

# Patient participation in transitional care of older patients

Doctoral Thesis by

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I dedicate this thesis, with deep respect and dignity in memory of my  
parents and to my parents-in-law.

Thank you for having been such valuable role models, I feel grateful  
and blessed!

“I have a dream that one day this nation will rise up and live out the  
true meaning of its creed: We hold these truths to be self-evident, that  
all men are created equal”.

Martin Luther King

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## Summary

**Background:** Older patients often have several health challenges, with multiple medications, which leads to a need of treatment and care from diverse healthcare services. These patients are often in need of transitions from different levels of care, specifically during hospital admission and discharge. Patient participation is highlighted and stated in patients' rights and healthcare directives, with patients being informed and involved in all treatment and care processes. Nevertheless, literature reveals a lack of patient participation, with minimal information in transitional care.

**Aims:** The overall aims of this thesis were 1) to give an overview of the research literature on older patients' participation in transitional care, 2) to explore older patients' perspectives on participation during hospital admission and discharge, 3) to explore healthcare professionals' perspectives on patient participation and identify factors influencing older patients' participation during hospital admission, and 4) to conduct and describe interprofessional simulation to improve competencies about patient participation in transitional care.

**Methods:** The study comprises several qualitative methods, applied in four partial studies. First, a literature review was written involving 30 studies, 15 exploring older patients' participation in transitional care and 15 studies on experiences with tools to support patient participation. In 2012, 41 older patients were included in participant observations, 21 in hospital admission and 20 in hospital discharge. Further, 27 personal interviews with different healthcare professionals (ambulance workers, nurses, doctors) were conducted. In November 2013, interprofessional simulation was carried out.

**Results:** Paper 1 reveals variable information and patient participation among older patients during hospital discharge in the literature review. Results show that older patients often were excluded and not participating in discussions about discharge. When present, they often felt they were not being seen or heard by healthcare professionals, and a paternalistic approach was revealed. Several tools to support patient participation in transitional care have been implemented, with variable results. Most successful were family meetings, checklists and education programs.



Paper 2 identifies variable degrees of information exchange between healthcare professionals and patients, and a lack of involvement of the patient in decision-making were observed and experienced by the patients. Next of kin appeared to be important advocates for the patients in admission and provided practical support both during hospital admission and discharge. Data suggests that patient participation in admission and discharge is influenced by time constraints and heavy workloads of healthcare professionals. Patients' health conditions also influenced participation.

Paper 3 shows the interviews with healthcare professionals, wherein it was found that patient participation in hospital admissions was influenced by five main factors: routine treatment and care during hospital admission, particularly procedures like medical examinations; the frail and thankful older patients, with the compound picture of their medical needs; hospital resources, such as available staff and beds; healthcare professionals' attitude towards patients' experiences; and the presence of a supportive and demanding next of kin, acting as an advocate for the patient.

Paper 4 describes interprofessional simulation focusing patient participation of older patients in transitional care. Healthcare professionals from one hospital and one municipality participated in the simulation, with a film scenario, which was based on findings from the observational study. Results show that healthcare professionals did not have any common arenas to meet and discuss work issues and specific or general challenges related to transitions. The film scenario emotionally affected several participants, revealing a lack of information and lack of care, with decisions taken by healthcare professionals. Log reports show that all participants were concerned to provide sufficient information to patients and next of kin and vice versa, as well as involving the patient in treatment, care and discharge planning. Several suggestions came up and the follow-up meetings showed that some wards had continued their work to improve the quality of transitional care.



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## **Part I**





# **1 Introduction**

Research shows that older people with multiple diseases and medication regimes have complex care needs and often experience transitional care as they transfer between community and hospital healthcare services (Coleman et al., 2004). These patients are a vulnerable group during transitional care (e.g., hospital admission and discharge) due to illness, physical disabilities, confusion, poly-pharmacy or deterioration of health (Foss & Askautrud, 2010; Griffiths, Morphet, Innes, Crawford & Williams, 2014). Being transferred across different healthcare settings increases the risks for fragmented care and patient participation is suggested as one useful approach (Coleman et al., 2004; Laugaland, Aase, & Barach, 2011). Necessary elements for patient participation in transitional care includes information from healthcare professionals to the patient about what to expect at the next care site and opportunities for involvement in decision-making and acknowledgment of the patients' values and preferences for follow-up care (Coleman & Boulton, 2003). Variation in how patient participation is managed and experienced by older patients and their caregivers is reported (Almborg, Ulander, Thulin & Berg, 2008; Benten & Spalding, 2008; Coleman & Boulton, 2003; Flink et al., 2012; Foss & Hofoss, 2011; Perry, Hudson, & Ardis, 2011; Roberts, 2002; Stephens et al., 2013). A study on transitional care of re-hospitalized older patients revealed several challenges, both from the patients' perspective and healthcare professionals' perspective (Stephens et al., 2013).

## **1.1 Key concepts in the thesis**

A patient is a person in need of medical help from healthcare services (Norwegian Ministry of Health and Care Services, 2001, § 1-3 a). Patients are entitled to receive relevant healthcare information and to participate in decisions about their treatment and care. Patient participation is defined by the WHO (2011) as the patient's right to participate in decision-making concerning relevant health- and treatment-related decisions, such as level of care and where to live. Patient participation involves sharing of information, power transfer from healthcare professionals to patient, intellectual and/or physical activities and the benefits of these activities (Cahill, 1996). Patient participation is a

matter of cooperation between patient and provider. Patient-centered care and shared decision-making incorporate patient participation and the patients' experiences with care. Patient-centered care involves healthcare professionals' responsiveness to the individual patient's needs and preferences, as well as patient involvement in care and decision-making (Norwegian Directorate of Health., 2005; Institute of Medicine, 2001).

Older patients are often in need of medical treatment and care because of several diagnoses and a compound medical picture, often with multiple chronic conditions (Aase, Laugaland, Dyrstad & Storm, 2013; Bernabeu-Wittle, Ollero-Baturone, Nieto-Martin & Garcia-Morillo, 2013; Coleman & Boulton, 2003). Together with complex health problems, many have reduced mental capacity and they are in need of several transitions and transitional care, moving within and across different healthcare settings (Coleman & Boulton, 2003).

Transitional care is defined as a set of actions ensuring the coordination and continuity of healthcare as patients transfer between different levels of care within the same location or between locations; i.e., hospital admission and discharge (Coleman & Bolt, 2003). Hospital admission in this study means admission of older patients from a nursing home or their home with home-based care services to a hospital. Hospital discharge means the discharge of older patients from specialist healthcare (hospital) to a nursing home or their home with home-based care services (Aase et al., 2013). Many care transitions are unplanned and patients and their next of kin are unprepared. In addition, inadequate discharge planning often leads to readmission (Huber & McClelland, 2003). The patients and their caregivers are most often the only common and stable factor moving across different levels and sites of care (Coleman & Berenson, 2004).

## ***1.2 Patient participation in transitional care***

Patient participation can start at hospital admission and continue until discharge (Saunders, 1995, p. 42). For patients to participate in transitional care they need sufficient information about their illness(es) and the possible course of the illness(es), care rehabilitation, participation in discussions about medical treatment, goals and needs for care, services and the rehabilitation process (Almborg et al., 2008). The research literature reveals challenges to patient

participation in transitional care relating to informing patients and the next of kin for upcoming transitions (Fröjd, Swenne, Rubertsson, Gunningberg & Wadensten, 2011; Storm, Siemsen, Laugaland, Dyrstad & Aase, 2014). Regarding hospital admission, Fröid et al. (2012) found that patients admitted in emergency situations receive little information about the results of their medical treatment and care.

Stephens et al. (2013) reported that older patients had difficulties recalling their care plans and their current medications, resulting in lack of control or ownership of their own care. Laugaland, Aase and Waring (2014) reported in their observational study that older patients often experienced unexpected discharges with minimal information about and involvement in the discharge planning process. Flink et al. (2012) reported a gap between the information patients received and what they actually needed, specifically concerning medication information. This resulted in exclusion of patients from active participation in follow-up, as they were discharged without a new and updated medication list and insufficient information on how to handle it. Foss and Hofoss (2011) reported that older patients experienced receiving minimal information, they perceived little possibility of speaking with healthcare personnel, telling their views and, to a limited degree, participating in shared decisions. A large-scale survey on patient experiences of somatic inpatients in Norwegian hospitals (Norwegian Knowledge Centre, 2014) reports that patients experienced insufficient information in discharge and long waiting time prior to the hospital stay. Minimal coordination among caregivers between specialist care and municipality care was found. The Norwegian Board of Health Supervision (2016) conducted a survey on hospital discharge to municipality healthcare services. The survey revealed that several patients got minimal or no information about treatment given at the hospital and procedures during the discharge day.

Several studies show that patient participation depends on healthcare professionals' knowledge, skills, attitudes and work practices (Angel & Frederiksen, 2015; Frank, Asp, & Dahlberg, 2009; Stephens et al., 2013). Stephens et al. (2013) found in their study that patients were discharged too early due to physical symptoms that were not fully addressed and poor communication between care providers. Both situations contribute to patients' readmission. Several studies on healthcare professionals report that some are

aware of involving patients in decisions concerning their treatment and care, while others lack such competencies (Almborg et al., 2008; Benten & Spalding, 2008; Flink et al., 2012; Foss & Hofoss, 2011; Storm et al., 2014a). It can be challenging for healthcare professionals to focus on the individual patient's preferences and views when older patients in the emergency department (ED) have a complex medical history and multiple medications (Crouch, 2012). In particular, healthcare professionals can easily focus on medical problems and not patients' individual preferences and opinions during hospital admission, with time pressure and a strong emphasis on clinical efficiency (Flink et al., 2012; Nyström, Dahlberg, & Carlsson, 2003).

Angel and Frederiksen (2015) indicate that nurses are gatekeepers in relation to the patient's participation, specifically because they can enhance patient participation or hinder it, depending on their attitudes about participation. Not spending enough time talking with their patients is another barrier for participation. A negative climate for communication between healthcare professionals and patients and being too busy to communicate with the patients can lead to neglect of patient needs (Flink et al., 2012). A study of medical encounters (Zandbelt et al., 2007), shows that patient participation is enhanced when doctors show facilitating behavior, such as verbal and non-verbal encouragements and the doctor's summary of what the patient said.

Studies illuminate the importance of having next of kin present in hospital admission and discharge, as they receive and give information about the patient's illness and health condition (Bull & Roberts, 2001; Coleman & Boulton, 2003; Laugaland, Aase, & Barach, 2012; Storm et al., 2014a). Coleman and Boulton (2003) emphasize that patients and their next of kin must be prepared to receive care in the next setting and be actively involved in decisions related to the transitional care plan. Information about how to recognize warning symptoms indicating a worsened condition, how to contact healthcare professionals and how to seek care in the new setting are all important. The observational study by Storm et al. (2014a) revealed that next of kin play important roles in hospital admission and discharge. They provide important information about the patient's health conditions, advocate for proper health services and support the patient with self-care. But they need to be sure to request information about the patient's health condition, medication and follow-up care from healthcare professionals.

Studies of transitional care across levels of care have primarily been concerned with hospital discharge, as compared to hospital admission (Richardson, Casey, & Hider, 2007). It has been asserted that to develop patient-centered care in transitions, it is necessary to better understand the experiences of patients during both the hospital admission and discharge processes.

### ***1.3 Interprofessional simulation training to improve patient participation***

To enhance patient participation in transitional care, education and training of healthcare professionals has been suggested (Coulter, 2011; Gordon & Findley, 2011; Institute of Medicine, 2001; Laugaland et al., 2012; Philibert & Barach, 2012; Stoyanov, Boshuizen, & Groene, 2012; Norwegian Directorate of health, 2005).

According to Coulter (2011), training of healthcare professionals is a key to improving patient participation. She holds that healthcare professionals must learn how to interact with and care for patients. ‘Patients want clinicians who can empathize and understand what it means to be ill, who listen to them and respect their concerns and preferences, who inform and involve them and support their efforts in self-care’ (p. 143). Further, patients want more responsive and better integrated health systems that provide effective, equitable and coordinated care. To deal with these challenges in healthcare, professional training programs are suggested for clinicians to learn how people experience disease and treatment, how to communicate clearly and effectively with patients and how to support them through illness and recovery (Coulter, 2011; Wallin & Thor, 2008).

To improve collaborative work practices, simulation training and learning are considered useful approaches to achieving a competent healthcare team (Cooper et al., 2011; Husebø, Rystedt, & Friberg, 2011; Missen, Sparkes, Porter, Cooper & McConnell-Henry, 2013; Pfaff, 2014). Dieckmann (2009) has developed a team-oriented simulation model including a facilitator introducing the course, theory input, briefing before and debriefing after the scenario, ending with a summary. Participants then apply what they have learned to their own clinical work. Conducting simulation scenarios on patient participation in

hospital admission or discharge might be suggested in terms of increasing healthcare professionals' competence and awareness of patient participation in transitional care.

Using simulations in training for interprofessional collaboration is suggested to engage clinicians from different organizational cultures (Jeffries, 2012, p. 27). In order to achieve successful simulation, Jeffries (2012) identified five characteristics: clear objectives, fidelity, problem solving, participant support and reflective thinking (debriefing). The use of simulation training seems to be useful, giving increased competence, according to some systematic reviews from healthcare education (Cook et al., 2011; O'Regan, Molloy, Watterson & Nestel, 2016; Okuda et al., 2009). The review of Cook et al. (2011) with technology-enhanced simulation training in health professions education found large effects on outcomes of knowledge, skills and behaviors. In O'Regan et al.'s (2016) review, the observer role in simulations was reviewed. Five out of nine studies suggested that the observer role gives the same or better learning outcomes than hands-on roles in simulations. Tools such as checklists, feedback using an observation guide or observer role instructional briefings were used by the observer groups. All studies, except one, included the observers in the post-simulation debrief.

#### **1.4 The Norwegian healthcare system**

The Norwegian healthcare system is organized in two levels: primary care and specialized (secondary) care. Primary care involves home care services and nursing homes. Specialized secondary care consists of state-owned hospitals, which are organized in four regional health authorities (Ringard, Sagan, Sperre & Lindahl, 2013).

The Patient Rights Act was established in Norway in 1999 and was implemented in 2001 (Norwegian Ministry of Health and Care Services, 2001). It states that patients should be informed about and involved in options of treatment, and decisions of treatment and care level (§3-1). This involves the patients' right to necessary healthcare, to get adjusted information concerning their rights, treatment alternatives, approval or denial of treatment, as well as the right to participate in treatment decisions. The patient, therefore, should be involved in accomplishing healthcare services. What kind of involvement

practiced, must be adjusted to the patient's ability to give and receive information, as well as participate in decision-making.

In the same way as patients are given rights, healthcare professionals are obliged to include users and patients in healthcare decisions through the Norwegian Health Personnel Law (Norwegian Ministry of Health and Care Services, 2001). This implies that service providers must establish systems for systematic quality improvement and patient and user safety, both in specialist healthcare and in municipality.

Political documents in Norway (Norwegian Directorate for Health and Social Affairs, 2005; Norwegian Ministry of Health and Care Services, 2001, 2009) emphasize patient role and patient participation in transitional care. The Norwegian Coordination Reform (Norwegian Ministry of Health and Care Services, 2009, p. 24) focuses on the user or patient's needs for coordinated services, encouraging a clearer role for the patients in transitional care. The reform requires municipalities to ensure that patients with needs for coordinated services are assigned one contact person as a contact point for all services.

From a health policy perspective, strengthening the patients' role is emphasized in Norway by giving patient-centered care and enhancing patient participation (Norwegian Directorate for Health and Social Affairs, 2005; Norwegian Ministry of Health and Care Services, 2001, 2009). In common with the Institute of Medicine (2001), healthcare quality is stated in the Norwegian healthcare system (Deilkås, Ingebrigtsen, & Ringård, 2015). Healthcare quality is characterized as the overarching umbrella consisting of six specific aims for improvement in healthcare. To ensure high healthcare quality, treatment and care is stated to be effective, safe, patient-centered, coordinated, resource effective and accessible (Deilkås et al., 2015; Norwegian Directorate for Health and Social Affairs, 2005).

## **1.5 The research project ‘Quality and safety in Transitional Care of the Elderly’**

This study is part of a larger research project: ‘Quality and Safety in Transitional Care of the Elderly’ (2011-2015), which aimed to explore different aspects of transitional care of older patients in different contexts (Aase et al., 2013). The overall aims of the larger study were to:

1. Explore different aspects of transitional care of the elderly (e.g., coordination, multi-professional collaboration, patient participation) in different contexts (e.g., admission or discharge, densely or sparsely populated geographical areas) and how they might explain the quality and safety of care (phase 1).
2. Design and test an evidence-based intervention programme to assess the impact of transitional care on quality and safety and to implement improvements within the transitional care of the elderly (phase 2).

In phase 2, a cross-level educational programme called ‘The Meeting Point’ was conducted to improve quality and safety in transitional care of older patients (Storm et al., 2014b). ‘The Meeting Point’ participants were healthcare professionals from hospital and municipality healthcare services who met for half-day seminars. ‘The Meeting Point’ consisted of an educational section and a discussion platform. Three thematic areas relating to quality and safety in transitional care were addressed: (1) risk factors, (2) patient perspectives and (3) system perspectives. Qualitative data from the three ‘Meeting Point’ seminars using interprofessional simulations to focus the patient perspectives and participation, and four follow-up meetings are included in this PhD study.

The research team in the larger project consisted of a project leader, two PhD students, a post-doctoral candidate and six master students. The collaborating partners involved in the project have been the University of Stavanger (project owner); a regional center for age-related medicine, two health trusts; the Norwegian Research Council; and an international expert advisory board with members from Denmark and England. This PhD study is funded by the Norwegian Research Council (grant no. 2011/1978) and the University of Stavanger (Aase et al., 2013).



## **1.6 Aims and research questions**

The overall aim of this PhD study is to explore participation of older patients in transitional care from the patients' and healthcare professionals' perspectives, and to develop and conduct interprofessional simulations to improve patient participation in transitional care. The thesis aims and research questions are presented below.

### **Aims of the thesis**

1. To give an overview of the research literature on older patients' participation in transitional care (paper 1).
2. To explore older patients' perspectives on participation during hospital admission and discharge (paper 2).
3. To explore healthcare professionals' perspectives on patient participation and identify factors influencing older patients' participation during hospital admission (papers 2, 3 and 4).
4. To conduct and describe interprofessional simulations to improve competencies about patient participation in transitional care (paper 4).

### **Research questions of the thesis**

- a) What are the key issues reported in the literature that influence older patients' participation in transitional care? (paper 1)
- b) What are the experiences of older patients and their next of kin with participation in hospital admission and discharge? (paper 2)
- c) How do healthcare professionals practice participation of older patients during hospital admission and discharge? (papers 2, 3, 4)
- d) What are healthcare professionals' perspectives on patient participation in hospital admission? (papers 3, 4)
- e) How can interprofessional simulations increase healthcare professionals' awareness of and competencies about patient participation in transitional care of older patients? (paper 4)

## **1.7 Structure of the thesis**

This PhD thesis is divided into two main parts: part 1 and part 2. Part 1 consists of six chapters, with chapter 1 providing the introduction to the thesis, explaining key concepts, then introducing the main focus in the thesis, which is patient participation in transitional care of older patients. Chapter 2 presents the theoretical framework, including patient-centered care and patient participation. Then follows the methodological approach in chapter 3, including study context, study design, analysis, ethical aspects and research quality. In chapter 4, the main results from the four research articles are summarized. In chapter 5, the results from the four papers are discussed in relation to patient participation from the patients' and the healthcare professionals' perspectives, as well as measures, methodological issues, and implications of the study, and with conclusions in chapter 6. In part 2, the following four papers, on which this thesis is based, are presented:

1. Dyrstad, D. N., Testad, I., Aase, K. & Storm, M. (2015a). A review of the literature on patient participation in transitions of the elderly. *Cogn Tech Work*. Springer. 17:1, 15–34. Doi:10.1007/s10111-014-0300-4
2. Dyrstad, D. N., Laugaland, K. L. & Storm, M. (2015b). An observational study of older patients' participation in hospital admission and discharge. *Journal of Clinical Nursing*. 24, 1693–1706. Doi:10.1111/jocn.12773
3. Dyrstad, D. N., Testad, I. & Storm, M. (2015c). Older patients' participation in hospital admission, through the emergency department: an interview study of healthcare professionals. *BMC Health Services Research*. 15:475. Doi:10.1186/s12913-015-1136-1
4. Dyrstad, D. N. & Storm, M. (2016). Interprofessional simulation to improve patient participation in transitional care. *Scandinavian Journal of Caring Sciences*. Online 21 Jul. Doi:10.1111/scs.12341

## **2 Theory**

This chapter presents an overview of theoretical perspectives useful to understanding patient participation in transitional care of older patients. First, the traditional relationship between patient and healthcare professionals is briefly explained. Then, patient-centered care is described as a theoretical perspective, followed by a presentation of models illustrating patient participation, which is the main concept in this thesis.

### **2.1 *The patient role***

To understand the relationship between healthcare professionals and patients, we can look to the traditional model, which is the paternalistic approach (Coulter, 1999; Emanuel & Emanuel, 1992; Parsons & Shils, 2001). Coulter's definition of paternalism in healthcare services is: 'doctor (or nurse) knowing what is in their patients' best interest, making decisions on behalf of patients without actual involving them in the decision-making' (Coulter, 1999, p. 719).

Patient-centered care and patient participation in healthcare aim to maintain dignity and the individual patient's autonomy (Rothman, 2001). Human dignity and patient autonomy are values protected by the Universal Declaration of Human Rights (UN, 1948). The Norwegian Patient Rights (Norwegian Ministry of Health and Care Services, 2001) aims to enhance a trusting relationship and take care of the patient's life, integrity and human dignity (§1-1), which also is stated in the professional ethics for healthcare workers (American Medical Association, 2001; International Council of Nurses, 2012). Patient autonomy can be explained as the capacity of thinking freely or independently, enabling patients to make decisions of their own (Friedman, 2003). Respect for autonomy involves 'allowing or enabling patients to make their own decisions about which healthcare interventions they will or will not receive' (Entwistle, Carter, Cribb & McCaffery, 2010, p. 741). Coulter (2011) suggests three main reasons for enhancing patients' participation in their own treatment and care: 1) a belief that giving patients a say is 'the right thing to do' and accords with the ethical principle of autonomy; 2) an improvement on current informed consent procedures, and 3) as a means of ensuring that patients

receive the tests and procedures they want and need, no more and no less (p. 75).

## **2.2 Patient-centered care**

Patient-centeredness, patient participation and shared decision-making are, according to Storm and Edwards (2013), related concepts that incorporate the patients' experiences with care (Berwick, 2009; Cahill, 1996; Coulter, 2005; Elwyn et al., 2001; Thompson, 2007).

