



Patient participation in everyday life in special care units for persons with dementia

Ann Karin Helgesen

Faculty of Health, Science and Technology

Nursing Science

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Aim: The overall aim of this thesis was to acquire knowledge about patient participation in the everyday life of persons with dementia living in special care units (SCUs) in nursing homes.

Methods: The qualitative studies (I-III) were carried out using the Grounded Theory methodology. Data was collected in SCUs for persons with dementia by means of open non-participant observations - in total 51 hours, complemented by conversations with eight residents and 17 health care personnel, in total 34 conversations (I), interviews with 12 relatives, in total 24 interviews (II), and 11 nursing personnel, in total 22 interviews (III). Data collection in the quantitative study (IV) was carried out in SCUs in 19 municipalities by means of a study-specific questionnaire based on the findings of the two first studies. 233 (67%) relatives participated. Data were analyzed with descriptive and non-parametric statistics.

Findings: Presence of nursing personnel in body, mind and morality was found to be the prerequisite for patient participation (I). This required personnel with high competence in dementia care, commitment to and interest in the resident, and continuity in their work (I and III). Wellbeing and dignity in the resident's everyday life was found to be the most important goal in the care, not necessarily a high level of patient participation (I-III). The level of participation had to be adjusted to the resident's ability and wish to take part in decisions in the very moment. However, the level was often primarily adjusted to suit the personnel's ideas about how to carry out daily care and to get routines to function. Hence, patient participation was often 'a losing principle' in the SCUs (I and III). Relatives had an important role in the participation process by interacting, and exchanging information with the personnel. By forming a basis for individualised care in this way, relatives could make a difference to the resident's everyday life and contribute to their wellbeing and dignity (II and IV). Organizational factors concerning leadership, care culture, routines and number of personnel, and housing factors concerning architecture and sharing accommodation, greatly affected the occurrences and possibility of patient participation, either as stimulation or hindrance (I-III).

Conclusions: Patient participation must be given attention by leaders and be prioritised in dementia care in SCUs. Nursing personnel can enhance patient participation by promoting relatives' partaking in the participation process, as this has potential for further contributing to quality of care.

Keywords: patient participation, dementia, special care units for persons with dementia (SCUs), relatives, nursing care personnel, Grounded Theory, cross-sectional

Pasientmedvirkning i dagliglivet ved skjermede avdelinger for personer med demens.

Hensikt: Avhandlingens overordnede hensikt var å fremskaffe kunnskap om pasientmedvirkning i dagliglivet ved skjermede avdelinger for personer med demens.

Metode: I de kvalitative studiene (I-III) ble “Grounded Theory methodology” benyttet. Data ble samlet i skjermede avdelinger for personer med demens ved hjelp av: åpne ikke-deltagende observasjoner - totalt 51 timer, supplert med samtaler med åtte beboere og 17 pleiere - totalt 34 samtaler (I), intervjuer med 12 pårørende - totalt 24 intervjuer (II), og intervjuer med 11 pleiere - totalt 22 intervjuer (III). I den kvantitative studien ble data samlet fra skjermede avdelinger i 19 kommuner, ved hjelp av et studiespesifikt spørreskjema basert på de to første studiene. 233 (67 %) pårørende deltok. Data ble analysert ved hjelp av beskrivende og ikke-parametrisk statistikk.

Funn: Fysisk, mental og moralsk tilstedeværelse av pleiepersonalet var forutsetningen for pasientmedvirkning (I). Dette krevde høy kompetanse i demens omsorg, engasjement og interesse for beboeren, samt kontinuitet i arbeidet (I og III). Beboerens velvære og verdighet i dagliglivet var det viktigste målet for omsorgen, ikke nødvendigvis høy grad av medvirkning (I-III). Graden av medvirkning måtte tilpasses beboerens evne og ønske til å medvirke i avgjørelser, i øyeblikket. Nivået av medvirkning ble ofte primært tilpasset pleierens tanker om hvordan utføre den daglige pleien og hvordan få utført de daglige rutiner. Pasientmedvirkning ble således ofte “et vikende prinsipp” (I og III). Pårørende hadde en viktig rolle i pasientmedvirkningsprosessen ved å samarbeide og utveksle informasjon med personalet. Ved å skape en basis for individuell omsorg, kunne pårørende utgjøre en forskjell i beboerens dagligliv og bidra til beboerens velvære og verdighet (II og IV). Organisatoriske faktorer som lederskap, pleiekultur og bemanning, og bofaktorer som arkitektur og å dele bolig med andre, påvirket i stor grad forekomsten av og muligheten for pasientmedvirkning (I-III).

Konklusjoner: Pasientmedvirkning må få oppmerksomhet av ledere og bli prioritert i skjermede avdelinger for personer med demens. Personalet kan legge til rette for pasientmedvirkning ved å stimulere pårørende til å ta del i medvirkningsprosessen, da dette kan øke kvaliteten på omsorgen.

Nøkkelord: pasientmedvirkning, demens, skjermet avdeling for personer med demens, pårørende, pleiepersonale, Grounded Theory, tverrsnitt studie

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Abbreviations

SCU special care unit for persons with dementia

CDR clinical dementia rating

GT Grounded Theory

Original papers

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

- I Helgesen AK, 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*. 5:169-178.
- II Helgesen AK, 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):1672-81.
- III Helgesen AK, Larsson M & Athlin E (2013). Patient participation in SCUs for persons with dementia: A losing principle? *Nursing Ethics*. doi:10.1177/0969733013486796.
- IV Helgesen AK, Athlin E & Larsson M. Relatives' participation in everyday care in SCUs for persons with dementia. *Submitted*.

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Introduction

After some years as a clinical nurse and head nurse in hospital, I changed my place of working to a regular unit in nursing home. That was a shocking experience; I perceived that some of the respect for patients which influenced the care in the hospital was often lacking, especially for residents suffering from dementia. The experience from a special care unit for persons with dementia where all of the personnel took part in an education program before the unit opened, was totally different. My impression from this unit was that the residents and their relatives were mostly met respectfully and they expressed satisfaction with the care provided. However, when I think back (to the late 1990s) it was we - the personnel - who took most of the decisions about the patients' care in accordance with what we considered was best. When working as a nurse lecturer in geriatric care many years later, I experienced that students often told about similar situations where the elderly in nursing homes were not always treated with respect. In tandem with my personal experiences as a nurse and nurse lecturer, issues of patient participation in health care were coming onto the agenda in Norway and many other Western countries. I started to wonder: what about patient participation in special care units for persons with dementia? That was the starting point of this project.

Background

The movement towards patient participation in health care

In many modern societies nowadays, the paternalistic health care model has fallen out of favour, to be replaced by the patient-centred model, which emphasises the patient's participation, autonomy, informed consent and empowerment with regard to medical treatment and nursing care (Edwards & Elwyn, 2009; Eldh, Ehnfors, & Ekman, 2004; Nordgren & Fridlund, 2001). Hence, the position of patients has changed from being passive recipients to active participants (Heggland & Hausken, 2012; Stiggelbout, Weijden, Wit, De Frosch, Légaré, Montorim, et al., 2012). One reason for this change was political, as complex social movements of the 1960s and 1970s challenged former social hierarchies in favour of individual autonomy, including for patients in health care (Rothman, 2001). In the late 1990s New Public Management ideas about market solutions and the concept of patient participation and empowerment were promoted in the public sector (Dahle & Thorsen, 2004; Heggland & Hausken, 2012). According to this, patients should be perceived as customers and be given more power to choose about how their care and treatment should be provided (Almond, 2001). This new view of patients will most likely represent a challenge for one of the most rapidly growing areas in health care - elderly care in general and dementia care in particular (Ferri, Prince, Brayne, Brodaty, Fratiglioni, Ganguli, et al., 2005; Wimo, Jonsson, & Winblad, 2006).

Patient participation has become a common term in the legislation of many Western countries, determining that patients have a legal right to participate in decisions regarding treatment and care (Edwards & Elwyn, 2009). When the patient is obviously incapable of safeguarding his or her own interests due, for instance, to severe dementia, relatives may have a right to participate in the necessary decisions (Collins, 2007; Coulter & Magee, 2003; Edwards & Elwyn, 2009; Hill, 2011).

In Norway, the Patients' Rights Act (1999) states that:

'the form of participation shall be adapted to the individual patient's ability to give and receive information. If the patient is not competent to give consent, the patient's next of kin is entitled to participate together with the patient (section 3-1). If the patient consents thereto, or circumstances justify it, the patient's next of kin shall receive information concerning the patient's health condition and the health care that is being provided. If the patient is over 16 years of age and obviously incapable of safeguarding his or her own interests due to a physical or mental disorder, senile dementia or mental retardation, both the patient and his or her next of kin are entitled to information (section 3-3). Health care may only be provided with the patient's consent, unless legal authority exists or there are other valid legal grounds for providing health care without consent (section 4-1). Competence to give consent may cease to apply wholly or partly if the patient, on account of senile dementia, is clearly incapable of understanding what the

consent entails (section 4-3). If a patient who is of full legal age and legal capacity is not competent to give consent, the health care provider may make decisions concerning health care that is not of a highly invasive nature with regard to its extent and duration (section 4-6)'.

The nursing codes of ethics internationally (International Council of Nurses (ICN), 2012) and nationally (Norwegian Nurses Association, 2011) have been described as having a patient-autonomy-oriented approach to ethics (Chiovitti, 2011), which is in line with both the political and judicial aspects of patient participation. The concept of patient participation is not explicitly mentioned in ICN's code of ethics (2012); it is however stated that:

'inherent in nursing is a respect for human rights, including cultural rights, the right to life and choice, to dignity and to be treated with respect. In providing care, the nurse promotes an environment in which the human rights, values, customs and spiritual beliefs of the individual, family and community are respected'.

Patient participation - the concept

The policy documents have been criticized as containing statements about patient participation without addressing fundamental questions about how such policies should be implemented (Dewar, Tocher, & Watson, 2003). The concept in itself has often been criticized for being everything and nothing (Croft & Beresford, 1992) and open to interpretation (Roberts, 2002). As a result of this, health care professionals may adopt the concept, but because there is no clear description of what is really meant, patients are subject to the professionals' perceptions of how and when they should be involved. This undermines, rather than supports, patient participation (Davies, Laker, & Ellis, 1997; Dewar, et al., 2003).

Patient participation has become a central concept in nursing literature and the subject of many research studies (Cahill, 1996, 1998; Foss, 2011; Florin, 2007; Eldh, 2006). However, over almost two decades, studies have emphasised that consensus concerning its meaning is lacking (Cahill, 1996, 1998; Eldh, 2006; Florin, 2007; Frank, Asp, & Dahlberg, 2009a; Larsson, 2008; Thompson, 2007). The concept of patient participation is often applied interchangeably with user/consumer/client - participation/involvement/ collaboration/decision-making (Brearley, 1990; Cheston, Bender, & Byatt, 2000; Dewar, et al., 2003). In the present thesis, the term 'patient' in patient participation is used as it is used in the laws (Patients Rights Act, 1999), in the code of ethics (Norwegian Nurses Association, 2011) and in nursing research literature (Florin, 2007; Frank, et al., 2009a; Henderson, 1997; Sahlsten, Larsson, Sjöström, & Plos, 2009). In addition, it is considered

an appropriate term for indicating a person's need for help from health personnel who have a responsibility for the person receiving care. The term 'participation' is used as it is common in the nursing research literature (Florin, 2007; Frank, Asp, & Dahlberg, 2009b; Henderson, 1997; Sahlsten, et al., 2009). Despite choosing the concept of patient participation, the terms 'person with dementia' or 'resident' are used in this thesis when referring to persons living in the SCU. This is because people suffering from dementia are often referred to as 'persons with dementia' (Edvardsson, Winblad, & Sandman, 2008; Kitwood, 1997), and persons living in elderly care institutions are commonly called 'residents' rather than 'patients' (Kutner, Mistretta, Barnhart, & Belodoff, 1999).

