en DPIA. For bistand til behovsvurdering og/ eller gjennomføring av DPIA kan man kontakte avdeling for forskningsstøtte.

Formell beslutning for gjennomføring av konsekvensutredningen ligger hos avdelingsleder. Dersom det besluttes at det ikke er behov for å gjennomføre en DPIA, skal det begrunnes hvorfor.

Avdelingsleder ved HØKH, Avd. helsetjenesteforskning Hilde Lurås har besluttet at det skal:

☒ Gjennomføres en personvernkonsekvensvurdering (DPIA)

☐ Ikke gjennomføres en personvernkonsekvensvurdering (DPIA)

Begrunnelse for gjennomføring/ ikke gjennomføring av DPIA: Dette er et nytt prosjekt som samler ny informasjon om enkeltpersoner

Organisering av personvernkonsekvensvurderingen og ansvarsforhold

Prosjektleder, (eventuelt med bistand fra en prosjektgruppe) har gjennomført en personvernkonsekvensvurdering. Vurderingen er godkjent av (ansvarlig leder i henhold til fullmakt).

Følgende personer har deltatt i prosjektgruppen som har gjennomført personvernkonsekvensvurderingen:

Navn	Rolle/funksjon	Avdeling
Jorun Rugkåsa	Prosjektleder	HØKH
Kristin Häikiö	PhD stipendiat	HØKH
Hilde Lurås	Avd.leder	HØKH

1. Behandling av personopplysninger i prosjektet

1.1 Formålet med behandlingen av personopplysninger

Formålene skal være spesifikke, uttrykkelig angitte og berettigede. For forskning innebærer det at det må formuleres konkrete forskningsspørsmål som skal besvares gjennom bruken av opplysningene. Prosjektbeskrivelse/forskningsprotokoll skal vedlegges.

Prosjektleders beskrivelse av formålet:

Pårørende er i økende grad tiltenkt en rolle i hvordan offentlig politikk søker å utøve helsetjenester. Det er imidlertid variasjon i hvordan pårørende er rustet til, og opplever denne rollen. Pårørende til personer med demens er ofte spesielt aktive i omsorgen som ytes, ikke minst som et bindeledd mellom ulike aktører. I analysene av dybdeintervjuer i kvalitativt prosjekt om pårørende til personer med demens (PVO ref: 17/128) fant vi at begrepet 'Health Literacy' kan ha potensiale til å øke forståelsen av pårørenderollen. 'Health Literacy' er beskrevet som følger: *"Health Literacy is linked to literacy and entails people's knowledge, motivation and competences to access, understand, appraise and apply health information in order to make judgments and take decision in everyday life concerning health care, disease prevention and health promotion to maintain or improve quality of life during the life course"* (Sørensen, Van Den Brouche et al. 2012).

Formålet med dette prosjektet er å gå videre med funnene fra den kvalitative undersøkelsen i en spørreundersøkelse hvor vi skal måle nivået av Health Literacy hos pårørende til eldre personer med demens og undersøke assosiasjonen mellom Health Literacy og livskvalitet, pårørendebyrde, tidsbruk, og utdanning/yrkesbakgrunn. I tillegg justeres analysene av sosiodemografiske variabler. Forskningsspørsmålene er som følger:

- What is the level of Health Literacy among family carers to older people with dementia in Norway?
- What is the association between Health Literacy and subjective carers' burden?
- What is the association between the level of Health Literacy and Health related Quality of Life?
- What is the association between Health Literacy and how much time family carers spend on caring?
- What is the association between Health Literacy and a background variable as a health care worker?

1.2 Datakilder

Kryss av for om det skal innhentes nye personopplysninger (egen datainnsamling) og/eller allerede registrerte opplysninger, og spesifiser i feltet under.

☒ Egen datainnsamling (prosjektet vil innhente <u>direkte</u> fra den opplysningen(e) gjelder)

☐ Sentrale helseregistre
☐ Helseundersøkelser (eksisterende)
☐ Kvalitetsregistre
☐ Pasientjournal
☐ Bildediagnostikk
☐ Folkeregisteret
☐ SSB
☐ NAV

☐ Internett
☐ Annet (spesifiser under)

Spesifisering av datakildene det er krysset av for:

Spørreundersøkelse i papirversjon eller digital versjon til pårørende til eldre personer med demens som er i kontakt med helsetjenestene. De fleste data er ikke sensitive. Et begrenset antall data er indirekte identifiserbare når de sees i kombinasjon.

Dersom det er krysset av for kvalitets- eller helseregistra, angi hvilke:

Beskriv kobling dersom dette er relevant:

1.3 Registrerte

Registrerte er den/de opplysningene gjelder, ofte kalt prosjektdeltakere.

Kryss av for hvilke kategorier av registrerte det skal behandles opplysninger om.

☐ Elever/studenter/barnehagebarn

☐ Pasienter/klienter/brukere

☐ Barn, spesifiser aldersgrupper

  ☐ 0-11
  ☐ 12-15
  ☐ 16-18

☒ Pårørende

☐ Etniske minoriteter

☐ Avdøde

☐ Pasienter uten samtykkekompetanse

☐ Annet (spesifiser under)

Beskriv utvalget, eventuelt underutvalg:

Ca 500 pårørende til eldre personer med demens i fra ulike steder i Norge. Pårørende kan være familie, venn eller nabo. Pårørende vil få tilbud om å delta i studien gjennom demensteam, hjemmesykepleiere eller annet helsepersonell som er i kontakt med familien. Link til spørreundersøkelsen vil også gjøres tilgjengelig på f.eks. kommunens nettsider, i digitale nyhetsbrev og på relevante Facebook-sider. Det er frivillig å delta.

Antall registrerte:

500 utsendte spørreskjemaer og forhåpentligvis ca 150 spørreskjemaer som leveres tilbake til oss i utfylt tilstand

Geografisk omfang:

Hele Norge

1.4 Kategorier av personopplysninger

Kryss av for hvilke kategorier personopplysninger som vil behandles i prosjektet.

Kategorier av personopplysninger

☐ Navn

☐ Adresse

☐ Fødselsdato

☐ Fødselsnummer (11 siffer)

☒ Andre opplysninger, for eksempel telefonnummer, e-postadresse, IP-adresse, demografiske variabler, sosioøkonomi (utdanning, inntekt, yrke), familiestatus, biometri

Angi hvilke:

Om pårørende:
Kjønn, fødselsår, om vedkommende er født i Norge (ja/nei), utdanningsnivå, relasjon til personen de er pårørende til, om pårørende bor sammen med personene med demens, yrke, og grad av yrkesaktivitet.

Om personen med demens spørres den pårørende om :
Vedkommende er født i Norge (ja/nei), om vedkommende bor i egen bolig, institusjon eller sammen med pårørende.

Særlige kategorier av personopplysninger (tidligere kalt sensitive opplysninger)

☐ Rasemessig eller etnisk bakgrunn

☐ Politisk, filosofisk eller religiøs oppfatning

☐ At en person har vært mistenkt, siktet, tiltalt eller dømt for en straffbar handling

☐ Seksuelle forhold

☐ Medlemskap i fagforeninger

☐ Biometri med det formål entydig å identifisere en person

☐ Helseforhold:

  ☐ Diagnoser

- ☐ Legemiddelbruk
- ☐ Kognitive evner
- ☐ Genetiske opplysninger
- ☒ Annet, spesifiser under

Spesifisering av hvilke opplysninger:

Vi måler Helserelatert Livskvalitet hos pårørende i form av problemer med gange, personlig stell, vanlige gjøremål, smerter/ubehag og angst/depresjon.

Vi måler pårørendes opplevelse av belastning i form av i hvilken grad de opplever ulike negative følelser.

Vi ber pårørende vurdere funksjonsnivå hos personen med demens i form av hvor godt de klarer seg selv eller trenger hjelp i kjente og ukjente omgivelser

Nivå på variabler:

Data samles på personnivå, men ingen variabler analyseres på personnivå. Alle data analyseres på gruppenivå

1.5 Behandling av personopplysninger

Med «behandling» menes enhver operasjon eller rekke av operasjoner som gjøres med personopplysninger.

Kryss av for hva som skal gjøres med personopplysningene i prosjektet og eventuelt spesifiser. Behandlingene må være i samsvar med det oppgitte formål.

- ☒ Innsamling
- ☒ Lagring
- ☐ Sammenstilling, kobling
- ☒ Analysering
- ☐ Utlevering ved overføring
- ☐ Tilgjengeliggjøring
- ☐ Gjenfinning *(for eksempel ved planlagt tilbakemelding til de registrerte)*
- ☒ Sletting, anonymisering
- ☐ Annen bruk (spesifiser under)

Spesifiser behandlingen av personopplysningene:

Opplysninger samles inn via spørreskjema på papir eller digitalt. Papirbesvarelser oppbevares i låsbar skuff på låsbart kontor. Elektronisk versjon er kryptert og lagres på tilgangsstyrt forskningsserver. Informasjonen overføres til statistikkprogrammet SPSS før forskerne får adgang. SPSS-filen lagres, og alle analyser gjennomføres på forskningsserver. Resultater formidles nasjonalt og internasjonalt på konferanser, fag-tidsskrifter og forskningstidsskrifter i et format hvor ingen enkeltpersoner kan gjenkjennes. Før publisering vil vi gjøre en særskilt vurdering av muligheten til å gjenkjenne enkeltpersoner. Data slettes senest 1.7.2025

Angi frekvens på innsamlingen:

Opplysninger samles inn en gang

Beskriv hvordan opplysningene samles inn:

Spørreskjema på papir og digitalt. Spørreskjemaet sendes tilbake til forskeren i ferdigfrankerte, adresserte konvolutter. Svarene plottes inn i en SPSS-database på forskningsserver av to personer. De to filene sammenlignes og ved eventuell diskrepans går man tilbake til papirskjemaet, kontrollerer og retter opp feil.

De digitale spørreskjemaene bruker Snap Survey som er utviklet av Ahus' datafangsgruppe, og prosessen er riskikovurdert (ROS-analyse). Personen som skal svare på spørreskjema setter seg ved en pc som er koblet til internett. Brukeren klikker på en web-link som åpner web-siden hvor undersøkelsen ligger. Websiden for undersøkelsen er lokalisert hos Ahus. Kommunikasjonen mellom personen som registrerer og web-serveren er kryptert, med et sertifikat som har 1024 bits krypteringsnøkkel. Etter at et skjema er fylt, og knappen "send inn" er klikket på, genereres det en fil av svarene. Filen legges på et bestemt område på web-serveren. Det er kun root/system brukeren som har tilgang her. Det er satt opp en tjeneste i intern sone hos Ahus. Denne tjenesten flytter data fra dmz sonen til server i intern sone hvert 10 minutt. Filene i intern sone vil ved jevne mellomrom bli tatt hånd om av It-personer ved Ahus. Registrerte data for spørreskjema blir lest inn i SnapSurvey ved jevne mellomrom. Data ligger på egen server i Ahus' interne nett. Data blir deretter eksportert til SPSS(eller Excel) fil. Forskeren som foretar undersøkelsen vil så få tilgang til SPSS/Excel filen på nettverket til Ahus.

1.6 Lagringssted og lagringsmedier

Angi hvor og hvordan personopplysninger skal lagres og håndteres.

☐ Tjenester for Sensitive Data (TSD)
☒ Tilgangsbegrenset forskningsfilmappe
☐ Sikker sone
☐ Kryptert minnepinne
☐ Annet, spesifiser:

Spesifiser lagringen av personopplysningene:

Det samles kun indirekte identifiserbare data. Disse lagres i tilgangsbegrenset forskningsfilmappe.

1.7 Dataansvarlig, datatilgang og databehandlere

1.7.1 Dataansvarlig og personer med datatilgang

Dataansvarlig:

Følgende prosjektmedarbeidere og annet personell vil ha tilgang til data i prosjektet:

Navn	Rolle/funksjon	Virksomhet
Jorun Rugkåsa	Prosjektleder	HØKH, Ahus
Kristin Häikiö	PhD stipendiat	HØKH, Ahus
Jurate Saltyte Benth	Statistiker	HØKH, Ahus

Navn	Rolle/funksjon	Virksomhet
Kim Rand	Prosjektmedarbeider	HØKH, Ahus

Hvordan medarbeiderne skal få tilgang til data:

Prosjektleder autoriserer tilgang og ber datafangstgruppen på Ahus om å gi medarbeiderne tilgang på dataområdet.

Dersom studien gjennomføres som en multisenterstudie med felles dataansvar, angi hvilke institusjoner som deltar:

Ikke aktuelt

Hvilke opplysninger overføres:

Hvordan opplysningene vil overføres:

1.7.2 Databehandler

Dersom det benyttes databehandler(e), fyll inn informasjon:

Virksomhet	Rolle/funksjon	Land
Datafangst, Ahus	Lager og håndterer digitalt spørreskjema	Norge

Hvordan personopplysninger utleveres til ekstern institusjon:

Ingen

For hver databehandler skal det godtgjøres at de gir tilstrekkelige garantier for at behandlingen oppfyller kravene i forordning og vern av den registrertes rettigheter.

For databehandler(e) er følgende oppfylt:

☐ Databehandleravtale som oppfyller forordningens krav

☐ Mottatt og gjennomgått ROS (vedlegges)

☐ Mottatt beskrivelse av tekniske og organisatoriske tiltak

☐ Mottatt oversikt over underleverandører

Hvis man benytter databehandlere, er det viktig at disse selv bidrar med informasjon om blant annet personopplysningsvern/informasjonssikkerhet, og kontakten bør beskrives.

Er databehandlerne involvert i personvernkonsekvensvurderingen? Beskriv hvordan databehandler(e) har vært involvert:

1.7.3 Overføring av personopplysninger til andre land og/eller internasjonale organisasjoner

Skal personopplysninger utleveres til personer/institusjoner utenfor Norge?

Nei

Dersom ja:

Skal personopplysninger føres til tredjeland (utenfor EU/EØS) og/eller internasjonale organisasjoner?

Ja/ nei

Dersom ja:

I den grad personopplysninger skal overføres til land utenfor EØS-området eller internasjonale organisasjoner, må det beskrives hvordan pliktene etter kapittel V i personvernforordningen skal oppfylles.

Overføringene vil skje på følgende grunnlag:

☐ Beslutning om at det aktuelle land har et tilstrekkelig beskyttelsesnivå

☐ Overføringen er omfattet av nødvendige garantier, slik som EUs standardavtaler, beskriv under:

____

☐ Overføringen er underlagt bindende virksomhetsregler, beskriv under:

____

☐ Unntak for særlige situasjoner, beskriv under:

____

Hva er rettslig grunnlag for overføring utenfor EØS?

Redegjør for hvordan personopplysningene overføres og lagres ved overføringen:

1.8 Adferdsnormer

I den grad det finnes godkjente adferdsnormer for den aktuelle behandling, f.eks. NORMEN eller BBMRI Code of Conduct, skal disse angis og det skal opplyses om de vil følges i behandlingen av personopplysninger i prosjektet.

Det er foreløpig ikke etablert godkjente adferdsnormer, og dette punktet er ikke obligatorisk. Vi har derfor ikke gjort vurderinger her.

Oppgi dersom adferdsnorm skal følges i behandlingen av personopplysninger:

2 Rettslig grunnlag for behandling av personopplysninger

2.1 Rettslig grunnlag for behandling av personopplysninger

Nr.	Vurderingsspørsmål	Svar (forklar svar)
1.	Er behandlingen av personopplysninger lovlig etter personvernforordningen artikkel 6?	Behandlingen faller etter vår vurdering under artikkel 6.1.e. om *å «utføre en oppgave i allmennhetens interesse»*. Vi vil særlig undersøke konsekvenser og muligheter i pårørenderollen i utøvelsen av omsorg til personer med demens, noe som er et underutviklet kunnskapsområde samtidig som pårørenderollen stadig blir viktigere i offentlig politikk og tjenesteutøvelse
2.	Er behandlingen av særlige kategorier av personopplysninger lovlig etter personvernforordningen artikkel 9?	Behandlingen, slik vi beskriver den i dette dokumentet faller etter vår vurdering under artikkel 9.2.g om *«viktige allmenne interesser….som skal stå i et rimelig forhold til det mål som søkes oppnådd, være forenlig med det grunnleggende innholdet i retten til vern av personopplysninger og sikre egnede og særlige tiltak for å verne den registrertes grunnleggende rettigheter og interesser»*.
3.	Finnes det hjemmelsgrunnlag i forskrift eller lov for behandlingen av personopplysninger?	Ja, som over
	Finnes det forhåndsgodkjenning fra REK eller konsesjon fra Datatilsynet, eller dispensasjon fra taushetsplikten?	Vurdering fra REK om at studien faller utenfor helseforskningsloven: Ref.nr 2018/1725

2.2 De registrertes rettigheter

Alle kan trekke seg fra studien eller la være å delta i studien uten å oppgi forklaring/årsak

2.2.1 Samtykke

Dette punktet gjelder for de prosjektene hvor det skal innhentes eget samtykke eller benyttes opplysninger fra allerede innsamlede befolkningsbaserte helseundersøkelser.

Spesifiser og vurder prosess for innhenting av samtykke:

Nr.	Vurderingsspørsmål	Svar (forklar svar)
1	Forutsettes det samtykke for behandlingen?	Ja
2	Hvordan vil samtykke bli innhentet?	Det beskrives i informasjonsskrivet at det å besvare spørreskjemaet og sende inn besvarelsen vil bli regnet som samtykke til å delta i studien. I den digitale versjon, vil deltakerne krysse av for at de samtykker til deltakelse før spørreundersøkelsen starter. De vil ikke kunne besvare før de har krysset av.
3	Er alle kravene til samtykke oppfylt? Samtykke fra den registrerte må være frivillig, spesifikk, informert og utvetydig (GDPR art.4).	Ja, dette spesifiseres i informasjonsskrivet
4	Hvordan dokumenteres samtykke?	Mottatt spørreskjema er et dokumentert samtykke for papirskjemaer, og for de digitale er samtykket avkrysset.
5	Kan samtykke trekkes tilbake like enkelt som det gis?	Ja, ved hjelp løpenummer kan deltakere trekke sin besvarelse fra studien
6	Foreligger det informasjon til den registrerte om muligheten til å trekke tilbake samtykke?	Ja, dette er eksplisitt beskrevet i informasjonsskrivet
7	Omfatter samtykket alle behandlinger og behandlingsformål som nevnt i kapitel 1?	Ja

Samtykkeerklæring skal vedlegges

Evt kommentarer:

Det spesifiseres at ved å besvare og returnere spørreskjemaet, vil dette tolkes som et samtykke til å delta i studien. Vi ber ikke om samtykkeerklæring med navn og/eller signatur, siden dette vil kompromittere anonymiteten.

2.2.2 Informasjon om behandlingen

Det må beskrives hvordan informasjon om behandling av personopplysninger vil gis til de registrerte. Informasjonsplikten gjelder for alle forskningsprosjekter uavhengig om det er samtykkebasert eller det kun benyttes registerdata.

Informasjonen gis på følgende måte(r):

☒ Informasjonsskriv i forbindelse med samtykke

☐ Generell informasjon om forskning i innkallingsbrev

☐ Informasjon på nett

☐ Nyhetsbrev

☐ Brev

☒ Sosiale medier

☐ Offentlig informasjonskampanje

☐ Annet, spesifiser:

Utarbeidet informasjonsmateriell skal vedlegges (eller lenke til informasjon på nett):

Informasjonsskriv er vedlagt.

2.2.3 Rett til innsyn, behandlingsbegrensning, retting, sletting og portabilitet

Hvilke virkemidler er etablert for å ivareta de registrertes rett til innsyn, innsigelser (behandlingsbegrensning), retting og sletting og (eventuelt) hvordan retten til dataportabilitet oppfylles, samt hvordan eventuelle krav som dataansvarlig mottar vil følges opp overfor databehandlere.

For de prosjektene som ikke har direkte personidentifiserbare data eller tilgang til koblingsnøkkel, skal henvendelser henvises til forvalter av eventuell koblingsnøkkel.

Følgende virkemidler etablert:

☒ Kontaktinformasjon for innsynskrav – *skal stå i informasjonsskriv*

☐ Skjema for å be om innsyn – *kan utarbeides for forskningsprosjektet med egen innsamling*

☐ Retningslinje for behandling av innsynskrav (jf. EQS rutine *Ahus - Den registrertes rettigheter i kvalitets- og forskningsprosjekter*)

☐ Retningslinje for retting og sletting (jf. EQS rutine *Ahus - Den registrertes rettigheter i kvalitets- og forskningsprosjekter)*

☐ Mal for standardsvar – *dette kan utarbeides ved planlagt tilbakemelding til deltakere eksempelvis om analyseresultat*

☐ Databehandleravtale med klausuler som sikrer de registrertes rettigheter – *aktuelt ved bruk av databehandler(e)*

☐ Annet, spesifiser under:

2.2.4 Ivaretakelse av de registrertes rettigheter og friheter

Personvernskovensjonens fortale pkt 4:

«Behandling av personopplysninger bør ha som formål å tjene menneskeheten. Retten til vern av personopplysninger er ikke en absolutt rettighet; den må ses i sammenheng med den funksjon den har i samfunnet, og veies mot andre grunnleggende rettigheter i samsvar med forholdsmessighetsprinsippet.»

