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Constructions of user participation in home-based dementia care

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Working with this thesis led me onto a side-track when I was invited to participate in a book project with the title 'Ways of Home Making in Care for Later Life'. This was one of the highlights of my PhD-time, and I would like to thank Oddgeir Synnes, Bernike Pasveer and Ingunn Moser for inviting me into this project.

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Oslo, June 2020

Ingebjørg Haugen

Sammendrag

I denne avhandlingen utforsker jeg temaet brukermedvirkning for hjemmeboende personer med demens. Utgangspunktet for valg av tema er det økte politiske fokuset på brukermedvirkning i demensomsorgen, samtidig som det fortsatt er lite forskning på temaet i denne konteksten. Min forskning kan ses på som et bidrag både til forskning på brukermedvirkning, og til forskning på hjemmebasert demensomsorg. Oppgaven ble levert ved PhD-programmet Diakoni, Verdier og Profesjonell Praksis ved VID vitenskapelige høgskole. Avhandlingen består av denne kappen og tre individuelle akademiske artikler.

Det overordnede målet i avhandlingen var å utforske brukermedvirkning i hjemmebasert demensomsorg. Dette ble operasjonalisert i tre forskningsspørsmål:

- Hvordan forstås brukermedvirkning i hjemmebasert demensomsorg?

- Hvordan praktiseres brukermedvirkning i hjemmebasert demensomsorg?

- Hvilke grader av brukermedvirkning kvalifiserer som 'ekte' brukermedvirkning i hjemmebasert demensomsorg?

Denne avhandlingen har et utforskende, beskrivende, og fortolkende design. Dette begrunnes med viktigheten av å beskrive fenomener eller kontekster som det har blitt forsket lite på. Avhandlingen ble designet som et «best case» studie. Dette betyr at vi har samlet inn data i to kommuner som vi ut fra gitte kriterier antok ville være gode på demensomsorg. Tanken med dette er at hvis vi klarer å beskrive utfordringene de gode kommunene opplever i forhold til brukermedvirkning for personer med demens, kan vi anta at kommuner med mindre ressurser og/eller kompetanse vil oppleve mange av de samme problemene. Funnene kan dermed ha overføringsverdi selv om de ikke kan generaliseres.

Forskningsspørsmålene er utforsket fra de fire følgende perspektivene: 1. Forskningslitteratur (presentert i artikkel 1), 2. Hjemmeboende personer med

demens (presentert i artikkel 2), 3. Pårørende (presentert i artikkel 2), 4. Ansatte i hjemmebasert demensomsorg (presentert i artikkel 3).

Artikkel 1 er en litteraturgjennomgang av faktorer som påvirker mulighetene for brukermedvirkning i hjemmebasert demensomsorg. Søket som ble gjennomført for litteraturgjennomgangen var bredt for å inkludere flere aspekter ved brukermedvirkning. Gjennomgangen viser at brukermedvirkning er et dårlig definert begrep, og at det finnes lite forskning på brukermedvirkning i hjemmebasert demensomsorg. Til tross for mangel på en felles definisjon av brukermedvirkning, forstås det imidlertid oftest som deltakelse i beslutningsprosesser. Artikkelen diskuterer fem forskjellige kjennetegn som påvirker hvordan brukermedvirkning blir gjennomført for personer med demens som bor hjemme. Dette er: egenskaper ved personene med demens, egenskaper ved de ansatte, beslutningsegenskaper, relasjonelle egenskaper og organisatoriske egenskaper.

Artikkel 2 presenterer data fra intervjuer med syv hjemmeboende personer med demens. I artikkelen er brukermedvirkning beskrevet i to forskjellige kontekster; i eget hjem og på dagsenter. Funnene viser at de syv personene med demens forholdt seg forskjellig til egen deltakelse i beslutningsprosesser. Mens enkelte foretrakk at andre tok beslutninger for dem, understreket andre at det var svært viktig for dem å ha kontroll i eget liv ved å bestemme selv. I diskusjonen ses disse funnene i sammenheng med kontekst og relasjon. Jeg hevder at personer med demens tilpasser seg konteksten de er i ved å ta hensyn til andres behov, og viser hvordan relasjoner med ulik grad av tillit kan føre til ulik grad av behov for kontroll og selvbestemmelse.

I artikkel 3 presenteres data fra intervjuer med 12 ansatte i hjemmetjenesten. Artikkelen beskriver og diskuterer fem forskjellige barrierer til brukermedvirkning; pasientene er for syke, brukermedvirkning kolliderer med velgjørenhets- og ikke-skadeprinsippet, mangel på bakgrunnsinformasjon, motstridende interesser mellom pasienter og pårørende, og organisering av tjenester. Funnene diskuteres i forhold

til gjeldende politiske reformer, organisering av hjemmetjenesten og dikotomiseringen mellom brukermedvirkning og omsorg.

I kappen introduseres sosialkonstruksjonisme som et analytisk verktøy i et forsøk på å kombinere funnene fra de tre individuelle artiklene til en mer teoretisk basert diskusjon om brukermedvirkning i hjemmebasert demensomsorg. I diskusjonen beskriver jeg hvordan brukermedvirkning er konstruert i hjemmebasert demensomsorg av de forskjellige informantene i min studie. Jeg viser at de ansattes ideal av brukermedvirkning ikke stemmer overens med hva de tenker er behovene til pasientene, og setter spørsmålstegn ved om denne forståelsen reflekterer den dominante diskursen av brukermedvirkning i demensomsorgen. Jeg viser også at det finnes forskjellige praksiser av brukermedvirkning, med ulik vekt på autonomiprinisippet. Idealet av brukermedvirkning til de ansatte, personene med demens og pårørende blir sammenlignet med modeller og ideologiske forklaringer på brukermedvirkning, og diskutert i lys av flere konsepter fra sosialkonstruksjonismen.

Summary

In this dissertation I explore the topic of user participation for people with dementia living at home. The reason for the choice of topic is the increased political focus on user participation in dementia care, while there is still scarce research on the topic in this context. My research can be seen as a contribution both to research on user participation and to research on home-based dementia care. The thesis was submitted to the PhD program Diakonia, Values and Professional Practice at VID Specialized University. The dissertation consists of this synopsis and three individual academic papers.

The overall aim in the dissertation was to explore user participation in home-based dementia care. This was operationalized in three research questions:

- How is user participation understood in home-based dementia care?
- How is user participation practiced in home-based dementia care?
- What degrees of user participation qualifies as ‘real’ user participation in home-based dementia care?

The design of this dissertation is exploratory, descriptive, and interpretative. This is justified by the importance of describing phenomena or contexts in which there is little research. The dissertation was designed as a ‘best case’ study. This meant that we collected data in two municipalities which we assumed would be good in dementia care based on given criteria. The idea behind this is that if we manage to describe what the good municipalities are struggling with in terms of user participation for people with dementia, we can assume that municipalities with less resources and/or expertise will experience many of the same problems. The findings may thus have transfer value even if they cannot be generalized.

The research questions have been explored from four perspectives: 1. Research literature (presented in paper 1), 2. People with dementia living at home

(presented in paper 2), 3. Family caregivers (presented in paper 2), 4. Professional caregivers in home-based dementia care (presented in paper 3).

Paper 1 is a literature review of factors affecting user participation in home-based dementia care. The search done for the literature review was broad in order to include multiple aspects of user participation. The review shows that user participation is poorly defined and describes how there is currently scarce research on user participation in relation to home-based dementia care. However, despite a lack of an agreed-upon definition of the concept, user participation is mostly understood as participation in decision-making. The paper discusses five different characteristics that affect how user participation is enabled for people with dementia living at home. These are: individual characteristics, professional caregiver characteristics, decisional characteristics, relational characteristics and organisational characteristics.

Paper 2 presents data from interviews with seven people with dementia living at home. The paper describes user participation in two different contexts: in their own home and at the day care centre. The findings show that the seven people with dementia related differently to participation in decision-making. While some preferred that others made decisions for them, others emphasised that it was very important for them to have control in their own lives by deciding for themselves. In the discussion, these findings are viewed in relation to context and relationship. I argue that people with dementia adapt to the context they are in by taking into account the needs of others, and show how relationships with different degrees of trust can lead to different needs for control and self-determination.

Paper 3 presents data from interviews with 12 professional caregivers in home-based dementia care. The paper describes and discusses five different barriers; patients are too ill, user participation collides with beneficence and non-maleficence, lack of background information, conflicting interests between patients and family caregivers, and organization of services. The findings are

discussed in relation to current policy reforms, ways of organizing home care and the felt dichotomization between user participation and care.

In this synopsis, social constructionism is introduced as an analytical tool in an attempt to combine the findings of the three individual papers into a more theoretically based discussion of user participation in home-based dementia care. In the discussion, I describe how user participation is constructed in home-based dementia care by the different informants in my study. I show that professional caregivers' ideals of user participation do not match what they think are the needs of their patients, and I show how these constructions reflect the dominant discourse of user participation in dementia care. I also show that there are different practices of user participation, with different emphasis on the principle of autonomy. The ideals of user participation of the professional caregivers, the persons with dementia and the family caregivers are contrasted with models and ideological explanations of user participation, and discussed in light of different concepts from social constructionism.

List of papers

Paper 1

Haugen, Ingebjørg, Slettebø, Tor, and Ytrehus, Siri. (2019). Factors affecting user participation for elderly people with dementia living at home: a critical interpretive synthesis of the literature. *European Journal of Social Work*, *22*(6), 974-986.

Paper 2

Haugen, Ingebjørg, Ytrehus, Siri, and Slettebø, Tor. (2019). User participation among people with dementia living at home. *Nordic Social Work Research, 9*(2), 147-159.

Paper 3

Haugen, Ingebjørg, Ytrehus, Siri, and Slettebø, Tor. (2019). Barriers to user participation in home-based dementia care: experiences of professional caregivers. *Nordic Social Work Research,* 1-13.

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1 Introduction

Worldwide, around 50 million people have dementia of some sort, a number that is expected to increase to 82 million by 2030 and 152 million by 2050 (Patterson, 2018). The expected increase is partly explained by an ageing population, as the risk of getting dementia increases with age. One in four people above the age of 80 is expected to get dementia (Brækhus, Dahl, Engedal, & Laake, 2013). In the Norwegian context, the estimated number of people with dementia today is between 80 000 and 100 000, where the vast majority of these are more than 65 years old and about half live in the community (The Public Health Department, 2014). With an ageing population, 'ageing-in-place' has become a socio-political goal both nationally (Norwegian Ministry of Health and Care Services, 2008-2009; Official Norwegian Reports [NOU]) 2011:11, 2011) and internationally (World Health Organization, 2002). One of the keys for achieving this is user participation.

The emphasis on user participation in dementia care is part of a wider emphasis on the concept in health care and in society in general in the Western world (World Health Organization, 2013). Today, user participation is an important principle in healthcare and is often seen as synonymous with good health care. Some describe it as a 'buzzword' (Beresford, 2012; Stewart, 2013), but there is consensus that the concept is a vital component of securing equal and fair healthcare services for everyone. User participation is highlighted in a number of policy papers, both international (World Health Organization [WHO], 2017) and national (Norwegian Ministry of Health and Care Services, 2007, 2012-13, 2015), and it is enshrined in the law in many countries. In Norway, the Patients' Rights Law states that 'the patient or user has the right to assist in the implementation of health and care services…The services should be designed as far as possible in collaboration with the patient or user. Emphasis should be placed on what the patient or user thinks in designing services according to the Health and Care Services Act §§ 3-2, first paragraphs 6, 3-6 and 3-8' (Patients' Rights Law, 1999, my translation).

User participation is not a new idea. The history of user participation, in its broadest sense, can be traced back to ancient Greece and the development of democracy (Beresford, 2012). The modern history of user participation, however, began in the 1960s and 1970s with public participation in planning in the US and UK, such as the establishment of community health councils in the UK (Askheim, Christensen, Fluge, & Guldvik, 2017; Beresford, 2012). Individual user participation did not appear as a concept or a focus of study before the 1980s, when it emerged as a result of a strong desire to move away from the paternalistic top-down approaches associated with the welfare state and create more user-centred services (Askheim et al., 2017; Beresford, 2012).

Norwegian policy papers on elderly care have highlighted user participation since the 1990s. In the *Action Plan for Eldercare* from 1997, one of the objectives presented was to 'provide greater opportunities for user participation and personal choices in daily care' (The Norwegian Ministry of Social Affairs and Health, 1996-97, p. 5, my translation). The plan focused on housing and the need to build better home care services so older people could live at home for as long as possible. In the 2012–2013 white paper *Tomorrow's Care* (Norwegian Ministry of Health and Care Services, 2012-13), the focus shifted from presenting user participation as a way to improve care and empower older people to the obligations that the idea includes. The emphasis on obligation is quite strong, and we learn that society 'will not accept that senior life should be lived secluded from societal obligations and responsibilities' (Norwegian Ministry of Health and Care Services, 2012-13, p. 56, my translation). There is little mention of frailty and disease, and older people are presented as resourceful individuals who are both capable and demand higher degrees of user participation than earlier generations.

Specifically related to dementia care, we find the policy paper *Dementia Plan 2020* (Norwegian Ministry of Health and Care Services, 2015). In the plan, user participation has a prominent role and is one of six strategic approaches mentioned for improving healthcare services for people with dementia. User participation is described as promoting dignity, self-respect and equality. The plan was made in cooperation with people with dementia and their caregivers. It aims at continuing to reduce discrimination against people with dementia by creating a more dementia friendly society, increasing knowledge about dementia among professional caregivers and in society in general, and enabling more user participation for people with dementia.

User participation is often understood as influence in decision-making processes. In its 1978 Alma-Ata Declaration, the World Health Organization stated that ‘the people have a right and duty to participate individually and collectively in the planning and implementation of their health care’ (1978). The following description is often used in the Norwegian context: ‘those affected by a decision, or users of services, will influence the decision-making process and the design of the service provision’ (Rønning & Solheim, 1998, p. 21, my translation). While the two definitions both see user participation as related to decision-making, the Alma-Ata declaration leans more clearly towards a democratic understanding of user participation than the Norwegian definition (Sørvoll & Gautun, 2020). In addition, it can be noted that neither definition of user participation mentions how it can be achieved with people with declining cognitive abilities.

1.1 The socio-cultural and historical context of user participation

‘Ageing-in-place’ has become an important political goal in Norway (Norwegian Ministry of Health and Care Services, 2008-09, 2012-13; Official Norwegian Reports [NOU]) 2011:11), as well as in many western countries (World Health Organization, 2002). The focus on ageing-in-place has clear economic motives, as providing health care to people at home is more cost effective than having them in institutions (Norwegian Ministry of Health and Care Services, 2008-09). However, aging-in-place is also often described as promoting the wishes of the elderly themselves, as living at home instead of in an institution is believed to help them maintain their autonomy as it enables continuation of the their social networks and relations (Lausund, 2017). Aging-in-place is also seen as closely linked to another term often used these days, namely ‘active aging’ (Jacobsen, 2015; World Health Organization, 2002). The association between ageing-in-place, active-aging and user participation is made in several policy papers. For example, in the following Norwegian policy paper from 2018, we read that

> Most older people in Norway live good lives. They shape their own everyday life. They are active and participate in the society. They receive good quality health and care services when they need them. They contribute to working life, their families and friends, their local communities, and their contribution is valued. All older people should be able to continue to enjoy such a good everyday life, including when their health deteriorates and they may need assistance from public authorities. Several good solutions are available in communities that may help to attain this goal. However, several of the good solutions are put to practice haphazardly and in too few municipalities. Hence, the services are not good enough and the quality of the services varies too much. Earlier reforms have often been preoccupied with [social] systems. "Living the Whole Life" is about humans. The most important thing in life. Community, activity, good food and healthcare. With "Living the Whole Life" [reform], older people will get the opportunity to master their own lives where they live, their whole life. (Norwegian Government 2018:7, au.tr.)

In the quote, living at home in old age is presented as something positive. The elderly themselves are presented as resources, who will continue to participate in society. Activity and mastery are words that are highlighted. There is no specific mention of illness or frailty. According to Jacobsen (2015), who has reviewed multiple Norwegian policy papers to see how they narrate about aging, this is the typical narrative of aging in current Norwegian policy papers. He explains that the papers can be characterized by what they state and what they omit, and that these papers have a strong focus on positive aging, while clearly omitting any positive associations to dependence and interdependence.

This strong focus on aging-in-place and positive aging in Norway is an echo of EU goals such as decentralized health and care services, increased involvement of volunteers and family caregivers, and user participation (Tritter, 2009; World Health Organization, 2002). It is also understood as a result of the democratization process that has taken place in Norway and other countries over the last four decades, with a move away from a paternalistic state towards citizenship, equality and involvement (Askheim et al., 2017). User participation is highlighted as becoming increasingly more important, as the elderly of the future will have more resources, be healthier, and demand more involvement in their own health care. These goals are also emphasized in dementia care, which is increasingly performed in people's own homes (Norwegian Ministry of Health and Care Services, 2012-13).

Norwegian home care is divided into two different services: nursing assistance and practical assistance (Lausund, 2017). In this synopsis, home care will refer only to nursing assistance. Nursing assistance refers to professional care practices performed by both nurses and care assistants. Home care is responsible both for people living in their own homes and for people living in supported housing (Daatland, Høyland, & Otnes, 2015). The organization of home care in Norway is influenced by ideas from New Public Management, the core elements of which are contracts, competition, and control (Lausund, 2017). In contracted care, explicit formal specifications dictate what services each care receiver will get (Lausund, 2017).

1.2 Dementia

Dementia is a syndrome, meaning that it refers to a group of related symptoms (World Health Organization, 2019). The most common type of dementia is Alzheimer's Disease (60 per cent), followed by vascular dementia (20 per cent), dementia with Lewy bodies, and frontotemporal dementia (Brækhus et al., 2013). The symptoms displayed by someone with dementia depends on the underlying condition, but there are also general symptoms that most people with dementia will get, such as deficits in memory and thinking. The World Health Organization defines dementia as follows:

> 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 behavior, or motivation (World Health Organization, 2019).

Dementia is progressive, meaning the symptoms will gradually get worse. It is therefore often described in terms of stages (Engedal & Haugen, 2009). The most commonly used description divides dementia into mild, moderate and severe cases. Mild dementia refers to symptoms such as forgetfulness and disorientation in time and space. Moderate dementia refers to more pronounced symptoms, such as difficulties communicating and difficulties with daily life activities, and at this point a person will need substantial assistance. A person with severe dementia has often lost speech and the ability to walk and is incontinent (Engedal & Haugen, 2009).

More than its biological aspects, dementia is also understood within a specific historical and cultural context. How a phenomenon is framed affects how we perceive it. In the case of dementia, a long tradition of discrimination has been well documented (Butler, 1969; Kitwood, 1997; Milne, 2010) and is yet to be overcome. Numerous researchers, possibly the most influential being Kitwood (1997) and Sabat (2008), have described how people with dementia have been dehumanized. Kitwood (1997) writes about what he calls a ‘malignant social psychology’, and his theories form the basis for the well-acknowledged person-centred care, which as I later will explain, shares certain ideas with user participation. Sabat (2005, 2008) approaches the long-standing debate about whether or not people with dementia have a self by arguing that some parts of our selves are social constructions, and that people with dementia are bereaved of this aspect of themselves through social exclusion and dehumanization, with every action seen as pathological instead of as a natural response to the environment. Seen from a social-psychological view, the gradation of dementia according to the biological criteria described above can be dangerous, as many types of behaviours (such as anger or passivity) are as likely to be the result of social disregard or malignant social psychology.

Dementia must therefore be understood as both a biological disease with consequences for affected persons' ability to perform user participation *and* as a social construction in that how society thinks about and treats people with dementia also has consequences. While people with dementia have been, and sometimes still are, socially constructed as 'demented', they are now increasingly viewed as resourceful people, able, willing, and expected to participate in society. One of the main challenges presented in research concerning this view and the calls for user participation in dementia care, is the difficulty combining user participation of people with dementia, often understood as their right to autonomy (Smebye, Kirkevold, & Engedal, 2016), with their need for protection and care.

1.3 Literature review

In this section, I will present the literature review that was conducted as the background for this synopsis. The current review has a different focus than the review presented in paper 1. Before I describe what is new in the current review, I will start with a short summary of Paper 1.

Findings from the review presented in Paper 1:

The aim of the paper was to highlight factors that affect user participation for people with dementia living at home. The paper shows that the greatest barrier to user participation is discriminatory practices that prevent people with dementia from participating in decision-making processes. Relations to others are highlighted as crucial in enabling user participation for people with dementia, as user participation is usually facilitated by family or professional caregivers. The paper also shows that professional caregivers often lack knowledge of how to perform user participation, and there is often disagreement between family and professional caregivers over whether to emphasize the person with dementia's safety or their autonomy. Finally, the paper mentions organisational barriers such as late service entry and lack of actual choices. The paper concludes that user participation is usually seen as a positive concept, but that research is lacking, especially on user participation in home-based dementia care.

The focus in the first review was very broad. This partly reflects the fact that it was written early in my PhD process, as well as reflecting the specific review method used. In this review, I was less restrained by formal review methods and instead aimed to find literature that best informs the debate about user participation in home-based dementia care that I want to enter into in the current synopsis. My aim with the review is to find research that can highlight how user participation is understood in home-based dementia care. Therefore, I will first present research focusing on what I believe is one the most central debates concerning user participation in dementia care, namely the debate on how to balance the rights of people with dementia to both autonomy and safety. Next, I present research with an explicit focus on user participation in dementia care, since in the first review I did not distinguish between research on user participation and research on overlapping concepts, such as autonomy, involvement and decision-making. I will then go on to explore understandings of user participation, which were only indirectly addressed in the first review. As research on the understanding of user participation in dementia care is scarce, I will include research on the understanding of user participation in municipal health care in general. The last topic is research on people with dementia's experiences participating in decision-making.

1.3.1 Between autonomy and safety

A contingent question to explore in relation to user participation in dementia care is how it relates to the debate about autonomy and safety for people with dementia (Landau & Werner, 2012; Smebye et al., 2016; Vetlesen, 2003). Based on the principles of biomedical ethics (Childress & Beauchamp, 2001), autonomy is one of four ethical principles to follow in dementia care, together with dignity, maleficence, and non-maleficence (Smebye et al., 2016). Several authors have described how these principles often collide in dementia care (Fjelltun, 2009; Helgesen, Larsson, & Athlin, 2010; Smebye et al., 2016), and it has been argued that autonomy seems to have precedence today over the other principles, both on a structural level and as reflected in the attitudes of professional caregivers (Mol, 2008; Vetlesen, 2003).

The ethical situations often considered most challenging are those possibly involving coercive treatment. Many countries have laws regulating the use of coercive treatment in dementia care. Still, several studies show that various sorts of coercive treatment are common, and professional caregivers sometimes find force or coercive treatment necessary and justifiable to make sure their patients are safe (Helgesen et al., 2010; Kirkevold and Engedal 2009, Lejman, Westerbotn, Pöder, & Wadensten, 2013;) or to preserve their dignity (Jakobsen and Sørlie 2010). The nurses in the study of Lejman et al. (2013) felt that avoiding coercive treatment was unrealistic, and that to do so they would have needed to be one-to-one with the patients. In addition, the authors found that when patients had been subjected to coercive treatment for longer periods of time and had not objected verbally, some professional caregivers considered this as equivalent to the patients' having given their consent. In the study of Helgesen et al. (2010) the nurses expressed that they believed that providing good care did not always mean respecting the patient's wishes. However, a recurring theme is that while professional caregivers see the need for various paternalistic measures, many view using such measures as the opposite of respecting patients' autonomy.

This view of autonomy as the opposite of both paternalism and coercion is usually a reflection of the professional caregivers participating in various studies. The authors of the same studies often describe a more nuanced understanding of the situation. For example, in their study on ethical dilemmas that arise when people with dementia wish to live at home, Smebye et al. (2016) claim that paternalism can sometimes be a pre-requisite for autonomy. They differentiate between soft and hard paternalism and categorize persuasion as and example of the former. The authors found that both types of paternalism are seen as necessary in some situations in order to respect the person's autonomy in the long run. The authors also comment on how the idea of autonomy being equivalent to independence is not useful in dementia care and argue for the need of an ethics of care to inform the debate. Norheim and Vinsnes (2008) similarly note that feeling safe is increasingly important as dementia progresses and that in order to feel autonomous, people with dementia also have to feel safe.

The debate over whether to emphasize people with dementia's autonomy or safety is relevant to any discussion of user participation in dementia care, as it begs the question of where in this landscape user participation is situated. At the moment, this seems conceptually unclear; research shows that many professional caregivers see user participation as something close to meaning 'an autonomous person who makes autonomous decisions', while researchers seem to operate with more complex understandings of the relation between user participation and autonomy. The application of the traditional concept of autonomy to people with dementia have been criticized (Smebye et al., 2016) and the importance of relational understandings of autonomy for this group is underlined (Agich, 2003). I believe it is reasonable to argue that there is a similar need in relation to user participation in home-based dementia care.