Patient participation is generally taken to mean being informed and taking part in decisions regarding one's care and treatment (Eldh, 2006). It has been described as a dynamic process between the care provider and the person (Tutton, 2005), but most often as a hierarchy with increasing degrees of participation (Cahill, 1996; Florin, 2007; Thompson, 2007). Thompson's taxonomy (2007) is often referred to in nursing literature (Foss & Hofoss, 2011; Smebye, Kirkevold, & Engedal, 2012) and this defines five levels of patient-determined involvement: non-involvement, being given information, dialogue, shared decision-making and autonomous decision-making. Typical for most descriptions is that, in order to make patient participation possible, a degree of knowledge, information and competence is needed among the actors (Cahill, 1996; Heggland & Hausken, 2012; Thompson, 2007). Common to many descriptions of patient participation is that they place heavy demands on the patient's competence to give informed consent (Brearley, 1990), resulting in the exclusion of patients who have lost such competence. This means that studying patient participation among persons with dementia in the context of special care units, which is the focus of this thesis, would not be relevant, as most of these persons have reduced competence to give such consent. However, even if a person has been found legally incompetent to decide about health care matters, this does not necessarily entail that the person is globally incompetent, as they might be competent in everyday decision-making (Holm, 2001; McCormack, 2002). In this thesis, a looser understanding of the concept, where participation means getting involved, or being allowed to become involved in decision-making processes, is used (Brearley, 1990; Brownlea, 1987). Brownlea's broad approach to the concept was considered suitable for the exploratory design of this thesis, as it opens up for daily-living activities (Henderson, 2002), and is interpreted as providing opportunities for persons with reduced ability to give informed consent, to also be involved in the participation process.

Patient participation in nursing research

A number of studies have focused on patient participation in the context of hospitals (Eldh, et al., 2004; Florin, 2007; Frank, Fridlund, Baigi, & Asp, 2011; Henderson, 1997; Sahlberg-Blom, Ternstedt, & Johansson, 2000; Sahlsten, Larsson, Sjöström, Lindencrona, & Plos, 2007). Studies relating to the context of nursing homes and home care are rarer (Bradley, Peiris, & Wetle, 1998; Jewell, 1994; Tutton, 2005). Common to most of the studies has been the highlighting of factors which could stimulate and/or hinder patient participation. The following have been found to be important for patient participation: a supportive organisation; mutual information exchange, and trust between the patient and the personnel; mutual willingness to cooperate and negotiate; continuity in the relationship and sufficient time; that the nurses know the patient well, have positive attitudes to the patient and patient participation, and are professionally skilled; and that the patient feel supported and involved, and want to participate (Henderson, 1997; Jewell, 1994; Larsson, 2008; Maslin-Prothero, 2003; Nordgren & Fridlund, 2001; Sahlsten, et al., 2007). When these factors were lacking, patient participation could be hindered. Research has also suggested that the patient's preferences for participation in decision-making differ due to age, sex, socio-economic status and severity of illness (Florin, 2007). There is considerable debate whether or not elderly people participate in decision-making concerning their care (Bastiaens, Van Royen, Pavlic; Raposo, & Baker, 2007; Doherty & Doherty, 2005; Foss & Askautrud, 2010; Henderson, 2002; Penney & Wellard, 2007; Roberts, 2002). The literature search showed that research on patient participation and similar concepts which concerned elderly care in general and dementia care in particular was scarce. Studies about patient participation in the context of special care units (SCUs) for persons with dementia were not found.

Dementia disease and its treatment

As a consequence of a greater prevalence of elderly people in society due to demographic changes, the incidence of persons with dementia has increased internationally (Ferri, et al., 2005; Hjort & Waaler, 2010; Menne & Whitlatch, 2007). There are estimated to be 48.1 million people with dementia in the world in 2020, and 90.3 million anticipated in 2040 (Prince, Bryce, Albanese, Wimo, Ribeiro, & Ferri, 2013). The prevalence of people with dementia is increasing in Norway as well (Norwegian Directorate of Health, 2007), with an annual incidence of approximately 10.000 new cases. It is estimated that 68.000 people in Norway suffer from dementia, a figure that is expected to double in the coming 30 years (Landmark, Kirkehei, Brurberg, & Reinar, 2009).

Dementia (called senile dementia in the Patients Rights Act, 1999), is a collective term for several diseases that permanently and progressively reduce cognitive functions

(Landmark, et al., 2009). Alzheimer's disease is the most common cause of dementia, followed by vascular dementia, Lewy Body dementia and frontotemporal dementia (Ballard, Gauthier, Corbett, Brayne, Aarsland, & Jones, 2011; O'Brien, Burns, & Group, 2011; Prince, et al., 2013). A definition of dementia which is considered to cover the nursing aspect is as follows:

‘an acquired syndrome that is chronic, progressive and debilitating. The syndrome is characterized by global impairments that affect higher brain functions. People with the syndrome find it difficult to remember what has happened to them, communicate with other people and undertake skilled social behavior. While dementia is usually seen as a memory disorder, it is more accurate to think of it as comprising a wide range of physical, emotional, behavioral and social phenomena that progressively impair people’s ability to undertake socially accepted activities of everyday life’ (Adams, 2008 page 2).

There is no medical curative treatment of dementia. Studies concerning cholinesterase inhibitors (donepezil, rivastigmine and galantamine) in mild cognitive impairment have shown that the use of these medications was not associated with any delay in the onset of dementia (O'Brien, et al., 2011; Raschetti, Albanese, Vanacore, & Maggini, 2007). However, cholinesterase inhibitors are found effective for mild to moderate Alzheimer’s disease and memantine for moderate to severe Alzheimer’s disease. Cholinesterase inhibitors are not found effective in frontotemporal dementia but are recommended for the treatment of Lewy Body dementias. Concerning vascular dementia, the effect of these drugs has not been sufficiently explored (O'Brien, et al., 2011).

Along with the progression of the dementia, the psychiatric and behavioural symptoms which have been recognized as an essential part of the dementia syndrome, will increase in frequency. These symptoms can lead to excessive use of psychotropic drugs and constraints (O'Brien, et al., 2011; Selbæk, Kirkevold, & Engedal, 2007, 2008). In late stages, dementia leads to complete helplessness (Landmark, et al., 2009). As there is now cure for dementia, specific nursing care that positively affects the quality of life of the person is of utmost importance (Edvardsson, et al., 2008; Kada, Nygaard, Mukesh, & Geitung, 2009).

Patient participation and dementia care

Research about dementia care has exploded in recent decades. There is also a growing body of research concerning the competence of persons with dementia to make decisions, and their participation in health-care decisions (Davies, et al., 1997; Hirschman, Joyce, James, Xie, & Karlawish, 2005; Menne & Whitlatch, 2007; Sabat, 2005; Tyrrell, Genin, &

Myslinski, 2006). However, there is limited research about the participation of persons with dementia in decision-making concerning daily life (Menne & Whitlatch, 2007; Tyrrell, et al., 2006). It has been argued that it is the day-to-day decisions that are really omnipresent for persons with dementia. These decisions may contribute more to improved quality of life than decisions concerning medical treatment (Menne & Whitlatch, 2007). The possibility to participate in decisions concerning everyday life will most likely impact on the person's wellbeing and their experience of dignity, integrity and personhood (Gallagher, Li, Wainwright, Jones, & Lee, 2008; Kitwood, 1997; Robinson & Gallagher, 2008). Nevertheless, along with increased cognitive and physical impairment, comes decreased decision-making involvement, including within day-to-day situations (Menne & Whitlatch, 2007).

In recent decades, the understanding of dementia has changed. Kitwood's work has been the most influential in challenging the standard biomedical paradigm and offering an alternative for understanding dementia (Edvardsson, et al., 2008; Kitwood, 1989, 1997). His conceptualisation of dementia highlighted the dialectic interplay between neuropathology and the social-psychological context of the individual, and contributed to the development of person-centred care within dementia care (Capstick & Baldwin, 2007; Dupuis, Gillies, Carson, Whyte, Genoe, Loiselle, et al., 2012; Kitwood, 1997). Since Kitwood's work, various descriptions of person-centred care have been developed (Brooker, 2007; McCormack & McCance, 2010). Other related concepts such as relationship-centred care (Nolan, Davies, Brown, Keady, & Nolan, 2004), senses framework (Nolan, Davies, & Brown, 2006), and dementia care nursing (Adams, 2008) are also presented. These descriptions and concepts have much in common with patient participation by supporting the person's rights, values and beliefs, and involving the person in decision making (Adams, 2008; Brooker, 2007; Edvardsson, et al., 2008; Kitwood, 1997; McCormack & McCance, 2010; Nolan, et al., 2004).

In dementia care, the patient-autonomy-oriented approach in ethical codes could be challenging as the patient's competence for making autonomous choices and reasonable decisions may be reduced due to their progressively more severe symptoms (Boer, Hertogh, Dröes, Riphagen, Jonker, & Eefsting, 2007; Hirschman, Xie, Feudtner, & Karlawish, 2004; Karlawish, Casarett, Propert, James, Bioethics, & Clark, 2002). There might also be a conflict between autonomy and dignity. If a person with severe dementia 'chooses' to ignore e.g. conventional standards of hygiene, this could lead to offence of her/his human dignity (Gallagher, et al., 2008).

Special care units for persons with dementia

In parallel with the movement towards patient participation and person-centred dementia care, there has also been a shift in the attitude to institutional care in nursing homes, from emphasising on medical and physical care, to be more focused on emotional comfort and resident's choices (Reimer, Slaughter, Donaldson, Currie, & Eliasziw, 2004). In order to provide improved care for residents with dementia, special care units (SCUs) with a small number of residents in a homely domestic setting where personal care is integrated into daily routines, have been created (Gold, Sloane, Mathew, Bledsoe, & Konanc, 1991; Zingmark, Sandman, & Norberg, 2002). In Norway, SCUs are common in most municipalities (Eek & Kirkevold, 2011). The criteria for these units are however vaguely defined, as only the size of the units (4–12 residents) and a thorough examination of the residents, including a diagnosis of dementia, are mentioned in the regulations. No particular staff ratio or staff qualifications are specified (Eek & Kirkevold, 2011; Ministry of Health and Care Services, 1988; Selbæk, et al., 2008). In a recent national survey, it was stated that the number of beds in each unit on average was eight (mostly ranging between 4 and 12 beds) and that the units had on average three residents per carer on an ordinary weekday day-time shift and four residents per carer at weekends and in the evenings (Eek & Kirkevold, 2011; Kirkevold, Eek, & Engedal, 2012). Several positive effects of SCUs with regard to the quality of life of the resident (Reimer, et al., 2004) the quality of care (Kirkevold & Engedal, 2006), the use of mechanical restraints (Frisoni, Gozzetti, Bignamini, Vellas, Berger, Bianchetti, et al., 1998; Kirkevold, Sandvik, & Engedal, 2004), the resident's behavioural symptoms, and the use of psychotropic medication (Rovner, Steele, Shmuelly, & Folstein, 1996) have been demonstrated, even if the findings are sometimes contradictory (Selbæk, et al., 2008). In SCUs, the residents' and their relatives' participation in everyday care is often highlighted as important to fulfil the philosophy of maximising the quality of life of the residents, in which individual care and the possibility to participate in decision-making are important elements (Gruneir, Lapane, Miller, & Mor, 2008; Zingmark, et al., 2002).

Relatives' participation in dementia care

Various studies have demonstrated that relatives remain involved in the lives of their loved ones after admission to a nursing home (Gaugler, 2005; Yamamoto-Mitani, Aneshensel, & Levy-Storms, 2002). The involvement embraces visiting (Yamamoto-Mitani, et al., 2002), advocating and taking part in both socio-emotional and direct care (Gaugler, 2005). In dementia care literature, relatives' involvement has been stated as important with positive effects both on relatives and on persons with dementia (Adams & Gardiner, 2005; Davies & Nolan, 2006; Woods, Keady, & Seddon, 2008). However, being a relative of a person with dementia is often reported to be distressing and experienced as

a burden, especially when the person has severe behavioural and psychological symptoms (Black & Almeida, 2001; Matsumoto, Ikeda, Fukuhara, Shinagawa, Ishikawa, Mori, et al., 2007; Ulstein, Bruun Wyller, & Engedal, 2007). The distress has been found to continue also after institutionalisation of the person with dementia (Gaugler, Anderson, Zarit, & Pearlin, 2004; Whitlatch, Schur, Noelker, Ejaz, & Looman, 2001). Negative interactions between the relative and the personnel, and perceptions of low quality of care may have negative impacts on their stress and wellbeing (Almberg, Grafström, Krichbaum, & Winblad, 2000; Tornatore & Grant, 2002).