Nr.	Vurderingstemaer	Svar (forklar svar)
1.	Vurder hvordan de registrertes friheter i forhold til Den europeiske menneskerettskonvensjonen (EMK) er tatt hensyn til:	
	• Retten til privatliv og kommunikasjonsvern	Deltagelse er frivillig og alle svar gis på frivillig basis
	• Retten til ikke å bli diskriminert	Data er kun indirekte identifiserbare og vil ikke analyseres på individnivå. Det samles ikke sensitive data om f.eks etnisitet eller religion. Resultatene av studien har potensiale til å identifisere ulikehet og bidra til å hemme disse. Før publisering vil vi gjøre en særskilt vurdering av muligheten til å gjenkjenne enkeltpersoner.
	• Tanke-, tros- og religionsfrihet	Som over
	• Ytrings-, og informasjonsfrihet	Som over

2.3 Personvernsprinsippene

Nr.		Vurderingsspørsmål	Svar (forklar svar)
1		Er behandlingen basert på lovlighet, rettferdighet og åpenhet (GDPR art.5.1 bokstav a og art.6 og 9)?	
	a.	Kommer det rettslige grunnlaget/behandlingsgrunnlaget tydelig frem?	Vi vurderer at behandlingen har lovgrunnlag idet den er nødvendig for formål knyttet til vitenskapelig, forskning. Samfunnets interesse av at behandlingen finner sted overstiger etter vår mening ulempene for den enkelte

	b.	Vurder rimeligheten av behandlingen: *Hva er forventede fordeler ved behandlingen? For virksomheten, den registrerte, samfunnet for øvrig osv.*	Gjennom å belyse pårørendes syn på helsetjenestene til eldre personer med demens, kan vi videreutvikle helsetjenestene og bidra til bedre, tryggere og mer kostnads-effektive helsetjenester
	c.	Hva vil konsekvensene være dersom behandlingene ikke gjennomføres?	Vi vil vite mindre om hvilke fordeler og ulemper pårørende til eldre personer med demens opplever i relasjon til helsetjenestene og i større grad kunne tilpasse fremtidens helsevesen til behov
2	Formålsbegrensninger		
	a.	Er formålet definert slik at det samsvarer med forventningene til de registrerte?	Ja, formålet er klart beskrevet i informasjonsskrivet og delvis gjentatt i spørreskjemaet
	B	Har det vært vurdert andre alternativer for å oppnå formålet med behandlingen?	Det ble vurdert at det var behov for å undersøke temaet i på et større utvalg enn det som er tilfelle ved en-til-en intervju. Anonyme spørreskjemaer ble vurdert som nyttig til formålet og lite inngripende for deltakerne
	c.	Finnes det mindre personverninngripende alternativer for å oppnå det samme formålet?	Nei
3	Dataminimering. Kan formålet oppnås ved for eksempel:		
	a.	å begrense innsamling av personopplysninger?	Nei, det er tatt nøye stilling til om alle spørsmålene må være med i studien. Dataomfanget er allerede minimert i lys av en kvalitativ studie i forkant som har gjort denne spørreundersøkelsen til en fokuset og avgrenset studie
	b.	med mindre detaljerte personopplysninger?	Vi spør ikke om full fødselsdato, kun årstall, da det er tilstrekkelig nyansert for vårt bruk
	c.	uten fortrolige eller sensitive personopplysninger?	Opplysningene er kun indirekte identifiserbare og vi samler ikke informasjon om diagnoser
	Begrunn nødvendighet og relevans relatert til formål for alle opplysninger som behandles.		
4	Riktighet		
		Vurder hvordan personopplysninger holdes	Det er kun et datasamlingspunkt.

		korrekte og oppdaterte, med og uten den registrertes involvering.	Alle data gis av deltageren som dermed har full kontroll på dataene som registreres om dem. Alle data plottes og kontrolleres av to personer. Ved eventuell diskrepans går man tilbake til papirskjemaet, kontrollerer og retter opp feil.
5	Lagringsbegrensning		
	a.	Vurder om personopplysninger lagres etter at formålet er oppnådd og når opplysningene slettes.	Vi samler ikke personidentifiserbare opplysninger. Sosiodemografiske opplysninger samles på forskningsserveren og slettes ved prosjektslutt, 1.7.2018
	b.	Vurder når personopplysninger anonymiseres eller pseudonymiseres som muliggjør videre lagring.	Alle data er kun indirekte identifiserbare. Hvert enkelt spørreskjema vil slettes/makuleres ved prosjektslutt.
	c.	Vurder hvilke garantier som må være plass dersom personopplysninger skal lagres i lenger perioder grunnet arkivformål i allmennhetens interesse, for formål knyttet til vitenskapelig eller historisk forskning eller for statistiske formål (GDPR art.89 nr.1).	Lagrer kun indirekte identifiserbare data og disse er lagret på tilgangsstyrt forskningsserver

Følgende tiltak planlegges for å sikre formålsbegrensning og dataminimering:

For eksempel: Dokumentasjon av hvilke data som hentes ut fra kliniske systemer, og at dette er i tråd med forskningsspørsmålet. Data må avidentifiseres, og kodeliste lagres på adskilt område fra dataene.

2.4 Lagring

Lagringstid skal beskrives og begrunnes.

Prosjektleder må ta stilling til hvor lenge det vil være behov for behandling av personopplysningene:

☒ Forhåndsfastsatte slettedatoer (spesifiser, og begrunn med tid for analyse, etterfølgende oppbevaring for dokumentasjon/arkivformål

☐ Tidsbegrenset, men uten fastsatt dato (angi kriterier for fastsetting av varighet)

Her må det fastsettes en foreløpig slettedato eller dato for ny vurdering av behov for videre oppbevaring.

Spesifiser lagringstid og dato for sletting/anonymisering:

Vi vil analysere dataene frem til prosjektslutt i 1.7.2025 og da skal alle dataene slettes. Skulle det i perioden frem til da oppstå hensyn til etterprøvbarheten av analysene som gjør at det er viktig å lagre dataene lenger, vil dette kun gjøres etter tilrådning av PVO.

Beskriv hvordan det er vurdert ulik lagringstid for ulike data, både i prosjektperioden og av hensyn til etterprøving:

Alle data vil lagres like lenge.

3 Personvern, risikoanalyse og tiltak

Vurdering av risiko for de registrertes rettigheter og friheter, og planlagte tiltak for å håndtere risikoene.

3.1 Medbestemmelse, åpenhet, forutsigbarhet

Vurdering av risikoens opprinnelse, art, særegenhet og alvorlighetsgrad. Vurderingen skal gjøres fra de registrertes perspektiv for hver risiko:

Deltagelse er frivillig. Deltagelse innebærer ingen endringer i nåværende tjenester, behandling eller tilbud. Prosjektet informerer om formål og konsekvenser for deltakerne og gir dem frihet til å la være å delta og å trekke seg fra studien. De har også mulighet til å kontakte forskeren og stille ytterligere spørsmål. Et informasjonsskriv som forklarer formål, rettigheter og konsekvenser for deltakerne, samt hvordan dataen vil brukes, noe som gjør databruken forutsigbar for deltageren. Vi samler kun indirekte identifiserbare data, disse lagres på tilgangsstyrt forskningsserver og analyser skjer kun på gruppe-nivå, tiltak som alle reduserer risikoen for deltakerne.

Avklar potensielle konsekvenser, anslå alvorlighetsgrad, identifiser trusler og anslå sannsynlighet.

3.2 Tiltak

Beskriv tiltak for å håndtere risikoene for de registrerte og andre berørte personers rettigheter og berettigede interesser.

Tiltak:

- Spesifikke garantier for å minimere inngripen
- Spesifikke sikkerhetstiltak som angår personopplysninger som skal behandles
- Generelle sikkerhetstiltak som iverksettes på systemet hvor behandlingen utføres
- Organisatoriske tiltak (styring)

f.eks

Følgende tiltak vil gjennomføres:

-Informasjon om at deltakere ikke vil bli identifisert i resultatene
-Vi informerer om retten til å avstå/trekke seg fra deltagelse
- Alle får kontaktinformasjon til de forskningsansvarlige.

- Elektroniske data samles inn gjennom krypterte og anonymiserte prosesser (gjelder elektronisk spørreskjema)
-Det presiseres at deltakelse eller ikke-deltakelse ikke påvirker deres nåværende tjenester
- Resultater publiseres med deskriptiv statistikk og regresjonsanalyser med summerte variabler på gruppenivå.
- All elektronisk datalagring og analyser vil foregå på tilgangsstyrt forskningsserver

Ut fra tiltakene, vurder om:

- sikringen av vernet av personopplysninger er tilstrekkelig
- de registrertes og andre berørte personers rettigheter og berettigede interesser er hensyntatt
- identifiserte risikoer er håndtert og akseptable
- det er restrisiko etter alle planlagte tiltak

Vi vurderer av vi i tilstrekkelig grad har tatt hensyn til sikring av personopplysninger, deltakernes rettigheter og interesser og redusert risiko for identifisering. Dette gjennom innsamling av kun nødvendige opplysninger, kun indirekte identifiserbare data, lagring på tilgangsstyrt forskningsserver, åpen informasjon til deltakerne og analyser på gruppenivå

3.3 Samlet vurdering av personvernet

Prosjektleder skal gjøre en oppsummering av personvern og personopplysningssikkerheten:

Vår samlede vurdering er at personvernet er tilstrekkelig beskyttet i dette prosjektet. Da det kun samles ikke identifiserbare persondata er det svært lite risiko for at noen vil kunne koble besvarelser til identitet. Etter vår vurdering, som også bekreftes etter fremleggvurdering til REK, faller dataene utenfor helseforskningsloven og ansees dermed ikke som helseopplysninger. Vi mener at vi i tilstrekkelig grad har tatt hensyn til sikring av personopplysninger, deltakernes rettigheter og interesser og redusert risiko for identifisering. Dette gjennom innsamling av kun nødvendige opplysninger, datareduksjon, innsamling av kun indirekte identifiserbare data, lagring på tilgangsstyrt forskningsserver, åpen informasjon til deltakerne gjennom informasjonsskriv og Facebook, og analyser utført på gruppenivå.

4 Brukermedvirkning

Som utgangspunkt skal man innhente synspunkter på behandlingen fra de registrerte eller representanter for de registrerte når det er relevant. Dette kan eksempelvis være brukerutvalg, pasientforeninger, fokusgrupper, pasientombud, mv.

Synspunkter er innhentet:

Ja, HØKH, Avdeling for helsetjenesteforsknings permanente brukerutvalg har deltatt i utformingen av studien, i utformingen av informasjonsskrivet og i utformingen og piloteringen av spørreskjemaet. Tilbakemeldinger har bidratt til utvikling av prosjektet

Begrunnelse:

Formålet med brukermedvirkningen er at prosjektet skal ta godt hensyn til de berørtes interesser, og at deres perspektiver har vært med på å forme prosjektet og dets formidling.

5 Involvering av personvernombudet og forhåndsdrøftelse med Datatilsynet

5.1 Personvernombud

Vurdering fra personverombudet:

I forbindelse med vurderingen av DPIA, har følgende blitt presisert av prosjektmedarbeider Kristin Häikiö:

Det er helsepersonell som deler ut spørreundersøkelsen i papirversjon til pårørende som de er i kontakt med i sitt arbeid. Prosjektmedarbeiderne vil ikke ha informasjon om hvem disse mottakerne er.

Den elektroniske spørreundersøkelsen kan helsepersonell velge å publisere på relevante sider (f.eks. kommunens hjemmeside for demensteam/ hukommelsesteam, i nyhetsbrev som sendes ut til bruker osv). Ved hjelp av denne lenken ønsker vi også å kunne invitere til spørreundersøkelsen gjennom en åpen invitasjon f.eks. på facebook eller andre relevante web-sider hvor de som ønsker å delta selv går inn og følger lenken. Informasjonsskriv (elektronisk versjon) vil også ha en QR-kode til undersøkelsen slik at informasjonsskrivet kan legges ut på venterom til hukommelsespoliklinikker eller geriatriske poliklinikker. Da kan de som ønsker å delta gå inn via QR-kode og besvare undersøkelsen.

Under forutsetning av at prosjektet gjennomføres slik som beskrevet i det overnevnte, med gitte presiseringer fra prosjektmedarbeider, anses risikoen for personvernskonsekvenser å være på et akseptabelt nivå.

For personvernombudet

Line Mostad Samuelsen
Jurist/ personvernrådgiver

5.2 Forhåndsdrøfting med Datatilsynet

Vurdering av hvorvidt Datatilsynet kontaktes for forhåndsdrøfting? Dette er aktuelt når prosjektet innebærer høy risiko for personvernet.

Konklusjon:

Ja/nei.

Begrunnelse:

5.3 Plan for implementering av tiltak

De tiltak som er identifisert som hensiktsmessige for oppfølging av denne personvernkonsekvensvurderingen er følgende:

Oppsummering av supplerende risikoreduserende tiltak fra risikoregisteret og tiltak fra eventuelt andre kapitler.

For å ivareta personopplysningssikkerheten i prosjektet, vil følgende tiltak iverksettes:

Tiltak	Tidsfrist	Ansvar

6 Godkjenning

Dato	Versjon av DPIA	Godkjent av (henhold til fullmakt)

Appendix VII

Information sheets

1. Information sheet and written consent form for Substudy 1
2. Information sheet and written consent form for Substudy 2
3. Information sheet with QR-code for Substudy 2

Akershus universitetssykehus

FORESPØRSEL OM DELTAKELSE I FORSKNINGSPROSJEKTET

Å VÆRE PÅRØRENDE TIL PERSONER MED DEMENS

Vi tror at du som pårørende har viktige erfaringer og kunnskap om helsetjenestene til personer med demens i norsk helsevesen. Vi har lyst til at din stemme skal bli hørt i planleggingen av helsetjenestene i fremtiden. Derfor er dette en invitasjon til deg om å delta i et forskningsprosjekt hvor vi ønsker å lytte til pårørendes perspektiver og bidrag til helsetjenesten til eldre personer med demens.

Du er invitert til å delta i undersøkelsen fordi du er pårørende til en person over 65 år som kan ha eller har påvist demenssykdom. Studien er en del av et større prosjekt som forsøker å finne frem til bedre, tryggere og mer kostnadseffektive helsetjenester til eldre.

I denne studien ønsker vi å intervjue totalt 20-30 personer. Studien er finansiert av Norsk Forskningsråd og gjennomføres ved Avdeling for Helsetjenesteforskning (HØKH) ved Akershus Universitetssykehus. Avdelingen er organisert under sykehuset, men er helt uavhengige i forhold til de helsetjenestene som du mottar. Akershus Universitetssykehus er databehandlingsansvarlig for studien.

HVA INNEBÆRER PROSJEKTET?

Deltagelse innebærer at du lar deg intervjue av en kvinnelig forsker og intervjuene vil foregå som en-til-en-samtale i ca. en til to time. Det er ingen rette eller gale svar, vi er derimot åpne for å høre om dine erfaringer og opplevelser. Intervjuene kan finne sted på et sted og en tid som passer for deg. Intervjuet vil gjennomføres som en samtale hvor du vil bli spurt om hvordan du opplever å være pårørende til en person med demens og hvilke tjenester dere mottar fra helsevesenet. Vi ønsker å belyse hvordan samarbeidet med helsetjenestene er, fra ditt synspunkt som pårørende, til en person med demens.

Det vil i denne forbindelse bli spurt om generelle kjennetegn ved personen med demens, slik som alder, kjønn, boforhold, sivilstand osv. Tilsvarende vil det samles demografiske data om deg som pårørende.

Det vil ikke bli samlet inn navn eller personnummer om den demente eller om deg, og du velger selv hvilke opplysninger du deler under intervjuet. Jeg ønsker å intervjue mennesker av ulik bakgrunn, men opplysninger etnisitet, religion, seksuell legning eller politisk ståsted ville ikke bli lagret.

Intervjuet vil bli spilt inn på en lydopptaker og deretter skrevet ned som tekst (transkribert). Dette skjer med det du forteller oss:

- Lydfilene skrives ut som tekst så fort som mulig etter intervjuet, og da tar vi bort alle navn, stedsnavn og andre direkte identifiserbare kjennetegn fra teksten. Teksten er da avidentifisert.
- I tilfelle noe skrives ned galt eller må sjekkes av forskeren på et senere tidspunkt, lagres lydopptaket på en sikker dataserver hvor bare forskeren har tilgang.
- Vi bruker de avidentifiserte teksten fra ditt intervju i analyse sammen med tekstene fra de andre deltagerne i prosjektet

- Vi skriver rapporter og fagartikler slik at ingen kan vite hvem som sa hva. Om nødvendig endrer vi små detaljer eller kjennetegn.

MULIGE FORDELER OG ULEMPER

Deltagelse i denne undersøkelsen vil ikke medføre noen risiko eller enderinger i forhold til de tjenestene dere mottar fra helsevesenet i dag.

FRIVILLIG DELTAKELSE OG MULIGHET FOR Å TREKKE SITT SAMTYKKE

Det er frivillig å delta i prosjektet. Du har også mulighet til å trekke deg underveis i intervjuet eller i etterkant dersom du skulle ombestemme deg. Du behøver ikke å oppgi noen årsak til at du trekker deg. Du vil også ha mulighet til å velge ikke å besvare enkelte spørsmål dersom du ønsker det. Dette vil ikke få konsekvenser for videre behandling eller pleie til personer med demens.

Dersom du trekker deg fra prosjektet, kan du kreve å få slettet innsamlede opplysninger, med mindre opplysningene allerede er inngått i analyser eller brukt i vitenskapelige publikasjoner.

Dersom du ønsker å delta, undertegner du samtykkeerklæringen på siste side.

Dersom du senere ønsker å trekke deg eller har spørsmål til prosjektet, kan du kontakte forsker Kristin Häikiö, tel 67968584, epost: kristin.haeikioe@ahus.no Eller prosjektleder: Jorun Rugkåsa, tel: 67968724 epost: jorun.rugkasa@ahus.no

HVA SKJER MED INFORMASJONEN OM DEG?

Informasjonen om deg skal kun brukes slik som beskrevet i hensikten med studien. Funnene vil publiseres som artikler i faglige tidsskrifter. Du har rett til innsyn i hvilke opplysninger som er registrert om deg og rett til å få korrigert eventuelle feil i de opplysningene som er registrert. Samtykkeskjemaet som du signerer med navn vil bli lagret på et trygt lagringssted og ikke knyttes opp til svarene du gir.

Prosjektleder har ansvar for den daglige driften av forskningsprosjektet og at opplysninger om deg blir behandlet på en sikker måte. Alle opplysninger vil behandles strengt konfidensielt, og lagres på egen sikker dataserver ved Ahus. All informasjonen vil slettes senest 01.07.2022.

GODKJENNING

Prosjektet er vurdert og tilrådet av personvernombudet ved Akershus Universitetssykehus, saks.nr. 17-128.

SAMTYKKE TIL DELTAKELSE I PROSJEKTET

JEG ER VILLIG TIL Å DELTA I PROSJEKTET

Sted og dato

Deltakers signatur

Deltakers navn med trykte bokstaver

2019

Forespørsel om deltakelse i forskningsprosjekt

HØKH - Avdeling for helsetjenesteforskning

FORESPØRSEL OM DELTAKELSE I FORSKNINGSPROSJEKTET

OM Å VÆRE PÅRØRENDE TIL PERSONER MED HUKOMMELSESSVIKT ELLER DEMENS

Vi ønsker å høre dine erfaringer om det å være pårørende til en eldre person med hukommelsessvikt/demens. Hensikten med denne spørreskjemaundersøkelsen er å få en bedre forståelse av din situasjon slik at vi kan finne ut av hvordan pårørende, pasienter og helsetjenesten bedre kan jobbe sammen. Vi ønsker å ha med de som er pårørende til en person over 65 år som har symptomer på aldersrelatert hukommelsessvikt, mistenkt demens eller påvist demenssykdom. Med pårørende mener vi familie, venn, nabo eller lignende som hjelper personen på frivillig basis. Du får denne invitasjonen fordi dette kan være aktuelt for deg.

Studien er finansiert av Norges Forskningsråd og gjennomføres ved HØKH Avdeling for Helsetjenesteforskning, ved Akershus universitetssykehus.

HVA INNEBÆRER PROSJEKTET?

Det vil ta ca. 15-20 minutter å svare på undersøkelsen. Når du har besvart alle spørsmålene putter du spørreskjemaet i den vedlagte ferdig frankerte konvolutten, limer igjen og sender konvolutten i posten. Du vil være en av ca. 500 personer som mottar invitasjon til undersøkelsen.

MULIGE FORDELER OG ULEMPER

Ved å dele dine erfaringer kan du bidra til bedre forståelse av hvordan det er å være pårørende til eldre personer med hukommelsessvikt/demens og hvordan dette kan bli bedre i fremtiden. Din besvarelse vil ikke påvirke de tjenestene dere mottar fra helsevesenet i dag og du vil ikke risikere at opplysningene kan misbrukes av andre. Din identitet vil ikke bli brukt i studien og vi samler ikke direkte identifiserbare opplysninger om deg.