Ensuring that patient values guide all clinical decisions is acknowledged in patient-centered care (Coulter, 2011). Patient-centered care is built on information, empathy and empowering interactions between patients and healthcare professionals. In other words, patient-centered care can be seen as the way healthcare professionals should care for their patients, treating the patients with dignity, enabling patient autonomy and striving for their involvement in their treatment, care and decisions. To be patient-centered can be viewed as providing care that is respectful of and responsive to patients' preferences, needs and values (Institute of Medicine, 2001).

Patient-centered care has roots in psychology, in the theory of client-centered therapy developed by Carl Rogers (1965). The theory relies heavily on the qualities of each individual who possesses considerable qualities by him/herself, drawing strength from their own resources. Rogers turns the individual into the subject of his/her own therapy and what is important. The therapist's role is to accompany the restoration of the patient's health, by adopting a non-judgmental attitude, and being attentive, understanding and tolerant. By showing sensitivity and empathy, the therapist will help the person to regain full self-confidence (Leplege et al., 2007; Rogers, 1965).

Kitson, Marshall, Bassett & Zeitz (2012) conducted an overall review and synthesis of literature, identifying core elements of patient-centered care, within health policy, medicine and nursing. They found that several traditions exist, although they are all engaged around the same concerns such as empathy, sensitivity and helping the patients (Balint, 1969; Benner, Tanner, & Chesla, 1996; Kitson et al. 2012; Mead & Bower, 2000; Rogers, 1965; Watson, 1999). Based on numerous empirical studies, Mead and Bower (2000) have developed

five key dimensions within patient-centeredness. These are: the biopsychological perspective, involving the full range of patients' challenges, also non-medical aspects; the patient-as-person, implying to understand the personal meaning of illness for the patient, before understanding illness and suffering; sharing power and responsibility with the patient; the therapeutic alliance, including the therapists' attitudes of empathy, enhancing a good relationship between the doctor and the patient; and the doctor as a person, involving the personal qualities of the doctor with sensitivity and insight used for therapeutic purposes. Patient-centeredness can be rooted back to Balint's philosophy (1969), which proclaims the change from illness-oriented medicine to patient-centered medicine. Illness-oriented medicine includes finding and localizing a fault, setting an illness diagnosis and treating it. Patient-centered medicine means to examine the whole person to form an overall diagnosis. Here, the patient has to be understood as a unique human being, rather than only focusing on the illness or medical problem. Patient-centered care is emphasized in Watson's (1999) nursing theory where 'caring' is present as a moral ideal of nursing practice. Watson considered nursing as a holistic practice, holding high regards for a person's life and dignity, non-paternalistic values, emphasis on human autonomy, freedom and choice (p. 35). Important caring aspects can be nurse presence and spending time with patients, included follow-up checks (p. 34).

Providing information to the patient is important to ensure patient-centered care. Information needs to be timely, relevant, reliable and easy to understand (Coulter, 2011). For the patient, information is important to gaining understanding of what is wrong, gaining a realistic idea of prognosis, choosing a provider, understanding the process and outcomes of tests, treatment and services, participating in care and treatment decisions and at last for self-care or self-management. Patient-centeredness is the professionals' responsibility to practice by informing and involving patients in treatment and care (Cahill, 1996; Coulter, 2011).

### 2.3 Patient participation

The concept of patient participation has become widely used in healthcare today and needs to be explored (Cahill, 1996). It is often used in relation with concepts like patient involvement, partnership and patient control (Storm & Edwards, 2013). These concepts are often used interchangeably with patient participation; hence, they are similar but have distinct differences.

Patient participation has been applied and related to different areas, such as medical consultations (Mead & Bower, 2000; Thompson, 2007), and nursing (Cahill, 1996). Thompson (2007) has developed a five-level taxonomy of patient-desired involvement, contrasted with professional-determined levels of involvement identified from literature (p. 1297). The patient perspective levels are: 0) non-involvement where the patients are passive recipients of care and treatment; 1) patients receive and seek information, which is a prerequisite to take part in decisions; 2) professionals and patients give information; 3) shared decision-making, with professionals and patients finding the best solution together and; 4) decision-making, where the patient makes decisions independently without consulting professionals (Thompson, 2007). The levels of involvement are shown in Table 1.

Table 1: Thompson's levels of involvement (Thompson, 2007)

Patient-desired Level	Patient-determined	Co-determined	Professional-determined
4	Autonomous decision-making		Informed decision-making
3		Shared decision-making	Professional as agent
2	Information-giving	Dialogue	Consultation
1	Information-seeking/receptive		Information-giving
0	Non-involved		Exclusion

The professional perspective levels consist of: 'Exclusion', which is the lowest level and non-involvement of the patient. The next level is 'Information-giving', where professionals inform patients; then comes 'Consultation', lacking reflection of the patient's agenda, which is denoted in the 'Professional-as-agent' level. Highest on the professional perspective-level rungs is 'Informed decision-making', with professionals giving their expertise to patients who decide themselves. The 'co-determined' levels exist at levels two and three; the first detected is 'Dialogue', with professionals giving consultations and perhaps patients giving information. The next is 'Shared decision-making', enabling patients to make the decision. This implies that participation does not necessarily include the sharing of decisions, as some patients do not wish to be involved due to vulnerability, lack of interest or apathy. Meanwhile, the common substance between these models seems to be the emphasis on information and decision-making as important parts of the concept of patient participation.

Cahill (1996) conducted an in-depth analysis of patient participation to give meaning to it within the context of nursing practice. The concept is used to explain improved decision-making, encouraging self-medication, patient education and sharing of information. Cahill (1996) has developed a hierarchical relationship between the concepts 'patient involvement/collaboration', 'patient participation' and 'patient partnership', as shown in Fig. 1:

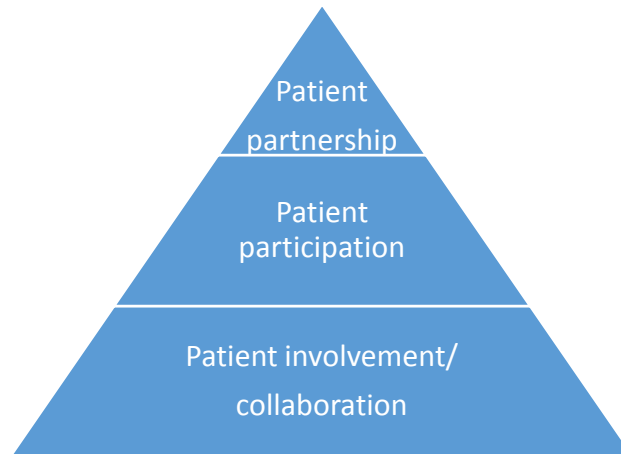


Figure 1: Cahill's hierarchical relationship between the concepts patient involvement/collaboration, patient participation and patient partnership (Cahill, 1996)

'Patient involvement/collaboration' form the base of a pyramid, being the precursors to 'patient participation', ranked at the middle stage, which in turn is serving as the precursor to 'patient partnership' on the top. This means that the lower concepts serve as fundamental aspects to the concept ranked above. According to Cahill (1996), patient participation involves a power transfer from the health professional's perspective to the patient perspective. This means there is a sharing of information between healthcare professionals and patients, and patient participation in decision-making about treatment and care.

The concept is analyzed according to five attributes: 1) a relationship between patients and professionals, where both parts are involved in an activity, such as discharge planning; 2) information, knowledge and/or competence gap between the nurse and patient must be narrowed; 3) there must be a surrendering of power and control from the nurse to the patient, with patient engagement being evident; 4) there must be engagement in selective intellectual and/or physical activities during some of the phases of the healthcare process; and 5) a positive benefit associated with the intellectual and/or physical activity with the patient who might achieve self-care (Cahill, 1996, p. 565). In an opposite case, where a relationship between a nurse and patient does not exist, then the knowledge and information gap is not narrowed. If there is no dialogue about forthcoming events, there will be no engagement of the patient, and consequently the patient has not accrued any benefit.



Antecedents and consequences of the concept of patient participation are outlined within the context of nursing practice (Cahill, 1996). The antecedents include communication systems, from a reciprocal respect from both parties in the nurse-patient relationship, and a competent nurse, with a desire to relinquish a degree of power, control and authority. In the same way, there should be a desire from the patient to assume a degree of power, control and responsibility, with access for patients to appropriate information and knowledge. Finally, an understanding for the patient of appropriate information and knowledge is needed. If these antecedents are present, then the consequences of patient participation can be improved in nurse-patient communication and satisfaction, with better patient adjustment and decreased number of complaints. Further, it might result in patients feeling empowered, with diminished feeling of powerlessness, apathy and dependency, thereby enhancing decision-making and enriching the quality of life.

## **2.4 Shared decision-making**

Shared decision-making is suggested as one useful approach for involving patients and placing the person in the center of care (Charles, Gafni, & Whelan, 1997; Emanuel & Emanuel, 1992; Institute of Medicine, 2001; Storm & Edwards, 2013; Storm & Wiig, 2015; Thompson, 2007). Shared decision-making is one of the models within patient participation that places the patient in the center of care when decisions are to be taken (Storm & Edwards, 2013; Storm & Wiig, 2015). Emanuel and Emanuel (1992) have explored different models concerning the doctor-patient relation. They suggest the deliberative model to be practiced, as the doctor informs the patient about the clinical situation and then helps explain the types of values embodied in the available options. In the model, patient autonomy is important and engages the patient in dialogue. Emanuel and Emanuel (1992) is referred to by Charles et al. (1997, p. 682): ‘Shared decision-making is seen as a mechanism to decrease the informational and power asymmetry between doctor and patients by increasing patients’ information, sense of autonomy and/or control over treatment decisions that affect their well-being’.

Shared decision-making is a clinical model ensuring that healthcare professionals make decisions based on knowledge, experience and the latest

scientific evidence. It requires professionals to inform patients broadly and enable patients to take part in all important aspects of the medical decisions (Elwyn et al., 2001). One important aspect of shared decision-making is to acknowledge patient experiences, values and preferences, equalizing together with scientific and professional knowledge (Elwyn et al., 2001; Storm & Wiig, 2015). Shared decision-making involves three key components: 1) provision of reliable, balanced and evidence-based information on treatment options, outcomes and uncertainties; 2) decision support counselling with a clinician or a health coach to clarify options and preferences; and 3) a system for recording, communicating and implementing patients' preferences (Coulter, 2011). For a patient to participate and achieve shared decision-making, the doctor-patient relationship is important. In 2010, shared decision-making was incorporated in both the US and the UK governments' plans for health reform (Coulter, 2011).

The three models, patient-centered care, patient participation and shared decision-making, are all aiming to include the patients and involve them in treatment and care (Cahill, 1996; Coulter, 2011; Elwyn et al., 2001; Thompson, 2007). Nevertheless, barriers to implementing the model in the clinical area have been reported (Lègarè et al., 2014). Examples include time pressure and lack of motivation amongst healthcare professionals, which are seen as important factors to success. Meanwhile, interventions targeting patients and healthcare professionals together show promising results (Lègarè et al., 2014). Comments to the deliberative model are that recommendations and care provided to patients should not depend on the doctor's judgment of the patient's values, nor the doctor's own particular values (Emanuel & Emanuel, 1992).

## **3 Methodology**

This chapter first contains the study context, then the study design, followed by an overview of the study methods used in this thesis. The data collection methods used are: literature review, participant observations, individual interviews and interprofessional simulation, with follow-up meetings carried out in the study. The chapter also presents the analytic methods used for both the literature review and the empirical studies. Last, ethics and research quality is reflected on, and then the final section addresses the trustworthiness of the study.

### **3.1 Study context**

The empirical study was carried out over a period of 6 months with data collection for papers 2 and 3 during 2012 in Norway in two hospitals – one larger city hospital with 595 patient beds and one smaller district hospital with 206 patient beds. The hospitals involved in the study were situated in two geographical areas belonging to the same Regional Health Authority. The reason for choosing two hospitals (involving both hospital admission and discharge) was to explore different and multiple contexts, which is particularly relevant for the study of transitional care (Aase et al., 2013). The city hospital is situated in a medium-size city with 128,369 inhabitants at the time of the fieldwork (in 2012), who all belong to the same hospital, with nursing homes and home care services in each municipality. One ED ward, two medical wards (pulmonary medicine, geriatric) and two surgical wards (orthopedic) were included in this thesis from the city hospital. The rural hospital is situated in a smaller district with 12,559 inhabitants at the time of the fieldwork (in 2012) with nursing homes and home care services in each municipality. The ED ward, two medical wards and one orthopedic ward at the rural hospital were included in this thesis.

### **3.2 Study design**

The overall study design in this PhD thesis is qualitative, inspired by descriptive and explorative approaches. In qualitative research, the world is culturally or individually constructed (Crotty, 1998; Sandelowski & Barroso, 2003). Qualitative studies often seek understanding of the complexity of clinical situations and in that way they can be approached in their own context only (Morse & Richards, 2002).

The methods used in research design refers to the entire research process from problem identification to data analysis (Blaikie, 2010). This study has used a descriptive research method, which is characterized as ‘research that has as its main objective the accurate portrayal of people’s characteristics or circumstances and/or the frequency with which certain phenomenon occur’ (Polit & Beck, 2012, p. 725). A descriptive approach has its roots in Giorgi’s phenomenological research with focus on individual experiences in their natural context (Giorgi, 1985). This PhD thesis has also used an explorative research method. Explorative research means the way it ‘investigates the full nature of the phenomenon, the manner in which it is manifested, and the other factors to which it is related’ (Polit & Beck, 2012, p. 18). Explorative research makes a need of asking ‘what’, ‘how’ and ‘why’ to explore the evidence of research within the field, patients’ and healthcare professionals’ experiences and also measures carried out in the study (Blaikie, 2010; Polit & Beck, 2012).

The study design consists of four approaches; a literature review, qualitative data from participant observations, personal interviews and data from interprofessional simulation, as illustrated in Figure 2. The specific data collection methods used will be presented below, involving arguments for the choices.

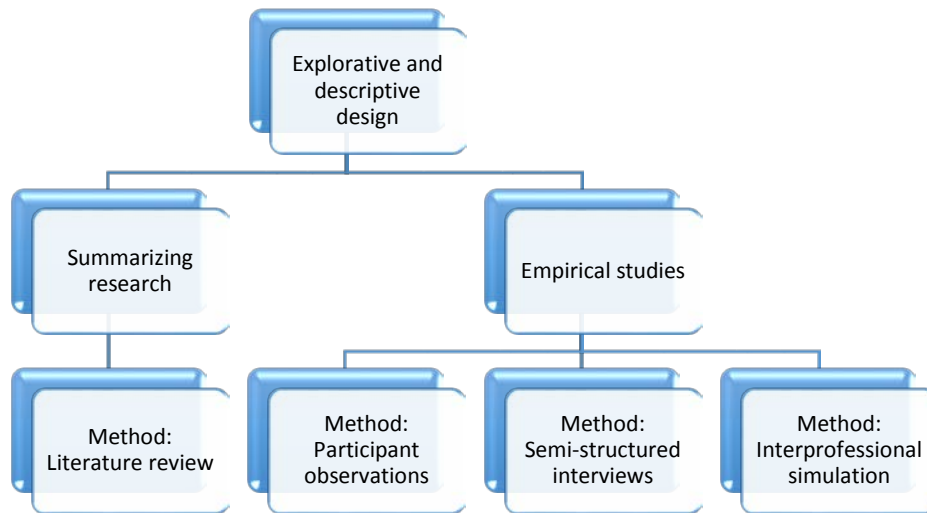


Figure 2: Study design

### 3.3 Literature review

A review of the existing literature (paper 1) was conducted to give an overview of what has been studied and written on older patients' participation in transitional care (aim 1). A literature review is, according to Boote and Beile (2005), the foundation for useful research.

To get a comprehensive overview and understanding of patient participation as a phenomenon in transitional care, there are different approaches, depending on the aims and methods (Gough, Thomas, & Oliver, 2012). When writing a review, specific methodological issues such as methods of searching, identifying, coding, appraising and synthesizing evidence have to be given consideration. A literature review may or may not include comprehensive searching, as well as quality assessment of the chosen studies (Grant & Booth, 2009). Different kinds of reviews often have commonalities. A systematic review is characterized by the use of checklists, for example the Prisma 2009 Checklist, which can be useful to structure the process, and reasons for

inclusion and exclusion of articles identified using a flow diagram for illustration (Moher, Liberati, Tetzlaff & Altman, 2009).

### ***3.3.1 Search strategy and inclusion criteria***

The literature review in this thesis is made by means of specific search terms and inclusion criteria, using parts of the Prisma 2009 Checklist (Moher et al., 2009), with a flow diagram to show inclusion and exclusion of studies that emerged.

In order to find all relevant studies in the field, a structured search was conducted in the electronic databases Cinahl, Medline, Academic Search Elite, Scopus, ISI Web of Science and the Cochrane Database of Systematic Reviews. These databases were considered most appropriate for the literature searches as they provide peer-reviewed articles within the field of health and social sciences (Dyrstad et al., 2015a). The Cochrane database was chosen to find review articles that include empirical studies relevant to our study, but none were identified with the search terms used. A librarian at the university assisted in the search process, using specific terms and MESH words presented in paper 1, Table 1.

Inclusion criteria in the literature review were decided to include articles from 1 January, 2000 until 15 September, 2012 in order to find relevant and updated literature. English was chosen as the language out of the necessity to understand the content of the literature. Further, the specific search terms and peer-reviewed articles published in scientific journals, to secure the quality of the papers, were searched. Studies using different methodologies, both qualitative and quantitative were included in the review.

In the search process it is important that two researchers review the identified studies to ensure the relevant studies are included in the review (Whittemore & Knafl, 2005). My main supervisor was a second reviewer in this process, as she assisted with the selection of the relevant studies identified. In that stage, some abstracts were also read through, in the case relevance was questioned. Excluded studies were either studies of mental health, transition to a hospice, transition within municipality healthcare institutions or the study did not address patient participation according to our definition. The inclusion and

exclusion process are shown in a flow diagram (Fig. 1) in paper 1, as part of the Prisma 2009 Checklist (Moher et al., 2009). The checklist was used in the search and organizing process.

Studies including theoretical and/or empirical literature with multiple research designs and methodologies can be called integrative reviews, which are used to more fully understand a phenomenon (Whittemore & Knafl, 2005). The purpose for using integrative research is to define concepts, review theories, review evidence and analyze methodological issues of a specific topic. Lack of clarity about methods used can limit the subsequent use of the review and several challenges might be found, according to Gough, Thomas and Oliver (2012), as review methods are undergoing rapid development and the methods are often being updated and refined.

### **3.4 Observational studies**

Observations were used as part of the empirical approach in this PhD study, in order to focus on older patients' participation in transitional care, specifically hospital admission and discharge (aim 2 of this thesis). The observational research method is known as a data collection method described as unique when studying people in collaboration, gaining greater understanding of phenomena from the participants' point of view, which would not have been possible in other methods (Dewalt & Dewalt, 2011).

In this study, 'participant observation' or 'moderate participant observation' was used, taking part in the social interaction with the study participants. This kind of observation allows the researcher to be present and identifiable while observing and interacting occasionally, but not actively participating (Dewalt & Dewalt, 2011, p. 23). The method is characterized as the most commonly used observation method, and means that the observer stays with the research participants in their field (Arman, Dellve, Wikström & Törnström, 2009; Polit & Beck, 2012). The researcher participates in daily activities and learns to be polite in the local context, writing about the studied field. Being a present subject, having a participating role and not being a spectator only leads to engagement because the researcher becomes known among the people in their own environment (Dewalt & Dewalt, 2011). Conducting participant observations in this study was purposive, to get first hand experiences, as well

as avoiding influence on the participants, making them stressed by the researcher's presence. It involved daily conversation with patients, their next of kin and healthcare professionals and sometimes giving a hand, like helping to lift the patient into the bed. All observation methods are very time consuming and they generate an immense amount of empirical material and handwritten notes that must be transcribed (Arman et al., 2009).

### ***3.4.1 Study setting***

Observations in hospital admission took place in two emergency departments (ED) conducted in the two chosen hospitals (Dyrstad et al., 2015b). The ED at the city hospital consisted of a triage unit and a treatment unit. In triage, the patients arrived by ambulance and were placed in a bed, lying side by side among other patients, up to 15 in total in the triage room. There were only single rooms (13 rooms) in the treatment part and each nurse cared for 2-3 patients each, also serving the doctor during the medical examination. The ED at the rural hospital was organized with both triage and treatment rooms in the same unit, with altogether eight single rooms. Patients arriving by ambulance were moved into a single room and placed in a bed, having the same room and the same nurse to care for them during their stay in the ED. In some cases, the patient first was transported to the x-ray ward lying on the ambulance stretcher, to check a potential fracture.

The study setting in hospital discharge involved the two hospitals with altogether seven hospital wards: three medical wards, one geriatric ward and three orthopedic wards (Laugaland, Aase & Waring, 2014). The hospital wards consisted of plural rooms for the most patients, with a few single rooms that were prioritized for the most severely ill patients. The wards were all organized in almost the same way, with hospital discharge initiated by conducting a pre-ward round, involving a review of patients' progress and whether they are fit for discharge (Laugaland et al., 2014).

### ***3.4.2 Study participants***

The inclusion criteria were set in the overall research project (Aase et al., 2013). Inclusion criteria were: older patients >75 years of age, acute orthopedic (upper femur fracture) and medical conditions and poly-pharmacy (>5 medications



daily) during hospital admission and discharge. The project aimed to include patients having the following health challenges: hip fracture (upper femur), problems related to chronic obstructive pulmonary disease (COPD) with pneumonia and pulmonary disorders, other medical conditions such as infections, inflammatory diseases and heart problems and poly-pharmacy (more than five medications). Patients with cognitive impairments and who met the above inclusion criteria were included, having a short conversation with next of kin. Next of kin, for the patients meeting the above inclusion criteria, were included (Aase et al., 2013).

Healthcare professionals involved in the patient observations were included in the study. In admissions, these were ambulance workers, nurses and doctors, all involved in hospital admission. In discharge, professionals such as nurses, doctors and physiotherapists involved in hospital discharge were included. In qualitative research there are no rules for sample size, as it depends more on the content of the data gathered and variation in the data material, the last making a larger number necessary (Patton, 1990). It was estimated that the sample should include around 20 observations in hospital admission and 20 in hospital discharge. The number was set in order to cover different and complex hospital admission and discharge situations to understand the compound picture of transitions of older patients (Aase et al., 2013). Forty-one patient observations (21 in hospital admission and 20 in hospital discharge) were conducted. Fourteen patients upon admission had a medical diagnosis (urinary infections, heart attack, COPD complicated with pneumonia) and seven had an orthopedic diagnosis. Thirteen patients upon discharge had a medical diagnosis (chest pain, pneumonia, urinary sepsis, heart attack and reduced general health) and seven involved patients with an orthopedic diagnosis. A summary of observations is shown in Table 2.

