UiT
THE ARCTIC
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The Faculty of Health Sciences. Department of Health and Care Sciences

Speaking on behalf of the person with dementia in home-based care

A qualitative study of collaboration between formal and family caregivers in Sami and Norwegian municipalities

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Lill Sverresdatter Larsen

A dissertation for the degree of Philosophiae Doctor – May 2017

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Lill Sverresdatter Larsen

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English abstract

Dementia is a chronic and progressive illness that results in cognitive impairments. In Norway today, approximately 70,000 people over the age of 65 live with dementia, and statistical projections for the next 30 years indicate that this number will almost double. Approximately half of all people with dementia live at home; however, only 25% of these people receive assistance from public health services. Family caregivers provide a significant portion of care work for this group of patients.

To meet challenges related to the increasing prevalence of dementia and thus increased healthcare costs, the Norwegian authorities have developed strategies to improve existing health services and establish new ones. One important health policy measure is to offer home-based care in the early stages of the disease to enable patients to live at home as long as possible and to reduce the burden to their family caregiver. Collaboration between home and healthcare providers is therefore a prerequisite. However, few researchers have addressed this topic. Due to the lack of research on formal and family caregivers' collaborative practice, this study's primary objective was to contribute to knowledge regarding how formal and family caregivers described and reflected on collaboration in home-based dementia care.

In this study, I defined collaboration in home-based care as depending on trust, an experience of necessity and a mutual understanding of the situation. Furthermore, I interpreted collaboration in home-based care to be entangled with political objectives such as user involvement and continuity of care, and within this particular field to include indigenous rights such as that of the Sami. Policies can be understood as ideals, and formal caregivers' discretionary work is key to implementation. The operationalization of rights requires interpretation and collaboration between patients and formal and family caregivers. To enable me to explore and describe such collaboration, I developed two research questions:

1. How do formal and family caregivers describe collaboration in home-based care for people with dementia?
2. What barriers could inhibit the collaboration between formal and family caregivers?

I based my interpretations on positioning theory, a theory of social interaction. The research field was rural, multi-ethnic municipalities in northern Norway, and the study relied on data from 18 in-depth interviews with formal (11) and family caregivers (7) and from brief fieldwork in which two dementia teams were followed over two days. The analytical strategy was

a mix of thematic analysis and use of the positioning triad to help explore how ethnic affiliation, user involvement and continuity of care concepts influence formal and family caregivers' collaboration. The analysis resulted in three articles, and an overall discussion as presented in this thesis.

In the first article, we explored the participants' experience with decision-making processes. User involvement for people with dementia and their families is one of the goals of Norwegian health policy. However, we found conflicting positioning between formal and family caregivers when important decisions concerning the patients were negotiated. Negotiations occurred because of different interpretations of the patient's consent and the associated spokesperson's positioning. The conflicts were particularly apparent in situations where formal caregivers stated organizational constraints as reasons for not providing specific services and when negotiations and conflicts added to the family caregivers' care burden.

In the second article, we explored how ethnic affiliation influenced home-based dementia care in rural municipalities in northern Norway. The Sami have been recognized as an indigenous people in Norway and are thus entitled to special protection and rights. To implement these political rights in home-based care, formal caregivers must recognize and accept ethnic positions. This study found extensive negotiations of ethnic positioning in practice. Ethnic and particularly ethno-political positioning could create major barriers to collaboration.

In the third article, we explored how formal and family caregivers reflect on their collaboration in home-based dementia care, focusing on continuity of care and the use of individual plans. Continuity of care is an important health policy goal, and recent governmental reports explicitly emphasize its importance for people with dementia. In Norway, the statute mandating individual plans aims to ensure user involvement, improve continuity of care and increase collaboration between home and formal healthcare providers. However, we found gaps between practice and healthcare policy objectives with regard to continuity of care and to Norway's statutory individual plan in particular. Differences in formal and family caregivers' perceptions of collaborative practice may inhibit the attainment of such policy objectives. Furthermore, the article provided new insight regarding how caregivers' positions may enable or hinder continuity of care for people with dementia.

Overall, I argue that formal and family caregivers negotiate collaboration as a social practice in home-based dementia care. How this collaboration is negotiated and practised is presented in the three articles through the analogy of a 'collaboration mosaic'. The mosaic features "tiles" such as trust, necessity of services, understanding ethnic entitlement, understanding of

user involvement as a practice, and coordination. I have focused on “cracks” in the "tiles", or “uncomplete patterns”, understood as positions that create conflicts or lead to missing formal encounters to indicate barriers to collaboration between the caregivers. Thus, this study is a step towards enhancing our understanding of collaborative practice in home-based dementia care. I hope that the results will be beneficial in improving further research and practice on this subject.

Abstract in Norwegian

Demenssykdom har en progressiv, kronisk karakter og gir kognitive svekkelser. I Norge i dag lever rundt 70 000 personer over 65 år med demenssykdom og statistiske framskrivninger de neste 30 år tilsier nær fordoblet prevalens. Halvparten av personene med demenssykdom bor hjemme, og 25% av disse mottar offentlige helsetjenester. Pårørende utfører betydelig omsorgsarbeid for denne pasientgruppen.

For å møte utfordringsbildet knyttet til demenssykdom, har skandinaviske myndigheter fremmet styringsredskap for å videreutvikle eksisterende, samt etablere nye helsetjenestetilbud. Et viktig helsepolitisk tiltak er å tilby hjelp tidlig i sykdomsforløpet slik at pasienten kan bo lengst mulig hjemme og at pårørende får nødvendig støtte. Helsemyndigheten beskriver styrket samhandling mellom hjem og helsepersonell som en forutsetning. Det er gjennomført lite forskning på samhandling mellom helsepersonell og pårørende til personer med demenssykdom som mottar kommunale omsorgstilbud i hjemmet.

Derfor har denne studiens overordnede mål vært å skape kunnskap om hvordan helsepersonell og pårørende beskriver samhandling om omsorgen for hjemmeboende personer med demenssykdom. Gjennom fortolkende analyser ved hjelp av posisjoneringsteori, en teori om sosiale interaksjoner, viser studien hvordan posisjoner forhandles og får betydning for samhandling.

I denne studien har jeg fortolket samhandling til å forutsette tillit, en opplevelse av nødvendighet og en felles forståelse av situasjonen som samhandling inngår i. Videre har jeg fortolket at samhandling i hjemmetjenester er sammenvevd med politiske mål som brukermedvirkning, kontinuitet i pleien og i dette området samiske rettigheter. Politiske mål kan forstås som idealer hvor implementering av målene får relevans (eller ikke) i praksis. Operasjonalisering av rettigheter gjøres i et praksisfelt som krever faglig skjønnsmessige vurdering, fortolkning og samhandling mellom pasient, helsepersonell og pårørende. Ut fra en slik forståelse av praksis utviklet jeg to forskningsspørsmål:

1. Hvordan beskriver helsepersonell og pårørende samhandling i hjemmetjenester knyttet til personer med demenssykdom?
2. Hvilke barrierer kan hindre eller oppstå i samhandling mellom helsepersonell og pårørende

Studien har konstruert data i rurale kommuner ved hjelp av 18 dybdeintervju med helsepersonell (11) og pårørende (7), og fra et kort feltarbeid hvor to demensteam ble fulgt over to dager. Analysestrategien er tematisk innholdsanalyse og analyse ved hjelp av posisjoneringsteo-

ri. Posisjoneringsteori, særlig ved hjelp av posisjoneringstriaden er benyttet for å belyse hvordan etnisk tilhørighet, brukermedvirkning og kontinuitet i pleien får betydning for helsepersonells og pårørendes samhandling om omsorg for personen med demens. Analysen resulterte i tre artikler samt en overordnet diskusjon av disse i denne avhandlingen.

I den første artikkelen undersøkte vi deltakernes erfaring med beslutningsprosesser. Brukermedvirkning for personer med demenssykdom, med involvering av pårørende, er et helsepolitisk mål. Studien viste konfliktfylte forhandlinger mellom pårørende og helsepersonell når det kom til beslutninger av betydning for pasientene, helsetjenestene og pårørende. Forhandlingene fremsto som en konsekvens av ulike fortolkninger av pasientens samtykkekompetanse og talspersonposisjoneringer. Konfliktene kom særlig til syne i situasjoner hvor fagpersonene oppga organisatorisk mangel på ressurser, og når pasientens beslutninger hadde betydning for pårørendes omsorgsbyrde.

I den andre artikkelen undersøkte vi etniske posisjoneringer. Nasjonale dokumenter gir uttrykk for bestemte rettigheter for samer begrunnet i særskilte utfordringer med tanke på språk, tradisjon og assimileringspolitikk. For at slike politiske føringer skal kunne gjennomføres, må etniske posisjoner gjenkjennes og aksepteres. Studien viste omfattende forhandlinger av etnisk posisjonering i praksis. De etniske, og særlig de etno-politiske posisjoneringene kunne skape til dels store barrierer for samhandling.

Den tredje artikkelen omhandlet deltakernes refleksjoner over samhandling med fokus på kontinuitet i pleien og bruk av individuell plan. Kontinuitet er et viktig helsepolitisk mål som særlig er lagt vekt på for personer med demenssykdom. I Norge tar den lovbestemte pasientrettigheten individuell plan sikte på fremme kontinuitet, sikre brukermedvirkning samt å øke samhandling mellom hjem og offentlige helsetjenester. Artikkelen viser hvordan helsepersonells og pårørendes posisjoner i samhandling kan aktivere eller skape barrierer for kontinuitet i pleien for personer med demens. Artikkelen demonstrerer et gap mellom praksis og politiske mål med hensyn til kontinuitet, og særskilt når det gjelder bruk av den lovhjemlede individuell plan. Studien viste videre deltakernes ulike oppfatninger av informasjonsflyt og koordinering av tjenester, og også ulike oppfatninger av offentlige helsetjenesters tilstrekkelighet i demensomsorg.

Studien som helhet fremviser hvordan samhandling forhandles mellom helsepersonell og pårørende i hjemmetjenester for personer med demensomsorg. Hvordan samhandlingen kan forstås og utøves i praksis presenteres gjennom de tre artiklene samt gjennom metaforen «samhandlingens mosaikk». Mosaikken har «fliser» eksemplifisert som tillit, aksept av nød-

vendighet, forståelse av hvem som er same og hvem som har rett til samiske særtiltak, forståelse av brukermedvirkning som konsept og praksis, samt organisatorisk koordinering av tjenestene. Jeg har fokusert på «sprekker» i «flisene», eller «ufullstendig mønster», forstått som posisjoner som skaper konflikter eller fører til manglende formelle kontaktpunkt som skapte barrierer for samhandling mellom partene. Sådan er denne studien et skritt mot å styrke forståelsen av samhandling knyttet til hjemmetjenester og demensomsorg. Jeg håper at resultatene vil være til nytte for å forbedre praksis på dette området, og også for videre forskning.

List of articles

This thesis is based on the following original papers, which will subsequently be referred to by their Roman numerals:

I. Larsen, L. S., Normann, H. K., & Hamran, T. (2015). Processes of user participation among formal and family caregivers in home-based care for persons with dementia. Dementia. doi:10.1177/1471301215584702

II. Larsen, L. S., Normann, H. K., & Hamran, T. (2015). Collaboration between Sami and non-Sami formal and family caregivers in rural municipalities. Ethnic and Racial Studies, 1-19. doi:10.1080/01419870.2015.1080382

III. Larsen, L. S., Normann, H. K., & Hamran, T. (2016). Continuity of home-based care for persons with dementia from formal and family caregivers' perspective. Dementia. doi:10.1177/14713012166826

List of abbreviations

Dementia:	Dementia diseases
GP:	General practitioner
IP:	Individual plan
NORUT:	The Northern Research Institute
NPM:	New Public Management
NSD:	Norwegian Social Science Data Services
NWS:	Norwegian welfare state
PPS:	Purchaser-provider split service delivery model
REK:	Regional Committees for Medical and Health Research Ethics
WW2:	World War II

1.0 Introduction

The aim of this project is to gain knowledge regarding formal and family caregivers' experiences of collaboration in home-based care for people with dementia.

The study commenced in October 2012, and the methods for constructing data were individual in-depth interviews with caregivers and brief fieldwork that involved following two dementia teams. Data construction occurred in rural municipalities traditionally populated by Sami, Norwegians, Qvens[1] and mixed populations. I deemed such municipalities appropriate because several government documents refer to Sami people with dementia as a particularly vulnerable group due to language, culture and tradition barriers and the history of Sami assimilation policies (cf. Ministry of Health and Care Services, 1999:3; Ministry of Health and Care Services, 2010b; Ministry of Labour and Social affairs, 2008).

In the last decade and in particular after the implementation of the national healthcare reform – the 'Coordination Reform' – in 2012 (cf. Ministry of Health and Care Services, 2009), most healthcare services have been performed in municipalities and as home-based care (Jacobsen, 2015). The Coordination Reform emphasizes collaboration between home and formal services. Several other official reports describe family caregivers' central role in healthcare, in particular for people with dementia (Ministry of Health and Social Affairs, 2004; The Norwegian Directorate of Health, 2015a).

Dementia is a progressive and chronic brain disease with symptoms that are connected to the impairment of multiple cognitive abilities, including memory, that is sufficient to interfere with self-maintenance, work, or social relationships (Lipton & Weiner, 2012:11). The symptoms eventually necessitate heavy reliance on healthcare services (Brodtkorb, Kirkevold, & Ranhoff, 2008). In its late stages, dementia impairs the affected individual's ability to communicate and ultimately impairs their ability to be involved in or to influence decisions (Brodtkorb et al., 2008). The challenges with regard to involvement and decision-making processes necessitate further improved collaboration between formal and family caregivers to ensure the rights of the person with dementia (World Health Organization, 2015).

[1] The Sami are an indigenous minority population in Norway. The Qvens are linked primarily to farmers who emigrated, most often from Finland, to northern Norway in the mid-1800 (Otnes, Niemi, & Eriksen, 1995). I have further elaborated on the concept of ethnicity in chapter 2.3.

Given the estimated prevalence of the disease (cf. Ministry of Health and Care Services, 2013; Prince et al., 2013), the challenges for healthcare services domestically and worldwide are substantial, and society faces an increase in healthcare expenses (Bergh et al., 2015; Wimo, Jonsson, Bond, Prince, & Winblad, 2013). In Norway, half of all people with dementia live at home (Ministry of Health and Care Services, 2015a). Of those, only 25% receive formal home-based care, and the efforts of family caregivers are substantial (The Norwegian Directorate of Health, 2016). Mostly because of the unpaid work of informal caregivers, home-based care costs less than residential care (Wimo et al., 2013). However, a large amount of research notes the heavy burden of care on family caregivers (Graneheim, Johansson, & Lindgren, 2014; Murray & McDaid, 2002).

To reduce family burden and to postpone institutionalization, several policy documents state the importance of improved collaboration between home and formal services (Ministry of Health and Care Services, 2009, 2010a, 2013, 2015a, 2015b, 2015c). The change in policy strategy emphasizing substantial collaboration has specific consequences for the way people develop new roles or positions in healthcare (Orvik, 2015). However, research on Norwegian healthcare has scarcely explored collaboration between caregivers (The Research Council of Norway, 2016).

This project concerns caregiving work for Sami people with dementia. The Sami, as indigenous people, have distinctive rights according to the ILO 169 convention (Ministry of Local Government and Modernisation, 1989) and the Sami Act of 1987 (Ministry of Government Administration Reform and Church Affairs, 1987). Current Norwegian health policy emphasizes that persons should have equitable access to healthcare regardless of ethnicity (Ministry of Health and Care Services, 2015c), and health policy guidelines also suggest specific arrangements to ensure equitability for individuals of Sami ethnicity, e.g. access to Sami-speaking nurses and other facilitations for the Sami population (Ministry of Health and Care Services, 2013).

Implementation of official policies and acts concerning health and Sami rights depends on formal caregivers, who act as street-level bureaucrats and thus apply a considerable amount of discretion when they make their judgements in practice (Molander, Grimen, & Eriksen, 2012). Discretionary judgements are based on acts, norms and available resources, and such interpretations may create tension in practice when formal caregivers must decide what healthcare services to offer to whom and when. Because of the complex field of home-based care, formal caregivers' assessment of services for people with dementia of Sami ethnicity

calls for an even more comprehensive collaboration between patient and formal and family caregivers.

Using these caregivers' descriptions of their practice in home-based care and guided by theoretical concepts, this study aims to describe formal and family caregivers' positioning with respect to duties and rights and to further discuss how these positions may influence collaborative practice in various ways. Conflicting positions can be construed as barriers to collaborative practice and can ultimately inhibit the achievement of quality aims in national health services. Discussing positioning and barriers to collaboration may help uncover challenges and allow possible changes. Thus, the study may benefit persons with dementia and their caregivers in clinical practice and help health policy makers improve healthcare strategies accordingly.

1.1 Outline of the thesis

When I began work on my thesis, I found inspiration in colleagues' work. Early on, I created a template that consisted of the abstract, introduction, background, aims, theoretical framework, methods, results and discussion. Writing the abstract served as a guideline for the rest of the thesis. As the thesis changed and I added new chapters and new insights, the abstract changed accordingly. I was inspired by Haara and Smith (2011) and concluded that a template is useful, but you must make the thesis your own. Coffey and Atkinson (1996:159) wrote: "In taking ideas that link one's own data with other social domains, one is moving towards the production of generic concepts and formal theory." I emphasized the connections among the three articles and the comparison of the findings with theoretical frameworks at a level that transcends the theoretical concepts applied in each article.

Following this introduction, the second chapter describes the background of the study, including relevant research literature. In chapter three, I define the overall aim of the study and the corresponding three articles. Chapter four presents the theoretical framework. The methodological perspective, methods and ethical considerations are presented in chapter five, and the results including findings from the three articles are found in chapter six. In chapter seven, I discuss the study's reliability, validity and generalizability. Chapter eight contains my discussion of the main results and ends with concluding remarks and implications, followed by references. Finally, the three individual articles are provided.

2.0 Background

The term collaboration concerns the health services' ability to distribute work tasks among different people to achieve a mutual goal and the ability to perform the tasks in a coordinated and effective way (Kassah & Tønnessen, 2016). Collaboration is a complex term, and in this project the concept is based on Orvik's (2015:209) brief description connecting collaboration with co-operation and coordination.

Co-operation is not formalized or systemized but depends on the positive attitude of individuals in continuous, informal contact. Collaboration is more specific and committing for the actors involved. Both parties must perceive collaboration as necessary, have a shared understanding of the situation, trust each other and mutually adjust work tasks to their interpretation of role and function. Collaboration presupposes that the individuals' actions are coordinated to ensure workflow so that the patient and family caregivers experience coherence of services. Coordination both within and between healthcare organizations is a prerequisite for collaboration, and coordination thus requires formalized decisions at the management level (Orvik, 2015).

Based on Orvik's (2015) description of collaboration to explore home-based care practice, collaboration involves trust, necessity, shared understanding of the situation and administrative coordination approaches.

In national and international policy documents, the term collaboration is often used alongside terms such as user involvement and continuity of care as crucial for quality of care (Alazri, Heywood, Neal, & Leese, 2007). Several international healthcare strategies advocate that the aim of user involvement be achieved through comprehensive collaboration between home and healthcare services (cf. Christensen & Fluge, 2016; Holum, 2013). Additionally, continuity of care, as a key political aim resulting from the last decade's fragmented services due to the healthcare reforms, concerns individual and administrative collaborative efforts to reduce discontinuity in care and make the patients experience safety and coordinated services (Gjevjon, 2014).

Thus, the political terms collaboration, user involvement and continuity of care are intertwined and complex. A collaborative practice that involves the user and family caregivers' opinion may contribute to improved collaboration, and conversely, user involvement will be difficult to achieve if the parties do not collaborate. The practice of both collaboration and user involvement depends on continuity of care approaches.

Therefore, I start with a clarification of the terms user involvement and continuity of care with emphasis on developments in national health policy and services for people with dementia. Because the study takes place in rural, multi-ethnic municipalities in northern Norway and the patients, whom the caregivers describe as receiving home-based care, are Sami, I also provide a brief outline of the term ethnicity to explore how ethnic affiliation may influence collaboration.

To close this chapter, I describe the municipalities where the data was constructed and the disease dementia and conclude with an overview of research relevant to home-based care for persons with dementia.

2.1 User involvement

A common distinction in the definition of user involvement is between the individual level that concerns decisions regarding available and justifiable personal examinations and treatment and a collective level that concerns the representation of various forms of user groups to ensure involvement in the design of services (Barnes & Walker, 1996). In this dissertation, I explore the individual level that is process oriented with the aim of activating the user in terms of both planning and outcome of treatment and care (cf. Rappana Olsen, 2005).

The Norwegian Patient Act § 3 (cf. Ministry of Health and Care Services, 2016a) distinguishes between patient and user, where a patient is a person who requests or receives healthcare services and a user is someone who receives healthcare services over a longer period. However, in accordance with the participants' descriptions in the articles, I use the term patient as referring to the person with dementia who receives formal healthcare services.

The term user involvement is vaguely defined (Christensen & Fluge, 2016; H. Hansen, Humerfelt, Kjellevold, Norheim, & Sommerseth, 2015; Rappana Olsen, 2005) and encompasses several overlapping terms[2] (Rappana Olsen, 2005). However, the overlapping terms all involve placing the interest of the user first and concern decision-making processes (Christensen & Fluge, 2016). In article I, I used the terms "user participation" and "user-centred care" without definition. Working on the thesis, I noticed that recent policy documents establish the term user involvement, and my subsequent work accordingly draws on H. Hansen et al.'s (2015:31) definition of user involvement: "A systematic and open process, where the user and

[2] Overlapping terms for user involvement include user perspective, user participation, user management, empowerment, user-centred care, to have respect for the user and to make use of the users' competence (Rappana Olsen, 2005).

formal caregivers' perspective and arguments lead to a reasonable, safe and qualified decision"[3].

The description of user involvement in official documents has changed over the years from a relatively paternalistic perspective on users' involvement to a more dynamic and collective interpretation of the practice of user involvement (H. Hansen et al., 2015). Christensen and Fluge (2016) describe the last decade's political discourse regarding user involvement as a pairing of two ideologies: social citizenship and consumerism.

Social citizenship is closely linked to the ideology of secularization, liberalism and democracy (cf. Christensen & Fluge, 2016; Marshall, 2003). In line with this ideology, individuals' right to be informed, contribute to and collaborate in their own health treatment and care has been emphasized in international healthcare policy since the late 1970s (World Health Organization, 1978: 35). The Norwegian state perceived the elderly as citizens who had a right to obtain care based on their fulfilled duties, and the state had duties (Christensen & Fluge, 2016).

In the 1990s, consistent with the development of the personhood and relational perspective in healthcare (cf. Kitwood, 1997), the concept of user involvement was explicitly mentioned in official documents as a way to respect and safeguard the user (Ministry of Social Affairs and Health, 1996). User involvement was legislated in many Western countries in the late 1990s and in Norway in 1999 (Smebye, Kirkevold, & Engedal, 2012). The Patient Act §3 affirms the patient's right to involvement and influence in decisions regarding available and justifiable examinations and treatment. Further, the act states that the information must be adapted to the person's capabilities, language and culture and that services should be based on the recipient's own goals, resources and needs along with technical evaluations and formal caregivers' knowledge (Ministry of Health and Care Services, 2016a).

A more individualized argument for user involvement is suggested by Christensen and Fluge (2016) based on the ideology of consumerism (cf. Barnes & Walker, 1996) and characterized by terms such as the market and freedom of choice. The market economic perspectives have influenced the last decade's political health strategies with terms such as scorecard, competition, decentralized management and users' freedom to choose and are contained in a more abstract and universal management model, the 'New Public Management' (NPM) (Kristiansen, 2016). The relationship between individual and state is oriented more towards the indi-

[3] My English translation of the Norwegian sentence "begrunnet og faglig forsvarlig beslutning".

vidual through aims of increasing cost efficiency and a notion that the individual user's needs should set the ground for defined terms for choices (Christensen & Fluge, 2016). In this ideology, user involvement could be understood as part of the development of the NPM practice in health and welfare services (Juritzen, Engebretsen, & Heggen, 2012).

User involvement as an NPM tool is criticized. Bradshaw (2008) catalogued and debated policies regarding user involvement in England and wrote that the aim of these policies was to reduce the individual's dependency on the state by empowering users. He further wrote:

> So while the intention to include them in the determination of their own care is seemingly about their well-being, they are being used simultaneously, through the notion of user choice and satisfaction, as a tool to drive market solutions into the delivery of more efficient healthcare (Bradshaw, 2008:679).

Researchers have been questioning the concept of user involvement in Norway as well (Høybråten Sigstad, 2004; Juritzen et al., 2012; Mol, 2008). Juritzen et al. (2012) wrote that the displacement of responsibility from state to individual based on the right to choose may also lead to increased self-regulation.

In sum, in this dissertation user involvement refers to a practice connected to individual patients and to what formal and family caregivers perceive as normative and legal rights and duties in home-based care. I have followed Tritter and McCallum's (2006) suggestion with regard to understanding the meaning of user involvement in decision-making processes in social interactions, and thus, I have explored formal and family caregivers' descriptions and reflections regarding decision-making processes pertaining to the patient with dementia in home-based care. As noted in this chapter, the parties' interpretation and fulfilment of user involvement in practice can be subject to discourses that differ in their orientation towards the individual's or the state's responsibility.

2.2 Continuity of care

Continuity of care is an important feature in healthcare services and refers to quality of care over time (Alazri et al., 2007; Gulliford, Naithani, & Morgan, 2006; Haggerty et al., 2003; Heaton, Corden, & Parker, 2012; Hellesø & Lorensen, 2005; Naert, Roose, Rapp, & Vanderplasschen, 2017). Norwegian health strategies highlight continuity of care as an aim of healthcare services by pointing to discontinuity as a challenge (Ministry of Health and Care Services, 2009, 2013, 2014, 2015a, 2015b). In Norwegian healthcare policies, continuity of

care refers to the notions that each patient's trajectory should be integrated and coordinated and patients should perceive this trajectory as seamless across and within healthcare levels (Gjevjon, 2014).

The emphasis on continuity of care in healthcare can be understood as a consequence of more fragmented services resulting from healthcare reforms, encompassing new responsibilities and tasks in a constrained municipal economy and the ideal of improved collaboration across professions, services and levels (Kassah & Tønnessen, 2016). Thus, the term concerns the formal caregivers' joint efforts to improve quality in healthcare through approaches that aim to reduce the fragmentation in care and ensure that the patients experience safety, services based on their individual needs, connection and coordination between services (Gjevjon, 2014).

Despite the increasing focus on continuity of care, the concept is vaguely defined and interpreted in various ways that result in divergent practices (Heaton et al., 2012). Colloquially, the term is often associated with the number and consistency of health personnel caring for a patient (Gjevjon, 2014). However, a literature review conducted in 2007 showed many different types of continuity, e.g. experienced, relational, team, cross-boundary, flexible, management, geographic and informational (Alazri et al., 2007). A more recent review (Uijen, Schers, Schellevis, & van den Bosch, 2012) showed that a considerable amount of literature focuses on continuity of care using various categorizations and several overlapping terms[4] interchangeably and often without definition. However, these terms all involve relationships among the patient and caregivers, where communication and collaboration are both a process and an outcome of care (Uijen et al., 2012).

Similar to the change in the understanding of user involvement over time towards a dynamic and collective interpretation of practice (cf. H. Hansen et al., 2015), Heaton et al. (2012), through their development of the 'professional, perspectivist and partnership paradigms', indicated a change in the interpretation of the term continuity of care. 'The professional paradigm' operated primarily until the 1990s. Formal caregivers had the necessary competence and insight to assess causes and factors that might inhibit or enable continuity of care, and patients were perceived as passive recipients who received care. Consequently, discontinuity was a failure of the system (Heaton et al., 2012). 'The perpectivist paradigm' emerged from the work of Freeman et al. (cf. 2001) and Reid et al. (cf. 2002) suggesting that patients, care-

[4] Examples include coordinated care, integration of care, discharge planning, person-centred care, case management and seamless care.

givers and formal caregivers have different perspectives. However, these authors highlighted patients' and caregivers' experiences. Discontinuity was connected to patients' experience and could appear both in process and outcome (Heaton et al., 2012). The notion of 'partnership paradigm' suggests an emphasis on the relational, collective and dynamic processes in collaborative care networks. Hence, continuity of care is co-constructed in interactional processes, and its achievement depends on the strength of the connections and relationships in such processes (Heaton et al., 2012).

I have explored collaboration by searching for discontinuity in formal and family caregivers' descriptions of home-based care, and I have drawn on Reid et al.'s (2002) suggestion of a tripartite structure comprising relational, management and informational continuity of care. Most of the literature on continuity of healthcare draws on this particular analytical split (Gjevjon, 2014).