FRIVILLIG Å DELTA, OG MULIG Å TREKKE SEG FRA UNDERSØKELSEN

Det er frivillig å svare på undersøkelsen, og du trenger ikke å oppgi noen grunn for ikke å besvare. Dersom du velger å svare og sender inn din besvarelse, tolker vi det som samtykke til å delta i undersøkelsen. Dersom du ønsker å trekke deg etterpå kan du kontakte forskeren og oppgi løpenummeret som står på spørreskjemaet.

HVA SKJER MED INFORMASJONEN OM DEG?

Alle svarene plottes inn i et dataprogram som lagres på en sikker dataserver uten tilgang for andre enn forskerteamet. Resultatene blir til statistikk som analyseres og publiseres i faglige tidsskrifter. Det er dermed umulig å gjenkjenne det den enkelte har svart og informasjon fra spørreskjemaet brukes kun slik som beskrevet her.

Prosjektlederen har ansvar for at opplysninger du gir blir behandlet på en sikker måte og vi sletter alle opplysninger ved prosjektslutt eller senest 01.07.25

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2019

Forespørsel om deltakelse i forskningsprosjekt

HØKH - Avdeling for helsetjenesteforskning

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OM Å VÆRE PÅRØRENDE TIL PERSONER MED HUKOMMELSESSVIKT ELLER DEMENS

Vi ønsker å høre dine erfaringer om det å være pårørende til en eldre person med hukommelsessvikt/demens. Hensikten med denne spørreskjemaundersøkelsen er å få en bedre forståelse av din situasjon slik at vi kan finne ut av hvordan pårørende, pasienter og helsetjenesten bedre kan jobbe sammen. Vi ønsker å inkludere alle pårørende som hjelper en person over 65 år, dersom denne personen har symptomer på aldersrelatert hukommelsessvikt, mistenkt demens eller påvist demenssykdom. Med pårørende mener vi familie, venn, nabo eller lignende som hjelper personen på frivillig basis.

Studien er finansiert av Norges Forskningsråd og gjennomføres ved HØKH Avdeling for Helsetjenesteforskning, ved Akershus universitetssykehus.

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Det vil ta ca. 15-20 minutter å svare på undersøkelsen og dette kan gjøres på pc, nettbrett eller smarttelefon. Du kan bla frem og tilbake mellom spørsmålene og endre svarene inntil du trykker du på knappen «send». Da sendes din besvarelse til forskerteamet. Du vil være en av ca. 500 personer som mottar invitasjon til undersøkelsen og du blir ikke spurt om direkte identifiserbare opplysninger. Du kommer til spørreundersøkelsen ved å bruke QR-koden nederst på siden eller ved å følge denne lenken: https://survey.ahus.no/surveys/pathwaysWP3/index/introduksjon.html

MULIGE FORDELER OG ULEMPER

Ved å dele dine erfaringer kan du bidra til bedre forståelse av hvordan det er å være pårørende til eldre personer med hukommelsessvikt/demens og hvordan dette kan bli bedre i fremtiden. Din besvarelse vil ikke påvirke de tjenestene dere mottar fra helsevesenet i dag og du vil ikke risikere at opplysningene kan misbrukes av andre. Din identitet vil ikke bli brukt i studien.

FRIVILLIG Å DELTA, OG MULIG Å TREKKE SEG FRA UNDERSØKELSEN

Det er frivillig å svare på undersøkelsen, og du trenger ikke å oppgi noen grunn for ikke å besvare. Dersom du velger å svare og sender inn din besvarelse, tolker vi det som samtykke til å delta i undersøkelsen. Dersom du likevel ønsker å trekke deg etterpå, kan du kontakte forskeren og oppgi den unike koden som du blir bedt om å lage når du besvarer undersøkelsen. Din besvarelse vil da kunne trekkes fra studien.

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Alle svarene plottes inn i et dataprogram som lagres på en sikker dataserver uten tilgang for andre enn forskerteamet. Resultatene blir til statistikk som analyseres og publiseres i faglige tidsskrifter. Prosjektleder har ansvar for at opplysninger du gir blir behandlet på en sikker måte og i henhold til formålet. Vi sletter alle opplysninger ved prosjektslutt eller senest 01.07.2025.

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Scan me

Appendix VIII

Survey, paper

1

Er du pårørende (familie, venn, nabo etc) til en person med aldersrelatert hukommelsessvikt eller mistenkt/påvist demenssykdom? **Ja** ☐ **Nei** ☐

Svarte du nei, trenger du ikke å fylle ut mer av undersøkelsen.

2

Hvilket av disse utsagnene beskriver best det daglige funksjonsnivået til personen med hukommelsessvikt/demens? Sett ett kryss for det du synes passer best.

Klarer seg selv i alle omgivelser, men er glemsom eller avbryter ofte aktiviteter i dagliglivet.. ☐

Fungerer uten rettledning i kjente omgivelser.. ☐

Trenger veiledning for å fungere selv i kjente omgivelser. Kan nyttiggjøre seg muntlige instruksjoner .... ☐

Trenger assistanse for å fungere. Klarer ikke å følge kun muntlige instruksjoner .... ☐

Er fysisk sprek, men trenger hjelp for å fungere. Kan ikke kommunisere muntlig på en meningsfull måte .... ☐

Sengeliggende eller sitter i en stol uten evne til å gå rundt, reagerer kun på berøring .... ☐

3

Mange bruker mye tid på å hjelpe og støtte personer med hukommelsessvikt/demens.
Kan du anslå hvor mye tid du bruker på en typisk omsorgsdag?
En typisk omsorgsdag er en gjennomsnittlig dag hvor du hjelper vedkommende.

På en *typisk omsorgsdag*, hvor mye tid brukte du på å hjelpe personen med oppgaver som toalettbesøk, måltider, påkledning, stell, forflytning og bading? .... timer

I løpet av de siste 30 dager, hvor mange dager brukte du på å hjelpe personen med slike gjøremål? .... dager

På en *typisk omsorgsdag*, hvor mye tid brukte du på å hjelpe personen med oppgaver som innkjøp, matlaging, husarbeid, klesvask, hagearbeid, vedlikehold av bolig, medisinering og håndtering av økonomi? .... timer

I løpet av de siste 30 dager, hvor mange dager hjalp du personen med slike gjøremål?........... dager

På en *typisk omsorgsdag*, hvor mye tid per dag brukte du på å snakke med personen i telefonen? .... timer

I løpet av de siste 30 dager, hvor mange dager brukte på dette? .... dager

I løpet av de siste 30 dager, hvor mange ganger fulgte du personen til avtaler (legetime, tannlege, frisør, fotpleier, fysioterapi, dagsenter etc) .... ganger

Hvor lang tid brukte på dette pr gang? (i gjennomsnitt) .... timer

I løpet av den siste **uken**, hvor mye tid brute du på å prøve å få tak i helsepersonell, koordinere/omrokkere på avtaler eller søke etter informasjon om helsetjenester på vegne av personene med hukommelesessvikt/demens? (inkludert møter, telefontid, søk på internett osv) .... timer

4

Vi ønsker å vite i hvilken grad du opplever noen belastning ved å være pårørende til en person med hukommelsessvikt/demens. For hvert spørsmål, sett en ring rundt det tallet som passer best for deg fra 1=aldri/ingen, til 5=alltid/svært mye

	aldri/ingen **1**	sjelden/litt **2**	av og til/moderat **3**	ofte/ganske mye **4**	alltid/svært mye **5**
Føler du noen gang at du ikke lenger holder ut?	1	2	3	4	5
Føler du noen gang at du trenger ferie/avkopling?	1	2	3	4	5
Blir du noen gang deprimert over den situasjonen du er i?	1	2	3	4	5
Går omsorgsarbeidet ut over din egen helse?	1	2	3	4	5
Er du redd det kan skje en ulykke med pasienten?	1	2	3	4	5
Føler du noen gang at det ikke finnes løsning på dine vanskeligheter?	1	2	3	4	5
Er det vanskelig for deg å kunne dra på ferie?	1	2	3	4	5
Hvor mye går omsorgen for pasienten ut over ditt sosiale liv?	1	2	3	4	5
Hvor mye er rutiner i hjemmet ditt blitt forandret på grunn av pasienten?	1	2	3	4	5
Er søvnen din forstyrret på grunn av pasienten?	1	2	3	4	5
Er din livskvalitet/livsstandard blitt redusert på grunn av pasienten?	1	2	3	4	5
Er du flau på vegne av pasienten?	1	2	3	4	5
Er du forhindret fra å ha gjester hjemme grunnet pasienten?	1	2	3	4	5
Blir du noen gang sliten og sur på pasienten?	1	2	3	4	5
Blir du noen gang frustrert (oppgitt) sammen med pasienten?	1	2	3	4	5

5

Du som er pårørende kan også ha egne helseplager.
Vi ønsker å kartlegge din helse slik du opplever den akkurat nå.

Under hver overskrift ber vi deg krysse av den ENE boksen som best beskriver helsen din I DAG.

GANGE

Jeg har ingen problemer med å gå omkring ☐
Jeg har litt problemer med å gå omkring ☐
Jeg har middels store problemer med å gå omkring ☐
Jeg har store problemer med å gå omkring ☐
Jeg er ute av stand til å gå omkring ☐

PERSONLIG STELL

Jeg har ingen problemer med å vaske meg eller kle meg ☐
Jeg har litt problemer med å vaske meg eller kle meg ☐
Jeg har middels store problemer med å vaske meg eller kle meg ☐
Jeg har store problemer med å vaske meg eller kle meg ☐
Jeg er ute av stand til å vaske meg eller kle meg ☐

VANLIGE GJØREMÅL *(f.eks. arbeid, studier, husarbeid, familie- eller fritidsaktiviteter)*

Jeg har ingen problemer med å utføre mine vanlige gjøremål ☐
Jeg har litt problemer med å utføre mine vanlige gjøremål ☐
Jeg har middels store problemer med å utføre mine vanlige gjøremål ☐
Jeg har store problemer med å utføre mine vanlige gjøremål ☐
Jeg er ute av stand til å utføre mine vanlige gjøremål ☐

SMERTER / UBEHAG

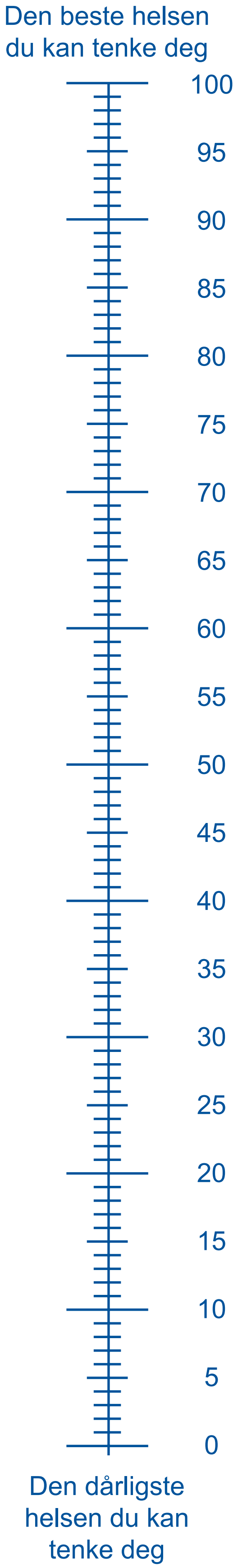
Jeg har verken smerter eller ubehag ☐
Jeg har litt smerter eller ubehag ☐
Jeg har middels sterke smerter eller ubehag ☐
Jeg har sterke smerter eller ubehag ☐
Jeg har svært sterke smerter eller ubehag ☐

ANGST / DEPRESJON

Jeg er verken engstelig eller deprimert ☐
Jeg er litt engstelig eller deprimert ☐
Jeg er middels engstelig eller deprimert ☐
Jeg er svært engstelig eller deprimert ☐
Jeg er ekstremt engstelig eller deprimert ☐

- Vi vil gjerne vite hvor god eller dårlig helsen din er I DAG.
- Denne skalaen er nummerert fra 0 til 100.
- 100 betyr den beste helsen du kan tenke deg.
  0 betyr den dårligste helsen du kan tenke deg.
- Sett en X på skalaen for å angi hvordan helsen din er I DAG.
- Skriv deretter tallet du merket av på skalaen inn i boksen nedenfor.

HELSEN DIN I DAG =



6

Noen opplever det vanskelig å få den helsehjelpen de trenger. Vi vil kartlegge hvor lett eller vanskelig du synes det er å finne, vurdere og benytte helseinformasjon. Selv om ikke alle spørsmålene er relevante for deg er det fint om du svarer det som passer best.
Sett en ring rundt ett av tallene 1-6 på hver linje. 1=veldig lett, 6= veldig vanskelig

	veldig lett					veldig vanskelig
Hvor lett/vanskelig er det for deg å:	**1**	**2**	**3**	**4**	**5**	**6**
- finne opplysninger om behandlinger av sykdommer som gjelder deg?	1	2	3	4	5	6
- forstå hva som bør gjøres i en medisinsk akuttsituasjon?	1	2	3	4	5	6
- vurdere fordeler og ulemper ved ulike typer behandling?	1	2	3	4	5	6
- følge bruksanvisningene som er angitt på forpakningen til legemidler?	1	2	3	4	5	6
- finne informasjon om hvordan psykiske problemer som stress og depresjon kan takles?	1	2	3	4	5	6
- forstå hvorfor du har behov for generelle helseundersøkelser (f.eks. mammografi, måle blodsukkeret og blodtrykket)?	1	2	3	4	5	6
- vurdere om opplysninger som media gir om helserisiko er til å stole på (TV, internett eller andre medier)?	1	2	3	4	5	6
- avgjøre hvordan du kan unngå sykdom på bakgrunn av råd fra familie og venner?	1	2	3	4	5	6
- finne informasjon om sunne vaner, som mosjon, sunn mat og riktig ernæring?	1	2	3	4	5	6
- forstå informasjon på matemballasje?	1	2	3	4	5	6
- bedømme hvilke hverdagsvaner som har sammenheng med helsen din (spise- og drikkevaner, mosjon, osv.)?	1	2	3	4	5	6
- ta avgjørelser for å bedre helsen din?	1	2	3	4	5	6
- forstå medisinsk fagspråk og terminologi	1	2	3	4	5	6
- forstå hvilken informasjon som er relevant å gi til helsepersonell	1	2	3	4	5	6
- formidle helsetilstanden og dine behov til helsepersonell på en medisinsk forståelig og effektiv måte	1	2	3	4	5	6

7

Hvilket år er du født?...................

Er du født i Norge? Ja ☐ Nei ☐

Kjønn: Kvinne ☐ Mann ☐

Er den du er pårørende til, født i Norge? Ja ☐ Nei ☐

Hva er ditt **postnummer**........................

Bor den du hjelper:

I egen bolig ☐ På institusjon ☐ Sammen med deg ☐

Hvem er den du hjelper? (sett ett kryss)

Ektefelle/samboer/partner ☐ Annen familie ☐ Annet ☐

Hva er den høyeste utdanningen du har fullført? (sett ett kryss)

Grunnskole	☐	Høgskole/universitet inntil 3 år	☐
Videregående skole/fagbrev/mesterbrev	☐	Mer enn 3 år på høgskole eller universitet	☐

Har du noen gang arbeidet som helsepersonell? Ja ☐ Nei ☐

Er du yrkesaktiv nå? (sett ett kryss)

Ja, jeg jobber vanligvis ....timer pr uke

Nei - jeg er pensjonist ☐

- jeg er uføretrygdet ☐

- jeg er ikke yrkesaktiv av annen årsak ☐

Har ditt rolle som pårørende ført til at du har: (sett ett kryss)

- arbeidet mer eller holdt deg lenger i lønnet arbeid	Ja ☐	Nei ☐
- avsluttet yrkesaktiviteten tidligere	Ja ☐	Nei ☐
- redusert stilling eller byttet til lavere lønnet arbeid	Ja ☐	Nei ☐

Tusen takk for hjelpen!

Paper I

Häikiö, K., Sagbakken, M., & Rugkåsa, J. (2019. Dementia and patient safety in the community: A qualitative study of family carers' protective practices and implications for services. *BMC Health Services Research, 19*, 635.

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BMC Health Services Research

RESEARCH ARTICLE Open Access

Dementia and patient safety in the community: a qualitative study of family carers' protective practices and implications for services

Kristin Häikiö[1,2*], Mette Sagbakken[2] and Jorun Rugkåsa[1,3]

Abstract

Background: Dementia is a cause of disability and dependency associated with high demands for health services and expected to have a significant impact on resources. Care policies worldwide increasingly rely on family caregivers to contribute to service delivery for older people, and the general direction of health care policy internationally is to provide care in the community, meaning most people will receive services there. Patient safety in primary care is therefore important for future care, but not yet investigated sufficiently when services are carried out in patients' homes. In particular, we know little about how family carers experience patient safety of older people with dementia in the community.

Methods: This was an explorative study, with qualitative in-depth interviews of 23 family carers of older people with suspected or diagnosed dementia. Family carers participated after receiving information primarily through health professionals working in dementia care. A semi-structured topic guide was used in a flexible way to capture participants' experiences. A four-step inductive analysis of the transcripts was informed by hermeneutic-phenomenological analysis.

Results: The ways our participants sought to address risk and safety issues can be understood to constitute *protective practices* that aimed to prevent or reduce the risk of harm and/or alleviate damage from harm that occurs. The protective practices relate to four areas: physical harm, economic harm, emotional harm, and relational harm. The protective practices are interlinked, and family carers sometimes prioritize one over another, and as they form part of family practice, they are not always visible to service providers. As a result, the practices may complicate interactions with health professionals and even inadvertently conceal symptoms or care needs.

Conclusions: When family caregivers prevent harm and meet needs, some needs may be concealed or invisible to health professionals. To recognize all needs and provide effective, safe and person-centered care, health professionals need to recognize these preventive practices and seek to build a solid partnership with family carers.

Keywords: Dementia, Alzheimer disease, Family caregiver, Patient safety, Primary health care, Health care quality, access and evaluation, Frail elderly, Community health services

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Background

Dementia is a chronic and progressive disease that leads to deterioration in memory, thinking, behavior and the ability to take part in daily activities [1]. It is strongly associated with old age [1–3], and symptoms in the early stages often go undetected [4]. Dementia is a cause of disability and dependency [5, 6] and associated with high demands for health services, with significant impact on resources [7–12]. Despite fewer risk factors in later-born people and a reduction of age-related dementia, the prevalence of dementia is expected to increase in Norway [13] and elsewhere [5, 14], due to the growing number of older people in the population [15–17]. The general direction of international health care policy is increasingly to provide care in the community, which, for those affected by dementia in Norway, often means in primary care, nursing homes and various services provided in people's own homes. Simultaneously, care policies increasingly rely on family caregivers to contribute to service delivery to older people. Policy documents point out that new ways of organizing health service delivery in cooperation with family carers must be found to meet future demands of dementia care in a sustainable way for all parties [18–21]. Guidelines for family carer involvement have been developed in Norway [22] and elsewhere [23, 24], and many national dementia strategies highlight the importance of supporting family carers to maintain their capacity to engage in such roles over time [25, 26]. In order to understand how these policies are implemented on the ground, it is important to understand family caregivers' perspectives and expectations in their own rights, even though these might differ from those of care-recipients.

Patient safety has been another key area of health policy worldwide since the late 1990s [27, 28]. Discussions about patient safety have moved beyond a concern for avoidable medical errors and hospital mortality to now also direct focus on broader issues of how to maintain quality of life and dignity in health service delivery, both in hospital and community settings [27]. Related to community-based dementia care, identified safety issues include falls, food safety, traffic safety, wandering around disorientated, and polypharmacy [29, 30]. Despite the shift towards care in the community, little is known about how patient safety is practiced in this setting [31–33]. Importantly, there is a dearth of research in the perspective of family carers of what constitutes risk of harm to persons with dementia and how family carers seek to address these risks [31, 32, 34]. Given their increased role in health service delivery, this lack of knowledge is a concern, not least because family carers, patients, and health professionals may have different perspectives on these issues. In this article, we examine family carers' perspectives on how to prevent different forms of harm to those living with dementia while receiving community-based services, and how their efforts to alleviate those risks might affect and interact with health professionals' activities in this regard.

Method

Setting

Norway has a publicly funded health service available to all citizens [35]. The more than 400 municipalities are responsible for primary care, which typically includes home care, nursing homes and general practitioners. Specialist care is provided by regional health authorities and consists of hospitals and specialized units, such as memory clinics and geriatric outpatient clinics [36]. The principle of lowest effective level of care was introduced in Norway in 1974 [37, 38]. Therefore, older people living with dementia receive services while living at home when possible.