Table 2: Summary of Observations

Patient categories	Hospital admission	Hospital discharge
Medical diagnosis	14	13
Orthopedic diagnosis	7	7
<b>Total</b>	<b>21</b>	<b>20</b>

### ***3.4.3 Conducting the observations***

Using observations in this study was useful to get real time information and better understand patient participation in the admission and discharge processes when older patients are transferred (Aase et al., 2013). The observations covered acute hospital admissions of older patients fulfilling the above-mentioned inclusion criteria, coming from municipality home care services or nursing homes, as well as hospital discharges to follow-up care in municipality care. The observations included short conversations with both healthcare professionals and patients and/or next of kin who were involved in the transition, with the purpose of capturing their experiences with participation in hospital admission and discharge (Aase et al., 2013). Dewalt and Dewalt (2011) call this kind of conversation informal interviewing, characterized as a casual conversation where the researcher is looking for new insights within the research.

The observations were conducted by two researchers. I was responsible for the observations of hospital admissions and the other PhD student in the overall project was responsible for observations of hospital discharge. The observations during hospital admission started with the patient transfer from ambulance personnel to the ED nurse and continued until the patient was transferred to the hospital ward. During the observations, I stayed in the patient's room to note the procedures according to the medical examination and nursing care for the patient. If the patient was carried to the x-ray ward, I tried to follow the patient in the transfer. Informal conversation with patients and next of kin were conducted either on the day of admission or the subsequent day, depending on the situation, and when the patient's health condition had stabilized. This was important, as interactions were sometimes limited due to the illness of the patients with pain, dizziness, sickness, confusion, etc. The purpose of the patient and next of kin conversations was to capture their experiences with participation in admission and discharge.

The observations during hospital discharge started on the morning of the day of expected discharge. The researcher stayed at the ward from the morning, observing and notifying the nurses' and doctors' ward routines and the process of planning of the patients' hospital discharge. Conversations with patients were conducted on the day of discharge, as their physical conditions were more

stabilized. Conversations with next of kin were carried out by phone post-discharge, with the patients' approval, as next of kin usually were not present in the ward on the day of discharge.

Data collection was conducted using a structured observation guide (appendix 4) involving specific themes to observe, as described in the literature (Carthey, 2003). The observation guide was used both in hospital admission and discharge. The guide was based on relevant issues in the overall research project and was developed following the literature reviews made within the project (Dyrstad et al., 2015a; Laugaland et al., 2012; Laugaland, Aase & Barach, 2011). The themes of interest to observe included: (1) coordination/interaction among care providers (experiences, success, insufficiency, improvements); (2) multidisciplinary collaboration; (3) information exchange; (4) knowledge sharing; (5) quality and safety; (6) patient and family involvement/education; (7) structure/planning; and (8) challenges/barriers (Aase et al., 2013). Point 6 with a focus on patient, family and involvement has constituted the main part of this thesis. Field notes were written during the observation process and a summary of each observation was written in electronic format immediately after the observations to catch all relevant moments. We also tried to note direct quotations from the patients and their next of kin in order to get firsthand information from the main persons in the study (Aase et al., 2013; Dyrstad et al., 2015b).

#### *3.4.4 The observer's role and preunderstanding*

It is of high importance for the researcher to be aware of one's own preunderstanding ahead of a research project (Hammersley & Atkinson, 2007; Malterud, 2001). The so-called 'ascribed' characteristics such as gender, age, race and ethnic identification might be a barrier to conducting research methods like participant observation and interviews (Hammersley & Atkinson, 2007). These characteristics may cause challenges or benefits in the relationship between the researcher and the study participants. Additionally, this includes a preunderstanding involving all previous professional work experiences, theoretical knowledge, life experience and motivation for starting the research project, and also the expected findings (Malterud, 2001).

Both researchers involved in the data collection had a nursing background and were dressed in hospital clothing, in order to be unnoticeable (Hammersley & Atkinson, 2007). Having a professional background as a nurse was beneficial, in order to understand the necessity of the examinations conducted and the reasons for routines such as the triage of the patients with priority due to the severity of the patients' medical conditions. The presence of an observer may stimulate modifications in behavior, leading the observed persons also to reflect on their own activities (Pope & Mays, 2006). Occasionally I took part in some activities, such as giving water to the patient, to be helpful and to socialize in the situation. The impact of the observer can, according to Pope and Mays (2006), be minimized by participating in the ward activities taking place while observing them. I reflected on my appearance in the studied field; how much did it influence the health professionals' work achievement? I presume it influenced to some degree, but being a participant observer I tried to be more or less unnoticeable.

I entered the research field with my own experiences, such as being a married Norwegian woman, a mother of four children, and a nurse, or, more specifically, an intensive care nurse (ICU nurse). As an ICU nurse, caring for critically ill patients, being employed and working at the intensive care unit at a hospital for many years, I had preunderstanding of what a hospital admission and discharge included. To be aware of hospital admission and discharge procedures, with vital observations necessary to triage the patients' severity of illness, was advantageous for me and helped me to better understand the situation. Having an idea of what kind of competence is needed from healthcare professionals to take care of older patients in transitions was also beneficial, as was my knowledge about patient participation. In the same way, it was beneficial that the observer in discharge had a nursing background, knowing daily routines at the hospital wards and who was used to caring for older patients.

### **3.5 Interview studies**

To deeper explore patient participation in transitional care of older patients, semi-structured interviews were conducted with healthcare professionals. The aim was to identify factors influencing patient participation by exploring healthcare professionals' views on patient participation during the hospital admission of older patients through the ED (aim 3).

Individual interviews are a commonly used data-collection method within qualitative research in which an interviewer asks questions of a respondent, usually face-to-face (Polit & Beck, 2012, p. 731). According to Kvale (1996, p. 38), the qualitative research interview seeks to describe the meaning of central themes in the life world of the subjects. Interviews are particularly useful to explore experiences, views, motivations and beliefs of individual participants. One reason for choosing professionals involved in hospital admissions only was that only studies on hospital discharge were identified in the literature review (paper 1). Another reason was to delimit the study field and data collection.

There are three major forms of the interview: structured, semi-structured and unstructured (Gill, Stewart, Treasure & Chadwick, 2008). Semi-structured interviews, which are based on several key questions in an interview guide were used (Kvale, 1996). The interview guide provided some guidance on what to talk about, at the same time giving the interviewee a possibility to more freely tell his/her story through use of follow-up questions. The interviews were carried out with healthcare professionals involved in hospital admissions, to get an understanding of the viewpoint from several professions included in hospital admission of older patients.

#### **3.5.1 Study setting**

The interviews with ambulance workers took place in an office at the ambulance station, also away from work tasks, although they had to be on 'stand-by' and ready to respond to the ambulance alarm. Medical and orthopedic doctors were interviewed in their own offices and were available by phone. The places chosen did not interfere with the interviews, except once where the interview was interrupted by an emergency call at the ambulance

station. The specific interview continued and was fulfilled later on in the evening.

### 3.5.2 Study participants

Participants in the interview study were ambulance workers, nurses and doctors (medical, orthopedic doctors and interns), and they were all involved in hospital admission. The rationale for these inclusion criteria was to interview different professionals with different skills and experiences, which was purposive to get more in-depth information about patient participation in hospital admission of older patients (Aase et al., 2013).

The ambulance workers were working at the ambulance station connected to the hospital, responding to emergency calls, transporting patients to the hospital and triaging patients based on the severity of their illness. The nurses all worked in the ED (triage unit and treatment rooms), providing nursing care for incoming patients. The doctors were working at medical or orthopedic hospital wards while serving the ED, depending on their specialty. The interns rotated between medical and orthopedic wards while working in the ED. The leaders at the respective wards were told to interview professionals with different work experience. An overview of interview participants is presented in Table 3.

Table 3: Interviews with Hospital Healthcare Professionals

Profession	Gender, age	Professional work experience in field
8 ambulance workers	2 females, 6 males Mean age 41	Mean 15 years
9 nurses	9 females Mean age 46	Mean 8 years
4 doctors (2 internal med., 2 orthopedic)	1 female, 3 males Mean age 36	Mean 5 years
6 medical interns	4 females, 2 males Mean age 28	Mean 6 weeks

### ***3.5.3 Data collection***

A semi-structured interview guide (appendix 5) was used during the interviews with ambulance workers, nurses and doctors. The guide was adjusted according to the profession of the interview participants, related to the individual's work tasks and involvement during the transition. The guide was not used strictly; the range of the questions differed and some were left out as they were not relevant. Participants were told to be free and tell stories of relevance, making the process more inductive.

## ***3.6 Interprofessional simulation***

As part of the cross-levelled educational program 'The Meeting Point', we conducted three half-day seminars over a 1-month period (November 2013), using interprofessional simulation to focus the patient perspectives and participation in transitional care (Storm et al., 2014a). The aim of paper 4 was to describe the learning activities framed as interprofessional simulation, and to assess whether this was useful to increase healthcare professionals' awareness of and competencies about patient participation in transitional care of older patients (aim 4).

### ***3.6.1 Study setting***

The study was performed at a simulation center, SAFER, situated in Stavanger, Norway. The center is a foundation between a medical product factory/center (Laerdal Medical), the local hospital and the local university. The lectures and group work took place in an auditorium at the center and lunch was also served there. Arranging meetings at such a center was preferable, as it was a neutral place for both employees from hospital and from municipality, although the last group was not familiar with this center. This was nevertheless seen as positive, as the center might be a common place for training and learning activities (simulation) in future.

### ***3.6.2 Organizing interprofessional simulation***

'The Meeting Point' seminars focusing on patient participation in transitional care were framed as interprofessional simulations. We were inspired by

Dieckman's simulation model (2009) containing the following sections: introduction, theory input, scenario briefing, simulation scenario, debriefing and ending.

Ahead of the interprofessional simulations, several arrangements were needed, such as registration of participants, organizing groups and including different healthcare professionals from both hospital and municipality in each group. Lunch was ordered and served upon arrival at the seminars. Serving lunch was purposive with participants in each group being socialized before the formal meeting started.

The introduction part of the interprofessional simulation involved brief information about the program, and was conducted by the leader of the overall research project. Another member of the research team prepared and held a 1-hour lecture called 'Patient perspectives in transitional care', serving as the teaching section or theory input in the model. Afterwards, there was a short introduction about the simulation scenario, the film, held by another member of the research group (me). The film was based on anonymized field note data from observations of an older patient in hospital admission and discharge, showing realistic patient situations and work practices in transitions. The film was prepared at the simulation lab at the university, with colleagues playing different roles and an elderly man playing the patient role. A professional cinematographer filmed the scenario and also prepared the layout. The voice-over was made afterwards in a film studio.

A brief outline of the film:

An older man lies in his bed after arriving at the ED, with pre-existing epilepsy and diabetes. He seems to be in pain. In the triage area, nobody talks to him, but soon his daughter arrives and sits at his bedside. He asks for his medication and she looks in her purse to find it. After 2.5 hours he is transferred to a treatment room in the ED. A nurse takes care of him, taking vital signs and informing him about the planned examination and tests, after which an intern comes into the room. At discharge, the patient is lying in his bed when a doctor comes in on her rounds. The doctor stands by the end of the bed, informing the patient that other patients need his place and that he is going to have a short stay at a nursing home



today. The nurse states that he has to leave very soon, before lunch. No next of kin is present at discharge (paper 4).

The debriefing section was carried out as group work, with questions from the film scenario and also from the participants' own wards. The focus was the patient's perspective and patient's participation and how healthcare professionals involved patients and next of kin in decisions in the film scenario and in the participants' own wards. They were also asked to suggest improvements on how to better involve older patients in transitions.

After the group work, the ending section consisted of a presentation and plenary discussion, with a summary and a request to take back suggestions to the participants' own work places.

### ***3.6.3 Data material***

The data material from the interprofessional simulation were written feedback from participants, minutes from the plenary sessions, the log reports of group work facilitators and study participants' written notes from the group work activities. Data collection and report writing was conducted by one member of the research team in each group, serving as the facilitators in the groups and also by one specific person taking notes during the meetings. The follow-up meetings were recorded and transcribed to electronic text format by a research assistant.

### ***3.6.4 Study Participants***

In total, 85 healthcare professionals (nurses, nursing assistants, physiotherapists, doctors and ward leaders) from the city hospital with the belonging municipality participated in the three interprofessional simulations. Thirty-five participants were from a hospital and 50 were from one municipality. An overview of participants at 'The Meeting Point' is shown in Table 4.

Table 4: Participants in Interprofessional Simulation at The Meeting Point

Healthcare services	Participants from healthcare units	Nurses	Nursing assistants	Physio-therapists	Doctors	Leaders	Adm. personnel
Hospital	1 Adm. unit						2
	1 Emergency Department (ED)	9				2	3
	2 Medical Wards	16			2	1	
	Summary Hospital (35)	25			2	3	5
Municipality	2 Patient Coordinating Units						16
	4 Nursing Homes	16	2	1	3	4	
	4 Home-Based Services	7				1	
	Summary Municipality (50)	23	2	1	3	5	16
<b>In total</b>	<b>85 Participants</b>	48	2	1	5	8	21

Four follow-up meetings with, in total, 28 participants were conducted, addressing the implementation of the measures suggested at ‘The Meeting Point’. Two members of the research team conducted the follow-up meetings, one was responsible for the interviews, the other took notes. The follow-up meetings were recorded and transcribed afterwards by one of the members of the research group. The data material consisted of transcripts from the 3 interprofessional simulations and the 4 follow-up meetings, with 135 pages in total of log reports and transcripts.

### 3.6.5 Organizing the follow-up meetings

Follow-up meetings both at wards at the city hospital and nursing home wards in municipality were carried out around one month after the interprofessional simulation. The aim was to identify how the professionals at the specific wards had continued their work to improve patient participation. Leaders from the

wards that participated at interprofessional simulation were contacted in order to arrange follow-up meetings around a month after the simulation at the simulation center. The follow-up meetings were arranged by appointment between the researcher responsible for the interprofessional simulation and the leader at each ward. The meetings were carried out around lunchtime, to meet as many participants as possible, and they were held where the employees have lunch or at a specific meeting room. The meetings started with a summary of the findings from the interprofessional simulation. An interview guide was used with questions about further work done to improve patient participation at the participants' own wards. The follow-up meetings lasted around one hour each, depending on how busy work at the specific ward was, and how active the participants were to talk about their improvement efforts.

### **3.7 Analysis**

According to Polit and Beck (2012), analysis of qualitative data means systematic organization and synthesis of research data and is particularly challenging for three reasons. First, there are no universal rules for analyzing qualitative data; second, substantial amounts of work are required; and third, to reduce the data reporting by a balance between being concise and reporting the richness and value of the data. The analysis process is continuous and starts during the data collection. As the design is based on descriptive research (Giorgi, 1985; Polit & Beck, 2012), the methods used in the analysis process are more descriptive than interpretative, in order to stay close to the data material (Malterud, 2012). The data sets in this study are analyzed using thematic analysis (Braun & Clarke, 2006; Polit & Beck, 2012) and systematic text condensation (Malterud, 2012).

#### **3.7.1 Thematic analysis**

Thematic analysis was used to analyze the data material gathered in the literature review and from the interprofessional simulation. Thematic analysis is used to identify codes, search for themes, reviewing themes, defining and naming themes (Braun & Clarke, 2006).

### **Literature review**

Data analysis within integrative reviews are one of the least developed and most difficult aspects of the process (Whittemore & Knaf1, 2005). Thematic synthesis (Polit & Beck, 2012) was used to analyze the results from the research studies included in the review. The process started with reading and re-reading the data material, then coding by marking important features and searching for repetitive patterns across studies, ending with abstracting of major themes (Polit & Beck, 2012). Each empirical study was analyzed according to the first research question in this thesis, identifying key issues reported in the literature that influence older patients' participation in transitional care. The first theme was 'Older patients' participation in transitional care', with sub-themes or categories. The second theme was 'Tools to support older patients' participation in transitional care', describing tools suggested and implemented.

### **Interprofessional simulation**

The data material gathered from the interprofessional simulations were analyzed using Braun and Clarke's (2006 ) thematic analysis. It was natural to search for themes to describe what the participants said instead of analyzing underlying meanings of the expressions. In phase 1, both researchers familiarized themselves with the data by reading and re-reading the transcripts. Phase 2 involved identification of codes, with data collated to each code. Phase 3 consisted of search for themes, gathering data to each theme. In phase 4, the researchers reviewed the themes and checked the relation to the coded extracts; and in phase 5, themes were refined and named based on specifics for each theme. Finally, in phase 6, the paper was produced. Extracts from the thematic analysis phases 2-5 are presented in paper 4 (Table 3).

### **3.7.2 Systematic text condensation**

Malterud's (2012) systematic text condensation was used in the analysis of both the observation and the interview field notes conducted in this thesis. The analysis is based on a descriptive approach, where the experiences of the participants are as expressed by themselves, rather than exploring underlying meanings of what is said (Malterud, 2012). The strategy consists of the following steps: 1) total impression of the data, identifying preliminary themes,

which was done ahead of meetings with all authors of the papers; 2) identifying and sorting meaning units or text fragments into codes and code groups, sorted out during the seminars; 3) condensation by systematic abstraction, sorting code groups into subgroups, which was done in a later meeting; and 4) synthesizing the condensates, developing descriptions and concepts into categories until reaching a consensus in the group (Malterud, 2012). An extraction of the analysis process of participant observations during hospital admission and discharge is presented in paper 2, Table 2. Further, an extraction of the ‘systematic text condensation’ analysis of interviews with healthcare professionals in hospital admission is presented in paper 3, Table 2.

### **3.8 Ethics**

The study was approved by Western Norway Regional Ethics Committee for Medical Research (REC, no. 2011/1978) (appendix 1). The participants included in the study were informed and aware of the research process and the researchers’ presence.

The process of recruiting participants to the observational study started ahead of the observation period (both for hospital admission and discharge), information meetings with leaders at the respective wards were held, and were followed by an information letter (appendix 2) given to each healthcare professional who attended to the study. In addition, a specific information letter (appendix 3) was given to patients and/or next of kin together with oral information, to include the patients in the study. Next of kin consented on behalf of the patient, if he/she suffered from cognitive impairment. One or two days later, the hospital ward was contacted, and the nurse in charge asked the patient if a short conversation could be conducted. Interview participants were recruited by the leader of each of the professional groups (ambulance workers, nurses and doctors), who gave approval for the interviews to be carried out. Participants at the interprofessional simulation were recruited by a formal invitation letter to the leaders of hospital wards and in the municipality. The invitation letter contained information about location, address, theme and practical information, such as lunch being served upon arrival and also group work. Information meetings in each ward were held by the research team to ensure leader support and inspire the staff to participate in the study (Storm et

al., 2014b). It was necessary to remind the leaders at the different wards about the importance of the meetings and encourage them to enroll their employees and staff in the study due to their busy workday and numerous work tasks.

When including older patients in research, and specifically in acute hospital admissions with patients having multiple health challenges, several considerations have to be taken. These patients are particularly vulnerable, due to their medical condition and complex needs (Coleman, 2003; Coleman & Boulton, 2003; Naylor & Keating, 2008). Older patients suffering from a disease or a fracture have pain, nausea, feel dizzy and might be confused (Foss & Asgautrud, 2010). Efforts were made to be humble and let the decision to talk be on the patient's and/or next of kin's premises and took into consideration the patient's physical and mental condition.

As a participant observer, my involvement was limited to social interaction with patients, next of kin and professionals, and giving a hand if, for instance, the patient's position in bed should be changed. I had some reflections concerning to which degree I ought to intervene in case an emergency situation occurred. Being a healthcare professional and an intensive care nurse, I found that my responsibility to help in an emergency situation is mandatory if needed, according to ICNs' ethical directives for nurses (International Council of Nurses, 2012). I concluded that my responsibility would be the same as it always has been if acute situations occur. No emergency situations occurred during the observations. Ahead of the interviews, all participants were asked by their leaders, as the participation was voluntary, and they gave written consent, with the possibility to withdraw at any time without any consequences.

### **3.9 Research quality**

In qualitative research, the research quality is described as enhancing the trustworthiness of the study's data (Lincoln & Guba, 1985; Polit & Beck, 2012). Several dimensions are used to achieve trustworthiness, such as credibility, dependability, confirmability and transferability.

### **3.9.1 Credibility**

Credibility refers to the extent that the research methods create confidence in the truth and in the interpretation of the data (Polit & Beck, 2012). To achieve credibility in this project, the quality of the literature review, the observations, interviews and the interprofessional simulations should be examined. Having two researchers to decide inclusion or exclusion of the studies in the literature review using a flow diagram contributes to gain credibility. In the observation study, moments like staying in the ED in two different hospitals for a longer period has strengthened the credibility of the results in the study. Short conversations with healthcare professionals (ambulance workers, nurses, doctors) were held right after the observations were completed to catch the professionals' view concerning quality of the specific transition.

The observations were conducted and completed before the interviews started, which contributed to a better understanding of the healthcare professionals' explanations during the interviews. To ensure credibility during the observation study in the ED and at the hospital wards, the characteristics, such as common functions and routines performed during hospital admission and discharge, were identified and described. The choice of different participants' qualifications such as observing ambulance workers, nurses and doctors with different roles and views of patient participation aimed to strengthen credibility in the observations and individual interviews. Another important moment here is that participants also had different work experiences, as well as variation in age, profession and work experience in general. During the observation period, my supervisor observed for a few hours in the ED in order to validate the descriptions of the context, which was useful in the analysis of the data collected. She also was apparent, taking notes and observing one of the patient situations in hospital admission. Hence, together with the qualifications and the clinical experience of both researchers (in hospital admission and discharge), the credibility of this research is strengthened. To obtain credibility for the results of the data from the interprofessional simulations, notes were taken both by each supervisor at each group, the participants in each group and one researcher who was responsible for notes from the plenary discussion. For the follow-up meetings, one researcher took notes and in addition to a recorder that was used, to secure that all moments were captured. The data were transcribed verbatim into text material by one of the researchers in the research team.

### ***3.9.2 Dependability***

Dependability refers to consistent and stable evidence (Lincoln & Guba, 1985). Consistency in this study might, in the literature review, be the stability of the research process, using the same search terms in all databases to achieve a more stable evidence. Concerning the observations and interviews, one researcher was collecting all empirical data in hospital admission; another researcher was conducting all observations during hospital discharge. Hence, there is not consistency between the participants in hospital admission and discharge, as we never managed to observe the same patients from admission to discharge. However, we collaborated in developing the observation guide and also the interview guide, to find the right questions to figure out what we were looking for. Consistency was obtained by informal and formal meetings to discuss observations, as well as co-existence in timing of the observations. The three interprofessional simulations were carried out using the same program and the same researchers with an educational part and a discussion part, to achieve consistency. In the same way, the follow-up meetings were conducted to obtain dependability.