Due to the progressive dementia symptoms, over time it will become more difficult for the person suffering from dementia to express themselves, make choices, communicate their wishes, retain and understand information and understand their present circumstances (Bolmsjö, Edberg, & Sandman, 2006; Powers, 2001). When this happens, the relatives might be entitled, according to political documents, the laws and nurses' ethical codes (International Council of Nurses, 2012; Norwegian Directorate of Health, 2007; Norwegian Nurses Association, 2011; Patients Rights Act, 1999), to receive information and to participate, together with the patient, in order to take care of the person's interests. Hence, relatives would be an important part of the patient participation process when the person is incapable of safeguarding their own interests. Although the relatives' right to participate was described in the laws in the late 1990s in Norway, studies which focus on the relatives' role in the patient participation process in dementia care have not been found. International research has, however, revealed that relatives in general usually felt excluded from, rather than involved in, the participation process in dementia care (Dewar, et al., 2003; Hertzberg & Ekman, 2000; Pickard & Glendinning, 2002; Walker, Dewar, & Riddell, 1999; Walker & Dewar, 2001).

Rationale for the thesis

In Norway and many other western countries, patient participation in health care is a political idea, a legal right and an ethical issue in nursing. Since persons with dementia are heavy consumers of health services and the prevalence of persons with dementia is increasing both nationally and internationally, nursing personnel will face several challenges in the future when providing dementia care. One such challenge concerns patient participation. Patient participation in everyday-life decisions for persons with dementia is seldom the focus of research literature, even though these decisions have been deemed very important for the quality of life of dementia sufferers.

Persons with dementia have symptoms such as memory loss, poor concentration and communication problems, which make it difficult for the nursing personnel to interpret and fully understand their wishes and needs. Hence, the persons with dementia need assistance to communicate their preferences and habits concerning everyday life, and to safeguard their interests. Relatives, therefore have an important role in the patient participation process in participating together with or on behalf of their near one. Studies that explore patient participation in everyday life in what is one of the most rapidly-growing areas of health care – elderly care in general and dementia care in the context of SCUs in particular – are still limited.

Overall and specific aims

The overall aim of this thesis was to acquire knowledge about patient participation in the everyday life of persons with dementia living in SCUs in nursing homes.

The specific aims were to:

- I. explore patient participation in everyday activities for persons with dementia living in SCUs in nursing homes.
- II. explore the role of relatives in the patient participation process for persons with dementia living in SCUs in nursing homes, with focus on everyday life.
- III. explore the experience of nursing personnel with respect to patient participation in SCUs for persons with dementia in nursing homes, with focus on everyday life.
- IV. examine relatives' participation in their near ones' everyday care, the level of burden experienced and important factors for participation.

Methods

Paradigmatic considerations

In this thesis, two different traditional paradigms were combined. Three of the studies (I-III) were anchored in the constructivist paradigm. Major ontological, epistemological and axiological assumptions of this paradigm are that reality is multiple and mentally constructed by individuals, that the researcher interacts with those being researched and that findings are created through an interactive process. Subjectivity and personal values are seen as inevitable and desirable (Polit & Beck, 2012; Corbin & Strauss, 2008). These assumptions which give methodological directions towards a qualitative approach were judged to fit the nature of the aims of these studies, namely to explore patient participation in SCUs for persons with dementia, as observed, and from the viewpoint of residents, relatives and nursing personnel (I-III). Findings from observations and interviews (I and II) were used as a basis for generating questions for a questionnaire which was used in study IV. As this questionnaire has a quantitative approach, it can be described as anchored in the positivist paradigm. Major ontological, epistemological and axiological assumptions of this paradigm are that reality exists, that the researcher is independent from those being researched, and that findings are not influenced by the researcher. Personal values and biases are to be held in check as objectivity is sought (Polit & Beck, 2012). According to Polit & Beck (2012) nursing research needs designs which mirror the multidimensionality and complexity of practical nursing knowledge. Combining the different research strategies is considered to increase the potential to provide such a multifaceted view (Foss & Ellefsen, 2002).

Design

This thesis has an explorative and descriptive design and combines qualitative and quantitative approaches by means of method triangulation, in order to provide a comprehensive understanding of the phenomenon being studied (Strauss & Corbin, 1998). In this thesis, data triangulation and investigator triangulation were also used (Denzin, 2009; Thurmond, 2004). Data triangulation, which involves the use of multiple data sources (time, space and person), was performed as follows: the data collection in the SCUs (I) was performed around the clock, seven days a week (time), the data was collected (I-IV) from multiple sites (space), and the data was collected (I-IV) from residents living in SCUs, nursing personnel and relatives (person). Investigator triangulation was used as the research team comprising three persons with a complementary blend of skills and expertise collaborated in the entire research process (I-IV). Overview of the studies is shown in Table 1.

Table 1: Overview of the studies

Study	Design	Methods	Data collection	Participants
I	Explorative	Grounded Theory	August 2008 - January 2009 27 observations 34 conversations	Residents n=27 Nursing personnel n=30
II	Explorative	Grounded Theory	January 2010 - March 2011 Interviews x 2	Relatives n=12
III	Explorative	Grounded Theory	August 2011 - June 2012 Interviews x 2	Nursing personnel n=11
IV	Descriptive	Cross-sectional	March 2012 - September 2012 Questionnaires x 1	Relatives n=233

Grounded Theory (I-III)

The Grounded Theory (GT) method emerged from the studies by sociologists Barney G. Glaser and Anselm L. Strauss on patients dying in hospitals (Charmaz, 2006; Corbin & Strauss, 2008; Glaser & Strauss, 1967). GT has its roots in symbolic interactionism, which states that meaning is constructed through interaction between people and assumes that people can and do think about their actions rather than respond mechanically to stimuli (Blumer, 1969; Mead & Morris, 1934). By the mid-1960s, quantitative methods were dominant in sociology, however Glaser and Strauss countered the prevailing positivist paradigm assumptions with their book *The Discovery of Grounded Theory* (Charmaz, 2006; Glaser & Strauss, 1967). Despite their struggles to challenge the dominance of quantitative research in the 1960s, GT was criticised in the 1990s for its positivist assumptions (Charmaz, 2006). After some years, Glaser and Strauss took divergent directions and, since their original 1967 publication, many different approaches to undertaking GT have emerged (Morse, Stern, Corbin, Bowers, Charmaz, & Clarke, 2009).

In this thesis, GT which aims to generate concepts, models or theories was chosen, as knowledge about patient participation in the context of SCUs for persons with dementia is limited. In addition, the method was considered suitable for exploring a phenomenon such as patient participation in which social interactions are fundamental requirements. The method described by Strauss & Corbin (1998) was primarily chosen as it offers a flexible approach to the identification of the research problem (McCann & Clark, 2003).

Cross-sectional survey (IV)

A cross-sectional design is the most frequently used design in survey research and is considered ideal for descriptive analysis (De Vaus, 2002). Polit & Beck (2012) state that cross-sectional studies are appropriate for describing the status of phenomena or for describing relationships among phenomena at a fixed point of time.

In this thesis, a cross-sectional survey was used in order to describe ‘what things are like’ (De Vaus, 2002) with regard to relatives’ participation in everyday care in SCUs for persons with dementia.

Setting

Studies I, II and III were conducted in the eastern part of Norway, in three SCUs for persons with dementia in nursing homes representing both urban and rural districts. Each of these SCUs housed nine residents on average (range 7-11). Study IV was conducted in SCUs for persons with dementia in 23 nursing homes in 19 randomly selected municipalities within three counties representing different parts of Norway. The total number of SCU beds in the nursing homes was reported to be 496, ranging from 6-12 beds per unit and including both permanent and short-stay beds for persons with dementia.

Participants

In this thesis, residents (I), nursing personnel (I and III) and relatives (II and IV) were included. Table 2 shows the characteristics of the participants in the four studies (I-IV).

Table 2. Characteristics of the participants in studies I-IV.

	Study I ¹		Study II	Study III	Study IV
	n=8	n=17 ²	n=12 ³	n=11	n= 233
Participants	residents	personnel	relatives	personnel	relatives
Sex					
Female	8	15	7	9	154
Male		2	5	2	79
Age					
Median/mean	83/83.5	54/57	59/60	54/50	61/61.6
Range	78-89	50-67	40-82	28-61	34-91
Personnel's occupation					
Registered nurse		4		4	
Enrolled nurse		10		4	
Social worker		1			
Assistant occupational therapist		1			
Unskilled assistant		1		3	
Time working in the SCU					
Median		10 years		6 years	
Range		A few days -18 years		2 months -17 years	
Resident's length of stay in the SCU					
Median	6.5 months		13.5 months		
Range	1 week- 24 months		1 month- 48 months		0 - >2 years
Relation to the resident					
Spouse			5		45
Child			5		152
Other			2		36

¹Only participants who had active roles and had conversations with the researcher are characterised.

²Personnel included in active roles in study I were not included in study III.

³Relatives in study II were not included in study IV.

Residents in the SCUs (n=27) participated in study I in an active (n=8) or passive role (n=19) depending on their ability to give informed consent. The resident's ability to give such consent was judged by the head nurse and a registered nurse who knew the resident well. Residents who were considered to possess such competence were later clinically assessed according to the clinical dementia rating scale (CDR) (Hughes, Berg, Danziger, Coben, & Martin, 1982). Inclusion criteria to participate in an active role were: be living in the SCU permanently, be diagnosed with mild to moderate dementia with a score of 1-2 on the CDR, be able to give informed consent and to speak Norwegian. Having active roles meant being observed in both day and private rooms and taking part in subsequent conversations with the researcher. Inclusion criteria to participate in a passive role were:

be living in the SCU and be diagnosed with dementia. Having passive roles meant only being observed in the day rooms.

Nursing personnel participated in study I (n=30) and III (n=11). Inclusion criteria were: be working in the SCU during the study period and be able to speak Norwegian (I and III). In total, 30 members of nursing personnel who were on duty during the course of observation participated in study I. Seventeen of them who were directly involved in interactions with the residents in daily life activities, took part in a subsequent conversation. Eleven members of nursing personnel were included in study III.

Relatives participated in study II (n=12) and IV (n=233). Inclusion criteria were: be the nearest relative to a resident living permanently in the SCU according to the patient journal, be able to speak Norwegian and be competent to sign the informed consent form. Twelve relatives were included in study II. Two hundred thirty-three of 348 invited relatives were included in study IV, a response rate of 67%.

Non-respondents (IV)

Age, sex and relationship to the resident were variables which were recorded to describe relatives who did not respond to the questionnaire. The intention was to compare this characteristic data with those of participants. However, for the 115 non-respondents, only 44 forms were completed, so no comparison could be done. Based on recorded information from non-respondents, the mean age was 58 years, 72% were females, 18% were spouses, 64% were children and 18% were more distantly-related to the resident.

Data collection

Data was collected by means of open non-participant observations with subsequent conversations (I), interviews (II and III) and questionnaires (IV).

Study I

In order to explore patient participation as it occurred in the naturalistic setting of the SCU, data was collected by the first author (AKH) by means of open non-participant observations which were complemented with information from conversations (Glaser & Strauss, 1967; Holloway, 2005; Polit & Beck, 2012). The data collection took place from August 2008 until January 2009 and included 10 observations in the residents' private rooms, 17 observations in the day rooms, 14 conversations with residents and 20 conversations with personnel. The focus was on activities such as personal hygiene, meals and other care situations related to daily life. The total duration of observation, which was carried out around the clock, was 51 hours, in periods ranging between 15 minutes and 6

hours (median 60 minutes). The length varied due to the different situations. The personal hygiene situation, for instance, could go on for only 15 minutes but contained a lot of information. On the other hand, observation time could last several hours without any interaction between the residents and personnel at all during the night shift. Some of the observations were completed with a subsequent conversation in order to gain a deeper understanding of what was observed. The conversation with the resident was conducted in their private room immediately after the observation. The conversation was based on keywords from field notes taken during observations (Fog, 2004; Holloway, 2005) and focused on how the resident experienced their opportunity to participate in decision-making during the particular observed situation, and what stimulated or hindered participation. The conversation with personnel was conducted in a meeting room as soon as they could leave work, and focused on how they experienced patient participation in the observed situation, and what stimulated or hindered participation. The conversations with the residents and personnel lasted between 10 and 40 minutes (median 15 minutes).