Design

Given the lack of previous research on family carers' experience and contributions to preventing harm to older people with dementia, and their interaction with health services, we designed an exploratory study. Semi-structured qualitative interviews were used to maintain a flexible and open approach that would allow participants to talk about issues relevant to them. We developed a topic guide, based on existing research, with themes such as carers' contributions and interactions with health services, service integration and quality of services, and burdens or benefits they experience. This ensured we discussed the same topics with all interviewees. The guide was applied in a flexible manner, allowing the interviewer (KH) to follow up on clues and turns in the interviews, which helped us capture nuances and reflections expressed in participants' own words and framed in the context of their lives [39].

We consulted a user panel of 11 people with personal and/or professional experience from a range of health services, institutions or organizations, on study design, recruitment strategy and developing the topic guide. A pilot interview was conducted with one panel member, and the topic guide and interview approach were found to work well.

Definitions and descriptions of the sample

The main inclusion criteria were that interviewees should be an informal carer for a family member, neighbor or friend aged 65 years or older who received health services due to symptoms of dementia. Dementia was defined as symptoms of dementia with or without a formal diagnosis. If diagnosed, all forms of dementia were included. We wanted to obtain maximum variation [40, 41] in the experiences of caregiving and therefore sought men and women with different relationships to the person with dementia, living in rural and urban areas, and born in Norway and abroad.

We sampled in three phases. In the first phase, health professionals who worked with older people with dementia passed along information about the study to potential participants on our behalf. From this, we obtained contact details of potential participants, and others contacted us directly. We also spread information through the study's Facebook page. We interviewed the first ten participants who volunteered through these methods, the majority of whom were women and spouses of persons with suspected or diagnosed dementia. To balance the sample, in the second phase, we asked health professionals specifically to invite male participants, non-spouses and people born outside of Norway. We also engaged in targeted snowballing through earlier participants and personal networks and recruited five additional participants. After these first 15 interviews, few new experiences or information emerged. However, because all participants lived in the eastern part of Norway, in the third phase, we recruited six additional participants from the northern part of the country. This was again through health professionals and snowballing. This added the perspectives of caregivers with Sami (indigenous) background and participants from rural, small communities with vast distances to specialist services. Of the 26 people recruited, three cancelled before the interviews were conducted, two due to acute illness, and one did not give a reason. In the final sample of 23 participants, some cared for people with symptoms of advanced dementia, while others were in the phase where they suspected dementia or of ongoing medical investigations to reach a diagnosis. The majority of our sample are female, spouses and middle aged. Overall, an acceptable degree of breadth in participants' characteristics was achieved, as shown in Table 1.

Collectively, the participants had experience with a variety of services, including nursing homes, home care nurses, day care centers, walking buddy services, volunteer visitors, food delivery services, personal assistants, home help, dementia teams, general physicians, pharmacists, psychologists, physiotherapists, as well as non-government organizations and interest-groups.

Data collection and analysis

Data was collected between June and October 2017. The first author was the interviewer and a PhD student who had some former experience and training with in-depth research interviewing and qualitative analyses.

Participants chose the time and place of the interviews, which were conducted in participants' homes, workplace, or in a neutral meeting room or cafeteria with only the participant and the researcher present. It had the character of an informal conversation where the participant was encouraged to speak freely, and KH followed up on clues and new topics relevant to the aim of the study. The interviewer presented herself as a researcher with a nursing background. All participants were informed that what they said would be treated in strict confidence and that they could refrain from questions or withdraw from the interview at any stage. No participants chose to avail of either option. On the contrary, they seemed eager to tell their stories and motivated to contribute to the study's aims, which gave us rich descriptions of their perspectives. Most interviews lasted approximately 1.5 h. All interviews were audio recorded and transcribed verbatim by the first author. Participants were interviewed once, but one interview was disrupted and continued a week later.

Table 1 Characteristics of the sample at the time of the interview, $n = 23$

Characteristics	$n = 23$	
Gender, n (%):		
Female:	17 (74)	
Male:	6 (26)	
Age, years min-max (median):	44–83 (62)	
Relationship, n (%):		
Spouses	12 (52)	
Adult children	9 (39)	
Adult siblings	2 (9)	
Geography[a], n (%):	Urban areas, $n = 14$ (61)	Rural areas, $n = 9$ (39)
North of Norway, $n = 6$	0	6
East of Norway, $n = 17$	14	3
Living arrangements, n (%):		
Shared household with the person with dementia		11 (48)
Not sharing household with the person with dementia		6 (26)
Care recipient lived in nursing home		6 (26)

[a] Rural areas = municipalities with less than 20.000 inhabitants, Urban areas = municipalities with more than 20.000 inhabitants. We classified patients' home municipality into rural and urban based on a combination of population density and proximity to regional centers and other towns/cities first calculated by Rugkåsa et al. [42] and available on request

Analyses of the transcripts were informed by hermeneutic-phenomenological approaches [43, 44] and conducted in four analytic stages as shown in Table 2. These were conducted by KH, and discussed in detail with JR. Findings and interpretations were examined and discussed among the authors and feedback was provided by a wider research group, but not by participants.

In the presentation below, quotes from the transcripts are included to illustrate and validate our interpretations [50] and, unless otherwise specified, represent common views in the sample.

Table 2 Analysis made in four stages, combining different techniques

Stage 1	Stage 2	Stage 3	Stage 4
Transcribing and first impressions	Interim analysis	Inductive coding	Connecting codes and themes
• Interviews transcribed verbatim, usually before the next interview was conducted [48]. • Transcribing while listening shaped initial overall impressions and informed subsequent interviews [47, 48]. • Naïve reading gave an overview of within-case experiences and perspectives [46, 49].	• Memo-writing and the constant comparison method were used to track and elaborate differences and similarities between cases [45]. • Initial interpretative analysis conducted to understand different aspects: 1) describing how participants understood themselves, 2) interpreting the meaning of their narratives, 3) interpreting underlying and hidden interests, hidden agendas and using critical interpretation [44]. • Emerging themes were compared to earlier research.	• NVIVO (v. 11) was used to break the text into smaller units [48]. • Inductive, line-by-line coding resulted in 1383 descriptive and interpretive codes [45, 46]. • These were organized hierarchically in 53 main codes and numerous sub-codes [43].	• Codes were interpreted and abstracted into themes [46, 47] • Mind-mapping in NVIVO connects codes to themes. • Themes that integrated impressions from earlier phases were followed [43]. • A high-level theme of "protecting the person with dementia from harm" was identified. • Codes within that theme were categorized into 4 protective practices described by participants, related to potential physical, economic, emotional and relational harm.

Results

From the interviews, we found that some of the ways in which our participants supported the person with dementia can be understood to constitute *protective practices* aimed to prevent or reduce the risk of harm and or alleviate damage from harm. The protective practices relate to four areas: physical harm, economic harm, emotional harm, and relational harm. We describe each and then further elucidate how these protective practices are interlinked, how family carers sometimes prioritize one over another, and how these practices may complicate interactions with health professionals and even inadvertently conceal symptoms or care needs.

Preventing physical harm

The first area of protective practices involved various ways family carers sought to protect the person with dementia against potential physical harm. Sub-themes include 1) preventive presence, 2) tailored use of protective aids and 3) monitoring of health professionals.

Preventive presence

Visiting or being present with the person with dementia, continuously or frequently, was considered an important preventive measure because it enabled participants to react immediately, prevent harm such as falls or accidents at home or in traffic, and limited the consequences of physical harm that did occur. Those living in the same household as the person with dementia were often present with the person in daily tasks such as helping out with grooming, organizing meals, eating together, assisting or guiding the person when walking around in the house or outside. Hannah explained her own role in preventing physical harm to her husband by being present.

> *If I'm going anywhere, I always have someone look after him. … So that's like, I feel I am on guard the whole time. That I am, well, waiting for some noise. Being alert all the time.* (Hannah, 62, caring for her husband)

Others too said that they could not leave the person with dementia alone and asked someone to come when they needed to leave the house. Those who lived separately usually paid frequent visits or phoned to confirm everything was all right. If the person living with dementia did not answer the phone, the family carer would often stop by. Some explained that the person with dementia would remove their portable alarm (often worn as a watch or a necklace) when going to bed or taking a shower and then forget to put it back on and consequently be unable to call for help. The carer would, therefore, routinely remind the person with dementia to put the alarm back on or make sure that the phone was in good order, with easy access to the most important telephone numbers, such as the number to the family carer.

As symptoms varied from day to day, carers needed to be present and able to adapt to shifting needs and tailor their support. This was, for many, one of the most important safety measures. However, being present meant different things for different carers. For some, it meant being together at the same place and guiding the person with dementia through the day, or monitoring by phone. It could also relate to specific activities, such as being present when the person with dementia was driving. Lenita described how she was worried about her husband's driving and assisted him in handling it.

> *I feel I always need to be his co-pilot and keep an eye on things. … So it's like, him needing to focus on the driving and that, and I need to, like, navigate.* (Lenita, 61, caring for her husband)

Several participants who lived separately from the person with dementia, worried about the time lapse between visits from home care nurses and compensated with frequent visits and phone calls. This indicates that family carers sometimes considered health services to be insufficient in protection against physical harm. Participants sometimes wanted to involve health professionals in protecting against such risk. This was sometimes difficult because the person with dementia gave a better impression to the professionals than they did in their daily life at home. For example, the persons living with dementia could "pull themselves together" during meetings, and symptoms could vary during the day or between "good and bad days". Elinor said her father's GP referred him for a renewal driving test. On that day, her father pulled himself together and passed the test, which Elinor found distressing.

> *He had to go out with a driving instructor. And on that day, he had a good day. He'd slept well, got his coffee, and he drove like a prince. But it was only a week before he almost crashed into an ambulance (laughs) because he didn't heed the right-of-way.* (Ellinor, 49, caring for her father)

Other participants also said that since they were the ones knowing the person with dementia the best, they detected needs that were not easily discovered by others, and it could be difficult to communicate the scope of the situation to professionals who were not present as much.

Tailored use of protective aids

Health services frequently provided a range of aids to protect against physical harm, such as stove guards, electronic calendars, portable alarms, or single-dose medication containers. While these can be helpful, many participants expressed that such protective aids often were offered too early or too late in the illness trajectory, or that they were not always tailored to the situation of the person living with dementia and their household. Grethe explained how gadgets they would not use were distributed routinely to her husband. She put them at the back of the cupboard and found her own techniques to manage.

> *Grethe: And they came with this calendar … You plug it in, and it shows you the day and date. I've pushed that to the back of the cupboard … We don't need it. Because I put a note on the fridge that is a reminder to both him and me about what day it is. And that works for both of us … And then they gave us a stove guard … . That probably works really well for those who are demented and use the stove … Well, it was the local authority who said that you need to have one of those. Okay, we said.*
>
> *KH: So, you were not asked about your needs?*
>
> *Grethe: No, we got it delivered.* (Grethe, 79, caring for her husband)

In other cases, illness progression meant gadgets were no longer useful. Jenny's mother could no longer use the portable alarm provided by services, and instead she called Jenny when she needed help.

> *Before, she understood intuitively that she should push* [the button on the personal alarm], *but now she sometimes calls me when she needs help, because she doesn't understand that she should push it.* (Jenny, 55, caring for her mother)

Finding the right equipment for the right protection at the right time was challenging, and family carers often found their own solutions. Eva, living with her husband with dementia disease in the north of Norway, implemented a creative solution to prevent him from leaving the house unattended and risking hypothermia.

> *Then someone told me, why don't you hang a bell over the entrance door … so that I wake up. Because I sleep so deeply that I haven't heard that he's put his shirt on and gone out … ".* (Eva, 71, caring for her husband)

For persons living with dementia in their own homes, continuous surveillance such as GPS tracking, camera surveillance or other forms of real-time observations of the person living with dementia were mentioned as potentially useful, but these were not offered from health services.

Monitoring health professionals

Some variation in the degree of trust was expressed vis-à-vis health professionals. While some participants said services were helpful in protecting patients against physical harm, others described situations where care was suboptimal or even downright dangerous. Vera talked about her experience with several incidents at the local health service institution.

> *When she was at the short-stay unit it was like, "I wonder how she'll look when I collect her this time. Is she blue and black?" Because there were cuts here and there … And once when I collected her … when I took of her pantyhose there was a big cut like this* [indicates 6 cm across the knee]. *So I call the unit and ask if they've seen this big cut. You know, it's not, it's really big. She needed stitches. "She has had a shower today, but didn't you notice the cut?" None of them had actually seen it.* (Vera, 49, caring for her mother).

Several family carers explained such unsafe care with staff having too little time and resources, often combined with insufficient, or no, training. Due to such experiences, some said they needed to monitor health professionals. This could be done by visiting at unpredictable hours or routinely asking detailed questions about daily routines to make staff aware that they paid attention. This was the case for Vera when her mother eventually was moved to a nursing home.

> *Sometimes I go late, sometimes in the morning, and sometimes in the middle of the day, I just stop by, just to check .... So I feel that I'm a bit of a control freak. Cos I don't trust them 100% ...* (Vera, 49, caring for her mother)

The monitoring of health service personnel, and making their attention known, was described by most carers and added pressure to staff to increase patient safety and care quality.

Preventing economic harm

Protective practices related to prevention of economic harm surrounded how participants helped the person living with dementia manage their finances. Sub-themes that emerged were 1) practical assistance, 2) monitoring and preventing unnecessary spending and 3) taking full responsibility.

Practical assistance

The person living with dementia's inability to handle internet banking, personal identification number (PIN codes) and other financial transactions was mentioned by many participants and represented a potential threat of economic harm. Many participants assisted in these matters from the early stages of the disease, sometimes before dementia was discovered. For many, like Jenny, her involvement in financial matters gradually increased as the illness progressed.

> *She can't manage internet banking, so I've paid her bills for many years. And withdrawn* [money] *and organized food, so I take care of everything.* (Jenny, 55, caring for her mother)

Economic assistance usually developed over time without formalizing access to bank accounts or internet banking. Most spouses found this unproblematic, as they had long histories of shared economic responsibilities. Those who had formalized their access said the process was cumbersome, such as Kjersti when she suddenly took over the care of her father with dementia after her mother died.

> *"You see, my dad is demented and can't handle this ... but there is an application in at the moment about him not being able to, or that I will be his guardian and that". "Yeah,* [continues in a sarcastic tone] *but you're not allowed to use his online bank codes, you know". "No, but who will get it done then?" You know, it's like,* [these institutions were] *not very understanding.* (Kjersti, 46, caring for her father)

While the banks maintained their security procedures to protect their customer against economic harm, the family carer had no immediate way of implementing their practices of protection against economic harm.

Monitoring and preventing unnecessary spending

As the dementia progressed, several participants said that they needed to intervene to prevent the person with dementia from spending money unwisely. Ellinor explained that her mother's ways of handling her money and credit cards left her vulnerable, and Ellinor needed to monitor her spending.

> *She hasn't a clue about her cash point card. She doesn't know a single PIN code .... She lost her purse, her card .... So she always has to take out that note with her PIN code on, which is in her purse together with her card. We are really scared. So we've got to keep an eye on her account, and if there is too much money there, we'll transfer it, in case she loses it again, you know.* (Ellinor, 49, caring for her mother)

Another reason for monitoring spending was vulnerability to abuse by others, such as telesales persons. There were many examples of how persons with dementia had been persuaded to accept subscriptions on books, magazines or services they did not need, value or understand. Trine had to end several of her sister's subscriptions purchased this way.

> *She's spent a huge amount of money on rubbish. We've discovered she was paying for three TV licenses. ... For a while she was getting all these books and she didn't know she'd said yes to them* [offers made by salespersons by telephone]. *And then we had to fix all of that.* (Trine, 77, caring for her sister)

Taking full responsibility

Protective practices in financial matters usually developed within families over the years. None of the participants mentioned that monitoring the handling of money was something they discussed with health professionals in the early stages of the disease. The most common reason to involve health services in an attempt to prevent economic harm was when they chose to apply for legal guardianship. Only a small number of participants had considered getting such guardianships or other formal arrangements in place and most managed well without. Some participants said it felt difficult to deprive a person of the right to handle his or her money. Therefore, it was only after long periods of difficulty that they finally sought advice from professionals about these matters. Daniel (55), caring for his brother, explained that he sought the help of his brother's GP to obtain legal guardianship after years of assisting and monitoring his brother's bank accounts. Bettina (70) was among the few participants with several powers of attorney in place even before her husband got ill. She had since extended the range of things she could legally do on his behalf.

> *I had formal access to all his accounts, long before he got ill … But in 2010, he became 100% disabled and then he said that we've got to set up the power of attorney. So we signed the papers where I am allowed to check … without him present.* (Bettina, 70, caring for her husband)

Preventing emotional harm

All participants emphasized the importance of preventing emotional harm, and this was done in different ways. Sub-themes were 1) maintaining respect and dignity, 2) preventing loneliness, 3) avoiding negative feelings and 4) promoting good moments and positive feelings.

Maintaining respect and dignity

Maintaining dignity and respect was important for how family carers interacted with both the person with dementia and health professionals. For example, to respect the integrity and wishes of the person with dementia, the carer often found it difficult to correct them when they provided inaccurate information to health professionals. Lenita said she tried discretely to include the necessary information about her husband's diagnosis when she went with him for his first visit with a new GP.

> *She* [the GP] *didn't know that he had Alzheimer's. But I sort of weave it into the conversation without me opening the door and starting off with "here is a patient with Alzheimer's".* (Lenita, 61, caring for her husband)

While most participants valued the services provided by nursing homes or day care centers, some worried that the person with dementia would not be met with respect or consideration for their emotional needs. For several family carers, this was so concerning that they chose to limit the use of some services. Eva (71) said that her main reason for caring for her husband at home was her worry that disrespectful comments and treatment in the nursing home would harm his integrity and dignity. They were both of Sami origin, and she gave an example of behavior she thought would not be respected or understood by non-Sami professionals.

> *When he gets to his bed, he does like this* [indicates spitting left and right in accordance with Sami protective traditions]. *But that doesn't matter, let him live like that … , cos we've grown up in the same culture and know our Sami culture … and I think that is tremendously important. … that's why I don't want anyone to say this it just nonsense. Cos he lives the way he was taught.* (Eva, 71, caring for her husband)

Among others from minority backgrounds, worries were often related to insufficient knowledge about, or respect for, their traditions and a lack of agreement about what was important and acceptable. Among all participants, concern about emotional wellbeing such as dignity and integrity was usually expressed as a lack of respect for the person "behind the disease". It was important for the family caregiver that the person living with dementia was treated like a person worthy of the same respect and dignity as everyone else, despite their changed behavior.

Preventing loneliness and other negative feelings

Loneliness was a common theme in discussions about emotional wellbeing, and many carers made great efforts to prevent the person they cared for being lonely, such as visiting regularly. Many participants also perceived health services to address loneliness by offering day care centers, activity groups, visiting partner, or drop-in centers. However, the person with dementia often resisted these services, and the family carer tried to get around this resistance. Caroline reflected upon this.

> *If we'd keep listening to them* [persons with dementia], *they'd be sitting alone in their house or flat until they rot. I mean, loneliness is worse than the disease maybe. … Don't let them sit there alone even if they claim they'd rather.* (Caroline, 53, caring for her mother)

Family caregivers also sought to prevent other negative emotions for the person with dementia. Many spoke about how the care recipient's irrational behavior and resistance against daily activities were hard to deal with. This could cause irritability, and they did their best to prevent these feelings from affecting the person living with dementia. A few carers, such as Hannah, sought advice from, or learned from, health professionals about how they could deal with this issue.

> *When* [the dementia team] *comes, I think they are so pleasant towards him. I'm the wife and can get a bit*

> *irritated, but I think I learn a lot from them, from how they talk to him.* (Hannah, 62, caring for her husband)

Many carers also learned to deal with negative feelings from other family carers they met in organized support groups or from family carer academies (*pårørendeskoler*). However, in many cases participants also spoke about lack of knowledge among staff, and how to avoid confrontations, conflicts and negative interactions with the person living with dementia by using different techniques, including white lies.

> *When I sit here in the common room and see some of* [the health professionals] *working with* [the patients] *say that we're going to bed now, and when they refuse, rather than phrasing it a bit differently, if they know that the person likes to go shopping for instance, they could rather say that. … you have to keep on playing tricks. Yes, you become skilled at lying (laughs).* (Vera, 49, caring for her mother).

Creating good moments and positive feelings through activity

Many carers spoke about how difficult it was for the person with dementia to accept the decline in everyday functioning, and how this could lead to sadness and depression. To combat this, many tried to create positive experiences. Line used to give her husband "good moments" by working in their garden together.

> *So, I take out the hedge trimmer and charger and stuff, and he runs around and wants to, thinks he needs to set it up with cables and, he doesn't really understand that it doesn't need plugging in (laughs). But then I've got it going and he can keep at it. … And then he is very pleased with himself afterwards.* (Line, 79, caring for her husband).

Several carers spoke about positive experiences through activities that could bring them closer together, and prevent boredom, feeling useless, restless and sometimes prevent aggression.

Preventing relational harm

Many participants spoke about how dementia led to changes that could be harmful to social relationships. Many tried to prevent loss of social relationships and contribute to forging new social relationships for the person living with dementia. Withdrawn behavior or lack of initiative from the person living with dementia was presented as a threat to social relationships. Mari explained how she first discovered this when she encouraged her father to go with them to the grocery store, but he wanted to avoid his declining memory causing embarrassment.