### ***3.9.3 Confirmability***

Confirmability concerns objectivity; the degree to which study results are derived from characteristics of participants and the study context (Lincoln & Guba, 1985). To secure confirmability in this thesis, several approaches have been used (Polit & Beck, 2012). The methods used to collect data in this thesis include participant observations, individual interviews, discussions (seminars) with study participants and watching participants' behavior. This might also involve the way different healthcare professionals were included in the study, such as ambulance workers, nurses and doctors, to explore and understand the complexity of the admission and discharge situations. Efforts were done to be structured in the data collection (getting all questions answered), as well as in the analysis process, using Malterud's (2012) stages with systematic text condensation. In addition, as a member of a larger research project, there was collaboration with the members of the research team and with an expert advisory group. Preliminary findings have been presented for some of the



participating wards at the hospital and the municipality, when showing the film based on the observations in the interprofessional simulations.

### ***3.9.4 Transferability***

Transferability is another aspect of trustworthiness and refers to the extent to which qualitative findings can be transferred to other settings, contexts or groups (Lincoln & Guba, 1985). To promote transferability, rich descriptions of the research context are important, so that others can make inferences about contextual similarities. This thesis' findings might be transferred to other settings, due to the purposive sampling with relatively detailed described context and professionals involved, owing similarity to other hospital admission and discharge settings. The analysis process for all the data gathered is thoroughly described with extractions of tables, showing each stage of the analysis and will ease the understanding of the categories emerged. Findings, both empirical and in the literature review, are also in accordance with findings in other research studies, which will strengthen the results.



## **4 Results**

In this chapter, the study aims and research questions are first described, followed by study results in the four papers in this thesis.

### **4.1 Paper 1**

The aim of conducting ‘A review of the literature on patient participation in transitions of the elderly’ in paper 1 (Dyrstad et al. 2015a) was to give an overview of the existing research on older patients’ participation in transitional care. The following research question is addressed in the study: What are the key issues reported in the literature that influence older patients’ participation in transitional care?

A final sample of 30 articles included in the review was made. Results revealed two main themes. The first theme was: ‘Older patients’ participation in transitional care’, which had eight categories/sub-themes identified: information; participation in discharge planning; formal assessment on functional ability; paternalism; disempowerment; the content meaning of participation; ‘good’ experiences of transitional care; and family support.

The first sub-theme, lack of ‘information’ to patients during the discharge process, was reported in several of the studies. In the second sub-theme, minimal ‘participation in the discharge process’ was found. This involved lack of involvement in the decision-making process on where and when to go home, and the patients were not invited to the weekly team conference, resulting in no involvement in the goal setting and action planning processes. The third sub-theme, ‘formal assessment on functional ability’, revealed that patients were not aware of formal assessment of their physical, personal or social needs, or rehabilitation goals set for them on admission. In the fourth sub-theme, ‘paternalism’, with professionals attempting to persuade the patients to accept their suggestions and nurses not supporting the patients’ wishes during the care plan meetings, was identified. The fifth, ‘disempowerment’, was the result of patients and relatives feeling like they were not heard. The sixth sub-theme ‘the content meaning of participation’ revealed that the concept was unfamiliar and also there was a lack of understanding of the language used by professionals.

In the seventh, ‘‘good’ experiences of participation in transitional care’ was reported when patients felt informed, with more understanding of service decisions and possibilities. Finally, in the eighth sub-theme, ‘family support’ was reported to be important and made the patients feel safe, especially during or after discharge.

The second main theme addressed ‘tools to support older patients’ participation in transitional care’. Several sub-themes were identified, such as measures and interventions, which were developed, tested and implemented in clinical practice. There were family meetings, discharge care plans, checklists, education programs (for example ‘the Transition Program’ to prevent re-hospitalization and the ‘professional-patient partnership model’) and home visits conducted by healthcare professionals. The checklists improved patients’ preparedness for discharge. Other measures were not successful in terms of improving participation as patients were not invited to take part in meetings and conferences. Only studies from the hospital setting and discharge were identified, suggesting hospital admission transitional care is poorly explored (Dyrstad, Laugaland & Storm, 2015a).

In summary, the literature review reveals that older patients’ participation and decision-making was low, although patients wanted to participate. Some tools were successfully implemented, though others did not enhance patient participation. There is a need for clinical practice to consider implementing tools to support patient participation to improve the quality of the transitional care of older patients.

## **4.2 Paper 2**

The title of paper 2 is: ‘An observational study of older patients’ participation in hospital admission and discharge – exploring patient and next of kin perspectives’ (Dyrstad et al., 2015b). The aim of the study was to explore older patients’ participation during admissions to, and discharge from, the hospital. The following research questions were addressed: 1) How is patient participation attended to by healthcare professionals during hospital admission and discharge? and 2) What are the experiences of older patients and their next of kin with patient participation in hospital admission and discharge?

## *Results*

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Twenty-one observations (21 admissions, 20 discharge) (paper 2) were collected between March 2012-October 2012 and consisted of 72 hours (80 pages) of field notes of participant observations in hospital admission and 92.5 hours (153 pages) of field notes in hospital discharge. The analysis, using systematic text condensation (Malterud, 2012) of the observational data material resulted in four categories: observing professionals' information dissemination and decision-making; older patients' experiences with integration of information; older patients' preferences for involvement in decision-making; and next of kin advocacy.

In the first category, 'observing professionals' information dissemination and decision-making', variable information exchange between healthcare professionals and patients, and a lack of involvement of the patient in decision-making, was observed and experienced by the patients and their next of kin. In the second category, 'older patients' experiences with integration of information', several of the patients said they were satisfied with information given in hospital admission, others missed information and some had forgotten what they were informed about. Upon discharge, the patients received information about medical treatment given, further treatment and discharge decisions. Patients often struggled to understand the oral information provided on the day of discharge.

Within the third category, with 'older patients' preferences for involvement in decision-making' about transitional care, the patients had a range of thoughts. Several were satisfied with the admission and said they had the opportunity to describe their symptoms, they were familiar with the routines, trusted the healthcare system and were comfortable letting the staff make decisions for them. Upon discharge, some patients were satisfied, although they did not have many opportunities to speak with nurses and doctors during the stay. The patients' preferences were sometimes respected, as some patients were allowed a longer hospital stay, and some patients were able to transfer to the nursing home of their own choice. Nevertheless, several patients felt the day of discharge came upon them suddenly and unexpectedly and they were unprepared, as decisions were taken by healthcare professionals without consulting them. Some patients were told that there was a shortage of beds at the ward and that they needed to make room for incoming patients. Despite patients' objections and arguments, the decision was most often made by

healthcare professionals, with patients being transferred to follow-up care in municipality. The category ‘next of kin advocacy’ revealed that the patient’s next of kin played an important role in hospital admission, by providing and receiving information and supporting the older patient’s participation in hospital admission and discharge.

Summarized, the observational study indicates a variable degree of information exchange between healthcare professionals and patients, as well as a lack of patient participation (in admission and discharge). Next of kin played an important role, advocating for the patient in hospital admission, and providing practical support both in admission and discharge. Increased support for patients’ participation is needed in clinical practice.

### **4.3 Paper 3**

In paper 3, an interview study of healthcare professionals in ED was conducted, entitled ‘Older patients’ participation in hospital admissions through the emergency department: an interview study of healthcare professionals’ (Dyrstad et al., 2015c). The aim of the study was to explore healthcare professionals’ views on factors influencing patient participation in hospital admission of older patients through the ED.

In total, 27 individual interviews resulting in 274 pages of transcripts were conducted with healthcare professionals connected to hospital admission. Results show that healthcare professionals’ views on patient participation during hospital admission of older patients were influenced by five factors (categories), shown in Fig. 3: routine treatment and care during hospital admission; the frail and thankful older patient; hospital resources, i.e., available staff and beds; healthcare professionals’ attitudes towards exploring older patients’ experiences; and presence of a supportive and demanding next of kin.

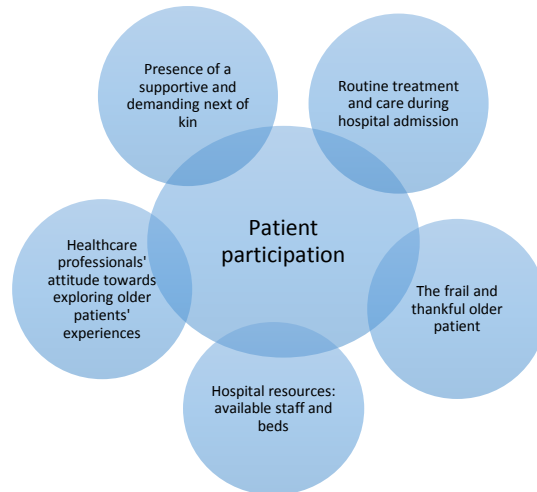


Figure 3: Healthcare professionals' perspectives on patient participation.

The category 'routine treatment and care during hospital admission' report that a first priority is to save the patient's life by triaging the severity of the patient's illness, and conducting observations of the patient's vital functions and information. Also, questions about the patient's symptoms and current health condition were asked. At the hospital, minimal information from nurses to the patient was given in the triage part of ED, due to waiting for a medical examination. In the treatment section, proper information about surgery or other treatment was focused, but involvement of the patients varied. In the category 'the frail and thankful older patient', health professionals characterized older patients as a challenging patient group to involve in their own treatment and care. They were seen as thankful for help, being difficult to involve in treatment and care decisions, as they usually do not complain but rather accept healthcare professionals' decisions.

The category 'hospital resources, i.e., available staff and beds' suggest a shortage of staff and beds, as a challenge to patient participation in both hospital and municipality healthcare services. This leads to hospital admission of patients in municipality, especially on weekends with a shortage of staff. At the

hospital, however, the number of available staff is lower during weekends and nights. The examination of older patients is time consuming, and the patients often were stopped when trying to explain what is wrong. The category 'healthcare professionals' attitudes towards exploring older patients' experiences' indicated that professionals tried to explore older patients' experiences, asking questions about health problems and respecting their wishes. Others felt that patient participation was not relevant in the ED. The last category, 'presence of a supportive and demanding next of kin' showed that next of kin was seen as a good source of support in hospital admission, providing valuable information, receiving necessary information about treatment and care and being a practical support. Next of kin was also seen as demanding, being a challenge as their opinions and proposals might not be consistent with the patient's needs and wishes. Patients' needs and preferences were prioritized, although next of kin's views were taken seriously.

In summary, interviews with healthcare professionals show that patient participation of older patients in hospital admission is influenced by the organization of the service, the patients' condition, hospital resources, healthcare professionals' attitudes and support from the patient's next of kin.

#### **4.4 Paper 4**

The title of paper 4 is: 'Interprofessional simulation to improve patient participation in transitional care' (Dyrstad & Storm, 2016). The aims of the study were 1) to describe the details of the learning activities used at The Meeting Point, focusing on the patient's perspective and participation in transitional care, and 2) to assess whether the learning activities were useful to increase healthcare professionals' awareness of and competencies about the patient's perspective and participation in the transitional care. The learning activities were framed as interprofessional simulations, including a film scenario based on results from the observational study, and group work guided with related questions from the film scenario and from the participants' own wards.

The first theme identified from the film scenario was 'lack of information during hospital admission and discharge', showing decisions about discharge being taken ahead of the doctor's rounds and simply told to the patient.



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Healthcare professionals made decisions for a short stay (without asking the patient) and did not acknowledge the patients' preferences. The second theme from the film scenario was 'lack of care from healthcare professionals in the film scenario', with the patient being taken care of by his daughter in the triage part of the ED. Participants at meetings viewed next of kin as vital in hospital admission and missing at discharge. The film was considered to present common work practices, and participants were inspired to make improvements.

The group work resulted in a third theme emerging from the professionals' meanings and experiences from their own wards, stating that 'information dissemination to/from the patient and next of kin is vital'. Log reports show that all participants were concerned about providing sufficient information to the patients and their next of kin, and it was customary for geriatric ward staff to talk with patients during hospital admission about their needs after discharge. The last theme was 'let the patient decide', by involving the patient in treatment, care and discharge planning. Some wards had procedures, others had no such routines. The medical ward had started using a specific dialogue technique, 'motivational interviewing' with the goal to let the patient manage the conversation.

Suggested measures and written feedback from the interprofessional simulation were such as (paper 4, Table 4) regular interprofessional meetings focusing the patient's views and needs; information brochure in ED presenting routine treatment and procedures; have a face-to-face talk, ask about his/her views; checklist for the patient to tick off when examinations; repeat information about opportunities for rehabilitation and follow-up care; municipality healthcare services call the patient to ask 'how are you, what are your specific needs upon hospital discharge?'

Results from the follow-up meetings show that some wards both in municipality and at the hospital had continued their work to improve quality in transitional care. At the hospital, participants from the ED had prepared an observational waiting room for older patients that they plan discharge in hospital admission by checking the patient's history and asking the patient and next of kin about medical conditions and care needs ahead of hospital admission. Participants coming from a short stay at a nursing home planned to start using admission dialogues and 'motivational interviewing' with the

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patient, next of kin, nurses, doctors, physiotherapists and others to set the goals for the stay. Not all improvements can be seen as results from the interprofessional simulation.

In summary, the interprofessional simulation was valued by the participants. The film revealed a lack of information and lack of care to the patient, resulting in improvement ideas. The participants realized the importance of information dissemination to and from the patients and their next of kin. Further, they became more aware of involving patients in treatment decisions and care plans after hospitalization at an early stage during the hospital stay. Participants had several suggestions for improvements and some wards had started to improve quality in transitional care.

## **5 Discussion**

The overall aim of this study has been to explore participation of older patients in transitional care from the patients' and healthcare professionals' perspectives, and to develop and conduct an interprofessional simulation to improve patient participation in transitional care. To achieve this aim, research in the area is examined and patients' and healthcare professionals' experiences and views have been explored. Additionally, interprofessional simulation to enhance knowledge and awareness of patient participation in transitional care (hospital admission and discharge) has been developed and conducted.

In this chapter, the main contributions and implications of this thesis will be discussed. The overarching issues related to findings in the literature review and the three empirical studies are focused and connected to theoretical perspectives and current research.

### ***5.1 Patients' experiences with patient participation***

A new patient role, where patients are experts on their own health, has emerged over the last two decades, emphasizing on patient participation (Norwegian Directorate for Health and Social affairs, 2011-2015). There is an expectation from patients, next of kin, service users and policy makers that patients should be involved in their treatment and care. Hence, several studies suggest that patients are not encouraged to share their expectations and experiences concerning their health challenges with their healthcare providers (Coulter, 2011; Foss & Hofoss, 2011; Laugaland et al., 2014; Storm et al., 2014a).

The studies included in paper 1 (literature review) and paper 2 (the observational study) in this thesis report that older patients have numerous health challenges, such as several diagnoses, loss of hearing and multiple medications (Dyrstad et al., 2015a; Dyrstad et al., 2015b). Some patients struggled to understand and remember information about the discharge process because of professional medical language. Another reason for experiencing minimal information might be that information has been given, but the older patients have forgotten it, since integration of information is a challenge and they do not remember (paper 2). Stephens et al. (2013) interviewed 25

hospitalized patients in medical/surgical units. The patients reported knowledge gaps, such as inability to call their primary care provider, active medications or current care plan details. They had difficulty navigating the healthcare system, receiving appointments, obtaining medications and paying for transportation to necessary follow-up care. Additionally, they had complex psychiatric and social needs, and either a prior or active psychiatric illness, such as depression, post-traumatic stress disorder or anxiety disorder. This suggests a lack of information about treatment and care or that they had numerous health challenges and were discharged too early, like some patients in our observational study experienced (paper 2).

Coleman (2003) suggests that older patients with complex acute and chronic care needs are particularly vulnerable during transitions to and from hospitals. Similarly, the older patients in paper 2 were vulnerable, and they experienced receiving minimal information about new medications, changes of staff and different work shifts in new healthcare settings. Almborg et al. (2008) emphasized that patients need sufficient information about their illness, prognosis, care rehabilitation, opportunities for participation in discussions about medical treatment, goals and needs for care, services and the rehabilitation process.

Paper 2 (Dyrstad et al., 2015b) identifies a lack of information dissemination between healthcare professionals, the older patients and their next of kin. Relevant information from healthcare professionals is a prerequisite for patients to know which options they have and to be involved in decisions so that they know what to participate in (Thompson, 2007). Flink et al. (2012) found that lack of information about medication information was the main barrier to participation. When patients are well informed about what is happening, they feel confident to take initiative and make decisions about their care at the hospital (Henderson, 2003).

Patients expect to play an active role in their treatment and care, such as being informed about the causes of their illness, the prognosis, treatment options, being involved in decisions about treatment and doing all they can to promote their recovery (Coulter, 2011). There are also reports from the older patients with their health challenges, who prefer to participate during hospital discharge (Foss & Hofoss, 2011). Flink et al. (2012) reported that older patients preferred

to be key actors in the care transition process, being in a role of giving information to healthcare professionals. Patients could provide information about their current medications and previous care episodes in hospital admission and information about their general practitioner in hospital discharge. The patients got minimal opportunities to participate in the discharge process. Papers 1 and 2 in this thesis indicate that patients can take an active role, although next of kin used to have such a role with participation in transitional care or hospital discharge, as the older patients were not involved in discharge plans. This kind of power imbalance is also evident in Waterforth's study (1990). The author identified in their in-depth interview study with 12 patients that some patients were more concerned in pleasing the nurse, than they were in taking part in decisions concerning their care. The author concluded that individualized care is not necessarily synonymous with patient involvement. In other words, sometimes it seems like 'people are expected to fit around services, rather than services around patients' (Coulter, 2011, p. 3).

Some patients do not want to participate and play an active role in the treatment of their illness (Coulter, 1999; Flynn, Smith, & Vanness, 2006; Rothman, 2001). In the observational data and conversations with the older patients in this thesis, some patients held that the doctors should make the medical decisions, due to their expert competence. An 81-year-old woman said: *'They know everything. I have been here several times and they know what is best. One cannot interfere in the doctors' job; they find the proper treatment'*. This woman was very thankful and trusted the doctor's decision. Ekdahl, Andersson and Friedrichsen (2009) interviewed older patients and reported that the patients, to a large extent, trusted their doctor's decisions, and considered that he did what was best for them. The reason might be that older people often are characterized as incapable or unwilling to face choices about their medical care (Kennelly & Bowling, 2001). The authors found, in their focus group study of older cardiac patients, that few patients were involved in decisions on treatment and care. Most patients preferred that the doctor make the decisions about treatment options, but they still wanted to be involved in the decision-making process. Taylor (2009), in her critical literature review of patient centeredness and participation, reported that some patients with a cancer diagnosis and, in particular, older patients, were more comfortable with a paternalistic approach, which also is identified elsewhere (Coulter, 1999; Jones et al., 2004). Foss and

Hofoss (2011) emphasize that healthcare professionals need to actively look for older patients' desire to participate.

Several studies indicate the advantage for the older patients having their next of kin present during hospital discharge (Ellis-Hill et al., 2009; Hedberg, Johanson, & Cederborg, 2008; Perry, Hudson & Ardis, 2011; Roberts, 2002; Rydeman & Törnkvist, 2009). Next of kin are seen as crucial, although the older patients do not want to burden them (Perry et al., 2011). In the observational and interview study (paper 2 and 3), next of kin played an important role, as they supported and articulated the patients' needs in hospital admission. Having next of kin present made the older patients feel safe. Next of kin receive and give information to professionals, they stay bedside and support the older patients in hospital admission. In discharge, next of kin were commonly not present and were informed about the discharge after the decision was taken by healthcare professionals and the patient had been notified on the doctor's round. Similarly, Roberts (2002) explored older patients' participation during hospital discharge and found that only half of the patients had their relatives present during discharge. Rydeman and Törnkvist's study (2009) indicated that when patients have their next of kin present, both parties feel involved, they are heard and their views are considered. The interviews with healthcare professionals in hospital admission in this study (paper 3) revealed that although the patients' next of kin was seen as supportive, they were also demanding, as they were acting as advocates for the older patients. They could also be perceived to have wishes and concerns that could be different from the patient's preferences. According to professionals, they prioritized the patient's preferences if there were such differences. Systematic discharge planning, including information and involvement of both patients and next of kin, and inviting them to discharge planning meetings and the doctor's round could be useful approaches to supporting the role of next of kin in transitional care (paper 2).

The lack of information and involvement in transitional care suggests that paternalism is still prevalent in healthcare practice (Coulter, 2011; Dyrstad et al., 2015b; Dyrstad et al., 2015a; Groene et al., 2014; Spinewine, Swine, & Dhillon, 2006). Spinewine et al. (2006) revealed a paternalistic decision-making model concerning medication in acute care of older patients. With the results from recent research and the results from this thesis, one relevant question might be to ask if we have failed in the efforts to let patients experience

participation in healthcare? Real participation is, according to Cahill (1996), different from being involved, but the concepts of patient involvement and patient participation are often used interchangeably. In Cahill's (1996) hierarchical relationship, patient involvement forms the base of a pyramid, being a precursor to patient participation. Hence, patient participation is a more active concept, with patient partnership on the top. This suggests that the older patients in the observational study in this thesis, to some extent, were involved, but did not participate actively.

## **5.2 Healthcare professionals' role and perspective on patient participation**

Healthcare professionals' perspective has been explored within literature (paper 1) and in two empirical studies (paper 3 & 4) in this thesis. In paper 1, the review of older patients' participation in transitional care, paternalistic approaches were identified, with minimal information leading to disempowerment among patients.

The complex treatment of older patients with a compound medical picture, seems to contribute to minimal information from healthcare professionals in hospital admission and discharge (paper 1 – Dyrstad et al. 2015a). The nurse in hospital admission in the observation study gave information using common language and by repeating the information (paper 2 – Dyrstad et al., 2015b). One factor influencing information provision is the shortage of staff and beds available, both in municipality and at the hospital. Interviewed participants said that there was no time to inform the older patients properly. They also considered it time consuming to informing older people properly (paper 3 – Dyrstad et al., 2015c). This is also found in other studies, with healthcare professionals not prioritizing informing older patients having acute and chronic care needs (Drach-Zahavy & Shilman, 2014; Dyrstad et al., 2015a). Drach-Zahavy and Shilman (2014) conducted interviews with nurses where patients were characterized as bothersome when they asked questions about care plans and schedules during information exchange among nurses. It can be a dilemma for nurses to act patient-centered and giving important information to the patient when transferring sufficient and correct information to other healthcare professionals.

Interview results in paper 3 show that the study participants had good intentions to give high quality care and to see to the patients' needs. A medical doctor explained: *'The patients say what they want, if you sit down and ask them'*. Hence, not all were aware of informing and involving the frail and thankful older patients, who did not ask questions. A nurse did not figure out any possibility to involve the patient in the ED, as she said that the decision to admit the patient was already taken in municipality. In a study with participant observation, Henderson (2003) reported a power imbalance between nurses and patients. Nurses wanted to make decisions for patients instead of assisting them to make their own. Nurses gave procedural information and tried to persuade patients that they did what was in their patients' best interest, resulting in the patients perceiving that the nurses did not listen to what they had to say. This suggests that the nurses were not being patient-centered, ignoring the patients' preferences. From the patient's perspective, Epstein and Street (2011) indicate that the value of patient-centered care can best be judged by the patient.