1.3.2 Research on user participation in dementia care

Research on user participation for people with dementia seems to have dealt primarily with the inclusion of people with dementia in the development of IT applications (Bjørkquist, Ramsdal, & Ramsdal, 2015; McCabe & Innes, 2013; Slegers, Wilkinson, & Hendriks, 2013), in the development of services and policies (Hernandez, Robson, & Sampson, 2008; Kenny et al., 2016; Tooke, 2013), and as co-researchers in research (Darnell, McGuire, & Danner, 2011; Law, Russ, & Connelly, 2013; Thoft, Pyer, Horsbøl, & Parkes, 2018). There is substantially less research on user participation in relation to decisions about everyday life at home and in institutions and in relation to care services. A few exceptions are Helgesen, Larsson, and Athlin (2010, 2013, 2014), Larsen, Normann, and Hamran (2017), Norheim and Vinsnes (2008), and Sørly (2017) who all studied patient participation in institutional or home-based dementia care. Helgesen et al. (2014) found that professional caregivers viewed patient participation as an important principle guiding their care, and they described it as patients being masters of their own life. They saw this kind of participation as important for the dignity and self-esteem of the patients, but also said it could be destructive if practiced inappropriately, as it could put the patients' safety at risk. Although they considered including patients in decision-making an important principle, they often had to prioritize other tasks, especially due to time constraints. The use of coercion was seen as the opposite of patient participation but was sometimes considered the best care when a patient's dignity was at stake.

Larsen et al. (2017) focus on the collaboration between family and professional caregivers in enabling user participation for home-dwelling people with dementia. They describe how unequal power relations can make 'real' user participation difficult to achieve and point to the difficulties professional caregivers face when trying to put this concept into practice. In this study, many family and professional caregivers highlight persuasion as an unavoidable part of the decision-making process with people with dementia, who often no longer know what is best for them. Lack of insight into their own decreasing abilities is also mentioned as a challenging factor in situations of decision-making. Helgesen et al. (2014) describe similar challenges and conclude that user participation in dementia care is both complex and paradoxical, and they call for a debate on the meaning of the concept in dementia care.

Norheim and Vinsnes (2008) explored the possibilities and challenges of dementia care practices based on the principle of user participation. The study is the only one mentioned in this chapter that describes the theoretical underpinnings of user participation. The authors consider that decisions made by others on behalf of a person with dementia can also be understood as user participation. They describe the interplay between the values of user participation, human worth, and paternalism, showing how these concepts can either collide or overlap. They believe that the values overlap, meaning user participation is achieved if the patient voluntarily goes along with something the caregivers have suggested. The example they give is of an elderly woman who at first refused to move into a nursing home but then went along with the idea after having had time to get used to it.

As part of a newly established national documentation centre for research and development work in the health and care sector, Sørly (2017) has evaluated the concept of user participation in dementia care. The report is based on a broad review of literature on user participation for people with dementia. This includes research, policy papers, reports, books, master's theses, blogs, websites, and more. One of the conclusions in the report is that user participation is not an established practice in either nursing homes or home care in municipal dementia care, and Sørly especially underlines the need for a 'more systematic approach to user participation at the individual level in the municipalities' (p. 8). She describes how user participation has become more advanced at a system level, with the implementation of service statements, user surveys, and user choice. In addition, she claims that Norwegian dementia care is lagging behind countries such as England when it comes to attitudes towards people with dementia. She relates this to recent studies describing citizenship for people with dementia, which she sees as 'the fourth turn' (p. 34) in dementia care following a biological approach, a biomedical approach, and a relational approach.

1.3.3 Research on user participation in municipal health care services

While research on user participation has tended to focus more on how user participation is practiced than how it is understood by professional caregivers in dementia care, a broader search of research on home care and health care services in general, revealed studies that have thoroughly dealt with how user participation is understood.

Several studies have problematized the understanding of user participation in health care services for the elderly. One example is Haukelien, Møller and Vike (2011), who, as part of their 130-page report on user participation in municipal care services, ask whether we can actually achieve 'real' user participation in the health care sector or whether it is more of an advertised goal without much substance behind it'. Their implicit answer seems to be no, as they conclude that user participation at the individual level is more of a 'user-oriented practice' than true 'user participation'. They define a user-oriented practice as being a practice in which professional caregivers adjust their services based on their interpretations of what they believe are the users' needs. Within the category of user orientation, they also include actions such as convincing patients. The authors conclude that this might be the best form of user participation that can be achieved in some situations in the health care sector, such as for people with dementia.

Johannesen and Steihaug (2019) conducted a study where they explored the understanding of user participation in municipal acute wards and home care. They found that there was a difference between how professional caregivers (both nurses and physicians) in municipal acute wards and nurses in home care understood the concept of user participation. While the professional caregivers in the municipal acute wards underlined the importance of communication and dialogue with patients, the nurses in home care mainly understood user participation to mean making patients take charge of their own life. The authors note that this particular understanding of the concept actually challenges the idea of user participation, as patients are not given other choices besides active aging and independence, which they see as political demands rather than individual needs.

One study was found that explored how elderly people themselves understand user participation. The study was conducted by Foss (2011), who describes patient participation among elderly people admitted to hospital. One of her findings was that the idea of patient participation did not align with what the elderly's saw as proper behaviour at the hospital. They did not find it natural to 'state their right' to participate, an expression that Foss finds is expected in the dominant rights-based discourse on user participation. Foss notes that this discourse is based on the value of individuality, which can be foreign to the older generation. As a result, attempts at participation by the elderly were often not perceived as such by the professional caregivers because their ways of participating were more subtle and did not fit into the expected expressions of user participation.

1.3.4 Research on decision-making seen from the perspective of people with dementia

Over the last few decades, there have been a number of research projects exploring how people with dementia participate in decision-making processes. The vast majority of this research has focused on issues of capacity and consent (Hamann et al., 2011; Moye & Marson, 2007), but recently research has started to appear with a focus on everyday decisions for people with dementia (Helgesen et al., 2014; Smebye, Kirkevold, & Engedal, 2012). Much of this research includes the views of persons with dementia. It suggests that people with dementia see their participation in decision-making as vital for their dignity (Slettebø et al., 2017), their sense of self (Low, Swaffer, McGrath, & Brodaty, 2018) and for feeling in control of their own lives (Fetherstonhaugh, Tarzia, & Nay, 2013).

However, people with dementia report several barriers to their involvement in decision-making processes. Tyrell, Genin, and Myslinsk (2006) found that participants with dementia felt they were not given enough information to make proper choices. In addition, they felt they were not given enough time to consider their options. Witsø, Ytterhus, and Vik (2010) found that when informants with dementia expressed feeling like they did not participate in decision-making, it was mostly related to barriers at a system level and not to the individual caregivers working in the system. Swaffer (2015) is also concerned with barriers at a system level, and describes how the whole system is set up to disempower people with dementia by categorizing them as ‘victims’ or ‘sufferers’ (and consequently family caregivers as ‘martyrs’). Instead of being told to fight for their lives, Swaffer claims they are usually told to give up life as they know it, a process she refers to as ‘prescribed dis-engagement’. When people with dementia do not give their opinion in decision-making processes, this can be explained by a learned helplessness and loss of self-esteem.

People with dementia underline the role of others, especially their spouses, in enabling their involvement in decision-making. One way they describe others as being important is because of their role as facilitators (Fetherstonhaugh et al., 2013). The informants in the study by Fetherstonhaugh et al. (2013) described good support from others as ‘subtle support versus taking over’ (p. 146), thus suggesting the good support does not mean being overprotective of the person with dementia, but rather daring to let her or him have a go. However, they also underlined the importance of having people around them who were willing speak up if they were about to put themselves in a dangerous situation. They also mentioned that getting help to limit the range of choices available to them made it easier to make independent decisions.

Other studies have focused on how others not only facilitate decision-making but are also important co-decisionmakers due to their close relationship with the person with dementia. In a study of how people with dementia and their family caregivers handle decision-making at home, it was found that the people with dementia themselves saw mutual decision-making as ‘an inherent part of living with a partner’ (Samsi & Manthorpe, 2013, p. 955). Sinclair et al. (2018) describe how decision-making in couples where one partner has dementia must be understood as attempts to maintain couplehood and an awareness that most decisions will affect the couple, not just the individual persons. Samuelsson, Österholm, and Olaison (2015) show how some couples have ‘joint capacity’: in other words, they are able to cope with the challenges of everyday life by cooperating. This illustrates that decision-making is a continuous and ever-evolving process in which the different actors base their decisions on many factors besides rational reasoning, such as habits, emotions, and care for each other.

For people with dementia, participating in decision-making does not necessarily mean having the last word. If a relationship is based on trust and they believe that the other person wants what is best for them, people with dementia report wanting to delegate some decisions to others (Helgesen et al., 2014; Smebye et al.,2012). Some express relief at not to have to make all decisions themselves because they do not trust their own abilities and find it hard to make decisions (Samsi & Manthorpe, 2013). While being valued is often described as being strongly linked to being autonomous, receiving care from others has also been found to increase people’s feeling of being valued (Steeman, Godderis, Grypdonck, De Bal, & De Casterlé, 2007).

1.3.5 Conclusion from the literature review

The purpose of this review was to find research that, in different ways, explores how individual user participation in home-based dementia care is understood. It is clear from the research reviewed that user participation is a difficult concept in this context. The difficulty seems closely related to the lack of a developed understanding of user participation in home-based dementia care, partly seen in the fact that none of the included studies on user participation in dementia care or home-based dementia care have explored this topic in depth despite acknowledging the need for discussions and systematic approaches to user participation in this context. However, I did find research on the meaning of user participation in home care, and these studies can contain valuable insights for home-based dementia care. These studies raise important questions concerning the meaning of user participation: Can we achieve user participation in any meaningful sense at the individual level in home care for people with dementia? What degree of user participation qualifies as real user participation? Are there certain ways of understanding user participation specific to home-based dementia care? How does society’s call for user participation align with the elderly’s and people with dementia’s wishes? From the review, it is clear that research to answer these questions is lacking at present.

Along with the lack of a developed understanding of user participation, it is also clear that the difficulties of implementing user participation in home-based dementia care are related to the particularities of caring for people with dementia. Many people with dementia are vulnerable and dependent on care, and both family and professional caregivers often find themselves in difficult ethical dilemmas trying to balance the care receiver’s right to both autonomy and safety. Studies exploring these topics often note that coercion is seen as the opposite of user participation, while at the same time underlining the need for some paternalistic measures in order to ensure both the safety *and* the autonomy of the persons with dementia. More research is therefore required to explore how user participation is understood and implemented with people with dementia who have an increased need of safety and care.

1.4 Aim and research questions

The aim of this PhD project was to explore user participation in home-based dementia care through a literature review and a best case study consisting of interviews with 1) professional caregivers in home-based dementia care, 2) people with dementia living at home, and 3) their family caregivers. The project aimed to describe the informants' own experiences and understandings of user participation.

The overall aim was operationalized through the following three research questions:

- How is user participation understood in home-based dementia care?
- How is user participation practiced in home-based dementia care?
- What degrees of user participation qualifies as 'real' user participation in home-based dementia care?

The first two research questions guided the project from the drafting of the research proposal to the writing of the three individual academic papers. The last research question has been added on the basis of the literature review in this synopsis. All three research questions will be dealt with in the discussion.

1.5 Outline of the thesis

This thesis was submitted to the PhD programme Diakonia, Values, and Professional Practice at VID Specialized University. It consists of this synopsis and three individual academic papers. I want to situate my research in relation to the dual emphasis on values and professional practice in the PhD programme. I do not discuss my topic specifically in relation to values, but I hope the reader will appreciate my attempt to present user participation as an important value in my chosen research context. The research context in which I am situating this research is dementia care.

This introductory chapter has situated the research in relation to the strong political focus on the concept of user participation and showed how that concept emerged and has since evolved. The chapter also includes an outline of Norwegian dementia care and presents previous research, ending with the overall aim of the thesis and the research questions. Chapter 2 presents the conceptual framework for the study. Here, I elaborate on the concept of user participation by presenting different understandings and models of user participation. In order to take a more critical view of the concept in the discussion, I also include social constructionism in the conceptual framework. Chapter 3 deals with the design, methods and analysis chosen for this study, in addition to describing how this project came about and my evolution as a researcher. In chapter 4, I summarize the findings of the three papers, and in chapter 5, I bring together and discuss these findings in relation to the chosen conceptual frameworks and philosophical positions. In the discussion, I will not dwell on every finding from the three papers but rather focus on what I find most relevant in order to achieve the aim of the thesis and inform the broader debate on user participation. Chapter 6 presents the conclusions and the answers to the research questions.

2 Conceptual framework

The conceptual framework consists of two parts. The first part is a presentation of the concept of user participation with a focus on ideological understandings, followed by an outline of who the users are in the concept user participation. I then present three different models of user participation before ending with a description and discussion of how user participation is usually understood in dementia care. The second part of the conceptual framework consists of an outline of important features from social constructionism that I deem relevant for a more critical exploration of user participation in the discussion. Finally, I bring the concepts together and comment on their implications for the thesis.

2.1 User participation

2.1.1 Ideological understandings of user participation

Very broadly, user participation can be described as stemming from two very different traditions, either as a democratic right of all citizens or as part of a consumerist model of healthcare (Beresford, 2012; Tritter, 2009).

Within the first discourse, the focus is on democratic and empowerment processes that have shifted the power balance in public services away from a paternalistic way of understanding and practicing health care towards a more democratic way of organizing that allows patients to be more involved in their own health care (Seim & Slettebø, 2017; Thompson, 2007). This discourse is tied to the concept of citizenship and emphasizes human rights and human worth. While health care professionals, and especially physicians, have traditionally had monopoly on decisions regarding their patients care, patients now have the right to participate in these decisions. From this discourse also comes the current emphasis in healthcare on user participation can be described as an outcome of the various social movements from the 1950s and onwards that have fought against suppressive practices and structures with the goal of empowering suppressed groups (Alm Andreassen, 2013). The successful story of the disability movement is often mentioned, as is the dehumanizing treatment of people with psychiatric disorders, which has since changed for the better (Alm Andreassen, 2013; Froestad & Ravneberg, 1991). Within this discourse, user participation is understood as solely positive, and is about much more than decision-making, in particular collective freedom, inclusiveness and equity (Thompson, 2007).

The consumerist argument for user participation presents a more critical voice with its claim that user participation must first and foremost be seen as a means of achieving more cost-effective health care services (Bradshaw, 2008; Tritter, 2009). Proponents of this view claim that the focus on user participation is a direct consequence of the introduction of New Public Management (NPM) in health care, which has led to the decentralization of services and a strong focus on aging at home in Norway (Jacobsen, 2020; Kristiansen, 2016). As such, actions are often falsely framed as user participation when they actually qualify as competition between service providers or patient complaints (Tritter, 2009). However, the consumerist discourse is not only used to criticize the concept of user participation, it is also highlighted as a means of adapting health care services to best meet each user's needs. A key word often highlighted in relation to the consumerist ideology is 'patient choice' (Tritter, 2009).

The democratic discourse and the consumerist discourse are often presented as opposites; however, Alm Andreassen (2013) notes that the distinction is not always so clear-cut. She writes that the consumer ideology used to describe user participation in the Norwegian context cannot be seen only as a marketization or consumerization because it can also be said to entail democratic aspects with the aim of making the state responsive to individual needs. On a slightly different note, Beresford (2012) notes that the distinction between the two discourses can often seem blurry because they share a 'common language of participation and involvement' (p.26).

2.1.2 Who are the users?

Several authors have tried to answer the question of who the users implied by the concept of user participation are. Some find it unproblematic, including Rønning and Solheim (1998), who describe the user as 'one who is using public services' (p.

21, my translation). Some are more critical, such as Tritter (2009) and McLaughlin (2009), who believe that one reason why user participation is often perceived as an ambiguous concept is the inconsistent language used to describe the concept. They mention words such as citizen, patient, client, and consumer that are often substituted for user. Similarly, other words for participation include involvement, decision-making and self-determination. Several authors (Bochel, Bochel, Somerville, & Worley, 2008; Thompson, 2007) problematize this by commenting that the different words used synonymously with participation often suggest different degrees of participation in the decision-making process.

The uncertainty of which term to use to describe people with dementia receiving health care services might stem from the different associations the terms have. *Patient* might have associations with paternalism and passive recipients of care, and few or no associations with autonomy and user participation. The use of the term *user* is therefore believed to be based on associations with the democratic discourse of user participation. However, as McLaughlin (2009) states, in theory the term user is more closely connected to the consumer discourse, emphasizing a person's *use* of services. He sees this as a 'consumerist version of "service user as king"' (p.1109). This underscores the difficulty in trying to enable the opposing democratic and consumerist ideologies.

Another criticism of the term user has been that it fails to address the responsibility of health care professionals (Mol, 2008). The Norwegian Patients' Rights Law (1999) defines a patient as 'a person who approaches the health and care service with a request for health care, or who the health and care service providers offer health care in each case' (§ 1-3, my translation**)**. A user is defined as 'a person who requests or receives services covered by the Health and Care Services Act which is not a health care aid under letter C' (§ 1-3, my translation**)**. Letter C in the law states that health care is 'actions that have preventive, diagnostic, treating, health-preserving, rehabilitative or nursing and care purposes, and are performed by health professionals' (§ 1-3, my translation**)**. By definition then, persons receiving home care in Norway are patients of the health care professionals.

2.1.3 Levels, degrees and models

User participation is often divided into three different levels, namely individual, collective and political (Haukelien, Møller, & Vike, 2011; Sørly, 2017). Individual user participation is limited to the extent to which individuals participate to influence the development of services and measures in their particular case (Sørly, 2017). The aim of collective user participation, on the other hand, is to influence the general service offering. Examples of methods in collective user participation are user surveys, user councils, and collaboration with interest groups (Seim & Slettebø, 2011). Political user participation refers to the participation of user groups and user organizations at a political level (Haukelien et al., 2011). It is the intention behind an action that determines whether it can be described as individual, collective or political user participation (Seim & Slettebø, 2011). In this thesis, the focus is on individual user participation.

Another way to distinguish between different forms of user participation is to look at the degree of participation. This term refers to how much users affect the decisions that are made; this itself is affected by when in the decision process they are involved (Alm Andreassen, 2013). Most models of user participation are based on descending degrees of participation. The most influential is probably Arnstein's model from 1969, referred to as Arnstein's ladder of participation. Arnstein articulates a spectrum of citizen participation, identifying eight steps that move from least aligned to most aligned with citizen participation: manipulation, therapy, informing, consultation, placation, partnership, delegated power and citizen control (see figure 1 below). Arnstein considers only the three last steps – partnership, delegated power and citizen control – to be real participation (1969). The model was originally intended to describe collective user participation with examples from federal programmes in the US but is now widely referred to in research on user participation in general. Arnstein's understanding of user participation is clearly situated within the democratic ideology.

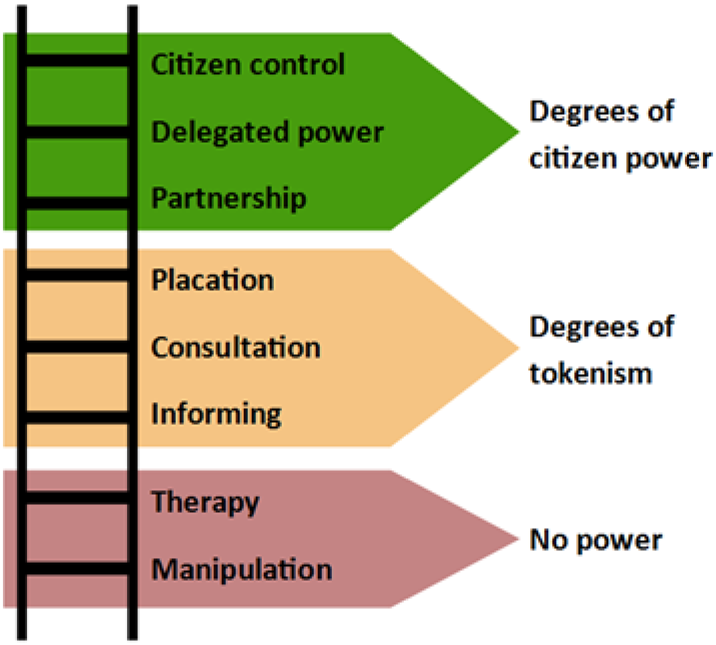

Figure 1 Arnstein's Ladder of Participation

Another model is Thompson's (2007) taxonomy of patient and public involvement. The model is based on individual and group interviews with 44 cognitively healthy citizens in England, the aim of which was to make the participants reflect upon their own, as well as the general public's, desire for involvement in healthcare consultations. Thompson describes his model as based on 'patient-desired involvement', contrary to other models which he sees as being based on 'professional-determined involvement'. The model presents the following steps, from least to most aligned with user participation: exclusion, paternalism (including information and consultation), professional-as-agent, shared decision-making and informed decision-making. In terms of the model's ideological underpinnings, Thompson describes both democratic and consumerist ideology but seems to favour the former. He also links user participation to 'person-centred policy' (p. 1298)

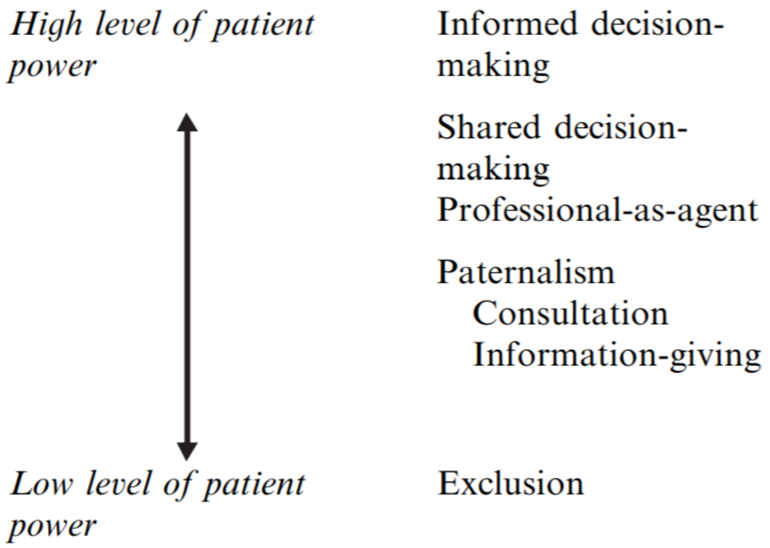

Figure 2 Thompson's taxonomy of patient and public involvement

A less hierarchical model of user participation in healthcare decisions has been proposed by Tritter (2009). Tritter is critical of the hierarchical organization of most of the models of user participation, as well as of how they ‘uncritically embrace citizen control as the ideal form of involvement’ (p. 276). According to Tritter, this understanding of user participation leads to the risk of user participation becoming a ‘tick-box activity’ as it fails to capture ‘the complexity of involvement’ (p. 276). Thus, the model proposed by Tritter aims to incorporate both more levels and more degrees of participation than the two previously mentioned models. Tritter divides involvement into three categories: direct/indirect, individual/collective and reactive/proactive. The first category is supposed to distinguish between involvement where users’ opinion is sought but not used (indirect) and involvement where users’ opinion is both sought and used in the decision-making process (direct). According to Tritter, most involvement in healthcare is indirect. The second category refers to whether the participation is happening on an individual level or a collective level. The third category, meanwhile, distinguishes between involvement that responds to already existing suggestions (reactive) and involvement that participates in creating new suggestions (proactive). Unlike Arnstein (1969) and Thompson (2007), Tritter does not base his model on an underlying ideological understanding of user participation but critically evaluates and discusses the consequences of both democratic and consumerist ideology as a basis for user participation.

	Direct		Indirect	
Individual	Proactive	Reactive	Proactive	Reactive
Collective	Proactive	Reactive	Proactive	Reactive

Tab 2-1: Tritter's Framework for Patient and Public Involvement

We can see from these models that there is no unified model of user participation. The models of Arnstein (1969) and Thompson (2007) are based on a hierarchical understanding of what qualifies as user participation, while Tritter (2009) rejects this understanding. Other differences also exist: while Arnstein (1969) would not qualify giving information as real user participation, both Thompson and Tritter see this as a form of ‘real’ participation (though it is a weak form in Thompson’s model). An important observation to make in relation to my project, is that all three models describe shared decision-making as real user participation.

2.1.4 User participation for people with dementia

The idea of user participation is widely accepted and can be said to have become a principle in dementia care. However, though it is generally thought that user participation for people with dementia is good, the implementation of this idea has met with considerable challenges in dementia care.

As shown in the literature review, there is little consensus on what user participation should mean in dementia care. Professional caregivers lack guidelines and a unified understanding of the concept, and as a result it is up to each professional caregiver to find out how to practice the idea of user participation (see Paper 1 and 3). Lack of clarity concerning user participation in dementia care specifically can be traced to a wider debate around the meaning of the concept. It has been argued that user participation works better in theory than in practice because it is essentially a slogan that is not very precise (Humerfelt, 2005; Rønning & Solheim, 1998). As shown with the models above, user participation is understood differently by different theorists, making it difficult to grasp what user participation actually is (Stewart, 2013).

However, although its meaning is unclear, the idea of user participation is based on the assumption of cognitively healthy people with the ability to make autonomous decisions. Critics argue that this understanding excludes the possibility of actual user participation for vulnerable groups with reduced capacity to make independent decisions (Helgesen et al., 2014). Nonetheless, there is evidence that user participation understood as autonomous decision-making is also prevalent in dementia care. For example, Helgesen (2013) describes how this understanding of user participation is reflected in the nursing codes of ethics with its patient-autonomy-oriented approach. Helgesen comments on the difficulty of combining this approach with patients' declining abilities to make autonomous decisions.