In order to portray the observed situation, thick descriptions which contained both descriptive and reflective notes were written immediately after the observations (Geertz, 1973; Strauss & Corbin, 1998). All notes from the observations and conversations were made discreetly to avoid disturbing the residents and the personnel.

Studies II and III

Data was collected by the first author by means of qualitative interviews in order to gain descriptions of relatives' (II) and nursing personnel's (III) experiences of patient participation in SCUs for persons with dementia (Geertz, 1973; Ponterotto, 2006; Streubert Speziale & Carpenter, 2003). The data collection took place from January 2010 until March 2011 (II) and from August 2011 until June 2012 (III). The interview guide in study II was based on findings from study I, and in study III the guide was based on findings from both study I and study II.

The first author and the head nurse of each SCU cooperated in the entire sampling procedure. In the beginning, the sampling of informants was purposeful. As the inclusion process proceeded, informants were theoretically chosen in order to saturate the emerging categories (Strauss & Corbin, 1998).

The interview guides were used as a reminder for the researcher to ensure that the themes were covered. The initial themes in the guides concerned how the informants experienced patient participation, whether it occurred or not and their role in the participation process. In order to obtain rich and meaningful data, probing questions were asked to extend or narrow the field of interest. Prior to data collection, pilot interviews with a relative of a

person with dementia living in a SCU (II) and an enrolled nurse working in SCU (III) were conducted to test the interview guide. A few semantic changes were made after these interviews, as some of the questions were unclear. To obtain broad and varied descriptions of the phenomenon under investigation, the interviews started as open dialogues in which the informants were encouraged to talk freely about how they experienced patient participation in everyday life in the SCU and their role in the patient participation process. As the studies progressed, the interviews were modified to focus on the emerging categories, their properties and dimensions and the different conditions in order to explore the phenomenon in more depth as well as to validate the findings (Holloway, 2005; Polit & Beck, 2012; Strauss & Corbin, 1998). Each informant was interviewed twice in order to deepen, broaden and validate the understanding of the first interview (Benner, 1994). When both interviews were analysed, a new informant was searched for and interviewed.

The interviews with relatives (II) lasted between 21 and 70 minutes (median 39 minutes) and the interviews with personnel (III) between 55 and 75 minutes (median 60 minutes) on the first occasion. The second interviews with relatives (II) lasted between 15 and 60 minutes (median 30 minutes) and with personnel (III) between 35 and 75 minutes (median 45 minutes).

The interviews with relatives (II) were conducted at their workplace, their private home or in a meeting room at the nursing home, depending on their wishes. One informant was interviewed by phone because of geographical distance. This interview did not differ from the other interviews in terms of content but was shorter in length. All interviews with members of nursing personnel (III) were conducted at their workplace. All interviews (II and III) took place in quiet rooms and with the exception of serving coffee (II) and a few phone calls (III), they were conducted without interruption.

All interviews (II and III) but two follow-up interviews with relatives (II) were recorded and transcribed verbatim. Twenty interviews were transcribed by a secretary and 26 by the first author. All transcriptions were controlled by simultaneously listening to the recording and reading the transcript (AKH). Concerning the two non-recorded interviews, the informants expressed their discomfort at being recorded, therefore only notes were taken. In these cases, the researcher gave the informant an oral summary of her interpretation of what was said and asked if that corresponded with their recollection of the interviews. In some of the first interviews, the informant continued to give important information after the recorder was switched off. Information concerning the issue of participation was noted and brought to the agenda in the second interview.

Study IV

Data was collected by the first author by means of a study-specific questionnaire. The data collection was carried out between March and September 2012. The head nurse of each SCU distributed the questionnaire to 348 relatives who satisfied the inclusion criteria. They were also responsible for reminding the relatives about the study if necessary, first orally and then by letter.

The questionnaire (IV)

The development of the questionnaire was based on the findings of the two Grounded Theory studies exploring patient participation and relatives' roles in the participation process in the context of SCUs for persons with dementia (I and II). In addition, a review of relevant scientific literature on the topic was carried out (Menne & Whitlatch, 2007). To test the validity of the questionnaire (Streiner & Norman, 2008), it was scrutinised by PhD students with various nursing and research experience, and clinically active nurses and nursing researchers with experience in dementia care (Streiner & Norman, 2008). A pilot study including relatives was also conducted.

The final questionnaire focused on relatives' participation in their near ones' everyday care. The questionnaire consisted of 50 items comprising demographic items, their actual and wished-for participation in decision-making, their way of participation, the level of burden experienced and important factors for participation.

Data analysis

Study I, II and III

All data from the field notes (I), conversations (I) and the transcribed interviews (II and III) were analysed according to the process of constant comparison. The data analyses were performed concurrently with data collection and in line with the method of open, axial and selective coding described by Strauss and Corbin (1998). In the open coding process, the text was scrutinised line by line to identify the meaning and process of the data, and thereafter grouped into preliminary and more abstract categories. Properties and dimensions were constantly sought in the emerging categories. In the axial coding process, the categories were further clarified and the different conditions identified. In the selective coding process, each category was densified and the impact of the conditions on different categories was sought. In the final step, the core category was identified, and thereafter a conceptual model was constructed.

The codes and, further on, the categories were constantly compared and contrasted by discussions within the research team. Comparisons were important as they enabled identification of variations and similarities in the patterns found in the data. Questions such as who, when, why, where, what and how were continuously asked in the process in order to gain a better understanding of the data. During the entire process, memos with thoughts, ideas, reflections and preliminary connections were written and discussed within the research team (Strauss & Corbin, 1998). To ensure saturation of the categories and their dimensions and properties, additional informants were included after saturation was reached in each of the studies (Strauss & Corbin, 1998).

Study IV

For the statistical analyses, the Statistical Package for Social Sciences (SPSS) version 20 was used (IV). Descriptive statistics were used to describe the characteristics of the relatives, their actual and wished-for level of participation, their way of participation, the level of burden experienced and important factors for participation. The Wilcoxon signed-rank test was used to compare differences between relatives' actual and wished-for participation. Twenty-two respondents were excluded from this test due to missing data. The Mann-Whitney U-test was used to compare differences between males and females and between spouses and children. When statistically significant differences were found, effect size was calculated ($r = .10$: small effect, $r = .30$: medium effect, $r = .50$: large effect) (Cohen, 1988; Field, 2005). Thirty-six relatives were excluded from this test due to distant or uncertain relationship. The tests were two-tailed and statistical significance was assumed at $p < .05$ (Altman, 1991). The Kruskal-Wallis test was used to compare differences between age groups (age group 1: ≤ 50 years ($n=31$, 13.3%), age group 2: 51-67 years ($n=149$, 63.9%), age group 3: ≥ 68 years ($n=53$, 22.7%)) and between education levels (level 1: compulsory schooling ($n=48$, 20.7%), level 2: upper secondary school ($n=88$, 37.9%), level 3: university ($n=96$, 41.4%)). When a statistically significant difference was found, further pairwise comparisons were performed using the Mann-Whitney U-test. Since three pairwise comparisons were made, a Bonferroni correction was used to protect against a type 1 error. This involved dividing the assumed significance level by the number of comparisons made ($p = .05/3$). In these cases, the significance level $p = .0167$ was used ($.05/3 = .0167$) (Field, 2005).

Trustworthiness, validity and reliability

This thesis combines qualitative (I-III) and quantitative approaches (IV). The two approaches have complementary strengths and weaknesses; by using both approaches, the strength of one method may compensate for the weakness of the other and increase the validity of the findings (Foss & Ellefsen, 2002; Streubert Speziale & Carpenter, 2007) and

providing a more comprehensive description and understanding of the phenomenon (patient participation in SCUs for persons with dementia) (Strauss & Corbin, 1998).

Trustworthiness (I-III)

Strauss and Corbin's (1998) criteria for evaluation, which are meant for evaluating both the research process and the empirical grounding of findings, were used with regard to trustworthiness. This means that the researchers have made efforts to establish an audit trail throughout all the qualitative studies and be transparent in the method descriptions (I-III). However, Strauss and Corbin (1998) described their criteria as a supplement to other well-established procedures of evaluation criteria. Therefore, Lincoln and Guba's (1985) criteria: credibility, dependability, confirmability, transferability and authenticity – for developing trustworthiness were also used during the research process (Polit & Beck, 2012). In order to achieve credibility, which refers to confidence in the truth of the data and interpretations of them, all informants were interviewed twice (II and III). By interviewing twice, the trust between the informants and the researcher could increase and the data become deeper and richer. In addition, the second interview elucidated uncertainties and validated the first interview. The interviews, which were recorded and transcribed verbatim, were read by the whole research team. In addition some of the interviews first were coded individually, and thereafter the codes were compared and discussed within the team. Quotations used to illustrate the categories were meant to further contribute to credibility. In order to achieve dependability, which refers to the stability of data over time and conditions, the researchers made efforts to make the trail of the entire research process visible. The findings of the studies (I-III) were found to have many similarities which might strengthen the findings in each of the studies. In order to achieve confirmability, which refers to objectivity, the initial literature review was disciplined and restrained in order to optimise the conditions for analysing the data in a 'neutral' way. To ensure that the categories were grounded in data and not a result of the researchers preconceptions, own preconceptions about the topic were discussed in the research team and efforts were made to bridle these during the entire process. To achieve transferability, which refers to whether the findings can be transferred to or have applicability in other settings and groups, descriptions have been provided so that the readers of the text can evaluate the applicability of the data by themselves. To achieve authenticity, which refers to the extent to which researchers fairly and faithfully show a range of realities, the researchers used different methods for data collection and strived to provide thick descriptions. By describing the properties and dimensions of the different categories, a range of realities were shown.

Validity and reliability (IV)

Validity refers to the degree to which an instrument measures what it is intended to measure (Polit & Beck, 2012; Streiner & Norman, 2008). The questionnaire was based on the findings of two Grounded Theory studies exploring patient participation in the context of SCUs for persons with dementia (I and II) which strengthen its validity. To test the questionnaire's face validity and content validity (Streiner & Norman, 2008), it was first scrutinised by seven PhD students in nursing science with various experiences of nursing and research. They were asked to critically examine whether the questionnaire appeared to assess the desired qualities (face validity) and whether it covered all the relevant or important content (content validity) (Streiner & Norman, 2008). In addition, they were asked to examine the layout of the questionnaire, the instructions and the answer alternatives. This resulted in some changes to the instructions and questions, and the answer alternative 'Don't know' was added to two questions. The revised questionnaire was later scrutinised by five nurses and two nursing researchers with experience in dementia care. Three of them also had experience as a relative of someone with dementia. This resulted in minor semantic changes to improve the understanding of some questions. Lastly, a pilot study was conducted with four relatives to assess whether the questionnaire was understandable and reasonable from their point of view. No further changes were made to the questionnaire.

Reliability refers to the consistency of measurements when the procedure is repeated. The first step in providing evidence of the value of an instrument is to demonstrate that the measurements produce the same or similar results under different conditions (Polit & Beck, 2012; Streiner & Norman, 2008). The questionnaire has not been tested in different populations in order to strengthen its reliability.

Ethical considerations

Approval

The Norwegian Social Science Data Services approved all studies (I-IV), which was sufficient for study III and VI. Study I and II were also approved by The Regional Committees for Medical and Health Research Ethics. Additionally, study I was approved by The Norwegian Directorate of Health. The studies were carried out in accordance with the principles of the Declaration of Helsinki (2009) and Ethical Guidelines for Research in the Nordic Countries (Northern Nurses' Federation, 2003). Written permission was obtained from the head of the nursing homes before the studies started (I-IV). The head nurse of each SCU, who was already informed by the head of the nursing home, was contacted by phone by the first author and asked to find potential

informants/respondents responding to the inclusion criteria, inform them about the study and ask for their consent to participate in it (I-IV). All head nurses of the SCUs also received written information about the study and what to do.