The traditional 'paternalistic' ways of conducting healthcare (Bransford, 2011; Miller & Wertheimer, 2007; Wilson, 2005) involves making decisions for the patients or keeping some information from them, reasoning that it would be better for patients not to know (Stirrat, 2007). This involves healthcare professionals making the decision, whilst the patient accepts it. Results in paper 2 show that decisions about hospital discharge were made without involving the patient ahead of the ward rounds, and were based on healthcare professionals' professional judgments and views of the older patients' health condition. To practice paternalism in healthcare decision-making might be seen the same as disregarding the patient's autonomy, encouraging passivity and undermining people's capacity to look after themselves (Coulter, 2011; Gallagher, 1998). In paper 2 in this thesis, this might indicate that patients' autonomy, in some cases, was disregarded. When the patient's autonomy is supported, integrity is protected, leading to the patient's dignity (Randers & Mattiasson, 2004).

According Coulter (2011), patient participation has been slow to implement in practice, which also is revealed in this thesis. An argument to conquer paternalism is that 'paternalism breeds dependency, encourages passivity, and undermines people's capacity to look after themselves' (Coulter, 2011, p. 2). This argues that further emphasis on patient participation in practice is needed.



## *Discussion*

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Our observations showed that healthcare professionals expressed not having time to inform the patients properly, and when patients tried to explain their problem, they had to stop them (paper 2 – Dyrstad et al., 2015b). Research reports that the patient's participation improved when the nurse was present and the unit was less loaded with patients, and that the nurse's initiative towards the patient was facilitated when next of kin was present (Drach-Zahavy & Shilman, 2014). This suggests the necessity for healthcare professionals to stay bedside, listen to the patients and also to invite and allow next of kin to be present both during hospital admission and discharge.

Results from the Norwegian survey (The Norwegian Knowledge Centre for the Health Services, 2014) with lack of information of the patients in hospital discharge, long waiting time prior to the hospital stay and minimal coordination among caregivers indicates that patient participation is not sufficiently implemented in the Norwegian Healthcare system. In their study with semi-structured patient interviews in hospital admission, Arendts, Popescu, Howting, Quine & Howard (2015) revealed lack of information about hospital admission decisions and also long waiting times as negative aspects of ED care. Similarly, the improvement of care processes shows that the NHS culture in England still appears more paternalistic than in many other developed countries' health systems (Coulter, 2006). Referring to Coulter, 'Doing things to people instead of with them can be profoundly disempowering' (Coulter, 2011, p. 2). To accommodate this, the British government made efforts to incentivize a more person-centered approach by promoting awareness of patients' rights and focused on systematically monitoring the experience of service users, giving regular feedback to providers.

This argues that complex treatment and care needs often require awareness and involvement of qualified healthcare providers at different levels of the healthcare system, involving patients being transferred between different levels of healthcare (Aase et al., 2013). It also suggests that a patient-centered approach is needed to empower patients and enhance patient participation, and interprofessional simulation might be one way to go.

### **5.3 Impact of interprofessional simulation**

Interprofessional simulation was used as a learning activity in paper 4. We used a film scenario and group work with a debriefing section to improve patient participation in this study. The simulation training was reported useful by the participants to increase awareness of patient participation in transitional care (hospital admission and discharge). The use of simulation-based training is an evolving methodology in healthcare and healthcare education (Groom, Henderson, & Sittner, 2014). It aims to mimic real clinical situations, using clear objectives, playing scenarios with variable complexity and can be used as part of clinical practice and in the education and training of healthcare professionals (Groom et al., 2014; Jeffries, 2005). Simulation training is reported as successful within areas such as skills training, professional communication and collaboration, which are valued to be cost-effective, efficient and improving quality of care (Jeffries, 2005; Pfaff, 2014).

Learning in teams by means of simulation has roots in a socio-cultural learning perspective (Säljö, 1979). The socio-cultural perspective is grounded on the assumption that knowledge is constructed through participation and interaction between participants in social practice, here as simulation and teamwork. This view has its roots from Vygotsky (1986), with the assumption that learning together with someone is useful. Vygotsky believed that everything is learned in two levels, first on the social level and then on the individual level, which is understood as first in a social interaction and then integrated into the individual's mind.

Simulation with healthcare professionals from different units and levels of care has been suggested to be useful in developing professionals' competencies about patient participation in transitional care, and in improving communication and collaboration between levels of care (Cooper et al., 2011; Kirsebom, Wadensten, & Hedström, 2013; Storm et al., 2014a). Kirsebom et al. (2013) reported that nursing home nurses wanted to involve the patients' next of kin, in the decision of whether to hospitalize the patient or not. Hospital nurses wished that nursing home nurses would dare to keep the patients at the nursing home longer, if the clinical situation deteriorated. Both parties agreed in the need of an extended collaboration between hospital and municipality,

such as job rotation and discussion platforms between hospital and nursing homes, to improve teamwork and develop collaboration.

Log reports from the debriefing in the interprofessional simulation in paper 4 indicate that participants from the hospital and municipality improved their understanding of each other's work situation. Similar findings are reported in other studies (Brock et al., 2013; Pfaff, 2014; Storm et al., 2014a; Titzer, Swenty, & Hoehn, 2012). Pfaff (2014) reported successful results from conducting interprofessional simulation training with nursing students and radiologic students. Specifically, interprofessional team training was seen as a valuable experience, with the participants reporting a better understanding of their own role when communicating with patients and family, other team members and a better understanding of the role of other professions.

The film scenario used in the interprofessional simulation showed hospital admission and discharge of an older patient, with lack of information and patient participation. The qualitative data presented in paper 4 suggests that the participants increased their awareness of including patients in transitional care by informing and involving them in decision-making about treatment and care processes. The participants did not actively take part in the simulation scenario, as they were observing the film; nevertheless, they reported having learned from the film scenario. A recent review by O'Regan et al. (2016) indicated that the observer role can optimize learning in healthcare simulation education. In five out of nine studies, learning outcomes in the observer role were suggested to be as good or better than hands-on roles in simulation. Observer tools like checklists, feedback or observation guide were used. In eight studies, the observers were involved in the post simulation debriefing. Similarly, in paper 4, the participants observed the film scenario and debriefed in the group work, using an observation guide with questions, given ahead of the film scenario.

#### **5.4 Methodological reflections**

Several methodological issues used in this thesis should be discussed. Included here might be the use of different designs, as well as methods such as literature review, observational study, interviews and interprofessional simulation, which all are used in this thesis. Choice of methods is important in qualitative research,

as it is a question of trustworthiness of the data (Lincoln & Guba, 1985). These issues are discussed below, in terms of strengths and improvements needed.

### **5.4.1 Strengths**

The design of this thesis has been descriptive and explorative, using several methodological approaches. A literature review (paper 1) was purposive, to increase knowledge and competence about patient participation practice and be updated in the field.

The observational study (paper 2) consisted of participant observations. This was useful, to get first-hand information about older patients' participation in transitional care (Aase et al., 2013). Liberati (2016) argues 'shadowing' to be the preferred method, as to witness clinical practice and observe individuals without interrupting their normal activities. Participant observation means staying together with the research participants and taking part in the social interaction with the participants (Dewalt & Dewalt 2011). The reason for choosing participant observation in this study, and having the researchers wear a hospital uniform, was to be more unnoticeable, for the study participants to 'ignore' the researcher and not be nervous by their presence. The observations were carried out with the researchers using an observation guide, with specific themes to look for and observe. The themes were set according to the aims of the observational study, also in the larger project, as well as findings from the literature review (Aase et al., 2013; Dyrstad et al., 2015a; Laugaland et al., 2011). The observation guide contributed to strengthen the consistency of the observations in hospital admission and discharge.

In paper 3 there were face-to-face interviews conducted (Denzin & Lincoln, 2011; Kvale, 1996) with healthcare professionals (ambulance workers, nurses and doctors) to get in-depth information on their perspectives on patient participation in hospital admission. Referring to Blaikie (2010), the qualitative interview keeps the researcher away from the natural setting, as it is conducted in a room or an office. This supports the range in which the two methods were conducted, to first observe and then carry out the interviews. The qualitative interview can get the researcher close to the social actors' meanings and interpretations of the social interaction in which they are involved. The

interview guide was based on the project aims (Aase et al., 2013; Laugaland et al. 2011) and paper 1 in this thesis (Dyrstad et al., 2015a).

Papers 2 and 3 in this thesis show that healthcare professionals from hospitals and from municipality did not have any common arena to meet and discuss issues related to transitional care (hospital admission and discharge). Additionally, lack of knowledge and awareness about involving patients and next of kin in transitions was identified in the review (paper 1). 'The Meeting Point' was designed based on key challenges identified in transitional care (Storm et al., 2014a) in the larger study, with data from the observational and interview studies (Dyrstad et al., 2015a; Dyrstad et al., 2015c). Some of the participants at the meetings were working at the wards involved in the observations and interviews. Using observational data from the participants' own wards in the film scenario made the participants feel that the scenario was familiar to them. One participant said in the group work: '*Unfortunately it showed a busy day at work and I got many ideas for improvements*'. To increase competence within the field, educational seminars were chosen and consisted of both an educational part and a discussion platform (Storm et al., 2014b).

### **5.4.2 Limitations**

In the literature review, the literature search was limited to year 2000 through September 15, 2012 to get the most updated research in the field. We used selected parts of the Prisma 2009 Checklist to guide the literature review process (Moher et al., 2009). If the checklist had been followed to the full extent, it could have been called a systematic review, which is a more 'strict' review form. Our review contributed with knowledge and value to the research within the field of patient participation in transitional care of older patients.

The observational study was carried out using participant observations in hospital admission and discharge. The observations could have lasted for the patient's whole hospital stay and not only during the admission and discharge situation, which would have provided a 'complete' picture of the transitions (Liberati, 2016). Meanwhile, this was not within the scope of the study. Ideally, the same researcher could also have conducted all the observations in the study (Dewalt & Dewalt, 2011). For the interview participants to be better prepared, the interview guide could have been sent to them ahead of the interviews. To

get the whole picture, the interviews could also include in-depth interviews with patients and next of kin.

Conducting an interprofessional simulation required administrative resources, both to invite and involve different wards from the hospital and municipality. One limitation was a lack of participants at the last session, reasoning sickness among participants, overloaded wards and perhaps lack of leader follow-up. Due to the small number of participants from some of the wards, follow-up meetings with all participants and wards were not arranged.

## **5.5 Implications**

The findings in this thesis demonstrate that older patients experience low participation in transitional care, and healthcare professionals are to some extent aware of including them in decisions in treatment and care. Hence, several implications need to be acknowledged and taken into account within education, practice and research.

### **5.5.1 Education and practice**

The literature review (paper 1) and the empirical studies (papers 2, 3 and 4) in this thesis reveal insufficient information and patient participation of the older patients in transitional care. The results suggest that one approach to implement patient participation in transitional care can be through improving provider competencies and training. A relevant concept is to focus on information, involvement and to prepare older patients for upcoming transitions. This involves training to improve provider-patient communication, especially sharing information with patients and their next of kin, talking to patients and involving them in care planning and adapting to the patients' health condition (paper 3).

The observational study in this thesis indicates that future education of healthcare professionals, such as ambulance workers, nurses and doctors, specifically needs to focus on the patient's perspective. To do this, learning about being patient-centered and seeing the patient as a unique person with needs and preferences and skills is elementary (Epstein & Street, 2011). Also, lectures on communication skills, how to collaborate with other professional

groups and learning from each other's competencies can be focused. Interprofessional training for nursing and medical students related to themes like clinical professionalism, team performance and patient-centered perspective are reported as being successful (Aase, Hansen, & Aase, 2014; Aase, Hansen & Aase et al., 2016). Similarly, simulation-based training in nursing education has been evaluated as a promising learning method to stimulate students' reflections on their own behaviors in the simulated scenario (Husebø, O'Regan, & Nestel, 2015). Focus on patient participation can be implemented in lectures within all healthcare education in the future, enhancing healthcare professionals' awareness of patient participation and involving the patients in all treatment and care processes. Further, all the above scenarios and subjects might be related to transitional care. One measure might be simulation scenarios showing interprofessional healthcare personnel reporting and transporting older patients from the municipality to the hospital.

Standardizing routines for information exchange, organizing meetings with next of kin to plan follow-up care and encouraging the next of kin to stay with patients during hospital admission have been suggested to improve quality in transitional care (Storm et al., 2014a). Measures related to improving patient-centered care and involvement of next of kin can be useful.

A recent cross-sectional survey (Wroblewski, Joswiak, Dunn, Maxson & Holland, 2014) with patients admitted to surgical units shows that no more time was needed to conduct discharge planning rounds at the bedside than when having the meetings in a conference room. Fewer re-admissions and clarifying calls were made after discharge in the group with bedside rounds. The authors concluded that bedside rounds with patient-centered care and active participation by patients and next of kin is feasible and effective. The study seems promising for the older patients and their next of kin in this thesis, to be informed at the bedside, being asked and to participate in treatment decisions and planning care at the next stay.

Simulation training of clinical skills and procedures, such as inserting peripheral intravenous lines, wound care, tracheostomy care, etc. can also be useful for healthcare professionals from the hospital and community setting, to improve their clinical skills. These implications might hopefully prevent

numerous transitions, such as a hospital stay or a re-admission of older patients who reported wishes to stay at home as long as possible.

### **5.5.2 Research**

Study results in paper 4 suggest that the participants want ‘The Meeting Point’ to become a regular interprofessional arena across specialist and municipality healthcare services (paper 4). Arranging such meetings on a regular basis might enable a longitudinal study to see if there are differences between wards and levels of care. Interesting research might be to educate healthcare professionals in patient participation, and reveal precautions and challenges to implement patient participation in transitional care within different contexts. The educational activities can be developed into full-scale simulation scenarios opening for discussions in the debriefing section. The focus can be on providing and receiving information to and from patients and next of kin. Additionally, awareness about how patients can be included in the decision-making about treatment and care in transitional care is relevant. Full-scale simulation can focus on structured observations of the patient’s vital signs and agreements on how and when to contact professionals in municipality and vice versa. This can improve the communication between staff at hospitals and in municipality. To communicate a patient’s deteriorating clinical situation, SBAR (Situation, Background, Assessment, Recommendation), explained as a tool for structured communication between healthcare professionals, is highly relevant (Thomas, Bertram, & Johnson, 2009). The communication tool can be used for both healthcare professionals at hospitals and in municipality healthcare services. A measure might be simulation scenarios, with interprofessional healthcare personnel reporting and transporting older patients from the municipality to the hospital.

Researchers may conduct studies on patient-centered care in several ways, to enhance and increase implementation of patient participation. One useful approach can be to conduct action research studies, involving participants/staff from hospital, and in the community health services in an exchange program, and vice versa.

Future research can include the patients in the research process, not only as study participants, but as user representatives and advisors for the research team



## *Discussion*

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on issues related to the research on patient participation. Research studies focusing on empowering patients and educating them on how to get involved and prepare for transitional care, can be one way forward. In particular, stimulating patients to ask questions to stand up for themselves and take part in decision-making, hospitalized or not, is important. Such a research program with the patient perspective to work with a patient-centered mindset and enhance patient participation might be a way to improve healthcare quality and also collaboration between hospitals and the municipality.



## **6 Conclusions**

This PhD thesis has contributed to exploring participation of older patients in transitional care from the patients' and healthcare professionals' perspectives. It was accomplished by reviewing existing literature, observing hospital admissions and discharges, exploring patients' experiences and healthcare professionals' views and experiences through interviews. The thesis has also contributed to conduct interprofessional simulation, with the purpose to increase healthcare professionals' competence and awareness of patient participation in transitional care of older patients. The study will conclude by answering the research questions directed in the thesis.

- a) What are the key issues reported in the literature that influence older patients' participation in transitional care?

The key issues reported in the literature were lack of information and minimal participation of the older patients in hospital discharge, with lack of involvement in the decision-making process on where and when to go home. Next of kin often stayed by the patients during or after hospital discharge and made patients feel safe. Several tools identified have been implemented with variable success, some due to unclear purpose and others how to implement it in the clinical area. The most successful measures included checklists, educational transition programs and home visits. These measures improved patients' preparedness for discharge and family involvement, enabling older patients to stay longer in their own homes.

- b) What are the experiences of older patients and their next of kin with participation in hospital admission and discharge?

In the observational study, the patients experienced minimal information in the triage part of the ED, but sufficient information and patient participation in the treatment part of the ED. In hospital discharge, poor information and patient participation was experienced by the older patients, feeling that hospital discharge came unexpectedly and they were unprepared, as decisions were taken by healthcare professionals without consulting them.

## *Conclusions*

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- c) How do healthcare professionals practice participation of older patients during hospital admission and discharge?

Observations during hospital admission from the triage part of the ED, illustrated there was not much time to attend to each patient, with minimal information from the nurses. In the treatment area, the nurse and the doctor, for the most part, stayed in the patient's room. Information about planned tests, treatment and length of stay in the ED was provided. Patients were commonly asked about their history of symptoms, pain and worries, as well as the patients' preferences. During discharge, there was shortage of beds with pressure to discharge patients in order to receive new patients. There was variability in time spent at the patients' bedside, with information about decisions to discharge decided at the pre-ward round. Some doctors chose to sit at the patients' bedside, others were standing at the end of the bed, communicating with junior doctors and the nurse only. Next of kin were called after rounds to inform them about discharge decisions. No scheduled discharge planning meetings with patients and their next of kin were arranged, and decisions were made among healthcare professionals at the hospital and in the municipality.

- d) What are the perspectives of healthcare professionals on patient participation in hospital admission?

Interviews with healthcare professionals showed that first priority in the ED was triaging the patient by checking vital signs to provide correct treatment. Older patients in the ED were often frail with several chronic diseases and numerous medications, hard of hearing, with feeling sick and dizzy upon hospital admission. They were therefore seen as a challenging group to involve in their own treatment and care. Due to lack of resources with minimal available staff and beds in municipality healthcare services, patients were often admitted to the hospital without adequate information about medical history and medications. Time pressure was reported to result in minimal time spent on each patient. The interviews indicated good intentions to include patients and give high quality treatment and care during hospital admission by sitting at the patients' bedside, asking about their health challenges. Healthcare professionals were also concerned about avoiding unnecessary hospital admission of older people, as they were perceived to stay at home for as long as possible. Healthcare professionals found presence of next of kin valuable when providing

### *Conclusions*

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information to the patients, as they were a valuable information source and they made the patients feel safe. Nevertheless, next of kin were challenging when their proposals were different from the patient's needs and wishes.

- e) How can interprofessional simulation increase healthcare professionals' awareness of and competencies about patient participation in transitional care of older patients?

Based on the data from the literature review and the empirical studies in this thesis, an interprofessional simulation was carried out. Interprofessional healthcare participants from both the hospital and municipality were involved in simulation-based training. The simulation included both an educational part and a discussion platform based on a film scenario and questions in group work. The interprofessional simulation contributed to drawing attention to the importance of patient participation of older patients in transitional care and the possibility to implement the suggested implications in healthcare education, practical areas and in research. At last, and most importantly, this study might contribute to increased patient participation in transitional care of older patients so that they feel heard, respected and so that their preferences are taken into account, thereby enhancing self-care and autonomy.



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## **List of papers**

### **Paper I**

Dyrstad, D. N., Testad, I., Aase, K. & Storm, M. (2015a). A review of the literature on patient participation in transitions of the elderly. *Cogn Tech Work*. Springer. 17:1, 15–34. Doi:10.1007/s10111-014-0300-4

### **Paper II**

Dyrstad, D. N., Laugaland, K. L. & Storm, M. (2015b). An observational study of older patients' participation in hospital admission and discharge. *Journal of Clinical Nursing*. 24, 1693–1706. Doi: 10.1111/jocn.12773

### **Paper III**

Dyrstad, D. N., Testad, I. & Storm, M. (2015c). Older patients' participation in hospital admission, through the emergency department: an interview study of healthcare professionals. *BMC Health Services Research*. 15:475. Doi:10.1186/s12913-015-1136-1

### **Paper IV**

Dyrstad, D. N., Storm, M. (2016). Interprofessional simulation to improve patient participation in transitional care. *Scandinavian Journal of Caring Sciences*. Online 21 Jul. Doi: 10.1111/scs.12341



## **Paper I**





## A review of the literature on patient participation in transitions of the elderly

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Karina Aase · Marianne Storm

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**Abstract** Patient participation is highlighted in healthcare policy documents as an important area to address in order to improve and secure healthcare quality. The literature on healthcare quality and safety furthermore reveals that transitional care carries a risk of adverse events. Elderly persons with co-morbidities are in need of treatment and healthcare from several care professionals and are transferred between different care levels. Patient-centered care, shared decision-making and user involvement are concepts of care that incorporate patient participation and the patients' experiences with care. Even though these care concepts are highlighted in healthcare policy documents, limited knowledge exists about their use in transitions, and therefore points to a need for a review of the existing literature. The purpose of the paper is to give an overview of studies including patient participation as applied in transitional care of the elderly. The methodology used is a literature review searching electronic databases. Results show that participation from elderly in discharge planning and decision-making was low, although patients wanted to participate. Some tools were successfully implemented, but several did not stimulate patient participation. The paper has documented that improvements in

quality of transitional care of elderly is called for, but has not been well explored in the research literature and a need for future research is revealed. Clinical practice should take into consideration implementing tools to support patient participation to improve the quality of transitional care of the elderly.

**Keywords** Healthcare quality · Patient participation · Transitional care · Elderly · Systematic review

### 1 Introduction

There is a fast-growing elderly population worldwide (WHO 2011a, b) often with several medical diagnoses and with an increasing need for clinical care across primary and secondary healthcare. This complex need for care and treatment is often caused by chronic diseases, physical disability, cognitive impairments and polypharmacy (Foss and Askautrud 2010; McCall et al. 2008) and require the elderly patients to transfer between different levels of healthcare, with an increasing risk of fragmented care and adverse events (Coleman et al. 2005; Danielsen and Fjær 2010). Awareness, involvement of qualified healthcare professionals and comprehension of the task distribution at different levels of the healthcare system are needed to ensure quality in the treatment and care of the elderly (Aase and Testad 2010). Over the last decades, patient participation in healthcare has been emphasized in health policy documents in Europe and globally, and the patient perspective is a main area of WHO's Patient Safety Strategy (WHO 2011a, b).

Transitional care is described by Coleman and Boulton (2003) as a set of actions ensuring the coordination and continuity of healthcare as patients transfer between

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different levels of care within the same location or between locations; i.e., admission to and discharge from specialist healthcare (hospital) to community care and elderly home care facility (Coleman and Boulton 2003; Laugaland et al. 2012). Many transitions are unplanned and patients and family members are unprepared. In addition, inadequate discharge planning often leads to readmission (Huber and McClelland 2003). The patients and their caregivers are most often the only common and stable factor moving across different levels and sites of care (Coleman et al. 2004). Involvement and participation of elderly in transitional care has been suggested as one way of preventing adverse events and improving the quality of transitional care (Foss and Hofoss 2011; Huber and McClelland 2003).