In terms of models or theories of user participation, there are, as far as I can see, none specifically aimed at dementia care. However, Smebye, Kirkevold and Engedal (2012) developed categories for levels of decision-making among older people with dementia., namely autonomous decisions, pseudo-autonomous decisions, delegated decisions, shared decision-making and non-participation. Their study showed variation in how people with dementia were involved in decisions, but shared decision-making was found to be the most typical pattern (Smebye et al., 2012). Shared decision-making is described as happening in situations where professional caregivers ensured the person with dementia had the information necessary to take a decision; it refers to situations where the opinion of the person with dementia made an actual impact on the decision.

The model of Smebye et al. (2012) is widely cited, and a range of different authors also identify shared decision-making as the optimal way to include people with dementia in decision-making (Samsi & Manthorpe, 2013; Sinclair et al., 2018;). However, there seems to be a difference between how professional caregivers understand of this form of decision-making and how they understand user participation, as many professional caregivers believe that the best form of user participation is autonomous decision-making (see the Literature section in this synopsis). It is also unclear as to what level of participation in shared decision-making is involved for the person with dementia. While shared decision-making ideally means taking a person's wishes into account, it could also mean convincing a person with dementia to go along with decisions that have already been made (Norheim & Vinsnes, 2008). All three theoretical models of user participation mentioned above see shared decision-making as legitimate user participation. In Arnstein's (1969) model, partnership is the lowest level of what she considers 'real' user participation, while in Thompson's (2007) model, shared decision-making is the second highest form of user participation. Thompson (2007) sees shared decision-making as a process in which the patient influences both the process and the outcome of the decision. Decisions taken by the professional holding the expert knowledge, while incorporating patient preferences fall under the 'professional-as-agent' decision-making model. However, for Arnstein, Thompson, and Tritter, user participation does seem to be about something more than the act of deciding.

Another conceptual framework that is often mentioned in relation to user participation, is person-centred policy or care (Helgesen, 2013; Thompson, 2007). Since the 1990s, when it was developed by Kitwood (1997), the theory person-centred care has gained influence in dementia care. In nursing, the theory has been translated into the VIPS-model in dementia care (Røsvik, Kirkevold, Engedal, Brooker, & Kirkevold, 2011). The VIPS model is mostly used in institutional care but has also recently been brought into home care (Janne Røsvik, personal communication, May 5, 2020). Making independent decisions is considered part of person-centred care (Edvardsson, Winblad, & Sandman, 2008). Person-centred care and VIPS have similarities with user participation, which emphasizes the value of all human beings and personal choice. Yet, as I showed in Paper 3, professional caregivers often see care and user participation as conflicting ideals. This raises important questions as to what user participation means in home-based dementia care. What might it contribute that is not already there in the form of person-centred care or other theories and approaches in nursing? One possible answer is suggested by Beresford (2012) who addresses the particularity of user participation by underlining the importance of treating it as an ideological matter connected to ideas of democracy, power, and citizenship. He claims that failure to do so will lead to a technical use of the term. Tritter (2009) similarly explains that the ideological basis for user participation must be clarified, as the democratic and consumerist ideologies have very different aims and outcomes. Based on this, it can be argued that both person-centred care and shared decision-making, despite their overlaps with user participation, represent something different than user participation.

In sum, this section has showed that user participation is not an easy concept to grasp, either in general or in relation to dementia care. Different and opposing ideologies are used to defend the focus on user participation in health care, and theoretical models of user participation portray the concept differently. In dementia care, user participation becomes especially difficult because it is highly associated with autonomy and autonomous decision-making and people with dementia have an increased need for protection and care as the disease progresses. There is no model of user participation specifically related to dementia care; however, because user participation is often understood as participation in decision-making, as well as individualized care, we can see that user participation overlaps with both shared decision-making and person-centred care. Nevertheless, it is my understanding that although user participation contains aspects of both these models (or is it maybe the other way around?), user participation is also distinctly different from either one.

2.2 Social constructionism

Social constructionism has been chosen as the second conceptual lens in this synopsis. As I worked on this thesis, I came to see that user participation is a very normative concept in dementia care (see point 3.6 for a description of how this realization came about). Attempts to explore its meaning are often construed as criticism, showing the high value placed on the concept. This is something I mentioned in all three research papers, but because of the papers' focus and the limited space available, I did not explore it any further. The normativity of the concept of user participation, as described above, seems to have affected and possibly changed ideas about what constitutes good care for people with dementia. Social constructionism seems a good choice as it aims to 'challenge' ideas that are taken for granted.

Social constructionism is a name given to various post-modern philosophies. There is not one school of thought in social constructionism, and the philosophers now viewed as representatives of this kind of theory did not view themselves as such. Nonetheless, Foucault and Derrida are often seen as two of the biggest influences of this framework (Berger & Luckmann, 1966, Gergen, 1999). The term social constructionism itself was introduced by the American sociologists Berger and Luckmann (1966) in their book *The Social Construction of Reality*. They underlined the importance of the mutual influence between society and humans: we affect society and we are affected by society.

Social constructionism is concerned with what counts as 'truth' in any given society at any given time. The belief is that there is not one truth out there independent of any social structure. Rather, there are multiple 'truths' within different contexts, 'useful for various people at various times' (Gergen, 1999, p. 12). Knowledge is thus a set of constructions that is shared at a certain time within a certain group. Foucault (2005/1966) refers to these constructions as discourses, a discourse being a culture's understanding of reality, and explains that discourses determine what is possible to say, as well as what we consider to be true and natural. Truths are useful within their specific context but can become oppressive if they become general truths. Noticing general truths can be difficult, especially if they are shared by everyone around you. Challenging what a certain group takes for granted can also be quite controversial, as it often goes beyond what is considered good and true at the time (Gergen, 1999).

This leads us to another core aspect of social constructionism, namely power. The philosophy itself grew out of a desire to question things that we take for granted, and especially to challenge power relations between those with power and the marginalized (Gergen, 1999). Foucault's ideas on power allow us to investigate and find power in places we would not normally look for it. For instance, Foucault (2012/1977) distinguishes between repressive power and normalizing power. Repressive power is power that makes us do things we do not want to do – an example would be professional caregivers coercing patients to take medication they do not want to take. Normalizing power, encapsulated in Foucault's concept of governmentality, refers to a less noticeable power in society, namely the forces that make you want to do what society wants you to do (Dean, 2010). It refers to expectations that are so ingrained in us that they have become part of our own assumptions, values, and beliefs, and thus construct how we understand the world and ourselves (Heggen & Engebretsen, 2012). A hypothesis in this thesis is that user participation is seen as good and desirable in dementia care. Contrary to repressive power, which is manifested in the form of specific people or institutions, the normalizing power of user participation is everywhere: in our families, in our educational system, in policy documents, and in the organization of home care.

Normalizing power also affects how we understand ourselves and the people around us. Hacking (1999) used the term 'interactive kind' to theorize how the labels we put on people affect what they think about themselves. Interactive kinds interact with those who have been classified in a particular way, not because the classified is aware of the classifications and internalizes them, but rather through surrounding institutions and practices. Hacking uses the example of the construction of 'women refugees' and of the 'child-viewer' to show how the construction of an idea of a person ends with the idea being taken up by the persons who fit into those categories. In relation to dementia care, the label demented is a clear example of an interactive kind that has clearly affected how people with dementia think about themselves and their abilities. Hacking notes that while the labels we use often seem inevitable, they can appear highly contingent in retrospect.

The third aspect that needs to be mentioned in relation to social constructionism, is language. Wittgenstein (1978), who has been an important inspiration in social constructionism, was especially interested in the language we use and the meaning we read into it. He claimed that the meaning of a word is its use in language, as opposed to it being found and made by the interpretive subject (Wittgenstein, 1978). If there is no objective truth out there, the world comes to be what it is for us through language. In social constructionism, the meaning of any concept depends on its relation to other concepts within a given language structure. Our constructions of different concepts therefore always also imply what they are not. This idea is built on the language philosophy of Saussure (Belsey, 2013) and is what Derrida (1997) terms binary oppositions. Said differently, in social constructionism it is believed that meaning depends on difference (Belsey, 2013). An important aspect of binary oppositions is that they are always value laden. This is especially true in the construction of more abstract concepts, such as user participation. Thus, user participation is often understood by professional caregivers in dementia care as the opposite of coercion (see page 13 in this synopsis). Since we cannot construct the meaning of these concepts by looking at physical representations of them, we construct them as a positive ideal based on what they are not. Language thus both enables and constrains. It creates room for shared understandings but constrains us from speaking about and thus seeing things differently. An important question in social constructionism is why certain binaries came to be.

Hacking (1999) explains that there are various forms of constructionism. While they all agree that whatever phenomenon is studied must be understood as historically situated, they differ in terms of what they want to do, and consider possible to do, with this knowledge. While some social constructionists simply aim to state knowledge (and thus do not present a much different view than historians), others aim to change practice. This latter form of social constructionism can take the form of either refuting or unmasking an idea. Refuting refers to showing that a thesis is false. Hacking’s metaphor unmasking is a reference to Mannheim’s (1925/1952, in Hacking, 1999) term *enthüllung,* usually translated as *exposing*. In unmasking a concept, the aim is to expose the extra-theoretical functions that a it serves. The belief is that showing the purposes that an idea serves will cause it to lose some of its appeal. It is this latter form of constructionism as exposing that I am aiming for in this synopsis.

Social constructionism is therefore mostly used to argue that certain ideas, concepts, and understandings of phenomena are socially constructed rather than that the phenomena themselves are socially constructed. This means that the practices of user participation, such as shared decision-making or convincing a patient to do something, happen independently of how we label the practice. However, it does not become user participation before we label it as such. Moreover, labelling practices user participation might in turn change them. The point of applying the lens of social constructionism in this thesis is therefore to explore how constructions of user participation affect the practice of home-based dementia care.

2.3 Theoretical implications for the thesis

I have now presented two concepts which, in different ways, provide perspectives on the understanding and practice of user participation for people with dementia living at home. The theories will serve different purposes in the synopsis. Models and discourses of user participation will be used for reference when exploring how user participation is understood and practiced. An aspect of the analysis will be to explore how the understanding and practice of user participation relate to the most well-acknowledged models of user participation, as well as to explore whether these understandings and practices align most with the democratic or consumerist ideology of user participation, or maybe a combination of these.

Social constructionism will be used to explore ideas of user participation and show how these ideas are conditioned by certain ideological frameworks. My analysis takes as its point of departure the fact that participation has become a 'truth' in dementia care. As social constructionism is concerned with how ideas are often constructed as opposites through language, as well as with questioning these 'truths', I find it suitable for revealing the normativity that exists around the concept of user participation in dementia care. In the discussion, I will show how discourses about user participation affect the practice of that concept.

In this thesis, the term user participation will be used instead of patient participation. This choice is based on Beresford's (2012) argument concerning the ideological origins of the term, which I believe is better reflected in the term user participation than patient participation, as user participation in its original sense, as well as in the way it is portrayed in policy papers, relates to the ideological discourse of user participation. However, the term patient will be used to refer to the people receiving home care since this reflects the preference of the professional caregivers I interviewed and my own conviction of the importance of not hiding the suffering involved in a dementia diagnosis.

A main argument in this synopsis is that there are a variety of understandings of user participation. I therefore refer to different and opposing definitions, theoretical models and ideologies in the theory chapter to show the breadth of the field of user participation, as well as the tensions that exist. I do not base my understanding of user participation on any one specific definition, model or ideology. Rather, these frameworks will be used to show how they possibly affect different constructions of user participation in home-based dementia care.

However, though I will not define user participation, it could be argued that the term user participation begs the question ‘participation in what?’ As I argued earlier in the text, as well as in the individual papers, the answer to that question in relation to dementia care seems to be ‘decision-making’. As to what participation in decision-making must look like for it to be considered user participation, I will leave that question open for now and address again in the discussion.

3 Design and methods

3.1 Descriptive, explorative and interpretive

The purpose of this study was to explore how user participation is understood and practiced in home-based dementia care. The thesis has an explorative, descriptive and interpretive design, and is based on qualitative research conducted in two municipalities in southeast Norway. Applying an explorative, descriptive and interpretive design is recommended when the there is little research on a topic, a topic in a certain context (Blaikie, 2000). The research consists of interviews with three different groups of informants and a literature review. However, the project was originally designed differently, and the originally envisioned design affected choices made in relation to both research questions and methods. As the study went along and I developed as a researcher, I also saw the need to include new conceptual perspectives in this synopsis. This chapter describes how this project was originally designed, as well as my own development as a researcher and how this affected the ontological positioning.

3.2 Case study

The project was initially set up as a best case study. A case study is understood as a study that applies various methods to investigate a phenomenon in-depth (Flyvbjerg, 2006). The decision of applying a case study was made on the belief that all knowledge of human affair is context-dependent (Flyvbjerg, 2006), and that in-depth study of the dementia care in a few municipalities could give us valuable information of the concept of user participation. This is based on the assumption in case study research designs that analytic rationality needs to be coupled with experience from specific cases if we are to excel from novices to experts on a topic (Flyvbjerg, 2006). The choice of case study was therefore based on the belief of the need to study user participation in context.

The term best case is a modification of Flyvbjerg's (2006) term critical cases. The latter term refers to outlier cases in either a positive or a negative direction; the choice to concentrate on these cases is justified because they give richer descriptions than average cases. The choice of best case municipalities was based on a desire to describe good examples of user participation. Factors that inhibit user participation in these municipalities may have a transfer value because problems with implementation will probably also apply to other municipalities. There is no exact method of how to choose critical cases, but the idea was to find municipalities that we believed would be good at providing home-based dementia care, as we believed there would be a link between good dementia care and a developed understanding of user participation.

Flyvbjerg (2006) writes that 'good social science is problem-driven and not methodology-driven, in the sense that it employs those methods which for a given problematic best helps answer the research questions at hand' (p. 27). In this project, data was to be collected from interviews with three different groups of informants, in addition to a questionnaire distributed to professional caregivers in home-based dementia care services in two municipalities.

The questionnaire was created in Questback, and approval was sought from NSD. We developed the questionnaire ourselves, building on the answers from the interviews with the professional caregivers. The questionnaire included both open ended questions and multiple choice. The aim was to seek descriptions of how user participation was understood and practiced. It included questions such as whether or not the professional caregivers had received training in user participation, whether they had guidelines, how they understood user participation and how they practiced it with patients with dementia. Because the answers were to be categorized in terms of educational level and work experience with people with dementia, the questionnaire would have allowed us to compare the informants' descriptions of user participation to these categories. The questionnaire was distributed in May 2016 by e-mail to all the professional caregivers in home care in the two municipalities. Unfortunately, the response rate was so low (23%, or 88 informants out of 378 in total) that we decided not to include the questionnaire in the study.

3.3 Municipalities and participants

Early in the process of selecting the municipalities, I was in a meeting with a representative of the Norwegian Health Association (Nasjonalforeningen for Folkehelsen) to explore which municipalities stood out positively in terms of their dementia care. We discussed the characteristics of these municipalities, and based on this discussion I ended up with the following criteria for inclusion:

- Must have a dementia team with a geriatric physician
- Must have a day care centre for people with dementia
- Must have groups and/or courses for family/relatives

Several municipalities had both dementia teams and day care centres for people with dementia, but few had a geriatric physician in the dementia team. I eventually ended up with only two municipalities, which I then contacted via e-mail with information about the project and an invitation to participate. The first contact with both municipalities was with a member of the dementia team. A dementia team is a multidisciplinary resource group at the municipal level responsible for the follow up of people with dementia in the municipality (Gausdal & Michelet, 2011). Typical tasks consist of home visits, evaluation of memory problems, contact with family caregivers, assessment of care needs, and courses for both professional and family caregivers. Dementia teams can receive inquiries from anyone, including family members, neighbours, home care providers, physicians, and hospitals.

Both municipalities were willing to participate, and we scheduled interviews with the members of the dementia teams. These participants then suggested both other care professionals and patients that they thought would be a good fit for the project. The selection criteria for the former were that they worked in home-based dementia care and that their colleagues believed them to be good at their job.

In terms of persons with dementia, the inclusion criteria were the following:

- Must have mild dementia,

- Must be able to communicate verbally,
- Must receive services from home care and/or attend a day care centre,
- Must have a family caregiver who would also like to participate.

The persons with dementia and their family caregivers were contacted by a member of the dementia team about possible participation, and their contact information was forwarded to me if they were willing to participate.

In the following I will present the municipalities and the informants.

Municipality A

This is a municipality with between 10 000 and 20 000 inhabitants. The municipality had two day care centres for people with dementia. At the time of the interviews, most of the professional caregivers in dementia care had either completed or were in the process of completing the Dementia Care ABC course, which is aimed at strengthening professional caregivers' knowledge of dementia and how to provide holistic dementia care. This also included the drivers who picked people with dementia up at home and drove them to the day care centre. The dementia team in this municipality was established in 2012, and included a dementia coordinator with a nursing background, a geriatric physician, and a nurse assistant. A new dementia centre opened in this municipality in 2016.

Municipality B

This municipality has more than 50 000 inhabitants. The municipality had one supported housing[1] facility exclusively for people with dementia, staffed 24/7. There was one day care centre exclusively for people with dementia and one that was mixed. The dementia team in this municipality had been established in 2011

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[1] Supported housing is an umbrella term for several types of housing ranging from homes for healthy elderly with no staff on site to more institutional-style buildings with care staff employed 24/7 (Daatland et al., 2015).

and was staffed by one nurse and one geriatric physician. Within regular home care, they had established something they referred to as a ‘dementia routes’. This was a way of organizing care for people with dementia so that they got the same professional caregivers every day. The nurses working in the dementia routes were referred to as ‘dementia contacts’. The dementia contacts on the dementia route had more time than regular home care providers.

Informants[2]

There are three groups of informants in this study.

I. **Seven persons with dementia**: five men and two women. Their ages ranged from 67 to 89. Five lived at home with their spouse, one lived at home with his spouse and teenage children, and one lived in a supported housing facility. They were recruited on the basis of having mild dementia, but formal tests were not applied to assess the professional caregivers’ assessment. Neither of the dementia teams were able to find eligible patients receiving home care, as the individuals in this group were all described as too ill. The final sample of persons with dementia therefore consisted of people with dementia who were or had been in contact with the dementia teams and who attended a day care centre. The interviews with the persons with dementia therefore focus on their participation at home and at the day care centres.

II. **Nine family caregivers of the persons with dementia:** five wives, one husband, one son in his 60s, one daughter-in-law in her 60s, and one teenage daughter.

III. **12 professional caregivers working in home care:** two geriatric physicians, two nurses and one nurse assistant working in dementia teams; one nurse assistant and two nurses working in regular home care; two nurse managers

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[2] I have chosen to use the term informants instead of participants as the latter is very similar to the word participation, which is repeated often throughout this synopsis.

of elderly care in the municipality; one nurse assistant working in a day care centre for people with dementia; and one nurse working in a supported housing facility, which in Norway is considered to be the patients' own home.

3.4 Hermeneutic phenomenology

Case studies are used for projects with all kinds of different ontological assumptions. This can be seen in the fact that there are both quantitative and qualitative case studies and in how the term case study has been used by both positivists and interpretivists (Yin, 2017). This project was initially conceptualized within a hermeneutic phenomenological framework. Hermeneutic phenomenological research studies meaning in context and informants 'are naturally engaged in their worlds' (van Manen, 1990, p.18). This aligns with the idea of best case design.

Hermeneutic phenomenology is a branch of interpretive phenomenology that combines a phenomenological and a hermeneutic approach, and important contributors are Heidegger, Gadamer and van Manen (Thomassen 2020; Zahavi, 2019). There are big debates as to what hermeneutic phenomenology is and how it differs from phenomenology. Some see it as the working methodology of phenomenology, differing from phenomenology in having added the aspect of interpretation to the phenomenological aim of description (Laverty, 2003; van Manen, 1990, 2017a, 2017b). Others argue that interpretation also is a vital part of Husserlian phenomenology (Zahavi, 2019). The debate is too complex to enter into at length in the present synopsis, and it is possibly not necessary either, as there seems to be agreement that hermeneutic phenomenology encompasses both description and interpretation (van Manen, 1990; Zahavi, 2019).

According to van Manen (1990) the aim of hermeneutic phenomenology is to reach an understanding of the essence of the phenomenon under investigation through descriptions of people's lived experience with the phenomenon. To explain what essence is, he refers to Merleau-Ponty (1962) who writes that essence should not be understood as some mystic entity of meaning, it simply refers to the description of a phenomenon. Zahavi (2019) agrees with van Manen’s commitment to searching for the essence of a phenomenon through our lived experience of it but adds that this cannot be the final aim of phenomenology. He argues that if description of the essence of a phenomenon was our aim, it would be superfluous, as this aim would already be reached in our experience of the phenomenon. Zahavi therefore argues that the aim of phenomenological research is to ‘provide us with a deeper understanding of fundamental ontological questions’ (Zahavi, 2019, p. 902).

If the aim, or means to reach the aim, of hermeneutic phenomenology is to find the essence of the phenomenon, this implies that truth exists ‘out there’ (van Manen, 2017b). However, unlike the realist position, hermeneutic phenomenology believes that the truth can only be accessed through subjective experiences of it (Thomassen, 2020). The consequence of this is that epistemologically, hermeneutic phenomenology is based on an interpretivist paradigm in which the relationship between the researcher and what can be known are seen as inseparable (Laverty, 2003). This implies that researchers’ ability to understand the research participants depends on the formers’ own pre-understandings. Having a pre-understanding of the topic can open up room for more in-depth engagement with the topic (Armour, Rivaux, & Bell, 2009). However, awareness of one’s pre-understandings is seen as vital in order to avoid projecting one’s own values and prejudices onto interpretations of the lived experiences of the informants. For example, to use one of van Manen’s examples, it is difficult to reach an understanding of parenthood without being a parent oneself. This does not imply that a researcher is expected to have a lived experience of the topic under investigation, but it is seen as a strength. This aligns with the phenomenological idea of bracketing, which entails setting aside theoretical presuppositions in favour of lived experience (Zahavi, 2019).

In this study, we chose hermeneutic phenomenology because we[3] wanted to explore the experiences of user participation from a first-person perspective. Our

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[3] ‘We’ refers to my supervisors and myself. As I will explain in 3.7 my supervisors created the initial design and project descriptions. I therefore use ‘we’ when describing choices made early on in the

starting point was that there are truths concerning user participation. Though user participation can be said to be a recently created concept, there are dominant ways of understanding this concept that affect practice in certain ways. By exploring lived experiences of user participation, we were hoping to get a deeper understanding of the concept of user participation, or in phenomenological terms, to get closer to the essence of user participation.

A concluding remark must be made regarding how I can defend classifying a project on *user participation* as phenomenological. In her chapter 'The many faces of phenomenology', Thomassen (2020) describes how both phenomenology and hermeneutics have given rise to very different approaches, some closer to the work of the 'founders' of phenomenology and hermeneutics than others. This is worth noting, as some would argue that the study of an abstract concept such as user participation is not compatible with phenomenology, as it is not directly accessible to us through our un-reflected experience of the world. It cannot be said to be an object of experience in the same way as a child's smile, for example, or grief. Thomassen refers to Gschwandtner (2018, in Thomassen 2020), who has argued that these phenomena can still be studied phenomenologically, as they are still given to us through our experience of them. Thomassen argues that a broadening of the horizon of phenomenology is far from a betrayal of its original intentions, but rather 'can provide opportunities for exploring practice-relevant situations and concepts' (p. 129, my translation) that were previously unthinkable.

3.5 Hermeneutic phenomenological methods

van Manen (1990) has written that 'the method of phenomenology and hermeneutics is that there is no method' (p. 30). He describes how hermeneutic phenomenological studies are based on skills carefully developed by the researcher that are dependent on pre-understandings, writing skills, and sensitivity to the topic. However, this is not to say that anything goes. First, the methods used must

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project, as well as in decisions related to the individual papers, as the papers were written by the three of us.

allow for the ontological and epistemological underpinnings of hermeneutic phenomenology. This limits the methodological choices, obviously excluding methods such as quantitative measurements but also structured interviews that would not allow for studying the lived experience of the informants (van Manen, 1990; Armour et al., 2009). As I will show below, van Manen does include some advice for less experienced researchers regarding how to best collect and analyse data in a hermeneutic phenomenological project.

Whichever method is chosen, the focus of a phenomenological study should be on the meaning of the phenomenon. In explaining what it means to focus on meaning, van Manen (1990) uses the example of learning, noting that a phenomenological study would not ask *how* children learnt specific material. Instead, it would look for the nature or essence of learning, to get a better understanding of what learning is like for children. If we relate this to my study, this means that I am not interested in the informants' private stories, such as why they became nurses, or when they got dementia. My focus is on the meaning of user participation, and I believe this can be determined by exploring how my informants have experienced this phenomenon.

As its aim is to uncover the essence of a concept, a hermeneutic phenomenological approach can be considered inductive (Lindseth and Norberg, 2004; van Manen, 1990). An inductive approach refers to not trying to fit the phenomenon into pre-existing theories, as we need to interpret before we can understand. Specifically, this means the construction of interview guides and the analysis of interview transcripts should not be guided initially by theory or reflect the researcher's unconscious presupposition on the topic. This meets the phenomenological requirements of bracketing. In a hermeneutic phenomenological spirit, both the literature review and the interviews in my study were mainly inductive. This will be explained in more detail under each separate heading.

van Manen (1990) writes at length about the significance of research questions in hermeneutic phenomenological studies. As the research question should function as a kind of steering wheel that brings us closer to the essence of the phenomenon, it should be possible to rephrase the question as ‘what is something like?’ The research question that has followed me throughout this project has been ‘how is user participation understood and practiced in home-based dementia care?’ This question could easily have been written as ‘what is user participation like in home-based dementia care?’ The fact that it has followed me throughout the project and not been changed relates to another one of van Manen’s points about research questions, namely that they must be clear. He claims that ambiguity in the research question can lead to unfocused data collection that will produce superficial data, failing to elicit descriptions of the nature of the phenomenon in question.