Relational continuity is the bridge between past, present and future care through an ongoing relationship between a patient and one or more care providers who knows the patient and whom the patient trusts (Haggerty et al., 2003). It is a dimension of continuity that is strongly supported and a principal component of healthcare (Heaton et al., 2012) and is highlighted as necessary for healthcare providers' understanding of patients' needs and to build trustful relationships (Gjevjon, Romøren, Kjøs, & Hellesø, 2013). According to Gjevjon (2014), strategies for achieving relational continuity may include trust-building measures, in which allocated time and defining primary carers' responsibilities and roles are key, in addition to holding the number of caregivers involved to a minimum.

Informational continuity focuses on the use and transfer of information regarding past events, personal circumstances and present needs to adapt current and future care to each individual regardless of the healthcare provider or service level (Haggerty et al., 2003). Gjevjon (2014) suggests written patient records, oral and written reports and formal and informal conversations with patient and family caregivers as tools to achieve informational continuity.

Management continuity refers to a consistent and coherent management approach that is responsive to the patient's changing needs. Gjevjon et al. (2013) refer to the previous work of several researchers, e.g. Krogstad, Hofoss & Hjortdal (2002), Saultz (2003) and Woodward et al. (2004), who established the management structure of continuity of care as a precondition for other dimensions. Management continuity is thus understood as a "backstage" continuity that establishes the strategies and measures for achieving "front stage" continuity in certain fields (Gjevjon et al., 2013). Examples of management continuity include planning employ-

ees' shift arrangements, working conditions, technological equipment, collegial, management communication, and available resources (Gjevjon, 2014).

2.3 Ethnicity

Eriksen (1991) described how research on ethnicity has changed from previous identification of ethnicity as a property of "cultural groups", in which culture was a fixed entity, towards the use of more dynamic and interpersonal concepts as developed by Barth (cf. Barth, 1969) and Eidheim (cf. Eidheim, 1969).

In the latter understanding of ethnicity, it is not relevant to assign cultural traits or patterns to certain populations or groups, e.g. the Norwegian culture or the Sami culture. The use of ethnicity as a classification to distinguish among people from different cultural groups based on shared ideas or common myths, descent and history may lead to stereotypes that easily overrule other more important positions (Eriksen, 1995). However, in some social practices, ethnicity is an ordering principle that unfolds in local contexts and influences people's everyday life (Olsen, 2010). Nadim (2015) suggests an understanding of ethnicity as a process through which both members and non-members of a group position themselves in relation to one another. Similarly to other social positions such as gender and social class, the ethnic position can be explored to disclose, for instance, productions and reproductions of ethnic categories (Eriksen, 1995). Thus, a persons' ethnicity is an analytical concept that is made concrete in negotiated positions in social contexts (Olsen, 2010).

I explore if and how the Sami ethnicity of the person with dementia influences formal and family caregivers' collaboration. I adhere to the understanding of ethnicity as negotiated positions in social contexts, and I use the term ethnic affiliation to capture and emphasize dynamic positioning of ethnicity in everyday life.

Olsen (2010) suggests that Norwegian public policies have constructed a "touristic" and stereotyped Sami position as seen in official documents, museums and heritage preservation efforts. Thus, the Sami ethnicity on a micro-level must be assessed with regard to policy discourses and the collective understanding that these discourses may have constructed (Olsen, 2010). To assess the political discourses that may influence the formal and family caregivers' understanding of ethnic affiliation, I have elaborated in chapter 2.2.3 regarding Sami ethnopolitical rights in Norway.

2.4 The research field

The research field is home-based care in rural, multi-ethnic municipalities in northern Norway, which in this study requires specific attention to Sami ethno-political rights.

2.4.1 Home-based care in Norway

Home-based care refers to work or activity provided to assist someone who lives at home (Wimo et al., 2013). Latimer (2012) describes home-based care's connection to the construction of a person's needs and thus constituted in a user-provider dyad in the complex location where home-based care take place. Thus, the right to necessary healthcare in municipal services (cf. Ministry of Health and Care Services, 2016a) initiates the collaboration between home and formal care services.

My interpretation of home-based care draws on Ceci, Björnsdóttir, and Purkis's (2012:15) definition: "an ongoing accomplishment of the concerted activities of people-patients, families, formal care providers, administrators, policy makers and so on".

Daatland and Otnes (2014) described home-based care's roots as unpaid and informal family care in addition to voluntary and humanitarian work, mainly performed by women. The ideological change in the mid-60s that emphasized social citizenship led to a re-definition and development of home-based care in Norway that aimed to postpone institutionalization (Christensen & Fluge, 2016). Formal responsibility for the elderly in need of care was assumed to belong to the welfare state, as detailed by the Social Care Act of 1964, and thus, family caregivers were compelled to assist due to informal norms but no longer by law (Daatland & Otnes, 2014). Home-based care became a publicly funded part of municipalities' responsibility within the Norwegian welfare state (NWS), and the number of patients to receive formal home-based care services increased fivefold from 1965 to 1975 (cf. Ministry of Social Affairs, 1964).

Christensen and Fluge (2016) wrote that since the late 1980s there has been a widespread political perception that the NWS needed to be more efficient because the growing number of elderly people were perceived as a financial burden to the welfare state. Combined with a lack of nursing homes and formal caregivers to care for the elderly, a series of political reforms emerged (Christensen & Fluge, 2016; Latimer, 2012). Health strategies in the mid-90s redefined the elderly as able to stay at home through further development of formal home-based care and with due consideration for safety, respect and high quality services (Christensen & Fluge, 2016; Ministry of Social Affairs and Health, 1996).

In Norwegian health policy documents, the elderly are now presented as more inclined to state demands regarding individualized care and range of services, and thus, official documents stress the elderly's own responsibility to be involved and stay active to be able to stay at home (The Norwegian Directorate of Health, 2009). Home-based care is stated as the first choice in terms of services (Ministry of Health and Care Services, 2005, 2006, 2009). The Coordination Reform led to a further shift of responsibility and tasks towards the municipalities (cf. Ministry of Health and Care Services, 2009).

Vabø (2007) describes home-based care in the last decades as influenced by NPM and suggests that this influence has had important consequences in terms of formal caregivers' collaboration with patients as exemplified by the purchaser-provider split (PPS) service delivery model in Norwegian municipalities. Prior to the PPS, formal caregivers could negotiate services directly with the patient, but administrative responsibility is now separated from the service providers, and the idea is that healthcare services deliver performance in line with agreed specifications and contracts (Kassah & Tønnessen, 2016; Ministry of Health and Care Services, 2011).

Regardless of reforms, the majority of informal and formal caregivers in home-based care are still women (cf. Nordbø, 2014). The scale of informal care is substantial, and it is mostly performed by spouses and children (Bergh et al., 2015). Formal home-based care is provided by staff with varying degrees of qualification, commonly nurses and nursing assistants (Ceci et al., 2012). Furthermore, formal home-based care requires three staff shifts, and because of the extensive use of part-time positions, the number of personnel to visit someone's home is extensive (Gjevjon, Eika, Romøren, & Landmark, 2014).

2.4.2 Rural and multi-ethnic municipalities in northern Norway

According to the Ministry of Foreign Affairs (2015) Norway is populated by approximately 5 million people, of which approximately 70% live in cities and towns. The country's narrow and long coastline results in dispersed settlements mostly in coastal municipalities but also in inland municipalities along the main communication roads. Northern Norway is characterized by particularly long distances between dispersed settlements in rural areas and low population density. While the population of northern Norway consists of only 9.4% of the total population, the area of northern Norway is 34.9% of the total Norwegian mainland. In the last 40 years, there has been extensive migration from rural to urban areas and from northern Norway to cities in the southern part of the county (The large Norwegian Encyclopedia, 2017).

In Norway, the Sami are an official minority population with the status of indigenous peoples and thus distinctive rights according to the ILO 169 convention (Ministry of Local Government and Modernisation, 1989) and the Sami Act (Ministry of Government Administration Reform and Church Affairs, 1987).

Norway has two official languages, Norwegian and Sami. There are ten different Sami languages (The Sami Parliament of Norway, 2016), but only three of them are official in Norway (Ministry of Foreign Affairs, 2015). However, most Sami speak Norwegian or are bilingual and speak Sami and Norwegian (Blix, 2016). The most concentrated areas of Sami settlement are in northern Norway, and thus, the Sami language is mostly associated with some of the northern Norwegian municipalities (Ministry of Foreign Affairs, 2015; The large Norwegian Encyclopedia, 2017).

Based on the understanding of ethnicity as a negotiated position in social contexts, it is difficult to assess who is Sami. In Norway, a Sami can register to vote for the Sami Parliament, and a criterion for registering is that at least one of your parents has already registered. Other criteria are that the person must express a Sami affiliation and that he or she or at least one relative within three generations speaks or spoke Sami at home or during adolescence (Ministry of Government Administration Reform and Church Affairs, 1987). However, how many fulfil the criteria for Sami designation today and how many choose to remain outside the registered Sami population is impossible to determine.

As the Sami population is not a homogeneous group, a common way to discuss differences within the Sami population colloquially is by contrasting the interior and coastal municipalities. The interior municipalities are historically involved in reindeer herding, while in the coastal municipalities, the Sami have traditionally worked as farmers and fishermen (Hoëm, 2007). In the last decade, the concept of an "urban Sami" has emerged. An urban Sami is a Sami person who lives in a city (Selle, Semb, Strømsnes, & Nordø, 2015).

In this thesis, data construction occurred in both interior and coastal municipalities. "Sami" refers to a participant who, in the interviews, stated a Sami ethnic affiliation. In article II, I chose the category "non-Sami" because of the possible misunderstanding of the term "Norwegian" as indicating that the Sami are not Norwegian citizens (cf. Selle et al., 2015:34). However, henceforth I use the category "Norwegian" to refer to participants who stated an ethnic Norwegian or mixed genealogy but emphasized their ethnic Norwegian affiliation.

All participants experienced their ethnic affiliation in societies where the history of Sami assimilation policies and Sami revitalization are vibrant. Therefore, an elaboration of the development of Sami ethno-political rights in Norway is necessary for further reading.

2.4.3 Sami ethno-political rights in Norway

The Sami's rights in Norway have changed throughout history and have been affected by global, national, regional and local policy (Blix, 2016). In Norway, the Sami's formal position as Norwegian citizens is described as uncontroversial, in contrast to some other countries with indigenous populations (Selle et al., 2015). The Sami were understood to be an original population and, when national Norwegian borders were drawn in 1751, the Sami were highlighted and recognized in the Sami codicil (Pedersen, 2006).

However, the international emergence of nationalistic ideology in the 1800s, along with the assumed risk that Russia or Finland might expropriate the county of Finnmark, led to the Sami assimilation policy (Otnes et al., 1995). In that policy, the Sami were considered "questionable citizens" who had to become more strongly aligned with the Norwegian language and culture (Selle et al., 2015). The government interpreted loyalty and a sense of belonging to Norway in terms of speaking Norwegian and considered it necessary for the Sami to abandon their culture and language (Ministry of Labour and Social affairs, 2001). In addition, in Social Darwinism, the central ideology at the time, the Sami were considered a primitive population that needed help from others to develop a more civilized society. The Sami thus became "citizens-minus", and the Sami identity was stigmatized (cf. Selle et al., 2015). The Sami assimilation policy had the greatest impact in coastal municipalities, mostly because of a mixed population that made the Sami culture and language difficult to maintain (Eidheim, 1969).

World War II (WW2) had serious consequences for the population of the northernmost part of Norway because of "scorched earth tactics" that destroyed most homes and cultural monuments, separated families and moved most of the population further south. Some of these people never moved back after the war. The consequences were particularly harsh for the Sami population because of the challenges with language and stigma that they faced in areas populated by the majority population. The period after the war focused on the ideals of equality and fellowship, and ethnic affiliation had little or no importance. The sense of a Norwegian national identity was strong, even among the Sami. The Sami were referred to as 'Samish-speaking Norwegians' in official documents (Selle et al., 2015). Thuen (2007) called the period after WW2 a time of 'passive Sami assimilation policy' and described how the centralization of settlement contributed to the difficulty of maintaining Sami identity.

The Sami assimilation policy resulted in early attempts at Sami politicization, and several Sami symbols, such as the Sami people's song, were created in the early 1900s. During the post-war period, society in general experienced increasing political awareness. The revitalization of the Sami language and culture through 'the Sami movement' made the Sami's special position visible and debated, in particular after 'the Alta affair' (Blix, Hamran, & Normann, 2013). The close connection between Sami political organizations and the international indigenous people's organization led to the global promotion of political demands concerning the Sami (Selle et al., 2015). The international acceptance of the hideous consequences of the Sami assimilation policy became a key instigator of the dramatic change in Norwegian Sami policy.

The first official document that planned for a Sami parliament in Norway was issued in 1984 (Ministry of Justice and Public Security). Norway was the first state to ratify the ILO 169 convention in 1990 and thus to recognize the Sami as indigenous people with special rights (Magga, 2014). Since 1980, the Sami population has developed a national flag, and 6 February has been established as National Sami Day. Selle et al. (2015) describe this era as a national interpretation of the Sami as a "citizen-plus", with all the rights of a citizen of Norway in addition to special rights as a Sami.

Norwegian healthcare strategies and international healthcare policy (World Health Organization, 2007) underline the ethnic position as possibly vulnerable in light of language, culture, tradition and the history of Sami assimilation policies in several Scandinavian countries (Ministry of Health and Care Services, 1999, 2010b, 2015b; Ministry of Labour and Social affairs, 2008). Norwegian policies and nursing literature suggest cultural facilitation as an approach to interaction that aims to understand "the other" in the light of previously recognized patterns of behaviour under certain circumstances. It encompasses having a cultural landscape, knowing something about the history of a people and being aware of one's own prejudices. Being culturally sensitive can also mean being critical of stereotypes (Qureshi 2005).

Thus, the rights of the Sami population relate to international human and citizen rights protecting them from discrimination but also rights regarding language, culture and religion (Ministry of Government Administration Reform and Church Affairs, 1987; Ministry of Local Government and Modernisation, 1989).

2.5 Dementia – the problem that initiates collaboration

Dementia has been a well-known disease throughout history (Aquilina & Hughes, 2006). Today, dementia is understood as a collective term for several diseases, among which Alzheimer's disease is the most common (Lipton & Weiner, 2012). The World Health Organization (2016) defines dementia in the following way:

> Dementia is a syndrome – usually of a chronic or progressive nature – in which there is deterioration in cognitive function (i.e. the ability to process thought) beyond what might be expected from normal ageing. It affects memory, thinking, orientation, comprehension, calculation, learning capacity, language, and judgement. Consciousness is not affected. The impairment in cognitive function is commonly accompanied, and occasionally preceded, by deterioration in emotional control, social behaviour, or motivation (World Health Organization, 2016)

The disease primarily affects older people, and because of the ageing population, the disease is a major global health problem (World Health Organization, 2012). Norwegian health authorities estimate that there will be 160,000 people in Norway with dementia in 2050, approximately double the current number (Ministry of Health and Care Services, 2013).

The symptoms of the disease commonly follow three stages – early, middle and late, where the early stage is often overlooked and misinterpreted as a normal part of old age (World Health Organization, 2012). The diagnosis, which in Norway is made by a general practitioner (GP), depends on the patient's level of function. GPs base their assessment on clinical examination and the person's history, which is often provided by family members (cf. Bergh et al., 2015). After the diagnosis is established, a health professional, usually a nurse, visits the patient in their home and provides information regarding the disease and available healthcare services while simultaneously evaluating the patient's and the family's capabilities and needs (The Norwegian Directorate of Health, 2015b).

An official Norwegian website designed to inform patients of their healthcare rights states that persons with dementia may be entitled to several healthcare services, e.g. home-based care, day-care services, short stays in residential care units, support staff, personal assistants, food delivery, dentistry and technological and other equipment (The Norwegian Directorate of Health, 2015b). The services offered depend on the formal caregivers' administrative assess-

ment in the PPS service delivery model. Thus, how formal caregivers understand the dementia diseases and patients' corresponding rights influences which healthcare services are offered.

2.5.1 The rights of the person with dementia

Since the mid-nineteenth century, the biomedical perspective on disease has prevailed. From the biomedical perspective, research, treatment and care have focused on mechanisms to slow or reverse the damage to the brain. Since dementia is nevertheless an incurable disease, the consideration of experience tended to focus on the family caregivers' burden (Ablitt, 2008). The solely biomedical perspective shifted towards a personhood perspective in the 1990s, when Kitwood (1997) launched the concept of "personhood" for people with dementia. "Personhood" represented an acknowledgement of the person with dementia as an individual with a personal history and dynamic positions who engaged in interactions with others. The person and not the disease should thus be at the centre of treatment (Kitwood, 1997).

Several other researchers have developed the relational perspective by exploring the self of the person with dementia (cf. Sabat & Harré, 1992) and how people's beliefs regarding the capabilities of the person with dementia appear to lead to social exclusion and worsen the symptoms of the disease (Baldwin, 2008; Behuniak, 2011; Hedman, 2014; Kelly & Innes, 2013). In the last decade, several researchers have advocated strengthening the rights of people with dementia diseases and argued that such an approach necessitates collaborative teams that support the sense of self of the person with dementia (Baldwin, 2008; Bartlett & O'Connor, 2007; Brannely, 2011; Nedlund & Nordh, 2015).

In line with the changed awareness of the rights of the person with dementia, the rising number of patients and thus the economic challenges in healthcare, national and global healthcare strategies regarding dementia have been formally established (Ministry of Health and Care Services, 2015a; cf. World Health Organization, 2012). The international aim to optimize care for patients with dementia is stated as: early diagnosis and support; optimizing physical health, cognition, activity and well-being; detecting and treating behavioural and psychological symptoms; and providing information and long-term support to caregivers (World Health Organization, 2012:8). To make possible the WHO's principal policy objectives and hence postpone institutionalization and ease family burden, an important part of the Norwegian health strategy regarding people with dementia relies on substantial and improved collaboration between formal and informal caregivers, user involvement and continuity of care in home-based care (Ministry of Health and Care Services, 2015a).

2.5.2 Norwegian policies of user involvement and continuity of care pertaining to people with dementia

The need for continuity of care is projected through several official reports pertaining to people with dementia by examples of administrative discontinuities involving patients and family caregivers struggling to receive information, coordinate care efforts and determine the best pathways in formal care services (Ministry of Health and Care Services, 2009, 2014). Additionally, three Norwegian nationwide inspections of services concluded that home-based care services for people with dementia were insufficient (Norwegian Board of Health Supervision, 2006, 2011, 2014).

User involvement for people with dementia is emphasized in all the most recent official documents (Ministry of Health and Care Services, 2013, 2015a, 2015b). However, it is well recognized in international research and policy that, while inclusion in decision-making processes is important for people with dementia, exclusionary practices are expected to occur when the cognitive and communicative capabilities of the person with dementia are threatened (Brannely, 2011; World Health Organization, 2015).

User involvement necessitates an assessment of the user's consent (Rappana Olsen, 2005), and the document "Dementia strategy 2020" (Ministry of Health and Care Services, 2015a) describes the challenging nature of determining consent for people with dementia and further the need for more knowledge regarding decision-making processes. Chapter four of the Patient Rights Act (cf. Ministry of Health and Care Services, 2016a) indicates that people with dementia constitute a possible exception for consent. The Act states that consent can be provided expressly or tacitly and the healthcare provider must constantly assess the person's capability to consent and thus document the rationale behind their judgements.

If the person with dementia is determined to have lost his or her ability to consent in certain situations, formal caregivers can make decisions on their behalf. However, formal caregivers must obtain and document the family caregivers' opinions if the decisions are of a more serious nature (Ministry of Health and Care Services, 2016a). Several recent official documents emphasize the family caregivers' central role in decision-making processes pertaining to people with dementia (Ministry of Health and Care Services, 2015a, 2015b). The most recent health policy document (cf. Ministry of Health and Care Services, 2015a) strongly emphasizes the involvement of the family caregivers and further aims for the personalized master treatment and care plan – the 'individual plan' (IP) – to be offered to all persons with dementia by 2020.

The IP is legislated in the Patient Rights Act paragraphs §2.5, and the right applies to patients with long-standing needs for coordinated services (Ministry of Health and Care Services, 2016a). The IP is a formal written plan that involves the management continuity of care by placing responsibility for services with the formal healthcare coordinator while concurrently emphasizing user involvement and other collaboration processes that include the user and formal and family caregivers (Berven, Ludvigsen, Christensen, & Nilssen, 2013; Holum, 2012). Furthermore, the IP can help document pre-consent that requires formal and family caregivers consideration of the patient's previously established wishes in later on decisions regarding serious matters (The Norwegian Directorate of Health, 2015b).

2.6 Research pertaining to people with dementia – an overview

Dementia has been extensively studied. Hallberg et al. (2014) note that despite the change towards a political emphasis on personhood, network and user involvement, most international research conducted on or for people with dementia still focuses primarily on diagnosis, treatment and residential care. Several researchers state the need for more attention to collaborative practices in home-based dementia care (Chenoweth, Kable, & Pond, 2015; Chester et al., 2016; Daly, Bunn, & Goodman, 2016; Miller, Withlatch, & Lyons, 2016; Samsi & Manthorpe, 2013; St-Amant et al., 2012).

The vague definitions and the many overlapping terms related to the intertwined concepts of collaboration, user involvement and continuity of care made the search for relevant research difficult, and hence, I do not present a complete review but an overview of relevant full-text research articles from 1998 to 2017. Following searches in Cinahl, Pubmed, Medline and Google Scholar, I used the references in the chosen articles to extend the search. The search terms were:

Table 1 – Search terms

1	**Dementia or Alzheimer or cognitive impairment or memory loss**			
2	a) Collaboration or co-operation (21)	b) Home-based care or home-based or home (22)	c) User involvement or participation or engagement or involvement, shared decision-making, decision-making or decision (28)	d) Continuity of care, coordination of care, integration of care, person-centred care, case management, seamless care (43)
3	Caregivers or carers			

2.6.1 Home-based care and caregivers

Little knowledge is established regarding the effectiveness, acceptability or usefulness of home-based care other than estimates of costs (Comas-Herrera, Wittenberg, Pickard, & Knapp, 2007; Russell, Rosati, Rosenfeld, & Marren, 2011). Even less research has been conducted on the acceptability or usefulness of home-based care for people with dementia (Chenoweth et al., 2015).

Collaboration in home-based care concerns the challenge of working in someone's home (Bratteteig & Wagner, 2013). One of these challenges involves formal caregiver positions, namely, `guest' and `professional', between which a choice must be made because it is impossible to be both simultaneously (Öresland, Määttä, Norberg, Jörgensen, & Lützén, 2008).

The family caregiver burden accompanying home-based dementia care is a well acknowledged challenge described by researchers and policy makers (Graneheim et al., 2014). Family caregivers report unmet needs in home-based care with respect to safety, meaningful activities, information and education regarding diagnosis and prognosis and the need for respite (Black et al., 2013; Chester et al., 2016; Peeters, Van Beek, Meerveld, Spreeuwenberg, & Francke, 2010; Zwaanswijk, Peeters, Beek, Meerveld, & Francke, 2013). A review indicates in particular the need for psychosocial interventions concerning education and counselling of the person with dementia and their carers to reduce family burden and support the person with dementia appropriately in home-based care (Elvish, Lever, Johnstone, Cawley, & Keady, 2013). Several interventions have been tested, including "Caring for older adults and caregivers at home (COACH)", a programme that is strongly aligned with quality measures (D'Souza et al., 2015). However, a recent European cross-sectional study concluded that, although formal support (e.g. counselling, caregiver support, and education) for informal caregivers of persons with dementia are widely available in European countries, they are rarely utilized (Lethin et al., 2016).

The need for respite is another highlighted challenge concerning the family caregiver burden. However, an Australian review study (L. Phillipson, Jones, & Magee, 2014) shows that the use of respite services tends to be low. The non-use of out-of-home services such as day-care or residential care is associated with patients' and informal caregivers' beliefs concerning stigma, outcome of treatment or care, available services and access to services in addition to moral and personal duties (L. Phillipson et al., 2014; L. Phillipson & Jones, 2012; Lyn Phillipson, Magee, & Jones, 2013).

In Norway, several “schools” for family caregivers of people with dementia and day centres have been created in municipalities in the last decade (Eek & Kirkevold, 2012). Although research on out-of-home services are sparse, some studies show that day-care centres can reduce family caregivers’ burden and increase their motivation to continue as caregivers if the services meet their needs for flexibility, support, information, and responsibility sharing (Brataas, Bjugan, Wille, & Hellzen, 2010; Tretteteig, Vatne, & Rokstad, 2017). However, another recent study indicated that formal caregivers insufficiently involved family caregivers as partners in care, and the family caregivers thus experienced vague and undefined roles, lack of information, insufficient knowledge of the staff and how home-based care is formally organized (Aasgaard, Disch, Fagerström, & Landmark, 2014; Aasgaard, Fagerström, & Landmark, 2017).

2.6.2 User involvement in home-based care

There is a large amount of research on user involvement; however, although it is well known that the symptoms of dementia diminish a person’s capacity to make decisions, the everyday decision-making of people with dementia in their homes is unexplored (Daly et al., 2016; Samsi & Manthorpe, 2013). Therefore, I have included relevant articles from nursing home and extended care settings in the overview but circumscribed the search to decision-making processes.

Capacity to make decisions concerns consent, and the issue of assessing this capacity both legally and ethically is of paramount importance (Ford, 2010). However, most research on the capacity of people with dementia to make decisions concerns involvement in research or medical treatment.

A review study (Miller et al., 2016) on the decision-making processes of people with dementia shows that there is little knowledge regarding patients’ preferences in terms of involvement and that the range of involvement for persons with dementia is dynamic, contextual and concerns everyday care, medical treatment, and long-term placements. Context is also addressed by Boyle (2013) in a study on how non-cognitive factors such as gender can influence caregivers’ assessment of the capacity of the person with dementia to be involved in financial management. The patient’s involvement hence depends on the caregivers’ positioning of the patient, the modifications made by family caregivers to support the patient’s autonomy and non-cognitive factors such as age, education, gender and kinship (Miller et al., 2016). Fetherstonhaugh, Rayner, and Tarzia's (2016) review study suggests decision-making for people

with dementia should transition from supported to shared decision-making to substituting with decision-making by carers.

Family caregivers' involvement is considered important to the process of translating values (Miller et al., 2016; Stephan et al., 2014), and one study specified that family caregivers mostly had a good sense of the preferences of the person with dementia, in particular regarding safety and quality in care (Whitlatch, Pipiparinen, & Feinberg, 2009). However, pseudo-autonomous decisions or decisions on behalf of the person with dementia occurred regarding safety risks or if the caregivers had exhausted all strategies to assist in decisions (Samsi & Manthorpe, 2013). Formal caregivers also used pseudo-autonomous decisions because they assumed they knew what the person with dementia wanted (Smebye et al., 2012).

Several studies report extreme difficulties for family caregivers in performing the balancing act of assisting (and not taking over from) the patient in their decision-making, and difficulties when the assessment is conflicting and support from formal caregivers is lacking (Chang & Schneider, 2010; Lord, Livingston, & Cooper, 2015; Whitlatch & Menne, 2009). One of the most difficult decisions from family caregivers' perspective concerns nursing home placement, and Chang and Schneider (2010) note these decisions are often made on behalf of the patient and initiated because the symptoms were worsening, the family caregiver's health was deteriorating or the caregiving work disturbed family life or family relationships.

Research has long noted family caregivers' unmet needs connected to decision-making processes, e.g. lack of information, inclusion, case manager and responsiveness to the family caregivers' needs (Lord et al., 2015; Walker & Dewar, 2001). Lord et al. (2015) indicate in their review study that some decision-specific manualized tools have been developed, but none of them appear to reduce the conflicts related to decision-making processes for people with dementia.

2.6.3 Continuity of care in home-based care

Research on continuity of care addresses the provision of coordinated and uninterrupted healthcare services to patients (Russell et al., 2011). Mainly, the research addresses better outcomes (cf. D'Errico & Lewis, 2010; Gjevjon, 2014; Saultz, 2003), more efficient resource utilization and thus lower healthcare costs (cf.Midtbø & Kvåle, 2010).

Several studies concern the particular advantages of relational continuity of care on patients' emotional status, satisfaction and trust as well as its contribution to good communication (Alazri et al., 2007; D'Errico & Lewis, 2010; Gjevjon, 2014; Khanassov & Vedel, 2016;

Minkman, Ligthart, & Huijsman, 2009; Russell et al., 2011). One review study indicated that relational continuity was connected to reduced hospitalization and thus reduced health costs (Alazri et al., 2007). Two studies (Khanassov & Vedel, 2016; Minkman et al., 2009) emphasized dementia case managers, who are responsible for follow-up, coordinate individual care, and liaise with other healthcare providers, and their important position in addressing the unmet needs of patients or their family caregivers. A Norwegian study by Aasgaard et al. (2017) indicated that person-centred dementia care can be realized with a skilled dementia team and organizational structure supporting the team that emphasizes a continuity of care approach. However, another Norwegian study showed that there is considerable potential for improvement of relational continuity of care in terms of the number of formal caregivers in long-term home healthcare (Gjevjon, 2014).