Healthcare quality is by patients and relatives characterized as individualized, patient-focused care, attending to the needs and concerns of the patient and provided through a caring and committed relationship between staff and patient, demonstrating patient involvement and participation (Attree 2001). User or patient participation is defined by WHO (2011a, b) as the patient's right to participate in decision-making concerning level of care and where to live. Patient participation involves sharing of information, power transfer from nurse to patient, intellectual and/or physical activities and the benefits of these activities (Cahill 1996). Patient collaboration is a matter of cooperation between patient and provider. Patient-centered care and shared decision-making incorporate patient participation and the patients' experiences with care. The Quality Chasm' report defines "patient centeredness" as staff providing care that is respectful and responsive to the individual patient's preferences, needs, encouraging patient involvement in care and decision-making. Shared decision-making is suggested as one useful tool placing the person in the center of care (IOM 2001). It aims to increase patients' knowledge and control over treatment decisions by involving both the patient and the service provider in the decision-making about treatment and care (Storm and Edwards 2012). To achieve shared decision-making, there has to be a partnership between provider and patient where the provider listens to and respects the patient's views about their health, where both parties share information, discuss diagnosis, treatment and care needs in order to maximize the patient's opportunities and abilities to make decisions and respect the patient's decisions (Godolphin 2009).

In the present study, we examine patient participation in the specific context of elderly patients' involvement and participation in transitional care. It involves patients and healthcare professionals sharing information about medical concerns, diagnosis, prognosis, medications and relief measures. It includes considering the patient's views and wishes at admission to or discharge from hospital. It also includes patient involvement in care planning and decision-

making about; time of discharge, whether to go home or to a care home, follow-up care, physiotherapy and other vital decisions. There is limited knowledge about how patient participation is adapted to transitional care for the elderly, and how patient-centered care and shared decision-making models of patient participation are integrated (Storm et al. 2012). This paper therefore provides an overview of the existing literature describing patients' participation in transitional care as well as different tools for supporting it.

## 2 Aim of the study

The overall aim of the study was to give an overview of the existing literature on elderly patients' participation in transitional care. Hence, the following key research question is addressed in the study:

What are the key issues reported in the literature that influence on elderly patients' participation in transitional care?

## 3 Methodology

### 3.1 Literature review and data collection

A literature review was performed, using the 27 point Prisma Checklist of the relevant literature (Moher et al. 2009). An integrative approach was used including the literature with multiple research designs and methodologies (Whittemore et al. 2005).

#### 3.1.1 Databases

The literature searches were performed in the electronic databases Cinahl, Medline, Academic Search Elite, Scopus, ISI Web of Science and the Cochrane Database of Systematic Reviews. These databases were considered most appropriate for our literature searches as they provide peer-reviewed articles within the field of health and social sciences. The search was done performing an open-ended search with the terms "patient participation" or "consumer participation" or "patient-centered care" or "user involvement" or "shared decision\*" in Cinahl, Medline and Academic Search Elite. The search words were combined with "transitional care" or "care transit\*" or "patient transfer" or "handover" or "admission" or "discharge" and combined with "elder\*" or "aged" or "old\*". Then searches with all the search terms were conducted in Cochrane, Scopus and ISI Web of Science. The terms "patient participation", "patient transfer" and "aged" were chosen as they are MeSH words. The other search words were used due to their relevance to our study. The

**Table 1** Databases, search strategy, search terms and results

Database	Search strategy: (1) Years 2000-15th September, 2012 (2) English language (3) Terms used (4) Peer-reviewed (5) Content	Search terms: “patient participation” or “consumer participation” or “patient-centered care” or “user involvement” or “shared decision*” AND “transitional care” or “care transit*” or “patient transfer” or handover or admission or discharge AND elderly or aged or old*	Search results (n)	Accepted research articles (n)
Cinahl	All criteria used	All search terms used	90	19
Medline	x	x	203	6
Academic Search Elite	x	x	21	3
Cochrane	x	x	1	0
Scopus	x	x	428	0
ISI Web of Science	x	All search terms except the last conjunct	49	0
Hand search	x	All search terms used	5	2
Total			797	30

Cochrane database was searched in order to find review articles including empirical studies that could be relevant to our study. The search was performed with the string spelled out in all 6 databases, but in ISI, we excluded the last conjunct, as the search otherwise yielded no results.

### 3.1.2 Inclusion criteria and search strategy

Titles, abstracts and full-text articles were analyzed independently by two researchers to ensure that all relevant studies were retrieved, according to the inclusion criteria; i.e., (1) articles from January 1, 2000 until September 15, 2012, (2) English language, (3) search terms, (4) peer-reviewed articles published in scientific journals and (5) content: elderly patients’ participation in transitional care between different levels of care or between locations to improve the quality of care. Patient-centered care and shared decision-making were used as search terms as these incorporate patient participation and the patients’ experiences with care. These concepts were combined with terms synonymous to “transitional care” and “elderly” as presented in Table 1.

### 3.2 Review sample

The flow diagram for reaching the final sample with articles included in the review is presented in Fig. 1 (Moher et al. 2009).

Excluded studies (550) from the Ebsco Host search engine (Cinahl, Academic Search Elite, Medline), Cochrane, Scopus, ISI Web of Science and hand searches were either studies of mental health, transition to a hospice, transition within healthcare institution or the study did not

address patient participation, according to our definition. A total of 204 abstracts were read independently by two researchers. Sixty-five full-text articles were assessed for eligibility and 30 studies were included in this review. Fifteen studies were on patient experiences with participation in transitional care and 15 on tools to support elderly patients’ participation in transitional care.

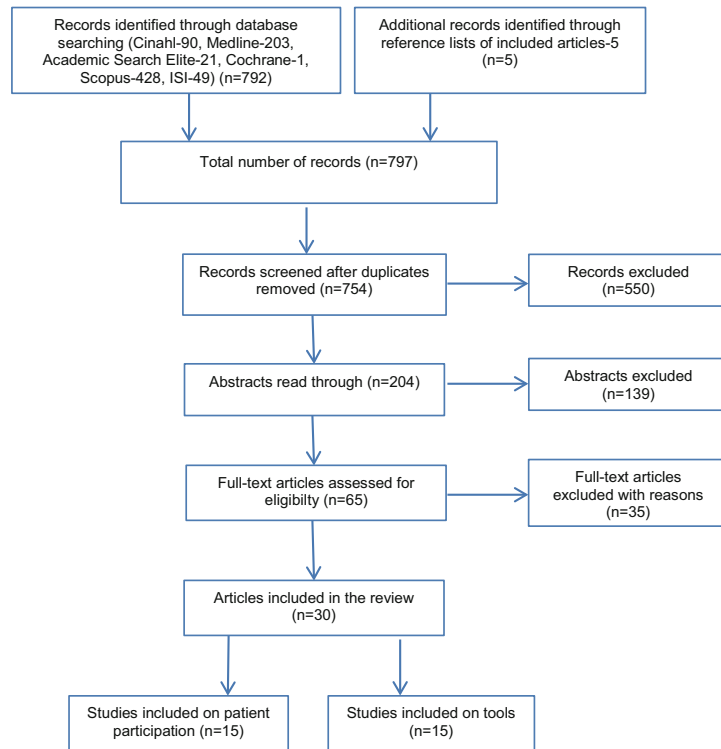
### 3.2.1 Analysis

Thematic synthesis was used in this review to explore the current research question (Polit and Beck 2008). For studies on elderly patients’ participation in transitional care, each article was summarized according to the following items: study (author, year, country and journal), aim, definition patient participation, design, participants, recruitment, results, implication/contribution and reported credibility. For studies on tools to support patient participation in transitional care, the review sample was analyzed according to the following items: study (author, year, country and journal), tool/intervention, definition patient participation, study design, outcome focus, participants, results, reported validity and reported reliability. For the review, sample information on country of first author and publication year was reported.

## 4 Results

In the first part, studies exploring elderly patients’ participation in transitional care are reported. In the second part, studies on tools to support elderly patients’ participation in transitional care are presented.

**Fig. 1** Flow diagram for final review sample



#### 4.1 Elderly patients' participation in transitional care

Studies included were designed to describe elderly patients' participation in discharge and rehabilitation planning. All sixteen studies included older patients, age span from 60 and older. The sample size varied from eight to 3,538 participants. All studies explored elderly participation in the discharge process. Eleven studies were performed by semi-structured interviews focusing on the discharge process, three were observation studies of discharge meetings with follow-up interviews (Hedberg et al. 2008; Huby et al. 2004, 2007) and two used a quantitative questionnaire followed by qualitative interviews (Roberts 2002; Somme et al. 2008). Of the fifteen articles, four included the carers or the relatives (Ellis-Hill et al. 2009; Hedberg et al. 2008; Roberts 2002; Rydeman and Törnkvist 2009) and three had a dual perspective on both patient and professional carers (Hedberg et al. 2008; Huby et al. 2004, 2007). The studies were published in nursing, physiotherapy, occupational therapy and public health journals. Some studies specified the diagnoses, which varied from medical diagnoses such as stroke or orthopedic diagnoses such as lower limb or hip fractures, while some

studies referred to ordinary rehabilitation patients. The concept "participation" was defined in five studies (Table 2).

Included studies most often had a patient perspective and were related to participation in discharge planning. Analysis revealed the following main categories: information, participation in discharge planning, formal assessment on functional ability, paternalism, disempowerment, the content meaning of participation, "good" experiences of transitional care and family support.

##### 4.1.1 Information

Lack of information concerning the discharge process was apparent in several of the studies exploring the patients' perspective on discharge planning (Benten and Spalding 2008; Ellis-Hill et al. 2009; Foss and Hofoss 2011; McKain et al. 2005; Perry et al. 2011; Swinkels and Mitchell 2008). Information was provided orally. In one study by Benten and Spalding (2008), written information had been provided as an information leaflet covering the purpose and goal of the intermediate care unit. Despite this none of the elderly patients had been informed about intermediate care,

**Table 2** Studies exploring elderly patients' participation in transitional care

Study (author, year, country, journal)	Aim	Definition patient participation	Design and discipline	Participants	Recruitment	Results	Implication/contribution	Reported credibility
Foss and Hofoss (2011) Norway <i>Patient Education and Counseling</i>	Describe patients' experiences with participation in discharge planning	Thompson's (2007) taxonomy: noninvolvement, information, dialogue, shared decision-making, autonomous decision-making	Quantitative study. Face-to-face interviews w/elderly using a questionnaire nursing	$N = 254$ patients (mean age 86.9)	Participants identified by head nurse at home care offices in different municipalities	Preference for participation, low opportunity to share decisions. "Real participation", minor "shared decision" (58 %), received information (<43 %), opportunity to speak (56.5 %). Family present (22 %)	Actively look for elderly's desire to participate in research and in hands-on processes of discharge	Use of personal interviews analyzed by SPSS 17
Perry et al. (2011) New Zealand <i>Journal of Rehabilitation Medicine</i>	Explore perceptions of being discharged home following lower limb orthopedic surgery	No	Qualitative design. Interviews w/elderly physiotherapy	$N = 11$ patients >65 years	Recruited in the Greater Wellington Region of New Zealand	(i) Lack of shared decision (ii) Dependent on family to go home (iii) Trial and error rehabilitation	The importance of family and/or friends for indirectly providing financial, social and emotional support	Using interpretative phenomenological analysis
Ellis-Hill et al. (2009) New Zealand <i>Disability and Rehabilitation</i>	Understand "good" or "poor" experience in the transition from hospital to home following a stroke	No	Qualitative design. Semi-structured interviews social science	$N = 20$ (mean age 70 years) patients. 13 carers	Stroke diagnosis. Patient and carer within one month of being discharged from hospital	(1) continuity in recovery versus loss of momentum, (2) being supported versus being abandoned, (3) being in the picture versus being in the dark	Healthcare professionals should get a clear model of recovery. Follow-up and support based on physical support	Analytical member check
Rydeman and Tomkvist (2009) Sweden <i>International Journal for Older People, Nursing</i>	Examine and model home-nursing care and their relatives discharge process experiences	No	Qualitative design. Semi-structured interviews Discipline not reported	$N = 26$ patients >65 years (mean age 79 years) and their relatives	Geriatric, orthopedic, infectious, neurological and rheumatological patients 4–8 weeks after discharge from hospital	Main concern is to "feel prepared for life at home". Resulted in a theoretical model	Train discharge process skills and checklists to determine individual needs	Constant comparison through collection, selection, coding and analysis of data

Table 2 continued

Study (author, year, country, journal)	Aim	Definition patient participation	Design and discipline	Participants	Recruitment	Results	Implication/contribution	Reported credibility
Almberg et al. (2008) Sweden <i>Journal of Clinical Nursing</i>	To describe stroke patients' perceptions of participation in the discharge planning process	(1) As information about illness, care, rehabilitation (2) discussions of medical treatment and (3) goals, needs for care, services, rehabilitation	Quantitative design. Face-to-face interviews 2–3 weeks after discharge Discipline not reported	N = 188 patients (mean age 74 years)	All patients from two municipalities who were admitted to the stroke unit at a hospital	Participation in discharge planning: (72–90 %) according to information, (29–38 %) according to medical treatment and (15–47 %) according to goals and needs	Implemented methods for goal setting and identify patients' needs	Univariate analysis and exploratory factor analysis
Benten and Spalding (2008) USA <i>Quality in Ageing</i>	To explore service users' experiences of an intermediate care service	No	Qualitative design. Face-to-face semi-structured interviews with a follow-up interview Occupational therapy	N = 8 patients >65 years	Purposive sample	Users' understanding, Assessment and goal setting, Interventions, Transfer home, Poorly informed, unable to make decisions, 37 % felt involved in decision-making	Recommendations toward service, improvement feedback to managers	Phenomenological approach with open-coding and recoding analysis
Hedberg et al. (2008) Sweden <i>Journal of Clinical Nursing</i>	To explore how stroke survivors, their relatives and professionals communicated in care-planning meetings as part of discharge planning	No	A qualitative and a quantitative design. Observation and audio-recorded care-planning meetings Nursing	N = 14 patients >64 years N = 41 professionals (nurses, social workers, occupational therapists)	Hospital geriatric rehabilitation ward, different rehabilitation centers	Professionals dominated the discourse space (58 % compared to patients and relatives 42 %). Staff communicated in an informative and explaining manner (42 %)	In-depth education and training in how to communicate in multidisciplinary teamwork	Independent coded and categorization

Table 2 continued

Study (author, year, country, journal)	Aim	Definition patient participation	Design and discipline	Participants	Recruitment	Results	Implication/contribution	Reported credibility
Swinkels and Mitchell (2008) UK <i>Health and Social Care in the Community</i>	Participants' perceptions on the effects of delayed transfer into community, involvement in discharge planning and care needs	No	Phenomenological approach Conversational interviews Discipline not reported	$N = 23$ patients >65 years (mean age 82 years)	Discharge Liaison Nurses (DLN) made all initial approaches	Actively or passively relinquishing of involvement in the process of discharge planning, no significant role in discharge processes	Engagement of older people in the process of provision of long-term care outside of hospital	Use of NVivo data analysis software
Somme et al. (2008) France <i>Arch Gerontological Geriatrics</i>	Identify factors influencing residents' involvement in decision-making prior to the admission to a long-term care setting	Involvement as a fundamental legal right	Quantitative using national survey data Discipline not reported	$N = 3,538$ (below 80, 80–90 and over 90 years)	Random selection (10 % of the permanent residents)	Involvement in admission low, Risk factors: loss of autonomy, not being able to provide income data, age less than 80 years, being married	Not reported	Univariate analysis with X-test, multivariate analyses, logistic regressions
Huby et al. (2007) UK <i>Journal of Interprofessional Care</i>	Understand perception and experience in discharge planning	"Enabling Older People to make informed Choices as Active Participants in Care" (NHS Scotland 2004)	Mixed method design, Semi-structured interviews and systematic observation. Discipline not reported	$N = 22$ patients >60 years, $N = 11$ staff	Purposive sampling	(1) "Participation" and "decision-making". 2. "Independence" Procedures are initiated, but not comprising decision-making	Patients and carer concerns in decision-making is an ethical imperative	Triangulation of methods
McKain et al. (2005) Australia <i>Older people</i>	Gather information about patients' needs prior to the transfer from acute care to a rehabilitation setting that assist patients to engage actively in rehabilitation activities	No	Qualitative design. Semi-structured interviews Nursing and physiotherapy	$N = 9$ patients, mean age 74.9 years	Patients admitted to rehabilitation unit during a two-month period	Participants received very little information about what to expect on admission to the rehabilitation unit	Active engagement in program planning. Be cognizant of the perceived power differential between staff and patients. Early discharge as a motivator	Four of the nine participants were interviewed one more time after discharge

Table 2 continued

Study (author, year, country, journal)	Aim	Definition patient participation	Design and discipline	Participants	Recruitment	Results	Implication/contribution	Reported credibility
Gibbon (2004) UK <i>Jama</i>	Exploring service users' experiences of their rehabilitation	No	Qualitative design. Semi-structured interviews nursing	$N = 24$ stroke patients >65 years	Patients with a stroke diagnosis, cared for at a stroke unit been discharged to their own homes	"Key contributors", "goal setting", "discharge home". Key contributors: doctors, physiotherapists, occupational therapists and nurses. Nurses most valued. No direct patient involvement in goal setting	Experiences provide valuable insights into aspects of care and service delivery, participation in goal setting	Pilote testing of data collection tool
Huby et al. (2004) UK <i>Health, Risk and Society</i>	Develop a methodology to explore participation in discharge decision-making	See Huby et al. (2007)	Qualitative design. Ward-based observation and formal interviews Discipline not reported	$N = 22$ older patients (not any specific age)	A care of the elderly department	Participation in decision-making linked to systems of risk management. Patients not able to express their views and staff did not trust the patients' competence to take part in decision-making	The dynamics excluded both patients and staff from active decision-making and produced new risks	Triangulation of data and researchers
Roberts (2002) UK <i>Journal of Advanced Nursing</i>	Develop user participation in health and social care	Individuals active role in decisions of personal care; participation with service providers on an individual basis	Quantitative and qualitative design. Questionnaires and interviews Nursing	$N = 260$ questionnaires $N = 30$ interviews (age 70+)	All patients aged 70+ discharged from one hospital to home over a 5-month period	63 % felt involved in decisions regarding discharge, 33 % felt able to communicate with doctors, 63 % with other professionals	Reasons for the level of users' involvement in decisions needs to be identified	SPSS, thematic and content analysis



Table 2 continued

Study (author, year, country, journal)	Aim	Definition patient participation	Design and discipline	Participants	Recruitment	Results	Implication/contribution	Reported credibility
Roberts (2001) UK <i>Health and Social Care in the Community</i>	Explore health and social care users' participation on discharge	No	Qualitative design. Interviews	See Roberts (2002) $N = 30$ interviews	Respondents from the questionnaire study (Roberts 2002) were asked to take part in an interview. $N = 30$	22 interviewees reported having been consulted	'Seamless' care	Tape recorded interviews, transcribed verbatim. QSR Nud 1st used to organize the data

before it was suggested by professionals that they were to be transferred. Service users therefore lacked the understanding and the awareness of the potential and the goals of the intermediate care services. McKain et al. (2005) also reported patients receiving very little information about what to expect on admission to a rehabilitation unit.

Two studies (Perry et al. 2011; Swinkels and Mitchell 2008) documented that some patients were not aware of their own formal discharge plan. One study (Foss and Hofoss 2011) revealed sparsely information to patients about discharge. This was in contrast to Almborg et al. (2008) who found that the elderly patients felt they had received sufficient information about their illness, tests, examinations, medication, rehabilitation and possibility to ask questions.

#### 4.1.2 Participation in discharge planning

Minimal participation in the discharge process was reported in several studies (Almborg et al. 2008; Bente and Spalding 2008; Foss and Hofoss 2011; Perry et al. 2011; Somme et al. 2008). Swinkels and Mitchell (2008) focused on elderly patients' perceptions of effects of delayed transfer into the community, involvement in discharge planning and future community care needs. Decision about transfer to a residential or nursing care was, according to the patients, taken by healthcare professionals. This led to feelings of distress and several patients speculated about self-discharge.

Bente and Spalding (2008) investigated the experiences of older people moving from hospital to intermediate care. The authors found that few participants felt they were involved or participated in the decision-making process. Patients thought that the main reason for transfer was that they were "bed-blockers" and did not know that they were enrolled in an active rehabilitation program.

Perry et al. (2011) revealed lack of shared decision on when to go home and dependence on family to feel confident. Some patients expressed the view that they could not go home unless a formal or informal care was arranged. The elderly patients trusted the health services system, they did what they were told and did not complain. Patients could not actively take part in decision-making plans, as they were not aware of the formal discharge plans.

Gibbon (2004) found that many patients expressed a desire to go home as soon as possible, but worried about how to cope and they wanted to be cared for by the family. The staff had a weekly team conference, but the patients were not invited. This made the patients passive in goal setting and action planning. The author suggests that professionals were uncomfortable with or feared having unrealistic aims about the patient recovering from stroke.

#### 4.1.3 Formal assessment on functional ability

The purpose of Huby et al.'s case study (2007) was to understand how elderly patients experienced participation and how professionals enacted participation in discharge planning. They found a procedurally driven care, not comprising decision-making. Discharge planning sometimes started on admission, but relied to a large extent on formal assessments. The use of formal assessments of the patients' health condition produced patterns of involvement which "broke down each patient's identity into a collection of graded physical and cognitive abilities and made it difficult to include patient-centered views on independence" (p. 63).

In Bente and Spalding's study (2008), most patients were not aware of rehabilitation goals being set for them. The rehabilitation concept was seen as little purposeful for active rehabilitation; nevertheless, some were involved in preparation for going home. Most of them were not aware of a formal assessment of their physical, personal or social needs, or rehabilitation goals on admission.

Huby et al. (2004) documented that goal settings for rehabilitation were set by physiotherapists and occupational therapists together with the patients. However, since patients were not present at the meetings, staff had limited information about the patients' competence to manage on their own, according to cognitive and physical ability. This inhibited communication between staff and the patients. Staff explained lack of patient participation as due to lack of patient motivation when they failed to engage the patient in the rehabilitation goals, although the patients had clear thoughts about how to cope with the situation. Huby et al. (2004) raised the question "whether the patients failed to engage in the system, or whether the system of care failed to engage the patient" (p 128).

#### 4.1.4 Paternalism

Several studies revealed a paternalistic approach, but few used the term "paternalism" (Almborg et al. 2008; Ellis-Hill et al. 2009; Perry et al. 2011). A paternalistic medical model was suggested by Almborg et al. (2008) as participants to a limited degree experienced participation in medical treatment decision-making. Contact with health professionals was characterized as one-way communication in order to inform patients (Perry et al. 2011). Some professionals explained it as "the patients did not want to be involved in discussions concerning their treatment" (Almborg et al. 2008, p 205).