Finally, van Manen (1990) addresses the researcher’s role in relation to the research question. As van Manen sees it, in a true hermeneutic phenomenological study, the researcher engages with the research question in a deep manner: it should be ‘lived’ (van Manen, 1990). To live a research question means to ponder, examine, and go back to the question repeatedly until hopefully this questioning is able to reveal some of the true nature of the phenomenon in question. I believe I have succeeded in this by letting myself be troubled by the research question. The quest to find out what user participation actually is in home-based dementia care has been more than a mere job. And though I have hopefully been able, with this thesis, to shed some light on the nature of user participation, I continue to ponder the question. van Manen (1990) writes that phenomenological texts are seldom conclusive and might give an impression of missing the punch of a definite argument. Thus, my work will probably disappoint those looking for a definite and final answer to the question of what user participation is. However, I hope I can succeed to invite a dialogical response from the reader.

In the following, I will outline the specific methods and methodological procedures used in my study, as well as how these methods align with the aims and assumptions of hermeneutic phenomenology.

3.5.1 Critical interpretive synthesis

Data in hermeneutic phenomenological studies are typically human experiences. As such, conducting a literature review cannot be said to be a typical hermeneutic phenomenological method. However, the type of literature review chosen is based on many of the same assumptions as that underlying hermeneutic phenomenological research.

The literature review was inspired by a method known as critical interpretive synthesis, which was developed by Dixon-Woods et al. (2006) in response to the lack of review methods that could deal with large samples of both qualitative and quantitative studies using a variety of methods. In their study, Dixon-Woods et al. claim that critical interpretive synthesis is especially applicable when the literature on the topic of interest is large, complex, and diverse, appearing across a variety of fields, and lacking a unifying definition or operationalization. Critical interpretive synthesis therefore seemed an appropriate review method for the current study, as the concept of user participation is poorly defined and the investigation of it would require the inclusion of several overlapping terms.

The main difference between critical interpretive synthesis and traditional systematic reviews is the distinction between aggregation and interpretation of evidence. Critical interpretive synthesis has a strong foundation in the latter, but it also aims to generate new concepts and theory by critiquing and reconceptualizing the concept that is being studied (Dixon-Woods et al., 2006). The double aim of describing and interpreting is in line with hermeneutic phenomenology. Since we did not generate new theory in our review, but otherwise followed the procedures of critical interpretive synthesis, we have chosen to say that the review is inspired by this method, rather than being an example of it.

To explore complex topics within a given field that lack clear definitions or clear boundaries, Dixon-Woods et al. (2006) suggest having a broad starting point, without *a priori* definitions of either review questions or categories, in order to not miss out on important information. The focus, and therefore the review questions, is then guided by the results in an iterative process. This deviates from the hermeneutic phenomenological aim of clarity in research questions, but it aligns with the approach’s inductive logic. The literature review can also be seen as a way for me as researcher to broaden my pre-understandings of user participation before addressing the topic in a more hermeneutic phenomenological way.

To demonstrate their method, Dixon-Woods et al. (2006) use examples from their review of literature on access to healthcare for vulnerable groups. This topic has been researched extensively in a variety of fields, with many different methods, yet no unifying definition or operationalization exists. The initial research question in their review was therefore ‘tentative, fuzzy and contested at the outset’ (Dixon-Woods et al., 2006, p.3). It included a focus on how best to understand access to health care for vulnerable groups and a focus on equity. The review question was then modified in response to the findings. In our review, the initial aim was to see how research has treated the topic of user participation for people with dementia living at home. We searched broadly, using multiple terms overlapping with user participation. At a later stage, based on the literature that we found, we ended up with the following research question: What factors influence user participation for people with dementia living at home? The details of the search process are outlined in paper 1.

The analysis was inductive and not guided by theory. First, the included studies were read and reread to give an overview of the material. Most of the included studies had a different focus than this review, so they were read for interpretations beyond those reported by the authors. The first author began by coding each result section and extracting themes. Key information such as aim, methods, participant characteristics and concept explored were extracted, and a summary was written of each article. The results were eventually organized into five different categories representing factors of user participation for people with dementia living at home. This gradually also became the research question of the review.

In literature studies, there is an ongoing debate about the advantages of qualitative and quantitative methods similar to the one found elsewhere in the research world. Literature studies like mine, whose findings are essentially qualitative, have been criticized for trying to pass themselves off as quantitative (Dixon-Woods et al., 2006). The criticism is that one cannot measure the quality of these studies as easily as with quantitative studies, and that the rigorous search and reporting system removes the essence of the findings (Dixon-Woods et al., 2006). In line with an interpretivist ontology, Dixon-Woods et al. (2006) rhetorically ask whether not wanting to generalize is necessarily a negative thing, comparing it to how the same set of interview transcripts will yield different results under the scrutiny of different researchers. They call it a 'dilemma between the "answerable" question and the "meaningful" question' (p.11). Addressing a similar issue, van Manen (1990) writes that the question should perhaps not be what we can do with a hermeneutic phenomenological study but what such as study can do with us.

3.5.2 Interviews

The interviews in this study took place in spring 2015 and spring 2016. Semi-structured interviews were used to interview the persons with dementia (n=7), their family caregivers (n=9), and the professional caregivers working in homebased dementia care (n=12). The findings from these interviews are presented in Papers 2 and 3. All interviews were audiotaped and transcribed verbatim and analysed using a combination of NVIVO 11 and manual analysis. I chose to include the latter method because I was new to NVIVO, and while it helped me to get an overview of the material, I found that I sometimes also needed a pen and a paper to avoid letting the software guide my analysis too much.

A number of researchers have highlighted interviews as a good phenomenological method (Creswell & Poth, 2016; Laverty, 2003; Sloan & Bowe, 2014). Though van Manen (1990) has said that there is no method in hermeneutic phenomenology, he seems to favour in-depth interviews in his various studies employing hermeneutic phenomenology. The aim of a hermeneutic phenomenological interview is to gather experiential descriptions of a phenomenon (van Manen, 1990), and the number of informants is therefore usually quite small. Creswell and Poth (2016) suggest ten informants as being appropriate.

When creating the interview guide, I sought support from my two supervisors to assure that possible lacunae in my pre-understandings of dementia and user participation would not lead me to construct a shallow interview guide failing to ask questions that would get to the essence of user participation in dementia care. One of my supervisors is a registered nurse and has both worked in dementia care and written extensively on various topics related to elderly care. The other supervisor has extensive knowledge about the theoretical foundations of user participation, as well as related debates, and has also published a number a research articles on the topic. I also asked the informants who had direct lived experience with the topic to comment on the interview guide after the interviews. Had I asked the questions that best brought forward the lived experience of user participation and dementia? Most of them had suggestions for small changes I could make to improve the interview guide. One example of a change I made based on these suggestions is that I added a question about the Coordination Reform for the professional caregivers.

In a hermeneutic phenomenological spirit, the interviews were mainly inductive and not informed by specific theories. van Manen (1990) writes that the aim is not to inform practice with a pre-chosen theory, but that theory is used to enlighten practice after reflection on the practice has taken place. The aim with the interviews was to bring the informants' understandings to the fore, without trying to fit them into pre-determined theories. For example, the concept of user participation was not defined for the professional caregivers. However, because of the abstract nature of the concept, it had to be defined for the persons with dementia and their family caregivers and was therefore defined as participation in decision-making. Apart from that, these interviews were largely conducted in an inductive manner with the aim of exploring the informants' lived experiences of user participation. As mentioned in Papers 2 and 3, the interview guides did include some specific questions; however, the aim of these questions was to elicit information on how the informants understood, practiced and experienced participation.

In an attempt at inductive, open interviewing, I aimed at eliciting a rich number of examples of the experiences with user participation. In line with van Manen's suggestion of eliciting specific descriptions that capture the mood, feelings and emotions that a person's experience evoked, I asked informants for examples of what they were describing. In retrospect, I believe I captured several good hermeneutic phenomenological descriptions. For example, a nurse quoted in paper 3 described how it felt to realize one afternoon that three persons with dementia had stayed in bed the whole day because of what she thought was her colleagues' misunderstanding of user participation (page 6 in paper 3). Her language is expressive and emotional. Another example of a hermeneutic phenomenological quote is from the man with dementia referred to as Lars in paper 2, who described how making decisions gives him anxiety and stomach pain (page 153 in paper 2). Most importantly, I believe both these descriptions serve as important examples of the nature of user participation.

3.5.3 Thematic analysis

Thematic analysis was chosen as the method of analysis for the interviews. Thematic analysis is mentioned by van Manen (1990) as a good way of seeking meaning in interviews. He describes a theme as a means to get to the essence of a phenomenon. By examining and reflecting upon the written interview, the researcher can 'unearth something "telling", something "meaningful", something "thematic"' (van Manen, 1990, p. 86). van Manen suggests different ways to go about a hermeneutic phenomenological thematic analysis, such as focusing on the whole, selecting phrases that stand out, or interpreting every sentence in the text. As I understand it, what is most important is not the specific method but rather finding themes that can describe the essence of the phenomenon in question.

I decided to follow Braun and Clarke (2006), who offer a step-by-step yet flexible guide to performing thematic analysis. Braun and Clarke argue that thematic analysis needs to be 'named and claimed' because although this kind of analysis is widely used, it lacks a definition and a 'manual' for how to perform it. For this reason, research that uses thematic analysis often claims to use something else (for example content analysis or grounded theory); or often a researcher will only claim to have done qualitative analysis where themes emerged. Clarity in the research process is important in order for other researchers to evaluate the work and to compare it with work on similar topics. Braun and Clarke (2006) have therefore developed a five-step method for conducting thematic analysis.

The method consists of the five following steps: familiarising oneself with the data, generating initial codes, searching for themes, reviewing the themes, defining and naming themes and producing the report. These steps, however, are not performed in a linear process; instead, the researcher jumps back and forth between them, much like in the hermeneutic circle. This entails shifting the gaze from the smaller units of meaning to the bigger whole and then back to the smaller units and so on. Also, just like in the hermeneutic circle, it is up to the researcher to decide when to stop the analysis process.

In line with a hermeneutic phenomenological approach to writing up results, the themes were both descriptive and expressed in everyday language (Lindseth & Norberg, 2004). I did not create abstract categories as themes. For example, in analysing the interviews with the persons with dementia, the first list of themes produced was quite extensive and included themes such as ‘my spouse is very kind’, ‘I can’t complain’, and ‘the caregivers are doing their best’. An example of a final theme in my analysis is ‘placing the group’s interest before individual needs’.

3.6 Reflexivity

Qualitative research never aims to be objective, but it is important for researchers to be aware of their own subjectivity and how it affects the research design and research process. This is referred to as reflexivity (Creswell & Poth, 2016). Reflexivity refers both to how the researcher’s physical presence in the field affects the informants and to how the researcher’s choices in relation to design, theories, method and interpretation influence the results.

Pillow (2003) claims that there are four main strategies for understanding reflexivity in qualitative research. These are ‘reflexivity as recognition of self’, ‘reflexivity as recognition of other’, ‘reflexivity as truth’, and ‘reflexivity as transcendence'. The two first refer to what the researcher and the informants bring to the table. It is evident that my age, gender, work experience, and education affect how I relate to the people I am interviewing; the relation between me and an older male geriatric physician will naturally be of a different character than the relation between me and a female nurse assistant my own age. Likewise, in the interviews with the people with dementia, I was the age of their grandchildren, I was a stranger, I spoke a different dialect and so forth. While the different relative positions of the people I interviewed undoubtedly shaped my data, I wish to focus more on what Pillow calls 'reflexivity as truth', as this has shaped my entire research process. Reflexivity as truth refers to the process of questioning what counts as 'truth' in a given context. This has come to be a crucial point in my research, and I will now elaborate on how my reflexivity as truth has developed.

My entry into this project was by applying to a PhD position for an already established project. My supervisors wrote the project description and applied for funding to hire a PhD student, and I therefore did not participate in the planning of this project. With a master's in developmental psychology, I had no theoretical education on the concept of user participation. My knowledge of dementia was broader, having written a master's thesis about homesickness in people with dementia and having worked in various services for people with dementia, including nursing homes, home care and supported housing. In addition, I am also a trained Marte Meo dementia supervisor. This means that I did not enter this project as a blank slate with no preconceptions of what constitutes good dementia care and how user participation should be understood and practiced in this context. I had been present in many situations involving the dilemma of whether or not to respect the patient's wishes. More directly, I had witnessed situations of both coercion and neglect that left a deep impression on me.

Nonetheless, I was rather naïve when beginning my work on this project, and I spent the first few months trying to get an overview of the literature on user participation. The result of this process is Paper 1, in which I explore factors affecting user participation in home-based dementia care. Interested in the essence of user participation in home-based dementia care, I devoted a lot of time initially to trying to determine what user participation *is* before going out and asking my informants the same question.

One of my first discoveries was that user participation is perceived as a vague concept; it was as if no one knew what it really was. It is believed to refer to participation in decision-making. But at what level? I understood there were disagreements. At the same time, there seemed to be very little disagreement that user participation is good. Since I only gradually realized the strength of this normativity, I directly questioned the concept on a few occasions when I was presenting my research. The reactions I got felt comparable to what Becker (1993) describes in his renowned article 'How I learned what a crock was'. In the article, Becker writes about his experience as a young sociologist in a medical ward. He had just overheard a medical student calling a patient a crock and asked the student bluntly what a crock was. 'He looked at me as if to say that any damn fool would know that' (p.2). In my own attempts at trying to understand what user participation is, I have been asked questions such as 'so you support coercion?', 'so you don't believe in human rights'? While these reactions can perhaps partly be justified by an initial lack of academic tone on my part, I still firmly believe that they bear witness to the strong moral associations of the concept of user participation. Thus, my emerging feeling that user participation is treated as 'the truth' and my questioning of this truth can be seen as a reflexive process in line with what Pillow (2003) refers to as reflexivity as truth.

It should also be noted that as a researcher and a person, I am not neutral relative to certain normative discourses concerning user participation. By asking how user participation is understood and practiced, I might be guilty of implying that it *should* be practiced and thus understood in a certain way. In searching for the truth about user participation, what truth have I given the impression of holding or being in search of? It eventually occurred to me that I was not asking critical questions such as, *why* is user participation practiced? What are the possible negative effects of this focus on user participation? As these questions were not addressed in the papers, it seems important to me to address them in the synopsis.

Klevan (2017) describes challenging one's own assumptions as a way of 'becoming as a researcher'. In the following, I will describe how challenging my own assumptions led me to exchange hermeneutic phenomenology for social constructionism in the synopsis.

3.7 From hermeneutic phenomenology to social constructionism

As noted above, in the process of conducting this project, I gradually became aware of the normativity of the concept of user participation. For example, as I describe in paper 3, there was a striking imbalance between how the professional caregivers understood user participation and how they practiced it. Despite describing user participation as autonomous decision-making and best practice, they related to their patients in ways that more closely resembled a 'care paradigm'; however, they refused to call their own actions care, which they saw as something negative. In hermeneutic phenomenological terms, part of the essence of user participation seems to be that it is the opposite of care. This finding in particular increased my interest in the role of language in shaping how user participation is understood.

I therefore made a choice to take a second look at the findings through social constructionism in this synopsis, as it offers a framework for making these normative assumptions more explicit by looking more at how language shapes the discourses, and thus the 'truths', about user participation (see Chapter 2/p. 28-32).

The leap from hermeneutic phenomenology to social constructionism might not be as big as it first seems. Thomassen (2006) writes that social constructionism is actually 'regarded as a further development and radicalization of hermeneutic perspectives' (p.180, my translation). Both hermeneutic phenomenology and social constructionism hold that meaning is created through our transaction with the world and that it is created through language, but they differ as to whether or not it is possible to escape these meanings (Laverty, 2003). Hermeneutic phenomenology is based on the belief that we cannot escape our pre-understandings, which are part of our being in the world (Laverty, 2003). Thus, language and understanding are inseparable in hermeneutic phenomenology. Social constructionism is also concerned with how discourses form our understandings of the world, but says that it is possible to achieve awareness of the discourses one is ‘trapped in’, and thereby also the possibility to question one’s pre-understandings or discourses appears. How these two theories approach meaning therefore differs, with hermeneutic phenomenology focusing on meaning itself, and social constructionism focusing on the content and context of meaning (Thomassen, 2006). In addition, while both focus on language, social constructionism offers a much more explicit framework for understanding the relation between language and meaning.

In terms of methodological differences and similarities between hermeneutic phenomenology and social constructionism, neither critical interpretive synthesis nor thematic analysis are foreign to the epistemology of social constructionism. There are however differences in how I have used the methods in my papers and how they would have been used in a pure social constructionist study. A study founded in social constructionism would have emphasized greater involvement of the informants, for example by conducting several rounds of interviews or engaging them in the analysis process (Borg & Kristiansen, 2009). As I used them, the methods were more descriptive.

Another difference that should be mentioned concerns the role of the researcher in the different frameworks. Both hermeneutic phenomenology and social constructionism acknowledge an active role for the researcher and believe that the researcher’s pre-understandings affect the findings. The difference lies in how researchers deal with their pre-understandings. While a researcher using hermeneutic phenomenology will state his or her pre-understandings in an attempt to show that they did not bias the analysis, social constructionism is less apologetic when it comes to the researcher’s pre-understandings, as the research is often motivated by a desire to provide some sort of critique (Hacking, 1999).

3.8 Ethical reflections

3.8.1 Informed consent

Informed consent is a requirement of all medical research today (Ruyter, 2007). Informed consent was included as an absolute requirement in the Nuremburg Code but was later omitted in the Helsinki Declaration because it would preclude the inclusion of different vulnerable groups (Ruyter, 2007). Kvale and Brinkmann (2012) describe informed consent as when research participants are aware of the overall goal of the study, as well as possible risks and benefits of participating.

However, in response to the challenges of meeting the demands described above when including people with dementia as research participants, alternative ways of approaching informed consent have been developed. These alternative ways of seeking consent are seen as necessary in order to avoid discriminatory practices of excluding certain groups from research. The Helsinki Declaration states that ‘groups that are underrepresented in medical research should be provided appropriate access to participation in research’ (World Medical Association, 2001). It is a delicate balance: on the one hand, it is ethically questionable to treat people with reduced capacity in some fields as being generally incompetent; on the other hand, it is obvious that with reduced ability to give informed consent comes an increased need for protection.

In my study, informed written consent for the participation of the persons with dementia was gathered both from the persons with dementia themselves and from the family caregivers. The persons with dementia were not subjected to formal tests to assess their capacity to consent; rather, they were assessed by nurses who worked closely with them and who knew them well. All persons with dementia were able to grasp the general context of their participation: a student was doing research on the topic of people with dementia and wanted to speak with people with the disease. For a few of the persons with dementia, I had to frame the project as being a school project. However, I believe this has more to do with sociocultural explanations than cognitive ones. Given the medical situation of the persons with dementia, consent was sought in several rounds. First, they gave oral consent to the nurse who contacted them, then again to the family caregivers who reminded them about their participation on the day that it was planned. Immediately before the interview, they signed a written consent. The professional and family caregivers all gave informed written consent prior to their participation.

3.8.2 Balancing risks and benefits

This study included three groups of informants: people with dementia, family caregivers of these people, and professional caregivers. The possible harm caused by or benefits of being included should be assessed independently for each group. For the professional caregivers, the risk from the interviews was minimal. They were all very interested in participating, and the topic was not a sensitive one. The focus in this section is therefore on the persons with dementia and their family caregivers.

As research participants, people with dementia are regarded as a vulnerable group, and they should only be included if the possible risks of participation are minimal. What is meant by minimal is both patient-specific and context-specific, but in general we say that the probability of the inclusion causing harm should not be greater than the probability of harm that the informants face in their everyday life (Slaughter, Cole, Jennings, & Reimer, 2007).

The first step towards minimizing harm to the informants in this project was taken in the recruitment stage by having nurses suggest to patients with dementia that they might enjoy speaking to me. Patients with anxiety, and patients they believed would experience stress in an interview situation, were excluded. The interviews took place in the patients' own homes, where I believed they would feel most comfortable. The actual interviews took the form of a conversation, where I tried to the best of my ability to stay attuned to the patients' preferred conversational style and their cognitive abilities. It was important to me that they did not feel as though they were being questioned, but rather that they were participating in a conversation that they were also free to influence. This meant that I accepted 'going off track' much more than I probably would have with cognitively healthy participants. I let the patients set the rhythm for the interviews and tried to gently guide them back to the topic if they went too far off. These techniques have also been described by Wogn-Henriksen (2012).

Family caregivers have also been described as vulnerable participants in research (Larsen et al., 2017), as they are often in a difficult life situation and can end up revealing confidential information about themselves and the patients they are caring for. Several of the family caregivers did open up and shared with me the difficulties they were facing. One was the teenage daughter of a man with dementia, who felt as if she had lost her father. In this situation, I had to step out of my role as a researcher. We spoke at length about the difficulties she was facing, and I advised her to contact a person in home care who I found especially competent and emphatic. At the end of the interview, she expressed gratitude for the opportunity to share her thoughts and feelings. I contacted her (as well as the other family caregivers) a few days later to ask how they had felt about the interview and to hear if they needed any follow up. The daughter informed me she had been in touch with the nurse I suggested, and the other participants thanked me for listening.

A project like mine cannot be expected to offer great personal benefits. However, I left most of the interviews with the impression that the informants had enjoyed speaking to me. The professional caregivers seemed to appreciate a context where they could speak freely about frustrations and challenges related to their work, the family caregivers expressed gratitude to finally have someone listen, and the persons with dementia seemed pleased to have had my attention.

3.9 Quality criteria

There is a big debate around whether or not qualitative research benefits from and should adopt the quality criteria (validity, reliability, and generalizability) developed for and used in quantitative research. Those who are critical of using these terms claim that applying quantitative requirements to qualitative research is often counterproductive. For example, Yardley (2000) explains how quantitative researchers' criticism of small sample sizes in qualitative research ignores the latter's aim of in-depth analysis. If qualitative researchers were to employ a statistically representative sample, in-depth analysis would not be possible. Specifically relating to quality criteria, reliability is seen as an inappropriate criterion for qualitative research studying processes of change or wanting to offer one of several possible explanations. Yardley (2000) also notes how a concept such as 'inter-rater reliability' to ensure objectivity is meaningless in qualitative research, which has as its foundation that knowledge is always shaped by the context and relations it is created it.

As a result, a number of alternative ways of appraising qualitative research have been proposed, although so far with little consensus (Dixon-Woods, Shaw, Agarwal, & Smith, 2004). Some approaches prefer to stick to the 'quantitative terms' (Kvale & Brinkmann, 2012; Tjora, 2012), while others have introduced more qualitative sounding words, such as trustworthiness and authenticity (Lincoln & Guba, 1986).

According to van Manen (1990), objectivity in human sciences should be understood as being '*oriented* to the object' or being 'true to the object' (p.20). This entails an obligation to become a 'guardian and a defender of the true nature of the object' (p. 20). The researcher should be driven by a desire to reveal the nature of the object, while being aware that one can be misled by one's own unreflected pre-understandings.

To describe the quality criteria I have used in this study, I will use the four principles suggested by Yardley (2000). These principles are sensitivity to context, commitment and rigour, transparency and coherence, and impact and importance.

Regarding *sensitivity to context*, Yardley (2000) believes that good qualitative research should be sensitive to sociocultural context, contextual factors in the interviews and the context in which the interviews take place, as well as the theoretical context. By theoretical context she means knowledge of both the literature addressing the topic and the intellectual history of the topic, as well as philosophical grounding in the adopted approach. This point has turned out to be especially important for my study, as I learnt early on that user participation is a concept without much theory behind it. This is a fact I have tried to address throughout this thesis, both in the individual papers and in this synopsis. I have tried to provide an informative introduction to how the concept has developed and how this development affects practice. In terms of the context of the interviews, I have provided a description of the organization of home care in Norway. The contexts of specific interviews are described in the methods section. In the discussion, I will try to show how the sociocultural context has affected the concept I am studying.

Commitment and rigour refers to the thoroughness of the study, or more specifically 'in-depth engagement with the topic; methodological competence/skill; thorough data collection; depth/breadth of analysis' (Yardley 2000, p.219). To get an in-depth understanding of the topic of user participation, I familiarized myself with policy documents, read books describing how the concept has developed, and studied literature from various fields, such as social work and nursing, to see how the concept is presented, trying to detect possible differences. The discussion in this synopsis will hopefully reflect both an in-depth engagement with the topic and a depth/breadth of analysis. In terms of developing methodological competence, I devoted a considerable amount of time to reading the methodological literature, in addition to attending several courses in methods. I discussed my analysis with my supervisors, who read through the interview transcripts, and we had several meetings discussing my interpretations. The papers include a rich amount of citations to enable the reader to follow my interpretations. The methodological process and my themes were the topics of several research seminars and in the psychology and religion research group.

T*ransparency and coherence* refers to the fit between research questions, method, and philosophical positions, as well as to the researcher's ability to build a convincing argument. I have attempted to be transparent in the research process by explaining the different decisions made during the process, such as sampling decisions and how I got access to the field. In terms of my argument, I have tried to show that I have developed a thorough understanding of the concept I am studying by presenting the various ways it can be understood and relating it to relevant discussions.