The review study of Alazri et al. (2007) on medical disciplines also indicated that relational continuity may increase costs because GPs appear to do more for patients they know well. Additionally, the relationship between a patient and a GP may be a disadvantage even if they have relational continuity. Certain issues may be challenging to discuss with patients because they know them too well or because "the chemistry" does not match.

Heaton, Corden and Parker's paper (2011) indicated that the experience of continuity of care did not necessarily involve consistency with regard to nurses as much as to the formal caregivers' manner and communication skills as well as the time made available. Furthermore, they broadened informative continuity beyond the provision of information to include communication and trustful interaction, which are important for defining the patients' capacities and the caregivers' role. Management continuity with regard to coordination between formal caregivers and the administrative level were valuable; however, coordination with informal caregivers was also important for continuity of care (Heaton et al., 2012).

2.6.4 Healthcare challenges in rural municipalities and with regard to the Sami population in particular.

Little is known regarding the situation of Sami people who live with dementia, their families and collaborative practices with formal healthcare services (Blix, 2016).

According to Silviken, Berntsen, and Dyregrov (2014), multiple relationships in rural municipalities may trigger particular barriers to the utilization of healthcare services among some Sami individuals. The disadvantages of relationships between caregivers and patients who were described as possible negative consequences of relational continuity of care (cf. Alazri et

al., 2007) may be particularly pronounced in rural areas (Ness, Hellzen, & Enmarker, 2015). Additionally, the prevalence of dementia is combined with a decline in the workforce available to care for them that is most prominent in rural areas (cf. Broderstad & Sørlie, 2012). There may not be numerous choices of formal caregivers.

Some research has noted that the Sami population uses fewer healthcare services (Turi, Bals, Skre, & Kvernmo, 2009). The reduced use of healthcare services is linked to the Sami perspective on health and disease (Bongo, 2012) and Sami societies' low level of confidence or trust in healthcare treatment and healthcare providers (Daerga, Sjölander, Jacobsson, & Edin-Liljegren, 2012). However, Blix's (2016) review study suggests that Sami people use healthcare services to the same or an even higher extent than the majority population but are less satisfied with the services, and a recent cross-sectional study showed that ethnic affiliation appeared to affect treatment (Broderstad & Melhus, 2016).

The survey studies SAMINOR I and II[5] showed that people with a Sami affiliation described more ethnic discrimination, experiences of bullying and psychological stress than the majority population.

The Northern Research Institute (NORUT) (Angell, Balto, Josefsen, Pedersen, & Nygaard, 2012) has further outlined several barriers to healthcare among the Sami population. NORUT describes the low degree of institutionalization of the Sami Acts; the lack of accountability of the "appropriate authorities"; additional costs related to bilingualism; the knowledge and attitudes of the general population, politicians and the administration; and the lack of Sami-speaking and Sami culture-competent healthcare workers (Angell et al., 2012).

However, the literature is inconsistent, and it is difficult to determine causalities (Blix, 2016). Blix (2016) described a need to nuance the Sami's perspective as different from that of the majority population and noted that the Sami are not a homogenous group and that Sami people today use formal healthcare services to the same extent as the majority population.

[5] SAMINOR I (2003-2004) and II (2012-2014) are surveys that explored health and living conditions in areas with Sami and ethnic Norwegian populations. For more information, see: https://uit.no/forskning/forskningsgrupper/gruppe?p_document_id=425187

3.0 Aims

Health policies pertaining to people with dementia aim to provide assistance during the early stages of the disease and provide the family caregivers necessary support to enable the patient to live at home as long as possible. Collaboration between home and formal healthcare services is one of several preconditions of Norwegian health policy goals and an important determinant of which healthcare services are offered and how the services are utilized. However, collaboration is vaguely defined, and few descriptions or guidelines exist regarding formal and family caregiver collaboration in home-based care.

This project's principal aim is to investigate collaboration between formal and family caregivers in home-based care. Because of the distinctiveness of the research field – northern Norwegian municipalities populated by Sami and ethnic Norwegians – I also aimed to examine whether and how ethnic affiliation affect collaboration.

Research concerning collaboration in home-based care for people with dementia in rural multi-ethnic municipalities is sparse. Knowledge is crucial for formal caregivers to develop appropriate procedures in practice. Describing barriers to collaboration may lead to changes and improve healthcare services for the person with dementia and their family caregivers.

The research questions were twofold. The first question was explorative, while the second question sought to describe barriers to collaboration and possible discrepancies between health policy objectives and practice.

1. How do formal and family caregivers describe collaboration in home-based care for people with dementia?
2. What barriers could inhibit collaboration between formal and family caregivers?

To investigate the research questions, I sought formal and family caregivers' descriptions of how they perceived home-based care practices pertaining to the patient with dementia and further analysed their descriptions and reflections based on the theoretical framework of positioning theory and other analytical concepts such as collaboration, user involvement, continuity of care and ethnic affiliation.

The research questions are considered in three articles and in this thesis. All three articles aimed to explore how formal and family caregivers experienced collaboration. However, each had a different thematic focus. Article I, "Processes of user participation among formal and family caregivers in home-based care for persons with dementia", focused on descriptions of influence and user involvement. Article II, "Collaboration between Sami and non-Sami for-

mal and family caregivers in rural municipalities", explored whether ethnic affiliation influenced collaboration. Article III, "Continuity of home-based care for persons with dementia from formal and family caregivers' perspectives" emphasized the caregivers' descriptions of coordination of care services understood as healthcare objectives with regard to continuity of care and the statutory act addressing IPs.

4.0 Theoretical framework

Collaboration in healthcare is influenced by the caregivers' attitudes and assumptions as well as administrative resources and formalized routines (Orvik, 2015). In official documents, the specific collaboration between formal and family caregivers in home-based care for persons with dementia is connected to concepts such as user involvement and continuity of care (Ministry of Health and Care Services, 2009, 2015a). User involvement is a legislated concept, whose normative intentions caregivers must interpret in clinical practice. Thus, collaboration in home-based care could depend on how caregivers interpret and negotiate the distribution of rights and duties invoked by such concepts.

Conversely, given the substantial need for discretionary judgements in home-based care, the government offers few descriptions or guidelines on how such collaboration should be practised. Furthermore, research on collaboration between caregivers in home-based care is sparse.

Due to the lack of knowledge on collaborative practice, I aimed to obtain caregivers' descriptions and reflections through a bottom-up research strategy (cf. Blaikie, 2007:27) in order to explore and describe patterns of collaboration.

I based my interpretations on positioning theory, which is a theory of social interaction (Van Langenhove & Harré, 1999a). Positioning theory allowed me to contextualize the caregivers' descriptions and reflections and thus aim for "a higher level of generality" (Blaikie, 2007:131), reverting to a more generalized 'reality' further interpreted through analytical tools.

Positioning theory as a theoretical framework acknowledges the emergence of discursive and dynamic negotiation processes on a micro level and how these micro-level processes are situated within broader macro-level discourses (Van Langenhove & Harré, 1999a). I was particularly interested in whether and how health policy intentions such as user involvement, continuity of care and Sami rights influenced how caregivers understood and practised collaboration.

In my understanding, theories of social interaction aim to describe complex and dynamic interpersonal encounters. These theories suggest collaboration is influenced by peoples' assumptions regarding informal and formal rights and duties in different situations and thus what they perceive as conventional, legitimate and appropriate. How people interact in social

practices concerns what is perceived as allowed to be said or done, understood as a right to define what is important or not (Lock & Strong, 2014c).

From the social interactional perspective, micro-level studies are characterized by a) the emphasis on language in the construction of what people perceive as real in social life, b) the notion that language has the power to organize social life, c) language as symbolic communication that has the power to influence social life and finally, d) the regulatory aspects of language that inform what is allowed to be said or done and the capabilities that influence explanations, negotiations and the construction of meaning in interactions (Tirado & Galves, 2007:2).

These performative qualities of language allowed me to explore the object of research understood as the caregivers' descriptions of social interaction through analytical tools such as position with regard to duties and rights, storyline and the social force of speech acts.

4.1 Positioning theory to explore collaboration on a micro-level

Rom Harré is one of the main founders of positioning theory. Harré argued that research should focus on people's reflections upon acts to explore what people are permitted or forbidden to do and say in social interaction (Lock & Strong, 2014c).

Van Langenhove and Harré (1999a) referred to research that focuses on people's reflections as 'accountive positioning' – a talk about talk. In my understanding, accountive positioning is how people, in retrospect and through their reflections in conversation, position themselves and others when they recount meeting points in a social practice.

Meeting points refer to social episodes, which are happenings with some principle of unity that can be observed but which also include "thoughts, feelings, intentions and plans" (Harré & Van Langenhove, 1999:5). Following Harré and Van Langenhove (1999), the concept of social episodes suggests that the dynamics of a meeting between formal and family caregivers will be different at the local grocery store versus during home-based care visits. Both social episodes have normative rules regarding what the caregivers perceive they are allowed to say or do; however, the episode of home-based care visits also involves formal rules connected to the role of nurse, for example. Episodes, either informal or formal, are shaped by the participants. Concurrently, specific episodes have an impact on the participants' actions and utterances.

Thus, an understanding of social episodes must identify the dynamic positions claimed or bestowed explicitly or implicitly in relation to the episode under study (Harré & Van

Langenhove, 1999). People who attempt to collaborate, e.g., formal and family caregivers, will constantly adopt and revise positions for themselves and others, and the expectations regarding each position may vary across interactional situations (cf. Harré & Slocum, 2003).

Thus, positioning theory is a further development of Goffman's work on roles and performances (cf. Goffman, 1956). Goffman's role theory describes stable, long-standing beliefs regarding assigned rights and duties within roles. However, the critique stated through positioning theory is that roles are excessively fixed categories of the psychological bases of social interaction; in contrast, positioning theory highlights that people continuously construct recognizable positions in dynamic meeting points in social life (Davies & Harré, 1999).

The dynamic positions can be explored through the interpretation of *why* people use language the way they do (Van Langenhove & Harré, 1999a). This focus on the utilitarian use of language implies that language as symbolic communication has the power to influence social life due to normative and often unconsciously imposed duties and rights. Harré and Van Langenhove (1999:1) define "the everyday language use" as discourse. Following Harré and Van Langenhove's (1999) definition, discourses can be identified at the micro level understood as, for instance, collaborative practices in home-based care and at the macro level understood as policies, acts and, for instance, broader discourses regarding the elderly.

Thus, the discourses are the connection between micro and macro because people's understanding of what is occurring and rules for micro-level episodes are situated within broader macro-level discourses (Harré, 2001). The micro-level discursive negotiations processes result in a type of consensus policy at the macro-level against which the individuals at the micro level must further position themselves, and this is a continuous process that operates both ways (Lock & Strong, 2014c).

In this perspective, conflicts in social interaction emerge from differing understandings of what is occurring or differing understandings of rules that govern social episodes. Differing understanding of rules suggest conflicting views on the distribution of duties and rights. Harré and Slocum (2003) wrote that there is not much to study if all is going well. Thus, the researcher should seek the breakdown, the point(s) at which the actors do not get along.

To analyse the conflicting, dynamic, discursive processes in collaboration between formal and family caregiver, I used the positioning triad (Van Langenhove & Harré, 1999a:16). The positioning triad consists of entangled position(s), storyline(s) and social force. The positions people impose on self or others are linked to the storylines, and the interpretation of storylines

depends on the social force of the storyline. These three structures affect how we speak, think and view other peoples' actions; consequently, conflicts in interactions can be attributable to any of the three aspects (Harré, 2004).

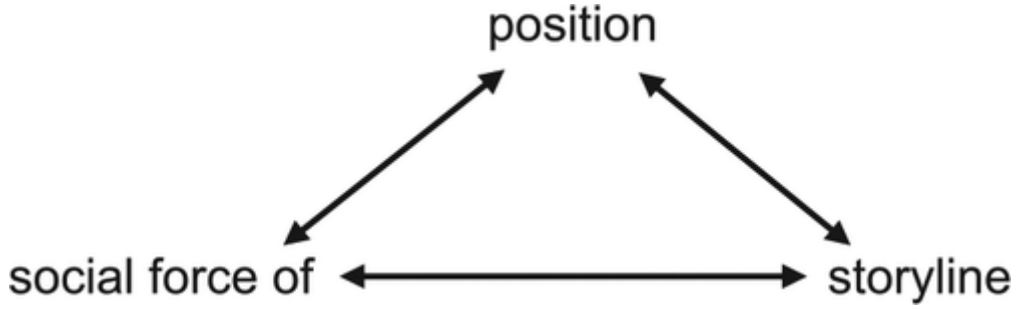

Figure 1. Positioning triad. Van Langenhove and Harré (1999, p. 18).

4.1.1 Positions

Van Langenhove and Harre define positions as follows:

> A position is a complex cluster of generic personal attributes, structured in various ways, which impinges on the possibilities of interpersonal, intergroup and even intrapersonal action through some assignment of such rights, duties and obligations to an individual as are sustained by the cluster (Van Langenhove & Harré, 1999a: 1).

From the perspective of positioning theory, the collaboration between formal and family caregivers occurs in discursive social practice, and positioning is inevitable in a patient-family caregiver-formal caregiver relationship (cf. Lock & Strong, 2014c; Måseide, 2008). However, according to Harré and Slocum (2003) a position is always connected to the situation; it is ephemeral and is only a small part of a given social interaction. People define positions based on beliefs regarding a person's (or their own) competence, history and personality as well as the interpreted pre-positions of the individual in terms of gender, ethnic affiliation, distinct social class, and disease, among others. Therefore, positions can be accentuated in terms of a person's traits and are often regarded as bipolar dimensions, such as strong and weak (Harré & Slocum, 2003). Nevertheless, what people know and think of as common is thus most likely the position people claim or bestow upon others, and positions similarly to roles can be a part of common knowledge and thus pre-exist the people who occupy them (Harré, 2004).

Because of the interactional influence on positioning, the attempt to position oneself or others may be rejected or challenged in social exchanges, creating the need to negotiate both one's position and the understood episode. Being assigned to or taking a position in an interaction

has an immediate effect on the way one's own and others' actions are interpreted (Davies & Harré, 1990). In accordance with this understanding and to explore the caregivers' positioning, I explore how the person with dementia is assigned with duties and rights and similarly which duties and rights caregivers assign themselves and other caregivers in various storylines.

4.1.2 Storylines

Harré and Dedaic (2012:51) define storylines as "strips of life [that] unfold according to narrative conventions". A conversation may contain several storylines, and through the way people tell stories, they position themselves and others. Some storylines are embedded in such a way that they are difficult to suspend, while other storylines are told for the first time and thus easier to challenge (Harré & Dedaic, 2012).

From the perspective of positioning theory, a storyline is a term that originates in narratology and structural analysis of, for example, folktales (Harré, 2004). The narrative sociologist Frank (2010: 167) wrote that definitions of stories varied among multiple disciplines and showed considerable disparities that consequently made him steer away from definitions and mainly concentrate on stories as tools to explore what the stories were able to accomplish, which is understood as the capacity of the stories. In my interpretation, given the way Van Langenhove and Harré (1999a) posit storyline as an important part of the positioning triad, they also emphasis the capacities of storylines and, in particular, the storylines that can be interpreted as causing trouble or making one perspective more important than others.

To interpret the participants' descriptions of episodes and interactions, the analysis of a storyline's capacities is central. A storyline's capacity contains both interpretations of "conversational history and sequence of things already being said" and the "actual sayings with the performative qualities to influence or shape certain aspects of the social world " (Harré & Van Langenhove, 1999:6).

In other words, historicity and social relationships are important for interpreting why people use a storyline the way they do. Harré (2004:5) used the example that "the words 'twin towers' today have different meanings than before 9/11". Beyond positioning, both face-to-face and retrospective reflections had to be considered because the storyline's meaning could have been interpreted differently in another social relationship.

According to this understanding of a storyline, I explore the caregivers' utterances for why they use language the way they do and further seek patterns embedded in the participants'

storylines. I found it necessary to assess the meaning of each storyline with regard to relationships and historicity concerning, for example, the political concepts of home-based care, user involvement, continuity of care and Sami ethno-political rights because the way the meaning of these concepts appears to have changed over time can influence my interpretation of the storyline. Following positioning theory as a search for conflicts (cf. Harré & Slocum, 2003), I have emphasized the storyline's capacity to cause trouble or make one point of view more important than others.

4.1.3 Social force of the storyline

An important inspiration for Harré's emphasis on language was, according to Lock and Strong (2014c), J.L. Austin, who was Harré's teacher. Austin was a student of Wittgenstein, and their philosophy of 'speech acts' (cf. Austin, 1962) and normative expectations for language is visible in Harré's suggestion of the social force of storylines (Lock & Strong, 2014b, 2014c). Social force refers to Austin's (1962) distinction between the illocutionary and perlocutionary force where both provide a social meaning of a speech act (Lock & Strong, 2014c). The illocutionary force concerns what is achieved *in* saying something, while the perlocutionary force concerns what is achieved *by* saying it (Van Langenhove & Harré, 1999a). Examples of social force in home-based care can be requesting, promising or ordering services that can enable the family caregivers to obtain formal healthcare services for the patient.

The understanding of the social force of storylines helped me to explore and describe the participants' utterances and provided me with tools to reflect on what the participants intendedly or unintendedly achieved by, for example, requesting services.

The meaning of a storyline and what it accomplishes in a conversation is likely to vary from time to time and situation to situation, and the social force of an utterance thus depends on the context.

5.0 Methodology and methods

In this dissertation, I have chosen to explore and describe collaboration in home-based care as a social practice. I use positioning theory, which establishes social interaction and discourses as basic features of all social practices (cf. Harré & Slocum, 2003).

In positioning theory, collaboration is understood as an *interactional* practice that is created in and through the discursive processes of verbal and non-verbal communication, and thus I required methods that would enable me to explore "conversation and conversation-like activities" (cf. Harré & Van Langenhove, 1999:3). Such methods include, for example, interviews and observations where the researcher is in interaction with the social practice under study (Järvinen & Mik-Meyer, 2005; Van Langenhove & Harré, 1999a). Therefore, data were constructed primarily via in-depth interviews and brief observations to explore the participants' descriptions, reflections and discourses on the micro level.

5.1 Interactionism

I make use of positioning theory to analyse the caregivers' interactions. I interpret the theory as a tradition within the broader perspective of interactionism in sociology including both European and American contributors (cf. Atkinson & Housley, 2003). Interactionism is linked in particular to Blumer's work based on Mead (cf. Blumer, 1969) and to Goffman's work (1956). Despite the multitude of interactional traditions, Järvinen and Mik-Meyer (2005) state that all have in common the understanding of social reality as complex, instable and ambiguous in social practices.

Thus, interactionism is underpinned by the social constructionism perspective (Atkinson & Housley, 2003; Järvinen & Mik-Meyer, 2005), which thus forms the basis of my pre-understanding of knowledge and determines what knowledge I am able to construct through this project.

In social constructionism, social reality is understood as socially constructed through people's interactional experiences and the situations in which the experiences occur (cf. Berger & Luckmann, 1966; Veiden, 2006). Lock and Strong (2014a:31) offer an overview of the basic premises of social constructionism. The interpretation of verbal and non-verbal communication, both in the retrospective descriptions and in face-to-face interaction, is crucial for understanding and co-creating meaning and further understanding what is occurring in 'reality'. People negotiate their understanding intentionally or unintentionally by positioning themselves and others in social interactions.

In line with positioning theory and its methodological implications, I understand that formal and family caregivers' collaborative practice in home-based dementia care is established by these caregivers' interpretation of what is real and meaningful in their social interactions and by their understanding of reality. This is a continuous process that may vary based on place, time and nature of the relationships (cf. Van Langenhove & Harré, 1999a). Thus, to explore and describe collaboration between formal and family caregivers, I needed to seek the participants' point of view through their language, non-verbal symbols and discourses as embodied in their utterances. My focus was on the participants' collaboration on a micro level, how collaborative episodes emerge and how the episodes can form the basis of further interaction and people's assumptions of norms and 'reality' (cf. Järvinen & Mik-Meyer, 2005).

According to Järvinen and Mik-Meyer (2005) the interactional perspective values and emphasizes the researcher's own contribution to the creation of meaning. The researcher interprets how people define their situation, how they perceive symbols, and how they view the overall situation, in addition to what may be taken for granted in everyday life. It is not only 'what' the participants say that is of interest to research but attention to the 'how', understood as how data are influenced by the participants' understanding of reality and discourses in use, in addition to my own prejudice and interaction with the participants. My methodological considerations are found in chapter seven.

5.2 Preparation

Because existing research on my field of study was sparse, the research questions were designed to be explorative and to seek descriptions. Järvinen (2005:30) describes the interview as the most common form of empirical data in interactional studies and furthermore as a set of "descriptive performances" where the participants position themselves and others in whatever way they find most expedient in the situation. Their positioning concerns both the face-to-face interaction between the researcher and the participant and the positioning they describe in the interviews. Similarly, Van Langenhove and Harré (1999a) emphasize interview data as the most appropriate way for researchers to explore the question of what and why through the talk about talk that can position the participants and others involved in a prior conversation understood as a re-description of the event.

To explore and describe collaboration within theoretical frameworks, while allowing the inductive be the starting point of the research, I chose the stepwise-deductive induction research strategy (cf. Tjora, 2012). Blaikie (2007) suggests that the induction research strategy aims for descriptions of characteristics and patterns where the researcher construct data and descrip-

tions and further relates these to the research question. However, Tjora (2012) emphasizes the work-in-progress nature of analysis and suggests that the researcher look for everyday lay concepts, meanings and motives that may form described patterns or regularities. Thus, inductive findings must be tested by theories or concepts to eliminate false ones and corroborate the survivor (deductive). The aim of positioning theory is thus to construct generic positions relevant to social interaction (Tjora, 2015). I found this strategy combines the necessary attention to the unexpected in the induction portion of the methods and the inductive understanding of research, which is always influenced by theory and literature regarding the research project's assumptions.

I decided primarily to perform in-depth interviews with both formal and family caregivers to obtain descriptions and reflections on collaboration processes and further to interpret possible conflicts. To supplement the interviews, I aimed to understand these descriptions in relation to the places and situations in which the work occurred and thus chose to conduct brief fieldwork.

I aimed to recruit participants regardless of gender, age or profession. However, I used a purposeful sampling (cf. Polit & Beck, 2008, p. 355) because I wanted the participants to be formal and family caregivers of people with dementia who receive formal help in their homes. Because of policy documents regarding barriers in healthcare, particularly with regard to the Sami population, I decided that such persons with dementia should have a Sami affiliation and live in a multi-ethnic municipality in northern Norway.

The data analysis method was planned as a thematic analysis as described in the stepwise-deduction induction method (cf. Tjora, 2012) and using the computer program Nvivo (QSR International Pty Ltd Ltd. 1999-2014, 2014). Further, the analysis explored social practices through the lens of positioning theory (cf. Harré & Slocum, 2003; Van Langenhove & Harré, 1999a) with an emphasis on reflexive positioning and the positioning triad with the aim of obtaining a general perspective on specific patterns in the inductive findings.

5.2.1 Fulfilment of ethical and formal requirements

This project was fully funded by UiT, The Arctic University, and thus had no financial constraints other than the period available for PhD scholarship.

In Norway, ethnicity is sensitive information; therefore, I chose to contact the local regional ethical committee (REK) (Regional Committees for Medical and Health Research Ethics, 2016). I clarified that ethnic affiliation was not the main topic of the project but could be un-

derstood as a politically defined barrier to collaboration. The participants' ethnic affiliation could be revealed in the data construction process even if I did not ask about it because I had asked family caregivers caring for people with a Sami ethnic affiliation to participate and asked open questions regarding specific challenges for Sami people with dementia or specific arrangements in home-based care for Sami patients.

However, the Regional Committees for Medical and Health Research Ethics deemed that approval from them was unnecessary. The project is registered with the Norwegian Social Science Data Services (NSD; no. 32173) and was stored according to NSD guidelines (cf. Norwegian Social Science Data Services, 2012).

Prior to completing the interviews, I was aware of specific challenges and possible bias in the research process related to language and cultural differences. Many acquaintances with both Sami and Norwegian ethnic affiliations stated prior to the study that Sami people would not talk freely to Norwegians. Although I do not consider myself Sami and do not speak Sami, my experience collaborating with Sami people contrasted with these statements, and I wondered whether this understanding was influenced by stereotypes regarding Sami people. In my opinion, it was important to challenge such stereotypes while simultaneously recognizing that reflections on cultural sensitivity and reflexivity were necessary for this project.

I chose to inform the participants regarding the possibility that I would bring an interpreter to the interviews and emphasized that it was I and not they who needed an interpreter if they spoke Sami. However, all of the participants spoke Norwegian and considered a translator unnecessary. The participants provided their written consent to participate in the study. They received written information regarding the study's purpose, voluntary participation, confidentiality, and the possibility of withdrawing before the data analysis process in advance of their participation. Just before the interview started, they had the opportunity to ask questions regarding the study before they provided their oral consent.

5.2.2 Participants and recruitment

Healthcare managers in eight rural and multi-ethnic municipalities (three interior and five coastal) in northern Norway were provided oral and written information regarding the study. I asked the managers to help recruiting participants. Five of them responded positively, and data construction occurred in five rural municipalities, four coastal and one interior. One manager from a coastal municipality declined to participate, stating that they were not serving any Sami patients at the time. I was never able to make phone or email contact with two man-

agers from interior municipalities. Another manager from an interior municipality stated that they were tired of research commitments in this area and did not want to participate. The difficulties of gaining access to the municipalities are discussed further in chapter 7.1.1, which addresses reliability and sampling bias.

I knew the participants who gave pre-interviews. The family caregiver was a connection in my extended family, and the formal caregiver I knew from a work relationship. I had no relationships with the other participants, and the healthcare managers helped me to recruit ten formal caregivers and four family caregivers. I reached the two other family caregivers through a family caregiver who was already participating and with help from a local dementia group in one municipality. The recruitment process resulted in eighteen participants, including seven family caregivers and eleven formal caregivers. The formal caregivers included mostly nurses or healthcare workers with less formal education, a GP and an occupational therapist. All of the formal caregivers had several years of experience in healthcare. The formal and family caregivers comprised one man and seventeen women from mostly coastal municipalities. Three of the family caregivers were from an interior municipality. The seven family caregivers' ages ranged from approximately 50 to 80 years old, and the eleven formal caregivers' ages ranged between 30 and 60 years old. All of the family caregivers had previously worked in healthcare services, but they were not chosen expressly for this reason. Nine of the participants declared they were Sami, four described themselves as having a mixed[6] ethnicity, and five stated they were Norwegians. Three of the family caregivers lived in the same house as the person with dementia, and the other five participants lived nearby. Two of the family caregivers spoke retrospectively about the home-based care they provided, in one case because her relative had recently moved to a residential unit and in the other because her relative had died.

5.3 Data construction

The interviews and the observations are perceived as social meetings, and thus, the data from the interviews is a result of socially situated interactions. The researcher's effect on the data is not a bias but a recognized effect that contributes to the analysis, that is, the interviews do not function as 'a mirror' of the participants' thoughts but as meaning co-constructed in a social

[6] I understood mixed ethnicity as a result of "the three tribes" (Bjørklund 1985), a multi-ethnic population including the Sami, the Qven (of Finnish origin) and the ethnic Norwegians who all had lived together in the same municipalities for a long time. I have chosen to use their own category, "mixed", in further work.

research interaction (cf. Järvinen & Mik-Meyer, 2005). The success of the interviews depends on the interaction and thus the trust between the interviewer and the interviewee (Staunes & Søndergaard, 2005). Before I conducted the interviews, colleagues and friends who were Sami warned me that Sami people could perceive questions regarding ethnicity as rude. I did not ask about the participants' own ethnic affiliation; however, I asked about measures for Sami patients. Consequently, to gain trust, I attempted to downplay the ethnic affiliation aspect in the informational letter regarding the study and in the interviews.

I prepared for face-to-face interviews that allowed sufficient time for reflexivity, sensitivities and creativity (cf. Staunes & Søndergaard, 2005). I had already selected a methodological stance and reviewed some literature and theory on the topics of this study, which impacted the design of the interview guide because I wanted the questions to be sufficiently open to allow stories that I could not have anticipated beforehand. I prepared follow-up questions focusing on what and how and aimed to avoid why questions to ensure openness and encourage examples and stories.

The guide for the family caregiver interviews included topics such as a) discovering the symptoms of dementia, b) the need for formal help and collaboration during healthcare service provision and c) future projections. The guide to the formal caregiver interviews included a) diagnostic of dementia and measures offered, b) IP, c) specific arrangements or challenges for Sami patients, d) stories of failure and success and e) future projections. The interview guide was used most often at the beginning of the interviews to start the conversation and at the end to check whether there were topics that we had not touched upon. At the end of each interview, I asked the participants if they had advice for others in similar situations. I did not send the interview guide to the participants beforehand.