Hedberg et al. (2008) conducted observations of inter-professional care-planning meetings. Study results showed that patients needed communicative alliances with family members or other participants when negotiating their needs

and desire for further care. There were illustrations of how professionals attempted to persuade the patients to accept their suggestions, and nurses that did not support the patients' wishes during the care plan meetings. The study revealed a need of further knowledge on how to involve vulnerable patients in communication.

Foss and Hofoss' (2011) results suggest that the elderly patients preferred participation, but they did experience few opportunities to speak, to be heard, and to be involved in shared decisions and therefore not often experienced "real participation".

#### 4.1.5 Disempowerment

Not involving patients in decisions concerning their own treatment, care or discharge process may lead to disempowerment of patients (Bente and Spalding 2008). Swinkels and Mitchell (2008) reported patients' experiences of depression, change in functional ability, dependence on others, hopelessness, apathy, grief and loss of personal autonomy. Patients felt imprisoned in hospital and disempowered, but despite this several speculated about self-discharge.

When professionals had an unstructured approach, they were often task-oriented, and the patients' individual needs risked being unsatisfied. Patients and relatives did not feel they were heard or seen and they felt not involved in the discharge planning process. Patients felt resignation and powerlessness when they experienced that professionals had made up their mind before discussing with patients and their family and being discharged when feeling unprepared (Rydeman and Törnkvist 2009).

#### 4.1.6 The content meaning of participation

Huby et al. (2004, 2007) found that the concept participation was unknown among the participants and did not have a useful meaning to them. Patients also lacked understanding of the language used by professionals and the purpose of rehabilitation in the discharge planning meetings. There was a link between participants' reduced ability to take part in decisions and their frailty making them more dependent on others to make decisions on their behalf.

Roberts (2001, 2002) found that the majority of the patients felt they were involved in decisions about discharge from hospital and had opportunities to express their wishes to healthcare staff, although some patients let the professionals make decisions on their behalf. This was in contrast to interview results where one elderly patient revealed what the meaning of participation could entail by saying: "they've told me what they were going to do, and they've done it" (Roberts 2002, p. 413). The participants

were not involved in transitional care, except for being informed and they understood this as participation.

#### 4.1.7 “Good” experiences of participation in transitional care

Ellis-Hill et al. (2009) reported that patients perceived discharge as successful when they felt informed. The authors argued that sharing of information gave patients more understanding of service decisions and possibilities, resulting in a more honest and less paternalistic approach.

Rydeman and Törnkvist (2009) showed that patients felt prepared for life at home when their needs were met such as caring issues, activities of daily living and where to return. Feeling prepared was explained as having a satisfactory understanding of how life at home would be. It was important for the participants that professionals had preparation skills and used a guiding approach, meaning that the professionals gave individual information, instructions regarding disease and treatment and discharge time scale. When the elderly’s views were considered and there was time available for conversation, patients felt involved and secure in the discharge process.

#### 4.1.8 Family support

Some studies had a patient and carer perspective documenting the seemingly advantageous position of elderly patients having their family or carer present to support and articulate their needs (Ellis-Hill et al. 2009; Hedberg et al. 2008; Roberts 2002; Rydeman and Törnkvist 2009). Roberts (2002) found that only half of the older participants in the study had their relatives present in the discharge meeting. Family members often stayed by the patients during or after discharge. It made the patients feel safe and could for example prevent newly operated patients from falling. Family support was crucial, although the patients did not want to burden their relatives (Perry et al. 2011). When professionals had a guiding approach to the older persons and their families they felt involved and secure in the discharge process, that they were heard and their views were considered (Rydeman and Törnkvist 2009).

### 4.2 Tools to support elderly patients’ participation in transitional care

Tools<sup>1</sup> to support elderly patients’ participation in transitional care were all implemented as part of discharge planning and rehabilitation. All fifteen studies included

<sup>1</sup> Several concepts are used in the review sample for tools. In this study tools is a collective term for concepts like measures, interventions, initiatives.

older patients and the sample size in each study varied from seven participants to 310. Five studies used a quantitative design and were carried out as an intervention (Bull et al. 2000; Coleman et al. 2004; Jangland et al. 2012; Preen et al. 2005; Watkins et al. 2012). Eight studies had a qualitative approach, using semi-structured interviews (Brooks 2002; Clarke et al. 2010; Efraimsson et al. 2006; Moats 2007), a combination of semi-structured interviews and focus groups (Griffith et al. 2004; Reed and Stanley 2003), observation (Grimmer et al. 2006a) and in combination with video-recorded meetings and follow-up interviews (Efraimsson et al. 2004). Two studies were performed using both a quantitative and a qualitative approach (Grimmer et al. 2006b; Parry et al. 2008). Four studies defined patient participation. An overview of included studies and methodological approach is presented in Table 3.

The review revealed several measures and interventions developed and implemented to support patient participation in discharge of elderly patients. The introduction of these tools resulted in both positive and negative experiences and outcomes.

#### 4.2.1 Family meetings

Griffith et al.’s study (2004) was on family meetings, involving family members, the patient and hospital personnel in discussions concerning the patient’s illness, treatment and discharge plans. The goal was to explore opinions of the participants in order to improve the quality of care planning. Several patients reported that they had no opportunity to participate in family meetings. Six out of sixteen patients had not been informed about the family meeting being arranged for them. Furthermore, there was a lack of informed consent and lack of clarity of the purpose of family meetings. These results suggested a need for a family meeting model with a clear agenda for the meetings, a documented informed consent from the patient, purpose with the meeting and support for the patient to express their own views.

#### 4.2.2 Discharge care plans

The Care Transition Intervention (Coleman et al. 2004; Parry et al. 2008) is patient-centered and rooted in principles of self-management and continuity. The intervention comprised four conceptual areas: medication self-management, a patient-centered record, primary care and specialist follow-up, education about “red flags” or warning symptoms indicating worsening health condition. The intervention was carried out using a personal health record and a transition coach providing follow-up telephone calls and home visits to ease the care transition. Results showed

**Table 3** Studies on experiences with tools to support elderly patients' participation in transitional care

Study (author, year, country, journal)	Tool/intervention	Definition patient participation	Study design	Outcome focus	Participants	Results	Reported validity	Reported reliability
Jangland et al. (2012) Sweden <i>International Journal of Nursing Studies</i>	"Tell-us card": Patients' written questions and concerns (daily or prior to the discharge)	Inspired by Eldh (2006): "the patient has knowledge of, and when possible, control of, the disease and treatment..."	Quasi-experimental design	Patients' perceptions of quality of care	$n = 310$ patients mean age 58 years*	Improved patient participation, significant difference ( $p = 0.020$ ) in opportunity to participate in decision-making, no significant differences in quality of care, lack of information	Statistical tests Chronbach alpha coefficients range from 0.81 to 0.9	ABA-design
Watkins et al. (2012) USA <i>Professional Case Management</i>	Transition Program: Hospital to Home Program, social worker navigator, transitional care model	No	Descriptive study	Re-hospitalization, quality of life, patient outcomes	$n = 292$ patients >65 years	Reduction in hospital readmission (61 %), improved healthcare quality of life, high overall satisfaction with tools	$t$ tests, patient satisfaction survey Internal consistency (0.82–0.93)	Home visits, medical management, referrals for other services, follow-up phone calls
Clarke et al. (2010) UK <i>Quality Safety Health Care</i>	An early supported discharge service (EDS)	No	Qualitative design. Semi-structured face-to-face interviews	To explore patients' views of an early supported discharge service (EDS) for chronic obstructive pulmonary disease (COPD)	$n = 23$ patients, most of them were frail and had other chronic conditions*	Themes: (1) Negotiation for consent—not ready to negotiate, (2) Process of discharge from hospital—difficulties with transport and medication, (3) Life at home after a hospital admission was difficult	Interviews with patients after implementation of the intervention	Interviews continued until data saturation was reached
Parry et al. (2008) USA <i>Home HealthCare Services Quarterly</i>	Patient-centered coaching: Transition coach, personal health record	"Activated patients"... "have skills and knowledge to manage their condition, collaborate with health providers, maintain their health and functioning, and access appropriate and high-quality care" (p. 40)	Qualitative explorative design + quantitative measurement ( $n = 976$ )	Patients' experiences with the tool	$n = 32$ patients >65 years	Increased comfort during transitions, home visits most beneficial component, Personal Health Record used by 50 %	Reported limitations in generalizability (small sample size, social desirability effects, education level)	Researcher triangulation, peer debriefing, negative case comparison, audit trails

Table 3 continued

Study (author, year, country, journal)	Tool/ intervention	Definition patient participation	Study design	Outcome focus	Participants	Results	Reported validity	Reported reliability
Moats (2007) Canada <i>Canadian Journal of Occupational Therapy</i>	Client-defined decision-making OR negotiated decision-making	“Enable people to choose, organize and perform occupations they find useful or meaningful in their environment” (p. 2)	Qualitative study	Therapists’ experiences with the tools	n = 10 occupational therapists	Therapists’ client-centered practices, styles of decision-making, the importance of the home (home visits), A negotiated model of decision-making	Reported validity measures (pilot interview, code-recode, member check, triangulation)	Purposefully stratified sample
Efraimsson et al. (2006) Sweden <i>Scandinavian Journal of Caring Science</i>	Discharge Planning Conference	No	Qualitative design	Patients’ the tool	n = 7 female patients >70 years	Four themes reflected the women’s experiences of taking part in the DPC: Being affiliated, standing outside, being in focus, being unprepared	Reported validity lag after DPC, pilot interview)	Purposive sampling, mixed methods (video-recording, face-to-face interviews)
Grimmer et al. (2006a) Australia <i>The Internet Journal of Allied Health Sciences and Practice</i>	Practical Patient-Centered Checklist (discharge)	“To understand and interpret patient and carer needs from patients’ and carers’ perspectives post-discharge” (p. 1)	Longitudinal observational study	Development of tool	n = 100 patients >60 years* Family members Staff	Development of discharge planning checklist for patient and carer (common patient concerns)	Reported validity measures (patients’ comments and revision)	Based on findings in the qualitative data Purposive sampling to ensure good representation of patients and staff members
Grimmer et al. (2006b) Australia <i>The Internet Journal of Allied Health Sciences and Practice</i>	Patient-Generated Checklist	See Grimmer et al. (2006a)	Quasi-experimental design	Patients’ the tool	n = 148 patients >60 years*	Opportunity for discussion, decision-making, patients’ preparedness Subjects unaware of hospital staff’s discharge plans. >95 % wanted the checklist on admission to spend time to stay at home safely (67 %), driving and transport (61 %), medications (52 %), pets, garden, house care (46 %), getting home successfully (42 %), services (38 %) equipment (36 %)	Student t tests Chi squared statistics, logistic regression models	Qualitative measures by telephone interviews

Table 3 continued

Study (author, year, country, journal)	Tool/intervention	Definition patient participation	Study design	Outcome focus	Participants	Results	Reported validity	Reported reliability
Coleman et al. (2004) USA <i>The American Geriatrics Society</i>	“The Care Transitions intervention” by use of a transition coach	No	Quasi-experimental design, an intervention group and a control group	To test whether an intervention designed to encourage older patients and their caregivers to assert a more active role during care transitions can reduce re-hospitalization rates	$n = 158$ patients aged 65 years and older $n = 1,235$ control patients	Median days for re-hospitalization for intervention subjects—225.5 days, 217.0 days for control group. Intervention patients reported confidence in information, communication with healthcare team, and understanding their medication regimen	Rates of post-discharge hospital use at 30, 60 and 90 days	Intervention subjects’ care experience was assessed in telephone interviews using the care transition measure
Preen et al. (2005) Australia <i>International Journal for Quality in Health Care</i>	Discharge care plan outlined in the Australian Enhanced Primary Care Package	No	A prospective, randomized, controlled, clinical trial	The impact of a hospital-coordinated discharge care plan, on length of hospital stay, quality of life and patients’ and GPs’ satisfaction with discharge procedures	$n = 189$ patients, 91 intervention, 98 control group. Age range 26.8–100.2, mean age 75.1	The discharge plan improved quality of life, involvement and satisfaction with discharge care, and hospital-general practitioner integration	A patient and GP discharge satisfaction questionnaire	Patients were identified via ward staff at each location. Patients’ GPs were contacted to obtain approval for participation. A sample size estimate was performed
Efraimsson et al. (2004) Sweden <i>Journal of Clinical Nursing</i>	Discharge planning Conference	See Efraimsson et al. (2006)	Qualitative design	Patients’ experiences with the tool	$n = 8$ patients >70 years	Limited participation, seldom decision-makers, persuaded to accept proposals, decisions made prior to the meeting, lack of information	Purposive sampling (participation criteria)	Researcher triangulation (systematic, step-by-step data analysis)
Griffith et al. (2004) New Zealand <i>Age on Ageing</i>	Family meetings	No	Qualitative design	Participants’ experiences with the tool	$n = 22$ elderly patients Staff sample not documented	Importance of preparation, staff skills, aftermath, patient and family satisfaction, unclear agenda	Informed consent from patients, support for patient participation in the meeting	Purposive sampling, reported limitations (no audio recording and transcription)

Table 3 continued

Study (author, year, country, journal)	Tool/ intervention	Definition patient participation	Study design	Outcome focus	Participants	Results	Reported validity	Reported reliability
Reed and Stanley (2003) UK <i>Health and Social Care in the Community</i>	Daily Living Plan (DLP)	No, but the DLP...“should be completed in partnership with the older person”	Qualitative design	Development of the tool	n = 48 (hospital staff) n = 19 (homecare staff) n = 25 (elderly)	Increased efficiency in person-centered communication between hospitals and care homes	Mixed sample (hospital staff, homecare staff, elderly)	Evaluation by participants
Brooks (2002) UK <i>British Journal of Community Nursing</i>	Intermediate Care Rapid Assessment Support Service (RASS)	No	Qualitative design	Unnecessary emergency admissions	n = 20 patients and their carers	Partnership, patient independence, relief of carers, integration of healthcare assessment, professionals’ time efficiency, integration with other services, reduced unnecessary emergency admissions	Storytelling close to discharge, multidisciplinary team, patients remain in their own homes with support	Analysis according to the Business Excellence Model, diaries and storytelling
Bull et al. (2000) USA <i>Applied Nursing Research</i>	A professional-patient partnership model of discharge planning	No	Quasi-experimental study using before and after nonequivalent control group design	1. Patients’ experiences with the tool 2. Differences in outcomes following use of the professional-patient partnership model 3. Differences in costs on readmission or ER	n = 180 elder/caregiver dyads	50 % of the elders and 60 % of the caregivers acknowledged difficulty evaluating and managing symptoms and recognizing complications of illness 2 weeks and 2 months post discharge	t tests, $\chi^2$ tests or Mann–Whitney U test. Multivariate comparisons between intervention and control cohorts, using nonparametric method of O’Brien and a Mann–Whitney U test	Patient interviews 1 day before discharge, follow-up telephone interviews 2 weeks and 2 months post-discharge

\* Not all patients were elderly, but the study was included since the tool was purposive to all ages

reduced readmissions. Patients also reported confidence in managing their condition and medications and in communication with healthcare staff (Coleman et al. 2004; Parry et al. 2008). Reed and Stanley (2003) conducted a study with a user-led daily living plan (DLP) to promote person-centered care and to stimulate effective person-centered communication between the hospital and the care home. Implementation of the DLP plan resulted in a more positive feeling among the older patients about the discharge process pointing to the need for developing a discharge plan from the start of the hospital stay.

Another discharge care plan (Preen et al. 2005) included problems identified from hospital notes and patient/care-giver consultation, goals developed with the patient/caregiver on personal circumstances and identified interventions and community service providers who met patient needs. Results from patient surveys showed that satisfaction with input into discharge care planning was significantly greater for patients receiving the care plan compared with the control group. Two studies (Efrainsson et al. 2004, 2006) described the communication at the discharge planning conference (DPC). DPC is a meeting between professionals and patients aimed to co-ordinate resources and to enhance patient involvement in care. Only a few patients were invited to participate and negotiate in the DPC, some chose to not participate or was excluded from the discussions, and were unable to influence on their own situation. Another aspect was the feeling of being in focus at the DPC. Although the participants were grateful, they also felt that their dependence and disability were publicly exposed. They were expected to decide what help they wanted after discharge, without knowing what resources offered, lack of knowledge about the care system, including health professionals' role in decision-making.

#### 4.2.3 Checklists

Grimmer et al. (2006a) developed a practical discharge planning checklist from patient and carer concerns when preparing for discharge, providing an opportunity for shared decision-making about daily living. The list was developed to assist with the practicalities of coping at home after discharge. The checklist covered the following areas: safe transport from hospital to home, cash to pay medications, assessing and access to medical care, the use of activity aids such as a walking frame, someone around to care for the patient and the caring responsibility. The checklist was evaluated with patients having received it within 24 h after admission to hospital as an adjunct to formal discharge planning. Results indicated that some patients felt too tired and unwell to consider the practicalities of returning home. Despite this the checklist

improved patients' preparedness for discharge and family involvement (Grimmer et al. 2006b).

The "Tell-us card" written by the patient was introduced as an intervention to improve patient participation in a surgical care unit (Jangland et al. 2012). Areas addressed by patients as important at discharge were: information about self-care, information about the operation and follow-up, coordination of care and practical support. The Tell-us card gave significant improvements in participation abilities for patients in nursing and medical care decisions during hospitalization, especially in interaction with nurses. Patients reported significantly higher nursing care quality regarding commitment and respectful treatment; although about half of the patients reported they did not receive useful information about self-care.

#### 4.2.4 Education programs

Implementation of The Transition Program for Frail Older Adults, designed to prevent re-hospitalization, resulted in a positive outcome (Watkins et al. 2012). The program included education of patients about warning signs that may lead to readmission, a what-to-do plan for self-management, reconciling medication regimens and education on appropriate use.

The professional-patient partnership model (Bull et al. 2000) is an intervention to facilitate identification of elderly people's needs for follow-up care providing an opportunity for interaction and participation between the elderly, caregiver and hospital staff in discharge planning. The intervention contained an educational program for nurses and social workers, a self-administered Discharge Planning Questionnaire (DPQ) for patients, a videotape preparing patients and caregivers for hospital discharge, medication information and a brochure on how to access community healthcare. Patients in the intervention group felt more prepared to manage their own care, they reported receiving more information about their condition, medication, and community services and felt in better health than the control group.

#### 4.2.5 Home visits

Clarke et al. (2010) investigated COPD patients' experiences with participation in an early supported discharge service (EDS) intervention with daily home visits by a nurse for 3 days, and then as required up to 2 weeks. Results show that patients felt they were discharged from hospital too early, they felt unable to negotiate time of discharge and that life at home was difficult.

Brooks (2002) evaluated a rapid assessment support service (RASS), an inter-professional team providing support to elderly in their own homes, in order to reduce



unnecessary emergency admissions. The model dealt with care plans as a support in the home environment and was introduced as a partnership between professionals, carers and patients. The results demonstrated that the evidence of involvement of informal carers enabled older people to stay in their own homes. Their carers were involved in assisting with medications, changing dressings and giving injections and the patients experienced an inclusive, informed, empathetic and patient-centered service. The value of home visits and the importance of being at home also emerged in Moat's study (2007). The study was a comparison between a client-defined model and a negotiated model for decision-making. Therapists tried to balance the competing issues of patient autonomy and safety concerns. The therapists aimed for client-centered practice, where the client's wishes were included in the decision-making processes. The authors suggest a client-defined model for decision-making where providers facilitate patient participation in daily life.

## 5 Discussion

Findings from the literature review revealed that discharges are often accompanied by a lack of information to the elderly patient (Benten and Spalding 2008; Ellis-Hill et al. 2009; Foss and Hofoss 2011; Perry et al. 2011; McKain et al. 2005; Swinkels and Mitchell 2008). Minimal participation when elderly transfer between different levels of care, more specifically in discharge planning and decision-making related to this was found (Foss and Hofoss 2011; Gibbon 2004; Huby et al. 2004; Perry et al. 2011; Somme et al. 2008; Swinkels and Mitchell 2008). Some studies documented participation to a certain degree in decisions regarding discharge from hospital, having a positive effect on patients' wellbeing and satisfaction with healthcare (Almborg et al. 2008; Roberts 2001, 2002). The participants were to some extent aware of the complexity of arrangements being provided for them (Swinkels and Mitchell 2008). Potential challenges to ensure patient participation in transitional care are: the patients' health condition, lack of information, lack of involvement of elderly patients and their families in discharge planning, providers being paternalistic in the decisions on transitional care on behalf of their elderly patients, and the elderly not having a clear understanding of or any preferences for participation (Benten and Spalding 2008; Ekdahl et al. 2009; Grimmer et al. 2006b; Huby et al. 2004, 2007; Roberts 2002). To support patient participation in transitional care, several tools were implemented. Some of these showed positive results (Watkins et al. 2012; Jangland et al. 2012; Reed and Stanley 2003; Brooks 2002). Others had limited effects on participation (Efraimsson et al. 2006,

2004). Although good intentions existed from healthcare professionals to involve patients and improve the discharge process, not all efforts succeeded.

In the healthcare quality literature, patient experiences are recognized as a key area to attend to. Patient centeredness and patient participation is highlighted in policy documents worldwide (WHO 2011a, b). There is a relationship between patients' participation and their rating of quality of care. Patients reporting more participation are less likely to be admitted to the emergency department and more confident in their ability to express and protect themselves from adverse events (Weingart et al. 2011). Our results show limited participation of elderly in transitional care. Thompson (2007) identified five levels of patient-determined involvement: noninvolvement, given information, dialogue, shared decision-making and autonomous decision-making, where participation is ranging on the continuum from no participation to autonomous decision-making. According to Thompson's ladder, information is a prerequisite for active participation. Several of the studies in the review sample show a lack of information provided to patients, and professionals not explaining the meaning of participation to their patients (Benten and Spalding 2008; Swinkels and Mitchell 2008). When information was given, it was sometimes just to inform about decisions already taken by professionals (Efraimsson et al. 2004). "Real participation" belongs to the third and highest step of the ladder and was sparsely found (Thompson 2007). This concept has been explained in one of the studies as a high degree of shared decision (Foss and Hofoss 2011), and some participants experienced to be heard, involved and supported in their needs (Ellis-Hill et al. 2009; Rydeman and Törnkvist 2009). These results show that real participation may be difficult to achieve and that information is necessary for active participation in transitional care of the elderly.

Paternalism was apparent in the studies in different ways. It was demonstrated when professionals having a medical authority used professional language which patients had trouble to understand or when patients accepted being inferior to health professionals and doing what they were told and not complaining (Huby et al. 2004; Perry et al. 2011). This excluded elderly patients from participation in discussions relating to their need for care. Patients that experienced a paternalistic approach seemed according to Almborg et al. (2008) to be the same that did not have any active participation in the discharge process. Paternalism and lack of participation did not seem to concern some of the patients, they did not want to be involved in discussions or decisions about their treatment and care (Almborg et al. 2008; Huby et al. 2004, 2007; Perry et al. 2011), decisions were made for them in their best interest, so they chose to not participate (Ekdahl et al.