The last principle, *impact and importance*, refers to the impact and utility of the research: Does it tell us something useful? What is the use of this new knowledge? I believe the topic addressed in this thesis is relevant because while user participation is highlighted as an important part of caring for people with dementia, there is no clear definition of the term or descriptions of how to achieve user participation in practice. I believe my contribution lies in my attempt to challenge what I see as the normativity of the concept in question and to shed light on the need for understandings of user participation that are better adapted to dementia care.

4 Summary of papers

In the following, I will summarize the findings from the three individual papers on which this synopsis is based. Paper 1 was published in the *European Journal of Social Work*, and paper 2 and 3 were published in *Nordic Social Work Research*.

4.1 Paper 1

The title of Paper 1, which is a literature review, is 'Factors affecting user participation for elderly people with dementia living at home: a critical interpretive synthesis of the literature'. The findings show that these factors can be categorized as individual, professional, decision, relational, and organizational characteristics. Concerning the individual characteristics, the paper shows that user participation can be difficult for people with dementia because of the stigma associated with the disease. This can lead not only to automatic exclusion of people with dementia in decision-making processes but also to these people withdrawing from decision-making, as they do not trust their own ability to make sound decisions.

The second theme presents various professional caregiver characteristics that can affect user participation. The paper shows that there are different practices professional caregivers use to try to enable decision-making for people with dementia. The paper identifies two different practices of user participation. Typical of the first practice is that the professional caregivers are motivated by the patient's right to autonomy and user participation and will let their work be guided by these principles. In the second practice, the professional caregivers apply concepts such as autonomy and user participation more loosely letting their work be guided by what they think is the patient's best interest rather than only focusing on the patients' right to decide. This implies that they are more prone to use persuasion to make patients do what they think is in the patients' best interest. The paper shows that these different practices are related to educational level and experience.

The third theme in Paper 1 relates to different types of decisions. Research has found that decision-making relating to higher cognitive functions, such as financial decision-making, is more difficult for people with dementia than social decisions, for example, for which they seem to retain normal abilities throughout the disease progression.

The fourth theme, relations, shows that user participation for people with dementia depends on their being enabled by family and professional caregivers. The importance of including family caregivers in the decision-making process is emphasized, but potential problems arising from including family or professional caregivers are also commented upon, as patients, families and professionals can have different views and interests. Research has shown that disagreements can often be quite pronounced in matters where a person's autonomy has to be balanced with their safety, with family caregivers often emphasizing safety and professional caregivers emphasizing autonomy. The paper suggests that instead of thinking of this as an either-or matter, it can be useful to think of persons with dementia as having 'restricted autonomy', as proposed by Landau and Werner (2012).

Finally, the paper describes organizational barriers to user participation. These include time, system pressure, lack of information and lack of actual choices. The theme shows that despite professional caregivers' good intentions, including people with dementia might not be realistic in practice due to various organizational barriers. The theme also describes the difficulty many professional caregivers cite of having to adjust their communication to the patient's level: on the one hand, professional caregivers want to inform patients about their options, while on the other hand, they are afraid of overloading them with too much information. The paper shows how professional caregivers often approach this as a balancing act.

The discussion section sums up the main findings and elaborates on the conceptual issues related to user participation. It is argued that the concept of user participation is rarely used in dementia research and that lack of clarity around what user participation in dementia care should entail leads to uncertainty as to how to practice it. Questions are therefore raised regarding the advantages and disadvantages of a possible standardization of the concept. The need for country-specific guidelines is highlighted, and the question is posed as to whether or not dementia care would benefit from reframing the concept of user participation to focus more on relations.

4.2 Paper 2

Paper 2 is titled ‘User participation among people with dementia living at home’. The paper discusses user participation seen from the perspective of persons with dementia. The findings show that the persons with dementia described different levels of and wishes concerning participation, ranging from making all decisions themselves to preferring to delegate decisions to others. The findings are divided into two categories: user participation at home and user participation at a day care centre. The persons with dementia generally expressed that they had the opportunity to participate at home and that this was more important than having the opportunity to participate at the day care centre. This is explained by the different roles the different contexts evoke. At home, they are often dealing with the difficulties of accepting that their spouse is taking over, and the context also invites more honest feelings regarding their own frustrating situation. At the day care centre, in contrast, the persons with dementia view themselves as guests and are therefore more polite and tend to place their own needs and wishes in the background. They also acknowledged the group dynamic and explained that they would adjust to accommodate those who had more serious health problems than themselves.

The paper also describes the significance of the quality of personal relationships when it comes to how much the persons with dementia were included, as well as whether or not the persons with dementia wished to be included. We found that the persons with dementia who claimed to be happy with delegating decisions were in relationships that were characterized by both themselves and their spouse as harmonious and filled with trust. The spouses in these relationships seemed to practice shared decision-making but acknowledged that they usually had the last word. However, because the persons with dementia experienced a trusting relationship, they did not mind this. Other relationships, to the contrary, were described as chaotic. In these relationships, the persons with dementia either claimed to make all decisions for themselves or described being frustrated that they were now being left out of many decisions. These relationships were marked by high levels of conflict, and the person with dementia was generally characterized by their spouse as someone who had always been dominant and was used to getting their way.

The discussion section of the paper describes how context and social relations can affect how people with dementia participate in decisions. I question whether or not the degree to which people with dementia are included is related to the amount of knowledge about dementia and user participation possessed by the different types of caregivers. It is suggested that many family caregivers lack knowledge in these areas and therefore end up expecting too much of the person with dementia, often pushing them to participate at levels which are not in accordance with their reduced capabilities. Several examples from the interviews are used to show how unrealistic expectations can create anxiety for the person with dementia, which in turn can lead to withdrawal. On the contrary, it is suggested that professional caregivers can sometimes fail to challenge persons with dementia out of fear of pushing them too much. The discussion highlights the need to see the autonomy of people with dementia in a more relational light, and the term ‘bounded autonomy’ from Chrisp, Tabberer, and Thomas (2013) is used to explain situations where one person’s autonomy is contested by the autonomy of another person. The discussion ends by emphasizing trust as a key factor in enabling user participation for people with dementia in any context or in any social relation.

4.3 Paper 3

The title of Paper 3 is ‘Barriers to user participation in home-based dementia care - the perspectives of professional caregivers’. The data consists of interviews with 12 professional caregivers in home-based dementia care with various educational backgrounds. The results were divided into the following themes, each representing a barrier: patients are too ill for user participation; user participation collides with beneficence and non-maleficence; lack of background information, conflicting interests between patients and family caregivers, and organization of services.

The first theme, patients are too ill, addresses professional caregivers' existing understanding of user participation, which was difficult to put into practice with people with moderate to severe dementia. They believed that real user participation consists of supporting patients in making autonomous decisions, and since this is often unrealistic with their patients, they were left feeling as if they had failed to enable user participation. While they tried to enable user participation for patients in all stages of dementia, they noted that in the later stages, it was more about making patients feel as if they were making decisions than actually taking their opinions into account. Another reason they felt as if the patients were too ill for user participation was that it was difficult to get to know them once the condition was advanced. Early service entry was therefore seen as a prerequisite for user participation.

The second theme addresses the caregivers' impression that the obligation and desire to enable user participation conflicted with the principles of beneficence and non-maleficence. The professional caregivers also expressed concern that different work practices existed and that some professional caregivers were not able to properly balance different principles, instead working solely on the basis of the principle of autonomy. This led to situations where patients did not get the care they needed, and the professional caregivers interviewed claimed these actions resulted in neglect. In an attempt to avoid both coercion and neglect, the professional caregivers explained that they would 'sneak in the care', referring to actions such as convincing patients to go through with what the professional caregivers saw as good care.

The third theme addresses how lack of knowledge about patients is perceived as a barrier to user participation. This includes several types of knowledge: patients' preferences, life history, and medical knowledge of dementia. It was found that some professional caregivers feel that care assistants do not have a sufficient knowledge base to be able to assess patients' abilities and limitations. They sometimes struggle to see the whole patient, including his or her somatic diseases. In the discussion section, it is suggested that lack of education can lead to an outsized emphasis on autonomy, as can lack of work experience. These assumptions are discussed in light of previous research.

The fourth barrier relates to how professional caregivers sometimes struggle to balance the needs of their patients with the needs of family caregivers. Professional caregivers are described as sometimes feeling forced to focus on family caregivers' needs in order to relieve them of some of the caregiver burden. Situations where family caregivers are experienced as a hindrance to user participation are also described. The professional caregivers reported feeling as though they have to use a disproportionate amount of time educating family caregivers about dementia and the changes they might expect to see in their loved one.

The last theme describes organizational barriers, with a particular focus on the Norwegian Care Coordination Reform, a policy implemented in 2012 with the aim of better coordination of health care services. The Coordination Reform is perceived as a great barrier to user participation, as it has led to earlier discharge of patients from hospital and therefore an increase in the number of patients with severe health problems in home care. Patients often arrive home with treatment plans from the hospital, which sometimes require coercion to implement. Another organizational barrier mentioned is the increased documentation requirements, which have led skilled nurses into management positions and away from daily direct contact with patients and care provision.

The discussion section of this paper starts by looking at the difficulties professional caregivers face balancing autonomy and safety for their patients. It goes on to discuss the difficulty of enabling partnerships with people with dementia, especially focusing on how the professional caregivers feel trapped between the wishes of the patients and the wishes of their family caregivers. Next, the organizational barriers are discussed, with an emphasis on the negative impact of the Coordination Reform in enabling user participation. This is presented as a paradox considering the reform’s aim of increasing participation. The reform is compared with similar reforms in other countries. Finally, the discussion describes how NPM has been criticized for making it more difficult for professional caregivers to enable user participation, as it leaves less room for their tacit knowledge or for working in partnership with patients. It is questionable whether user participation sometimes empowers the market more than it empowers patients. The discussion ends by returning to the issue of conceptualization. It stresses that normative applications of user participation can lead caregivers to ignore beneficence and non-maleficence. The article concludes that user participation should be seen not as the opposite of care but as an integral part of it.

5 Discussion

In this thesis, I explore, describe and interpret user participation in home-based dementia care in Norway. We have seen that the policy goal of user participation is experienced as difficult to put into practice, partly because professional caregivers perceive the concept as vague. Other explanations relate to the disagreement among professional caregivers as to how it should be practised, with some strongly emphasising autonomy over beneficence and non-maleficence. There is also disagreement between professional caregivers and family caregivers. Supported by earlier research, my papers show that different practices of user participation exist, with varying emphasis on the right of people with dementia to exercise their autonomy. User participation is described as especially challenging in dementia care, as professional caregivers often deal with situations involving coercion, in which they must balance patients' right to autonomy with the principles of beneficence and non-maleficence. Despite caring for people with dementia who live at home, caregivers report that paternalistic measures are frequently to be necessary.

In this discussion, I will combine the findings from the three individual papers to support a broader and more theoretically oriented discussion of user participation in home-based dementia care. More specifically, I will look at my findings through the lens of social constructionism to explore how my informants constructed user participation and how this construction affected their practice. I believe this is important because, as I showed in the introduction, earlier research has rarely set out to explore how the concept of user participation is constructed in dementia care. In addition, social constructionism is concerned with questioning the discourses that we take for granted (Belsey, 2013; Hacking 1999) and, as such, can be a good lens to explore normative assumptions about user participation in home-based dementia care. Questions that will be explored include how user participation is constructed in home-based dementia care, whether or not alternative constructions exist and, if they do, what their consequences might be.

As described in chapter 3, social constructionism did not inform the study as a whole but was chosen as an analytical lens for the discussion of this synopsis. However, what I attempt to show in this discussion is how individual understandings of a phenomenon are always affected by how the phenomenon in question is constructed in the individual's social and cultural context. As such, the switch in terminology from 'understanding' to 'construction' in this synopsis can be viewed as a way of broadening the debate on user participation in dementia care from focusing on individuals to focusing on social structures.

The discussion is structured to reflect the research questions, as well as the different perspectives presented in Papers 2 and 3, namely those of professional caregivers, people with dementia and family caregivers. The literature study presented in Paper 1 will, together with the literature review for this synopsis, be used to discuss the findings. The headings used in the discussion refer to the perspectives of the different informants, while the research questions are addressed throughout the discussion. The discussion will show that the three groups of informants in this study construct user participation very differently, and explore what consequences this has for the practice of user participation in home-based dementia care.

The three research questions of this thesis were the following:

1. How is user participation understood in home-based dementia care?
2. How is user participation practised in home-based dementia care?
3. What degrees of user participation qualifies as 'real' user participation in home-based dementia care?

5.1 The professional caregivers' ideal of user participation

The papers in this thesis suggest that there is often a mismatch between professional caregivers' understanding of user participation and the needs of their patients. As shown in Paper 3, most of the professional caregivers in my study appeared to believe that 'real' user participation meant supporting their patients in making independent decisions. Their ideal of user participation could thus be said to be a type of user participation that requires ‘normal’ cognitive functioning. A direct result of this construction was that the professional caregivers felt that user participation was mostly for people in the early phases of the disease, and they spoke about their patients as being ‘too ill’ for user participation, despite living in their own homes (p. 5 in Paper 3). In relation to the models of user participation presented in chapter 2, this indicates that the professional caregivers’ construction of user participation was aligned with the models of both Arnstein (1969) and Thompson (2007), who see autonomous decision-making (referred to as citizen control and informed decision-making respectively) as the ultimate form of user participation. However, while both these models also include partnership and shared decision-making as real user participation, these terms were not mentioned by the professional caregivers. The model proposed by Tritter (2009), which includes a much broader range of activities as user participation, does not fit with these professional caregivers’ construction of user participation, despite having been made for a health care context. The caregivers also lacked an ideological basis for their understanding, as well as awareness of either collective or political forms user participation. Moreover, previous research has found that knowledge about user participation is limited to user participation at the individual level (Sørvoll & Gautun, 2020).

Despite having an understanding of user participation that did not align with the needs of their patients, none of the professional caregivers questioned the usefulness of the concept of user participation. In line with other research (Sørvoll & Gautun, 2020), there seemed to be no doubt that user participation was ‘best practice’, and they strived to live up to this standard. In his doctoral dissertation about parental participation when caring for a hospitalized child, Darbyshire (1992) describes how the expectation of involving parents in caring for their children was so ingrained in the nurses that it was not something they were for or against. It was simply, as Darbyshire explains, an ‘occupational reality’. Bartlett and O’Connor (2010) describe how such dominant discourses can be ‘recognised by the implicit “should”’ (p.52) and that this ‘should’ guides our personal meaning-making and actions. They give the example of the discourse that families *should* take care of their relatives. In such a discourse, the institutionalization of a family member will cause guilt, as it breaks with what one ‘should’ do. The professional caregivers in my study clearly felt they should enable user participation, and it could be argued that this perception had become an occupational reality, or in social constructionist terms, a ‘truth’ (Gergen, 1999). The fact that the professional caregivers did not question the concept of user participation can therefore be understood as reflecting a form of governmentality, which refers to the indirect forms of power that influence individuals to think and act in certain ways. Certain beliefs are so ingrained in the individual that the ‘governor and governed are two aspects of the one actor’ (Dean, 2010, p.19).

Understanding user participation as solely good seemed to affect people’s understanding of other concepts, such as coercion and care. My findings show that both these concepts were understood as the opposite of user participation. This parallels the discussion of whether care for people with dementia should emphasize patients’ autonomy or safety, which I have addressed throughout the papers and this synopsis. Seeing user participation as the opposite of coercion and care can be explained by the concept of binary opposites. Binary opposites is a term used in social constructionism to refer to humans’ tendency to understand the world in terms of pairs of opposites (Derrida, 1997). These opposites help us to define and understand the world by categorizing phenomena based on what they are not. Categories are helpful, but also prevent us from seeing the world diversified, as these constructed dichotomies give us the impression that there are no other ways of perceiving a certain phenomenon. A critical feature of binary opposites is the relation they have with each other within the language structure in which they are embedded (Belsey, 2013). For example, one concept is always preferred over the other: man is superior to woman, health is superior to disease, and so forth. Reaching an understanding of a concept must therefore entail an investigation of what aspects are not included in the concept. And as mentioned above, the professional caregivers in my study described both coercion and care as opposites of user participation. Similar findings have been described by both Helgesen et al. (2014) and Larsen et al. (2017). From the logic of binary opposites, it follows that if user participation is seen as the opposite of coercion and care, and coercion and care are seen as bad, user participation automatically becomes good.

While the professional caregivers saw user participation as a more noble concept than care, they seemed to prefer the term ‘patient’ over ‘user’ to describe their care recipients. This can be seen in how they referred to their care recipients in Paper 3 as ‘patients’. As I showed in chapter 1, the term user participation relates to ideologies that see people as users of services or citizens rather than patients. We can therefore describe the professional caregivers’ construction of user participation as ‘user participation with patients’. This shows the ambiguity of the user participation concept (Beresford, 2012; Bochel et al., 2008; Stewart, 2013; Tritter, 2009), as well as the difficulty of balancing it with the concept of care. The terms ‘patient’ and ‘user’ often have very different connotations, with one focusing on illness and dependence and the other on rights and autonomy. How can we combine the focus on autonomy with a focus on illness and dependence? This question has been debated by numerous authors (Brannelly, 2016; Barnes & Brannelly, 2008; Martinsen, 1989; Vetlesen, 2003). In her article ‘Washing the Citizen’, Pols (2006) poses a similar question while trying to describe how citizenship is enacted in psychiatric institutions: How does one wash a citizen? Similarly, both Vetlesen (2003) and Larsen et al. (2017) comment on the contradiction of terms in care practices focusing on autonomy, since care in itself presupposes uneven power relations between the giver and the receiver. Barnes and Brannelly (2008) call this a ‘tightrope’ that is ‘complicated to traverse’ (p. 60).

The professional caregivers’ ideal of user participation, as well as their reluctance to use the word care, can be seen to mirror the dominant political discourse on aging and dementia. Jacobsen (2015, 2020) has analysed Norwegian policy papers to see what they say about aging and care. He found that aging has been portrayed as increasingly positive over the last decades, while care has been downplayed. He found a strong focus on abilities and resources, while terms such as fragility, disease and dependence are hardly mentioned. Older people are now portrayed as a healthy generation of individuals who want to live at home and who want to participate and be involved. This is supported by the research of both Christensen and Fluge (2016) and Sørvoll and Gautun (2020). Scrutinizing the dementia plans in Norway, a similar construction can be found. Wanting to participate is presented as the right way to live with dementia: 'people with dementia want to be included in decisions concerning them…People with dementia shall be included in decisions concerning themselves' (Norwegian Ministry of Health and Care Services, 2015a, p.7 & 8). Jacobsen argues that we must be wary of reading these policy papers as factual statements and remember that people with their own interests have written these policy papers. He argues that the motivation behind the current policy papers is to make people age at home, and that user participation is presented as a tool to reach this aim. In line with the argument of Jacobsen, Vetlesen (2003) sees the negative connotations of the term care as a result of a wider and more problematic discourse in our society. According to Vetlesen, the concept of care is viewed negatively because current care practices ignore human dependency. Implicit in his writings lies the question, If dependency and weakness are negative, how can receiving care be positive?

While Jacobsen (2015, 2020) and Vetlesen (2003) are critical to the dominant discourse on aging and care, others are more supportive of applying a critical understanding to the concept of care. Several pages in the white paper *Innovation in Care* (Official Norwegian Reports [NOU]) 2011:11, 2011, p. 38-42) are devoted to critically exploring the concept of care. The paper concludes that the concept of care is overused and reflects an uneven power relation in which the care recipient is expected to take a passive role (which is implicitly understood as negative). It is further claimed that the negative connotations of the concept of care can be seen in the appearance of new terms such as 'self-care' and 'active care', which are all associated with autonomy and less so with disability and frailty (and are thus implicitly understood as positive). Bartlett and O'Connor (2010) write that the term care can give the impression of a static situation in which one part is always giving care and the other part is always receiving care. Seen from this perspective, the term care can create associations with the paternalistic aspects of the welfare state, which in turn gives the impression that it represents values that are the opposite of user participation. Those supportive of the concept of care, on the contrary, believe that seeing care as something negative disguises our shared dependency on each other and the fact that we have all been and will be dependent on care from others at some point in our lives.

While the ideal of user participation held by the professional caregivers aligns with both policy papers and ideals of user participation in nursing homes (Helgesen et al., 2014; Larsen et al, 2017), some authors have also claimed that user participation is constructed in a distinct way in home care. Both Johannesen and Steihaug (2019) and Sørvoll and Gautun (2020) found that user participation was strongly linked to independence and active aging in home care, and that the professional caregivers in home care focussed less on the relational aspects of user participation. Jacobsen (2020) similarly argues that ‘ageing in place’ and ‘active aging’ have blended and become part of the same parcel, and user participation is mentioned as a way of achieving this goal. My findings show that some professional caregivers understood user participation to mean that patients were masters of their own life. As both Johannesen and Steihaug, and Jacobsen argue, such a construction can end up challenging the idea of user participation, as it is not a given that all older people with dementia wish to ‘age actively at home’.

In sum, the construction of user participation as autonomous decision-making seems to be strong in home-based dementia care. It mirrors current policy papers and academic models of user participation but lacks the ideological or theoretical basis of these approaches. Sørvoll and Gautun (2020) argue that the ideal of user participation as autonomous decision-making is more affected by the increased focus on individualisation in society than it is a realization of political demands. However, as I have shown, as long as professional caregivers lack of an in-depth understanding of user participation, they risk seeing it as the opposite of care, as care can contain aspects of paternalism and coercion. Next, I address is how this ideal of user participation was translated into practice.

5.2 The practice of user participation by the professional caregivers

In their book about social citizenship, Bartlett and O’Connor (2010) write that while theoretical approaches to concepts might be intriguing, ‘their real value lies in their potential to inform practice’ (p. 51). To gain a better understanding of the practice of user participation in home-based dementia care was also the aim of the second research question of this thesis, ‘How is user participation practiced in home-based dementia care?’ In the following, I will describe how the construction of user participation by the professional caregivers discussed above affected their practice of the concept. In short, my findings in Paper 3 revealed two opposing practices of user participation: in the first, the professional caregivers adjusted the concept of user participation to fit the cognitive level and resources of their patients, while in the second, the professional caregivers practiced what can be described as a more literal understanding of user participation as autonomous decision-making.

A major finding in Paper 3 was that the professional caregivers’ descriptions of how they practiced user participation clearly diverged from their ideal of the concept and how they thought it should be practised. In fact, the professional caregivers believed that they seldom practiced ‘real’ user participation at all. This is in line with Haukelien et al. (2011), who suggest the term ‘user orientation’ to describe practices in health care where the patients do not have a real say in decisions. The main reason for this gap between the ideal of autonomous decision-making and the practice of user participation was that the professional caregivers often had to persuade patients to accept various forms of help. They would also use incentives, such as rewards, or ask for patients’ opinions just to make them feel included, even though decisions had already been made. They spoke about techniques of involvement such as limiting available choices and adjusting the communication to the level of the patients, techniques that are in line with how shared decision-making is described (Hamdy et al., 2017; Sinclair et al., 2018; Smebye et al., 2012; St-Amant et al., 2012), as well as what is considered ‘real’ user participation in the models of Arnstein (1969), Thompson (2007), and Tritter (2009). This indicates that the professional caregivers attempted to give patients more power, but their construction of user participation prevented them from seeing these actions as anything other than ‘fake user participation’.

On the contrary, they spoke with great concern of a different practice that they claimed existed among their colleagues, namely the practice of user participation as autonomous decision-making more literally. These other professional caregivers' considered autonomy to be the main principle guiding their work, which might have led them to neglect important care needs of the patients. Examples were given of professional caregivers who left patients in the bed the whole day, or who left the houses of people with dementia who did not immediately want to let them in instead of trying to gain their trust in order to provide them with the necessary care. This situation described by the professional caregivers seems to mirror situations in which user participation has been constructed as a one-off event rather than as a process (Seim & Slettebø, 2017). Some of my informants mentioned that user participation sometimes appeared to be a convenient excuse on busy days when some professional caregivers too frequently would say 'but he did not want [it]'. Previous research has described similar findings and argued that the emphasis professional caregivers put on patients' right to autonomy depends on their education and work experience, with higher work experience being associated with an increased ability to balance different ethical principles and patients' rights (Alonzi, Sheard, & Bateman, 2009; Brannelly, 2011; Forbes et al., 2011; McDonald, 2010). This was also commented upon by the professional caregivers I interviewed, who believed that user participation for people with dementia must include thorough knowledge about somatic diseases as well as legal and ethical aspects of dementia care. For them, this meant that facilitating user participation for people with dementia presupposed carers with a nursing education.

The two different practices of user participation described by the professional caregivers can therefore be said to differ in terms of the emphasis they put on autonomy and care or user participation and care. Mol (2008) uses the concepts of 'the logic of choice' and 'the logic of care' to differentiate between two equivalent practices in her study of diabetes care in the Netherlands. The logic of choice is described as a practice that has the patient's right of autonomy as its guiding principle. Professionals within this 'domain' tend to leave the final decision up to patients, including in situations in which this practice can have negative consequences for the patients. They are conscientious about not influencing patients to accept what they as professionals believe is the right thing to do. According to Mol, this can be problematic, as patients who do not have the capability to make good decisions are left alone with the responsibility if the decision turns out to be a poor one. User participation constructed as a logic of choice will focus on the patient's right to autonomy, even when they suffer from conditions such as dementia which can make autonomous decision-making difficult. Mol sees the logic of choice as a trait of neo-liberal care practices, a view supported by Øye and Jacobsen (2020). Bochel et al. (2008) explains that the understanding of user participation as individual choice is grounded in a consumerist ideology.