The difficulties of gaining access to the municipalities resulted in data being constructed over a ten-month period starting in February 2013. I audiotaped each interview with a digital recorder. The interviews lasted from 58 to 189 minutes, with an average time of 90 minutes. The interviews occurred in locations chosen by the participants. The long period required for data construction influenced the interview guide for the last interviews. I used the same interview guide throughout all interviews in written form; however, through the interview period I was able to ask more specific questions based on the preliminary findings from the prior interviews, e.g., collaboration influenced by ethnic affiliation and decision-making processes.

The brief fieldwork consisted of 18 hours of interactive observations (cf. Tjora, 2012:56), following a dementia team preparing for and debriefing after meetings with family caregivers.

Some of the formal caregivers who participated in the fieldwork had previously participated in interviews, which permitted additional discussion and questions after the fieldwork to ensure my understanding of work processes, interactions and situations. I took notes during the fieldwork and before and after the interviews to remember my first interpretation of what the participants were articulating, how they talked to each other, the work conditions, the symbols in use and my own position in the situation. These notes subsequently served as background for the first phases of analysis, but the quotes presented in the results are drawn exclusively from the interviews.

Both the interviews and the fieldwork emphasized the actors' positions, symbols and valuation of actions (cf. Järvinen & Mik-Meyer, 2005).

5.3.1 Qualitative in-depth interviews

I conducted two pre-interviews – one with a formal caregiver and one with a family caregiver – to obtain feedback and inspiration before entering the field. After the pre-interviews, I understood that some of my questions should be toned down to let the participant talk more freely and that I had to be more sensitive to discovering and examining storylines that could challenge my pre-interpretation. Subsequently, I observed that the descriptions I obtained from these interviews were partly similar to the other interviews and therefore chose to include them in the study. The participants in these two pre-interviews had already provided written consent to be included in the study if I subsequently deemed it appropriate.

All interviews started with an informal conversation to allow the participants and me to become acquainted. Most of the participants asked me questions regarding my family and hometown, but several asked specific questions regarding my ethnic affiliation before I could even start the interview and the recorder. The conversations lasted much longer with the family caregivers than with the formal ones. In the later interviews, I asked why some participants were concerned with my ethnic affiliation. In retrospect, I interpreted such conversations as a way for the participants to determine whether I was trustworthy. This appeared to be important both because of the conflicting topics, some of which were related to ethnic affiliation, but also because of the emotions involved, in particular for the family caregivers. Several of the family caregivers wept when they talked about their situation.

Staunes and Søndergaard (2005) wrote about the interviewer's responsibility to help construct an appropriate position in the situation and noted that his or her position as a researcher is also subject to negotiation. According to Van Langenhove and Harré (1999a), people's descrip-

tions depend on the audience, and the participants and I alternated in the audience position in this project. I asked questions as developed in the interview guide, and I uttered statements to legitimize the research. Sometimes I had to ask 'the why question' to verify my interpretations and challenge contradictory aspects of their communication. However, I mostly positioned myself as audience to their stories and aimed for nuanced and detailed descriptions.

Throughout the interviews, I understood that my position as a researcher sometimes shifted to the position of nurse or even friend. Both formal and family caregivers asked me questions as if I was a nurse. A family caregiver talked about the demanding symptoms of dementia and asked, "As a nurse, what do you think of this?" A formal caregiver asked, "You are a nurse; what would you have done?" Another family caregiver made a comment, "This is not something that I would have done for everyone, but I think we have such a good relationship." The descriptions I obtained were rich and filled with emotions, dilemmas and conflicts. I took that as a sign of trust.

Transcription

I performed the transcription a few hours after the interviews by listening to the audiotapes and transcribing them using the Microsoft Word text editor. The goal of interview transcription is to abstract and fix the data in written form, a construction that is formed by the translation of speech to text (Kvale & Brinkmann, 2009: 186). After each interview, I wrote notes that served as a first analysis of what the participants talked about; how they spoke; the reactions to certain topics, including notes regarding non-verbal language, irony and emotions; and the location where the interviews occurred. These notes became important during the transcription process. Back at the office, I downloaded the audiotapes and the transcriptions into the storage and structuring tool Nvivo (cf. QSR International Pty Ltd 1999-2014, 2014) to prepare for thematic analysis.

I then listened to the audiotaped interviews several times and checked them against the text. I noticed the difficulties I had remembering the looks on the participants' faces, their hand movements, and so on. My previously written notes helped the participants come forward in my mind as whole people and not just as sounds. I thought their physical presence was important for the interview analyses and therefore wrote annotations and memos of the transcribed text that included descriptions of the surroundings and context in addition to my prior expectations for the interview; my post-interview remarks; my comments on cadences, phraseology, pauses, laughter, sighs and crying, changes in physical position and interferences. I did not transcribe all verbal hesitations at the beginning of sentences (e.g. "Eh"), but I did

include those that I believed would have implications for the data analysis. I rephrased my first interpretations of the data several times during the transcription process because I found that I may have drawn conclusions too hastily. I tracked these changes in comments and the comments were important when conducting the next interview.

The in-depth interviews conducted for this project included several topics that had emotional components and that the participants stated that they would not have told many people. I deleted all interviews from the digital audiotape immediately after downloading them to a firewall-protected area in Nvivo, and I did not include the participants' names or ages at any point in the transcribed text. In some instances, I translated the participants' spoken words into more standardized written forms, in particular when their speech was strongly characterized by dialect. Nevertheless, I left the original transcribed text as a comment in Nvivo. Some parts of the text I further anonymized when I translated them into English for the articles, and in some cases, it was necessary to change certain circumstances described to ensure anonymity. Thus, I was able to ensure the participants' anonymity and make their utterances easy to read while maintaining the meaning of their descriptions.

5.3.2 Brief fieldwork

Fieldwork inspired by an interactional perspective studies social activities and participants' interactions and the ways situations may affect these interactions, and the focus of the analysis is on the positions and language that are used (Järvinen & Mik-Meyer, 2005: 98).

The observational method generates detailed data, but it is time consuming. Because of that, and because I had trouble gaining access to dementia teams (not all municipalities had a formed structure or personnel in teams), I conducted just brief fieldwork following two dementia teams preparing for and holding meetings with family caregivers, and I observed their work after the meetings. The travel routes to the municipalities are time consuming and costly so I conducted the fieldwork the day after the in-depth interviews but with the same participants.

My observations were interactive (cf. Tjora, 2012: 56), meaning that although I did not engage the formal caregivers in discussions, they often approached me to ask me my thoughts and show me around the institutions. I sometimes asked them questions when I wanted them to elaborate on a comment or provide further explanation. I hoped to obtain information that could shed light on their previous descriptions and perhaps reveal implicit or tacit information that could prompt further questions.

The notes from the fieldwork primarily referred to the interactions, the positioning in the room, and the allocation of time and place for collaborative work. The notes contain information regarding the actual discussions of care and treatment for the person with dementia because I wrote keywords pertaining to the topics that they discussed and the structure of the discussions in terms of the people involved. However, I did not audiotape these sessions. The participants' utterances are retained in my memory and were therefore not included among the utterances highlighted in the articles or this thesis. The written notes from the fieldwork thus served as inspiration for interpreting the context during the analysis (cf. Coffey and Atkinson 1996, 140).

Although brief, the fieldwork experience had an impact on my understanding of the participants' prior descriptions and prompted further questions and clarifications. For example, it clarified why the formal caregivers described mostly oral communication with other caregivers; namely, the nearby offices and many informal gatherings during the day made oral communication convenient. In two situations, I observed discrepancies and unfriendly body language among formal caregivers of different ethnic affiliations and was able to ask about this during their individual interviews.

5.4 Analysis

In an interactional perspective, the method for analysis clearly differs from other perspectives in its promotion of subjectivity; however, it does provide a systematic method for the analysis and presentation of results. The interpretation of the data began when I sought meaning in dialogue with the participants during the interviews and the fieldwork sessions. I selected the questions and topics for the interviews, while the participants chose which part of their story to tell and more or less intentionally hid other parts of their story. Our interaction created new understanding both as the participants reflected on their experiences but also through my tentative interpretations during our dialogue. As hasty as these preliminary analyses were, they were a necessary and important part of the method.

I further interpreted the meaning of their experiences when I transcribed the interviews into text and structured it for the more comprehensive thematic analysis process.

This interpretative analysis is based on hermeneutics philosophy (cf. Gadamer, 1959), which focuses on understanding the parts of a text in relation to the whole text and simultaneously understanding that it is not possible to gain complete insight into and understanding of a topic or a meaning. The goal of reflecting on what may influence the interpretation is to attempt to

understand, challenge and present how the interpretation, prejudice or prior understanding and context can change our understanding of the entirety. The new understanding of the entirety may necessitate a new investigation of the parts (Grondin, 1994).

5.4.1 Thematic analysis

The data for the analysis comprised the transcribed interviews and notes from both the interviews and my fieldwork. The amount of text necessitated a structural tool for analysis that could ensure that when I chose to further examine parts of the text, I could easily search for words or phrases in the text as a whole. I used the computer software QSR Nvivo 10 (QSR International Pty Ltd 1999-2014, 2014).

First, I coded the key phrases in all of the transcribed material. I kept the codes close to the original text. Subsequently, I constructed a set of codes (105) that represented the meaning in the close-to-text categories. I then interpreted these codes based on seven sorting categories:

1. Understanding user involvement
2. Needs that are not met
3. Preparation for institutionalization
4. Differences between Sami and Norwegians
5. Being outside
6. Helping to ensure safety
7. Young patients have multiple needs

At this phase in the analysis, all categories could be useful for answering the research question, but I chose three categories to work with for the articles. For the first article, I chose to assess category four, the differences between the Sami and Norwegians, because the problems related to ethnic affiliations appeared to require a solution both during the interview session and within their stories before collaboration could happen. The next portion of text I examined was chosen more randomly. Article II refers to category one, understanding user involvement, which I gradually understood was linked to category five, being outside. Category two, needs that are not met, I later linked to category three, preparation for institutionalization, and category six, helping to ensure security.

The search function in Nvivo 10 (QSR International Pty Ltd 1999-2014, 2014) was often applied to the entire text to find words or sentences that could be related to the codes with which I was working with but that were not in the chosen category for each article. I looked for

meaning in the participants' stories and sentences. Both the participants and I created meaning, and the results of this project depended on our interpretation during our interaction and on my further analysis. The results of the thematic analysis provided a direction that had to be validated through further theoretical analysis guided by the selected concepts.

5.4.2 Analysis influenced by positioning theory

The abovementioned concepts from positioning theory guided further analysis of the 'accountive positioning' (Van Langenhove & Harré, 1999a) that occurred in the families' and formal caregivers' descriptions of collaboration. According to positioning theory, the positions can be interpreted through analyses of a person's descriptions and reflections on acts, expectations, beliefs and presuppositions, and thus, their storylines are the first step in the analysis that aims to bring utterances to the surface and allow the researcher to interpret possible meanings (cf. Harré & Slocum, 2003).

My analysis of the already constructed categories concerned how formal and family caregivers positioned themselves, other caregivers and the patient in collaborative practices. I searched the material for rejections of positions through certain storylines to interpret which duties and rights such positions assigned, e.g., formal caregivers' storyline of "we want early intervention", as presented in article I that conflicted with family caregivers' storyline in the same article, "We want to preserve normality".

The interviews and the fieldwork transcripts and notes were re-read when I was working with these positionings to ensure the appropriateness of the interpreted meaning. In particular, the link between the respective concepts of the positioning triad and the matrix of the participants' gender, ethnic affiliation, municipality, age, occupation, and whether they lived with the person for whom they provided care were assessed periodically.

The storylines with social force and positions that I constructed were helpful to explore my intuitive interpretation of collaboration from the participants' description. Further, I structured the findings from the positioning against several other concepts, e.g. user involvement in article I, ethnic affiliation in article II, and continuity of care in article III. Creativity, reflexivity, transparency and structure were necessary for this interpretation, in addition to attention to possible biases and ethical dilemmas both as a reflective exercise on my own and with colleagues and supervisors.

Working with this thesis initiated another analysis phase. I found that, in the articles, I had not explicitly described the social force of the storylines and the connection to the positions. Fur-

ther analysis of the overall positioning in this thesis could develop this topic further. One example of the connection within the positioning triad can be exemplified by the storyline in article III, “I miss someone to coordinate and keep strings”. The context here is home-based dementia care, and the meaning may thus be interpreted as a lack of continuity of care and the social force as a request. However, the position is also important to interpret the meaning. If the position had been a formal caregiver or a manager, the meaning could have been interpreted through the social force of an argument for advertisement for staff. However, in this case, the speaker’s position is a family caregiver, and I interpreted the caregiver as speaking from an insecure position. Thus, the social force of the storyline became a justification for why the family caregiver no longer was capable of performing care in the home of the person with dementia without formal help. My influence on the storyline could also be assessed; for example, this storyline would perhaps not have been uttered in another face-to-face interaction, but because I was a researcher and perhaps my profession as a nurse also had impact on the stories, the caregivers were willing to share.

I created a table that presented all interpreted positions with storylines and social forces in all three articles. Using this model, I searched for internal connections between the findings to develop and summarize possible barriers to collaboration between formal and family caregivers. Based on the perspective of interactionism, the project’s premise was that "truth" is context-bound and that the results reflect one of several possible interpretations. Consequently, the understanding of collaboration between formal and family caregivers that this project proposes is a theoretical construction of the practical reality. Chapter seven in this dissertation further presents this overall discussion.

An example of analysis

In keeping with interactionism, I was concerned with the meaning of the text and how this meaning emerged through my influence in the interview. The following example of an interview analysis was not used in any of the articles. It is excerpted from a particular portion of the interview where participant (P) and I as the interviewer (I) negotiated the topic to be discussed, and this negotiation can be made visible through an analysis of storylines, positions and illocutionary forces.

> I: Can you describe Sami culture, what is it for you?
>
> P: What kind of a question is that (laughs)?

I: The reason for me asking is that nurses are supposed to facilitate Sami patients' culture, but several nurses describe this as difficult and end up with food traditions and interpreters because of lack of joint language.

P: Do you want the short or a long version?

I: Laughing.

P: (Sighs) Well, it concerns more than that, mostly because the culture forms the way I think about everything. It is challenging to describe because it is natural for me and not for you. It is about language, how I think and act. It is about traditions, food, music, the way we tell stories, and the way we think of kinship, and probably religion as well. In sum, it influences everything about me.

Table 2, Overview of analysis with use of the positioning triad

Role	**Storyline**	**Social force**	**Positioning of self**	**Positioning of other**
Speaker (Researcher)	Sami culture, what is it for you? Clarifying the question…	Request Wants to understand "Sami culture" that is mentioned many times Act: waiting for answers, laughs and stay silent	Non-Sami and researcher with the right to ask the participant to elaborate utterances from prior interviews Retrospective reflection: Hopelessly unaware of own culture or Sami culture as heterogeneous	Sami and thus enable to answer questions about Sami culture
Speaker (Family caregiver/women/Sami affiliation/work in health care sector/approximately 50 years old/does not live with the person with DD)	What kind of a question is that? Do you want the short or the long version?	Rejection Wants me to reframe or ask other questions. Act: laughs, awaiting clarification or adjustment	Person with the right to refuse to answer silly questions.	Silly person with the duty to ask proper questions to get answers
	Well, it concerns more than that, mostly because the culture forms the way I think about everything. It is challenging to describe because it is natural for me and not for you…	Compromising/adjustment Aim to educate me about the complexity of the question Act: answer the request and broaden the question with examples	Person who has said yes to the interview and has the duty to answer and thus the right to educate the interviewer	Person with rights to ask questions

I had been interviewing several participants that spoke of "the Sami manner" and the "Sami culture" but gave few examples of it. My initial question regarding Sami culture related to my interest in what this Sami person expected as rights related to the ethnic affiliation. Although I should have known in the situation that this was a loaded question, I still asked it without any description of the prior interviews to help her view this question in the same manner as I did. I

noticed her rejection and attempted to clarify the question. However, I had already positioned myself as Norwegian and rather unaware of my own culture. I attempted to escape this unpleasant position by adjusting the position towards the researcher with my further clarifying of the question.

When I position myself as a Norwegian, I simultaneously position her as Sami and as someone who could explain Sami culture. As a researcher, I assigned her the duty to answer my question. The participant reacted surprised and rejected both positions by not answering and returning the question with a hint that this was a challenging and strange question. Hence, we negotiated both the positions and the topic of the interview.

I was rather trapped in this storyline, clung to the researcher position and did not relent. She compromised and took an educational position where she described the challenges with the question and the subjective and heterogeneous character of any culture. However, when she first started to speak about culture, she actually provided many specific examples of how a Norwegian should not approach a Sami, which was useful for my understanding of what could be interpreted as cultural facilitation.

This example shows first how my influence led to a negotiation of topics to be discussed in the interviews, and it also serves as an example of the analysis. The interview's 'what' can be read from the transcript; however, the analysis with use of positioning theory indicated how the negotiation of positions brought forward negotiations of understandings – as in this case the understanding of a homogeneous Sami culture.

6.0 Results

The project consists of three sub-studies, as listed on page x. In this section, I briefly present the results of the three studies.

6.1 Article 1

The results indicate that negotiations among formal and family caregivers regarding involvement in decision-making fall within three main themes: “gaining consent from the person with dementia”, “formal care intervention” and “the right to speak on behalf of the person with dementia”.

Gaining consent from the person with dementia

Both formal and family caregivers viewed the patient as confused and no longer capable of knowing what was best for him- or herself. The confused patient position had no described duties but had a right to care. The formal and family caregivers understood their position as important guides in decision-making processes and described stretching their boundaries to persuade the patient. In many situations, formal and family caregivers expressed difficulties with decision-making processes and explained that the preferences of the person with dementia were followed as long as the person’s actions could be considered safe. The family caregivers’ dilemma was that while they considered the person with dementia unable to make appropriate decisions for their well-being, the person still had legal consent rights and, thus, the right to refuse help. Such situations made daily life extremely distressing for the family caregivers. The formal caregivers’ dilemma concerned their desire to relieve the family caregivers’ heavy burden of care while preserving the patient’s autonomy, preventing coercion and working within legal boundaries.

Formal care intervention

The family caregivers wanted to preserve normality as long as possible despite their heavy burden of care, and the formal caregivers wanted to provide early intervention to guide the patients and their families’ decisions and prepare for future situations. As a result, the schedule for formal care intervention was constantly negotiated.

The right to speak on behalf of the person with dementia

Most of the family caregivers indicated that after contact with the formal healthcare services was established, they experienced a fight for resources. All of the family caregivers expressed the belief that their involvement in decision-making processes could ensure the provision of individualized care. They were aware of the possible limitations and constraints created by

economic considerations and the lack of resources in the municipality, but they still wanted to discuss with formal caregivers how they as family could contribute to ensuring what they considered ideal care. When the person with dementia moved to a residential care unit or attended a day-care centre, the family caregivers ceased to worry about the person's safety or the heavy burden of performing nursing tasks. However, their care burdens were manifested in constant and emotional conflicts with formal caregivers when they felt disregarded during important decision-making processes. Conflicts between family members and formal caregivers typically arose when they were negotiating individual and psychosocial care measures.

Over time, the establishment of care changed the formal caregiver's position. When formal caregivers first intervened in a home, they collaborated with family caregivers and developed care measures with the patient and family caregivers, working as a team. Eventually, this collaboration changed to focus on the patient's current desires, even when they conflicted with the family caregivers' preferences. The formal caregivers assumed the position of the protector of the patient's rights and positioned themselves as the person's spokesperson, replacing the family caregiver. Nevertheless, the formal caregivers mentioned that it was extremely important to consider the family caregivers' demands because doing so could make it easier for the formal caregivers to request additional economic resources. The municipalities' economic situation was repeatedly cited as the reason the formal caregivers' nursing ideals were impossible to achieve.

The overall analysis revealed factors that enabled and inhibited types of collaboration in relation to discussing consent, providing intervention in someone's home, and speaking on behalf of a person with dementia. I understood these discussions as occurring within the broader discourse of user involvement in the field of dementia care.

Contribution

This article illustrated that current government health policy, which seeks to ease the family burden, provide early intervention and increase user involvement in home-based dementia care, faces several barriers that interfere with collaboration among formal and family caregivers. Formal and family caregivers' understanding of user involvement and consent differs in varying situations, and disagreements arise about who can claim to promote user involvement and for what reason. This article can help to inform future health policies by illuminating the comprehensive and sometimes conflicting negotiations related to consent and decision-making processes in clinical practice.

6.2 Article 2

Inspired by Ramstad and Thuen (2005) who wrote about the Sami ethno-political struggle, I categorized the participants within the positioning pair of "ethnic" and "ethno-political". In my categorization, the ethnic position involved "the Sami or the Norwegian manner", a vague description of how language and traditions in everyday life interfered in this collaborative practice. The ethno-political position involved a negotiation of ethno-political rights as described in national and international policies and acts (Ministry of Government Administration Reform and Church Affairs, 1987; Ministry of Health and Care Services, 1999, 2010b, 2013, 2015c; Ministry of Local Government and Modernisation, 1989, 2005). Ethnic affiliation in my categorization into ethnic and ethno-political positions appeared to influence the collaboration in specific ways.

The result showed negotiations of ethnic and ethno-political positions along two main themes: "Ethnic positions hamper collaboration" and "ethno-political positions reinforce stereotyped ethnic positions."

Ethnic positions hamper collaboration

Despite the participants' described problems with distinguishing people's ethnic affiliations, the ethnic positioning had a considerable impact on collaboration. Some of the participants were barely aware of any ethnic differences regarding the Sami in their municipality, while most of the participants talked about themselves and others in terms of ethnic categories. In some situations, some ethnic positions created tension, conflicts and negotiations. Ethnically ascribed positions had consequences for the way the participants viewed collaboration and triggered different sets of rules for the interaction. Problems with ethnic positioning can be addressed through formal caregivers' awareness of such ethnic negotiations, their tolerance of unpleasant positions and their willingness to speak openly about ethnic affiliation and how it may influence the particular collaboration in the specific situation.

Ethno-political positions reinforce stereotyped ethnic positions

Furthermore, the analysis showed that the participants supported the governmental goal of equitable services, but their interpretation of how this political objective should be implemented in practice differed according to their ethnic positioning. The colliding ethno-political perspectives differed in terms of both their understanding of ethnic affiliation and the need to differentiate the Sami people from other ethnic groups. The ethno-political positioning created

barriers to collaboration among colleagues and among formal and family caregivers in home-based care.

There may be different answers for why ethnic and ethno-political positioning appears so important in collaborative practice, as the results of this article show. We presented three hypotheses related to how an understanding of positioning in various settings could be exploited for conflict resolution: 1) Such positioning is a result of routinized stereotypes, 2) such positions are necessary for collaboration, and 3) such positioning is a way to preserve the Sami culture and language. In this article, we interpreted the latter hypothesis as the most reasonable explanation for the most severe conflicts. The most difficult conflicts related to the political discourse that preserving the Sami culture and language contrasted with the egalitarian ideal (cf. Gullestad, 2002).

Contribution

This article revealed mutual ethnic positioning that may serve as routinized stereotypes, as a necessary factor for collaboration, or as a way to preserve the Sami language and culture under pressure. Ethnic positions, particularly ethno-political positions, hamper collaboration among formal and family caregivers and can lead to delayed or non-utilization of formal healthcare services. The article contributes knowledge regarding possible barriers to collaboration in home-based care for patients with dementia and further contributes to the understanding and debate regarding positions in interactions between Sami and ethnic Norwegians.

6.3 Article 3

The results revealed a main theme: discrepancies between formal and family caregivers' experiences with continuity of care. Within this theme, four categories described the positions that formal and family caregivers take when collaborating with one another. The family caregivers' positions are "insecure participant" and "spokesperson". The formal caregivers' positions are "locals" and "subordinates". Within each position, particular stories regarding collaborative care practice, the patient and IPs are told.

In the insecure position, the family caregivers expressed that they had been left floundering in the caregiving position, had many questions related to treatment and care and expected progress and safety, among other things. All of the family caregivers expressed problems such as a lack of information, meetings and formal primary contacts. Others referred to the shortcomings of their care work and wished that formal healthcare providers could take more responsibility. Within this position, the family caregivers positioned the people with dementia as confused and thus unable to serve as credible sources of information. Four of the family caregiv-

ers mentioned IPs on their own initiative and regarded the IP as a means of addressing their problems with information flow, particularly given the establishment of a formal primary contact and regularly scheduled meetings.

Because the family caregivers positioned the people with dementia as confused, the spokesperson position emerged. All of the family caregivers emphasized the need for more individualized care and expected to be included in many decision-making processes. However, they described several experiences of exclusion.

Most of the formal caregivers identified themselves as locals. Non-locals still emphasized local knowledge as important in care. This position allowed the caregivers to make discretionary judgements based on what they considered thorough knowledge of the patients and their families. The formal caregivers provided several examples of how they used this familiarity to provide individualized care. The local position appeared to affect the formal caregivers' understanding of the need for written documentation, and they referred to the large volume of ongoing, undocumented and oral collaborative work in a generally positive manner. A substantial barrier to IP work in home-based care appeared to be the formal caregivers' familiarity with the municipality and their satisfaction with the existing approach to collaboration in home-based care. However, non-local workers could pose a problem during collaboration with patients and informal caregivers, and many formal caregivers expressed an urge to observe their non-local colleagues at work.

The subordinate position emerged when the formal caregivers described resource constraints. Some formal caregivers spoke of how individualized care and additional IPs were ideals that did not consider the resources and time available, and some called for management's involvement in such dilemmas. However, some formal caregivers spoke of people with dementia in a way that minimized their needs regardless of the organizational resources available.

Overall, the analysis of these discussions indicated that these positions leaned towards the analytical concept of continuity of care and demonstrated gaps between descriptions of practice and healthcare policy objectives for continuity of care, particularly Norway's statutory IP.

Contribution

The article provided new insight regarding how caregivers' positions may facilitate or hinder continuity of care for people with dementia. In particular, it illustrated that the current government health policy that emphasizes continuity of care and promotes the use of IPs in dementia care faces several barriers in clinical practice. IPs are not implemented by formal care-

givers for the patients they described in the data material. In addition, the article illustrated the need for a discussion regarding how to define continuity of care.

7.0 Methodological considerations

In the health field, strongly influenced by a biomedical perspective, qualitative research that relies on humanities and social traditions often has to argue for the right to be called scientific (Mays & Pope, 1995). Mays and Pope (2000) show that qualitative methods are increasingly adopted in health research, which has provoked a considerable debate regarding how knowledge created by such methods can be validated. Roughly speaking, there are two groups of discussions. One argues that qualitative and quantitative research are different and that qualitative research requires different validation criteria. The other discussion posits that quality can be assessed with the same broad concepts independent of research design but that the validation of qualitative research must be operationalized differently (Mays & Pope, 2000). According to Tjora (2012), reliability, validity and generalizability are excellent terms for assessing the quality of a qualitative research project, and I have chosen these terms for my methodological considerations.

7.1 Reliability

Reliability reflects the internal logic of the project. Due to the perspective of interactionism where subjectivity is considered a resource, I have made efforts to describe the way my subjectivity influenced the research. The greatest source of bias in interactional studies is pre-understanding, positioning and interpretation in the interview setting and in further analysis (Järvinen & Mik-Meyer, 2005:34-35). Therefore, I emphasized the transparency of my reflexive process.

7.1.1 Pre-understanding and interpretation bias

I aimed to take the researcher position; however, I consider my experience as a nurse and my three years working part-time in municipality healthcare to benefit this research. Knowledge regarding a field can be necessary to ask appropriate questions but can also create blind spots (Tjora, 2012). I felt that my prior work enabled me to notice variations from what I expected as common in the field and more easily grasp the descriptions related to dementia, healthcare organizations and services. However, several years had passed since I had worked as a clinical nurse, and I had never worked in the municipalities where I constructed data. In addition, the research design, which emphasized open dialogue and stories, allowed me to explore possible directions that I did not have in mind prior to the interviews. Further distance was created using a theoretical framework in the analysis of the text.

The notes that I wrote before and after each interview along with the memos and log entries created each month over the four years of study were highly important for allowing me to explore prejudices. The notes revealed changes in the way I understood the field, my positioning of the patients, how I thought about possible problem areas and how I interpreted the participants' descriptions initially and through the analytical tools. For example, at the beginning of the project, I felt sorry for the person with dementia and barely saw anything other than suffering. I thought of the person as a burden to his or her family and society. I have turned to these reflections many times throughout the project. In one of the earliest interviews, a participant expressed her anger about other people's assumption that her relative with dementia was solely a burden. The way the participant talked about the patient made me reflect on my assumptions regarding people with dementia. Like other people in society, people with dementia may be experienced as a burden from time to time, but they may hold other and more important positions. The change of view affected my understanding of dementia care and the rights and duties of people with dementia.