> *So, I say to him: why are you not coming along? No, he didn't really fancy that … "No, because I know the people in the village, but I don't remember the names anymore. And then they start to ask about my rein herd, where do you keep them, and I haven't been up there, so I sort of start making stories up".* (Mari, 56, caring for her father)

For those at more advanced stages of dementia, relationships could be challenged or damaged by strange behavior. Trine's sister, for example, frequently woke up the neighbors during the night, and Trine thought this was bound to put a strain on those relationships.

> *And then she'd knocked on the neighbor's door at four o'clock in the morning and that makes people very … when things happen in the middle of the night. That happened many times … So the neighbors weren't left alone, she could just turn up, late at night or early in the morning.* (Trine, 77, caring for her sister).

Changed behavior could make established relationships difficult, and this was particularly difficult before a diagnosis was set which provided an explanation. Eva explained how the early manifestation of her husband's illness made him rude, agitated and stubborn towards customers in his grocery shop and how she attempted to reduce the resulting relational harm.

> *He started complaining to the customers and doing strange things in the shop and becoming very insistent. And making up different explanations. He was painting the shop outside where we worked, and then he spilled some paint on the* [neighbor's] *car. And there was a heated argument with her … So I had to pay [compensation], but I paid without him knowing it.* (Eva, 71, caring for her husband)

For others, changed behavioral patterns caused concern that others would perceive the person with dementia as something they were not. Daniel expressed worry that his brother's fondness for playing with children could be misunderstood.

> *He loves playing with kids, anywhere. If he sees kids when we walk about, he starts to joke with them and I say, "Take it easy, maybe the parents … " You have to be a bit careful.* (Daniel, 56, caring for his brother)

Since the person living with dementia often changed behavior and acted in ways that they would not have done previously, the practices to prevent against relational harm were often about persuading or motivating the person to appear in socially acceptable ways.

Prioritization and the potential for concealment of needs

In some cases, family carers experienced risk in more than one area simultaneously. In the example above where Eva paid for the damage from the paint her husband spilled without him knowing, she tried to protect him emotionally at the same time as she did not want to damage social relationships. In situations with competing interests, there could be a need to prioritize which potential area of harm should be addressed by weighing up potential costs in another area. Family carers and health service personnel did not always intuitively agree on which potential harm to prioritize. While some carers usually accepted the advice of health professionals, others negotiated the prioritization of protective practices. Solveig expressed that she believed it was socially problematic when health professionals positioned her mother's new commode chair in her living room to avoid physical harm.

> (Her) *legs were so swollen that she couldn't walk … That's when the home nurse came with a commode chair to mum, which she actually placed in the living room* [sighs and rolls her eyes]. *And mum and them had the house full of visitors. I told the home nurse that we can't have the commode chair in the living room. That's not on.* (Solveig, 44, caring for her mother)

Solveig got the professionals to move the commode chair to a different room, and thus decided the resulting risk of physical harm was secondary to the potential for emotional and relational harm of having the toilet chair in the living room area.

As mentioned above, several carers described how persons with dementia could hide or underplay symptoms in their interactions with health professionals. It was then difficult for the carer to reveal such symptoms without risking emotional or relational harm to the person with dementia. As shown in an earlier example, Lenita included information about her husband's diagnosis in the conversation with the doctor in a way she hoped would protect her husband emotionally but provide enough information to reveal the need for prevention against physical harm. Kjersti explained that health professionals only saw her father a few hours a week in the day care center. Because he was able to pull himself together for short periods, they were given an impression that his overall daily functioning was far better than she experienced at home.

> *They thought he was so nice, like, didn't get why he was there. But that's because he was very good at pulling himself together when he met others.* (Kjersti, 46, caring for her father)

In addition, Kjersti routinely cleaned up her father's flat to make it "respectable" before the home care staff arrived. She realized, however, that this protection against relational harm in effect could conceal the extent of his symptoms and needs from health professionals involved in his care. Kjersti had gradually become aware of this, and had therefore started to take photos to give them, while also addressing her father's immediate needs.

> *And particularly because I did so much, it never came to the fore. But then I stopped. I took pictures of how things look down there* [in her father's flat], *things he was doing, you know, cutting holes in the carpet because there was someone down there he needed to help up. And there were buckets upside down, and there was a bike he was going to fix, the way it looked with all kinds of stuff and the soiled bathroom and toilet and, you know. And it dawned on me … of course when I was down there, I had to clean it all up, otherwise the flat would have been destroyed and my dad would then be living in a pigsty. And it wasn't, it was beneath his dignity. I mean, that's not how we are. And I think many would do the same.* (Kjersti, 46, caring for her father)

In retrospect, Kjersti was able to see that her father's ability to pull himself together, and her protective practices, prevented health professionals from seeing and understanding the scope of the situation, which could limit their ability to offer appropriate medical support, protective aids or sufficient supervision.

Discussion

By studying family carers' perspectives on what constitutes risks to people living with dementia and how they seek to prevent, reduce or alleviate harm, we found that they engage in what we call protective practices in four areas related to physical, economic, emotional and relational harm. This means they are involved in many aspects of care recipients' lives, making many everyday interventions. This is consistent with findings in earlier studies, showing that the majority of family carers to people with dementia are taking measures to prevent risk behaviors [51, 52]. By co-navigating in the car, cancelling duplicate subscriptions, ensuring the care recipient is well dressed and groomed, or making sure the person with dementia is not left alone without the ability to call for help, our respondents addressed many risks and concerns, some of which overlap with health professionals' remit, others that do not. While these practices may provide essential support to the person with dementia and to services, they might also have unintended consequences or dynamics. Such dynamics might, in part, stem from the different perspectives of those providing formal and informal care and have implications for how health services – and other public services – collaborate with family caregivers. We discuss these three topics in turn.

The potential for negative feedback loops

The different protective practices are interconnected and sometimes intertwined, making it necessary to resolve conflict between them or decide which area should be prioritized in a particular situation. Family carers and health service personnel sometimes prioritize differently. Our participants' stories, as well as previous research, indicate that while family carers often prioritize relational, emotional and economic protection, they perceive health professionals to prioritize prevention of physical harm over other needs [53, 54]. When the four protective practices are weighted against each other and prioritized differently among family carers and health service personnel, it may lead to different solutions and considerations.

Moreover, as carers' protective practices were usually part of everyday life, they might not be visible to health professionals, who may then not be aware of the full needs of the person with dementia. The effect of the contribution to care by the family carer may also be difficult to see, such as when family carers prevent falls and assist the person with dementia in daily activities. Some protective practices may therefore, in effect, conceal care needs and contribute to gaps between how health professionals and family caregivers perceive the situation. This can, in turn, impact on how targeted the support offered to the person with dementia is. This could, for example, be reflected in the provision of protective aids not suitable to the situation, or in a nursing home not providing food in a way the patient was able to eat. Poorly targeted provision of services can increase the risk of harm to patients by leaving needs unmet, which would trigger family caregivers to continue to engage in protective practices. If, as our participants suggest, they needed to do more as the illness progress, there could be a potential ongoing negative feedback loop where family carers take on increasing responsibility, but their input, and the scope of care needs, remain at least partly invisible to services. Figure 1 depicts such a potential negative feedback loop.

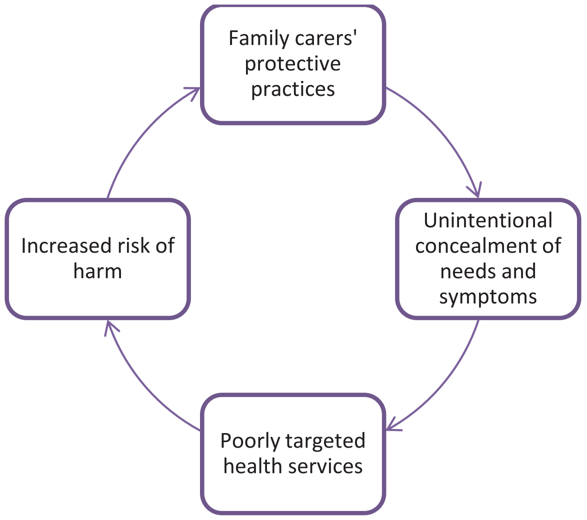

Fig. 1 The potential negative feedback loop

Difference of perspectives

Participants illustrated how they perceive a wide range of safety risks to persons living with dementia, many of which are not recognized by service personnel. This might be explained by the two very different perspectives from which family carers and health professionals approach their care work. From the perspective of family caregivers, they are involved in supporting, helping and caring for their relative because they are family or friends who share histories, identity and often homes. It is part of family practice [21]. As shown above, our participants seem to approach care in line with WHO's definition of health as "a state of complete physical, mental and social well-being and not merely the absence of disease or infirmity" [55]. This means their preventive practices for a person with dementia include addressing the individual's lack of ability to handle one's private economy or social relationships as well as medication and physical risks.

Health professionals, on the other hand, engage with the person with dementia as part of their professional practice, often over brief periods at the time, during busy shifts. Despite historic roots in a holistic philosophy of care consistent with the WHO's definition, professional practice today happens within tight boundaries of budgets and time schedules [56–58], and is expected to focus on detecting and meeting specific needs that fall within the scope of their service. Helping with management of personal finance at early stage dementia or maintaining neighborly relationships are usually considered outside the scope of services. Not surprisingly, formal and informal carers may disagree about what constitutes acceptable risks [59] and which safety concern should be given priority in a given situation. However, should a lack of awareness of family carers' protective practices result in negative feedback loops, it could both produce risky situations that could become services issues over time and impede their ability to provide high quality care that meets patients' needs. The need for health professionals to be more aware of family carers' perspectives and develop true partnerships with them is consistent with findings from other studies [53, 60, 61]. Our participants had experience with a range of services, and most service was given with the recipient living at home, often in their homes. This provides health professionals an opportunity to tap into the family practice of which protection against harm forms part. Health care policy is encouraging health professionals to form a partnership with family carers, specifically to provide better-quality care. To be successful in this, family carers' perspectives, should be considered [25, 26].

Implication for services

Awareness of how family carers perceive risks, their practices to protect against or alleviate the effects of such risk, and the potential negative feedback loop might be useful to health professionals' ability to understand the situation of persons with dementia, and in turn, improve the quality of care they provide to this patient group. This seems to require good, ongoing communication between family carers and health professionals and health professionals taking an interest in family practice surrounding patient safety even in areas outside their scope of service. Studies have found that mismatches occur between family carer's opinions of care needs and public services' ability to meet these needs through offered services [62–64]. Earlier research suggests that lack of information or awareness of available care and services may be reasons for this mismatch [65], but that the available types of care and service activities' appropriateness and alignment with needs may also be important reasons [63]. Previous studies have also pointed out that family carers may feel that their knowledge and resources are not utilized by formal carers [66] and that the partnership between them is weak [67]. This study adds to this knowledge by suggesting that better targeted services, tailored through improved partnerships between health professionals and family caregivers and awareness about the concealment of needs, most likely have the ability to be more effective and efficient and can ease the burden on family carers, thus, reducing patient risk. Findings in our and earlier studies [32, 33] suggest that family carers' protective practices prevent harm in areas within and outside the scope of services. To utilize family carers' resources, health services need to be aware that family carers' contribution extends beyond what is covered by, or visible to, health services. When health professionals evaluate family carers' resources, they must consider their total care contribution. A true partnership with the family carers is needed to be able to see behind the obvious, and tailor services to actual needs. Health professionals need to consider family carers' wishes to participate and be supportive of the family carer and acknowledge their contributions. Health services can benefit from a partnership which enables an informal carer to continue preventing harm in areas that fall between or outside existing services, while health services can co-exist when demands exceed family caregivers' capacity [48]. If we are to develop better and safer care for older people with dementia, more research is needed in all aspects of patient safety in primary care [68] as well as in how to build stronger partnerships between family carers and health professionals. It is also important to keep in mind that the views and experiences of the person with dementia may differ from those of their family carer [69].

Strengths and limitations

A strength of this study is the breadth of our sample as regards gender, age, care roles and geographic context. We deliberately applied a wide definition of dementia, including those with suspected dementia that was not yet diagnosed so as to include the perspectives of family carers at all stages of dementia. The interviews provided rich information about participants' experiences. It is possible that other methods could have given additional insights. This study does not include the perspectives of people with dementia, which might differ from the perspectives of family caregivers. The interviews were conducted by the main author after having received training in advanced qualitative methods, in close collaboration with the third author. Because our preunderstandings may potentially influence analytic choices and interpretations, these were examined in detail among the authors to reduce potential effect.

Conclusion

Family carers are involved in various protective practices surrounding physical, economical, emotional, and social harm. These practices illuminate what family carers identify as risks to persons with dementia and what they do to address those risks. As these practices are part of family practice, what they signify is not immediately available to health professionals. Certain practices might inadvertently conceal symptoms and care needs, which in turn could have an impact on how well services are targeted, potentially increasing patient risks. Improved communication and stronger partnerships between family carers and health professionals are needed to prevent such potential negative feedback loops and to improve health care quality for persons with dementia.

Abbreviations

KH: The first author, Kristin Häikiö

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Author's contributions

JR and KH planned the methodology and design of this study. KH made the interview guide, conducted the interviews and analyzed and interpreted the data with JR's supervision. JR and KH discussed interview transcripts and analysis during each stage. KH drafted the manuscript under JR's supervision. JR and MS contributed with complementing perspectives in the interpretations and suggested improvements to the text. All authors read and approved the final manuscript.

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KH holds a master's degree in health science and a bachelor's degree in nursing. She has 15 years of experience from clinical nursing, dominantly from hospital settings and emergency medicine.
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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 the privacy of participants and risk of indirect identification by characteristics given in the interviews. Transcripts are available from the corresponding author on reasonable request.

Ethics approval and consent to participate

The Health Research Act and the guide provided by the Ministry of Health and Care Services (English translation) define what is considered "medical and health research" in Norway. The Regional Ethical Committee (REC) judged this study outside the scope of the Norwegian Health Research Act (ref.nr 2017/756 B). The study was approved by the Hospital's Privacy Ombudsman (nr. 2018–126) after an assessment of data protection, impact assessment and risks for participants.
Participants received written information in advance, and informed consent form was signed and collected from all the participants prior to interview. They were informed that they were free to abort the interview or withdraw from the study at any time until data was analyzed and for practical reasons impossible to extract from synthesis.

Consent for publication

Not applicable

Competing interests

The authors declare that they have no competing interests.

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RESEARCH ARTICLE

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Family carers' involvement strategies in response to sub-optimal health services to older adults living with dementia – a qualitative study

Kristin Häikiö[1,2*], Mette Sagbakken[2] and Jorun Rugkåsa[1,3]

Abstract

Background: While dementia policy strategies emphasize the importance of partnerships between families and formal carers to provide tailored care and effectively allocate community resources, family carers often feel left out or excluded. Poor communication has been identified as one reason for the lack of good partnerships. Few studies have investigated how family carers seek to involve themselves when they experience sub-optimal services, and how their strategies may depend on different considerations and personal abilities.

Methods: Qualitative in-depth interviews were conducted with 23 family carers to explore their experiences with, perspectives on, contributions to, and interactions with healthcare services provided to older adults living with dementia. To capture nuances and variations, a semi-structured interview guide was used. Interviews were audio-recorded and transcribed verbatim. A four-step analysis of the transcripts was conducted, informed by hermeneutic and phenomenological methodology.

Results: Two main involvement strategies were identified: 1) being "the hub in the wheel" and 2) getting the wheel rolling. The first strategy was used to support and complement health services, while the second was used to add momentum and leverage to arguments or processes. The two main strategies were used differently among participants, in part due to differences in personal resources and the ability to utilize these, but also in light of family carers' weighing conflicting concerns and perceived costs and benefits.

Conclusions: Awareness and acknowledgment of family carers' strategies, personal resources, and considerations may help policymakers and healthcare personnel when they build or maintain good partnerships together with family carers. A better understanding of family carers' own perspectives on carer involvement is a necessary precursor to developing good care partnerships.

Keywords: Dementia, Caregivers, Health services for the aged, Health literacy, Social capital, Community care

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Background

The number of people living with dementia is increasing worldwide; consequently, dementia care represents a challenge to future health services. Family carers are contributing significantly to the care of older adults living with dementia [1], in terms of personal care, supporting daily activities, and interacting with healthcare personnel [2–5]. Their role is described in international and Norwegian health policy documents as a means of enhancing the quality of care, utilizing potential care recourses in both formal (services) and informal (family) sectors, and providing care tailored to individual needs [6, 7]. In many countries, dementia strategies [6, 8–10], healthcare reforms for senior citizens [7, 11], and action plans to support family carers [12, 13] emphasize that partnerships between healthcare personnel and family carers are needed to achieve high quality and sustainable care. According to the World Health Organization (WHO), partnerships in care should be based on trust, equality, mutual understanding, shared goals, and shared accountability [14]. This is reflected in policy documents, such as the UK strategy for family carers, which emphasizes that healthcare personnel should consider family carers as partners in care and recognize their unique expertise [13, 15].

The Norwegian national dementia strategy [10] highlights how family carer involvement can help to prolong the period of independent living for those living with dementia. Like other countries, Norway has developed guidelines for how services are expected to involve family carers [8, 16]. “Involvement” is described in various ways, but it usually entails information sharing, reciprocal discussions, and having a say in decision making throughout the care pathway [17, 18]. Even though many people living with dementia are capable of participating in decisions about their care [19], carer involvement is recognized as increasing in importance as care recipients’ symptoms progress [20].

Despite the good intentions of policies, research has identified substantial differences in family carers’ personal experiences of involvement in dementia care [21, 22] In the UK and in Norway, some studies report that many family carers are satisfied with the ways they are involved and supported in their role [23, 24] other studies, in contrast, find that many family carers experience that they are not involved, despite their important insights into the situation of the person living with dementia [6, 21, 25]. Some carers experience being actively excluded by healthcare personnel, which is sometimes explained by patient confidentiality [26]. Obstacles to well-functioning partnerships may include poor communication and a lack of feedback from relatives or staff [27]. In many countries, advocacy groups have emerged to support family carers in interactions with services [28].

The ways in which family carers and healthcare personnel interact are based on long traditions of hierarchical approaches to working together [29], which are sustained through education [30] and role expectations [3]. This is often seen to result in power imbalances between family carers and healthcare personnel, which create barriers to “real” or equal partnerships [31, 32]. SeParticipant 21 concepts have been developed to help understand these power imbalances and how people are differently equipped to address them. Social [33] and cultural capital [34] refer to personal resources in terms of connections or knowledge that can impact on such interaction. The concept of Health literacy (HL) is linked to such personal resources in the form of knowledge, motivation, and competency in terms of accessing, understanding, appraising, and applying information about health and healthcare systems [35]. HL can be understood as a particular level of skills or competencies to capitalize on knowledge relevant to the health field. HL has become increasingly important in public health and health care over the recent decades, and it contextualizes people’s approaches to health services in order to develop an understanding of what shapes these approaches [35].

As described in the literature, family carers can perceive that services sometimes provide insufficient or substandard care [36–38], and many studies have explored family carers’ experiences in such situations [15, 38–40]. There is a dearth of studies, however, that have investigated what family carers do in response to what they perceive as insufficient care. This is the focus of our study. Rather than discussing how services involve—or fail to involve—family carers, we investigate how family carers seek to involve themselves in formal service provision when they perceive that services, for various reasons, are not providing optimal care to their relative living with dementia. We believe this perspective is important to understanding family carers’ perspectives on carer involvement, which is a necessary precursor to developing good care partnerships and improved care pathways for families affected by dementia.

Method

The Norwegian service context

Norway offers a tax-based public health care service [41]. Primary dementia care is the responsibility of the approximately 350 municipalities, and typically includes general practitioners (GPs,) home care, nursing homes, and respite care. Respite care can be residential or day-time facilities. Most municipalities also have dementia teams or dementia coordinators, who support, plan, and coordinate care. Four Regional Health Authorities provide specialist dementia care through hospitals, memory clinics, or geriatric outpatient clinics [42]. In accordance with the principle of the lowest level of effective care [43, 44], people living with dementia receive most services from primary care providers and while living at home. National Guidelines for how services should involve family carers were updated and reissued in 2017 [16].

Design

Eligible participants included persons who provided unpaid support to a family member, friend, or neighbor who was aged 65 years or older and who received health services due to suspected or diagnosed dementia. Participation was voluntary and written consent was given from each participant prior to interview.

To achieve maximum variation [45–47] in the experience of caregiving, we actively tried to balance the sample in terms of gender, relationship to the care recipient, whether participants lived in rural or urban areas, or whether they were born in Norway or abroad.