The logic of care, on the other hand, starts from a recognition of the fragility of life; disease is not sidelined, and it entails suffering that renders us dependent on others. Within the logic of care, choices are made in the context of relationships. Mol (2008) calls this 'doctoring', and it can be performed by doctors, patients themselves, nurses and everyone else around the patients who naturally affect or are affected by whatever decisions are made. This means that when a decision is made that turns out to be a failure, the patient is not left alone with the responsibility or the guilt of having made the wrong decision. In this model, autonomy is not the opposite of care but an integral part of it. User participation constructed within the logic of care will see autonomy as important, but not as the only factor that should influence the treatment of a patient. Something akin to the logic of care, though expressed in different terms, is highlighted by numerous authors (Bartlett & O'Connor, 2007; Brannelly, 2016; Smebye et al., 2016) as the only way of providing good care to people with dementia, as it balances needs of autonomy and care better than a logic of choice. These authors are critical of models of autonomy, citizenship and user participation that have independence as their main goal and argue that there is a need to adjust these concepts to include people with cognitive challenges.

Based on this understanding, the professional caregivers in my study could be said to practise a form of relational user participation: in other words, they see it as important to get to know their patients and to build trusting relationships with them, not to mention having enough time to do this. Returning to the point about discourses, Bartlett and O'Connor (2010) write that the implicit 'should' that leaves us feeling inadequate or guilty is often a good indicator of what the dominant discourse is in a given context. That the professional caregivers felt guilty for not practising ‘real’ user participation, while at the same time enabling what in theory is described as shared decision-making (Smebye et al., 2012) or partnership (Arnstein, 1969), can help us single out the dominant discourse on user participation in dementia care in Norway today. It also raises the question of whether a more relational theoretical approach to user participation would be more beneficial in dementia care, as it would create a stronger link between theory and practice. As I showed in the introduction, such a relational theoretical approach seems to be lacking, specifically in relation to the user participation concept in dementia care. Other authors have also called for debate around what the concept of user participation should mean in dementia care (Helgesen et al., 2014).

The debate about how user participation is or should be understood and practiced in home-based dementia care is clearly linked to the question of what good dementia care is. Efraimsson, Sandman, Hydén, and Rasmusson (2004) write that awareness around the conflicting paradigms of care and efficiency in health care ‘is a prerequisite for improvements in working procedures congruent with a caring paradigm that support patient participation’ (p. 562). This can also be understood as a dilemma over which user participation ideology to use as a point of departure, democratic or consumerist. In the case of home-based dementia care, these conflicting paradigms, or ideologies, are both clearly present: professional caregivers are caring for a vulnerable group and seemingly trying to live up to the ideal of democratic user participation while working within an organization organized according to principles from NPM, such as efficiency, quality, and control (Ceci, 2013; Lausund, 2017). The professional caregivers in my study mentioned the increased work pressure that the home care services have experienced since the implementation of the Coordination Reform, which has been also documented elsewhere (Gautun & Syse, 2013). A considerable amount of nurses’ time is now spent on documentation and documenting deviations (Lausund, 2017). It can therefore be questioned whether the democratic ideology of user participation, or a care paradigm that includes user participation, has been clearly communicated to professional caregivers in home-based dementia care. Given how user participation is constructed as autonomous decision-making, it could be argued that both the understanding and practice of user participation are closer to the consumerist discourse, with its emphasis on individual choice and individual freedom In sum, it can be argued that professional caregivers in home-based dementia care need a more in-depth understanding of user participation, if it is to be understood as more than a technical procedure of decision-making. Both my own findings and other research call for guidelines concerning how to enable user participation for people with dementia, but even more so, the challenge seems to be one of changing minds. Referring to Løgstrup, Alvsvåg and Martinsen (2018) write that it is often more important to follow the spirit than the letter of the law, as intentions of 'the good' can end up not being fulfilled if the law is understood literally. However, it remains to be seen what the spirit of user participation is.

In sum, my findings show that the construction of user participation as autonomous decision-making results in two practices of user participation. In the first, professional caregivers deem their own understanding of user participation unfit for people with dementia, instead practicing what can be described as relational user participation. In the second, professional caregivers' practice autonomous decision-making understanding literally. It can be argued that the consequences of these two practices for patients are immense, showing the need for clarification of how user participation should be understood and practiced in home-based dementia care. The next section will focus on the ideal and practice of user participation by people with dementia and their family caregivers.

5.3 The ideals and practices of user participation by the persons with dementia and family caregivers

As showed in Paper 2, the persons with dementia and their family caregivers had very different perspectives than the professional caregivers concerning the ideals and practices of user participation. Professional caregivers must relate to the concept of user participation within a formal organizational framework with its own rules and regulations, which affect – at least indirectly – how they construct participation. People with dementia and their family caregivers, on the other hand, have no such formal rules guiding their construction of user participation. What is interesting to explore, then, is whether or to what extent these actors have internalized the dominant discourse of user participation, with its emphasis on autonomous decision-making. In this last part of the discussion I will therefore switch focus from professional caregivers to people with dementia and their family caregivers.

The concept of user participation was not known to either the persons with dementia or the family caregivers who participated in my research, and I therefore decided to use the phrase ‘participation in decision-making’ instead. None of the persons with dementia or their family caregivers mentioned or gave the impression of having any knowledge about collective or political user participation. This is especially interesting in relation to the man I call Olav in Paper 2, who expressed a strong desire to be in charge of his own life. My impression of Olav was that he would have had both the interest and the capacity necessary to participate in user councils. From the phase of the project in which I sought information about dementia care in various municipalities, I got the impression that there was not much cooperation or knowledge-sharing between various user groups and home-based dementia care. This further strengthens my impression that user participation lacks nuance in home-based dementia care and that there is a gap between theory and practice.

The persons with dementia in this study can be divided roughly into two groups in terms of how they wanted to be included in decision-making. The first group, which consists of four persons with dementia in my sample, did not express a strong desire for autonomous decision-making. The other group, consisting of three persons with dementia, expressed strong feelings about the importance of being in charge of their own lives. I will now describe these two ideals of user participation.

The persons with dementia representing the first group expressed in various ways that they did not put autonomous decision-making first. There were various reasons for this. One man told me that the thought of doing things on his own made him anxious and scared because he was aware of his cognitive decline and was afraid of hurting himself or getting lost (presented on page 153 in Paper 2). They all expressed concern for their spouses and felt that it would be unreasonable for their own needs to always take precedence. At the time of the interviews, one woman was in a short-term stay at a nursing home, to give her husband some space. This concern for their spouses was related to their awareness of having dementia; they perceived themselves as a burden on their spouses. However, these relationships were also described by both the persons with dementia and their spouses as relationships filled with trust, love and respect. Taking care of or being taken care of by a spouse, and also at times having a life partner make decisions, was seen as a natural part of the life course.

In relation to the day care centre, these persons with dementia saw themselves as guests and felt they had to be polite in that role. This included being considerate of the users that they judged as having more severe health problems than they did. The basis for user participation in this construction is not ‘I’, but ‘we’ (Hydén & Nilsson, 2015). This relational construction of user participation exemplifies what Samuelsson et al. (2015) call ‘joint capacity’, which I described in the introduction. In all, this shows that decisions are not only made by individuals. Because of the emotionally challenging process of living with dementia for both the person with the diagnosis and the family, decisions are often taken together as a family or couple (Wolfs et al., 2012). Even more than the professional caregivers described above, these couples seemed to practice a very real form of shared decision-making as described by Smebye et al. (2012) and the theoretical models of user participation.

The other group consisted of three persons with dementia who struggled with having decisions made for them. One woman did not accept the care staff in the supported housing facility making decisions for her such as what she was going to wear or when she was going to take a shower, and two men found it difficult to let their wives make decisions on their behalf. The difficulty of role changes for couples after one receives a dementia diagnosis has been explored by others. Boyle (2014) argues that such change can be especially difficult for men who have been in charge of the household. It is also possible that the need to be in charge is related to personality, as the three persons with dementia that I interviewed who were concerned about making independent decisions were all described by their family caregivers as strong-willed persons who were used to getting their way. Another possible explanation is the quality of the relationship they had with their spouse: the relationships of these two men with their wives were described as turbulent by their wives. This was confirmed by the two men with dementia, who expressed that it was much more difficult to handle lack of autonomy at home than at the day care centre. Smebye et al. (2012) also found that strained relationships lead to more autonomous decision-making by the persons with dementia in their study.

The day care centre, however, was perceived by these persons with dementia as a more public arena, where it was less natural to always fight to have their own wishes respected. Nonetheless, Olav constantly challenged the rules of the day care centre, which led to his having a level of involvement in decisions there that he claimed other users did not have because they were afraid of voicing their opinions. For example, while he had initially been denied permission to leave the day care centre, he now came and went as he pleased. To activate the users and himself, he had also spearheaded a garbage clean-up initiative, with garbage collecting tools supplied by the municipality. In some ways, this can be understood as Olav doing collective participation, defined as participation which aims to affect the service offer in general (Seim & Slettebø, 2011). It must also be noted that Olav comes across as a personification of the elderly person with dementia described in policy papers, namely a person who wants to remain active, contribute and make his or her own decisions.

What constructions of participation are we dealing with here? Once again, my analysis shows two constructions equivalent to the logic of care and the logic of choice described by Mol (2008). Considering how prevalent the construction of user participation emphasizing autonomous decision-making was among the professional caregivers in my sample, it is interesting to note that only three of the persons with dementia constructed user participation according to a logic of choice. In some ways, we can say that the persons with dementia and their family caregivers who constructed participation according to a logic of care are examples of people who do not fit the picture of older people presented in various policy documents as free, active and autonomous (Jacobsen, 2015). For example, where does the anxiety of the man with dementia fit into the political discourse on aging and user participation? However, their highlighting their own needs for care and support can be understood as something other than paternalism and passive acceptance of care. Jacobsen (2015) claims that instead of understanding elderly people’s positioning of themselves as sick and in need of care as a way of giving up all power, it can also be seen as a way to claim equal status as citizens. As I read it, the argument set forth by Jacobsen and other authors is that if user participation means viewing people with dementia as equal citizens, we must also acknowledge their frailty and illness. Otherwise, well-intended discourse on user participation can have unintended negative consequences if it leads to their need for protection and care being ignored.

In chapter 2 I described how Hacking (1999) uses the term ‘interactive kinds’ to describe how the labels put on people affect how people think about themselves and their abilities. These interactive kinds change the way people feel and think about themselves, meaning that if people hear enough talk about ‘active participating elderly people’, they might become active participating elderly people. Considering the logic of interactive kinds, it is worth asking how this attitude came about. Does it reflect the ‘true’ way of aging, or could it also be an example of governmentality, where the expectation of user participation is so ingrained in the individual that the governor and governed have become two aspects of the one actor (Dean, 2010)?

However, the theory of interactive kinds can also be used to argue that those who do not want to participate are constructed as ‘demented people’, who thus take on an inferior position both at home and at the day care centre because of internalized negative beliefs about themselves as people suffering from dementia. Hacking (1999) underlines that while individuals *can* be conscious of this happening, it is usually an unconscious process of being affected by surrounding institutions and practices. Seen from this perspective, modesty and politeness are not signs of adjusting to the group, but rather signs of prescribed disengagement (Swaffer, 2015), of the belief that they lack rationality and therefore agency (Boyle, 2014) or that they are positioning themselves as ‘the sick’ (Swaffer, 2015; Österholm & Hydén, 2018). As shown in the introduction, people with dementia have historically been constructed as less than human (Kitwood, 1997) and therefore not able to actively participate in their own lives and make decisions for themselves. Olav, who managed to make changes at his day care centre, can therefore be seen as someone daring to challenge what others take for granted.

6 Conclusion

The overall aim of this thesis was to explore user participation in home-based dementia care. This was operationalized in the three research questions:

- How is user participation understood in home-based dementia care?
- How is user participation practised in home-based dementia care?
- What degrees of user participation qualifies as ‘real’ user participation in home-based dementia care?

After having written this thesis, I am left with the impression that user participation is generally promoted as the best care for people with dementia, but there is both confusion and disagreement as to what it should entail. This is reflected in the fact that the two main models of user participation disagree on what qualifies as user participation, neither of these models is cited in research on user participation in dementia care, and policy papers do not explicitly state the ideological underpinnings of their emphasis on user participation. Further, the confusion and disagreement are reflected in the different forms user participation practiced by the professional caregivers, with some practicing autonomous decision-making literally, and others practicing a more relational type of user participation though sharing their understanding of what user participation is.

The answer to the first research question is therefore that user participation is most often understood as autonomous decision-making in home-based dementia care. In the discussion, I showed how this understanding mirrors the dominant political discourse of user participation. I have also showed how the professional caregivers seem to have constructed user participation as an either/or issue, contrasting user participation and autonomous decision-making with coercion such that actions involving any aspects of coercion are understood as not being user participation. As I have showed, this leads to very real issues for the professional caregivers, who are eventually faced with the question of whether to practice this understanding of user participation, which many of them deem unfit for their own patients.

A question I therefore raise in this synopsis, and which should be explored further, is how user participation relates to the concept of care. In my analysis of the second research question, ‘how is user participation practiced’, I have, with the help of Mol’s categories, showed that user participation is practiced as either a logic of choice or a logic of care. While most experts seem to agree that a logic of care is favourable for people with dementia, whether the aim is user participation or just providing the best possible care, this still does not mean that a logic of care equals user participation. For the professional caregivers in my study, it clearly did not, as they spoke about ‘sneaking in care’, as though care were something that did not fit with the aim of user participation. As do most of the questions that I will pose in this conclusion and have posed earlier in the synopsis, this leads us back to a question that has become central to my project: what is user participation really?

This leads us to the last research question: ‘What degree of user participation qualifies as real user participation in home-based dementia care?’ In a way, the answer to this question is the same as the answer to the first research question: ‘real’ user participation is autonomous decision-making because the professional caregivers see autonomous decision-making as a better, and sometimes the only, form of user participation. From a professional caregivers’ point of view, shared decision-making, though highlighted as the best form of decision-making for people with dementia, is not ‘real’ user participation. However, while ‘real’ user participation seems to be synonymous with autonomous decision-making, it also clearly seems to be about something more than mere participation in decision-making. My conclusion is that ‘real’ user participation seems to be linked to the democratic ideology of user participation. This can be seen in how the models of user participation clearly ascribe to such an understanding. In the democratic ideology, participation in decision-making becomes one step towards reaching a larger goal of equality, freedom, and citizenship. Though the policy papers do not mention this explicitly, they also seem to be inspired by the democratic ideology, as they focus on fighting discrimination of people with dementia and securing their freedom and independence. However, in these papers, the democratic ideology is clearly infused with ideas of active aging. It thus seems clear that the democratic ideology underlying the idea of user participation needs to be communicated to the professional caregivers more clearly if it is going to be adopted and implemented in a service strongly affected by both the consumer discourse and ideas of active and independent aging. An additional point concerning a possible strengthening of the link between user participation and the democratic ideology is assuring that a democratic ideology of user participation in dementia care also has room for ‘the sick and frail citizen’.

As I have attempted to show in this thesis, there is not one single answer to the question of what user participation should be in the context of home-based dementia care. User participation does not exist as an objective truth but rather is constantly formed and renegotiated through our understanding and practice of it. A core idea of social constructionism is that through language reality is shaped, but also re-shaped. It can help us recognize problematic ideas, but it also has the power to develop new and more relevant ‘realities’. I hope that this thesis will invite reflection and discussion around the current understanding and practice of user participation in home-based dementia care.

6.1 Implications for research and practice

This study has demonstrated that user participation in dementia care, especially home-based dementia care, is an under-researched area. Future research should therefore pay attention to the topic in general. Specifically, it seems necessary to perform a conceptual analysis focusing on the difference between user participation and concepts such as shared decision-making and person-centred care, as well as citizenship and autonomy. The fit between the current understanding of user participation and the practice of dementia care also needs attention. In this discussion, it would be relevant to continue the exploration of the relation between the concept of user participation and the concept of care that I have started in this synopsis. To clarify the meaning of user participation in dementia care, research on user participation should look into existing models of user participation to see if they can positively inform the understanding and practice of user participation in dementia care or if alternative models are needed. Relational approaches to both autonomy and citizenship should be considered here.

As far as the practice of user participation is concerned, this study has demonstrated a gap between the outlined health policy on user participation and how the same concept is constructed by professional caregivers in home-based dementia care. Successful user participation in dementia care requires a bottom-up approach whereby policies are affected by the actual practice of user participation. Policy-makers should therefore recognise professional caregivers' views and concerns regarding user participation, as well as the experiences of people with dementia and their families. Failure to do so can lead to unintended consequences, namely that professional caregivers practise user participation in a way that does not fit the needs of people with dementia because they believe that this specific practice is what is expected from them. This study has also shown that successful user participation in dementia care requires increased knowledge about user participation. This includes the development of guidelines, courses and education about user participation and making room for ethical reflection in practice.

References

Agich, G. (2003). *Dependence and autonomy in old age: an ethical framework for long-term care*. Cambridge: Cambridge University Press.

Alm Andreassen, T. (2013). En sosial bevegelse blant mennesker med psykiske problemer [A social movement among people with mental health problems]. In R. Norvoll (Ed.), *Samfunn og psykisk helse. Samfunnsvitenskapelige perspektiver* [*Society and mental health. Social science perspectives*] (pp. 285-312). Oslo: Gyldendal Akademisk.

Alonzi, A., Sheard, J., & Bateman, M. (2009). Assessing staff needs for guidance on the Mental Capacity Act 2005. *Nursing times*, *105*(3), 24-27.

Alvsvåg, H., & Martinsen, K. M. (2018). Omsorg og skjønn. *Tidsskrift for omsorgsforskning*, *4*(03), 215-222.

Armour, M., Rivaux, S. L., & Bell, H. (2009). Using context to build rigor: Application to two hermeneutic phenomenological studies. *Qualitative Social Work*, *8*(1), 101-122.

Arnstein, S. R. (1969). A ladder of citizen participation. *Journal of the American Institute of planners, 35*(4), 216-224.

Askheim, O. P., Christensen, K., Fluge, S., & Guldvik, I. (2017). User participation in the Norwegian welfare context: an analysis of policy discourses. *Journal of Social Policy, 46*(3), 583-601.

Barnes, M., & Brannelly, T. (2008). Achieving care and social justice for people with dementia. *Nursing ethics*, *15*(3), 384-395.

Bartlett, R., & O'Connor, D. (2007). From personhood to citizenship: Broadening the lens for dementia practice and research. *Journal of Aging Studies, 21*(2), 107-118.

Bartlett, R., & O'Connor, D. (2010). *Broadening the dementia debate: Towards social citizenship*. Bristol: Policy press.

Becker, H. S. (1993). How I learned what a crock was. *Journal of Contemporary Ethnography*, *22*(1), 28-35.

Belsey, C. (2013). Poststructuralism. In S. Malpas & P. Wake (Ed.), *The Routledge Companion to Critical and Cultural Theory* (pp. 67-77). New York: Routledge.

Beresford, P. (2012). The theory and philosophy behind user involvement. In P. B. a. S. Carr (Ed.), *Social care, service users and user involvement* (pp. 21-36). London and Philadelphia: Jessica Kingsley Publisher.

Berger, P. L. and Luckmann, T. (1966). The Social Construction of Reality. London: Penguin Press.

Bjørkquist, C., Ramsdal, H., & Ramsdal, K. (2015). User participation and stakeholder involvement in health care innovation–does it matter? *European Journal of Innovation Management, 18*(1), 2-18.

Blaikie, N. (2000). Designing Social Research. Cambridge: Polity Press.

Bochel, C., Bochel, H., Somerville, P., & Worley, C. (2008). Marginalised or enabled voices? 'User participation'in policy and practice. *Social Policy and Society, 7*(2), 201-210.

Borg, M., & Kristiansen, K. (2009). *Medforskning-å forske sammen for kunnskap om psykisk helse*. Oslo: Universitetsforlaget

Boyle, G. (2014). Recognising the agency of people with dementia. *Disability & Society, 29*(7), 1130-1144.

Bradshaw, P. L. (2008). Service user involvement in the NHS in England: genuine user participation or a dogma-driven folly? *Journal of Nursing Management, 16*(6), 673-681.

Brannelly, T. (2011). Sustaining citizenship: People with dementia and the phenomenon of social death. *Nursing Ethics*, *18*(5), 662-671.

Brannelly, T. (2016). Citizenship and people living with dementia: A case for the ethics of care. *Dementia, 15*(3), 304-314.

Braun, V., & Clarke, V. (2006). Using thematic analysis in psychology. *Qualitative research in psychology, 3*(2), 77-101.

Brækhus, A., Dahl, T. E., Engedal, K., & Laake, K. (2013). *Hva er demens?* [What is dementia?]. Tønsberg: Aldring og Helse.

Butler, R. N. (1969). Age-ism: Another form of bigotry. *The Gerontologist, 9*(4_Part_1), 243-246.

Ceci, C. (2013). 'To Work Out What Works Best': What is Good in Home Care?: Christine Ceci. In C. Ceci, K. Björnsdóttir, & M. Purkis (Eds.). *Perspectives on Care at Home for Older People* (89-108). New York: Routledge.

Childress, J. F., & Beauchamp, T. L. (2001). *Principles of biomedical ethics* (p. 618). New York: Oxford University Press.

Chrisp, T. A. C., Tabberer, S., & Thomas, B. D. (2013). Bounded autonomy in deciding to seek medical help: Carer role, the sick role and the case of dementia. *Journal of Health Psychology, 18*(2), 272-281.

Christensen, K., & Fluge, S. (2016). Brukermedvirkning i norsk eldreomsorgspolitikk–Om utviklingen av retorikken om individuelt medansvar [User participation in Norwegian elder care policy - About the development of the rhetoric on individual co-responsibility]. *Tidsskrift for velferdsforskning*, *19*(03), 261-277.

Creswell, J. W., & Poth, C. N. (2016). *Qualitative inquiry and research design: Choosing among five approaches*. Sage publications.

Daatland, S. O., Høyland, K., & Otnes, B. (2015). Scandinavian contrasts and Norwegian variations in special housing for older people. *Journal of Housing for the Elderly*, *29*(1-2), 180-196.

Darbyshire, P. (1992). *Parenting in public: a study of the experiences of parents who live-in with their hospitalised child, and of their relationships with paediatric nurses* (Doctoral dissertation) University of Edinburgh, Edinburgh.

Darnell, K. R., McGuire, C., & Danner, D. D. (2011). African American participation in Alzheimer's disease research that includes brain donation. *American Journal of Alzheimer's Disease & Other Dementias, 26*(6), 469-476.

Dean, M. (2010). *Governmentality: Power and rule in modern society*. London: Sage publications.

Derrida, J. (1997). *Of Grammatology.* Baltimore, MD: Johns Hopkins University Press.

Dixon-Woods, M., Cavers, D., Agarwal, S., Annandale, E., Arthur, A., Harvey, J., . . . Smith, L. (2006). Conducting a critical interpretive synthesis of the literature on access to healthcare by vulnerable groups. *BMC medical research methodology, 6*(1), 35.

Dixon-Woods, M., Shaw, R. L., Agarwal, S., & Smith, J. A. (2004). The problem of appraising qualitative research. BMJ Quality & Safety, 13(3), 223-225.

Edvardsson, D., Winblad, B., & Sandman, P. O. (2008). Person-centred care of people with severe Alzheimer's disease: current status and ways forward. *The Lancet Neurology*, *7*(4), 362-367.

Efraimsson, E., Sandman, P. O., Hydén, L. C., & Rasmussen, B. H. (2004). Discharge planning:'fooling ourselves?'–patient participation in conferences. Journal of clinical nursing, 13(5), 562-570.

Engedal, K., & Haugen, P. K. (2009). *Lærebok om demens. Fakta og utfordringer* [Textbook on dementia. Facts and challenges]. Tønsberg: Aldring og helse.

Fetherstonhaugh, D., Tarzia, L., & Nay, R. (2013). Being central to decision making means I am still here!: The essence of decision making for people with dementia. *Journal of Aging Studies, 27*(2), 143-150.

Fjelltun, A. M. S. (2009). *Waiting for nursing home placement: a study of the life situation of frail elderly and their carers*. University of Tromsø, Tromsø, Norway.

Flyvbjerg, B. (2006). Five misunderstandings about case-study research. *Qualitative inquiry, 12*(2), 219-245.

Forbes, D., Ward-Griffin, C., Kloseck, M., Mendelsohn, M., St-Amant, O., DeForge, R., & Clark, K. (2011). "HER WORLD GETS SMALLER AND SMALLER WITH NOTHING TO LOOK FORWARD TO": DIMENSIONS OF SOCIAL INCLUSION AND EXCLUSION AMONG RURAL DEMENTIA CARE NETWORKS. *Online Journal of Rural Nursing & Health Care, 11*(2), 27-42.

Foss, C. (2011). Elders and patient participation revisited–a discourse analytic approach to older persons' reflections on patient participation. *Journal of Clinical Nursing*, *20*(13-14), 2014-2022.

Foucault, M. (2005). *The order of things: An archaeology of the human sciences.* London: Routledge. (1966).