7.1.2 The exclusion of persons with dementia

The Patient Rights Act (1999), which establishes patients' rights to be involved in shaping their own healthcare can be understood as a right to also be involved in research regarding the disease and healthcare services. When I decided to exclude people with dementia from my study, it was because I thought the inclusion process would take a long time and I had to be pragmatic about the time available for the project. Another reason for excluding people with dementia was my assumption that symptoms of dementia would make participation challenging and that inclusion would risk creating unnecessary confusion for them. However, Karlawish, Rubright et al. (2009) argued that a considerable proportion of the population with Alzheimer's disease was able to provide informed consent in studies where the patient did not risk major difficulty. The patients primarily had preserved the ability to indicate a family member or informal caregiver who could help them or provide consent on their behalf. The authors claimed that this fact is rarely considered in research and that consequently, many patients are relegated to vulnerable groups and thus not included in research (Karlawish et al., 2009). Retrospectively, I believe that I could have involved persons with dementia with help from family caregivers or on an intermediate level by presenting and discussing the design of the study and findings with dementia user groups.

Regardless of my prior interpretation regarding the ability of people with dementia to be included in studies, the most important reason for excluding them was this project's aim to ex-

plore formal and family caregivers' collaboration. Family caregiving work in home-based care is substantial, they are often the first to contact formal healthcare providers with concerns, and they maintain this contact along with the person with dementia (Bergh et al., 2015). I assumed that it could be problematic for the family caregiver to describe events that concerned the person with dementia when he or she was present. I considered including the patient and conducting separate interviews, and if I had done so, I could have obtained consent from both the patient and the family caregivers; however, because of the project's timeframe and the lack of clear benefits from such an approach, I decided to exclude the person with dementia. Consequently, the study constructed knowledge based on the formal and family caregivers' perspective.

7.1.3 Sampling biases

Some health managers, particularly those in the interior municipalities, were hard to reach. The difficulties reaching the managers could be related to the challenges these managers experience in small rural municipalities, e.g., lack of staff, working in shifts, managing both clinical and administrative tasks, economic issues and long distances (F. H. Hansen & Nicolaisen, 2012).

Nevertheless, I wondered whether the difficulties reaching managers could indicate a resistance to participation in some municipalities and thus a sampling bias. In two municipalities, the health managers refused to allow access to possible participants because they claimed they were not providing services to Sami patients at the time and because they were exhausted by previous experience with research projects. In other municipalities, the managers expressed a need for research. However, in the same municipalities, it was also difficult to obtain written permission for constructing data from some healthcare managers, which was a problem because it typically required weeks for me to receive the written consent of formal and family caregivers after the health managers had accepted my request.

One report (Ministry of Health and Care Services, 2010b) indicated that people with Sami affiliation distrusted written enrolment because of the prior experiences with the Sami assimilation process, and I pondered whether distrust towards written enrolment could represent a sampling bias. Therefore, at the end of some interviews, I asked the participants about their views on the reported Sami cultural traits concerning written communication. Most of the formal caregivers indicated that some of the Sami family caregivers and patients they knew expressed not wanting formally to register for support. One family caregiver, as presented in article III, stated that written communication was no problem for participating in research.

However, she did not want formal caregivers in her own municipality to write down things regarding her family. She considered this type of written communication unnecessary and was afraid of slander. The other six family caregivers did not recognize any cultural traits related to written communication. However, the formal caregivers described another and perhaps more important explanation for the difficulties with reaching healthcare managers, namely, the managers themselves also worked as shift nurses in these small municipalities.

Nevertheless, the difficulties reaching managers and obtaining approval for constructing data in some municipalities may have contributed to sampling bias regarding ethnic affiliation. No formal caregivers from interior municipalities participated in the study. Although the descriptions provided by the family caregivers in the study were consistent regardless of whether they came from an interior or coastal municipality, the inclusion of participants from other municipalities, e.g. interior or urban, could have generated different results.

Only one male participated in the study. Several factors may have influenced the low number of men recruited. More women than men assume caring responsibilities at home (cf. Folbre, 2012). The members of the local dementia associations were reported to be mostly women, and few men worked as formal caregivers. The interview with the man in our study, who worked as a formal caregiver, did not stand out from the other participants' interviews. Nevertheless, I have wondered why it was so difficult to recruit male family caregivers. One formal caregiver told me that she had distributed information regarding the project to two male family caregivers. One just stated that he had nothing to tell and did not want to participate, but the other explained his rejection in terms of gender, indicating that as a man, it was hard enough to care for his sick wife, and he would not participate in research.

The fact that all family caregivers were women may have influenced the way the formal caregivers spoke of services. A recent Norwegian report showed immense variation in the home-based care services offered both between and within municipalities and found that formal caregivers appeared to offer fewer services to women than to men and to people whose daughters served as family caregivers (Berge, Øien, & Jakobsson, 2014). This thesis has no data indicating that the female family caregivers were offered fewer services. However, the findings from previous studies indicate differentiation based on gender to be unconscious. Thus, the formal caregivers' assessment of formal services to be offered to the patient and the family caregivers, which in this study were all women, could be influenced by formal caregivers' lack of awareness of the gender bias.

In this study, I could have described and taken into account such sampling bias when designing the study, and the research results may have been different if the gender distribution had been equal. However, because women predominate in both formal and informal caregiving positions, the sampling of women in this study is important for gaining their perspective.

Another important consideration is that people with a heavy burden of care may not participate in research, which could have a considerable impact on the results and their generalizability. However, several of the participants in this study had substantial responsibilities for the person with dementia, and some had problems scheduling appointments with me because they needed someone else to watch the person they cared for at home.

One particularity in the sampling was that all of the participants had experience working in healthcare services. It is possible that their insider knowledge of formal healthcare services was significant to their participation in the study and therefore to the results. In a prior study, formal caregivers stated that family caregivers who themselves had worked in healthcare were the most demanding next-of-kin to satisfy (Hamran & Moe, 2012). Thus, this particular group of family caregivers may be more liable to participate in studies where they can speak of a topic regarding which they have much knowledge and perhaps complaints. However, most family caregivers did not emphasize their experience as workers in a healthcare organization, and I interpreted the overrepresentation as unintended sampling mostly because the study involved small municipalities where women often find themselves working in healthcare at some point.

The opportunity to tell their stories anonymously without the risk of people in their municipality recognizing them was a factor that several of the participants emphasized when talking with me. One stated, “I could never have spoken about this to my superior.” The participants may have regarded me as an anonymous mouthpiece through which they could bring difficult topics out into the open. Therefore, I had to be sensitive to my own role as a researcher and the risks of mistreating the participants (cf. Hewitt, 2007). Guidance from supervisors and colleagues in the research group was helpful. In addition, I selected both the thematic analysis and analysis guided by analytical concepts to allow me to interpret, understand and conceptualize positions with underlying assumptions of ‘reality’, duties and rights to construct an improvement of the participants’ original utterances.

7.1.4 Risks or benefits for participation

All research involves a risk for those who participate, and an important principle has been that participation should occur only with voluntary and informed consent (Ministry of Health and Care Services, 2007).

The risks of participating in the project were assessed as low. The participants were healthy adults who obtained information and provided oral and written consent. However, the risks were somewhat different for the formal and family caregivers and for the patients whom the caregivers described. The patients with dementia could be at risk of being exploited because they had not been asked whether they wanted to be discussed in a research project. The formal caregivers could be at risk of revealing confidential information when they talked about their experiences with patients and related parties. In such situations, formal caregivers' ethical statutes regarding confidentiality must be observed (Ministry of Health and Care Services, 2007). I provided the formal caregivers both written and oral information regarding how to tell stories about collaboration without revealing sensitive information regarding the patient or family. When talking about collaboration, the participant could be at risk of discussing employers and colleagues in ways they would not have if they had been speaking to them directly and could feel uncomfortable about it subsequently.

Similarly, family caregivers could be at risk of feeling uncomfortable when sharing experiences. For me, it was key to ensure the participants' confidentiality throughout the entire project, from recruitment to the interview situation and de-identification for publication and the dissemination of results. This work had to be balanced against the maintenance of personal and contextual information in the findings. Some of the participants probably knew each other because in some municipalities I conducted interviews with both formal and family caregivers. The familiarity made the efforts to anonymize the participants even more important, and the translation of spoken data into English further helped me to retain the meaning of utterances while strengthening the participants' confidentiality.

Although participation in studies can be experienced as meaningful (cf. The Norwegian National Research Ethics Committees, 2009), I did not plan to offer a direct benefit to its participants through the study. However, participation may have been beneficial because it encouraged self-reflection during the interviews. In several interviews, the participants stated that they had not previously considered the topics discussed and that, in retrospect, they could have acted differently in some situations. Consequently, the research may have contributed to better collaboration among formal and family caregivers in the municipalities where data con-

struction occurred. However, the benefits I aimed for were post-publication, assuming that the results were perceived as meaningful and important to formal caregivers and policy makers and thus might yield results in the form of improved practice.

One family caregiver wept extensively during the interview. She felt abandoned and wondered whether her relative's actions were related to the dementia diagnosis or to the relative's viciousness. Evans and Finlay (2009) have written about participant distress and stated that the ethical solution lies in the relationship between the researcher and the participant. During the meeting with this particular participant, I asked if she wanted me to stop the audiotape, but she replied it was not necessary. At the end of the interview, I felt obligated not to leave her feeling upset and told her that to my knowledge as a nurse, dementia could have many different symptoms, including the ones she described. Furthermore, I suggested she contact formal caregivers and take advantage of the educational resources for family caregivers that I knew would soon be available in her municipality. Thus, I exceeded my position as a researcher.

Inspired by Evans and Finlay's chapter on relational ethics (cf. 2009-175), I chose to send all of the participants an email a few weeks after data construction, where I thanked them for participating and invited them to contact me if they had any questions or needed to follow up. I received replies from approximately half of the participants, most of which were just greetings. No one mentioned a need to follow up. The participant who became particularly emotionally distressed during the interview did not reply. However, if she followed my advice and initiated contact with formal caregivers, she may have obtained help in her difficult situation, and the research may thus have had a direct benefit for a participant.

7.1.5 Age and ethnic affiliation

Other positions based on age and hometown may have affected the interviews and thus the results. The participants and I differed in age; while some were younger, most were older. To my knowledge, no large bias occurred because of my age.

My own ethnic position, however, required considerable reflection. I grew up in a rural, coastal municipality traditionally populated by ethnic Norwegians, Qvens and Sami. People in my husband's family had Sami affiliation, and I had friends who were Sami, some of whom spoke Sami as their mother tongue. I conducted thorough genealogical research on my own family, and I found that my great-grandmother lived in a traditional Sami area, spoke Sami and wore traditional Sami clothing. However, these Sami roots were undermined. I have read several historical texts from my home municipality that described strong pioneering advocates

for the Sami assimilation policy. These texts made the ethnic context of the field partly recognizable for me, but prior to this project I had scarcely reflected on my own or others' ethnic affiliation and how it could influence interactions in today's social practices.

The Sami culture[7] is often perceived as "cultural", while the Norwegian culture is not mentioned, and my Sami acquaintances made me aware that ethnic affiliation is not necessarily manifested in all spheres. A person who in some relationships defines themselves as a Sami may wish to be considered and treated as a Norwegian in other situations, sometimes to avoid prejudice. Prior to the interviews, I did not think of ethnicity as a leading topic. However, I did reflect on ethnic barriers to collaboration, e.g. language. When designing the interview guide, I focused on collaboration rather than ethnicity.

As data construction continued and the participants told several stories regarding distrust between Sami and Norwegians, I felt it was necessary to ask them about my ethnic affiliation and its possible consequences for the interviews. One participant laughed and stated, "Well, that you have to figure out yourself. We (the Sami) will not tell you directly. You might understand it from what we tell you anyhow." I felt that my ethnic affiliation was something the participant and I had to clarify before we could discuss other topics that were relevant to the study. To minimize the risk of ethical misinterpretation related to ethnic affiliation, in the later interviews I asked questions about the stories I had been told regarding ethnic affiliation in prior interviews.

I felt a rapport with all of the participants, regardless of ethnic affiliation, and the interviews contained rich descriptions that were shared with engagement and emotions. However, the importance of ethnic affiliation surprised me. The reflections on how ethnic positions interfere with both collaboration and research practice followed me throughout the entire study. It is possible that the participants would have told other stories to someone who shared their ethnic affiliation, but several of the Sami participants expressed thoughts similar to those of one Sami family caregiver: "It is different with you. I knew from the information letter what you wanted to talk about and could be prepared." However, the participants may have emphasized to me an ethnic affiliation that would have been different in a meeting with another researcher, perhaps one with another ethnic affiliation.

[7] See chapter 2.3 for my understanding of the term culture in this context.

In addition, all the authors of the articles in this thesis consider themselves Norwegians, which may have introduced bias into the analysis. Nonetheless, the results show tendencies that are applicable to both Sami and other ethnic affiliations and, in a broader sense, to an understanding of the way that ascribed positions can define individual duties and rights.

7.2 Validity

Validity denotes a logical connection among the project's design, questions and results. Thus, validity requires discussions regarding whether the methods that produced the results of the project answer the established research questions (Tjora, 2012).

7.2.1 Reflection on methods

I present data primarily from interviews, and the observational data's main function was to supplement my understanding of context.

The formal and family caregivers' collaboration was explored through their retrospective descriptions of collaboration and reflections on expectations regarding collaboration, understood as 'accountive positioning' (Van Langenhove & Harré, 1999a). The data were mostly discursive, which implies storylines imbued with intentions, reasons and motives and which could thus help answer how the caregivers described collaboration and interpret barriers to collaboration. The consequences of mostly discursive data are related to validity through transparency and the elaboration of reliability in the previous chapter.

However, because of the brief fieldwork, I do not know much regarding what the participants actually *did* in the social interaction in their 'ongoing and lived storyline' (cf. Van Langenhove & Harré, 1999a: 21). The participants' retrospective storylines do not necessarily predict acts (Harré & Van Langenhove, 1999). For example, some of the Norwegian formal caregivers were interpreted as having a negative view of Sami cultural facilitation, e.g. in the storyline in article I, "The Sami are no different than us, raised under the same conditions". These participants reported they did not introduce any special measures for Sami patients or caregivers. However, what they actually did in social interaction with Sami patients, I am not able to present. Other storylines, conflicting positions or social forces may change the participants' acts from what they told me face-to-face.

Tjora (2012) criticized the fact that so many researchers choose in-depth interviews to study practice and wrote that the reason is probably pragmatic. Ideally, I could have conducted more fieldwork to capture formal and family caregivers' acts in collaboration. It is possible that further fieldwork would have been useful to increase my ability to interpret collaborative

practices among caregivers. However, due to pragmatic reasons such as time available, geographic distance and the economics of the project, my fieldwork was brief. For the same pragmatic reasons, I assessed that several interviews with the same participant would not provide additional insights. I considered conducting focus group interviews; however, because I had been told that participants with Sami affiliation could be particularly distrusting, and because of the long distances between participants' municipalities, I chose to conduct solitary in-depth interviews.

Nevertheless, the most important reason for primarily using interview data was the possibility to explore descriptions and reflections on collaboration situations as emphasized by Van Langenhove and Harré (1999a) and Järvinen (2005). In retrospect, the brief fieldwork inspired some ideas for new questions and understandings, but it did not generate much groundbreaking information that I had not obtained from the previous interviews.

7.2.2 Reflection on analysis

A strength of predominantly using interview data is that the participants and I could understand and interpret each other throughout the interview (Järvinen, 2005). The interviews flowed freely, and the interviewer did not have to ask many questions. I am pleased with the way I was able to elicit nuanced descriptions regarding the topic. However, the qualitative interview's strength is also its weakness in that the qualitative researcher's typically solitary work carries risks, particularly the risk of misinterpretation as discussed in the section on reliability.

In articles I, II and III, my influence on the data is not clearly presented. In this thesis, in the chapter on analysis, I provided an example of analysis to make my work more transparent and to describe my influence as the interviewer. Additionally, I operated a thorough reflection on my subjectivity, and I provided an overview of the research field and literature that I deemed relevant to this study.

The detailed, comprehensive and personal descriptions co-constructed through the interviews made the selection of data for the specific articles challenging, and I consider the thematic analysis method wherein I first transcribed and coded all of the available material very important for the selection of what data to include. It was a painstaking but necessary part of the analysis. The coding helped to create a necessary distance that detached the words and expressions used in the stories from the stories and the participants themselves. The coding facilitated the creation of a new understanding that could be tested by asking new questions

regarding the data. I wrote several notes during this process that reflected possible meanings and possible concepts for further analysis using positioning theory.

Another important choice with regard to the results was the method of analysis inspired by Harré and Slocum (2003) to search for *conflicting* storylines. Prior to this study I had read about possible barriers to collaboration, and an emphasis on conflicting storylines was thus appropriate to enable me to explore barriers. However, the risk with this emphasis was that other possible important storylines could be overlooked. I found Nvivo helpful to guide exploration of utterances of which I was unaware and had previously not selected because of my search for conflicting storylines. Searching for word frequencies helped me to increase my understanding of the material and sometimes provided direction for further searches, e.g. regarding trust.

Although Nvivo is a tool situated mostly in a quantitative and realistic philosophical tradition where it aims for rigor and efficiency in the analysis (Bergin, 2011; Zhao, Li, Ross, & Dennsi, 2016), I used Nvivo as a storage and structuring tool that allowed me to simplify the handling of the large amount of data material. To avoid the rigidity of the categories built using the tool, during the analysis I ran several queries for each category.

The strong emphasis on ethnic affiliation surprised me in the interviews, and I felt the corresponding storylines required analysis before any others. I sought Sami patients, and the patient's family caregiver positioned the person with dementia as Sami when they provided their informed consent to participate in the study. Thus, ethnic affiliation worked as a practical category (cf. Nadim, 2015). The ethnic categorization was in use by the participants in their everyday language; however, for further analysis, I used the ethnic category as an analytical category to explore and describe collaboration among formal and family caregivers.

Nadim (2015) stated that a problem with the use of ethnicity as an analytical category is the risk of stereotyping or that an emphasis on one category can displace attention from other, perhaps more important categories. I was aware of the risk of stereotyping, and in the analysis I emphasized, in line with positioning theory (cf. Van Langenhove & Harré, 1999a), the ethnic position as one of several possible positions a person can take or be assigned to.

For the other two articles, I could have selected different categories, e.g. possible discrimination against older patients versus younger patients. However, the storylines selected for the articles were inspired by the previously expressed research problems addressing possible barriers related to user involvement and IPs, as presented in article I and III.

Kvale and Brinkmann (2009) wrote about communicative validity in terms of people in the research community who test study results in dialogue with the study's researcher. Articles I, II and III have been published in international journals, and I have presented my work orally at national and international conferences several times. The results are accepted as valid and legitimate and appear to be accepted as premises for further dialogue with fellow researchers.

7.3 Generalizability

Generalizability is the discussion of the range of applicability of results, and generalizability in qualitative research is subject to controversy and debate (Nadim, 2015; Tjora, 2012).

This project's methodological perspective is interactionism, of which a common criticism is the problem with relativism. Critics argue that if people shape reality within a dynamic relationship with other individuals and in a specific context, it is impossible to agree about whether something is factual, ethical or valuable other than in snapshots (Harré, 2004; Lock & Strong, 2014c).

To exemplify how the problem with relativism was addressed, I use the following storyline from article III, page 11: "Think about it, losing your mother while she is still alive". The utterance was contextually contingent and thus influenced by social relationships and historicity. The utterance was 'true' for her but not necessarily the only truth that could exist in home-based care, and thus there was a risk of relativism and therefore a risk of generalizability. According to Tjora's description of "conceptual generalizability" (2012:215), theory or previous research can improve understanding and generalizability of empirical data. I validated the utterance by contrasting it with a larger pattern in the research data. I compared the utterance with those of several other participants who presented a different view of people with dementia and suggested that the storyline of "losing your mother while she is still alive" was influenced by the idea of "living dead" (cf. Behuniak, 2011) as described in the theory of malignant positioning (cf. Sabat, 2006).

The participant who uttered the storyline may retrospectively explain its meaning differently, and other researchers may interpret it differently. However, in my work I attempted to explore *why* the participant used language the way she did. Through the example above, I present how in my study I have strived to ensure validity through reliable use of the research data by keeping the actors' point of view intact via the use of the utterance in question. Then, using structured methods, the guidance of previous research, and positioning theory, I strived to offer descriptions providing conceptual generalizability. Through my reinterpretation and contextu-

alization of the utterance, I offer descriptions and explanatory models that can be recognized by others.

Nevertheless, the 'reality' that this project proposes is a theoretical construction of practical 'reality' and thus not meant to be generalized in a static way. However, my intention is that formal caregivers can make use of the findings and researchers further develop them (cf. Tjora, 2012).

Another question concerning generalizability refers to whether research into micro-level experiences may correspond to macro-level processes. A common and somewhat extreme criticism is that micro-interactionism can be understood as people creating their own realities without the influence of external realities (Järvinen & Mik-Meyer, 2005). In this dissertation, drawing on positioning theory, which situates micro-level processes within broader macro-level discourses (Van Langenhove & Harré, 1999a), I argue that the caregivers' descriptions of small-scale interactions are influenced by macro-social discourses such as public policies, for example. In article III, I indicate that the politically promoted and legislated tool for more coordinated and individualized services – the individual plan – is not being used for people with dementia. The formal caregivers offer several explanations for why they do not use it. My interpretation of data that points in particular to a local position, malignant positioning of the person with dementia and economic reasoning can challenge the *"arguments made at the general or macro level"* (cf. Ceci et al., 2012:15) and thus aim for a more responsive practice.

In the discussion, I proposed the metaphor of a mosaic to explore and describe collaboration between formal and family caregivers in home-based care. The mosaic is meant to be a tool to present an improved interpretation of the findings in article I, II and III and allows me to aggregate the micro-level findings into more generalizable concepts. Thus, the micro-level descriptions of collaboration, continuity and, in particular, user involvement as a legal right and duty can be fed into intermediate-level organizational planning and macro-level policy planning of collaboration between home and formal services (cf. Tritter & McCallum, 2006).

Representativeness is yet another concern with generalizability. Representativeness in qualitative studies relates to the researcher's reflections on the variety in the study sample (Nadim, 2015: 135). Empirical generalization is possible when at least two factors are considered. First, the researcher's information regarding the population should be assessed and compared with the typical or atypical cases in the empirical data material. Second, systematic methods should be used to select cases (Nadim, 2015).

In this study, I performed a purposeful sampling of participants, and thus, the participants represented important actors involved in collaboration in home-based care, namely, formal and family caregivers. The formal caregivers had various professions, and the family caregivers had various family relationships to the person with dementia. They were mostly women of varying ages living in rural municipalities that varied between coastal and interior and featured a mix of population and distance within the municipalities. Additionally, the caregivers varied in terms of ethnic affiliation. In sum, the variety was extensive, which was important to explore varying experiences to answer the research question. However, variety makes empirical generalizations difficult.

As described in the three articles, the participants' descriptions concerning, for instance, the understanding of people with dementia as confused and in need of help were often similar regardless of how the participants were categorized. The similarities among the storylines of both the formal and family caregivers may suggest a typical selection of women living in rural municipalities who take care of persons with dementia in home-based care. Nevertheless, if the participants are representative of women living in rural municipalities and with experience as staff in healthcare services, the findings cannot be generalized as static models. Some of the processes collaboration described promise a certain level of transferability; however, generalization based on individuals' descriptions can be perceived as inappropriate and abusive in all research, and particularly in research that includes minorities (cf. Nadim, 2015).

In contrast, conceptual generalization concerns the constructed positions in the three articles and this thesis. In article II, the distinction between ethnic and ethno-political positions can be used as a theoretical concept in other studies that do not necessarily involve the Sami population or rural municipalities.

In articles I and III, the categories that form the basis for research were formal and family caregivers, and the overall study focuses on formal episodes concerning collaboration in home-based care for persons with dementia. The analytical work identifies positioning of the person with dementia as confused, rational and in danger. Generalized, the positioning of the patient in this study concerns negotiations and doubts regarding the person's ability to exercise consent either legally or practically. Formal and family caregivers position themselves and the other caregivers on this basis. Thus, the negotiation of "de jure" and "de facto" consent is a prerequisite for further generalization of the findings.

In articles I and III, there are negotiation processes involving a certain level of transferability. However, through the study of the dynamic positions in home-based care, I present several

positions connected to the sampling category of formal and family caregivers. These positions can be used to identify conflicts and barriers to collaboration between formal and family caregivers in healthcare more generally. Thus, the positions in articles I and III may be used as a theoretical concept in other studies involving caregivers and in particular caregivers whose patient's "de facto" consent is negotiated.

8 Discussions of the main results

The issue that inspired this research concerned the political aim of improving collaboration between formal and family caregivers to enable people with dementia to live at home as long as possible (Ministry of Health and Care Services, 2009, 2015a; The Norwegian Directorate of Health, 2007). Political strategies are formulated in general terms, and it is challenging to present well-defined criteria regarding who has a legitimate claim on certain rights (Molander et al., 2012). This thesis addresses the vagueness and intertwining of the terms collaboration, user involvement and continuity of care in home-based care. This discussion of collaboration concentrates on the interpreted positioning that implies complex and intertwined barriers to collaboration, as previously presented in the articles.

Table 3. Interpreted positions and positioning-pairs in articles I, II and III

Article	**Family caregiver**	**Formal caregiver**	**Patient with dementia**
I	Hidden helper	Observer	Confused Rational In danger
I	Helper in public	Formal helper	
I	Spokesperson to protect the patient		
I and III	Spokesperson to request on patient's behalf	Spokesperson to arbitrate between efficiency demands, patient's needs and family's requests	
III	Spokesperson for the past	Local	
I and III	Disregarded	Formal helper, local or victim/subordinate	
III	Insecure		
II	Ethnic and ethno-political weak and strong positions		Sami

Discussing positioning and barriers can highlight challenges and allow possible solutions or changes to occur. However, merely being aware of the positions is often not sufficient (van Langenhove & Harré, 1999b). While attentive reflection on positions would be a first step towards change, methods or models to enable people to act and think in new ways linked to preferred positions in conflicted situations could further contribute to change (Lock & Strong, 2014c). Therefore, this study presents the metaphor of a mosaic of collaboration that consists of the tiles of trust, necessity, shared understanding of ethnic entitlement, shared understanding of user involvement and finally, the tile of coordination. Through the analogy of a mosaic, I pinpoint metaphoric speaking gaps or scratched tiles and describe variances in colours as seen from different views.

8.1 The tile of trust

Orvik (2015) describes trust as a premise for collaboration and as a relational phenomenon that concerns a person's willingness to chance that the other person in the interaction wishes them well so that these persons may engage in tasks together. Availability is a prerequisite for trusting relationships, and making time available is an individual and organizational responsibility in healthcare organizations (Orvik, 2015). Based on the findings in the three articles, I created the "Tile of trust" in the mosaic of collaboration.

Articles I, II and III present several storylines and positions that concern distrust. The 'ethnic' and 'ethno-political' positions as presented in article II work as both individual and organizational barriers and openers for trust. The 'local position' as presented in article III works as an individual barrier but mainly as an opener for trust. The 'hidden helper' position in article I and the 'spokesperson to protect' position in article III simply avoid collaboration due to lack of trust.

8.1.1 The ethnic and ethno-political position as a barrier and an opening for trust

Skirbekk and Grimen (2012) describe trust as taking fewer precautions and Norwegians as particularly trusting compared with other nations regardless of ethnicity or group affiliation. However, several official documents describe a distrust in the Sami population originating in the Sami assimilation policy (cf. Ministry of Health and Care Services, 1999; Ministry of Health and Care Services, 2010b). Additionally, several researchers have noted Sami distrust (cf. Bongo, 2012; Daerga et al., 2012; K. L. Hansen, 2015).

Article II refers to 'impersonal-institutionalized distrust' (cf. Grimen, 2009:101) as linked to ethnic positioning and worsened by ethno-political positioning. If the persons collaborating had the same ethnic affiliation, it could work as an opener for trust, and the collaboration appeared to work well. However, if they had a differing ethnic affiliation, or worse, were interpreted to be in conflicting ethno-political stances, the collaboration attempts appeared to face a much higher risk of conflict or rejection.

To increase trust someone must always take the first step, and in article II, the formal caregivers described the first step as their responsibility. Since the early 1990s, Norwegian political strategies have emphasized cultural facilitation as a bridge across language and cultural barriers in healthcare (cf.Ministry of Health and Care Services, 1999; Ministry of Health and Care Services, 2009, 2010b). However, there are few specifics on how to perform cultural facilitation in practice (Dagsvold, Møllersen, & Stordahl, 2015). The examples provided by official

documents concern the Sami language, interpretation services and cultural sensitivity and aim for trustful relationships. As presented in article II, the formal caregivers appeared to be aware of challenges in interactions with Sami patients and provided many examples of careful interactions in the patient's home. They mentioned examples of first steps such as informal visits, the need for Sami nurses in some interactions or at least as a mediator for interaction with Norwegian staff, interpretation services, services solely for the Sami population, and a particularly humble demeanour if the formal caregiver was Norwegian.