We constructed a semi-structured interview-guide, based on previous research on family carers' experiences with health services, including services to older people living with dementia. A draft guide was refined in collaboration with the research group's user-panel, consisting of non-researchers with diverse experiences of different health services. It was piloted with one of the panel members and was found to work well according to the purpose. The interview-guide was finally informed by previous research about family carers and dementia care [5, 25, 48–52]. Given the hermeneutic and phenomenological approach, the topic guide consisted of open questions about subjective experiences. Topics surrounded family carers' experiences of their contributions to and interactions with health services, and different views on service integration and quality. Examples of questions include: "How did you come in contact with health services?", "Can you tell me more about the health services he/she is using?", "Can you tell me about a good/bad interaction with the health services?" The guide ensured that we discussed the same topics in all interviews while capturing nuances and encouraging reflection [53]. It was applied in a flexible and exploratory manner that allowed the interviewer to follow up on points raised and allowed participants to bring up topics or issues relevant to them.

Sampling and data generation

We used purposive sampling using three strategies: 1) asking public healthcare personnel—such as dementia coordinators and staff in home care, hospital, and nursing homes—to recruit on our behalf by distributing a study information sheet. This resulted in 20 family carers volunteering to participate; 2) publishing an open invitation through Facebook, which resulted in 2 participants; and 3) using snowball sampling [54] through participants already interviewed, which resulted in 4 participants. A total of 26 family carers volunteered. Of these, three cancelled: two of them due to illness and one without giving a reason. We do not have information of how many participants who refused to participate or any characteristics of invited non-participators.

After the first 11 interviews, we sought to balance the sample by focusing recruitment activities towards male family carers and family carers born abroad. A saturation point was discussed after 16 interviews, but as these all came from the southern part of the country, included an additional 5 participants from the north of the country.

Interviews were conducted between June and October 2017. The interviewer (KH), who had some previous experience with qualitative interviews, presented herself as a PhD-candidate with extensive clinical nursing experience from emergency care, but not from dementia care.

Participants chose the time and place for the interviews; most of them were conducted in participants' homes or at the researcher's office. The interviews were carried out as a private conversation between KH and the participant, and all interviews were held in Norwegian. Participants were informed about their right to withdraw from the interview in whole or in part; none of them did. It was emphasized that data analysis and reporting would maintain confidentiality. The interviews lasted approximately 1.5 h and were digitally audio-recorded. No field-notes were made, but the interview was transcribed the same day or within a few days, usually before the next interview. Non-verbal language was written as comments in the transcripts when it was necessary to explain use of irony or emotions not captured by the text. Transcripts were not returned to participants for comments.

Participants seemed motivated to tell their story, and the interviews provided rich descriptions of their perspectives. Often, participants started to talk about their experiences before the first question was asked, and the researcher then guided the conversation to a relevant section of the topic guide. Participants were interviewed once.

As shown in Table 1, our final sample of 23 participants varied with regard to background characteristics. Some cared for relatives living in a nursing home, but most cared for relatives living at home. The conditions of the persons they cared for (symptoms, whether or not dementia was formally diagnosed, functioning level, and illness progression) also varied, as did kinship relations and living arrangements. Participants collectively had experiences of interacting with a wide range of services.

While we achieved a broad variation of experiences in the sample, it is likely that it consists of family carers who were eager to share their experiences. The sample might lack the perspectives of family carers who are less engaged in caring or for various reasons did not want to share their personal caring experiences.

Table 1 Characteristics of the sample

Characteristics	*n*=23	
Gender, n (%):		
Female:		17 (74)
Male:		6 (26)
Age, years min-max (median) :		44-83 (62)
Relationship, n (%):		
Spouse		12 (52)
Adult children		9 (39)
Adult siblings		2 (9)
Geography, n (%):	Urban areas, *n*=14 (61)	Rural areas, *n*=9 (39)
North of Norway, n=6	0	6
East of Norway, n=17	14	3
Living arrangements, n (%):		
Shared household with the person with dementia		11 (48)
Not sharing household with the person with dementia		6 (26)
Care recipient lived in nursing home		6 (26)

Data analysis

In this paper we report on the second strand of analysis from the data generated from interviews guided by the semi-structured interview guide and previous work as reported previously [55]. Our previous work identified how communication problems inadvertently can result in health services not meeting the needs of people living with dementia [55]. We therefore focused the present analysis on how participants endeavored to involve themselves in formal service provision when they felt that services did not provide optimal care, and identified various strategies. The analysis is informed by hermeneutic and phenomenological methodology [56, 57], which focuses on understanding experiences from subjective viewpoints and developing insight through cycles of analyses and reflection [53].

We conducted a four-step analysis, combining different qualitative techniques. Step 1 consisted of transcribing all data and obtaining an overview [58]. The transcripts were made in Norwegian and only quotations used in the article were translated to English. Step 2 consisted of an interim overview analysis exploring different perspectives, interpreting the data in light former research, empirics, and researchers preunderstanding [59–61]. Step 3 involved detailed inductive description through line-by-line coding of all text in the computer software NVIVO, version 11. This resulted in 1383 inductive codes, organized in 51 categories. In Step 4, we combined the interpretations and preliminary findings from Step 2 with the codes from Step 3 and connected codes with themes. All themes were thus derived from the data. These steps are described more extensively elsewhere [55]. Data analysis was led by KH, in close collaboration with JR and MS who both are social scientists with many years' experience of qualitative research.

In the present analysis, for the detailed analysis in Step 4 we applied codes related to participants' discussion surrounding how they sought to involve themselves in service. We categorized the various approaches described into two main themes that we call *involvement strategies*: 1) being "the hub in the wheel", and 2) getting the wheel rolling, each with seParticipant 2l subthemes. The categorizations emerged in discussions among the authors, and through feedback from the wider research group (but not by participants). Below, we present the use of the two main strategies and the specific approaches constituting each strategy. We also show how different approaches are sometimes weighed against each other and against considerations of potential costs and benefits. We use quotes from the transcripts to illustrate our interpretations [62], and pseudonyms are used to ensure participants' privacy. Unless otherwise specified, the quotations represent common views in the sample. Results were not discussed with participants.

Results

Being "the hub in the wheel": a supportive and complementary strategy

Participants interacted with a variety of service providers, and they frequently recognized discontinuities between these providers and/or between the providers and families. To contribute to more seamless care, participants described different approaches used to support and complement services: 1) rectifying incomplete information flows, 2) connecting disjointed services, and 3) filling care gaps.

Rectifying incomplete information flows between families and services

Many participants had experienced incomplete information flows between themselves, the person living with dementia, and healthcare personnel. They saw the role of family carers very clearly as providing accurate and up-to-date information so that services could be tailored to the needs of the person living with dementia. Many participants experienced that their relative trivialized dementia symptoms or were unable to pass on accurate/complete information to healthcare personnel. Therefore, many participants accompanied their relative to all appointments with GPs, hospitals, other healthcare personnel, or the pharmacy. Participant 1, who lived with a spouse with dementia, talked about how they rectified faulty information flows between the family and service providers:

> *I always go with* [care-recipient] *to check-ups, because I realized that I had to, otherwise I wouldn't hear anything. Because* [care recipient] *just said, "No, there wasn't anything in particular." And also I had to tell* [healthcare personnel] *how* [care recipient] *functions.* [Care recipient] *trivializes that whenever he/she is at check-ups. So I've been with* [care recipient] *everywhere.* (Participant 1, aged 70–80, caring for a spouse)

Many also wrote letters to the GP, home care services, the municipal commissioning office, or to nursing home staff to ensure these professionals were fully informed about their relative's situation and needs.

Some participants were concerned that sometimes, when they provided information to staff about needs that their relative was unable to express, it was not always passed on between shifts or between different providers. Many participants tried in different ways to rectify this. Participant 2 had talked to staff at the care recipient's nursing home several times about how their mother should be dressed to keep warm. When the situation did not improve, the family carer wrote down instructions:

> *She gets cold very easily. You know, old people sit still a lot and they easily get cold…But I wrote* [a note to staff] *that she needs to wear a long-sleevedt-shirt and a blouse and her cardigan and a kerchief.* (Participant 2, aged 40–50, caring for a parent)

Participant 2 thus attempted to correct what they saw as insufficiently tailored care by personally making the information available for staff across shifts.

Participant 3 explained that their mother, who suffered from Chronic Obstructive Pulmonary Disease (COPD) in addition to dementia, was unable to provide accurate information to ambulance personnel when an exacerbation required hospital admission. Therefore, Participant 3 made sure that the most recent discharge note was left visible:

> *I always leave the discharge note on her table where she also has her ventilator and everything is there. So if she struggles to breathe and presses the button* [on her alarm] *and the ambulance comes and she says "oh, my back is so sore,"* [but] *it isn't that, that's not why she calls. So then they at least have the discharge note and they have all the information about her diagnosis and my number and the name of her GP.* (Participant 3, aged 50–60, caring for a parent)

Participant 3, like many other participants, portrayed their self as central to rectifying disrupted information flows because of their relatives' lack of capacity or ability to express themselves.

Connecting disjointed services

Several participants discussed how the different services their relative was in receipt of, often were disjointed, and how they involved themselves to coordinate them. Participant 1 explained that, contrary to hospital policy, discharge notes were not always provided to other services involved in their spouse's care, and Participant 1 would take steps to make sure that the notes were distributed appropriately:

> *Participant 1: And we've asked* [hospital staff] *that the specialist in town* [private specialist in internal medicine] *gets the discharge note. So that, but this last time the GP hadn't received it. Sometimes it slips, but we've started asking wherever we are, that discharge notes are sent at least to the GP and the internist.*
> *KH: So you keep an eye on where it's sent, to make it work?*
> *Participant 1: Yes (laughs). We've discovered that we need to do that. Because at the beginning it wasn't sent automatically.* [care recipient] *has been at another hospital too, but the two hospitals don't send* [information] *to each other. Because of confidentiality and stuff.* (Participant 1, aged 70–80, caring for a spouse)

Several participants had similar experiences about the lack of services sharing information with each other. Participant 3 found that they was often the one informing one service about the activities of another, and even about where their mother was at any given time:

> *When my mother is discharged* [from the hospital], *there is an automatic message to the home care that she's returning home now. But this has been missed a few times…So like 2-3 weeks passed. And then I called the ones who are going to help her shower, because that's, you know, another unit, and they said, "yeah, but we thought she was at the hospital still. We haven't been told she's back." And then I said, "Yes, she is."* (Participant 3, aged 50–60, caring for a parent)

Several participants said that one of their most important roles was to obtain a full overview and to connect services when needed: Participant 4 described this as being the "hub in the wheel". This often also included changing appointments that conflicted, or letting home services know when they needed to finish their tasks for the day so that the care recipient could make it to other healthcare appointments on time.

Filling care gaps

Participants tried to complement and support service provision by doing tasks "here and there" when they saw it was needed. These were tasks that healthcare personnel forgot or did not have the time to do, or aspects of care that were considered by family carers to be important to the care recipient but were not necessarily prioritized by healthcare personnel. For example, Participant 5 explained that the nursing home staff did not have time to sit with the spouse [care recipient] during meal times, and as a result, the care recipient ate poorly. Participant 5 therefore visited the spouse daily to sit down with the spouse to eat and drink.

In many cases, participants' care recipient suffered from additional illnesses. Healthcare personnel involved in treating these illnesses did not always take into account their dementia related needs. Consequently, participants would often deem it necessary to help out so that their care recipient would, for example, show up at the right place and do what was required during assessments. Participant 4 explained how they provided such support when the spouse [care recipient] underwent minor surgery:

> *So* [care recipient] *was called in for an operation* [at the hospital]*…And then* [care recipient] *went into a cubicle.* [Care recipient] *supposed to take off all clothes except his/her underwear, and valuables and clothes are to be put in a cupboard. And where is the cupboard?* [Care recipient] *had perhaps just left all those things* [out]*. Because there was no one there to help. There was a lady there to hand out these clothes, right, but there was no one there to help, you know. Because* [care recipient] *looks well, there isn't an "A"* [indicating Alzheimer's disease] *on the forehead.* (Participant 4, aged 60–70, caring for a spouse)

Participants also gave examples of how they made sure the correct equipment was available. Participant 3, whose mother lived alone in her own apartment, said that their mother was once at an intermediate unit for observation after hospital discharge and before returning home, and she had been put in a wheelchair instead of given a walker. She was also left without her ventilator. Participant 3 describes how they rectified this:

> *She uses a walker…And the first thing I see when I get in was that the nurse said, "Your mother is sitting over there in the corridor, and we managed to get a wheelchair from another patient when she told us she was paralyzed from the waist down." And she is not paralyzed from the waist down. So they had not read the discharge note…"I don't know where I am,"* [care recipient] *says, "I don't know which room I live in." So I found that out and got her in there and, and I had brought her walker in the car, and they didn't have a ventilator either, so I had to go to her apartment and collect that.* (Participant 3, aged 50–60, caring for a parent)

Care gaps were filled in different ways in different situations, but this was commonly described as a way of tailoring care to personal needs and improving quality of care.

Getting the wheel rolling: an assertive strategy

Participants described situations in which they deemed it necessary to engage in more assertive approaches, in order to add leverage or pressure to arguments or processes, so as to ensure adequate care quality. These included: 1) keeping healthcare personnel on alert, 2) using relationships as leverage, and 3) filing official complaints.

Keeping healthcare personnel on alert

Several participants said that in situations where they were concerned about the quality of care, they kept a closer eye on services/providers and made sure the healthcare personnel were aware of this. Participant 2, who cared for their mother in the local nursing home, explained that they had told the nursing home staff that they believed her mother's frequent urinary tract infections were a result of her sitting for prolonged periods in wet diapers. Convinced that the staff did not act satisfactorily on this information, Participant 2 began to visit the care recipient at unpredictable hours—sometimes in the morning, sometimes in the evening, and sometimes in the middle of the day, to keep an eye on things.

Participant 6 believed that the quality of care often depended on the skills and attitudes of individual healthcare personnel, and would confront them if they thought they were negligent or careless:

> *And some of them* [the staff] *are, like: "I'll sit down and check my phone and Facebook and that"…Then I say, "what are you doing sitting here fiddling with private things rather than sitting down to talk to those who live here, or simply doing your job?"* (Participant 6, aged 40–50, caring for a parent)

Participant 7 would also confront staff when they thought it was necessary. Parthicpant 7 discussed how they had pointed out to the staff at the nursing home that locking the doors was unlawful and potentially dangerous to residents, and made explicit reference to their own expertise as a specialist nurse:

> *I asked* [staff at the supported housing]: *"Why do you lock the doors so that he can't go in there? Are you not aware that you're not allowed to lock the door? There has to be a legal order." I said: "That's not legal. You need to keep yourselves updated on laws and regulations! I am a Specialist Nurse, so I know these systems."* (Participant 7, aged 50–60, caring for a parent)

It was a common experience that participants sometimes needed to be involved in order to keep healthcare personnel on alert and ensure adequate quality of care. Participant 7 used their professional expertise to do so. Participant 7 made it clear that obtaining knowledge was crucial for family carers so that they could be proactive and not "just having to accept things".

Using relationships to add leverage

Participants discussed how they sometimes used social relationships to add pressure to situations where they disagreed with the service provider's approach. Participant 8 had initially been unsuccessful when writing to healthcare services to get respite care for the spouse. Participant 8 said that they would not have been able to make headway had it not been for their own daughter's who helped in arguing their case:

> *But I have a resourceful family around me…It's my eldest daughter who's written letters and things. So the first letters we got back* [from respite services] *said that* [care recipient] *has a spouse who is at home, and children and grandchildren. Then she* [the daughter] *wrote back and* [presented new arguments] *and we got an answer straight away. And we got a respite place for* [the care recipient]. (Participant 8, aged 70–80, caring for a spouse)

In some cases, healthcare personnel were considered gatekeepers to additional support that participants believed their relative ought to receive. Some described how they utilized their social network to get around such gatekeepers. Participant 9 provided an example of this when explaining how they got their mother tested for dementia, despite her GP's view that this was unnecessary:

> *But then I happened to speak with this psychologist, because I happened to be at a course and he says this and that and, yes, he can do a dementia test. So I sent mum to that and on the basis of that, he believed that she needed a full assessment.* (Participant 9, aged 50-60, caring for a parent).

Other ways of getting around gatekeepers was to go above their heads and speak directly to managers, service leaders, or local politicians. When Participant 10 overheard home care nurses say that their sister [the care recipient] was denied a place at the nursing home, Participant 10 demanded a meeting with the manager of the nursing home and home care services. When the meeting took place, Participant 10 was able to provide detailed information about their sister's situation directly to the decision maker:

> *So I went home and picked up the phone to the manager and demanded a meeting…*[At the meeting] *I tell her* [the manager] *how I experience my sister, everything that has happened…She gets more and more shocked…Then she says "I haven't heard any of this. No one told me this." (Participant 10, aged 70–80, caring for a sibling)*

Participant 10 explained that as a result of the meeting, their sister was given a place at the nursing home. Other participants also gave examples of how they had convinced decision makers about the need for additional services. However, not all of them were as satisfied or as successful in their efforts as Participant 10. Some said that because they had not been able to convince service providers to increase their care provision, they were now exhausted and in despair, having provided extensive care for years.

Filing formal complaints

If former approaches had failed, and participants still had strong concerns about the quality of care, some chose to file formal written complaints. Participant 3 formally complained about their mother's GP when he failed to provide a prescription for new medication suggested by hospital doctors, which meant the home care nurses were unable to administer what the family carer and the hospital physician thought was the best treatment. Participant 10, who was a professional nurse with specialist training in geriatric care, complained when their sister's treatment for an acute infection was delayed, despite having expressed clearly to nursing home staff that they needed to start treatment immediately. Participant 2 said that they felt compelled to complain after their mother had suffered repeated injuries during respite stays at the local nursing home, which the staff could not explain. Participant 2 experienced that the healthcare personnel were polite and nice when approached about this, but as injuries continued to happen, they filed a complaint with the County Medical Officer:

> *Participant 2: When she was at the respite care it was like "I wonder how she'll look when I collect her this time. Is she yellow and blue?" Because she had cuts in several places.*
> *KH: Fell several times, then?*
> *Participant 2: Yes. And "nobody knows anything." That is the weirdest thing about it. "Tell me, have you not [noticed]?" "Yes, but we haven't reported"* [the staff replied]. *So we have filed with the County Medical Officer.* (Participant 2, aged 40–50, caring for a parent)

Filing complaints was described as a last resort, one which participants only initiated after careful consideration, because they feared it could damage their relationships with healthcare personnel.

Weighing approaches

Examples of approaches from the assertive strategy were relatively uncommon in the narratives, compared to examples of approaches from the supportive and complementing strategy, but the stories that exemplified them were often presented as dramatic, negative experiences that were salient to the participants. Since adding pressure and momentum could create tension or conflicts, many expressed that they had to "choose their battles" and carefully weigh the risks of various approaches against other concerns.

Preserving good relationships with staff was one such concern. As explained above, Participant 5 worried about the care recipient's food intake. Participant 5 also emphasized several times that they made a great effort to maintain a "good relationship" with the nursing home staff and was careful not to criticize healthcare personnel directly, despite worrying about the limited emotional support and the quality of medical care which the care-recipient received.

The opportunity cost of spending time and energy on "fights" and complaints rather than on other activities was mentioned by several participants. Participant 11 had been angered by what they perceived to be disrespectful treatment of the care recipient during discharge from the hospital. The care-recipient had been spoken to in what Participant 11 described as insensitive language with a harsh tone and had been given little time for explanations. Participant 11 had been advised by friends to file a complaint, but prioritized spending her time and energy on caring:

> *The situation is as it is and there weren't any beds* [in the hospital] *and all of that, but it is possible to convey that in an OK way. Not like* [makes spitting noise] *and like "off you go,". Many people told me "you should report it." But I don't have the energy. I really have a few other things to concentrate on* [alluding to care tasks]. (Participant 11, aged 70–80, caring for a spouse)

As shown above, Participant 2 did at some point file a formal complaint with the County Medical Officer. However, when the office called some time later and asked if they wanted to pursue the case, their mother had moved to a nursing home and was no longer using the facility where these incidents had happened. For this reason, Participant 2 said that they now lacked both the incentive and the energy to continue the fight, even though they did considered it important:

> *They called and asked if I wanted to pursue the case; that would've been June of last year. I said, "I can't be bothered to pursue it, because now we're not with the home care service anymore, she's got a permanent place* [in a nursing home]. *But I hope you take this case further so that things can improve for others. But I can't be bothered, because I'd be spending my time on nonsense."* (Participant 2, aged 40–50, caring for a parent)

Participant 2 also said that the fear of being perceived as a "difficult" family carer was one reason why they sometimes let things go:

> *Participant 2: But, you know, you can't just keep complaining all the time.*
> *KH: No? What will happen then? It sounds like you have things to complain about, really.*
> *Participant 2: Yes, but no. I don't know. I suppose it is that you live in a small place and they'll think "oh, there they comes again"* [laughs]. *I don't know.* (Participant 2, aged 40–50, caring for a parent)

In sum, participants weighed a range of concerns when considering how to involve themselves if they experienced that services were somehow insufficient. These concerns included potential consequences for the relationship with healthcare personnel and how best to spent their own time and energy. Some also worried about potential negative consequences for the care recipient, although this was more expressed as a "gut feeling" than illustrated with examples.