Foucault, M. (2012). *Discipline and punish: The birth of the prison*. New York: Random House. (1977).

Froestad, J., & Ravneberg, B. (1991). Fra veldedighet til rettighet. Historien om Norges Handikapforbund *[From charity to entitlement. History of the Norwegian Disability Association]. Oslo: Norges Handikapforbund*.

Gausdal, M., & Michelet, M. (2011). *Demensteam – oppgaver og utfordringer [Dementiateams – tasks and challenges].* Aldring og Helse. https://www.regjeringen.no/contentassets/b6c354b55aae489ab27b54ed3dcd8bf9/rapport_demensteam_100212.pdf?id=2303443

Gautun, H., & Syse, A. (2013). *Samhandlingsreformen: Hvordan tar de kommunale helse-og omsorgstjenestene i mot det økte antallet pasienter som skrives ut fra sykehusene? [The Coordination Reform: How do municipal health services receive the increased number of patients discharged from hospitals?]* (Report No. 08/2013). Oslo: Norsk Institutt for Forskning om Oppvekst, Velferd og Aldring.

Gergen, K. J. (1999). *An invitation to social construction.* London: Sage.

Hacking, I. (1999). *The social construction of what?*. Cambridge, London: Harvard university press.

Hamann, J., Bronner, K., Margull, J., Mendel, R., Diehl-Schmid, J., Bühner, M., ... & Perneczky, R. (2011). Patient Participation in Medical and Social Decisions in A lzheimer's Disease. *Journal of the American Geriatrics Society*, *59*(11), 2045-2052.

Hamdy, R. C., Lewis, J., Kinser, A., Depelteau, A., Copeland, R., Kendall-Wilson, T., & Whalen, K. (2017). Too many choices confuse patients with dementia. *Gerontology and Geriatric Medicine, 3*, 1-7.

Haukelien, H., Møller, G., & Vike, H. (2011). Brukermedvirkning i helse-og omsorgssektoren. Retrieved from: https://openarchive.usn.no/usn-xmlui/bitstream/handle/11250/2439303/1911.pdf?sequence=1

Heggen, K., & Engebretsen, E. (2012). *Makt på nye måter*. Oslo: Universitetsforlaget.

Helgesen, A. K. (2013). *Patient participation in everyday life in special care units for persons with dementia* (Doctoral dissertation, Karlstad University, Karlstad, Sweden). Karlstads universitet. Retrieved from http://www.diva-portal.org/smash/record.jsf?pid=diva2%3A651778&dswid=-6526

Helgesen, A. K., Larsson, M., & Athlin, E. (2010). 'Patient participation' in everyday activities in special care units for persons with dementia in Norwegian nursing homes. *International Journal of Older People Nursing, 5*(2), 169-178.

Helgesen, A. K., Larsson, M., & Athlin, E. (2013). How do relatives of persons with dementia experience their role in the patient participation process in special care units? *Journal of Clinical Nursing, 22*(11/12), 1672-1681.

Helgesen, A. K., Larsson, M., & Athlin, E. (2014). Patient participation in special care units for persons with dementia: A losing principle? Nursing Ethics, 21(1), 108-118.

Hernandez, L., Robson, P., & Sampson, A. (2008). Towards integrated participation: Involving seldom heard users of social care services. *British Journal of Social Work, 40*(3), 714-736.

Humerfelt, K. (2005). Begrepene brukermedvirkning og brukerperspektiv: Honnørord med lavt presisjonsnivå *[The terms user participation and user perspective: Honuor words with low precision]*. I E. *Willumsen (red.), Brukernes medvirkning*, 15-33.

Hydén, L. C., & Nilsson, E. (2015). Couples with dementia: Positioning the 'we'. *Dementia*, *14*(6), 716-733.

Jacobsen, F. F. (2020). The Imaginaries of Home Making and Home Care in Public Policies. In *Ways of Home Making in Care for Later Life* (pp. 85-108). Palgrave Macmillan, Singapore.

Jacobsen, F. F. (2015). Understanding public elderly care policy in Norway: A narrative analysis of governmental White papers. *Journal of Aging Studies, 34*, 199-205.

Jakobsen, R., & Sørlie, V. (2010). Dignity of older people in a nursing home: narratives of care providers. *Nursing Ethics, 17*(3), 289-300.

Johannessen, A. K. M., & Steihaug, S. (2019). Brukermedvirkning i helsetjeneste for eldre. *Tidsskrift for omsorgsforskning*, *5*(02), 1-14.

Kenny, J., Asquith, I., Guss, R., Field, E., Slade, L., Bone, A., . . . Brooks, M. (2016). Facilitating an evolving service user involvement group for people with dementia: what can we learn? *The Journal of Mental Health Training, Education and Practice, 11*(2), 81-90.

Kirkevold, Ø., & Engedal, K. (2009). Is covert medication in Norwegian nursing homes still a problem? *Drugs & Aging, 26*(4), 333-344.

Kitwood, T. M. (1997). *Dementia reconsidered: The person comes first*. Buckingham: Open university press.

Klevan, T. (2017). *The importance of helpful help in mental health crises: experiences, stories, and contexts–A qualitative exploration* (Doctoral dissertation). University College of Southeast Norway, Kongsberg, Norway.

Kristiansen, M. (2016). *Contradictory management requirements and organisation of daily work in Norwegian nursing homes* (Doctoral dissertation). The Arctic University of Norway, Tromsø, Norway.

Kvale, S., & Brinkmann, S. (2012). *Det kvalitative forskningsintervju* [The qualitative research interview]. (2. utgave. utg.). Oslo: Gyldendal Norske Forlag AS.

Landau, R., & Werner, S. (2012). Ethical aspects of using GPS for tracking people with dementia: recommendations for practice. *International Psychogeriatrics, 24*(3), 358-366.

Larsen, L. S., Normann, H. K., & Hamran, T. (2017). Processes of user participation among formal and family caregivers in home-based care for persons with dementia. *Dementia, 16*(2), 158-177.

Lausund, H. (2017). *Contracted Care: An Ethnographic Study of Home Care Nursing in Norway* (Doctoral dissertation). MF Norwegian School of Theology, Religion and Society, Oslo, Norway.

Laverty, S. M. (2003). Hermeneutic phenomenology and phenomenology: A comparison of historical and methodological considerations. *International journal of qualitative methods*, *2*(3), 21-35.

Law, E., Russ, T., & Connelly, P. (2013). What motivates patients and carers to participate in dementia studies? *Nursing older people, 25*(9), 31-36.

Lejman, E., Westerbotn, M., Pöder, U., & Wadensten, B. (2013). The ethics of coercive treatment of people with dementia. *Nursing Ethics, 20*(3), 248-262.

Lincoln, Y. S., & Guba, E. G. (1986). But is it rigorous? Trustworthiness and authenticity in naturalistic evaluation. *New directions for program evaluation, 1986*(30), 73-84.

Lindseth, A., & Norberg, A. (2004). A phenomenological hermeneutical method for researching lived experience. *Scandinavian journal of caring sciences*, *18*(2), 145-153.

Low, L. F., Swaffer, K., McGrath, M., & Brodaty, H. (2018). Do people with early stage dementia experience Prescribed Disengagement®? A systematic review of qualitative studies. *International psychogeriatrics*, *30*(6), 807-831.

Martinsen, K. (1989). *Omsorg, sykepleie og medisin* [Care, nursing, and medicine]. Oslo: Universitetsforlaget.

McCabe, L., & Innes, A. (2013). Supporting safe walking for people with dementia: User participation in the development of new technology. *Gerontechnology, 12*(1), 4-15.

McDonald, A. (2010). The impact of the 2005 Mental Capacity Act on social workers' decision making and approaches to the assessment of risk. *British Journal of Social Work, 40*(4), 1229-1246.

McLaughlin, H. (2009). What's in a name: 'Client', 'Patient', 'Customer', 'Consumer', 'Expert by Experience', 'Service User' – Whats Next?. *The British Journal of Social Work, 39*(6), 1101-1117.

Merleau-Ponty, M. (1962). *Phenomenology of Perception*. London: Routledge & Kegan Paul.

Milne, A. (2010). The 'D'word: Reflections on the relationship between stigma, discrimination and dementia. *Journal of Mental Health, 19*(3), 227-233.

Mol, A. (2008). *The logic of care: Health and the problem of patient choice*. Amsterdam: Routledge.

Moye, J., & Marson, D. C. (2007). Assessment of decision-making capacity in older adults: an emerging area of practice and research. *The Journals of Gerontology Series B: Psychological Sciences and Social Sciences*, *62*(1), 3-11.

Norheim, A., & Vinsnes, A. (2008). Pasientmedvirkning i demensomsorgen - Muligheter og utfordringer. *Norsk Tidsskrift for Sykepleieforskning, 10*, 3-15.

Norwegian Ministry of Social Affairs and Health. (1997). Handlingsplan for eldreomsorgen: Trygghet – respekt – kvalitet (St.meld. nr. 50 (1996-1997)). [White Paper 50 Actionplan for elderycare: Safety – respect - quality]. Retrieved from: https://www.regjeringen.no/contentassets/0a9dcdebf5dc473eb8fdef01e0b5125d/no/pdfs/stm199619970050000dddpdfs.pdf

Norwegian Ministry of Health and Care Services. (2007). *Demensplan 2015 -Den gode dagen [Dementia Plan 2015 - The good day].* Retrieved from: https://www.regjeringen.no/globalassets/upload/HOD/Vedlegg/Omsorgsplan_2015/Demensplan2015.pdf

Norwegian Ministry of Health and Care Services. (2008-2009). *Samhandlingsreformen: Rett behandling – på rett sted – til rett tid [The right treatment, in the right place, at the right time].* Retrieved from: https://www.regjeringen.no/contentassets/d4f0e16ad32e4bbd8d8ab5c21445a5dc/no/pdfs/stm200820090047000dddpdfs.pdf

Norwegian Ministry of Health and Care Services. (2012-2013). *Morgendagens Omsorg* (Meld. St. 29 (2012-2013) *[White Paper 18 Tomorrows Care]*. Retrieved from: https://www.regjeringen.no/contentassets/34c8183cc5cd43e2bd341e34e326dbd8/no/pdfs/stm201220130029000dddpdfs.pdf

Norwegian Ministry of Health and Care Services. (2014-2015). *Fremtidens primærhelsetjeneste – nærhet og helhet* (Meld. St. 26 (2014-2015)). [White Paper 26 The primary health service of the future - proximity and wholeness]. Retrieved from: https://www.regjeringen.no/no/dokumenter/meld.-st.-26-2014-2015/id2409890/sec1

Norwegian Ministry of Health and Care Services. (2015) *Demensplan 2020 – Et mer demensvennlig samfunn [Dementia Plan 2020 - A more dementia friendly society].* Retrieved from: https://www.regjeringen.no/contentassets/3bbec72c19a04af88fa78ffb02a203da/demensplan_2020.pdf

NOU 2011: 11. (2011). *Innovasjon i omsorg* [Innovation in Care]. Retrieved from: https://www.regjeringen.no/contentassets/5fd24706b4474177bec0938582e3964a/no/pdfs/nou201120110011000dddpdfs.pdf

Patients´ Rights Law (1999). Lov om pasient- og brukerrettigheter (LOV-2019-06-21-43) *[Patient and user rights law]*. Retrieved from: https://lovdata.no/dokument/NL/lov/1999-07-02-63#KAPITTEL_3

Patterson, C. (2018). World Alzheimer Report 2018 – The State of the Art of Dementia Research: New Frontiers. London: Alzheimer's Disease International (ADI).

Pillow, W. (2003). Confession, catharsis, or cure? Rethinking the uses of reflexivity as methodological power in qualitative research. *International journal of qualitative studies in education, 16*(2), 175-196.

Pols, J. (2006). Washing the citizen: washing, cleanliness and citizenship in mental health care. *Culture, medicine and psychiatry, 30*(1), 77-104.

Ruyter, K.W. (2007). Forskningsetikk [Research ethics]. In K.W. Ruyter, R. Førde & J.H. Solbakk (Eds.), *Medisinsk og helsefaglig etikk* [Medical and health ethics]. Oslo, Norway: Gyldendal akademisk.

Rønning, R., & Solheim, L. J. (1998). *Hjelp på egne premisser?: om brukermedvirkning i velferdstjenestene* [*Help on their own terms?: about user participation in the welfare services*]. Oslo: Universitetsforlaget.

Røsvik, J., Kirkevold, M., Engedal, K., Brooker, D., & Kirkevold, Ø. (2011). A model for using the VIPS framework for person-centred care for persons with dementia in nursing homes: a qualitative evaluative study. *International journal of older people nursing*, *6*(3), 227-236.

Sabat, S. R. (2005). Capacity for decision-making in Alzheimer's disease: Selfhood, positioning and semiotic people. *Australian & New Zealand Journal of Psychiatry*, *39*(11-12), 1030-1035.

Sabat S.R. (2008) A bio-psycho-social approach to dementia. In M. Downs & B. Bowers (Eds.). *Excellence in Dementia Care: Research into Practice* (70–84). McGraw Hill, Maidenhead: Open University Press.

Samsi, K., & Manthorpe, J. (2013). Everyday decision-making in dementia: findings from a longitudinal interview study of people with dementia and family carers. *International Psychogeriatrics, 25*(6), 949-961.

Samuelsson, C., Österholm, J. H., & Olaison, A. (2015). Orally positioning older people in assessment meetings. *Educational Gerontology, 41*(11), 767-785.

Seim, S., & Slettebø, T. (2017). Challenges of participation in child welfare. *European Journal of Social Work*, *20*(6), 882-893.

Seim, S., & Slettebø, T. (2011). Collective participation in child protection services: Partnership or tokenism?. *European Journal of Social Work*, *14*(4), 497-512.

Sinclair, C., Gersbach, K., Hogan, M., Bucks, R. S., Auret, K. A., Clayton, J. M., . . . Kurrle, S. (2018). How couples with dementia experience healthcare, lifestyle, and everyday decision-making. *International Psychogeriatrics, 30*(11), 1639-1647.

Slaughter, S., Cole, D., Jennings, E., & Reimer, M. A. (2007). Consent and assent to participate in research from people with dementia. *Nursing Ethics, 14*(1), 27-40.

Slegers, K., Wilkinson, A., & Hendriks, N. (2013). *Active collaboration in healthcare design: participatory design to develop a dementia care app.* Paper presented at the CHI'13 Extended Abstracts on Human Factors in Computing Systems.

Slettebø, Å., Sæteren, B., Caspari, S., Lohne, V., Rehnsfeldt, A. W., Heggestad, A. K. T., ... & Aasgaard, T. (2017). The significance of meaningful and enjoyable activities for nursing home resident's experiences of dignity. *Scandinavian journal of caring sciences*, *31*(4), 718-726.

Sloan, A., & Bowe, B. (2014). Phenomenology and hermeneutic phenomenology: The philosophy, the methodologies, and using hermeneutic phenomenology to investigate lecturers' experiences of curriculum design. *Quality & Quantity*, *48*(3), 1291-1303.

Smebye, K. L., Kirkevold, M., & Engedal, K. (2012). How do persons with dementia participate in decision making related to health and daily care? A multi-case study.(Research article)(Report). *BMC Health Services Research, 12*, 241.

Smebye, K. L., Kirkevold, M., & Engedal, K. (2016). Ethical dilemmas concerning autonomy when persons with dementia wish to live at home: a qualitative, hermeneutic study. *BMC Health Services Research, 16*(1), 21.

St-Amant, O., Ward-Griffin, C., DeForge, R. T., Oudshoorn, A., McWilliam, C., Forbes, D., . . . Hall, J. (2012). Making care decisions in home-based dementia care: Why context matters. *Canadian Journal on Aging, 31*(4), 423-434.

Steeman, E., Godderis, J., Grypdonck, M., De Bal, N., & De Casterlé, B. D. (2007). Living with dementia from the perspective of older people: is it a positive story?. *Aging & mental health*, *11*(2), 119-130.

Stewart, E. (2013). What is the point of citizen participation in health care? *Journal of Health Services Research & Policy, 18*(2), 124-126.

Swaffer, K. (2015). Dementia and prescribed disengagement. *Dementia, 14*(1), 3-6.

Sørly, R. (2017). *Brukermedvirkning i demensomsorgen – En oppsummering av kunnskap*. Senter for omsorgsforskning. Retrieved from: https://omsorgsforskning.brage.unit.no/omsorgsforskning-xmlui/bitstream/handle/11250/2453660/Brukermedvirkning%20i%20demensomsorgen%20(2).pdf?sequence=3

Sørvoll, J., & Gautun, H. (2020). Brukermedvirkning i norsk eldreomsorg – følger kommunene opp statens styringssignaler? [User Participation in Norwegian Elder Care – Do Local Governments Follow the Lead of Care 2020?]. *Tidsskrift for omsorgsforskning, 6*(1), 1-16.

The Public Health Department. (2014, 30.6). Retrieved 20. September 2019 from https://www.fhi.no/nettpub/hin/ikke-smittsomme/demens/

Thoft, D. S., Pyer, M., Horsbøl, A., & Parkes, J. (2018). The Balanced Participation Model: Sharing opportunities for giving people with early-stage dementia a voice in research. *Dementia*, *0*(0), 1-20.

Thomassen, M. (2020). Fenomenologiens mange ansikter *[The many faces of phenomenology]*. In D. Jensse, M. Kjørstad, S. Seim & A. Tufte (Eds.), *Vitenskapsteori for sosial- og helsefag* (pp. 103-137). Gyldendal.

Thomassen, M. (2006). *Vitenskap, kunnskap og praksis: innføring i vitenskapsfilosofi for helse-og sosialfag [Science, knowledge and practice: introduction to the philosophy of science for health and social sciences]*. Oslo: Gyldendal akademisk.

Thompson, A. G. (2007). The meaning of patient involvement and participation in health care consultations: a taxonomy. *Social Science & Medicine, 64*(6), 1297-1310.

Tjora, A. (2012). *Kvalitative forskningsmetoder i praksis [Qualitative research methods in practice]*. Oslo: Gyldendal Norsk Forlag AS.

Tooke, J. (2013). Involving people with dementia in the work of an organisation: Service User Review Panels. *Quality in Ageing & Older Adults, 14*(1), 56-65.

Tritter, J. Q. (2009). Revolution or evolution: the challenges of conceptualizing patient and public involvement in a consumerist world. *Health Expectations, 12*(3), 275-287.

Tyrrell, J., Genin, N., & Myslinski, M. (2006). Freedom of choice and decision-making in health and social care: Views of older patients with early-stage dementia and their carers. *Dementia*, *5*(4), 479-502.

van Manen, M. (2017a). But is it phenomenology? *Qualitative Health Research, 27*(6), 775-779.

van Manen, M. (2017b). Phenomenology in its original sense. *Qualitative Health Research*, *27*(6), 810-825.

van Manen, M. (1990). *Researching lived experience: Human science for an action sensitive pedagogy*. London: SUNY Press.

Vetlesen, A. J. (2003). Omsorg-mellom avhengighet og autonomi. [Care-between dependence and autonomy]. In K. W. Ruyter & A. J. Vetlesen (Eds.). *Omsorgens tvetydighet-egenart, historie og praksis [The ambiguity of care-distinctiveness, history and practice]* (s. 27-40). Oslo: Gyldendal.

Yin, R. K. (2017). *Case study research and applications: Design and methods*. Beverly Hills, CA: Sage publications.

Witsø, A. E., Vik, K., & Ytterhus, B. (2012). Participation in older home care recipients: a value-based process. *Activities, adaptation & aging*, *36*(4), 297-316.

Wittgenstein, L. (1978). *Philosophical Investigations.* Oxford: Blackwell

Wogn-Henriksen, K. (2012). *«Du må... skape deg et liv»: en kvalitativ studie om å oppleve og leve med demens basert på intervjuer med en gruppe personer med tidlig debuterende Alzheimer sykdom* (Doctoral dissertation)*.* Norges teknisk-naturvitenskapelige universitet, Trondheim, Norway.

Wolfs, C. A., de Vugt, M. E., Verkaaik, M., Haufe, M., Verkade, P. J., Verhey, F. R., & Stevens, F. (2012). Rational decision-making about treatment and care in dementia: a contradiction in terms? *Patient Education & Counseling, 87*(1), 43-48.

World Health Organization. (2019). Retrieved from: https://www.who.int/news-room/fact-sheets/detail/dementia

World Health Organization. (2017). *Global Action Plan on the Public Health Response to Dementia 2017-2025.* Geneva: World Health Organization. Retrieved from: https://apps.who.int/iris/bitstream/handle/10665/259615/9789241513487-eng.pdf?sequence=1

World Health Organization. (2013). *How to use the ICF. A Practical Manual for using the International Classification of Functioning, Disability and Health (ICF*). Geneva: World Health Organization.

World Health Organization. (2002). *Active Ageing: A policy Framework.* Retrieved from: https://www.who.int/ageing/publications/active_ageing/en/

World Health Organisation. (1978). *Declaration of Alma-Ata. International Conference on Primary Health Care*. Alma-Ata, USSR. Retrieved from: https://www.who.int/publications/almaata_declaration_en.pdf

World Medical Association. (2001). World Medical Association Declaration of Helsinki. Ethical principles for medical research involving human subjects. *Bulletin of the World Health Organization, 79*(4), 373.

Yardley, L. (2000). Dilemmas in qualitative health research. *Psychology and health, 15*(2), 215-228.

Zahavi, D. (2019). Getting it quite wrong: Van Manen and Smith on phenomenology. *Qualitative health research*, *29*(6), 900-907.

Österholm, J. H., & Hydén, L. C. (2018). Autobiographical occasions in assessment meetings involving persons with dementia. *Qualitative Social Work*, *17*(1), 41-64.

Øye, C., & Jacobsen, F. F. (2020). Informal use of restraint in nursing homes: A threat to human rights or necessary care to preserve residents' dignity?. Health, 24(2), 187-202.

Appendixes

Appendix 1: REK (Regionale komité for medisinsk og helsefaglig forskningsetikk)

Vår ref.nr.: 2015/756 A

Vi viser til skjema for framleggingsvurdering mottatt 14.04.2015 angående prosjektet «Brukermedvirkning blant eldre med demens». Fremleggingsvurderingen er vurdert av komiteens leder på fullmakt.

Formålet med prosjektet, slik det fremkommer av fremleggingsvurderingen, er å undersøke i hvilke grad brukermedvirkning blir forstått og praktisert overfor eldre i kommunale helse- og omsorgstjenester samt undersøke hvilke faktorer som fremmer/hemmer brukermedvirkning hos eldre med demens. Opplysninger skal innsamles ved intervju av kommunalt ansatte (n=12), brukere (n=20) og pårørende (n=20).

Dette et nyttig og spennende prosjekt, i tråd med politisk føringer for den helseomsorg som skal tilbys hjemmeboende eldre med demens.

Etter REKs vurdering er prosjektet å anse som helsetjenesteforskning. Helsetjenesteforskning er et flerfaglig vitenskapelig felt hvor man studerer hvordan sosiale faktorer, finansieringssystemer, organisatoriske strukturer og prosesser, helseteknologi og personellatferd påvirker tilgang til helse - og omsorgstjenester, kvaliteten og kostnadene ved helse og omsorgstjenester, og endelig helse og velvære.

Helsetjenesteforskning er også forskning på forbedring av helsetjenesten og effektiv bruk av ressurser for samfunnet. I helsetjenesteforskningen studerer man blant annet hvordan helsetjenester leveres, hvordan de er utformet, og hvordan helsetjenesten fungerer som system.

Helsetjenesteforskning omfattes ikke av helseforskningslovens virkeområde, som omfatter prosjekter med det formål å skaffe ny kunnskap om helse og sykdom, jf. helseforskningsloven § 2 og § 4 a, og er dermed ikke fremleggingspliktig for REK.

Det er institusjonens ansvar på å sørge for at prosjektet gjennomføres på en forsvarlig måte med hensyn til for eksempel regler for taushetsplikt og personvern.

Vi gjør oppmerksom på at denne vurderingen er å anse som veiledende, jf. forvaltningsloven § 11.

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

Med vennlig hilsen
Anette Solli Karlsen

Komitesekretær

post@helseforskning.etikkom.no

T: 22845522

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

REK
REGIONALE KOMITEER FOR MEDISINSK OG HELSEFAGLIG FORSKNINGSETIKK

Norsk samfunnsvitenskapelig datatjeneste AS
NORWEGIAN SOCIAL SCIENCE DATA SERVICES

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nsd@nsd.uib.no
www.nsd.uib.no
Org.nr. 985 321 884

Ingebjørg Haugen
Senter for diakoni og profesjonell praksis Diakonhjemmet høgskole
Diakonveien 14-18
0370 OSLO

Vår dato: 26.01.2015 Vår ref: 41528 / 3 / LT Deres dato: Deres ref:

TILBAKEMELDING PÅ MELDING OM BEHANDLING AV PERSONOPPLYSNINGER

Vi viser til melding om behandling av personopplysninger, mottatt 09.01.2015. Meldingen gjelder prosjektet:

41528	*Brukermedvirkning blant eldre med demens, Del 1*
Behandlingsansvarlig	*Diakonhjemmet Høgskole AS, ved institusjonens øverste leder*
Daglig ansvarlig	*Ingebjørg Haugen*

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, ombudets kommentarer samt personopplysningsloven og helseregisterloven med forskrifter. Behandlingen av personopplysninger kan settes i gang.

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

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

Personvernombudet vil ved prosjektets avslutning, 01.07.2017, rette en henvendelse angående status for behandlingen av personopplysninger.