The political emphasis on the differences between people, which also exists in practice as demonstrated in article II, can also be interpreted as an acceptance of Sami distrust that provides Sami people with prerogative rights to assess whether the formal caregiver is to be trusted. If the Sami have a right to assess Norwegians' trustworthiness, the Norwegians have a duty to accept distrust and act in ways to decrease distrust. However, based on the participants' descriptions, I interpret that these rights and duties are negotiated, and thus, the political emphasis on cultural facilitation can be rejected in practice.

In article II, one Norwegian formal caregiver described her additional attempts to achieve trust after her initial collaboration with Sami family caregivers failed. She felt hurt and distrusted them as well. However, she accepted the distrust and reflected on her professional duty not only to take the first step but the necessary second and third step towards a trustful relationship, and after a time, collaboration operated more smoothly. Strategies that rely on Sami staff to meet with Sami patients appear inadequate or defective in most municipalities due to lack of staff with Sami affiliation. Therefore, "baby steps" as suggested by Grimen (2009:76) and additional allocation of time as suggested by Orvik (2015) can be particularly useful if the persons do not know each other because repeated collaboration over time can build familiarity and serve as a springboard for fewer precautions in interaction.

Because of the lack of Sami staff, the complex precautions established by Sami patients or caregivers appeared to lead to distrusting relationships for both formal and family caregivers and thus a possible risk of increased caregiving burden and ultimately a risk that the Sami patients would not utilize healthcare services. In these particular cases, the Sami staff appeared to be a prerequisite for collaboration to be initiated and maintained, either in direct collaboration or as a mediator. The Sami mediator attempted to create a 'chain of trust' (cf. Grimen, 2009:80) between Sami patients and Norwegian formal caregivers that aimed at minimizing and solving conflicts and perhaps act as a guarantor for the formal caregivers' intentions in home-based care.

However, as presented in article II, for some non-Sami formal caregivers, regardless of their attempts to perform cultural facilitation, the interaction led to conflicts. Grimen (2010) stated that the parties' must be aware of any precautions to be able to discuss if such precautions are necessary. Some of the staff may not be aware of the precautions established by the Sami because as one Sami formal caregiver described in article II, "the Sami manner" is impossible to learn for a non-Sami.

8.1.2 The hidden helper position side-steps the relationship between formal caregivers and home

Article I shows a position pair in pre-home-based care: the formal caregiver's 'observer position' and the family caregiver's 'hidden helper position'. The hidden helper position concerns the family caregivers' choice not to initiate collaboration with formal caregivers. One possible answer for why early intervention is problematic for formal caregivers can be what the family caregivers described as their own and the patient's fear of society's stigma, shown in the storyline of preserving normality in article I. In article III, the family caregiver through the 'spokesperson position' rejects formal care services because of distrust concerning formal caregivers' adherence to confidentiality and thus a perceived risk of slander.

Such positions can postpone a patient's diagnosis and treatment, and support for the family. The family caregiver burden accompanying home-based dementia care is well recognized and described by researchers and policy makers (Graneheim et al., 2014). In agreement with previous studies (cf. L. Phillipson et al., 2014), this study indicates underutilization of services due to fear of social stigma.

Their distrust may be justified, considering some formal caregivers' statements in article III indicating downgraded needs of people with dementia. Downgraded needs may be related to what Sabat (2006) called malignant positioning. Bartlett and O´Conner (2007) described that the primarily biomedical perspective on people with dementia changed in the 1990s, with Kitwood's (1997) help. However, they warned that even if researchers' perspectives have changed, malignant or negative positioning may very well persist in practice (Bartlett & O´Connor, 2010). Malignant or negative positioning of people with dementia leads to a considerable risk of marginalization of the patient and thus can be perceived as a substantial barrier to collaboration with family caregivers, who may view the person with dementia in other ways, as presented in all the articles. Thus, the distrust exemplified in the storylines that I used to construe the 'hidden helper position' suggests the need for formal caregivers to

change their approach towards the person with dementia on an individual and organizational level.

Retrospectively and in view of the burden, as presented in article I, the family caregivers stated that they should have initiated formal intervention at an earlier stage. These reflections indicate that, if formal caregivers initiate dialogue earlier, the barriers associated with the 'hidden helper position' appear to be negligible and easily modified. Nevertheless, formal caregivers cannot change the individual family caregiver's distrust without contacting them, and unfortunately, as described in article I, the collaborative situations often arose when the patient was in danger. Only then would the family caregivers find their prior distrust to be exaggerated.

8.1.3 The local position as an opener for trust

The formal caregivers in article III described the local position as an opener for trust. The local position concerns relational continuity of care as described by Reid et al. (2002). Relational continuity concerns the number and consistency of health personnel caring for a patient, and it is the bridge between past, present and future care through an ongoing relationship between a patient and one or more providers who know the patient and whom the patient trusts (Haggerty et al., 2003).

In articles I, II and III, in line with previous research (cf.Gjevjon, 2014; Haggerty, Roberge, Freeman, & Beaulieu, 2013), the formal caregivers emphasized relational continuity. However, they did not mention the number of caregivers involved. As the findings in article III suggest, they appeared to be satisfied in both process and outcome with the less formalized system to ensure a lower number of formal caregivers because they stated that by being locals they achieved continuity given that 'everyone knows everyone'. This storyline implies an established and informal relationship over time that appeared to build trust. The informal relationship can make the challenge of working in someone's home (cf. Bratteteig & Wagner, 2013) less difficult because the knowledge of each other they appeared to gain over the years appeared to enable a credible shift between 'guest' and 'professional' (cf. Öresland et al., 2008). Although some Sami formal caregivers stated in article II that in "some homes they had to be a Sami and not a nurse", they reported how the Sami and local position gave them the necessary opening to perform nursing tasks and discuss symptoms and caregiving needs during informal visits.

Previous studies indicate that the patient's experience of relational continuity had particular advantages with regard to emotional status, satisfaction and trust and contributed to good communication. Furthermore, it appeared to reduce costs because the patients among other justifications had fewer and shorter hospitalizations (Alazri et al., 2007). Although my study does not contain data from the patient's point of view, the findings indicate a similarity to the family caregivers' perspective. In all articles family caregivers reflected on barriers such as lack of trust, burden of care and dissatisfaction to have an impact on how long they could continue informal home-based care.

However, in agreement with previous research (Alazri et al., 2007; Ness et al., 2015; Silviken et al., 2014), the 'local position' may be a disadvantage because some topics may be challenging to discuss due to the fear of slander as mentioned in article III or because ethnic affiliations did not match as demonstrated in article II. The serious shortcomings regarding trust, however, referred to positioning based on "local" ethnic and ethno-political positioning.

8.2 The tile of necessity

Orvik (2015) noted that, if collaboration is to occur, both parties must perceive the collaborative practice as necessary. Article II demonstrates the caregivers' experience of necessity connected to ethnic and ethno-political positioning. Articles I and III demonstrate how the caregivers positioned the person with dementia. The collaboration was enabled when formal and family caregivers had the same assumptions regarding the patient and hampered when the positioning differed. Nevertheless, the family caregiver breakdown described in article I eventually led to the necessity of collaboration.

The formal caregivers' "expert" positions, understood as the 'local' and the 'spokesperson' positions described in article III and the 'protector position' in article I, all appeared to hamper collaboration because from these positions family caregivers' opinions were sometimes perceived as unnecessary.

8.2.1 Positioning of the person with dementia affects the necessity of collaboration

The caregivers' positioning of the person with dementia and their understanding of the patient's needs have tremendous influence on collaboration. Articles I and III present the caregivers' positioning of the patient as: in danger, confused, rational and with downgraded needs. However, their description of conflicts concerned divergent positioning of the patient in some situations.

The positioning of the person with dementia as confused, which all caregivers performed, did not necessarily affect the caregivers' assumption regarding the necessity of collaboration. However, the positioning of the patient as in danger necessitated a hasty initiation of collaborative processes. In contrast, when the formal caregiver positioned the person with dementia as rational and as a link for information with family caregivers, collaboration with family caregivers was perceived as unnecessary.

Article III presented formal caregivers' reflections on IPs, and one of the reasons for not implementing them related to the perception of downgraded needs and malignant positioning. Malignant positioning, additionally to being connected to the fear of stigma as previously discussed, can also influence the way formal caregivers consider the need for collaborative tools such as IP. If the caregiver assesses the patient's needs to be primarily physical, there is no need for extensive collaboration either with other professionals or with family caregivers.

8.2.2 The formal caregivers' "expert" positions make family caregivers' opinions unnecessary

Supporting the study of Aasgaard et al. (2014), which indicated that formal caregivers insufficiently involved family caregivers as partners in care, Article III presented how formal and family caregivers spoke from different and sometimes conflicting paradigms of continuity of care (cf. Heaton et al., 2012). The family caregivers primarily took a stand based on a 'perspectivist paradigm' in which they expected their and the patient's viewpoint to be sought and considered before decisions were made. The 'perspectivist paradigm' can be interpreted as a development within the concept of social citizenship (cf. Marshall, 2003) encouraged by the development of personhood (cf.Kitwood, 1997). Some formal caregivers' statements in articles I, II and III were interpreted based on a "professional paradigm" where as educated professionals they relied on their formal "expert" role. For example, in article I, formal caregivers described that they sometimes protected the patient against family caregivers' demands, and the family caregivers thus experienced being positioned in the challenging 'disregarded' position.

The "expert" position can also concern the "local position" as suggested in article III. If the formal caregivers interpreted their own local knowledge of the patient and caregivers to be adequate to make decisions, more formalized collaboration with family caregivers was perceived as unnecessary. However, the family caregivers described several shortcomings with regard to discontinuity and in particular to informational and relational continuity, as de-

scribed in article III. Formal and family caregivers' diverging perceptions of the necessity of collaboration had the potential to increase or at least not ease the family caregivers' burden.

If the formal caregivers positioned themselves as "experts", the family caregivers' perspective was of interest only if their positioning of the patient, understanding of needs and potential actions coincided with those of the formal caregivers. Conflicting perspectives appeared to be considered unnecessary distractions from the formal caregivers' actual work with the patient and thus to hamper the formal caregivers' experience of the need for collaboration with family caregivers. The "professional paradigm" may be one answer to why healthcare providers may appear to notice conflicts and the resulting family burden as presented in articles I and III but still do not initiate a dialogue regarding those topics with the family caregivers.

In some situations, the formal caregivers' professional knowledge can be particularly important for the patient's treatment and care; however, without dialogue with family caregivers, the next-of-kin are at risk of finding themselves in the difficult 'disregarded position' as presented in article I. In this respect, the "expert position" appears in some situations to be a substantial barrier to the experience of the necessity of collaboration.

8.2.3 Family caregiver breakdown initiates collaboration

Ample research describes the family burden perspective (Benzein, Johansson, & Saveman, 2004; Samuelsson, Annerstedt, Elmståhl, Samuelsson, & Grafström, 2001; Taghizadeh Larsson & Osterholm, 2014). This thesis described family burden that necessitated collaboration in terms of the "insecure position" in articles III and in terms of the "public helper" position in article I. Both positions implied a change from pre-home-based care towards a formalized collaboration with formal healthcare providers. The change appeared to follow a timeline in family caregivers' descriptions, from their initial discovery of symptoms towards storylines about breakdowns that initiated the need for collaboration with formal caregivers. In the family caregiver position, they experienced a normative duty to provide care. However, as presented in article III, family caregivers described a lack of competence and the need for someone else to coordinate care services. At some point, the family caregiver described a need for more formalized help and initiated contact with healthcare providers. Thus, the family caregiver burden and ensuing breakdown resulted in the family caregiver experiencing collaboration as necessary.

The family caregiver breakdown as an opener for the necessity of collaboration is connected to barriers to collaboration through positions that enable or hamper trust. However, the expe-

rience of the necessity of collaboration probably concerns more than the impact of trust. In my interpretation, it is connected to the insecure position as presented in article III, where the family caregivers lacks knowledge of the service offerings in home-based care, and more importantly to the normative duty regarding family caregiving that articles I and III implicitly describe through spokespersons positions.

8.3 The tile of shared understanding of ethnic entitlement

As presented in article II, the negotiation and "coding" of all participants, including my own ethnic position in the interviews, appeared to be of substantial importance for collaboration. The negotiations of ethnic affiliation could refer to the tile of trust as previously described. However, I argue that the findings also demonstrate how the understanding of ethnic affiliation varied and that the lack of shared understanding influenced collaboration.

This study supports previous research that describes the Sami position as complex, dynamic and difficult to differentiate from other ethnic positions in practice (Blix, 2013; Pettersen & Brustad, 2013). In article II, ethnic affiliation was reportedly not always acknowledged, even when someone openly identified him- or herself as Sami. Instead, ethnic affiliation was negotiated in meetings.

Ethnic affiliation is a private matter until formalized contact with healthcare providers is established. In formal healthcare, the formal caregivers are to meet the requirements of policies and acts that refer to the Sami population, and thus they need to determine the patient's ethnic affiliation. The determination of who is Sami can have implications for how formal caregivers understand the practice of cultural facilitation and which services they are supposed to offer. Consequently, the lack of shared understanding regarding who is a Sami may influence the collaboration in many situations.

The main problem connected to the understanding of ethnic affiliation concerned if and to what extent a Sami patient is deserving or entitled to certain rights or specific measures. Article II presented examples of how some Norwegian formal caregivers believed there were few differences between themselves and the Sami and thus were less willing to provide special measures for the Sami. Conflicting situations based on distrust appeared to make some of them even less willing to facilitate services in a specific manner for Sami patients. I interpret the negotiated ethnic position as part of a broader discourse of Sami rights according to law, politics and norms. Ethnic affiliation is the foundation of a person's entitlement to Sami rights, and therefore, I understood the participants' negotiation of this very foundation as ne-

gotiation of these ethno-political rights. Thus, the barrier to collaboration based on differing understandings of ethnicity and ethno-political rights appeared to be far more profound in society than with regard to healthcare collaboration specifically.

Sami rights in Norway are legislated through the Sami Act and the Norwegian acknowledgement of the ILO convention (Ministry of Government Administration Reform and Church Affairs, 1987; Ministry of Local Government and Modernisation, 1989). However, because the assessment of ethnic affiliation is challenging, the assessment of Sami rights is challenging. In municipal healthcare, economics is a constant issue. Consequently, formal caregivers probably assess Sami rights to have access to Sami nurses, interpretation services and other resources in the organization, alongside the prioritization of many other peoples' healthcare rights. Perhaps the challenges of a limited workforce and economic means in rural municipalities are one answer to why ethno-political positioning generated conflict.

Similarly to the NORUT survey (cf. Angell et al., 2012), article II noted few Sami healthcare workers and few Sami-speaking staff members. Despite the availability of economic scholarships for formal caregivers who register for Sami language courses, most of the participants as presented in article II did not perceive the courses as interesting or necessary because they assumed the Sami spoke Norwegians.

Most Sami in Norway are bilingual (Blix, 2016), and although article II presented few communication problems among formal and family caregivers concerning the Sami language, the ethnic affiliation issues linked to trust and the subtle assessment of "the Sami manner" were mentioned in relation to non-verbal communication. This non-verbal communication did not dictate whether an action was right or wrong, but it could cause conflicts in practice. Thus, this research supports Dagsvold et al. (2015), who stated that the choice of language in healthcare interaction is influenced by complex social and cultural factors.

However, as article II shows, the Sami participants note that they often prefer to express themselves in their mother tongue. The different understanding of who may "rightfully" claim to be Sami may influence the formal caregivers' assumption regarding the necessity of Sami courses.

Several Scandinavian researchers have explored the Sami population's negative experiences with healthcare services (Bongo, 2012; Daerga et al., 2012; K. L. Hansen, 2015; K. L. Hansen, Melhus, Hogmo, & Lund, 2008; K. L. Hansen & Sørlie, 2012; Hanssen, 2013; Møllersen, 2008; Nystad, Melhus, & Lund, 2008; Sørlie & Nergard, 2005; Tervo & Nikkonen,

2010; Turi et al., 2009). The negative experiences may concern distrust as presented in article II and the thesis. However, they may also relate to the discourse of the Sami as "citizen-plus" (cf. Selle et al., 2015), as in article II where Norwegian caregivers negotiate who is "Sami enough" to be entitled to special rights.

8.4 The tile of shared understanding of user involvement

The constructed positions in articles I, II and III helped to demonstrate how the practice of user involvement might affect the way formal and family caregivers collaborate to deliver care to persons with dementia. Tritter and McCallum (2006) suggest that user involvement depends on positioning in social interaction, shared understandings of situations and discourses, and organizational factors. These suggestions are similar to what Orvik (2015) suggests as features for collaboration. Thus, I interpret collaboration in home-based care between formal and family caregivers as including the practice of user involvement.

In agreement with Tritter and McCallum (2006), the interpreted meaning of involvement should be understood within decision-making processes. In article II, the decision-making processes concerned whether or not Sami nurses should care for Sami patients. Mostly, the formal caregivers attempted to fulfil the patients' wishes for Sami nurses, and the family caregivers thus influenced the care offered.

Miller et al. (2016) suggested that the patient's involvement depended on the caregivers' positioning of the patient. In articles I and III, the formal and family caregivers positioned the person with dementia as confused and consequently positioned themselves with the right to be involved in decision-making processes pertaining to the patient. The political aims with regard to family caregiver involvement in decision-making processes concerning people with dementia became relevant in practice because of the positioning of the patient (cf. Ministry of Health and Care Services, 2015a).

Article I indicated that the patient made most decisions in the early phase of the disease; however, the family caregivers reported gradually becoming more involved as the symptoms worsened and in situations where the patient's choice influenced the family caregivers' everyday life. As described in article I, the family caregivers were heavily involved in the initial formalizing of home-based care, and further, together with the formal caregivers, in guiding the patient's decisions towards accepting services. If the family caregivers perceived the patient to be in danger, they contacted formal caregivers to help them to convince or ultimately override the patient's wishes. Hence, some findings in article I support research indicating

that decisions on the patients' behalf occur, in particular regarding safety risks or if the caregivers has exhausted all strategies to assist in decisions (cf. Samsi & Manthorpe, 2013; Smebye et al., 2012). Some findings in this study also support literature that suggests decision-making for people with dementia is a transition from supported to shared to substitute decision-making (cf. Fetherstonhaugh et al., 2016).

The decision-making processes that were reported as conflicting among caregivers occurred after home-based care was formalized, as described by formal and family caregivers in articles I and III through the spokesperson, disregarded and subordinate positions. The conflicts concerned decisions regarding the patient's needs and thus which formal services to offer and accept.

As previously described, formal caregivers' 'expert position' may be one suggestion for why family caregivers reported they were sometimes excluded by formal caregivers from decision-making processes. The assumption that it is unnecessary to involve patients and family caregivers in decisions, as implied by the 'disregarded' family caregiver position in article I, may be connected to the paternalistic perspective of the mid-90s according to which formal caregivers should inform rather than involve (cf. Christensen & Fluge, 2016; H. Hansen et al., 2015). The caregivers' positioning of the patients in all articles does not mention any duties for the person with dementia, a finding that may position the patients as passive recipients and thus may encourage the paternalistic perspective in care. In recent official documents, the formal caregivers' 'expert' knowledge is stated as important for the patient to make informed and appropriate choices; however, the patient's experiences and goals should be included in the decision-making processes (Ministry of Health and Care Services, 2013). Although the political perspectives and ideologies concerning user involvement have changed, previous interpretations may persist in practice.

Making choices, as an ideal, may be understood within the ideology of market, freedom of choice and individualization (Christensen & Fluge, 2016). In the last two decades, healthcare has been influenced by NPM, which is influenced by market economic perspectives where the freedom to choose is fundamental (Kristiansen, 2016). Juritzen et al. (2012) criticize user involvement as a concept influenced by NPM because this understanding of involvement provides the user too much responsibility. In dementia care, it may be arduous for a patient to make choices, and thus, the individualized responsibility that follows from NPM is a challenge. In this ideology, the exclusion of the family caregiver in care and treatment plans may result from the idea that individual users are responsible for their own health and care tasks

based on the right to choose. Thus, family caregivers have less right to be involved in decision-making processes.

Another answer to why family caregivers report being excluded concerns Norwegian Patient Rights Act § 3.1 (Ministry of Health and Care Services, 2016a) that affirms the *patient's* right to be involved in care and treatment decisions. Knowledge of the issue at hand and an understanding of the consequences of one's choices are essential to decision-making (Mol, 2008), and § 4.3 of the act (Ministry of Health and Care Services, 2016a) mentions people with dementia as possible exceptions to consent requirements. However, in this study none of the patients discussed had been assessed by anyone who had the competence and right to withdraw someone's consent, and all thus maintained their legal right to consent. The formal caregivers' lack of formalized assessment of consent led to a legal duty to relate foremost to the patient and emphasize the patient's opinion if the family caregiver and the patient's opinions differed. The legal duty to emphasize the patient's opinion may be one reason why the family caregivers experienced the 'disregarded' position noted in article I. The family caregivers reported having an informal patient pre-consent due to their knowledge of the pre-disease wishes of the person with dementia but experienced that the formal caregivers' rejected their spokesperson position. However, the rejection may be interpreted as concerning the formal caregivers' legal duty to prioritize the patient's opinion. Hence, the family caregiver's rights according to the Patient Rights Act § 3.3 were solely to receive information if the patient agreed.

In articles I and III, the family caregivers requested more information and involvement. Studies have indicated that family and formal caregivers consider the family's involvement to be important for translating the patient's values (Miller et al., 2016; Stephan et al., 2014). The findings in articles I, II and III show that the family caregivers' expectations regarding involvement extended beyond purely informational and emphasized in particular their knowledge of the patient's values and prior identity. The family caregivers' efforts in home-based care appeared to be substantial and thus central to postponing institutionalization of the person with dementia (cf. The Norwegian Directorate of Health, 2016). Nevertheless, the formal caregivers' focus appeared to be on the patient's needs in real time and not necessarily on the patient's prior reported needs or the family caregivers' needs. Formal caregivers, as presented in article III, had no formalized structure for meeting points with family caregivers, and thus the information the family caregivers received appeared to be mainly oral and informal and provided little room for discussion or involvement.

Regardless of the formal caregivers' reasons for excluding the family caregivers in decision-making processes, the findings in the articles suggest that when the family caregivers were not present in decision-making processes, the family caregivers questioned whether the parties involved in formal decision-making had reached a "reasonable, safe and qualified decision" (cf. H. Hansen et al., 2015:31). The conflicts between formal and family caregivers described in articles I and III emerged particularly when the patient's choices had an impact on the family caregivers' physical, emotional and social burden. The formal and family caregivers reported fluctuating assessments of the consent of the person with dementia, which resulted in creative and sometimes emotionally difficult collaborative processes. Hence, despite the patient's 'de jure' consent, the family and formal caregivers continuously assessed and negotiated the patient's 'de facto' consent.

Bartlett and O´Connor (2007) argued that political and legal demands, such as user involvement, necessitate interpretation and assessment in a practice that involves several people and that concerns negotiation during interactions with others (Bartlett & O'Connor, 2007). Thus, the decision-making processes as presented in articles I, II and III can be interpreted as a negotiation of user involvement in practice and more specifically a negotiation regarding who is perceived as the "user" of services in specific situations and thus has the right to be involved. In the tile of shared understanding of user involvement, the exclusion of family caregivers is 'a gap' in the collaboration between formal and family caregivers, and the 'gap' is connected to the patient's consent.

I understand this 'involvement gap' as connected to the formal caregivers' responsibility regarding continuity of care (cf. Reid et al., 2002), in particular the division of informational continuity. Information flow regarding past events, present needs and future aims can be particularly challenging for persons with dementia and thus represents a risk in terms of the patient's user involvement. The term continuity of care is commonly associated with *patient* satisfaction (Saultz, 2003) and well-being (D'Errico & Lewis, 2010). However, some of the findings in this study demonstrate that the caregivers negotiate who is the "user" of the services – the patient or the family caregiver – to assess whether the criteria of satisfaction and well-being are met.

As demonstrated in article III, the formal caregivers' 'local position' could ensure informational continuity. However, family caregivers in article III reported that, despite their knowledge of the patient's past and personal circumstances, they were not consulted regarding service decisions and did not receive information regarding progress, plans or decisions.

The family caregivers' 'insecure position', as presented in article III, required more information because the person with dementia was considered unable to serve as an information link. Thus, the family caregivers describe discontinuity.

In Norway, one way to address conflicting negotiations in decision-making processes is through the legislated individual plan (IP). Official Norwegian documents argue that the IP is a tool to ensure individualized care services improves collaboration between the user and caregivers and enhances continuity of care through the processes of mapping the person's goals, capabilities and needs for services (Ministry of Health and Care Services, 2009, 2015a). The formalization of an IP at an early stage of the disease can make the difficult negotiations in decision-making processes emerge more openly in collaborative teams. The IP aims for the patient to set personal and long-term goals for living with the disease and for caregivers to offer necessary information for decision-making processes and to facilitate measures to achieve goals (Holum, 2012). The patient can provide pre-consent, as emphasized in the IP for people with dementia, and the IP allows them to describe how they want to live their life with the disease, assign spokespersons and thus influence future decision-making processes (cf. The Norwegian Directorate of Health, 2015b).

Thus, the IP promises to address some of the particular conflicts that formal and family caregivers navigate in home-based care collaboration. However, article III demonstrates that the IP is not used for people with dementia in home-based care. As previously described, the non-use of an IP can be connected to the malignant positioning of the person with dementia, but as indicated in this tile of shared understanding of user involvement, non-use can also be connected to formal caregivers' overly narrow assessment of whom to involve in decision-making processes.

8.5 The tile of coordination

Norwegian healthcare goals state that each patient's trajectory should be integrated and coordinated and should be perceived as seamless across and within healthcare levels (Gjevjon, 2014). I have explored collaboration in home-based care in rural municipalities. Rural municipalities face challenges in regard to dispersed settlements and long distances in addition to demographic challenges that result in few staff members in healthcare services, which requires even more efficient collaboration to ensure acceptable quality of services and use of resources (The Norwegian Directorate of Health, 2016). Orvik (2015) defined coordination of healthcare work tasks as a prerequisite for collaboration and further suggested that coordination requires formalized decisions at the management level. Coordination as a prerequisite for

collaboration is similar within the analytical triad concepts of relational, informational and management continuity of care (cf. Reid et al., 2002).

In article III, most family caregivers called for IPs as a tool that could help to address the patient's bodily, psychological and social needs and could help family caregivers to be more involved and to ease their coordination work. Lack of resources led formal caregivers to prioritize the physical needs of the person with dementia as a form of "firefighting", as described in articles I and III. In addition, in article III the formal caregivers mostly reported informal conversations with family caregivers to decrease bureaucracy. NPM models, where the service level and the administrative level are separated, limit formal caregivers' scope to define and respond with measures on a discretionary basis. The resources to be allocated in each individual case must adhere to allocation procedures that do not directly engage with the patient or the family caregivers. The formal caregivers' storyline of "less bureaucracy" in article III suggests that formalized tools, such as the IP, to ensure documentation of coordination work are not implemented. Thus, the formal caregivers' rejection of the IP can be interpreted as a rejection of the unnecessary bureaucracy that follows NPM care services models. To ensure continuity, the formal caregivers stated their local knowledge, namely, the "local position" as a substitute strategy.

However, the lack of formalized meeting points for formal and family caregivers, rejections of requests for services pertaining to the patients, and refusal to initialize an IP sometimes led to conflicts in home-based care. Reporting conflicts, the formal caregivers adopted a subordinate and somewhat arbitrational position in articles I and III, where they had to balance efficiency demands, the patient's needs and the family caregivers' requests. Additionally, the formal caregivers in article III blamed management's low level of interest in formalizing routines for work tasks regarding information to and involvement of family caregivers as well as IP work.

Ultimately, they described these conflicts as connected to organizational constraints stemming from a lack of skilled staff, as presented in article II, and to economic reasoning, as presented in articles I and III. Such organizational constraints in home-based care may be a substantial barrier to collaboration between home and formal services.

One solution to the problem, namely, more money to primary healthcare, is well known. However, a recent government report (Ministry of Health and Care Services, 2015c) states that the solution cannot solely depend on money. It must also rely on highly competent managers who are given time to find creative ways to improve services, even with limited eco-

nomic resources. The political solution refers to dementia teams in each municipality (Ministry of Health and Care Services, 2015a), and Aasgaard et al. (2017) indicate in their study that person-centred dementia care could be realized with a skilled dementia team and organizational structure around the team that emphasizes a continuity of care approach. In this study, at the time of data construction the municipalities had scarcely initiated dementia teams, and some had not at all.