Many reflected on whether it might be unreasonable to place more demands on healthcare personnel who already had very busy work schedules. Participant 6 expressed this about advising others on how to combine making demands with showing respect for the personnel's need to attend to many patients and many tasks:

> *Well, don't take things at face value. There are—God knows, there are many who do their best at those nursing homes. Don't shout. Be critical, but don't shout…I can speak very firmly sometimes. They need to understand that a spade is a spade. Yeah. But you've got to respect that they're doing a lot of good, really, very many of them.* (Participant 6, aged 40–50, caring for a parent)

In deciding how best to involve themselves, participants like Participant 6 thus carefully considered potential costs and benefits for the person living with dementia, for themselves, and for healthcare personnel.

Discussion

By interviewing family carers about how they got involved when they felt that services did not adequately meet the needs of their relatives living with dementia, we identified two involvement strategies. The first, and by far the most commonly described, largely involved complementing and supporting services. The strategy included different approaches for connecting disjointed services, completing information flows, and filling care gaps. In these approaches, participants portrayed themselves as "a hub in the wheel". The second strategy was more assertive and included approaches to add power, momentum, leverage, or pressure to arguments or processes. To determine which approach to use in a given situation, participants weighed a range of considerations. We will address each of these issues before discussing how they influence the opportunity for good partnerships in care.

The "hub in the wheel": essential but often unnoticed

A hub links together the spokes of a wheel, carries some of the weight, and facilitates the spinning of the wheel—ideally with a minimum of friction. Such functions were a dominant theme in the narratives of how family carers involved themselves by linking disconnected services and improving communication between families and services. By taking on this role, participants aimed to facilitate seamless care and allow health services to run as smoothly as possible.

Descriptions of hub functions discussed common, everyday, and often rather mundane tasks, such as reminding hospital personnel to send the discharge note, ensuring that the correct information reached the right people, that the right equipment was in the right place, or that their relative was sufficiently dressed and fed. When the wheel functions well, little attention is paid to the hub. In similar ways, family carers' contributions when using approaches associated with the "hub in the wheel" strategy, may be overlooked or taken for granted. While the literature on family involvement in care often emphasizes areas of tension or conflict [38, 63, 64] family carers' efforts to complement, repair, or connect services also deserve recognition. We have shown previously that when family carers' contributions go unrecognized, this can unintentionally lead to care gaps and to needs remaining invisible to health professionals [55]. It is therefore important that their involvement as "hubs" (which is well aligned with how policy describes their role) is recognized and acknowledged.

Adding leverage by applying personal resources

A number of examples were given of how participants experienced that they needed to involve themselves in more assertive ways. The more assertive approaches added momentum or pressure which enforced improvements or changes, like getting the wheel rolling in the direction they believed was in the best interest of the person living with dementia. As mentioned above, participants' narratives and experiences reflected an awareness of the power differentials between health professionals and family carers. This power imbalance is well described in the literature [65, 66], and for our participants, it often made it challenging to attempt to change healthcare personnel's decisions or improve service provision. The approaches to add leverage and power to arguments or processes included visibly monitoring services, using relationships as leverage or to get around "gatekeepers", and filing complaints. In doing so, participants drew on different types of personal resources at their disposal.

Several participants gave examples of how they involved people in their social networks to get around gatekeepers or to add weight to their arguments or positions, such as Participant 9 involving an acquaintance who was a psychologist. This and other examples showed how participants used their social capital (which refers to resources available through a person's social networks) as part of their involvement strategies [33]. When Participant 7 questioned the legality of the nursing home's routine of locking doors, they drew on her knowledge and experience from working in health care as a specialist nurse. This can be understood as drawing on their cultural capital (which refers to a person's accumulated knowledge, expertise, or skills) [34]. Such use of personal resources was displayed by how some of the participants referred to professional standards and legal requirements and even by filing formal complaints.

Such personal resources and how they are utilized in health care interactions can be understood through the concept of Health Literacy (HL), which refers to a person's capacity to obtain, process and use information about health and healthcare systems [35, 67]. As we have seen, family carers' may capitalize on these resources turning them into leverage. Fundamental to the HL concept is that people differ in their capacity to successfully navigate healthcare systems [35]: those with higher levels of HL will be better able to find their way through and be proactive users of healthcare systems than those with lower levels [68]. As HL level might affect communication, relationships, approaches and involvement strategies, it is critical that healthcare personnel are aware that HL levels vary among the family carers with whom they interact.

Differences in HL levels have been found to be closely associated with socioeconomic differences [69], and HL has been used to, in part, explain inequality in health and health care utilization [70–73]. Since family carers are often involved in identifying, applying for, and interacting with health services on behalf of older adults living with dementia, family carers' HL levels, along with their social and cultural capital, may therefore affect which services are received, and to some extent also care quality. This aspect of family carers' personal resources and its implications for dementia care is still under-researched [74], and further studies are needed to establish whether differences in such resources impacts equal access to and outcomes of health services.

Weighing conflicting concerns

The involvement approaches described in the interviews ranged from keeping healthcare personnel informed to filing formal complaints. In deciding how to proceed in any given situation, participants weighed conflicting concerns associated with the potential and actual costs and benefits of the various approaches.

Potential benefits of using approaches aligned with being the "hub in the wheel" include improved, more person-centered, seamless care to the person living with dementia. By almost unnoticeably involving themselves in care provision, they endeavored to build or maintain good relationships with healthcare personnel. However, using this strategy also had potential costs. Always being present to fill in or rectify information flows added responsibilities and was extremely time-consuming, and thus came with considerable personal costs. Since the supportive and complementing strategy was most commonly applied, such costs to carers may be extensive and could represent a threat to the resource they provide to services. Personal costs to the family carer are described in other studies [75, 76]—such as heavy carer burdens [77–80], negative health effects [81, 82], and reduced quality of life [83, 84]. It is well known that many family carers of older adults living with dementia spend significant amounts of time on caring duties and responsibilities [48].

At the other end of the spectrum, adding leverage and pressure could potentially improve care quality, obtain access to additional services, and remind healthcare personnel of their professional responsibilities. The assertive approaches had the potential costs of straining relationships with healthcare personnel or being perceived as a "difficult" family carer. Previous studies have shown how family carers worry about reprisals or retaliations when they act assertively [85], and many are worried it could affect the quality of care provided to their relative [86]. Such concerns indicate an awareness of the power differentials surrounding interactions between family carers and healthcare personnel [31, 87], which is recognized in the literature as a threat to real partnerships in care [31]. Asymmetric power relationship between family carers and physicians [29, 58] and other types of health care personnel [4, 31, 57] are recognized as impacting interactions in way ranging from deciding what information in relevant in a particular situation, to, making formal care decisions [57].

From the perspective of family carers, different approaches to involvement are associated with the costs that they weigh against the potential benefits. By being aware of this, and the context of asymmetric power relationships, healthcare personnel can acknowledge family carers' efforts to contribute, which might help redress some of the imbalance in those relationships.

Moving towards stronger partnerships in care

In a landscape of conflicting concerns, power differentials, and differences in personal resources or health literacy, family carers and healthcare personnel are expected to build partnerships in care. However, the way these partnerships are portrayed in policy documents often fails to take into account how family carers understand their responsibilities when their views and opinions differ from those of healthcare personnel, or when they perceive services to be insufficient or failing. As our findings show, family carers use different involvement strategies when they experience gaps or failures in services. One strategy is supportive or complementary, which is usually acceptable to and indeed welcomed by healthcare personnel, while the more assertive or challenging strategy might be unwelcome or result in strained relationships. Nonetheless, both strategies are central to how family carers understand their involvement and duty to enhance the quality of care; as such, it is important that healthcare personnel—who interact with them—and policymakers—who develop services for them—are aware of these strategies and acknowledge their role in improving care.

As mentioned above, a partnership should be based on trust, equality, mutuality, and shared goals [14]. Based on the accounts of our participants, it is clear that the conditions for good partnerships are not always present. The difficulties described by participants in trying to enforce changes or improvements, indicate that neither mutual understanding of the goal nor equal power to make decisions is always present. The power imbalance between healthcare personnel and family carers further indicates a lack of equality in the relationship. The fear of reprisals and the need to keep healthcare personnel on alert can be seen as signs of mistrust. Policies that expect good partnerships in care must take into account the dynamic between healthcare personnel and family carers supporting people living with dementia, as well as the strategies family carers use and the personal resources available to them in their efforts to build or maintain partnerships.

Conclusion

Using in-depth interviews with family carers of older adults living with dementia, we found that participants used two main types of strategies in their efforts to participate in and influence formal service delivery: 1) being "the hub in the wheel", and 2) getting the wheel rolling. The first type of strategy aimed to connect different services, tailor services to personal needs, and support and complement formal care delivery, maintaining good relationships with formal carers. The second strategy aimed to add more leverage to their arguments or processes in their effort to instigate improvements when they perceived services as insufficient and power imbalances made it difficult to influence decisions. Both strategies had potential costs and benefits, and many considerations were weighed when participants were choosing their approach.

Differences in personal resources—such as knowledge, motivation, and social and communication skills, which formed part of HL, may constitute differences in family carers' abilities to access and interact with health services on behalf of older adults living with dementia. Further research is needed to investigate whether this might be a contributing factor to inequalities in health care utilization among older adults living with dementia. Policymakers, family carers, and healthcare personnel can benefit from increased awareness about different family carers' perspectives, in order to establish stronger, more equal partnerships between formal and informal carers.

Abbreviations

KH: Kristin Häikiö, first author; MS: Mette Sagbakken, co-author; JR: Jorun Rugkåsa, last author

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Authors' contributions

JR and KH planned the methodology and design of this study. KH made the interview guide, conducted the interviews and analyzed and interpreted the data with JR's supervision. JR and KH discussed interview transcripts and analysis during each stage. KH drafted the manuscript under JR's supervision. JR and MS contributed with complementing perspectives in the interpretations and suggested improvements to the text. 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 available from the corresponding author on reasonable request.

Ethics approval and consent to participate

The Regional Ethical Committee (REC) judged this study outside the scope of the Norwegian Health Research Act (ref.nr 2017/756 B). The Health Research Act and the guide provided by the Ministry of Health and Care Services (English translation) define what is considered "medical and health research" in Norway, and an ethical approval from REC is not needed for studies judged outside the scope of the act. The study was approved by the Hospital's Privacy Ombudsman (nr. 2017–128) after an assessment of data protection, impact assessment and risks for participants.
All participants received written information in advance, and an informed consent form was signed and collected from all participants prior to interview. Participants were informed that they were free to abort the interview or withdraw from the study at any time until data was analyzed and for practical reasons impossible to extract from synthesis.

Consent for publication

Not applicable.

Competing interests

The authors declare that they have no competing interests.

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Paper III

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RESEARCH ARTICLE

Is health literacy of family carers associated with carer burden, quality of life, and time spent on informal care for older persons living with dementia?

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Abstract

Introduction

Family carers are cornerstones in the care of older people living with dementia. Family carers report extensive carer burden, reduced health-related quality of life (HRQoL), and extensive time spent on informal care (Time). Health literacy (HL) is a concept associated with people's ability to access health services, and navigate the healthcare system. This study's aim was to investigate HL among family carers, and investigate the associations between HL and carer burden, HRQoL, and Time spent on informal care.

Method

We designed a self-administered survey comprising validated instruments, including the Health Literacy Scale (HLS-N-Q12) to measure HL, Relative Stress Scale (RSS) to measure carer burden, the EQ-5D-5L instrument to measure HRQoL, and some modified questions from the Resource Utilization in Dementia (RUD) questionnaire to measure time spent on informal care (Time). Descriptive analysis in addition to bivariate and multiple linear regressions were undertaken. In multiple linear regression analysis, we used HL as the independent variable to predict the outcomes (carer burden, HRQoL, Time). Analyses were adjusted for the effects of explanatory independent variables: age, gender, education levels, urban residency, having worked as health personnel, caring for someone with severe/mild dementia, and being born abroad.

Findings

In a non-probability sample of 188 family carers from across Norway, most of them female and over the age of 60, we found high levels of HL. In the bivariate analysis, carer burden and HRQoL (EQvalue) showed significant associations with HL. In the multiple regression

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analyses, HL was statistically significantly associated with carer burden (B = -0.18 CI:-0.33,-0.02 p = 0.02), HRQoL (EQvalue: B = 0.003 with 95% CI: 0.001, 0.006 p = 0.04), and Time (B = -0.03 with 95% CI: -0.06, 0.000, p = 0.046), after adjusting for the effect of independent variables.

Conclusion

This is one of the first studies to investigate the associations between HL and different outcomes for family carers of older people living with dementia. Additional research into the associations identified here is needed to further develop our understanding of how to support family carers in their roles. Targeted support that increases family carers' HL may have potential to enhance their ability to provide sustainable care over time.

Introduction

The concept of Health literacy (HL) relates to self-management and constructive communication in healthcare contexts and concerns someone's ability to utilize health information to make decisions about their health. HL has been defined in many ways, but based on a systematic review of different definitions, it can be described as:

> "*people's knowledge, motivation and competencies to access, understand, appraise, and apply health information in order to make judgments and take decisions in everyday life concerning healthcare, disease prevention and health promotion to maintain or improve quality of life during the life course." [1, p. 3]*

Understood in this way, HL may be a key factor in how people manage their health [2]. Since the level of HL will vary across individuals in a population; it might be one factor contributing to unequal access to health services, and inequalities in health outcomes [3, 4]. For example, low levels of HL have been found to increase the use of acute care health services and prolong hospital stays [5]. Like literacy in general, HL is thought to be a learned skill [6], and it is positively associated with level of education in many studies [5]. A systematic review aimed at establishing the efficacy of interventions to improve health literacy and health behavior, concluded that HL interventions hold potential to combat health inequalities [2, 7, 8].

Studies of HL often focus on specific groups of patients. More recently, some studies have also focused on HL among family carers. Of the studies that have investigated HL and family carers, some have found that increased HL among family carers' improves knowledge about existing health services and the importance of keeping up to date about services [9], and improves communication with health personnel [10]. Higher levels of HL have also been associated with better access to carer support services [2–5].

In international and Norwegian health policy, family carers play an essential role in enhancing quality of care, supporting access and utilization of necessary services, and maintaining good quality of life through care that is tailored to individual needs [11, 12]. Family carer roles may be particularly important in the care of those with dementia, who often experience behavioral and cognitive challenges [13, 14], and progressive disability and dependency [15]. Family carers will often be the ones to notice symptoms first [16], and who, as the illness progresses, take on increasing care responsibilities [17]. Therefore, throughout the illness trajectory, family carers often play a key role in finding and accessing information and services for people living with dementia [18]. Consequently, their level of HL might thus potentially impact the services received [19, 20].

Given the rising number of older persons living with dementia world-wide [21], and the extensive role of family carers in their care, there is good reason to investigate how HL might be associated with the ability of family carers to carry out their role in the longer term. In this article, the care provided by family carers is referred to as informal care, in contrast to formal care which is care delivered by health professionals.

In the literature, it is well known that family carers of people living with dementia, experience heavier care burdens and poorer quality of life as a result of the informal care that they provide compared with those caring for family member with other conditions [22, 23]. The time spent on informal care can be considerable [24] and may limit the ability of carers to take part in recreational or social activities [25]. It might be the case that family carers with high levels of HL are better able to obtain support services that can mitigate some of these negative outcomes [19, 20, 26].

It makes sense that improved access to health services for the person living with dementia, gained through better knowledge about services and improved communication might also reduce carer burden, as well as increase quality of life for individuals and carers, and relieve the carer from tasks that they would otherwise do [27, 28]. For this reason, it is of interest to explore associations between the HL of family carers, and outcomes, such as carer burden, health-related quality of life (HRQoL), and the time spent on informal care. Very limited research exists, however that has examined these relationships.

A recent scoping review examined the relationship between HL and health outcomes for family carers [26]. The authors found one study that had investigated the association specifically between HL of family carers and family carers' outcomes indicating that low HL among family caregivers of older people, may increase carer burden [26]. The authors of the review emphasized the need for further examination of these associations. We were unable to find any studies that specifically examined HL in relation to key outcomes such as carer burden, health-related quality of life (HRQoL), and the time spent on informal care for family carers of older people with dementia. This is the gap that this paper aims to fill.

In the next section, we report findings from a survey of family carers from across Norway, designed to improve our understanding of the role that health literacy (HL) plays in family caregiving. The aims of this article are, first, to describe the level of HL among family carers of older people living with dementia, and second, to investigate whether there are associations between HL and: a) carer burden, b) health-related quality of life and c) time spent on informal care.

Methods

We constructed a survey to measure HL and the mentioned outcomes among adult family carers of older person living with dementia across Norway.

Study participants and recruitment strategy

We define a family carer as someone (a family member, neighbor or friend) who, due to the care recipient's health situation, carries out tasks of a supportive nature that go beyond normal relationships of reciprocity among adults [29]. Persons eligible for the study included any family carer to a person above 65 years of age with suspected, or diagnosed dementia, or symptoms of age-related memory loss. The care recipient could be living independently, in a nursing home facility, or in the same household as the carer.

We obtained a non-probability, opportunistic, convenience sample of family carers by contacting a large number of health personnel, such as those working in local dementia teams, out-patient clinics, nursing homes, and home care service providers, to help with recruitment. They were asked to distribute paper versions of the survey questionnaire, as well as to share a link to the electronic version. They also distributed a one-page information sheet that included a Quick Response code (QR code) that linked to the electronic version of the survey, and were asked to share the electronic link on their web pages or in relevant social media groups. We distributed 410 paper surveys, and 235 one-page information sheets to health personnel for redistribution to family carers. We have no information on the number of family carers who were exposed to information about the survey.

Those who responded online had to provide consent before opening the survey. The information sheet enclosed with the paper version informed potential participants that we considered receipt of the completed form as their consent to participate. All participants were informed that they could withdraw from the study after submission by contacting the research team. No participant availed themselves of this opportunity.

Data were collected between January—May 2019 and the questionnaire was self-administered. Paper-surveys were returned in a closed, prepaid envelope, while electronic forms were submitted online and forwarded to the research team via an encrypted data server.

The Research Ethics Committee judged this study outside their remit as defined by the Norwegian Health Research Act (ref.nr 2018/1725 C). After assessing our data protection and privacy impact assessment (DPIA) and potential risks for participants, the study was approved by the Akershus University Hospital's Privacy Ombudsman (ref. 2018–126).

Measures

Health Literacy (HL) was measured using the Health Literacy Scale, Norwegian translation (HLS-N-Q12), which is a 12-item, validated scale [30]. Each item is scored on a 6-point Likert scale ranging from 1 = "very difficult" to 6 = "very easy". Summed scores range from 12–72, with higher scores indicating a higher level of HL [31, 32]. To represent the level of HL as descriptive categories, we converted the 6 levels to 4 as suggested by the scale's developers, and we followed their procedures for calculating cut-off values [33]. By merging the four middle categories into two middle categories, and applying the cut-off values, the four levels of HL were identified as: inadequate level (score 12–26), marginal level (score 27–32), intermediate level (score 33–38) and advanced level (score 39–48). The 6-level measure was used in the regression analysis, and the 4-level measure in the descriptive analyses.

Carer burden was measured using the Relative Stress Scale (RSS), which has been used to measure such burden in previous dementia research in Norway [34]. RSS measures subjective burden in three areas: 1) emotional distress, 2) social distress, and 3) negative feelings [34]. Each of 15-items is scored on a 4-point Likert scale from 0 = never to 4 = always. Summed scores range from 0–60, and higher scores indicate higher levels of carer burden.

Health Related Quality of Life (HRQoL) was measured using the Norwegian translation of the EQ-5D-5L [35]. This instrument yields two values for HRQoL: a health profile (*EQvalue*), and a visual analogue scale (*EQvas*). The EQvalue is calculated by asking participants to rate potential problems in five dimensions of health: mobility, self-care, usual activities, pain/discomfort, and anxiety/depression. Each is rated on a five-point scale with levels of problems ranging from 1 = no, 2 = slight, 3 = moderate, 4 = severe, and 5 = extreme [36]. Each of 3125 possible combinations of responses (health states) is assigned a health state value, the EQvalue, and reported on a scale where 1 is equivalent to full health, and 0 is equivalent to being dead [36]. The EQvas was measured with a vertical, thermometer-like visual analogue scale (VAS), where respondents rated their current health on a scale ranging from 0 = "worst imaginable health" to 100 = "best imaginable health" [36].

Time spent on informal care (Time) was measured using items from the Resource Utilization in Dementia Questionnaire (RUD) [37], adjusted to fit the research questions. This included adding one more traditionally male chore; maintenance of the house, to make the measure more relevant to male carers. We also added time spent talking to the participant on the phone and time spent interacting with health personnel. Tasks were grouped in clusters: 1 = personal care, 2 = gardening, house work, shopping, medication and economy, 3 = talking with the care recipient on the phone, 4 = attending appointments with the care recipient, 5 = interacting with health personnel, or searching for information about services. The time spent on each of the five task clusters were calculated by multiplying the "hours spent on a typical care day" with the "number of days" in which this task was carried out during the last 30 days. The Time variable is calculated by adding up the time spent on all task clusters.