In study I, the researcher (AKH) made an appointment with the head nurse of each SCU about observation times. In study II and III, the researcher contacted the informants by phone in order to make further appointments about time and place for interviews. Prior to each observation or interview, the informants were informed orally in line with the written information, which they had received from the head nurse (I-III). In study IV, the head nurse delivered an envelope with information about the study, the questionnaires and informed consent form to the respondents. The written information forms followed the norm of the Norwegian Social Science Data Services (I-IV) and the Regional Committees for Medical and Health Research Ethics (I and II). Written approval was obtained from all participants who were competent to give informed consent.

Informed consent (I)

Research concerning people with dementia implies several ethical challenges; one of them concerns the demands of informed consent (Slaughter, Cole, Jennings, & Reimer, 2007). The purpose of informed consent is to protect especially vulnerable persons such as persons with dementia from being mistreated during research (Ruyter, Solbakk, & Førde, 2007). However, the demands of informed consent might on the other hand be interpreted so strictly that groups of patients might be denied participation in research (Nord, 2001).

Informed consent was obtained from residents who were judged to have competence to give such consent. According to the guidelines from the Regional Committees for Medical and Health Research Ethics and the Norwegian Directorate of Health, approval was in addition obtained from their relatives. Approval was also obtained from relatives for those residents without competence to give such consent by themselves. Due to the residents' cognitive impairment, information about the study was repeated every time the researcher visited the SCU. Additionally, the residents were asked if they approved the researcher's presence.

Beneficence and harm

The study, which was considered a low risk project, implied no special risk or beneficence for the participants. However, since the participants in the study (I, II and IV) were in a vulnerable situation, ethical considerations were fully discussed within the research team ahead of the study (Declaration of Helsinki, 2009). Persons with dementia living in SCUs are vulnerable due to their disease and dependency on health personnel. Their relatives are vulnerable since the burden of being in this role is distressing; they too can find

themselves dependent on health personnel. The request to participate in the study stressed that their decision would not impact on further treatments and care either way. The latter was clarified by the head nurses.

The researcher's experience from study I was that the residents were most often positive to the researcher's presence and research. Many of them expressed orally that it was nice to have a person sitting in the day rooms; other residents sought contact by sitting down beside the researcher and by making eye contact. In a few situations, the resident's reactions to the researcher's presence were interpreted as not welcomed. These situations concerned personal hygiene where the researcher had sight of the bathroom. In such situations, the researcher moved away and just listened to the conversation between the member of personnel and the resident.

In conversations, residents expressed their experiences and thoughts concerning their participation in decision-making in everyday care. Some of them stated that they seldom had such serious conversations nowadays. In some cases, the residents expressed sadness over their memory loss. In such cases, the researcher tried to be supportive. The residents were never left before conversation switched to a more happy topic, and personnel were informed about the residents' mood.

The themes in the interview guides for study II and III were considered in advance to be rather harmless and not to contain especially sensitive questions. However, the interview proved to be rather emotional for many relatives (II). Most of them expressed that it felt good to have an opportunity to talk about their experiences, but many exhibited sadness while being interviewed. Quite often they explained that it was not the questions themselves that were hard to deal with, but the interview was a reminder of the loss of a relative and both good and bad memories sprang to mind. When relatives started to cry, they were given time to calm down and then asked whether or not they wished to continue. No relatives ended the interview because of emotional reactions. The relatives were given the possibility to contact the researcher by phone or email after the interviews, but none of them did.

Most of the nursing personnel (III) expressed that joining the study had been a positive experience as it emphasised issues in their everyday practice which were rather seldom talked about. Some of them expressed that the interviews had inspired them to think about their own practice.

Confidentiality

All data was treated with confidentiality. The participants were encouraged not to use names of other persons or the nursing home in the interviews and were also told that the

researcher would not use their name or name of the nursing home during the interview (II and III). To ensure the participants' confidentiality as well as to avoid recognition, their names and SCUs were not referred to in any field notes, written interviews or questionnaires (I-IV). Field notes with supplementary conversations (I), transcription of most of the interviews (II and III) and punching of the quantitative data (IV) were done by the researcher (AKH). Less than half of the interviews where no names occurred were transcribed by a secretary (II and III). The data material (I-IV) was coded by numbers and words and kept locked in the researcher's office when not used. The key to the coding was kept separate from the data material. All written materials were kept locked in the researcher's office. Data used in the papers cannot identify the participants or the nursing homes.

Main findings

The main findings concerning patient participation in everyday life in SCUs for persons with dementia are presented under these headings:

- Patient participation in SCUs as observed, and experiences of residents and nursing personnel (I and III)
- Relatives' participation in the patient participation process and in everyday care (II and IV)
- Factors of importance for patient participation (I - IV)
- Comprehensive understanding of the findings (I - IV)

Findings in this thesis showed that occurrence and level of patient participation in the SCU as well as relatives' participation were related to the kind of care situation. Two different situations were identified: *healthcare situations*, which embraced physical and psychological health status/treatment, and *daily care situations*, which embraced getting-up/bedtime, personal hygiene, clothing, eating-drinking, personal interests, and desire to be alone/desire for company.

Patient participation in SCUs as observed, and experiences of residents and nursing personnel (I and III)

'Patient participation - a matter of presence' (I)

Observations and conversations with residents and personnel revealed that presence of the personnel and the resident determined the occurrence of patient participation. 'Presence of personnel' comprised three different levels of presence. 'Being there in body' required just the personnel's physical presence. 'Being there in mind' required their presence with all senses based on knowledge and competence. 'Being there in morality' was understood as being fully present, as it included the two other levels and was based on humanistic values. 'Presence of residents' comprised their 'ability and wishes' to participate and their 'adaptability' to the situation of living in the SCU.

The personnel's presence had a huge impact on the residents' ability and wish to actively participate, and the residents adapted their behavior to the personnel. The residents' presence had an impact on the personnel's presence as well. The more ability and wishes the residents showed, the higher the level of presence seen among the personnel. However, residents' presence seemed to impact to a lesser extent on the personnel's presence than vice versa.

The personnel's bodily presence was basic to making patient participation possible. However, their bodily presence could also have a negative effect on the residents when subsequent presence in mind and morality were lacking. The personnel's presence in mind was decisive for patient participation as their ability to interpret the behaviour of the residents, to communicate appropriately and to be one step ahead, required both knowledge and commitment. Thus, they had to be on duty with all their senses to motivate and initiate the residents' ability and wishes to take part in the participation process. If the personnel lacked these qualities, the residents' opportunity to participate could be inhibited. The personnel's moral presence was however revealed as most crucial, as treating the residents respectfully, seriously and as individuals, had a strong effect on the residents' ability and wishes to participate. In situations where the personnel acted disrespectfully, the residents became uncertain of themselves, passive and sometimes irritated. Then, patient participation seemed no longer to be an issue on the agenda.

The residents' opportunities to be present in the participating process were influenced by their ability and wish to express their thoughts regarding patient participation. Findings showed that residents could regard decisions in everyday activities as both important and not so important. The view of importance was influenced by their personality and previous preferences. Furthermore, the resident's level of adaptation to the situation and the personnel had an impact. This could vary between acceptance and resignation, but also resistance. The more symptoms the resident had the more difficult it was for them to understand information from the personnel, and the more difficult it was for them to make their own decisions about participation.

'Patient participation - as far as suitable' (III)

Interviews with nursing personnel revealed the finding 'Patient participation - as far as suitable'. Patient participation was considered to be grounded in the idea of being master of one's own life and important to the dignity and self-esteem of the resident. It was described as an important element of the care given in the SCUs, but also as a possible threat to a resident's dignity and self-esteem if it was inappropriately used. Findings emphasised that, to make patient participation successful, it had to be adjusted to the individual resident's abilities at the particular moment, as these abilities could vary greatly over time. However, patient participation was often primarily adjusted to suit the nurse's ideas about how to carry out the daily care in the SCU context and get routines to function, and only secondarily to the individual resident's needs and wishes. Patient participation was thus found to be a losing principle, as it did not have priority in the hectic everyday care.

Four different levels of participation that could be used in everyday care were found. 'Letting the resident make their own decisions' was seen as the highest level of patient participation and often underlined as being the ideal. The distance between letting the resident make their own decisions and care failure was, however, described as short and difficult to deal with, as the residents had more or less lost the capacity to understand the long-term consequences of their decisions. 'Adjusting the choices' in such a manner that the resident could make reasonable decisions was another level of patient participation that was often used. This was adopted because wrong decisions could have negative impacts, not only on the individual resident but also on the other residents. The nurses also pointed out that, when the residents were given too many options, the opportunity to make their own decisions was taken away from them, as they did not possess the ability to make extensive choices. 'Making decisions on behalf of the resident' was a level of patient participation used when the resident did not express any protest against the personnel's decisions. The consequence of giving residents without decision-making ability the opportunity to decide by themselves was described as a potential insult and threat against their self-esteem and dignity. Making decisions on behalf of the resident was in such cases considered to be good care. The nurses also described use of diverting actions as a way of handling resistance. The level of 'forcing the resident' described the case in which the resident was not involved in the decision making at all. Two kinds of forcing situations were found. One concerned the matter of living behind locked doors. This was seen as necessary for the residents' safety, but also as an obstacle to decisions to go out. Typical of the other forcing situation was when the personnel thought that the resident lacked the ability to make decisions and the resident resisted verbally and bodily against the activity. These situations most often concerned personal hygiene, and the decision to use force had been discussed and planned in the team. The action of forcing the resident was described as 'momentary insults' but also as responsible care, as letting the resident decide was thought to be an even more severe threat to their self-esteem and dignity. However, unplanned situations of force were also found where the nurse used force to get the care activity done, apparently without reflecting about the issue. This kind of force was most often used by unskilled nurses who were seldom on duty and regarded force as a normal part of the care as the resident was demented.

Relatives' participation in the patient participation process and in everyday care (II and IV)

'Transitions between different roles to secure the resident's wellbeing' (II)

Interviews with relatives discovered that they experienced their role in the patient participation process as a dynamic issue in which they moved between different roles to

secure the resident's wellbeing, which was understood as the resident's comfort and dignity. The four roles contained both different degrees and ways of participation. Which role the relatives stepped into depended mainly on how they perceived the resident's situation, but 'being a visitor' was found to be the prerequisite for the other roles. During the visits, the relatives judged the resident's situation by using their senses (looking, listening and smelling) and by observing changes in the resident's health, mood, behaviour and care. As long as the resident expressed satisfaction and the relatives perceived that everything was fine, their role seemed to be rather passive. When they perceived changes in the situation and a reduction of the resident's wellbeing, they took on a more active role. Relatives revealed that the visits could be rather demanding as it was hard for them to face the progression of the disease and deal with the symptoms. 'Being a spokesperson' was a more active role where relatives could impart information about the resident to the personnel and vice versa, act on behalf of the resident and take care of the resident's interests. Some relatives stressed that by actively speaking on behalf of the resident they contributed to taking care of the resident's personal preferences, which impacted on their dignity. 'Being a guardian' was found to be the most active role. All relatives stepped into this role when they perceived the resident's comfort and dignity, and thereby their wellbeing, to be threatened, and when they felt that they themselves were not being taken seriously as spokespersons. In this role, the relatives controlled the care and were highly attentive to changes in the resident's status and daily care. However, this role could be experienced as difficult as it was important for them to be liked by the personnel. 'Being a link to the outside world' was found to be a role which some relatives stepped into in order to give the resident an opportunity to catch a glimpse of 'ordinary life' outside the SCU. In this role, relatives could contribute to a more meaningful daily life, which was seen as important to secure the resident's wellbeing.

Different daily life situations triggered different roles. Relatives were most active as spokespersons concerning health status/treatment and clothing. The very same situations also provoked the guardian role, as when the relatives perceived that something was wrong concerning these issues, they were on alert. The relatives seldom committed themselves in matters concerning the resident's sleep and rest, personal hygiene and what to eat or drink. Concerning social activities, some relatives participated by being a link to the outside world.

'Relatives' participation in everyday care' (IV)

A majority of the relatives were females (n=154, 66.1%). Most relatives were children of the resident (n=152, 65.2%) and most relatives were working (n=144, 62.3%). The age ranged between 34-91 years (mean=61.6 years). A majority (n=194, 84.1%) of the relatives reported that they visited their near ones at least weekly. Spouses (females n=26,

58%; males $n=19$, 42%) visited the resident statistically significant more often than children ($z=-5.502$, $p=.000$) and the eldest visited more often than the youngest ($z=-4.550$, $p=.000$) and the middle age ($z=-4.935$, $p=.000$) relatives. The travelling distance from relatives' homes to the SCU ranged from 0 to 600 km (median 7 km, mean 33.5 km).