Family caregivers' experiences in home-based care services are important to achieve the political objective of postponing institutionalization. As discussed earlier, the tile of trust appears to be a prerequisite for relational continuity of care. However, few formalized coordination efforts to establish trust appear to be in place in home-based care. Another problem for relational continuity of care could refer to the family caregivers' challenges in finding their role, as presented in the 'insecure position' in article III. A lack of dialogue regarding the distribution of duties and rights among formal and family caregivers appeared to be part of the problem. Once again, there appears to be a lack of tools, formalized procedures and coordination of efforts to address relational issues that include family caregivers. This lack of coordination regarding how, when and with whom to pass and exchange information may in some sense result from the aforementioned tile of trust, necessity or shared understanding of entitlement but could also very well result from organizational constraints understood as the lack of skilled staff, economic means or formalized routines.

8.6 Concluding remarks and implications

Collaboration between home and formal healthcare services is a precondition for the fulfilment of several Norwegian healthcare policy strategies, and the overall aim of this dissertation was to explore and describe the social practice of collaboration between formal and family caregivers caring for people with dementia who live at home in multi-ethnic municipalities. I have based my interpretations on positioning theory, a theory of social interaction that focuses on conflicting negotiation processes (Van Langenhove & Harré, 1999a).

Few studies have explored collaboration between home and formal healthcare services (The Research Council of Norway, 2016). The result of this study presented through the articles and in the mosaic of collaboration developed in this thesis suggest several dynamic positions and distributions of duties and rights that can inhibit or enable collaboration and thus political and legal concepts such as user involvement, continuity of care and Sami rights.

Several official documents state the importance of improved collaboration between home and formal services in order to reduce family burden, postpone institutionalization and consequently reduce healthcare costs (Ministry of Health and Care Services, 2009, 2010a, 2013, 2015a, 2015b, 2015c). However, before policies and guidelines can be expected to work in action, any substantial barriers must be identified. This thesis indicates several barriers to collaboration among formal and family caregivers in home-based care pertaining to people with dementia. Bringing barriers to light is the first step towards any desired change.

The positions in the tile of trust concern the ethnic and ethno-political positions and the family and formal caregivers' positioning-pair of hidden helper-observer and spokesperson of the past-local position. Regardless of whether these positions hamper or enable collaboration, the implications of these findings are that trust-building policies and measures must be addressed. Some of the family caregivers' descriptions concerned stigma pertaining to people with dementia, and thus political strategies to reduce stigma are important because the utilization of formal support in home-based care appears to be affected. The concept of "a dementia friendly society" as referred to in the Dementia Strategy 2020 (Ministry of Health and Care Services, 2015a:15) and focus on person-centred care to reduce stigma and avoid marginalization of this group of patients may offer a pathway towards reducing distrust.

Ideally, if the aim to postpone institutionalization and to reduce family burden through increased and improved collaboration is to be reached, politicians and formal caregivers must promote the benefits of early intervention and make it easier to identify the range of services available to these patients. Additionally, because distrust is also connected to fear of slander the promotion of services must address formal caregivers' adherence to confidentiality. Hence, family caregivers may experience a need for collaboration in an early phase after the symptoms of the disease occur. The political effort to implement primary health service provider preventive home visits for all persons over 70 can thus be a start for promotion (cf. Ministry of Health and Care Services, 2016b).

However, a serious barrier to trust and the perception of necessity in this study appears to be ethnic and in particular ethno-political positions. As ethnic affiliation is debated in home-based care and even conflicting when the determination of ethnic affiliation is connected to specific rights, the implications of these findings suggest that official documents discuss not only problems that concern ethnic affiliation but also the more specific ethno-political position. Formal caregivers, managers or politicians who emphasize minority rights or cultural facilitation appear to overlook the complexity and dynamics involved in ethnic positions and

the ethno-political conflicts that challenge the mind-set of equality and reinforce stereotyped positions. A broader discussion of these problems could result in tools or guidelines to safeguard the Sami population's rights as well as aim to reduce conflicts in practice. The division between the ethnic and ethno-political positions as suggested in this thesis can serve as a starting point for dialogue.

The positions in the tile of necessity concerned positioning of the patient as confused, rational or in danger, in addition to the formal caregivers' "expert" positions that established family caregivers as "disregarded", and finally the positioning pair of public helper-formal helper who guides the family as a result of a family caregiver breakdown. All positions influenced the caregivers' experiences of the necessity of collaboration and thus influenced whether collaboration processes were initiated and maintained. The findings in this thesis suggest that a paternalistic perspective still lingers in practice, resulting in positioning of the family caregivers that inhibits collaboration.

The tile of shared understanding of user involvement concerns decision-making processes. I indicated an "involvement gap" with regard to family caregivers through the spokesperson and disregarded positions. The involvement gap is connected to the patient's consent. To reduce the barrier, formal caregivers should assess in varying situations whether the partnership model as described by Heaton et al. (2012) may be more appropriate. Additionally, the family caregivers' duties and rights in care must be discussed more broadly in society. Family caregivers have no legal duties to perform caregiving work for patients; however, they appear to experience a normative duty of great importance regarding how formal services are practised. In this thesis, I do not advocate for the removal of such normative obligations; however, as presented in articles I and III the family caregivers' own rights must be discussed.

A 'paradigm shift' regarding whose perspective to acknowledge would depend among others on formal caregivers' willingness and their awareness of such a barrier and on allocation of time and resources in home-based care practice. Thus, there is a need to address the boundaries of "de jure" and "de facto" consent in healthcare when the symptoms of disease make decision-making processes challenging. In particular, the discourse of entitlement regarding user involvement in dementia care practice must reach intermediate-level organizational planning and macro-level policy planning (cf. Tritter & McCallum, 2006) if conflicts in collaboration among caregivers are to be reduced and the patient's legal rights to user involvement and IP are to be met.

The tile of coordination concerns positioning connected to organizational constraints such as the spokesperson and subordinate positions. Implications of these findings suggest the need for more formalized routines for providing oral and written information to family caregivers, and families should have the option to identify a primary caregiver as a main contact for frequent communication. Formal caregivers' discretion depends on their interpretations of information regarding situations, norms and possible actions (cf. Molander et al., 2012), and thus they must have time to reflect on their own and others' positions in collaborative practice and discuss specific expectations regarding information flow, involvement and care responsibilities with family caregivers.

From the perspective of positioning theory, barriers will change in a dynamic and fluctuating health practice. Formal caregivers' own search for updated knowledge and the need for reflective dialogue in co-working teams and with service users is the most important response. Formal caregivers, particularly managers, are responsible for initiating these types of reflective practice. This thesis offers descriptions and an explanatory model of conceptual generalizability of formal and family caregiver positioning in home-based care that can be recognized by others. Thus, some findings may contribute to formal caregivers' reworking of some parts of the healthcare practice and to policy makers' development of more appropriate healthcare strategies.

8.6.1 Further research suggestions

I suggest further research to fill out the mosaic tiles of collaboration in healthcare. One tile could concern gender. The family caregivers in this thesis were all women. Based on research showing variation in the home-based care services offered to women and men (cf. Berge et al., 2014) and the idea of men as an "untapped resource" in home-based dementia care (cf. Ministry of Health and Care Services, 2013), retrospectively, I find the question of gender of particular interest in terms of further research. Another interesting question involves the possible impact of patients' and caregivers' gender on decision-making processes pertaining to dementia care.

Another research field of note is the lack of use of IPs. However, the Dementia Strategy 2020 heavily emphasized the aim of implementing IPs for people with dementia (cf. Ministry of Health and Care Services, 2015a). Thus, a follow-up to the implications of the strengthened political emphasis on IP could be interesting.

Previous studies have shown that 25% of all people with dementia receive formal home-based care services in Norway. The barriers to collaboration that I suggest in this study may be important also to those who do not receive services. Consequently, there is a need for more knowledge regarding why some people with dementia do not receive home-based care and how this affects their family caregivers, which implies a different and far broader recruitment strategy.

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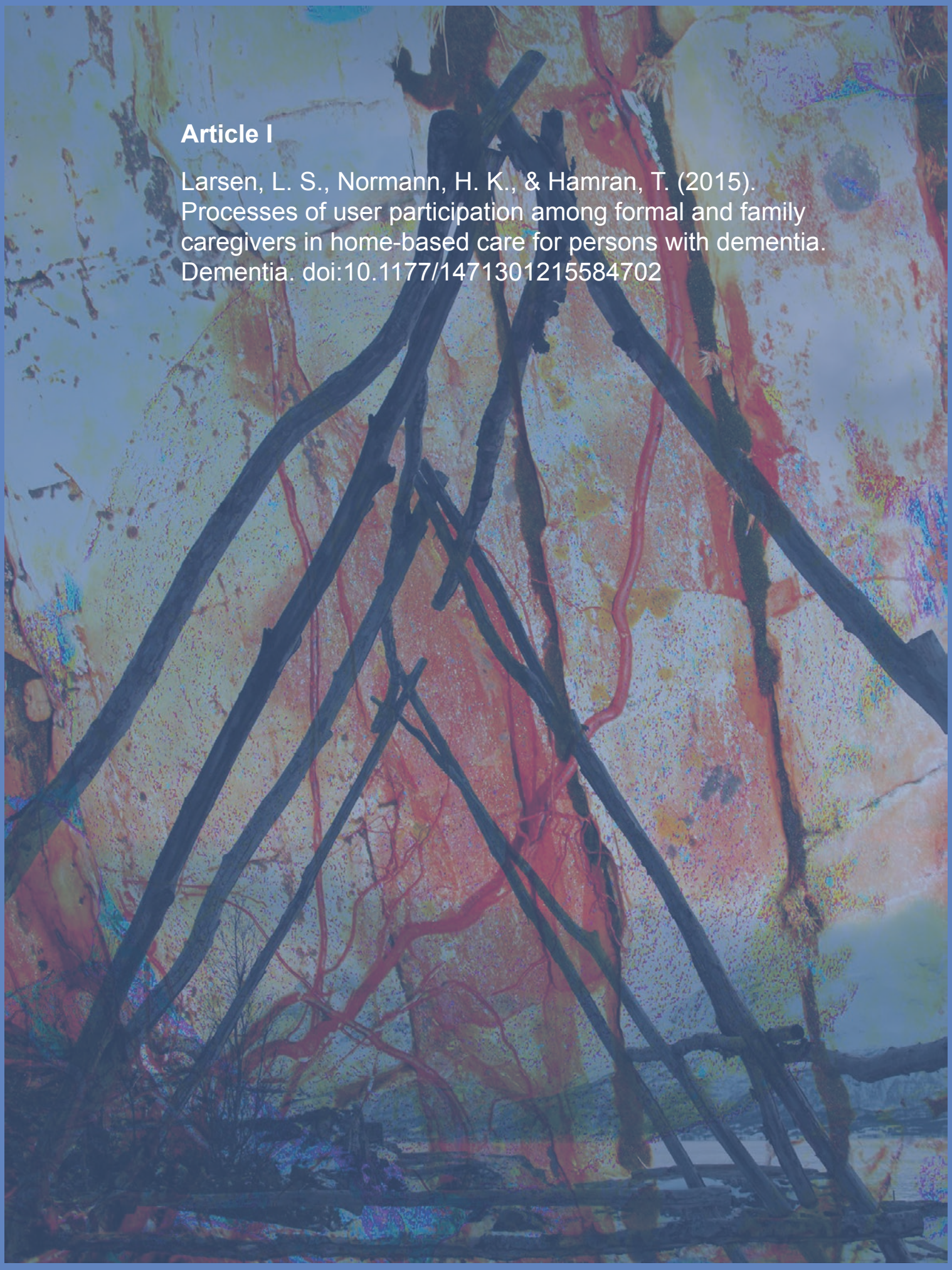
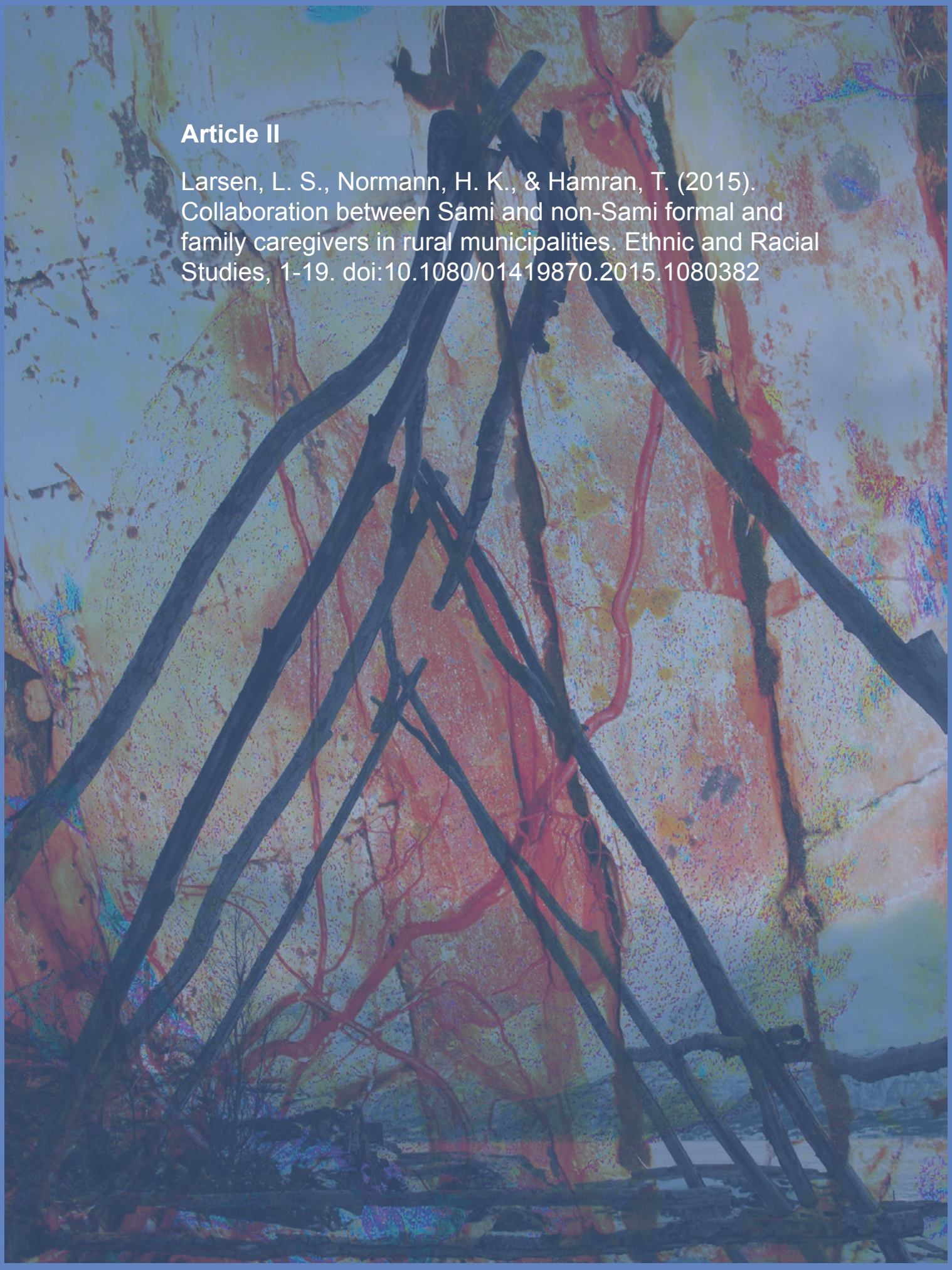


Article I

Larsen, L. S., Normann, H. K., & Hamran, T. (2015). Processes of user participation among formal and family caregivers in home-based care for persons with dementia. Dementia. doi:10.1177/14713012155847O2



Article II

Larsen, L. S., Normann, H. K., & Hamran, T. (2015). Collaboration between Sami and non-Sami formal and family caregivers in rural municipalities. Ethnic and Racial Studies, 1-19. doi:10.1080/01419870.2015.1080382

Article III

Larsen, L.S., H.K. Normann and Hamran, T. (2016). Continuity of home-based care for persons with dementia from formal and family caregivers' perspective. Dementia. doi:10.1177/147130121668826

APPENDIX 1

Decision Regional Committee for Medical and Health Research Ethics

REK
REGIONALE KOMITEER FOR MEDISINSK OG HELSEFAGLIG FORSKNINGSETIKK

Region:	Saksbehandler:	Telefon:	Vår dato:	Vår referanse:
REK nord	Veronica Sørensen	77620758	26.11.2012	2012/2067/REK nord
			Deres dato:	**Deres referanse:**
			20.11.2012	

Vår referanse må oppgis ved alle henvendelser

Lill Sverresdatter Larsen
Universitetssykehuset Tromsø

Framleggingsplikt

De prosjektene som skal framlegges for REK er prosjekt som dreier seg om "medisinsk og helsefaglig forskning på mennesker, humant biologisk materiale eller helseopplysninger", jf. helseforskningsloven (h) § 2. "Medisinsk og helsefaglig forskning" er i h § 4 a) definert som "virksomhet som utføres med vitenskapelig metodikk for å skaffe til veie ny kunnskap om helse og sykdom". Det er altså formålet med studien som avgjør om et prosjekt skal anses som framleggelsespliktig for REK eller ikke.

I dette prosjektet er formålet å øke kunnskapsgrunnlaget om arbeidsprosesser knyttet til samhandling og koordinering av arbeidsoppgaver i samiske forvaltningsområder, samt å kartlegge hvilken grad de nærstående til pasienter med demenssykdom opplever å ha rettigheter som innflytelse og brukermedvirkning. Opplysningene som skal samles inn er knyttet til prosesser, samhandling og brukermedvirkning, ikke helseopplysninger. REK kan ikke se at dette er egnet til å fremskaffe ny viten om helse og sykdom som sådan, prosjektet skal således ikke vurderes etter helseforskningsloven.

Det opplyses i fremleggingsvurderingen at det skal gjøres obesrvasjoner. REK forutsetter at helsepersonells lovpålagte taushetsplikt overholdes også i disse situasjonene. Dersom dette skal fravikes må det primært innhentes samtykke til dette, eller dersom det er vanskelig eller umulig så må det søkes om dispensasjon fra taushetsplikten. REK er tillagt oppgaven med å gi slike dispensasjoner også i prosjekt som ellers faller utenfor helseforskningsloven.

Vedtak
Etter søknaden fremstår prosjektet ikke som et medisinsk og helsefaglig forskningsprosjekt som faller innenfor helseforskningsloven. Prosjektet er ikke fremleggingspliktig, jf. helseforskningslovens § 10, jf. forskningsetikkloven § 4, 2. ledd.

Klageadgang
Du kan klage på komiteens vedtak, jf. helseforskningslovens §10,3 ledd og forvaltningslovens § 28 flg. Klagen sendes til REK nord. Klagefristen er tre uker fra du mottar dette e- brevet. Dersom vedtaket opprettholdes av REK nord, sendes klagen videre til Den nasjonale forskningsetiske komité for medisin og helsefag for endelig vurdering.

Vi ber om at tilbakemeldinger til komiteen og prosjektendringer sendes inn på skjema via vår saksportal: http://helseforskning.etikkom.no.

Øvrige henvendelser sendes på e-post til post@helseforskning.etikkom.no.

Vi ber om at en eventuell klage sendes inn på skjema via vår saksportal: http://helseforskning.etikkom.no

Vennligst oppgi vårt referansenummer i korrespondansen.

Med vennlig hilsen

May Britt Rossvoll

Veronica Sørensen
rådgiver

Kopi til:

APPENDIX 2

Norsk samfunnsvitenskapelig datatjeneste AS
NORWEGIAN SOCIAL SCIENCE DATA SERVICES

Harald Hårfagres gate 29
N-5007 Bergen
Norway
Tel: +47-55 58 21 17
Fax: +47-55 58 96 50
nsd@nsd.uib.no
www.nsd.uib.no
Org.nr: 985 321 884

Lill Sverresdatter Larsen
Institutt for helse- og omsorgsfag
Universitetet i Tromsø
MH-bygget
9037 TROMSØ

Vår dato: 23.11.2012 Vår ref:32173 / 3 / LMR Deres dato: Deres ref:

TILBAKEMELDING PÅ MELDING OM BEHANDLING AV PERSONOPPLYSNINGER

Vi viser til melding om behandling av personopplysninger, mottatt 20.11.2012. Meldingen gjelder prosjektet:

32173	*Samhandling og brukermedvirkning i samisk forvaltningsområde til hjemmeboende eldre som har demenssykdom*
Behandlingsansvarlig	*Universitetet i Tromsø, ved institusjonens øverste leder*
Daglig ansvarlig	*Lill Sverresdatter Larsen*

Personvernombudet har vurdert prosjektet og finner at behandlingen av personopplysninger er meldepliktig i henhold til personopplysningsloven § 31. Behandlingen tilfredsstiller kravene i personopplysningsloven.

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

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

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

Personvernombudet vil ved prosjektets avslutning, 31.10.2016, rette en henvendelse angående status for behandlingen av personopplysninger.

Vennlig hilsen

Bjørn Henrichsen

Linn-Merethe Rød

Linn-Merethe Rød tlf: 55 58 89 11
Vedlegg: Prosjektvurdering

Personvernombudet for forskning

Prosjektvurdering - Kommentar

Prosjektnr: 32173

Utvalget består av fagpersoner og nærstående til pasienter med demenssykdom. Data samles inn via personlig intervju/gruppeintervju og observasjon ved fagmøter.

Ombudet legger til grunn at taushetsplikten til fagpersonene ikke er til hinder, også ved observasjon ved fagmøter. Det anbefales at prosjektleder minner fagpersonell om sin taushetsplikt overfor forsker, i forkant av intervju/observasjon.

Førstegangskontakt foretas via ledelsen/kontaktpersoner ved helseforetak. De som ønsker å delta i intervju, tar direkte kontakt med prosjektleder. Det innhentes skriftlig samtykke basert på skriftlig informasjon om prosjektet og behandling av personopplysninger. Personvernombudet finner informasjonsskrivene tilfredsstillende utformet i henhold til personopplysningslovens vilkår.

Ifølge prosjektmeldingen skal prosjektet avsluttes 31.10.2016 og innsamlede opplysninger skal da anonymiseres og lydopptak slettes. Anonymisering innebærer at direkte personidentifiserende opplysninger som navn/koblingsnøkkel slettes, og at indirekte personidentifiserende opplysninger (sammenstilling av bakgrunnsopplysninger som f.eks. yrke, alder, kjønn) fjernes eller grovkategoriseres slik at ingen enkeltpersoner kan gjenkjennes i materialet.

APPENDIX 3


Approval of project changes Norwegian Centre
for Research Data

Fra:	Ida Jansen Jondahl
Til:	Lill Sverresdatter Larsen
Emne:	Prosjektnr: 32173. Samhandling og brukermedvirkning i samisk forvaltningsområde til hjemmeboende eldre som har demenssykdom
Dato:	22. februar 2017 12:32:38

BEKREFTELSE PÅ ENDRING

Viser til e-post registrert hos personvernombudet 22.02.2017.

Vi har nå registrert ny dato for prosjektslutt og anonymisering 30.11.2017.

Dersom det er aktuelt med ytterligere utsettelse etter dette, minner vi om at når personopplysninger skal behandles mer enn 1 år utover det som utvalget er informert om, er det vanlig praksis å informere utvalget om den videre behandlingen. Utvalget bør på ny få informasjon om at det er frivillig å delta og gis mulighet til å trekke seg fra behandlingen av personopplysninger.

Personvernombudet forutsetter at prosjektopplegget for øvrig gjennomføres i tråd med det som tidligere er innmeldt, og personvernombudets tilbakemeldinger. Vi vil ta ny kontakt ved prosjektslutt.

Vennlig hilsen

--
Ida Jansen Jondahl
Seniorrådgiver | Senior Adviser
Seksjon for personverntjenester | Data Protection Services
T: (+47) 55 58 30 19

NSD – Norsk senter for forskningsdata AS | NSD – Norwegian Centre for Research Data
Harald Hårfagres gate 29, NO-5007 Bergen
T: (+47) 55 58 21 17
postmottak@nsd.no www.nsd.no

APPENDIX 4

UNIVERSITETET I TROMSØ UiT

DET HELSEVITENSKAPELIGE FAKULTET
INSTITUTT FOR HELSE- OG OMSORGSFAG

Dato: 12.11.2012

Enhetsleder/Avdelingsleder

Forespørsel om datainnsamling til forskningsprosjekt

Ansvarlig prosjektleder: Professor Torunn Hamran

Prosjektmedarbeider: Stipendiat Lill Sverresdatter Larsen

Forskningsansvarlig: Senter for omsorgsforskning, Institutt for helse- og omsorgsfag, Det helsevitenskapelige fakultet, Universitetet i Tromsø.

Prosjektets varighet: oktober 2012 – september 2016

Jeg viser til muntlig kontakt om prosjektet. Vår forespørsel gjelder tillatelse til å gjennomføre individuelle intervju, gruppeintervju i tillegg til å delta som observatør på enkelte kontaktpunkter/møter i koordinerende team, demensteam eller liknende. Forespørselen gjelder forskningsprosjektet *«Samhandling og brukermedvirkning i samisk forvaltningsområde til hjemmeboende eldre som har demenssykdom»*. Henvendelse om intervju vil bli rettet til representanter for ulike yrkesgrupper som har tilknytning til kommunehelsetjenesten/spesialisthelsetjenesten i tre utvalgte kommuner i ulike fylker. Intervjuene vil foregå i den enkelte kommune, bli tatt opp på lydbånd og senere skrevet ut. Alle opplysninger vil bli behandlet konfidensielt og alle persondata anonymisert ved publisering. Prosjektet er meldt til Personvernombudet for forskning, Norsk samfunnsvitenskapelig datatjeneste. Se vedlegg – *«Forespørsel om deltakelse i forskningsprosjekt»* for ytterligere detaljer eller ta kontakt med undertegnede.

Din tillatelse gir du ved å sende epost til undertegnende med deres bekreftelse på mottatt informasjon og tillatelse til å gjøre studiens datainnsamling.

Vennlig hilsen

Lill Sverresdatter Larsen
Stipendiat
Telefon: +47 913 74037
Epost: lill.sverresdatter.larsen@uit.no

Vedlegg: «Forespørsel om deltakelse i forskningsprosjekt»

APPENDIX 5

UNIVERSITETET I TROMSØ UiT

DET HELSEVITENSKAPELIGE FAKULTET
INSTITUTT FOR HELSE- OG OMSORGSFAG

Til mulige kontaktpersoner

Dato: 12.11.2012

Forespørsel til fagperson om formidling av forskningsprosjekt.

Ansvarlig prosjektleder: Professor Torunn Hamran

Prosjektmedarbeider: Stipendiat Lill Sverresdatter Larsen

Forskningsansvarlig: Senter for omsorgsforskning, Institutt for helse- og omsorgsfag, Det helsevitenskapelige fakultet, Universitetet i Tromsø.

Prosjektets varighet: oktober 2012 – september 2016

Jeg viser til muntlig kontakt om prosjektet. Vår forespørsel gjelder hjelp til å komme i kontakt med mulige deltaker til prosjektet. Vi har innhentet tillatelse fra din leder til å gjennomføre individuelle intervju, gruppeintervju i tillegg til å delta som observatør på enkelte kontaktpunkter/møter i koordinerende team, demensteam eller liknende. Forespørselen gjelder forskningsprosjektet *«Samhandling og brukermedvirkning i samisk forvaltningsområde til hjemmeboende eldre som har demenssykdom»*. Henvendelse om intervju vil bli rettet til representanter for ulike yrkesgrupper som har tilknytning til kommunehelsetjenesten/spesialisthelsetjenesten, i tillegg til nærstående til personer med demenssykdom i tre utvalgte kommuner i ulike fylker. Intervjuene vil foregå i den enkelte kommune, bli tatt opp på lydbånd og senere skrevet ut. Alle opplysninger vil bli behandlet konfidensielt og alle persondata anonymisert ved publisering. Prosjektet er meldt til Personvernombudet for forskning, Norsk samfunnsvitenskapelig datatjeneste.

Jeg trenger din hjelp til å dele ut de to ulike vedlagte skjemaene:

- Til åtte personer som er nærstående til pasient med demenssykdom.
- Til åtte personer som er tilknyttet demensteam, koordinerende team eller på annet vis er fagpersoner i nært arbeid knyttet til personer med demenssykdom som bor hjemme. Fagpersoner kan være eksempelvis lege, sykepleier, fysioterapeut, ergoterapeut, sosionom eller andre.

De som kan delta bes om å gi sitt samtykke gjennom å signere og returnere vedlagte skjema i vedlagte ferdigfrankerte konvolutt. Jeg vil så ta direkte kontakt med deltakerne som har sagt seg villig. De tre-fem første som gir sitt samtykke vil bli inkludert i studien. Det ville vært fint om du også informerer om at din rolle er å gjøre studien kjent for deltakerne, men at du ikke vil kunne vite hvem som har sagt seg villig til å delta, eller følge studien videre. Se vedlegg – *«Forespørsel om deltakelse i forskningsprosjekt»* for ytterligere detaljer eller ta kontakt med undertegnede.