Dementia severity was measured using the Norwegian translation of the Berger Dementia Scale (BDS) to distinguish between those caring for persons living with severe versus mild dementia [38, 39]. The BDS was chosen because it is easy to use, does not demand any medical assessment, and has been used in previous research [40, 41]. The BDS consists of 6 statements that describe different levels of functioning, and asks the family carer which level best describes their care recipient. The statements are ordinal with the first three levels of BDS being classified as "mild dementia" (= 0) and the remaining three as "severe dementia" (= 1), as advised in the literature [39]. We assumed that differences in dementia severity could affect the carers' outcomes and we wanted to be able to adjust the regression analysis to account for this potential effect.

Socio-demographic variables included *age* (in years), and *gender* (female = 0/male = 1). *Urban residency* was coded on the basis of respondents' postal code (rural = 0/urban = 1). *Highest education achieved* was collected as 1 = primary school (9 years), 2 = secondary school (12 years), 3 = Up to three years of university education, and 4 = more than three years of university education. For use in the regression analyses, we distinguished between lower level of education (primary and secondary school, and up to 3 years of university education) and higher level of education (> 3 years of university education), and converted the variable into a dichotomous variable *higher education* (no = 0/yes = 1). *Health personnel* was a dichotomous variable, indicating whether the respondent had ever worked as health personnel (no = 0/yes = 1). The variable was included as work experience in the health sector might be linked with higher levels of HL. *Carer born abroad* (no = 0/yes = 1) indicates whether the carer was born outside of Norway, and was included because earlier studies have shown that immigrants may have lower HL than the other groups [20]. Information about whether the care recipient was living in a nursing home facility or not was collected and the variable was coded as: living in a nursing home facility (no = 0/yes = 1).

Statistical analysis

All analyses were conducted using SPSS version 25 for Windows. All tests were two-sided. Results with p-values below 0.05 were considered statistically significant.

To address our first research aim, we conducted descriptive analyses. We report categorical variables using percentages (%) and the number (n) of valid participants, and the number of missing values. For all continuous variables, we report the median, minimum and maximum values. The median was chosen instead of the mean because the distributions of several variables were skewed, and the median is a better measure of central tendency for skewed data. We chose to present all continuous variables in the same way.

To meet our second research aim, we conducted regression analyses in which the main independent variable was HL and the outcome variables of specific interest were carer burden, health-related quality of life (EQvalue, and EQvas) and Time.

We used bivariate regression analyses to investigate the association between HL and the outcome variables. We then used multiple regression analyses to investigate linear associations between HL and the four outcome variables when adjusting for the effect of the following 8 prespecified explanatory dependent variables: age, gender, higher education, urban, health personnel, dementia severity, and carer born abroad. The explanatory variables were chosen based on theory, correlation analysis, and the number of cases in the dataset. Imputation was undertaken for missing values for the following three of the variables: HL, carer burden and Time.

For the HL-variable and the carer burden variable; missing values were replaced with a mean value for each case [42, 43]. In those cases were imputation was undertaken, fewer than 3 values were missing.

For the Time variable imputation was undertaken according to the following two procedures: 1) In the few cases where the respondent had answered only one of the two questions used to calculate time spent on informal care, either "hours spent", or "number of days", we used imputation of the mean value for the sample. 2) When both values in a cluster of tasks were missing we used the value zero. This occurred in 32 cases. While this included the risk of underestimating the time spent on informal care, it reduced the risk of Type 1 errors in the regression analysis. To test whether this procedure increased the risk of Type II errors, we conducted a sensitivity analysis with imputed mean values.

We investigated the associations between HL and each of the outcome variables in the four multiple regressions models: Model 1: The relationship between HL and carer burden; Model 2: The relationship between HL and EQvalue; Model 3: The relationship between HL and EQvas; Model 4: The relationship between HL and Time.

HL, carer burden, EQvalue, and EQvas were treated as continuous variables in the regression models, using 6-levels of HL.

Model assumptions for the multiple regression analyses were tested. All variables except the Time variable had normally distributed residuals. We therefore used log time transformation [42] to meet the assumptions of linearity of the residuals for the Time variable. One minute was added to the total time for each participant in order to avoid logarithms of zero for these calculations. Linearity was checked using scatterplots and correlation analyses. The linearity between HL and the four outcome variables (carer burden, EQvalue, EQvas, and Time) was weak, and for that reason we further investigated the relationship between variables with boxplots of the quartiles of each outcome variable and HL. No other relationship than linear was found between the outcome variables and HL. Homoscedasticity was checked visually on scatterplots, and there was no substantial deviation from normality. There were no multicollinearity issues in the models ($VIF < 2$).

Results

As noted, a total of 188 questionnaires were returned. As shown in Table 1, the majority of participants were females (71%, n = 134), and the median age was 60 years old, ranging from 25 to 84. The majority of participants lived in urban areas 87% (n = 160). Around two-thirds (65%, n = 105) indicated that they were caring for a person with mild dementia. A third of the sample (31%, n = 54) had experience as health personnel. Only 9% of participants (n = 17) were born outside of Norway.

The median and minimum-maximum values for HL and the other outcome variables (carer burden, HRQoL, and Time) are shown in Table 1. The median value of the 6 level HL-

Table 1. Characteristics of the sample, n = 188.

	Valid	Missing
Age, median (min-max)	60 (25–84)	0
Gender, female, n (%)	134 (71)	1
Highest educational achievement:		2
Primary school (9 years), n (%)	11 (6)	
Secondary school (3 years), n (%)	47 (25)	
University education (1–3 years), n (%)	45 (24)	
Higher university education (>3 years), n (%)	83 (44)	
Living in urban areas	160 (87)	4
Have worked as health personnel, n (%)	59 (31)	7
Dementia severity of care recipient:		1
Mild dementia, n (%)	120 (64)	
Severe dementia, n (%)	67 (36)	
Carer born abroad, n (%)	17 (9)	2
Health literacy (HL 6 level scale), median (min-max)	61 (12–72)	8
Health literacy (HL 4 level scale), median (min-max)	41 (12–48)	8
Advanced level of HL, n (%)	104 (58)	
Intermediate level of HL, n (%)	59 (33)	
Marginal level of HL, n (%)	9 (5)	
Inadequate level of HL, n (%)	8 (4)	
Carer burden, median (min-max)	26 (0–48)	7
HRQoL (EQvalue), median (min-max)	0.79 (0.09–1)	5
HRQoL (EQvas), median (min-max)	80 (20–100)	0
Time (hours) spent on informal care pr month, median (min-max)	52.1 (00–1520*)	0

* Answers exceeded the maximum number of hours per month for 5 cases.

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scale was 61 (min-max: 12–72). The four descriptive categories of HL showed that almost two-thirds were at an advanced level (58%; n = 104), one third at intermediate level, and only 9% (n = 17) reported inadequate or marginal levels of HL.

The median score for carer burden was 26 (min-max: 0–48), and the median value for EQvalue was 0.79 (min-max: 0.09–1). For the EQvas the median value was high, at 80 (min-max: 20–100). The median time spent on informal care was 52.1 hours over the previous month (min-max: 0–1520 hours). Five cases reported time spent on care that exceeded 24 hours per day (i.e., >720 hours per month), possibly reflecting that several chores were carried out simultaneously. These five cases were kept in the sample after sensitivity analysis showed that excluding them from the dataset did not significantly change the results of the regression analysis.

Table 2 shows that in the bivariate regression analyses, HL was significantly associated with carer burden (B -3.21 CI:-0.37,0.34 p = 0.01) and the EQvalue (B 0.003, with 95% CI: 0.003,-0.005, p = 0.01).

The results from the multiple regressions are shown in Table 3. When adjusting the regression analyses for the explanatory independent variables, significant associations remained between HL and carer burden (B = -0.18 CI:-0.33,-0.02 p = 0.02), and between HL and EQvalue (B = 0.003 with 95% CI: 0.001, 0.006 p = 0.04). In addition it was significant for HL and Time (B = -0.03 with 95% CI: -0.06, 0.000, p = 0.046).

Of the explanatory independent variables affecting carer burden, being male, being born abroad, and caring for someone with severe dementia were statistically significantly associated

Table 2. Bivariate regression analysis with HL¶ as independent variable.

	B (95% CI)	Sig	N	R^2
Carer burden	-0.21 (-0.37, 0.04)	0.01*	179	0.03
EQvalue	0.003 (0.001,0.005)	0.01*	177	0.04
EQvas	0.21 (-0.06,0.47)	0.13	179	0.01
Time	-0.03 (-0.05, 0.003)	0.08	179	0.02

¶ The 6-level scale of HL is used in the regression

*$p<0.05$.

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with increased carer burden, while having completed more than 3 years of university education was significantly associated with less carer burden. See Table 3.

Several explanatory independent variables were associated with the outcome measures, as shown in Table 3. Increased EQvalue was associated with being male, and living in urban areas. Being male was also associated with EQvas, as was higher education (>3 years or higher university education). More time spent on informal care was associated with higher age and being female.

Sensitivity analyses

In 32 cases all values were missing in a cluster for the Time variable. The sensitivity analysis where we used imputed means instead of zero in these cases showed that a higher level of HL was still statistically significantly associated with less time spent on informal care (B -0.33 with 95% CI: -0.07, 0.000, p = 0.049). Five participants indicated having spent time exceeding the number of hours in a month (>720. Therefore, we ran the regression analyses of Time again, excluding these five cases. HL remained statistically significantly associated with Time (B -0.29 with 95% CI: -0.06,0.000, p = 0.049).

Table 3. Multiple linear regression models of HL and the four outcome variables¶.

	Model 1, n = 168 Carer burden R^2 = 0.224		Model 2, n = 167 Health-related quality of life (EQvalue) R^2 = 0.146		Model 3, n = 168 Health-related quality of life (EQvas) R^2 = 0.121		Model 4, n = 168 Time[a] R^2 = 0.075	
	B (95% CI)	**Sig**	**B (95% CI)**	**Sig**	**B (95% CI)**	**Sig**	**B (95% CI)**	**Sig**
(Constant)	33.39 (20.91,45.87)	0.00	0.51 (0.32, 0.69)	0.00	51.89 (30.49,73.29)	0.00	4.68 (2.34,7.04)	0.00
Health literacy	-0.18 (-0.33,-0.02)	0.02*	0.003 (0.001,0.006)	0.04*	0.20 (-0.06, 0.46)	0.13	-0.03 (-0.58, 0.000)	0.046*
Age	0.09 (-0.04, 0.22)	0.18	-0.001 (-0.002,0.001)	0.59	-0.05(-0.27, 0.17)	0.65	0.03 (0.001, 0.05)	0.04*
Gender, male[b]	-8.93 (-12.88, -4.98)	0.00*	0.11 (0.05, 0.16)	0.000*	8.36 (1.58, 15.13)	0.02*	-0.92 (-1.67, -0.18)	0.02*
Higher education[b]	-4.76 (-8.37,-1.16)	0.01*	0.03 (-0.03, 0.08)	0.31	6.69 (0.51, 12.87)	0.03*	-0.17 (-0.85, 0.51)	0.63
Urban residency[b]	1.42 (-3.73,6.56)	0.59	0.08 (0.01, 0.15)	0.048*	8.35 (-0.47, 17.17)	0.06	-0.33 (-1.30, 0.64)	0.50
Health personnel[b]	-1.66 (-5.53, 2.20)	0.40	0.03 (-0.03, 0.09)	0.26	5.56 (-1.06, 12.19)	0.10	-0.30 (-1.03, 0.42)	0.41
Dementia, severity[c]	5.47 (1.83, 9.11)	0.003*	-0.004 (-0.06, 0.05)	0.90	-1.00 (-7.25, 5.24)	0.75	-0.07 (-0.76, 0.62)	0.84
Carer born abroad[b]	6.95 (0.71, 13.19)	0.03*	-0.002 (-0.09, 0.09)	0.96	-4.34 (-15.05,6.37)	0.43	0.04 (-1.14, 1.21)	0.95

¶ Note: The 6-level scale of HL is used in the regression

*$p<0.05$.

[a] The Time variable is the log transformed variable.

[b] Variables are binary and coded no = 0/yes = 1.

[c] The variable Dementia severity is coded mild dementia = 0/severe dementia = 1.

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It is possible that the large differences in time spent on informal care could be related to whether the care recipient lived in a nursing home, which might reduce the need for carer input. We conducted a sensitivity analysis on the time variable using independent sample T-test to investigate difference of mean between those who cared for a person living in a nursing home and the remaining respondents. We found no statistically significant difference (mean 3.6 hours, SD 2.3 vs .2 hours, SD 2.6, p = 0.31). The correlation between the time variable and caring for a person living in nursing home was also not significant (Pearson's R = -0.14, p = 0.051).

Discussion

In a non-probabilistic sample of family carers of older people living with dementia, we found significant associations between HL and carer burden, HL and health-related quality of life when measured by the EQvalue, and between HL and time spent on care.

Health literacy among family carers

In general, there was a high level of HL in our sample. As many as 58% were in the category of advanced HL and only a small proportion of participants who had marginal or inadequate levels of HL (9%). This diverges substantially from previous studies of HL. Among people living with diabetes, and in the general population in Norway, 34–41% had low levels of HL (inadequate) [33]. In the general population across Europe, insufficient or problematic levels of HL were reported for 47% of the population [44]. Even though measurement instruments and the definitions of what constitutes low levels of HL differ between studies, our findings indicate a higher level of HL. This could result from participants having acquired HL as part of their experience as family carers [6]. Also, there may be selection bias in the participants in this study, such that those who chose to participate had higher levels of HL than the general population [45, 46]. A self-administered survey makes cognitive demands on participants [45], which might impact who volunteered to take part [46]. It may be likely that the combination of a non-probability sampling method, voluntarily participation of family carers, the self-reported nature of the HL-scale, and self-administration of the survey, have together contributed to participants with higher levels of HL.

Previous research from the US has found that adults without a high school diploma, with health-related restrictions and limited access to resources, who are immigrants and members of other minority populations have lower HL skills than others [47]. These groups were underrepresented in our sample. Participants born outside of Norway accounted for only 7% of our sample compared with 14% in the general Norwegian population [48]. A positive relationship has been reported between high HL and high educational achievement [49]. In our highly educated sample, a total of 68% had university education, compared to 34% in the general Norwegian population [50].

The association between health literacy and carer burden

We found a statistically significant association between higher HL and lower carer burden. In the literature, low levels of HL have been found to be associated with increased carer burden among family carers of people with other health conditions than dementia [26]. Family carers must often interact with service providers on behalf of the person living with dementia [51]. Such interactions might in themselves increase levels of HL, which then in turn might promote increased access to services that takes some burden off the carer.

Low levels of HL have been associated with reduced service use for chronically ill people [5], poor access to health care among older people [52] as well as for other populations [53], and reduced likelihood of being able to navigate within healthcare systems [2, 5]. We have shown previously how poorly targeted services may result in increased risks of harm for the person living with dementia and consequently increase carer responsibilities [54].

These studies are consistent with the association we found between lower levels of HL and increased carer burden (B = -0.18 with 95% CI:-0.33,-0.02 p = 0.02). Increase in carer burden was also significantly associated with female gender (B = -8.93 with 95% CI:-12.88, -4.98 p = 0.00). This is consistent with previous studies [55, 56]. Not surprisingly, perhaps, those caring for a person with severe dementia reported heavier carer burden, and this has also been reported elsewhere [41, 57].

The association between health literacy and health-related quality of life

We found that an increase in HL was associated with an increase in family caregivers' HRQoL as measured by EQvalue (B = 0.003 with 95% CI: 0.001, 0.006 p = 0.04). The association between EQvas and HL was in the same positive direction, but did not reach significance.

Quality of life has been found to be moderately correlated with HL [58]. A large cohort study in UK general practice found that low HL was an independent indicator of poor quality of life among older patients with long-term diseases [59]. However, the use of different instruments complicates comparisons across studies [60].

Few studies have investigated the association between HL and HRQoL in family carers. One study revealed that increased HL was associated with increased quality of life in a population of carers to people with different care needs [9]. Some studies have found positive effects between carer education and carer satisfaction [61]. We found a significant association between higher education and quality of life, for only one of the two HRQoL variables, the EQvas (B = 6.69 with 95% CI:0.51, 12.87, p = 0.03).

Being a male carer was significantly associated with increased EQvalue and EQvas. This is in contrast to a recent systematic review of factors associated with quality of life for family carers of people living with dementia that found no clear association between family carers' HLQoL and their gender [23]. The association between quality of life among family carers' and their age or education was unclear in the systematic review. In our study age was not statistically significantly associated with HRQoL in our study and higher education was statistically significantly associated with HRQoL only when measured with EQvas. Living in urban areas was significantly associated with HRQoL when measured with EQvalue in our study, The systematic review also discussed emerging evidence that the living situation of the care recipient and the family carer may impact carers' quality of life and was not tested in our study. This might be considered a weakness of our analysis.

The association between health literacy and time spent on informal care

We assumed that higher levels of HL would result in easier access to services or support [19], leading to participants' spending less time themselves on care tasks. Our multiple regression analysis confirmed this, showing significant associations between high HL, and less time spent on informal care (B = -0.03 with 95% CI: -0.06, 0.000, p = 0.046). The RUD questionnaire that informed our study is the most widely used and validated instrument globally, for collecting data regarding informal resource use in dementia care [37, 62, 63]. Nevertheless, our results underscore the fact that there are multiple challenges with measuring time spent on informal care, and the findings from this study should be interpreted carefully. In addition, the high number of missing values in our data for this variable represents a threat to the validity and reliability of this aspect of the overall analysis.

The option of reporting time spent on informal care in a way that allows the total time to exceed the number of available hours could be another limitation for our study. We interpreted the amplification of the number of hours spent on informal care as representing of the fact that carers might carry out several chores simultaneously. Because such an overlap of chores may be present in all cases, we did not exclude the 5 cases that exceeded maximum time.

The option of reporting simultaneous chores could explain why the weekly number of hours spent on care tasks (12.2 in our sample) was considerably higher than the 7.6 hours reported in a Norwegian study of family carers in general [64]. However, studies from the US show that family carers of people living with dementia spend significantly more time on care tasks than other carers, 17.1 hours per week, and 12.5 hours per week, respectively [65].

Our Time variable may therefore best be understood as a respondent rated measure that reflects an *objective* carer burden, similar to how the time variable is interpreted in other studies [66, 67], meaning that more time spent on informal care may indicate more care tasks being performed. The measures of time spent on tasks which were carried out simultaneously were measured equally for all participants. Consequently, it is likely that all participants have reported overlapping tasks when indicating time spent on informal care. It is likely then, that those reporting more hours, actually are providing more care tasks which represents a larger objective burden.

Older age and female gender were significantly associated with more time spent on care. Much of the literature confirms that females participate more in informal care, and spend significantly more time on caregiving for older people living with dementia compared to men [68, 69], but much of the caregiving literature is criticized for reflecting the female perspective [68, 70, 71], which may marginalize, and underestimate male caregiving [72].

It is possible that those caring for someone living in a care home spend less time on some care tasks. We did not include this variable among our pre-specified independent explanatory variables, but a sensitivity analysis did not show significant differences between this group of carers and the rest of the sample. Associations between HL and time spent on informal care in subgroups of family carers for people with dementia could be a direction for future studies.

Final considerations

In Norway, and in many other countries, policies encourage aging in place, and the delay in moving into long-term residential care. This places as increased reliance on family caregiving to achieve this goal. Despite a growing literature on the role of family carers of older people living with dementia [73–77], and the effects of this role, there is more to learn about how this policy direction influences family carers in the long run [78].

To our knowledge, our study is the first one to measure HL among family carers of older people living with dementia in Norway, and one of the first to investigate the associations between family carers HL and key outcomes that have implications for international lessons. Our key outcomes were measured with validated instruments, although the RUD questionnaire was modified. In our non-probability sample, we noted a bias towards the self-selection of participants with higher levels of HL. Consequently, the results should be treated as exploratory and are not necessarily generalizable to the Norwegian family carer population. The Time variable in particular, should be interpreted carefully because it revealed that carers may add time spent on chores together, even if they are performed simultaneously. Ultimately, the time that family carers spend on informal care should be investigated further with standardized methods and standardized analysis capturing a wider range of care types and time spent on each.

Conclusion

This study is the first to investigate the role of HL among family carers of older persons living with dementia in Norway, and to investigate whether HL is associated with family carers' level of carer burden, HRQoL, or time spent on informal care. In a sample of 188 family carers with high levels of HL, we found that higher HL was associated with lower carer burden, higher health-related quality of life, and lower time spent by family carers on different care-related tasks.

Viewing the results from this study in the context of earlier studies, it seems that family carers with high levels of HL might be better able to obtain support services that can mitigate negative outcomes. Future studies of HL should seek to obtain a representative sample of family carers to older persons living with dementia, to further investigate these relationships. Increased knowledge in this area would be meaningful to develop fuller understandings of how formal services may support family carers in their role, and support them to increase their HL and thereby potentially enhance their ability to provide sustainable care over time and minimize the burden they sometimes experience.

Supporting information

S1 File.
(SAV)

S2 File.
(SPS)

S3 File.
(PDF)

S4 File.
(PDF)

S5 File.
(DOCX)

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