The most common way to participate in the care was by being a spokesperson ($n=200$, 86.6 %). Females scored significantly higher on this item than males ($z=-2.35$, $p=.019$). About 70% ($n=164$) of the relatives reported that they were a link to the outside world and 35.9 % ($n=82$) reported that they participated by controlling the care. Some relatives ($n=35$, 15.2 %) participated by relieving the personnel. Participation was seldom reported as a burden ($n=6$, 2.6%).

Most relatives reported that they participated to quite a low degree or not at all in decisions about the resident's everyday care (Table 3). Statistically significant differences were found between relatives' actual and wished-for participation in decisions about the resident's everyday care in all items, but a majority did not wish to participate much more than they actual did (Table 4). Relatives scored especially low in decisions about getting-up/bedtime, eating/drinking and personal hygiene. They scored somewhat higher in decisions about personal interests, clothing, desire to be alone/desire for company and treatment of the resident's physical and psychological health.

Table 3. Description of relatives' actual and wished-for participation in decisions in the resident's everyday care

	To a very high degree	To quite a high degree	To quite a low degree	Not at all
	n (%)	n (%)	n (%)	n (%)
A¹ Treatment of the resident's physical health (n=229)	19 (8.3)	50 (21.8)	99 (43.2)	61 (26.6)
W² Treatment of the resident's physical health (n=224)	31 (13.8)	76 (33.9)	82 (36.6)	35 (15.6)
A¹ Treatment of the resident's psychological health (n= 224)	16 (7.1)	39 (17.4)	100 (44.6)	69 (30.8)
W² Treatment of the resident's psychological health (n=222)	32 (14.4)	69 (31.1)	83 (37.4)	38 (17.1)
A¹ Getting up time in the morning (n=227)	5 (2.2)	4 (1.8)	33 (14.5)	185 (81.5)
W² Getting up time in the morning (n=223)	10 (4.5)	13 (5.8)	53 (23.8)	147 (65.9)
A¹ Personal hygiene (n=229)	14 (6.1)	21 (9.2)	80 (34.9)	114 (49.8)
W² Personal hygiene (n=225)	21 (9.3)	30 (13.3)	84 (37.3)	90 (40.0)
A¹ Clothing (n= 228)	13 (5.7)	61 (26.8)	86 (37.7)	68 (29.8)
W² Clothing (n=224)	23 (10.3)	65 (29.0)	84 (37.5)	52 (23.2)
A¹ Eating and drinking (n=224)	6 (2.7)	16 (7.1)	90 (40.2)	112 (50.0)
W² Eating and drinking (n=221)	15 (6.8)	29 (13.1)	99 (44.8)	78 (35.3)

A¹ Personal interests (n=229)	14 (6.1)	49 (21.4)	113 (49.3)	53 (23.1)
W² Personal interests (n=224)	26 (11.6)	78 (34.8)	86 (38.4)	34 (15.2)
A¹ Desire to be alone/desire for company (n=228)	11 (4.8)	52 (22.8)	96 (42.1)	69 (30.3)
W² Desire to be alone/desire for company (n=224)	20 (8.9)	68 (30.4)	84 (37.5)	52 (23.2)
A¹ Bedtime in the evening (n=229)	4 (1.7)	9 (3.9)	49 (21.4)	167 (72.9)
W² Bedtime in the evening (n=225)	10 (4.4)	14 (6.2)	69 (30.7)	132 (58.7)

A¹ = actual participation, **W²** = wished-for participation

Table 4. Comparison of relatives' actual and wished-for participation in decisions in the resident's everyday care

Activities in everyday care	Grading of actual participation			Grading of wished-for participation			Wilcoxon rank test	signed test	p
	N	Mean ¹	SD	N	Mean ¹	SD			
Treatment of the resident's physical health	229	2.12	.90	224	2.46	.98	-5.268		.000
Treatment of the resident's psychological health	224	2.01	.88	222	2.43	.94	-6.194		.000
Getting up time in the morning	227	1.25	.60	223	1.49	.80	-5.296		.000
Personal hygiene	229	1.72	.89	225	1.92	.95	-3.302		.001
Clothing	228	2.08	.90	224	2.26	.93	-3.438		.001
Eating and drinking	224	1.63	.74	221	1.91	.87	-5.376		.000
Personal interests	229	2.10	.83	224	2.43	.89	-6.157		.000
Desire to be alone/desire for company	228	2.02	.85	224	2.25	.91	-4.770		.000
Bed time in the evening	229	1.34	.64	225	1.56	.80	-4.652		.000

¹Scores could range from 1 (not at all) to 4 (to a very high degree). ²Based on negative ranks. ³N=211

Factors of importance for patient participation (I-IV)

Findings discerned that different factors (I-IV) could stimulate or hinder the opportunity, occurrence and extent of patient participation. The factors were related to the actors in the participation process, the relationship between them and the SCU's context. The personnel's presence and the resident's presence were found to be the prerequisites for patient participation (I). The very same presences were also highlighted in studies II and III, under 'conditions impacting on patient participation'. In study IV, relatives' presence was revealed as important for the quality of care.

The residents' ability and wish to make decisions and to express these were important, as the better the ability, the more they seemed to be invited to participate in decisions. The ability and wish could however vary from time to time (I and III). The residents' ability to participate in decisions was reported as quite low or absent in issues regarding everyday care (n=200, 86.2%) and health care and treatment (n=217, 93.6%) by the relatives. A majority of the relatives (n=195, 84.1%) either did not know whether a professional assessment of the resident's competence to make decisions had been performed or reported that such an assessment had not been done (IV).

Factors were also found that impacted on relatives' ability and wish to take part in the patient participation process and the care (II - IV). It was reported by almost one third of them that the resident's ability to recognize them was crucial for their participation (IV). Relatives' experience of emotional closeness to and knowledge about the resident had also huge impact on their wish and effort to participate (II). In the survey, relatives reported that they were emotionally attached to the resident (n=220, 94.8%) and the majority (n=230, 98.7%) stated that they had good knowledge about the resident's habits and preferences (IV). Relatives' perception of the resident's ability and wish to participate was found to impact on which role they stepped into (II). The frequencies of relatives' visits and participation in the care declined along with progression of dementia symptoms (II). When residents had reduced ability to express their wishes verbally, their relatives played an important role in exchanging information with the nurses (III). Seventy-three percent (n=168) of the relatives had been asked to fill out an information form about the resident and of these 93.2% (164) had done so. Information was also exchanged when visiting the SCU (n=134, 58.5%). It was most important for the relatives to get information about changes in the resident's health and treatment (n=174, 66%) (IV). The relatives' trust in the personnel, influenced by their perception of the personnel's care skills, also affected their participation (II). However the findings were quite ambivalent regarding how. High competence and high level of trust seemed to motivate participation but this also could lead to passivity and handing over the responsibility for the residents' care to the personnel. In the survey study, relatives reported in general a positive view of the

personnel's skills and the care provided. More than half of them perceived that they shared the responsibility for the resident with the personnel. Almost one-third reported that it was important for them to be well-liked by the personnel and one-third reported it difficult to criticize the care. Half of them reported that their participation was crucial for the resident's wellbeing (IV).

The survey (IV) revealed that differences in relatives' scores were more often related to their relationship to the resident than to sex, age and education level. Spouses visited more frequently ($z=-5.502$, $p=.000$, $r=.39$), were more emotionally attached ($z=-3.305$, $p=.001$, $r=.23$), perceived their own participation as more important for the resident's wellbeing ($z=-2.557$, $p=.011$, $r=.18$) and felt more support in their role ($z=-2.501$, $p=.012$, $r=.18$), than children. On the other hand, it was more important for them to be recognized by the resident ($z=-4.164$, $p=.000$, $r=.30$), they found it more difficult to criticize the care ($z=-2.076$, $p=.038$, $r=.15$) and more important to be well-liked by the personnel ($z=-3.242$, $p=.001$, $r=.23$), than children.

The nursing personnel's ability to interpret and meet the individual resident at the particular moment seemed to be related to their qualifications in dementia care, expressed interest in caring for persons with dementia, and how often they were on duty. Their ability had a huge impact on the level of patient participation (I and III) and also on relatives' participation (II).

The SCU context (organisational and housing conditions) was also found to affect patient participation in a great extent (I-III). Care cultures in which the idea of patient participation was a well-known and common goal, where professional care development was essential, and the leader was visible, seemed to be stimulating (I and III). A culture in which the goal of the care was vague, professional care development not on the agenda, and the leader invisible, seemed to be inhibiting (I and III). The nurse leaders' way of exercising their leadership was found to be important especially for the personnel's ability and wish to make participation possible for the residents and their relatives. Routines concerning nursing reports and meals, and use of time were found to impact on the occurrence and extent of patient participation (I and III). The number of personnel was stressed as crucial, since a high level of patient participation was highly time-consuming (III). However, a high number of personnel could also have a negative impact as then they often showed more interest in talking to each other than to the residents who became disregarded (I). The housing conditions concerned inappropriate architecture of the units which hindered the personnel's bodily presence (I). Living behind locked doors was necessary for the residents' safety but an obstacle to decisions about going out. Sharing accommodation with others was a hindrance to the individual resident's opportunity to make their own decisions in everyday life (I and III).

Comprehensive understanding of the findings (I-IV)

Wellbeing and dignity in the resident's everyday life was found to be the most important goal for the care in the SCUs, not necessarily the attainment of a high level of patient participation (I-III). The level of participation had to be adjusted to the resident's ability and wish to take part in decisions in the very moment. Their ability and wish to take part in decisions were perceived as reduced and unpredictable, and were in great extent affected by the personnel's presence (I and III). Whether the personnel succeeded in their adjustment or not depended on their qualifications in dementia care, their interest and ability in caring for persons with dementia in a respectful way, and how often they were on duty (I and III). Level of participation was often primarily adjusted to suit the personnel's ideas about how to carry out the daily care and to get routines to function. Hence, patient participation was often 'a losing principle' in the SCUs (I and III). The relatives were often an important link between the personnel and the resident, and they thereby influenced positively on the patient participation process (II). Relatives considered themselves as the resident's spokesperson by exchanging oral and written information with the personnel (II and IV). This kind of information could, when correctly used, be a valuable basis for providing individual care, in order to secure the resident's wellbeing and dignity. Relatives were frequent on visits and judged the resident's situation, and thereafter they decided level and type of participation. Relatives' participation was seen as crucial for the resident's wellbeing, and the findings stressed that relatives could make a difference to the resident's everyday life and ensure quality of care (II and IV).

Organizational factors concerning leadership, care culture, routines and number of personnel, and housing factors concerning architecture and sharing accommodation, greatly affected the occurrences and possibility of patient participation, either as stimulation or hindrance (I-III).

Discussion

In this section, the meaning of patient participation in the everyday life of persons with dementia in SCUs will be discussed, followed by a discussion of how an adequate level of patient participation can be attained, and finally if and how relatives can be a link in the patient participation process.

What does patient participation mean in the everyday life of persons with dementia in SCUs?

In this thesis, both the nursing personnel and the relatives emphasized the wellbeing and dignity of the residents as the most important goal in the care of persons with dementia, rather than a high level of patient participation (I-III). This has not been found in previous research. The connection between patient participation and dignity has however been elucidated in previous studies. Eldh (2006) found in her study that patients considered 'being regarded as a person' and 'being respected' as important parts of patient participation. It has also been suggested that dignity can be preserved or enhanced by upholding a person's autonomy, giving individualized care, restoring control, showing respect, performing advocacy, and listening sensitively (Anderberg, Lepp, Berglund, & Segesten, 2007; Oosterveld-Vlug, Pasma, van Gennip, Willems, & Onwuteaka-Philipsen, 2013; Randers & Mattiasson, 2004), which all are concepts close to patient participation.