NO-9037 Tromsø • postmottak@uit.no • http://uit.no • Sentralbord: 77 64 40 00 • Faks: 77 64 49 00
Stipendiat Lill Sverresdatter Larsen • lill.sverresdatter.larsen@uit.no • Tlf 77 62 51 12
Professor Torunn Hamran • torunn.hamran@uit.no • Tlf 77 64 48 58

Kriterier for deltakelse

Deltakere velges ut etter følgende kriterier:

A)

- Nærstående til pasient over 60 år som har fått diagnostisert demenssykdom.
- Bosted i samisk forvaltningsområde.

Det er ikke et krav, men er en fordel om deltakerne identifiserer seg med samisk etnisitet.

B)

- Fagpersoner med rolle knyttet til diagnostisering og oppfølging av hjemmeboende, eldre personer med demenssykdom. Typiske roller er lege, sykepleier, fysioterapeut, ergoterapeut, sosionom, hjelpepleier, deltaker i koordinerende team eller demensteam.
- Arbeidsted i samisk forvaltningsområde-

Om du **ikke** kan hjelpe meg med dette ber jeg om tilbakemelding snarest.

På forhånd tusen takk for hjelpen,

Lill Sissel Larsen
Stipendiat
Telefon: +47 913 74037
Epost: lill.sverresdatter.larsen@uit.no

Vedlegg:

«Forespørsel om deltakelse i forskningsprosjekt – nærstående»

«Forespørsel om deltakelse i forskningsprosjekt – fagperson»

APPENDIX 6

Information letter and consent form – formal caregiver

UNIVERSITETET I TROMSØ UiT

DET HELSEVITENSKAPELIGE FAKULTET
INSTITUTT FOR HELSE- OG OMSORGSFAG

Dato: 12.11.2012

Fagperson med rolle knyttet til diagnostisering og oppfølging av eldre hjemmeboende med demenssykdom

Forespørsel om deltakelse i forskningsprosjekt

Ansvarlig prosjektleder: Professor Torunn Hamran

Prosjektmedarbeider: Stipendiat Lill Sverresdatter Larsen

Forskningsansvarlig: Senter for omsorgsforskning, Institutt for helse- og omsorgsfag, Det helsevitenskapelige fakultet, Universitetet i Tromsø.

Prosjektets varighet: oktober 2012 – september 2016

Bakgrunn og hensikt

Dette er et spørsmål til deg om å delta i en forskningsstudie. Din deltakelse kan bidra til å fremme kunnskap om oppfølging av hjemmeboende eldre som har demenssykdom og er bosatt i samiske forvaltningsområder. På sikt kan dette bidra til å synliggjøre behov og å forbedre oppfølging av personer med demenssykdom og deres nærstående.

Du forespørres fordi du har en rolle som fagperson knyttet til diagnostisering eller oppfølging av hjemmeboende eldre som har en demenssykdom.

Utgangspunktet for studien er at vi lever lengre i dag enn tidligere, og på grunn av demografiske forhold og økt levealder vil flere utvikle demenssykdom. Pasienter har rett til medvirkning når det kommer til utforming av egen helsehjelp, og pasienter med demens er en særlig sårbar gruppe. Gjennom denne studien ønsker vi å undersøke Gjennom denne studien ønsker vi å undersøke oppfølgingen av pasienter som har demenssykdom. Hvem vurderer hvilke behov pasienten har, hvem koordinerer og igangsetter nødvendige tiltak?

Kriterier for deltakelse

Deltakere velges ut etter følgende kriterier:

- Fagperson som lege, pleier, fysioterapeut, ergoterapeut, sosionom eller annen yrkesgruppe, deltaker i koordinerende team eller demensteam.
- Arbeidssted i samisk forvaltningsområde
- Rolle knyttet til diagnostisering og oppfølging av pasienter med demenssykdom

Hva innebærer studien?

Studien innebærer intervju på rundt 1 time, enten alene eller sammen med andre i gruppe. Digital taleopptaker kan bli benyttet og avtales nærmere i hvert enkelt tilfelle. Det kan også være aktuelt at jeg deltar i aktuelle møter som du allerede deltar på sammen med andre fagpersoner. Du mottar dette informasjonsbrevet gjennom din leder eller annen kontaktperson som kjenner til din rolle som fagperson. Din leder har tillatt gjennomføring av forskningsprosjektet. Formidleren av denne konvolutten kan ikke på noen måte få kjennskap til om du deltar i studien eller ikke. Samtykke gir du

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Stipendiat Lill Sverresdatter Larsen • lill.sverresdatter.larsen@uit.no • Tlf 77 62 51 12
Professor Torunn Hamran • torunn.hamran@uit.no • Tlf 77 64 48 58

ved å returnere samtykkeskjema i signert form i vedlagte ferdigfrankerte konvolutt. Du kan også ta kontakt direkte med Sverresdatter Larsen på telefon eller epost om noe er uklart. Dersom du ikke ønsker å delta i studien trenger du ikke gjøre noe.

Mulige fordeler og ulemper

Deltakelse i studien vil kreve tid til intervju, men ingen ekstra utgifter for deg. Deltakelse er ikke forventet å skape ubehag. Om du opplever ubehag er det viktig at du gir intervjueren informasjon om dette slik at vi kan ta pauser eller på annet vis hjelpe deg. Deltakelse i studien kan på sikt bidra til å videreutvikle hensiktsmessige rutiner innad i kommunehelsetjenesten, og mellom kommunehelsetjenesten og spesialisthelsetjenesten med tanke på oppfølging av hjemmeboende eldre som har en demenssykdom.

Hva skjer med informasjonen om deg?

Opplysninger som registreres om deg er informasjon fra intervju og notater prosjektmedarbeider eller leder gjør underveis. I tillegg vil det kunne være digitale opptak fra intervju. Studien er innmeldt til Norsk Samfunnsvitenskapelig datatjeneste (NSD). Følgende autorisert personell vil være knyttet til prosjektet og ha tilgang til opplysninger om deg:

- Prosjektleder og stipendiat *Lill Sverresdatter Larsen*, Institutt for helse- og omsorgsfag, UiT.
- Professor *Torunn Hamran*, Institutt for helse- og omsorgsfag, UiT.
- Professor *Hans Ketil Normann*, Institutt for helse- og omsorgsfag, UiT.

Det legges opp til å utveksle forskningsresultater med medlemmer flerfaglig forskningsgruppe for helse- og omsorgsforskning/Senter for omsorgsforskning. Resultater som utveksles vil bearbeides slik at det ikke er mulig å knytte opplysninger til personer. Datainnsamling til prosjektet er planlagt avsluttet ved utgang desember 2013. Alle opptak, notater og personopplysninger vil bli slettet etter at data er analysert og resultatene fra prosjektet publisert i vitenskapelige artikler, planlagt innen oktober 2016.

Informasjonen som registreres om deg skal kun brukes slik som beskrevet i hensikten med studien. Alle opplysningene vil bli behandlet uten navn og fødselsnummer eller andre direkte gjenkjennende opplysninger.

Det vil ikke være mulig å identifisere deg i resultatene av studien når disse publiseres.

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Stipendiat Lill Sverresdatter Larsen • lill.sverresdatter.larsen@uit.no • Tlf 77 62 51 12
Professor Torunn Hamran • torunn.hamran@uit.no • Tlf 77 64 48 58

Frivillig deltakelse
Det er frivillig å delta i studien. Dersom du ønsker å delta, undertegner du samtykkeerklæringen på siste side. Du kan uten å oppgi grunn trekke deg fra studien, med mindre opplysningene allerede er inngått i analyser eller brukt i vitenskapelige publikasjoner. Dette vil ikke få noen konsekvenser for deg. Dersom du ønsker mer informasjon eller har spørsmål til studien, kan du kontakte:

Lill Sverresdatter Larsen

Telefon: +47 913 74037

Epost: lill.sverresdatter.larsen@uit.no

Adresse: Lill Sverresdatter Larsen

Fakultet for helsevitenskap

Institutt for helse- og omsorgsfag

Universitetet i Tromsø

9037 Tromsø

Dersom du ønsker å delta i studien – vær vennlig å returnere underskrevet samtykkeerklæring, som du finner på siste side, i vedlagte ferdig frankerte konvolutt, samt at du beholder et eksemplar selv.

Du vil deretter kontaktes snarlig for videre avtale om tidspunkt for intervju.

Samtykke til deltakelse i studien

Jeg har mottatt skriftlig (og eventuelt muntlig) informasjon og er villig til å delta i studien *«Samhandling og brukermedvirkning i samisk forvaltningsområde til hjemmeboende eldre som har demenssykdom».*

Navn:_____

Telefonnummer:_____

Epostadresse:_____

Rolle:_____

(Nærstående, fagperson med tittel)

_____

(Signert av prosjektdeltaker, dato)

Jeg bekrefter å ha gitt informasjon om studien

_____

(Signert prosjektleder 05.12.12)

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Professor Torunn Hamran • torunn.hamran@uit.no • Tlf 77 64 48 58

APPENDIX 7

Semi-structured interview guide – formal caregiver

UNIVERSITETET I TROMSØ UiT

DET HELSEVITENSKAPELIGE FAKULTET
INSTITUTT FOR HELSE- OG OMSORGSFAG

Eksempel intervjuguide fagperson

Introduksjon

Presentasjon og rolleavklaring. Informere kort om intervju og gi mulighet til å trekke seg også her. Intervjuet handler om prosessene du har deltatt i knyttet til diagnostisering og oppfølging i etterkant av pasienters demensdiagnose.

Siden vi tenker at dette kan bidra til å forbedre helse- og omsorgstjenesten, er det viktig for oss å få tak i både de positive og de negative erfaringene dere gjorde dere. Vi ønsker å få en mest mulig riktig forståelse av dine erfaringer, og for å få det til kan det hende spørsmålene virker inngående eller unødvendig. Jeg ber deg gi meg beskjed om du ønsker en pause i intervjuet.

Alle opplysninger som gjør det mulig å identifisere deg og pasientene vil bli tatt bort i studien. Vi vil også understreke at intervjuet ikke skal brukes som en vurdering av deres arbeid her, men av behandlingstilbudet generelt.

Er det noe dere lurer på? Si fra om du vil ha pauser underveis. Intervjuet vil ta rundt 1 time.

Kontakt ved diagnostisering:

- **Kan du fortelle om din rolle tilknyttet diagnostisering av personer med demenssykdom eller i etterkant av at en pasient har fått diagnose demens.**
  - Hvem snakker med hvem (både individ og organisasjon)
  - Hva skjer etter at NN har fått diagnosen?
  - Hvilken kontakt er med nærstående?
  - (Hvilke ord blir benyttet om pasient?)
  - Særlige utfordringer innenfor samisk forvaltningsområder?
  - Hvilke lovverk, rutiner, forskrifter, muntlige og skriftlige retningslinjer arbeider du etter?
- **Hva mener du er kvalitet i helsetjenesten knyttet til individuell plan?**
  - Hva mener du om å skriftliggjøre NNs behov i et planverktøy?
  - Hvilke yrkesgrupper er viktige å ha med?
  - Opplæring
  - Tidsbruk
  - Prioritering
- **Har du vært delaktig i implementering av IP til noen pasienter?**
  - Hvordan ser du på dette verktøyet?
  - Fra hvem fikk du kjennskap og informasjon om IP?
  - Hvilke forventninger hadde du?
  - Når startet det opp og cirka hvor lenge det har vært brukt, hvor ofte møter? Fast struktur – hvilke roller hadde de som deltok?
  - Hva synes du dere får til gjennom å benytte et slikt verktøy?
  - Er det andre metoder eller personer som heller kunne vært brukt?
  - Hvem opplever du at du kan kontakte om det er noe du tenker på/lurer på i etterkant?
-

Aksept, mestring og kunnskap

- **Er det hendelser hvor du opplever det har vært gitt særlig støtte til pasienten eller hans/hennes nærstående i etterkant av diagnosen?**

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Professor Torunn Hamran • torunn.hamran@uit.no • Tlf 77 64 48 58

  - Noen spesielle yrkesgrupper?
  - Fikk NN det bedre og hva gjorde de/du?
  - Ble dette dokumentert?
- **Er det episoder du har reagert på, noe du skulle ønske hadde vært annerledes?**
  - Er det noen som vet at du opplever det slik?
  - Har du erfart noen konflikter mellom deg og pasient eller deg og andre hjelpere?

Tanker om hva som hjelper

- **Hva ser du for deg er den beste metoden for å håndtere NNs behov i framtiden?**
  - Hva trenger du?
  - Hva mener du NN trenger av hjelp?
  - Hvor finnes denne hjelpen?
  - Til hvem henvender du deg for hjelp?
  - Hva mener du om lovverket/rutinene/verktøyet som er knyttet til individuell plan?
  - Er det noe annet du mener kan ha betydning for at NN og hans familie skal ha det så godt som mulig til tross for sykdommen?
  - Hva tenker du skal til for at NN skal kunne bo og fungere hjemme lengst mulig?
  - Hvis du skulle gitt et råd til andre som kommer i en liknende situasjon – hva ville det vært?

APPENDIX 8

Information letter and consent form – family caregiver

UNIVERSITETET I TROMSØ UiT

DET HELSEVITENSKAPELIGE FAKULTET
INSTITUTT FOR HELSE- OG OMSORGSFAG

Dato: 12.11.2012

Nærstående til hjemmeboende eldre med demenssykdom

Forespørsel om deltakelse i forskningsprosjekt

Ansvarlig prosjektleder: Professor Torunn Hamran

Prosjektmedarbeider: Stipendiat Lill Sverresdatter Larsen

Forskningsansvarlig: Senter for omsorgsforskning, Institutt for helse- og omsorgsfag, Det helsevitenskapelige fakultet, Universitetet i Tromsø.

Prosjektets varighet: oktober 2012 – september 2016

Bakgrunn og hensikt

Dette er et spørsmål til deg om å delta i en forskningsstudie. Din deltakelse kan bidra til å fremme kunnskap om oppfølging av hjemmeboende eldre som har demenssykdom og er bosatt i samiske forvaltningsområder. På sikt kan dette bidra til å synliggjøre behov og å forbedre oppfølging av personer med demenssykdom og deres nærstående.

Du forespørres fordi du er vurdert eller kjent som nærstående til pasient med demenssykdom.

Utgangspunktet for studien er at vi lever lengre i dag enn tidligere, og på grunn av demografiske forhold og økt levealder vil flere utvikle demenssykdom. Pasienter har rett til medvirkning når det kommer til utforming av egen helsehjelp, og pasienter med demens er en særlig sårbar gruppe. Gjennom denne studien ønsker vi å undersøke i hvilken grad erfarer nærstående rettigheter som innflytelse og brukermedvirkning og hvordan kommer dette til uttrykk i oppfølgingen av pasient med demenssykdom og dens familie.

Kriterier for deltakelse

Deltakere velges ut etter følgende kriterier:

- Nærstående til pasient over 60 år som har fått diagnostisert demenssykdom
- Bosted i kommune i samisk forvaltningsområde

Ikke et kriterium, men er fordelaktig med personer som identifiserer seg med samisk etnisitet.

Hva innebærer studien?

Studien innebærer intervju på rundt 1 time, enten alene eller sammen med andre i gruppe. Digital taleopptaker kan bli benyttet og avtales nærmere i hvert enkelt tilfelle. Du mottar dette informasjonsbrevet av en som kjenner til deg og din rolle som nærstående til en pasient med demenssykdom. Før du gir ditt samtykke kjenner ikke vi til ditt navn, og formidleren av denne konvolutten kan ikke på noen måte få kjennskap til om du deltar i studien eller ikke. Samtykke gir du ved å returnere samtykkeskjema i signert form i vedlagte ferdigfrankerte konvolutt. Du kan også ta

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Professor Torunn Hamran • torunn.hamran@uit.no • Tlf 77 64 48 58

kontakt direkte med Sverresdatter Larsen på telefon eller epost om noe er uklart. Dersom du ikke ønsker å delta i studien trenger du ikke gjøre noe.

Mulige fordeler og ulemper

Deltakelse i studien vil kreve tid til intervju, men ingen ekstra utgifter for deg. Deltakelse er ikke forventet å skape ubehag. Om du opplever ubehag er det viktig at du gir intervjueren informasjon om dette slik at vi kan ta pauser eller på annet vis hjelpe deg. Deltakelse i studien kan på sikt bidra til å videreutvikle hensiktsmessige rutiner innad i kommunehelsetjenesten, og mellom kommunehelsetjenesten og spesialisthelsetjenesten med tanke på oppfølging av hjemmeboende eldre som har en demenssykdom.

Hva skjer med informasjonen om deg?

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- Prosjektleder og stipendiat *Lill Sverresdatter Larsen*, Institutt for helse- og omsorgsfag, UiT.
- Professor *Torunn Hamran*, Institutt for helse- og omsorgsfag, UiT.
- Professor *Hans Ketil Normann*, Institutt for helse- og omsorgsfag, UiT.

Det legges opp til å utveksle forskningsresultater med medlemmer flerfaglig forskningsgruppe for helse- og omsorgsforskning/Senter for omsorgsforskning. Resultater som utveksles vil bearbeides slik at det ikke er mulig å knytte opplysninger til personer. Datainnsamling til prosjektet er planlagt avsluttet ved utgang desember 2013. Alle opptak, notater og personopplysninger vil bli slettet etter at data er analysert og resultatene fra prosjektet publisert i vitenskapelige artikler, planlagt innen oktober 2016.

Informasjonen som registreres om deg skal kun brukes slik som beskrevet i hensikten med studien. Alle opplysningene vil bli behandlet uten navn og fødselsnummer eller andre direkte gjenkjennende opplysninger.

Det vil ikke være mulig å identifisere deg i resultatene av studien når disse publiseres.

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Stipendiat Lill Sverresdatter Larsen • lill.sverresdatter.larsen@uit.no • Tlf 77 62 51 12
Professor Torunn Hamran • torunn.hamran@uit.no • Tlf 77 64 48 58

Frivillig deltakelse
Det er frivillig å delta i studien. Dersom du ønsker å delta, undertegner du samtykkeerklæringen på siste side. Du kan uten å oppgi grunn trekke deg fra studien, med mindre opplysningene allerede er inngått i analyser eller brukt i vitenskapelige publikasjoner. Dette vil ikke få noen konsekvenser for deg. Dersom du ønsker mer informasjon eller har spørsmål til studien, kan du kontakte

Lill Sverresdatter Larsen

Telefon: +47 913 74037

Epost: lill.sverresdatter.larsen@uit.no

Adresse: Lill Sverresdatter Larsen

Fakultet for helsevitenskap

Institutt for helse- og omsorgsfag

Universitetet i Tromsø

9037 Tromsø

Dersom du ønsker å delta i studien – vær vennlig å returnere underskrevet samtykkeerklæring, som du finner på siste side, i vedlagte ferdig frankerte konvolutt, samt at du beholder et eksemplar selv.

Du vil deretter kontaktes snarlig for videre avtale om tidspunkt for intervju.

Samtykke til deltakelse i studien

Jeg har mottatt skriftlig (og eventuelt muntlig) informasjon og er villig til å delta i studien *«Samhandling og brukermedvirkning i samisk forvaltningsområde til hjemmeboende eldre som har demenssykdom».*

Navn:_____

Telefonnummer:_____

Epostadresse:_____

(Om du har, men er ikke nødvendig for deltakelse)

Behov for tolk_____

_____

(Signert av prosjektdeltaker, dato)

Jeg bekrefter å ha gitt informasjon om studien

_____

(Signert prosjektleder 05.12.12)

Med vennlig hilsen

Lill Sverresdatter Larsen

Stipendiat UIT

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Stipendiat Lill Sverresdatter Larsen • lill.sverresdatter.larsen@uit.no • Tlf 77 62 51 12
Professor Torunn Hamran • torunn.hamran@uit.no • Tlf 77 64 48 58

APPENDIX 9

Semi-structured interview guide – family caregiver

UNIVERSITETET I TROMSØ UiT

DET HELSEVITENSKAPELIGE FAKULTET
INSTITUTT FOR HELSE- OG OMSORGSFAG

Eksempel intervjuguide nærstående

Introduksjon

Presentasjon og rolleavklaring. Informere kort om studien og intervju og gi mulighet til å trekke seg her. Intervjuet handler om prosessene du og dere har vært gjennom i forbindelse med diagnostisering og oppfølging i etterkant av demensdiagnose.

Siden vi tenker at dette kan bidra til å forbedre helse- og omsorgstjenesten, er det viktig for oss å få tak i både de positive og de negative erfaringene dere gjorde dere.

Vi ønsker å få en mest mulig riktig forståelse av dine opplevelser, og for å få det til kan det hende spørsmålene virker inngående eller unødvendig. Jeg ber deg gi meg beskjed om det er noe du synes er ubehagelig.

Alle opplysninger som gjør det mulig å identifisere deres familie vil bli tatt bort i oppgaven. Vi vil også understreke at intervjuet ikke skal brukes som en vurdering av deres hjelpere her, men av behandlingstilbudet generelt.

Er det nå noe dere lurer på? Si fra om du vil ha pauser underveis. Intervjuet vil ta ca halvannen time.

Familiesituasjon ved diagnostisering:

- **Kan du fortelle om tiden rundt diagnostiseringen?**
  - Hvordan oppdaget dere sykdommen?
  - Hva var det som gjorde at dere søkte lege?
  - Hos hvem fikk dere den endelige diagnosen?
  - Hva skjedde så?
  - Hvordan vil du beskrive familiens situasjon på det tidspunktet?
  - Hvem har dere vært i kontakt med i etterkant?

Aksept, mestring og kunnskap

- **Hvordan opplever du situasjonen nå? (spørre forsiktig, med fokus på oppfølging)**
  - Hvordan har NN det nå?
  - Hva er mest krevende? (bytt om, ikke begynn med konflikter)
  - Hvordan har du det nå?
  - Hva strever du mest med?
  - Opplever du noen problemer mellom deg og NN, eller NN/deg og hjelpere?
  - Hvem har du hatt til å hjelpe deg og NN?
- **Er det hendelser hvor du opplever det har vært gitt særlig støtte til deg og NN i etterkant av diagnosen?**
  - Noen spesielle yrkesgrupper/kontaktpersoner?
  - Hva gjorde de for at du/NN hadde det bra?
  - Ble dette skrevet ned noe sted? Har dette blitt fulgt opp? Hva skjer om det kommer nye personer for å hjelpe, hvordan skal de kjenne til dette?
- **Er det episoder du har reagert på, noe du skulle ønske hadde vært annerledes?**

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Professor Torunn Hamran • torunn.hamran@uit.no • Tlf 77 64 48 58

- Er det noen som vet at du opplever det slik?
- Skulle du ønske du hadde noen kontaktpersoner?
- Er det mange nok, eller for mange kontaktpersoner?
- Hva med spesialisthelsetjenesten?

Tanker om hva som hjelper

- **Hva ser du for deg av hjelp for NN og deg i framtiden?**
  - Hva trenger du?
  - Hva mener du NN trenger av hjelp?
  - Hvor finnes denne hjelpen?
  - Til hvem henvender du deg for hjelp?
  - Er det særlige utfordringer tenker du innenfor samiske forvaltningsområder/din kultur? (skeptisk til skjema, helsetjenesten, mistenksom til autoriteter, formalier, åpenhet om sykdom innad i familien, lokalsamfunnet.
- **Kjenner du til tilbudet om individuell plan, og i så fall – hva tenker du om det?**
  - Fra hvem fikk du kjennskap og informasjon
  - Hvilke forventninger hadde du?
  - Har dere IP? Når startet det opp og cirka hvor lenge det har vært brukt, hvor ofte møter? Fast struktur – hvilke roller hadde de som deltok?
  - Hva synes du dere får gjennom å benytte et slikt verktøy?
  - Er det andre metoder eller personer som heller kunne vært brukt?
  - Hvem opplever du at du kan kontakte om det er noe du tenker på/lurer på i etterkant?
- **Hva betyr kvalitet i helsetjenesten for deg og NNs behov?**
  - Hva mener du om å skriftliggjøre NN og dine behov i et planverktøy?
  - Er det noe annet du mener kan ha betydning for at NN og hans familie skal ha det så godt som mulig til tross for sykdommen?
  - Hva tenker du skal til for at NN skal kunne bo og fungere hjemme lengst mulig?
  - Hvis du skulle gitt et råd til andre som kommer i en liknende situasjon – hva ville det vært?

APPENDIX 10

Oversikt over tidligere doktorgradsavhandlinger - PhD i helsevitenskap - ved Avdeling for sykepleie og helsefag / Institutt for klinisk medisin ved UiT i perioden 01.01.2007 til 15.05.2017

OVERSIKT OVER TIDLIGERE DOKTORGRADSAVHANDLINGER - PHD I HELSEVITENSKAP - VED AVDELING FOR SYKEPLEIE OG HELSEFAG/ INSTITUTT FOR KLINISK MEDISIN) VED UIT I PERIODEN 01.01.2007 TIL 15.05.2017

Sissel Lisa Storli – (2007)
Living with experiences and memories from being in intensive care. A lifeworld perspective.

Åshild Fause – (2007)
Forpleiningen tilfredsstillende. Prisen ligesaa.

Gunn Kristin Øberg – (2008)
Fysioterapi til for tidlig fødte barn. Om sensitivitet, samhandling og bevegelse.

Cathrine Arntzen – (2008)
"Jeg får ikke hendene til å gjøre det de skal gjøre". Å leve med apraksi etter hjerneslag.

Aud-Mari Soini Fjelltun – (2009)
Waiting for nursing home placement: A study of the life situation of frail elderly and their carer.

Liv Wergeland Sørbye – (2009)
Frail homebound elderly: basic nursing challenges of home care. A comprehensive study across 11 sites in Europe.

Gudrun Nilsen – (2009)
Smerter under Nordlyset. Den vanlige lidelsen. Det uvanlige livet.

Elin Damsgård – (2010)
Activity related pain in patients with musculoskeletal disorders. An explorative study.

Kirsti Torjuul – (2010)
Living with ethical dilemmas. The ethical reasoning of surgeons and nurses in surgical units.

Mari Wolff Skaalvik – (2010)
Nursing homes as learning environments: A study of experiences and perceptions of nursing students and supervising nurses.

Eivind Berthelsen – (2010)
Farvel. En fortolkning av et pleiepersonales erfaringer med å pleie døende og å stelle døde.

Randi Inger Johanne Nymo – (2011)
Helseomsorgssystemer i samiske markebygder i Nordre Nordland og Sør-Troms. Praksiser i hverdagslivet. En skal ikkje gje sæ over og en ska ta tida til hjelp.

Kitt Irene Berg Austgard – (2012)
Omsorgserfaring i tradisjon og moderne omsorgsfilosofi - en hermeneutisk studie av den sykepleiefaglige omsorgserfaringen i lys av Kari Martinsens og Ulrikke E. Nissens forfatterskap.

Gabriele Elfriede Kitzmüller – (2012)
Long-term experiences of living with stroke in a family context.

Bente Ervik – (2012)
Everyday life with prostate cancer: A qualitative study of men`s and spouses` experiences.

Berit Andersdatter Bongo – (2012)
Samer snakker ikke om helse og sykdom - Samisk forståelseshorisont og kommunikasjon om helse og sykdom. En kvalitativ undersøkelse i samisk kultur.

Grete Mehus – (2012)
Ungdom, risiko og snøscooterkjøring: En studie av ungdoms forhold til snøscooterkjøring, risikotaking, ulykker og uhell med foreslåtte forebyggingsstrategier.

Rannveig Lind – (2013)
Family members' experiences of decision-making processes in the context of withholding or withdrawing treatment in the ICU. A qualitative interview study.

Britt Normann – (2013)
Physiotherapy and professional clinical guidance in an out-patient clinic for people with multiple sclerosis. Body and movement in sense making and professional development.

Bodil Blix – (2014)
The construction of Sami identity, health, and old age in policy documents and life stories. A discourse analysis and a narrative study.

Astrid Gramstad – (2014)
Å få og å ta i bruk eit teknisk hjelpemiddel - ei gåtefull reise. Ei kvalitativ undersøking av heimebuande eldre sine erfaringar.

Anne Martha Kalhovde – (2015)
Living with voices and sounds others cannot hear.

Anne Winther – (2015)
Adolescents' lifestyle and bone health

Rajesh Shogdel – (2016)
Cortical porosity as a target for fracture prevention: The Tromsø study

Hege Selnes Haugdahl – (2016)
Mechanical ventilation and weaning: Roles and competencies of intensive care nurses and patients' experiences of breathing.

Rita Kristin Klausen – (2017)
Relational insight and user involvement in the context of Norwegian community mental health care: A narrative analysis of service users' stories.

Unn Sollied Manskow – (2017)
Caregivers to patients with severe traumatic brain injury. A national prospective study on caregiver burden, life satisfaction and health care experiences

Vår Mathisen – (2017)

Brukermedvirkning i distriktspsykiatriske sentre - et interaksjonsteoretisk perspektiv.
Praktisering av "brukermedvirkning" i fellesrom og rapporter.