Vennlig hilsen

Katrine Utaaker Segadal

Lis Tenold

Kontaktperson: Lis Tenold tlf: 55 58 33 77
Vedlegg: Prosjektvurdering

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

Personvernombudet for forskning

Prosjektvurdering - Kommentar

Prosjektnr: 41528

Personvernombudet registrerer at prosjektet omfatter intervju med 1) nøkkelinformanter, 2) hjemmeboende mennesker med demens og 3) pårørende. I innsendt meldeskjema er det kun vedlagt informasjonsskriv og intervjuguide for intervju med nøkkelinformanter. Personvernombudets godkjenning omfatter derfor kun den delen, og forutsetter at dokumentasjon for intervju med 2) og 3) ettersendes når det foreligger.

INTERVJU MED NØKKELINFORMANTER
Utvalget informeres skriftlig og muntlig om prosjektet og samtykker til deltakelse. Informasjonsskrivet er godt utformet.

Personvernombudet legger til grunn at forsker etterfølger Diakonhjemmet Høgskole AS sine interne rutiner for datasikkerhet. Dersom personopplysninger skal lagres på mobile enheter, bør opplysningene krypteres tilstrekkelig.

Forventet prosjektslutt er 01.07.2017. Ifølge prosjektmeldingen skal innsamlede opplysninger da anonymiseres. Anonymisering innebærer å bearbeide datamaterialet slik at ingen enkeltpersoner kan gjenkjennes. Det gjøres ved å:
- slette direkte personopplysninger (som navn/koblingsnøkkel)
- slette/omskrive indirekte personopplysninger (identifiserende sammenstilling av bakgrunnsopplysninger som f.eks. bosted/arbeidssted, alder og kjønn)
- slette lydopptak

Norsk samfunnsvitenskapelig datatjeneste AS
NORWEGIAN SOCIAL SCIENCE DATA SERVICES

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Ingebjørg Haugen
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Vår dato: 12.06.2015	Vår ref: 43386 / 3 / MHM	Deres dato:	Deres ref:

TILBAKEMELDING PÅ MELDING OM BEHANDLING AV PERSONOPPLYSNINGER

Vi viser til melding om behandling av personopplysninger, mottatt 07.05.2015. Meldingen gjelder prosjektet:

43386	*Brukermedvirkning blant eldre med demens, Del 2*
Behandlingsansvarlig	*Diakonhjemmet Høgskole AS, ved institusjonens øverste leder*
Daglig ansvarlig	*Ingebjørg Haugen*

Etter gjennomgang av opplysninger gitt i meldeskjemaet og øvrig dokumentasjon, finner vi at prosjektet ikke medfører meldeplikt eller konsesjonsplikt etter personopplysningslovens §§ 31 og 33.

Dersom prosjektopplegget endres i forhold til de opplysninger som ligger til grunn for vår vurdering, skal prosjektet meldes på nytt. Endringsmeldinger gis via et eget skjema, http://www.nsd.uib.no/personvern/meldeplikt/skjema.html.

Vedlagt følger vår begrunnelse for hvorfor prosjektet ikke er meldepliktig.

Vennlig hilsen

Katrine Utaaker Segadal

Marianne Høgetveit Myhren

Kontaktperson: Marianne Høgetveit Myhren tlf: 55 58 25 29
Vedlegg: Prosjektvurdering

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

Personvernombudet for forskning

Prosjektvurdering - Kommentar

Prosjektnr: 43386

VURDERING AV MELDEPLIKT
I telefonsamtale 11.6.15 informerer forsker om at hun vil registrere fornavn i lydopptakene, men at hun vil fjerne navn og eventuelle andre identifiserende opplysninger ved transkripsjon av datamaterialet. Prosjektet vil dermed ikke omfattes av meldeplikten etter personopplysningsloven.

Det ligger til grunn for vår vurdering at alle opplysninger som behandles elektronisk i forbindelse med prosjektet er anonyme.

Med anonyme opplysninger forstås opplysninger som ikke på noe vis kan identifisere enkeltpersoner i et datamateriale, verken:
- direkte via personentydige kjennetegn (som navn, personnummer, epostadresse el.)
- indirekte via kombinasjon av bakgrunnsvariabler (som bosted/institusjon, kjønn, alder osv.)
- via kode og koblingsnøkkel som viser til personopplysninger (f.eks. en navneliste)
- eller via gjenkjennelige ansikter e.l. på bilde eller videoopptak.

Personvernombudet legger videre til grunn at navn/samtykkeerklæringer ikke knyttes til sensitive opplysninger.

FORSKNINGSETISKE HENSYN
Personvernombudet minner om at forskningsetiske retningslinjer vil gjelde selv om prosjektet ikke omfattes av meldeplikten. Les gjerne mer om inkludering av personer med redusert samtykkekompetanse her på NESH sine hjemmesider: https://www.etikkom.no/forskningsetiske-retningslinjer/medisin-og-helse/redusert-samtykkekompetanse/

Ingebjørg Haugen
VID Diakonhjemmet VID vitenskapelig høgskole
Boks 184 Vindern
0319 OSLO

Vår dato: 25.04.2016 Vår ref: 48365 / 3 / BGH Deres dato: Deres ref:

TILBAKEMELDING PÅ MELDING OM BEHANDLING AV PERSONOPPLYSNINGER

Vi viser til melding om behandling av personopplysninger, mottatt 15.04.2016. Meldingen gjelder prosjektet:

48365	*Brukermedvirkning for personer med demens del 3*
Behandlingsansvarlig	*VID vitenskapelig høgskole, ved institusjonens øverste leder*
Daglig ansvarlig	*Ingebjørg Haugen*

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, ombudets kommentarer samt personopplysningsloven og helseregisterloven med forskrifter. Behandlingen av personopplysninger kan settes i gang.

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

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

Personvernombudet vil ved prosjektets avslutning, 31.10.2017, rette en henvendelse angående status for behandlingen av personopplysninger.

Vennlig hilsen

Kjersti Haugstvedt

Belinda Gloppen Helle

Kontaktperson: Belinda Gloppen Helle tlf: 55 58 28 74
Vedlegg: Prosjektvurdering

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

Prosjektvurdering - Kommentar

Prosjektnr: 48365

INFORMASJON OG SAMTYKKE

Utvalget (helsepersonell) informeres skriftlig om prosjektet og samtykker til deltakelse. Informasjonsskriv og samtykkeerklæring er noe mangelfullt utformet. Vi ber derfor om at følgende endres/tilføyes:
- At det er frivillig å delta og at man kan trekke seg når som helst uten begrunnelse
- Dato for forventet prosjektslutt (31.10.17) og at data vil bli anonymisert ved prosjektslutt
- Kontaktopplysninger til forsker

Revidert informasjonsskriv skal sendes til personvernombudet@nsd.no før utvalget kontaktes.

REKRUTTERING

I følge meldeskjemaet vil rekruttering skje ved at leder sender utvalget sin kontaktinformasjon til forsker. Personvernombudet forutsetter at leder har tillatelse til å gi ut kontaktinformasjonen. Hvis ikke bør leder sende ut spørreskjemaet på forsker sine vegne. Alternativt kan forsker motta utvalget sin kontaktinformasjon etter at utvalget viser interesse for deltagelse.

INFORMASJONSSIKKERHET

Personvernombudet legger til grunn at dere behandler alle data og personopplysninger i tråd med VID vitenskapelig høgskole sine retningslinjer for innsamling og videre behandling av forskningsdata og personopplysninger.

DATABEHANDLER

I meldeskjemaet har dere opplyst at dere skal ta i bruk den eksterne surveytjenesten Questback. I følge vedlegg til prosjektmeldingen er det inngått en databehandleravtale med Questback. For råd om hva databehandleravtalen bør inneholde, se Datatilsynets veileder: http://www.datatilsynet.no/Sikkerhet-internkontroll/Databehandleravtale/.

PROSJEKTSLUTT OG ANONYMISERING

I meldeskjemaet/informasjonsskrivet har dere opplyst om at forventet prosjektslutt er 31.10.2017. Ifølge meldeskjemaet skal dere da anonymisere innsamlede opplysninger. Anonymisering innebærer at dere bearbeider datamaterialet slik at ingen enkeltpersoner kan gjenkjennes. Det gjør dere ved å slette direkte personopplysninger og slette eller omskrive indirekte personopplysninger.

Vi gjør oppmerksom på at også databehandler (Questback) må slette personopplysninger tilknyttet prosjektet i sine systemer. Dette inkluderer eventuelle logger og koblinger mellom IP-/epostadresser og besvarelser.

Appendix 5:

Informasjonsskriv til tjenesteleder om forskningsprosjekt: «Brukermedvirkning blant eldre med demens»

Bakgrunn og formål

Undertegnede skal gjennomføre et doktorgradsprosjekt ved Diakonhjemmet Høgskole, i samarbeid med Nasjonalforeningen for Folkehelsen. Tema for prosjektet er demens og brukermedvirkning, og tittelen er «Brukermedvirkning blant eldre med demens». Formålet med prosjeket er å forstå hvordan brukermedvirkning blir forstått og praktisert i kommunale helse- og omsorgstjenester. I tillegg ønsker jeg å se på hvilke faktorer som hemmer og fremmer brukermedvirkning for eldre med demens.
Grunnen til at denne undersøkelsen er satt i gang er at det finnes lite forskning på hvordan brukermedvirkning best kan implementeres med brukere av helsetjenestene med diagnosen demens. Jeg tror at dette prosjektet vil bringe viktig kunnskap som kan brukes i arbeidet med mennesker med demens.

Hva innebærer deltakelse i studien?

Jeg har ut fra visse kriterier valgt ut to kommuner i Akershus, og ønsker i disse kommunene å gjennomføre intervjuer med 3 forskjellige grupper informanter:

- Hjemmeboende mennesker med demens som mottar hjemmesykepleie
- Pårørende
- Nøkkelinformanter: Ansatte i kommunen med spesiell kunnskap om demens

Alle informantene som blir intervjuet vil bli intervjuet en gang. Temaet for alle intervjuene vil være brukermedvirkning blant eldre med demens. Gruppe 1 vil få spørsmål om sin egen situasjon i forhold til temaer som kan knyttes opp mot brukermedvirkning. Pårørende i Gruppe 2 vil få spørsmål som kan supplere informasjonen gitt av Gruppe 1. Nøkkelinformantene vil få mer generelle spørsmål om temaet brukermedvirkning blant eldre med demens. Intervjuene vil bli tatt opp på bånd.

Hva skjer med informasjonen som blir samlet inn?

Alle personopplysninger vil bli behandlet konfidensielt. Materialet vil bli anonymisert slik at enkeltpersoner ikke kan gjenkjennes. Notater og lydopptak vil bli makulert/slettet ved prosjektets slutt, innen 31.12.2017.

Resultatet vil bli publisert i en avhandling, samt gjennom artikler.

Frivillig deltakelse

Det er frivillig å delta i studien, og alle informantene kan når som helst trekke sitt samtykke uten å oppgi noen grunn. Dersom noen trekker seg, vil alle opplysninger om denne personen bli anonymisert.

Dersom det er greit for deg at jeg setter i gang prosjektet i kommunen, vennligst undertegn samtykkeerklæringen på siste side. Du får en kopi av dette i underskrevet form. Dersom du har spørsmål om studien, kan du kontakte med når som helst.

Studien er meldt til Personvernombudet for forskning, Norsk samfunnsvitenskapelig datatjeneste AS.

Kontaktopplysninger:

Ingebjørg Haugen
Diakonhjemmet Høgskole
Postbok 184, Vinderen
0319 Oslo

Tlf: 22963721
Mob: 94278849
Epost: ingebjorg.haugen@diakonhjemmet.no

Med vennlig hilsen
Ingebjørg Haugen, Doktorgradsstipendiat

Samtykke til deltakelse i studien

Jeg er skriftlig og muntlig gjort kjent med Ingebjørg Haugens prosjektarbeid for Diakonhjemmet Høgskole og Nasjonalforeningen for Folkehelsen.

Jeg vet at deltakelsen i prosjektet er frivillig, og at jeg når som helst kan trekke meg uten å måtte oppgi grunn, og uten at det medfører negative konsekvenser for meg.

Jeg aksepterer at båndopptager blir brukt under intervjuene.

Jeg gir herved mitt samtykke til å delta i undersøkelsen.

(Signert av prosjektdeltaker, dato)

Appendix 6:

Forespørsel om deltakelse i forskningsprosjekt nøkkelinformanter: «Brukermedvirkning blant eldre med demens»

Bakgrunn og formål

Undertegnede skal gjennomføre et doktorgradsprosjekt ved Diakonhjemmet Høgskole. Tittelen er «Brukermedvirkning blant eldre med demens». Formålet er å få kunnskap om hvordan brukermedvirkning blir forstått og praktisert i kommunale helse- og omsorgstjenester. I tillegg skal prosjektet studere hvilke faktorer som hemmer og fremmer brukermedvirkning for eldre med demens.
Prosjektet finansieres av Extrastiftelsen gjennom Nasjonalforeningen for Folkehelsen.

Hva innebærer deltakelse i studien?

Du har blitt valgt som nøkkelinformant da du anses å ha spesiell kompetanse innenfor demensfeltet. Intervjuet vil dreie seg om din kunnskap og ditt syn på brukermedvirkning i demensomsorgen. Spørsmålene vil være av både generell og spesifikk art.
Intervjuet vil vare i ca 1t, og du velger selv hvor intervjuet skal foregå.

Intervjuene vil bli tatt opp på bånd.

På et senere tidspunkt skal det også foretas intervjuer med 10 hjemmeboende mennesker med demens i kommunen og deres pårørende.

Hva skjer med informasjonen om deg?

Alle personopplysninger vil bli behandlet konfidensielt. Materialet vil i rapporteringen bli anonymisert slik at enkeltpersoner ikke kan gjenkjennes. Notater og lydopptak vil bli makulert/slettet ved prosjektets slutt, innen 31.12.2017. Resultatet vil bli publisert i en avhandling, samt gjennom artikler.

Frivillig deltakelse

Det er frivillig å delta i studien, og du kan når som helst trekke sitt samtykke uten å oppgi noen grunn. Dersom du velger å trekke deg, vil alle opplysninger om deg bli slettet.

Dersom du ønsker å delta, så undertegner du samtykkeerklæringen på siste side. Du får en kopi av dette i underskrevet form.

Studien er meldt til Norsk Samfunnsvitenskapelig Datatjeneste (NSD).

Kontaktopplysninger
Ingebjørg Haugen
Diakonhjemmet Høgskole
Postbok 184, Vinderen
0319 Oslo
Tlf: 22963721/94278849
Epost: ingebjorg.haugen@diakonhjemmet.no

Med vennlig hilsen

Ingebjørg Haugen, Doktorgradsstipendiat

Samtykke til deltakelse i studien

Jeg er skriftlig og muntlig gjort kjent med Ingebjørg Haugens prosjektarbeid for Diakonhjemmet Høgskole og Nasjonalforeningen for Folkehelsen.

Jeg vet at deltakelsen i prosjektet er frivillig, og at jeg når som helst kan trekke meg uten å måtte oppgi grunn, og uten at det medfører negative konsekvenser for meg.

Jeg aksepterer at båndopptager blir brukt under intervjuene.

Jeg gir herved mitt samtykke til å delta i undersøkelsen.

(Signert av prosjektdeltaker, dato)

Appendix 7:

Forespørsel om deltakelse i forskningsprosjekt pårørende: «Brukermedvirkning blant eldre med demens»

Bakgrunn og formål

Undertegnede skal gjennomføre et doktorgradsprosjekt ved Diakonhjemmet Høgskole. Tittelen er «Brukermedvirkning blant eldre med demens». Formålet er å få kunnskap om hvordan brukermedvirkning blir forstått og praktisert i kommunale helse- og omsorgstjenester. I tillegg skal prosjektet studere hvilke faktorer som hemmer og fremmer brukermedvirkning for eldre med demens.
Prosjektet finansieres av Extrastiftelsen gjennom Nasjonalforeningen for Folkehelsen.

Hva innebærer deltakelse i studien?

I denne studien ønsker jeg å intervjue hjemmeboende personer med demens og deres pårørende. Planen er å gjennomføre intervjuene hver for seg, men om du skulle mene at jeg bør møte dere sammen, så kan vi også avtale dette.
I intervjuet med deg er målet å lære ditt familiemedlem med demens å kjenne, slik at jeg kan få til en best mulig samtale med han/henne. Jeg kommer til å spørre om bakgrunnen til personen med demens, dagens funksjonsnivå, og forhold til ansatte i kommunehelsetjenesten. Jeg ønsker å finne ut hvor mye personen med demens får bestemme i egen hverdag.
Intervjuene vil bli tatt opp på bånd, og dere er helt anonyme.

Hva skjer med informasjonen om deg?

Alle personopplysninger vil bli behandlet konfidensielt. Materialet vil i rapporteringen bli anonymisert slik at enkeltpersoner ikke kan gjenkjennes. Notater og lydopptak vil bli makulert/slettet ved prosjektets slutt, innen 31.12.2017. Resultatet vil bli publisert i en avhandling, samt gjennom artikler.

Frivillig deltakelse

Det er frivillig å delta i studien, og du kan når som helst trekke sitt samtykke uten å oppgi noen grunn. Dersom du velger å trekke deg, vil alle opplysninger om deg bli slettet.

Dersom du ønsker å delta, så gir du beskjed til meg via kontaktpersonen i hjemmesykepleien, eller kontakter meg direkte på telefon eller mail.

Studien er meldt til Norsk Samfunnsvitenskapelig Datatjeneste (NSD).

Kontaktopplysninger
Ingebjørg Haugen
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Med vennlig hilsen
Ingebjørg Haugen, Doktorgradsstipendiat

Samtykke til deltakelse i studien

Jeg er skriftlig og muntlig gjort kjent med Ingebjørg Haugens prosjektarbeid for Diakonhjemmet Høgskole og Nasjonalforeningen for Folkehelsen.

Jeg vet at deltakelsen i prosjektet er frivillig, og at jeg når som helst kan trekke meg uten å måtte oppgi grunn, og uten at det medfører negative konsekvenser for meg.

Jeg aksepterer at båndopptager blir brukt under intervjuene.

Jeg gir herved mitt samtykke til å delta i undersøkelsen.

(Signert av prosjektdeltaker, dato)

Appendix 8:

Forespørsel om deltakelse i forskningsprosjekt personer med demens: «Brukermedvirkning blant eldre med demens»

Mitt navn er Ingebjørg Haugen, og jeg studerer ved Diakonhjemmet Høgskole i Oslo. Jeg skal gjennomføre en undersøkelse som heter «Brukermedvirkning for eldre med demens».

Målet med denne undersøkelsen er å finne ut hvor mye mennesker med demens som mottar hjemmesykepleie, får bestemme i egen hverdag.
Jeg ønsker å snakke med både deg og en i familien din. Dere kan bestemme selv om jeg skal snakke med dere sammen, eller hver for seg. Dere bestemmer også selv hvor vi skal møtes, hjemme hos deg, hjemme hos et familiemedlem, eller kanskje på dagsenteret? Intervjuet vil ta ca 1t.

Jeg kommer til å ta opp intervjuene på band, men det er bare for at jeg selv skal klare å huske hva som blir sagt.
Dere er helt anonyme, og alt dere sier vil bli slettet når jeg er ferdig med prosjektet.
Det er selvsagt helt frivillig å delta, og man kan også trekke seg underveis. Hvis det skulle bli vanskelig for deg å vurdere dette underveis, kan pårørende motsette seg videre deltakelse.

Kontaktopplysninger
Ingebjørg Haugen
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0319 Oslo
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Epost: ingebjorg.haugen@diakonhjemmet.no

Med vennlig hilsen: Ingebjørg Haugen, Doktorgradsstipendiat

Samtykke til deltakelse i studien

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Jeg gir herved mitt samtykke til å delta i undersøkelsen.

(Signert av prosjektdeltaker, dato)

Appendix 9:

Intervjuguide nøkkelinformanter

Start intervjuet med en briefing: Definer situasjon, formål, forklar lydopptak.

Oppvarming:

- Kan du starte med å fortelle om deg selv? Navn, stilling, osv.
- Kan du fortelle om en typisk dag i din jobb?
- Hva forstår du med brukermedvirkning?
- Hva tenker du om brukermedvirkning for mennesker med demens?

Individuell brukermedvirkning:

- Har du et eksempel fra egen arbeidshverdag hvor brukermedvirkning blir/ble gjennomført overfor en bruker med demens?
- Har dere retningslinjer for hvordan brukermedvirkning skal gjennomføres?
- Hvordan kan brukerne med demens påvirke hjelpen de mottar?
- Hvilken rolle spiller pårørende i muligheten for brukermedvirkning?
- Vet du om livshistoriene til brukerne er skrevet ned?
    - Blir disse lest?
- Hva fremmer individuell brukermedvirkning for brukere med demens?
- Hva hemmer individuell brukermedvirkning for brukere med demens?

Kollektiv brukermedvirkning:

- Har brukerne med demens mulighet til å påvirke det generelle tjenestetilbudet?
- Hva fremmer kollektiv brukermedvirkning for brukere med demens?
- Hva hemmer kollektiv brukermedvirkning for brukere med demens?

Generelle spørsmål:

- Hvordan er det med kunnskapsnivået på demens blant de ansatte i hjemmetjenestene og på dagsenteret generelt tror du?
- Har du forslag til tiltak som vil gi økt brukermedvirkning for mennesker med demens?

Avslutning:

- Har du noe du ønsker å tilføye?
- Er det greit at jeg kontakter deg på telefon for eventuelle oppfølgingsspørsmål?

Takk for deltakelsen!

Appendix 10:

Intervjuguide pårørende

Introduksjon:

- Kan du først fortelle litt om deg selv og hva som er din relasjon til person med demens?
- Hvor lenge har person med demens vært syk?
    - Diagnose?

Om person med demens:

- Faktaopplysninger om:
- Bakgrunn
- Funksjonsnivå
- Sensitive temaer
- Hva tror du er det verste for person med demens ift demenssykdommen?

Om forholdet til hjemmesykepleien/dagsenter:

- Faktaopplysning
- Vurdering av:
    - Tilbudet generelt (får dere den hjelpen dere trenger?)
    - Hvem bestemte at person med demens skulle på dagsenter?
    - Person med demens sin opplevelse og trivsel
    - Samarbeid mellom pårørende og ansatte
    - Informasjonsutveksling
    - Ansatte
        - Kunnskap
        - Kommunikasjon

Om brukermedvirkning:

- Vurdering av brukermedvirkning for personer med demens
- Vurdering av brukermedvirkning for familiemedlem
- Har du eksempel på situasjoner hvor hjemmesykepleie/demensteam/dagsenter har gått i mot person med demens sine ønsker?
- Har du noen gang opplevd at de ansatte har lagt for mye ansvar på person med demens?

Temaer fra litteraturstudiet:

- Vurdering av telecare
- Vurdering av pleieplan for framtiden
- Vurdering av boform
- Vurdering av å få kunnskap om diagnose

Avslutning:

- Er det noe du ønsker å tilføye?
- Hvordan synes du det har vært å prate om dette?

Tusen takk for at du ville delta!

Appendix 11:

Intervjuguide Personer med demens

Introduksjon:

Presentasjon av meg selv, skape relasjon

Generelt:

- Kan du fortelle litt om deg selv? (alder, helse, interesser)
- Hvordan er det å bli gammel?
- Vurdering av å leve med demens (hva er vanskeligst)
- Vurdering av hjelpen du mottar (hva får du, hva trenger du)

Brukermedvirkning:

- Hvem bestemmer hva du skal ha hjelp til?
- Føler du at du får bestemme mye i eget liv?
- Hvor viktig er det for deg å bestemme selv?
- Hva liker du ikke at andre bestemmer for deg?
- Er det noe du føler det er greit at andre bestemmer?

Om dagsenteret:

- Trives du?
- Hvem har bestemt at du skal være på dagsenter?
- Vurdering av:
    - Å være på dagsenter
    - De ansatte (snille, flinke, god tid, kommunikasjon)
    - Aktiviteter på dagsenteret (hvilke aktiviteter, hvem bestemmer)
    - Annen medvirkning på dagsenteret

Forhold til familien:

- Får du mye hjelp av dem?
    - Med hva?
    - Hvordan oppleves dette?

Avslutningsspørsmål:

Sett at du kunne bestemme akkurat hva hjemmesykepleien/kommunen skulle hjelpe deg med – hvordan ville du da ha det?

Avslutning:

- Er det noe du ønsker å tilføye?
- Hvordan synes du det har vært å prate om dette?

Tusen takk for at du ville delta!

Papers

Paper 1

Haugen, Ingebjørg, Slettebø, Tor, and Ytrehus, Siri. (2019). Factors affecting user participation for elderly people with dementia living at home: a critical interpretive synthesis of the literature. *European Journal of Social Work*, *22*(6), 974-986. DOI: 10.1080/13691457.2018.1441133

Paper 2

Haugen, Ingebjørg, Ytrehus, Siri, and Slettebø, Tor. (2019). User participation among people with dementia living at home. *Nordic Social Work Research, 9*(2), 147-159. DOI: 10.1080/2156857X.2018.1494035

Paper 3

Haugen, Ingebjørg, Ytrehus, Siri, and Slettebø, Tor. (2019). Barriers to user participation in home-based dementia care: experiences of professional caregivers. *Nordic Social Work Research,* 1-13. DOI: 10.1080/2156857X.2019.1679661

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