According to residents with mild to moderate dementia (I), there were few things to make decisions about in their everyday life in the SCU, and deciding by themselves was not seen as important. On the other hand, some residents expressed that deciding was important but they had adapted themselves to the situation and to the personnel. These findings indicated that residents had accepted a low level of participation due to the circumstances. This impression was strengthened by the findings that the personnel's way of interaction with the residents also affected their ability and wishes to participate (I). This can be understood as the residents adjusted their level of participation in order to maintain wellbeing and dignity, which concurs with other findings about the situation of elderly persons dependent on care (From, Johansson, & Athlin, 2007).

In previous research, older patients' wish and capacity to participate in decisions have been debated, and the findings are contradictory (Bastiaens, et al., 2007; Florin, 2007; Foss, 2011) as they show both that the elderly want to take part in decisions about their care and medical treatment and conversely that they do not want so (Bastiaens, et al., 2007; Ekdahl, Andersson, & Friedrichsen, 2010; Foss & Hofoss, 2011). Studies have also shown that elderly persons felt it difficult to state their opinion without the risk of being

regarded as impolite (Berg, Hedelin, & Sarvimäki, 2005) or distrusting (Belcher, Fried, Agostini, & Tinetti, 2006). These findings make sense also in the present thesis, in which the residents are not only elderly, but also have a diagnosis of dementia. This makes them especially vulnerable in the participation process, which places heavy demands on the personnel in order to encourage the residents to take part in everyday care decisions (I and III).

According to the nursing personnel the practical use of patient participation in everyday care decisions represented a hierarchy (III) partly in line with what has been found in previous research (Foss, 2011; Smebye, et al., 2012; Thompson, 2007). The levels ranged from letting the residents make their own decisions to forcing them. The findings showed that most of the personnel were well aware of the need for adjustment of the level of participation to the resident's ability and wish in the very moment, and of the consequences participation would have. The more severe dementia symptoms and consequences for the resident and others, the lower level of participation could be used. It was however striking that, quite often, the level of participation was adjusted primarily to suit the personnel's ideas and routines, and only secondarily to the resident's needs and wishes. Hence, the findings in this thesis again illustrate what has been found in studies before (Robinson & Gallagher, 2008; Oosterveld-Vlug, et al., 2013), that despite awareness among the nursing personnel of the goal of keeping the patient in focus, care is often dictated by factors such as routines, and needs and wishes of the personnel, rather than by the patient's best. This insight will have meaning also when talking about patient participation in dementia care, as this group of patients has been found to be at risk of becoming objectified and seen as non-persons when the disease progresses (Capstick & Baldwin, 2007; Kitwood, 1997).

Interesting was that the nursing personnel described the use of force as the lowest level of the hierarchy of patient participation (III). This differed from the lowest level in other studies which is referred to as 'non-participation' (Smebye, et al., 2012; Thompson, 2007). Despite the use of force was deliberate and done with the positive purpose of safeguarding the resident (III), forcing the resident could hardly be seen as a level of participation. It must be stressed that force, enacted against the resident's expressed will, must always be seen as a potential risk for the person in need of care. Most of the forcing situations in this study (III) concerned personal hygiene, where the momentary use of force was seen as a way to attain dignity. This has similarities with studies showing that use of restraint is often justified as a way to improve the quality of care (Gjerberg, Hem, Førde, & Pedersen, 2013; Saarnio & Isola, 2010). A thought-provoking finding was that force also could be used without reflection and be regarded as normal care since the resident had dementia. These serious findings are supported by several studies, showing that persons with dementia are often subject to restraints and coercive care and treatment

(Gjerberg, et al., 2013; Kirkevold & Engedal, 2004; Lejman, Westerbotn, Pöder, & Wadensten, 2013; Selbæk, et al., 2008). As the use of coercion in somatic health care in Norway basically is illegal (Gjerberg, et al., 2013; Patients Rights Act, 1999) it is remarkable that the judicial aspect of patient participation and the prohibition of the use of force was not an issue for the personnel (I and III). This may be interpreted as the Patients Rights Act, which came into effect almost 15 years ago (1999), and its supplement (2009), had been insufficiently implemented in the SCUs.

A possible explanation of the lack of attention paid to the judicial aspects (I and III) may be related to the focus of this thesis: patient participation in everyday life. Perhaps decisions about everyday life were seen as so commonplace that talking about legal rights in regard to these matters was almost considered to be an exaggeration. Another explanation may be related to the resident's reduced competence to make decisions. The Patients Rights Act (1999) sets out requirements concerning the patient's competence to give informed consent for taking part in decision-making in healthcare (Smebye, et al., 2012). This competence is reduced in residents living in SCUs. However, this does not mean that the residents are globally incompetent, as they may be quite legally competent to decide about matters such as what to wear, getting-up/bedtime and what to eat, despite being legally incompetent to decide about e.g. major surgery (Holm, 2001). Everyday life decisions are, however, very much in focus in dementia care and important due to their impact on the patient's dignity (Gallagher, et al., 2008) and on person-centred care (Edvardsson, et al., 2008; Kitwood, 1997; Morgan & Yoder, 2012). A recent study found a gap between theory and reality in everyday practice in dementia care (Venturato, Moyle, & Steel, 2013). This gap was also obvious in the findings of this thesis, in that the political, judicial and ethical foundations of patient participation, which should theoretically create a superior framework for patient participation in SCUs for persons with dementia, were insufficiently implemented and followed in practice (I-III). This does not mean that the care in general was poor, but the findings indicated that it had the potential to be better.

How to attain an adequate level of patient participation for persons with dementia?

This thesis highlighted several factors of great importance for patient participation in dementia care in SCUs (I-IV). Outstanding was the importance of competent, committed and concerned nursing personnel, who were essential for the adjustment of the level of participation to the residents' ability and wish in the very moment. In the findings, this was described as 'the personnel's presence in body, mind and morality' (I). The existence or absence of these kinds of presence among the nurses seemed to be related to their

level of qualification in dementia care, their interest in caring for persons with dementia, and how often they were on duty (I and III). All are factors that previously have been highlighted as important for high quality of care (Larsson, Hedelin, & Athlin, 2007). To be bodily present was important, as this made it possible for the personnel to see the residents, to be seen by them, and to adjust participation to the very moment (I). Obstacles to this included shortage of personnel and inappropriate architecture (I and III). However, it was notable that the personnel's presence in mind (knowledge and competence) and morality (fully present, including presence in body and mind and based on humanistic values) seemed to be more important for correct adjustment and quality of care than the number of personnel on duty (I and III). Many nurses on duty could even hinder adjustment to an adequate level of patient participation, as the nurses seemed to be more eager to talk to each other than to the residents, who were disregarded (I). There is reason to believe that being disregarded is worse than not being physically seen, as it threatens dignity (Kitwood, 1997; Nåden, Rehnsfeldt, Råholm, Lindwall, Caspari, Aasgaard, et al., 2013).

Important factors for patient participation were 'continuity of care' and 'knowing the person' which are closely related, and highlighted as essential factors in individualised care (Adams, 2008; Edvardsson, et al., 2008; Kitwood, 1997; Woods, et al., 2008). Findings indicated that force used apparently without reflection was more often used by unskilled nurses who were seldom on duty than by others (III). This concurs with a recent study describing an explicit relationship between coercion and frequent use of temporary and inexperienced nursing personnel at weekends. These were less familiar with the residents and the ordinary practice. The fact that persons with dementia often become anxious and restless when meeting unknown people (Gjerberg, Førde, & Bjørndal, 2011) may trig the use of force. Findings in recent studies from nursing homes (Castle & Anderson, 2011; Havig, Skogstad, Kjekshus, & Romoren, 2011; Spilsbury, Hewitt, Stirk, & Bowman, 2011) have confirmed the importance of sufficient qualified staff for providing care of good quality, which also has been highlighted in this thesis (I-III). As nursing homes in general (Harrington, Choiniere, Goldmann, Jacobsen, Lloyd, McGregor, et al., 2012) are facing great challenges relating to a serious lack of personnel with formal health educations and difficulties in recruitment of qualified personnel, these findings are of great importance. This is a challenge in Norwegian nursing homes as well (Brevik, 2003; Gjerberg, et al., 2011), and a recent study reported that almost half of the personnel working at weekends were unskilled (Harrington, et al., 2012). Considering this in the light of the discussion above, it is remarkable that nothing is defined in the criteria for SCUs regarding requirement of competence and number of nursing personnel.

The qualifications of leaders of SCUs were also found to be an important factor for patient participation (I and III). Findings showed the necessity of the leaders as good role

models, since their attitudes defined a frame of reference for the care culture in the SCU (I). The nurse leaders' way of exercising their leadership was found to be important for the personnel's ability and wish to facilitate participation for the residents and their relatives. Routines and organization of the care impacted also on the occurrence and extent of patient participation (I). The great importance of highly competent leaders in elderly care has been described previously (Dwyer, 2011; Nolan, Davies, Brown, Wilkinson, Warnes, McKee, et al., 2008). A recent study concluded that leaders in nursing homes should use a 'task oriented' leadership with a focus on structure, coordination, clarifying of staff roles, and monitoring of care to increase quality of care (Havig, et al., 2011). This seems to correspond with the findings in this thesis (I and III) in which clear directives and expectations from the leaders were found to stimulate a high level of presence on the part of the personnel. However, the personnel (I and III) also needed a 'relationship-oriented' leadership (Havig, et al., 2011), with a focus on support and appreciation, and development of skills. As nurses' qualifications were found to be the most important issue for adequate level of patient participation in SCUs, the nurse leaders should be involved in the recruitment of personnel, to ensure that nurses with adequate qualifications are employed (Doyle, 2011). In addition, continuous clinical supervision to the personnel (Chenoweth, Jeon, Merlyn, & Brodaty, 2010; Hyrkäs, Appelqvist-Schmidlechner, & Haataja, 2006) with a focus on patient participation in dementia care could be of great value.

Can relatives and their participation be a link in the patient participation process in SCUs?

In this thesis, relatives were included, as they have previously been found to be of great importance in dementia care (Adams & Gardiner, 2005; Nolan, 2003; Woods, et al., 2008) and also in the patient participation process in general (Jewell, 1994; Patients Rights Act, 1999; Sahlberg-Blom, et al., 2000) The findings showed that the relatives (II-IV) really could be a link in the patient participation process as they through knowing the resident's life-history and preferences could share important information in writing and verbally with the personnel. This kind of information could be a valuable basis for individualised care when correctly used (Adams & Gardiner, 2005; Nolan, 2003; Woods, et al., 2008). However, about 30% of the relatives had not been requested to provide written information about their near one, which shows that there is room for improvement in this issue (IV).

Striking was the finding that the most important goal for relatives' participation in the care was to secure the resident's wellbeing and dignity, not to improve patient participation (II). In order to reach this goal, a majority of relatives visited the residents

weekly and acted as their spokesperson but, despite this, most of them reported that they seldom participated in decisions concerning everyday care, and they did not wish to increase this participation (IV). These rather contradictory findings can be interpreted as a result of their satisfaction with the care provided. Most relatives had a positive view of the personnel's skills and perceived that they showed respect to and spent time with the residents, and that both the resident's and their own points of view were taken into consideration in the care (IV). This may be understood as that the personnel's decisions in the everyday care were good enough, so there was no need for relatives' extended participation. However, despite this, their own participation in the care was stressed as crucial for the resident's wellbeing (II and IV). This concurs with studies describing relatives' potential for providing important extra facets to the care due to their biographical expertise, intimate knowledge about and emotional bond with the resident. According to these studies, relatives may improve their family member's opportunity to feel connected, appreciated, loved and known as a person by visiting them (Carr, Hicks-Moore, & Montgomery, 2011; Gaugler, 2005; Graneheim, Johansson, & Lindgren, 2013; Ryan & Scullion, 2000). This part of the relatives' role in dementia care should be encouraged and supported by the personnel, as it can make a difference to the everyday life of persons with dementia and contribute to their quality of life.

The relatives' perception that their participation was crucial for the resident's wellbeing can also be understood in the light of the finding that all relatives took on the guardian role, when they perceived that the resident's comfort and dignity were threatened (II and IV). This concurs with research reporting that relatives kept an eye on the care (Davies & Nolan, 2006; Gaugler, 2005; Graneheim, et al., 2013) in order to safeguard its quality. About 70% of relatives in our study also sometimes took on the role of being a link to the outside world (IV). In the interview study (II), relatives ensured that their near-ones thereby got the opportunity to catch a glimpse of ordinary life, according to their own preferences. Social activities have been found to often be given low priority in dementia care, despite repeatedly being highlighted as important for the quality of life of persons with dementia (Andersen, 2011; Bourret, Bernick, Cott, & Kontos, 2002). A recent study showed that the majority of care-home residents with dementia spent most of their time engaged in no activity at all, and they were 'bored to death' (Boyd, Payne, Hutcheson, & Bell, 2012), which illustrates the importance of relatives' participation also in this issue.

A possible explanation of many relatives' unwillingness to take part in decisions about everyday care activities might be that many of these decisions concern issues of a private nature, such as personal hygiene, what to eat and drink and what time to get up or go to bed. It is reasonable to believe that relatives kept a distance from these private issues as a way of showing respect for the resident (II). This concurs with Johansson (2010) who suggested that relatives' participation in everyday care even might insult the resident's

integrity. Additionally, previous studies have reported that relatives' values, opinions and preferences do not always correspond to the thoughts of the person with dementia on this matter (Carpenter, Lee, Ruckdeschel, Van Haitsma, & Feldman, 2006; Reamy, Kim, Zarit, & Whitlatch, 2011). Therefore, it is important to stress that personnel, in their interaction/collaboration with relatives, should carefully watch whose preferences are in focus, the resident's or the relatives'.

Quite alarming findings were that the frequency of relatives' visits and their participation in the care seemed to decline along with the progression of the dementia (II), and that about one-third of the relatives reported the resident's ability to recognise them as crucial for their participation (IV). These findings suggest that persons with severe dementia are at risk of losing the relative as their spokesperson in the participation process when those are most needed. A majority of the relatives in the survey were females. Those were also more active as the resident's spokesperson than males (IV). This is in line with results showing that wives and daughters also are the most common informal caregivers (Georges, Jansen, Jacksen, Meyrieux, Sadowska, & Selmes, 2008; Jansson, Almberg, Grafström, & Winblad, 1998; Söderlund, 2004). Spouses were more emotionally attached, and perceived their own participation as more important for the resident's wellbeing than children. They also reported that being recognized by the resident was more important for their participation, than children did (IV). It was also striking that spouses reported it more difficult to criticise the care and more important to be well-liked by personnel than children did (IV). These findings together indicate that spouses may be vulnerable relatives, which also has been suggested in earlier research (Etters, Goodall, & Harrison, 2008; Pinquart & Sörensen, 2011). This may also mean that they are a fragile link in the patient participation process, and need special attention and support from the personnel in order to find meaning in their participation, and stay involved in their husband's or wife's life (Hellström, Nolan, & Lundh, 2007; Shim, Barroso, & Davis, 2012).

Contradictory findings were gained in this thesis (II and IV) concerning relatives' experience of burden in regard to their participation. Our findings from the survey (IV) showed that relatives seldom experienced participation as a burden. This contrasts with many previous studies emphasising the high burden of being a relative of a person with dementia (Black & Almeida, 2001; Etters, et al., 2008; Matsumoto, et al., 2007; Ulstein, et al., 2007). However, findings from the interview study (II) were more in line with these studies, elucidating that participation in the care, e.g. the visits, could be rather demanding as the progression of the disease could be hard to deal with (II), and it could be hard to take on the guardian role (II) and criticise the care (II and IV). A possible explanation for the contrast between the survey (IV) and the interview study (II) might depend on how data collection was carried out. In the interview study (II), a deep and broad understanding (Polit & Beck, 2012; Strauss & Corbin, 1998) of relatives' experienced

burden, not explicitly connected to their burden of participation in the care, was gained. Hence, the question about relatives' experiences of burden specifically related to partaking in decisions on behalf of a near one with dementia needs to be further studied.

This thesis elucidates that how and when relatives should be invited to assist in decision-making together with and on behalf of the person with dementia, and on what issues, are very delicate questions, which can only be handled adequately at an individual level. A good collaboration between the nursing personnel and the relatives, built on continuity and trust (Caron, Griffith, & Arcand, 2005) and with the resident's interests in focus is suggested to be the best condition for a proper involvement of relatives in the patient participation process in SCUs. However, it has to be stressed that the quality of care provided to persons with dementia in SCUs first of all is a responsibility of the nursing personnel and their leaders, and relatives' participation should not be decisive. If this was the case, what would the situation be for residents without near relatives? Nevertheless, since relatives are found to have an important role in the patient participation process in order to secure the wellbeing and dignity of the resident, it is important to motivate them to continue visiting the residents and interacting with the nursing personnel.

Methodological considerations

In this thesis, qualitative and quantitative methods have been combined by means of method triangulation. Qualitative methods have the potential to describe the nature of a phenomenon and the emphasis is on deep understanding of human experiences. Quantitative methods, on the other hand, are suitable when the intention is to obtain a representative overview and an understanding in a broad sense. By using both approaches (Polit & Beck, 2012) it was possible to describe a multifaceted view of patient participation in everyday life in special care units for persons with dementia.

The qualitative approach in this thesis served well to explore and describe patient participation in everyday life in the SCUs context (I), the relatives' role (II) and the personnel's experiences (III). By performing qualitative studies (I-III) it was possible to gain a deep and broad understanding of patient participation in the SCUs. This was used (I and II) as basis for the development of the questionnaire for the quantitative study (IV). The findings from each of the studies in this thesis have been brought together and interpreted as a wholeness. However, it should be noted that this research is not finished. In order to secure depth and breadth in the wholeness (Corbin & Strauss, 2008) and to more fully understand 'Patient participation in everyday life in special care units of persons with dementia', more research is needed.

The qualitative studies

Efforts have been made to establish an audit trail throughout the studies and to be transparent in the method descriptions (I-III) (Strauss & Corbin, 1998). However, some more considerations need to be addressed to evaluate their strengths and weakness. One consideration concerned credibility - which refers to the truth of the data and their interpretation. Data in study I was collected by means of observations and conversations. Observations have their potential drawbacks, as the researcher may give meaning to the observations (Corbin & Strauss, 2008) and the researcher may have an impact on the participant's behaviour (Polit & Beck, 2012). To ensure credibility (Lincoln & Guba, 1985) of the data, the interpretations of the observations were checked out in conversations with the residents and the personnel. It seemed that the researcher's presence soon almost was forgotten by the participants. To strengthen the credibility of the data in studies II and III, all informants were interviewed twice (Benner, 1994).

The fact of doing research in SCUs and with persons with dementia was seen as challenging when planning this study. However, it was considered as right to meet the challenges, as the alternative of interviewing only relatives of persons with dementia and/or personnel was considered to be ethically worrying. The idea was that the best foundation of the study as a whole was observations and conversations with the main actors themselves - persons with dementia in interaction with personnel. Most residents were met twice in conversations; the data from the first conversation was repeated in the second conversation, which strengthens its credibility.

Another consideration concerned confirmability, which refers to objectivity. At the beginning of the project, the literature review was restricted to ensure that it did not block creativity, but was sufficient to enhance sensitivity to subtle nuances in the data collected (Strauss & Corbin, 1998). Long experience of working in SCUs for persons with dementia and education in dementia care were considered to be helpful and positive prerequisites in the meeting with the participant (Hellström, Nolan, Nordenfelt, & Lundh, 2007). However this experience and possible pre-understanding of the topic had to be taken into account, as these may have affected the research process. To bridle the pre-understandings (Dahlberg & Dahlberg, 2004), critical reflections and discussions within the research team about 'whose glasses are on' were made during the entire research process. Efforts have been made to be aware of the pre-understandings and not use them as data per se, but as a comparative case to stimulate thinking about various properties and dimensions of concepts (Corbin & Strauss, 2008).

The third consideration concerned transferability, which refers to whether the findings can be transferred to other groups or contexts. Descriptions of the informants, data

collection and analyses have been accounted for in the articles (I-III). By making efforts to be transparent in the logical reasoning, other researchers may evaluate the applicability of the data by themselves.

The sampling process was considered to be sufficient in each of the studies when the major categories showed depth and variation and the relationship to the other categories was clear. The researcher is however aware that total saturation might never occur (Corbin & Strauss, 2008).

The quantitative study

Some considerations need to be addressed to evaluate the validity and reliability of the quantitative study. Concerning the external validity of the study, the selection of municipalities was random in order to avoid selection bias (Polit & Beck, 2012). The head nurses at the SCUs recruited the respondents and judged whether the relatives should be asked to participate or not. This means that relatives may have been assessed as satisfying the inclusion criteria by some head nurses and not by others. This potential inconsistency may constitute a threat to external validity (Polit & Beck, 2012). The response rate of 67% was regarded as fairly good (Polit & Beck, 2012; Streiner & Norman, 2008). Analysis of the non-responding respondents is recommended (Polit & Beck, 2012). The intention of comparing characteristics of the non-responding relatives with the participants failed in this study, as only data from 44 of the 115 non-responding relatives were recorded. However, given that the response rate in this study is considered to be fairly good, the risk of bias due to the loss of subjects may be considered as low (Polit & Beck, 2012; Streiner & Norman, 2008).

Regarding the questionnaire, efforts were made to strengthen its validity. However, some weaknesses of the questionnaire were revealed when scrutinising the studies as a wholeness. Some questions were vague and might have been interpreted in different ways, which may explain some contradictory findings such as e.g. relatives' experience of participation as a burden.

Conclusions and implications for practice

- The most important goal in dementia care in SCUs is not a high level of patient participation, but preserved wellbeing and dignity for the residents. This may sometimes mean a low level of participation or even that decisions are taken against the resident's momentary wish.
- In order to enhance wellbeing and dignity, the level of participation must be adjusted to the very moment.
- Patient participation seemed to be a losing principle in the SCUs as the level of participation was often primarily adjusted to suit the personnel's ideas about how to carry out the daily care in the SCU context.
- The political, judicial and ethical foundations of patient participation were not systematically implemented in the reality of practice. This does not mean that the care provided was poor, but it indicates that the care has potential to be better.
- Patient participation in SCUs for persons with dementia places heavy demands on the personnel, as the resident's ability and wishes become more and more difficult to understand due to the progressive symptoms. More efforts should be made to support the personnel, so they better can meet these demands.
- The SCUs need fully competent leaders who are able to build a care culture where patient participation is an important element.
- Relatives are an important link in the patient participation process as they can impart information about the resident's preferences, habits and wants to the personnel. This is crucial for the personnel in order to provide individualised care in line with all aspects of patient participation. More efforts should be made to improve the information exchange and collaboration between relatives and personnel.
- Relatives are also an important link in the patient participation process when they participate by visiting their near one. Due to their biographical expertise, intimate knowledge about and emotional bond with the resident, they are capable of making a difference to the resident's everyday life and ensure quality of care.

- Along with the progression of the disease persons with dementia are in risk for being excluded from the participation process.

Future research

- The connection between patient participation, and wellbeing and dignity in persons with dementia need to be further explored to get a deeper understanding of the complexity.
- In order to implement the political, judicial and ethical fundamentals of patient participation in the reality of practice intervention studies should be performed.
- The leadership's and the care culture's impact on patient participation need to be further explored.
- Relatives' role in the patient participation process, especially the meaning of being a spokesperson and the experience of burden, should be further explored.
- The information exchange between residents, relatives and personnel and its impact on patient participation need to be further explored.
- It would be valuable to further develop and test the survey questionnaire in different population in order to strengthen its reliability.

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Patient participation in everyday life in special care units for persons with dementia

In Norway and many other western countries, patient participation in health care is a political idea, a legal right and an ethical issue in nursing. Since persons with dementia are heavy consumers of health services and the prevalence of persons with dementia has increased both nationally and internationally, nursing personnel will face several challenges in the future when providing dementia care. One concerns patient participation. This thesis used Grounded Theory and a survey study to acquire knowledge about patient participation in everyday life of persons with dementia living in SCUs in nursing homes. The most important goal was found to be wellbeing and dignity in everyday life, not a high level of patient participation per se. The level of participation had to be adjusted to the very moment as the resident's ability and wish were unpredictable. However, the level of participation was often primarily adjusted to suit the personnel's ideas about how to carry out daily care in the SCU context. Findings confirmed that relatives could enhance quality of care by actively partaking in the participation process. Therefore, it is imperative that nursing personnel promote relatives' involvement in dementia care, as this can enhance patient participation.

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