2009; Huby et al. 2007). Health providers suggested this attitude was caused by a lack of motivation (Huby et al. 2004, 2007) or that some of the elderly found it difficult to understand what health professionals talked about, they did not feel competent and lacked empowerment (Almborg et al. 2008). Tang and Venables (2000) suggest that the elderly of today are socialized into a patient role where participation sparsely exists and the “ideal patient” is the obedient and passive individual.

The presence of family staying with the patient seemed to be of high importance in several studies. They served as patient advocates and provided assurance for their elders (Ellis-Hill et al. 2009; Hedberg et al. 2008; Roberts 2002; Rydeman and Törnkvist 2009). This may indicate that the patients needed someone to speak for them while being hospitalized and also in transitional care. Education of elderly is suggested in the literature as important to stimulate participation in transitional care (Laugaland et al. 2012; Merten et al. 2011; Storm et al. 2012). In this review, several tools to support elderly patients’ participation in transitional care were identified and reported to have positive impact on the elderly patients. Comprehensive educational transition programs such as the Care Transitions Intervention have been developed and implemented (Bull et al. 2000; Coleman et al. 2004). The Care Transition Intervention prepared patients and caregivers for participation in care delivered across settings and has been effective in supporting patients’ self-management during transitions and reduced readmissions. Re-hospitalization was prevented significantly using a care transition program (Brooks 2002; Watkins et al. 2012). In the same way, the professional-partnership model resulted in fewer days in the hospital when patients were readmitted (Bull et al. 2000). A transitional coach and a personal health record made patients feel comfortable and safe (Coleman et al. 2004; Parry et al. 2008). Home visits revealed the importance of being at home for the elderly patient (Moats 2007), although other patients having COPD felt they were sent home too early (Clarke et al. 2010). A practical patient-centered checklist improved patients’ and families’ preparedness for discharge (Grimmer et al. 2006a, b). User-led daily living plan resulted in more patient-centered communication between hospitals and care homes (Reed and Stanley 2003).

Although several of the studies had positive consequences in terms of reducing readmissions, as increased information and participation using discharge plans (Coleman et al. 2004; Preen et al. 2005) supporting patients’ self-management and increasing preparedness for discharge, and transitional navigators that led to decreased readmissions, patient participation was not achieved in all studies on tools. One reason seemed to be the lack of information about implementation and use of the tool

(Jangland et al. 2012; Efrainsson et al. 2004; Griffith et al. 2004). Otherwise discharge seemed to be too early for some patients (Clarke et al. 2010). Tools or interventions in healthcare seem to be implemented in the patients’ best interest, in order to empower patients to participate in discharge planning. To provide input and stimulate participation and finally for the elderly to influence decisions, further efforts are needed. A review of interventions for improving older patients’ involvement show that face-to-face coaching sessions combined with written materials may be one-way forward (Wetzels et al. 2008).

### 5.1 Limitations

The current review has some limitations. The literature search was limited to year 2000 until September 15, 2012 caused to increase of the elderly population following changes in healthcare and to get the most updated research in the field. The search was comprehensive, but limited to six electronic databases so there is a possibility that published studies fulfilling our inclusion criteria have been missed. An important limitation in this study is that we have done an interpretation of other researchers’ interpretation of their studies. The literature review included only articles published in English. In the review, we focused more on results in the included studies, than on the methodology used. We did not rate methodological quality of the included studies according to the Prisma Checklist (Moher et al. 2009). We are aware of additional literature on interventions to support transitional care of the elderly (Laugaland et al. 2012). To be included in the review, studies had to attend to patient participation in transitional care of elderly.

## 6 Conclusion

Our review shows that studies exploring elderly patients’ participation in transitional care are related to discharge planning. Results show that elderly patients often were excluded and not participating in discussions about discharge. When they were present they often felt not being seen or heard by professionals. In addition, they sometimes did not perceive participation relevant. Our review identifies several tools implemented to support patient participation in transitional care. Some tools were successfully implemented while others were not experienced by patients as enhancing their ability to influence on their situation. The studies in this review indicate that elderlies’ participation in decision-making and transitional care is typically quite poor, but can be supported by use of tools for example transition coaches, post-discharge follow-up, care plans, information and education of patients about self-

management strategies and involvement of family and caregivers. Healthcare professionals need education and training to implement patient participation in a way that empowers patients. Patients and their families need to be made aware of and educated to use their rights to participate in decisions concerning their needs and care level. Healthcare professionals should facilitate transitional care practices setting the patient in the center of care, by listening to and supporting the patients, using common language to identify their needs. In this way, patient empowerment can be facilitated and enable elderly patients to take part in communication and decision-making in collaboration with healthcare professionals.

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## **Paper II**



ORIGINAL ARTICLE

## An observational study of older patients' participation in hospital admission and discharge – exploring patient and next of kin perspectives

Dagrunn N Dyrstad, Kristin A Laugaland and Marianne Storm

**Aims and objectives.** To explore older patients' participation during hospital admission and discharge.

**Background.** Patient participation is suggested as a means to improve the quality of transitional healthcare. Older people with chronic diseases, physical disabilities and cognitive impairments often need to transfer from primary to hospital healthcare and vice versa.

**Design.** This study adopts a participant observational research design.

**Methods.** Participant observations of 41 older patients (over 75 years of age) during hospital admission and discharge were conducted in two hospitals in Norway (in 2012). The observations included short conversations with the patient and their next of kin to capture their participation experiences. Systematic text condensation was used to analyse the data material from the field notes.

**Results.** Varying degrees of information exchange between healthcare professionals and patients, and a lack of involvement of the patient in decision-making (in admission and discharge) were observed and experienced by patients and their next of kin. The next of kin appeared to be important advocates for the patients in admission and provided practical support both during admission and discharge. Data suggest that patient participation in admission and discharge is influenced by time constraints and the heavy workloads of healthcare professionals. Patients' health conditions and preferences also influence participation.

**Conclusions.** Several issues influence the participation of the older patients during hospital admission and discharge. Participation of the older patients needs continuous support from healthcare professionals that acknowledges both the individual patient's preferences and their capacity to participate.

**Relevance to clinical practice.** Study findings report discrepancies in the involvement of older people and their next of kin. There is a need to increase and support older patients' participation in hospital admission and discharge.

**Key words:** experiences, observational study, older patients, patient participation, patient perspective, transitional care

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### What does this paper contribute to the wider global clinical community?

- Older patients' preferences and their capacity for participation in hospital admission and discharge varied considerably. This information must be taken into consideration to assist in informing healthcare workers about the appropriate level of patient participation.
- Heavy work load, crowded hospital wards, time pressure on healthcare professionals, ward routines constrain the participation of older patients during hospital admission and discharge.
- Increased awareness and competencies for healthcare professionals can be useful to improve patient participation during hospital admission and discharge.

## Introduction

Older people with chronic diseases, physical disabilities and cognitive impairments often need to transfer between primary and hospital healthcare services (Coleman & Boulton 2003). *Transitional care* is defined as a set of actions ensuring the coordination and continuity of healthcare, as patients transfer between levels of care, between locations or within the same location (i.e. admission to and discharge from hospital healthcare to community care) (Coleman & Boulton 2003). Policy documents emphasise the need for patient participation to improve the quality of transitional care (WHO 2011, Norwegian Ministry of Health & Care Services 2008–2009).

Under Norwegian law (Ministry of Health & Care Services 1999), patients are entitled to receive relevant healthcare information and participate in decisions about their treatment and care. Healthcare quality is characterised by patients and their next of kin as individualised and patient-focused, with healthcare personnel attending to the needs and concerns of patients and their next of kin (IOM 2001, Wiig *et al.* 2013).

Patient participation in transitional care might entail the receipt of sufficient information about their illness, course of illness, care rehabilitation, participation in discussions about medical treatment, goals and needs for care, services and the rehabilitation process (Almborg *et al.* 2008). Current research indicates that older patients' participation in transitional care is not well developed (Foss & Hofoss 2011, Flink *et al.* 2012). Variability in how participation is managed and experienced by older patients and their caregivers is reported (Roberts 2002, Almborg *et al.* 2008; Foss & Hofoss 2011).

Studies of transitional care across levels of care have primarily been concerned with hospital discharge, as compared to hospital admission (Richardson *et al.* 2007). It has been asserted that it is necessary to better understand the experiences of patients during the hospital admission and discharge process to develop patient-centred care (Richardson *et al.* 2007). This article focuses on older patients' participation in hospital admission and discharge.

## Background

Coulter (1999, p. 719) defined paternalism in healthcare services as 'doctor (or nurse) knows best, making decisions on behalf of patients without actual involving them'. In contrast to paternalism, patient-centred care, patient participation and shared decision-making incorporate the

patients' experiences with care (Berwick 2009, Storm & Edwards 2013). Comprehensive information and the involvement of the patient and their family members/caregivers in the decision-making process about their treatment and care is emphasised (Coulter 2005, Berwick 2009, Foss & Hofoss 2011).

Thompson (2007) suggests five levels of patient participation: (0) non-involvement, where the patients are passive recipients of care and treatment; (1) information-seeking, where patients are receptive of information which is a prerequisite to take part in decisions; (2) information-giving, where professionals and patients both provide the other with information; (3) shared decision-making, a cooperation between the professionals and the patients to determine the best solution and; (4) decision-making, where the patient makes decisions independently, without consulting professionals.

## Aim

The aim of this study is to explore older patients' participation during admissions to, and discharges from, a hospital. Two research questions are addressed:

- 1 How is patient participation attended to by healthcare professionals during hospital admission and discharge?
- 2 What are the experiences of older patients and their next of kin with patient participation in hospital admission and discharge?

## Methods

### Design and study setting

This study uses an observational research design that consists of participant observations (Polit & Beck 2008). Participant observation means that the observer takes part in the studied field with the research participants (Polit & Beck 2008, Arman *et al.* 2010). Observations took place in two hospitals in one Regional Health Authority during 2012 in Norway. Observations were conducted in two emergency departments and seven hospital wards: three medical wards, one geriatric ward, and three orthopaedic wards. The observations covered the acute hospital admissions of older patients from home-based care services or nursing homes, as well as hospital discharges to follow-up care in nursing homes or home-based care services. The observations included short conversations with the patient and/or their next of kin to capture their experiences with participation in admission and discharge (Aase *et al.* 2013).



The participant observations included frail older patients (over age 75) with an orthopaedic diagnosis (e.g. hip fracture) or a medical condition [e.g. pneumonia, chest pain, syncope, stroke, chronic obstructive pulmonary disease (COPD), reduced general health condition] and poly-pharmacy (>5 medications daily). Patients with cognitive impairments meeting the above inclusion criteria were included in the study (Aase *et al.* 2013).

The observations during admission started when the patient transferred from the ambulance personnel to the emergency department nurse. Observations continued until the patient was transferred to the hospital ward. Focus was placed on the interaction, coordination and dialogue among ambulance personnel, doctors, nurses and patients. Conversations were conducted with the patients at the hospital ward one or two days after their admission, when the patient's health condition stabilized. Conversations were also conducted with the patient's next of kin in the emergency department (ED) in hospital admission, either on the day of admission or the subsequent day at the hospital ward, if the patient consented.

The observations during discharge started on the morning of the day of their expected discharge. Focus was placed on the interaction, coordination and dialogue among doctors, nurses and patients. Conversations with patients were conducted during the observations, while conversations with their next of kin were conducted via telephone (if consent from the patient existed).

During the study, an observation guide was applied. The observation guide was developed based on: Laugaland *et al.* (2011), Laugaland *et al.* (2012), Storm *et al.* (2012) and Dyrstad *et al.* (2014). Observation guide themes included: (1) structures/plans, (2) coordination of care, (3) patient participation, (4) interdisciplinary collaboration, (5) documentation/information and (6) contextual factors. Patients and their next of kin were asked to describe their experiences with participation, information exchange, involvement in the decision-making process and their satisfaction with their care.

#### Data collection

Data were collected between March 2012–October 2012 and consisted of 72 hours (80 pages) of field notes of participant observations in hospital admission and 92.5 hours (153 pages) of field notes in hospital discharge. The researchers were present on the wards between 8:00 am–7:00 pm and identified the patients that were eligible for inclusion.

Forty-one patient observations (21 observations in admission and 20 observations in discharge) were conducted by

two researchers (first and second authors) with a nursing background. In 27 of the total 41 patient observations, the patients participated in conversations with the researchers at the hospital wards. The researchers conducted 10 patient conversations in admission and 17 in discharge at the hospital. There were conducted 28 conversations with the next of kin, 13 of which were conducted by telephone as next of kin had not been present during admission or discharge.

There were various reasons for patients not taking part in conversations with the researchers. Seven patient observations included patients that were cognitively impaired. Conversations were then conducted with their next of kin when this was possible. Patients were also occupied with tests and treatment when the researcher was at the hospital ward the first or second day after admission. Other reasons were early hospital discharge, patient transfer to the intensive care unit, and patients not feeling well and wanting to take part in a conversation.

In admission, seven observations were of patients with orthopaedic diagnoses (e.g., hip fractures) and 14 observations were of patients with a medical diagnosis (e.g. pneumonia). In discharge, seven observations involved patients with an orthopaedic diagnosis, while 13 patients had a medical diagnosis. Details of the patient observations are presented in Table 1.

Field notes were written by the two researchers during the observation process. A summary of each observation was written in electronic format immediately after each observation. Direct quotations from the patients and their next of kin were noted in some observations.

#### Ethical considerations

Approval for the study was obtained from the Western Norway Regional Ethics Committee for Medical Research (REC, no. 2011/1978). Patients were first approached by the nurse in charge of the ED (admission) and by the patients' primary nurse across the medical- and orthopaedic wards (discharge). Patients were asked by the nurse if they wanted to be included in the study. The researchers did not contact the patients until they had provided their verbal consent to the nurse. Participation was based on informed, voluntary consent. If the patient suffered from cognitive impairment, family members were required to consent on behalf of the patient.

#### Data analysis

An in-depth analysis of the qualitative data material from the field notes, was conducted using Malterud's (2012)

Table 1 Patient observations: Hospital admissions (21) and hospital discharges (20)

Patient characteristics	Medical and orthopaedic diagnoses*	Patient conversations at the hospital ward	Next of kin present during admission	Conversations with next of kin	Hours in the ED	Primary care service ahead of admissions
Hospital admissions						
Male, age 82	Chest pain	No	No	Daughter at ward	1.5	Nursing home
Male, age 86	Syncope	No	No	No	3	Living with brother, Home care nursing
Male, age 85	Urinary infection, nauseous	No	No	No	2	Living with brother, Home care nursing
Female, age 82	Cerebral insult	No	No	No	3	Nursing home
Female, age 81	Pneumonia	Yes	No	No	2	Living alone, Home care nursing
Male, age 86	Stroke, vomiting/diarrhoea	No (cognitively impaired)	No	No	2	Living with wife, Home care nursing
Male, age 84	Chest pain	Yes	No	No	3	Living with wife, Home care nursing
Male, age 73	Pneumonia	No	Yes	Wife in ED	2.5	Short stay nursing home
Male, age 87	TIA/concussion of the brain	Yes	No	Daughter at ward	4.5	Living with wife, Home care nursing
Female, age 86	Reduced general health condition	Yes	Yes	Daughter in ED	6	Short-time stay nursing home, Home care nursing
Female, age 91	Dehydration	Yes	Yes	Daughter in ED	2	Home care nursing
Female, age 83	Dehydration	Yes	Yes	Daughter in law in ED	7.5	Short-time stay nursing home, Home care nursing
Female, age 90	Delirium due to medications	Yes	Yes	Daughter in ED	5	Short-time stay nursing home, Home care nursing
Male, age 92	Fall	No	No	No	4.5	Living alone, Home care nursing
Male, age 85	Fracture collum femoris	Yes	No	No	2	Living alone, Home care nursing
Male, age 93	Fracture collum femoris	Yes	No	Daughter in law by telephone	2	Nursing home
Female, age 92	Fracture collum femoris	No (cognitively impaired)	Yes	Daughter in ED	2	Nursing home
Male, age 82	Fracture collum femoris	No (cognitively impaired)	Yes	Daughter in ED	5.5	Nursing home
Male, age 81	Fracture collum femoris	No	No	No	4.5	Living alone, Home care nursing
Male, age 74.5	Fracture collum femoris	No (cognitively impaired)	Yes	Wife in ED	4	Nursing home
Female, age 83	Fracture collum femoris	Yes	Yes	Daughter in ED	5	Home care nursing
Patient characteristics	Medical and orthopaedic diagnoses	Patient conversations at the hospital ward	Next of kin present during discharge	Conversations with next of kin	Days spent at the hospital	Primary care service at discharge
Hospital discharge						
Male, age 90	Reduced general health condition	Yes	No	Wife by telephone	8	Short-time stay nursing home
Male, age 89	Pneumonia	Yes	No	Daughter by telephone	6	Home with home care
Female, age 92	Urinary sepsis	Yes	No	No	9	Home with home care
Female, age 97	Heart attack	Yes	No	No	7	Home with home care

Table 1 (continued)

Patient characteristics	Medical and orthopaedic diagnoses	Patient conversations at the hospital ward	Next of kin present during discharge	Conversations with next of kin	Days spent at the hospital	Primary care service at discharge
Female, age 87	Malnutrition	Yes	No	Son by telephone	12	Short-time stay nursing home
Female, age 87	COPD, malnutrition	Yes	No	Son by telephone	19	Short-time stay nursing home
Male, age 77	Reduced general health condition	Yes	No	Wife at ward	23	Nursing home
Male, age 89	Arthritis	Yes	No	Daughter by telephone	8	Short-time stay nursing home
Female, age 89	Pneumonia	No (cognitively impaired)	No	Daughter by telephone	6	Short-time stay nursing home
Male, age 87	Pleural drainage	Yes	No	Son by telephone	18	Short-time stay nursing home
Male, age 80	Pneumonia	Yes	No	Daughter by telephone	20	Short-time stay nursing home
Female, age 86	Pain in knee	Yes	No	No	7	Intermediate care unit
Female, age 96	Urinary infection	Yes	No	Daughter at ward	9	Retirement home for older people
Female, age 75	Fracture collum femoris	Yes	No	Son at ward	15	Nursing home, Rehabilitation unit
Male, age 85	Fracture collum femoris	Yes	No	Son by telephone	9	Nursing home
Female, age 97	Fracture collum femoris	Yes	No	Son at ward	4	Intermediate care unit
Male, age 84	Fracture collum femoris	No (cognitively impaired)	No	Wife by telephone	2	Nursing home
Female, age 89	Fracture collum femoris	Yes	No	Son by telephone	5	Short-time stay nursing home
Female, age 86	Fracture collum femoris	No (cognitively impaired)	No	Sister by telephone	5	Short-time stay nursing home
Male, age 84	Fracture collum femoris	Yes	No	No	4	Short-time stay nursing home

COPD, chronic obstructive pulmonary disease; ED, emergency department

\*Most of the older patients had additional diagnoses (e.g., heart disorder, kidney failure, Parkinson's, diabetes, stroke, dementia, COPD and different types of cancer).

systematic text condensation approach. The method is based on 'a descriptive approach, presenting the experience of the participants as expressed by themselves, rather than exploring possible underlying meaning of what is said' (Malterud 2011, p. 796). A four-step analysis of the researchers' field notes was performed as follows:

- 1 The authors read through the text transcripts from the field notes several times to obtain a complete impression. Three preliminary themes emerged: the healthcare system, the older patient, and next of kin.
- 2 Meaning units ['a text fragment containing some information about the research question' (Malterud 2012, p. 797)] of participation in admission and discharge were identified from the field notes and divided into code-groups: observed practices, patient statements and next of kin statements.
- 3 Code-groups were coded into two sub-groups: information and decision-making.

4 Finally, the content was reduced into a condensate, an artificial quotation maintaining the original terminology as much as possible. Four categories emerged;

- a Observing professionals' information dissemination and decision-making.
- b Older patients' experiences with integration of information.
- c Older patients' preferences for involvement in decision-making.
- d Next of kin advocacy.

An extraction of the meaning units from the field notes during admission and discharge is displayed in Table 2.

## Results

The results are presented as descriptions of the observed practice from the field notes and as citations from the conversations with patients and their next of kin.

### Observing professionals' information dissemination and decision-making

There were variations in how healthcare professionals encountered the older patients in hospital admission and discharge. In admission professionals' information, dissemination took place when paramedics, nurses and doctors were observed offering information to patients and their families.

The ED is divided into two areas: the triage area and the treatment area. The triage area is an open area with 15 patient beds that can be separated by folding screens. The treatment area has 13 single patient rooms. In the triage area, where the patient first arrives, a nurse checks the patient's vital functions, orders blood tests and gives information to the patient about the assessments. Our observations illustrated that nurses working evening shifts had heavy workloads, as most patients arrived in the triage area after 12 pm. Doctors were called to the triage area when needed. When there were 15 patients in the triage area, the nurses did not have much time to attend to each patient.

In the treatment area, the nurse and doctor for the most stayed in the patient room and close to the patient's bedside. The nurses provided information to the patients about their planned length of the stay in the ED, their examination and their transition to the ward while caring for them. The doctors informed the patients about planned tests and treatments while examining the patients. To diagnose the patients' medical problems, the patients were commonly asked about their history of symptoms, pain and worries, as well as what they preferred to happen while they were in the hospital. The doctor in the treatment area made the final decision regarding whether the patient was to transfer to a hospital ward or not.

Several of the observations conducted during the patient discharge showed that the medical and orthopaedic wards often had a shortage of beds. Consequently, there was pressure to discharge patients to receive new patients. During the ward rounds, there were variations in how much time the doctors spent with patients. Some doctors chose to sit at the patient's bedside and engage with them in face-to-face conversations about his or her health, describing the discharge plans and the decisions made on the preward round. Professional and everyday language was used and the information was often repeated by the responsible nurse. On the other hand, some nurses and doctors focused on the patients' medical problems and paid little attention to the patients' opinions about their future healthcare needs and follow-up from healthcare services. The doctors could then choose to stand at the end of the bed, reading the

patient's chart and communicating only with the junior doctors and the nurse in charge. In a few patient observations, the doctor checked the surgical wound without warning the patient or explaining to them what he/she was doing before deciding on further treatment.

After the ward-round, the nurse commonly called the patient's next of kin by phone to inform them of the decisions. There were no scheduled discharge planning meetings with the patient and their family; the decisions were made among the healthcare professionals in the hospital and in the municipality. During discharge, prescriptions were sent with the patients and the discharge summary was sometimes available to the patients, but sometimes it was not.

### Older patients' experiences with integration of information

During the study period, older patients were found to have numerous health challenges and impairments (e.g. loss of hearing, limited vision, trouble with mobility and balance) during both hospital admission and discharge. During hospital admission, the observations illustrate that some patients were confused, tired, dizzy and anxious about their medical conditions. They also had difficulty describing their symptoms and how they were feeling. Providing information to the patient could therefore be complicated.

Several patients said to the researcher that they were satisfied with the information provided to them on the day of admission, but they often did not remember much of it. In particular, patients with an unresolved health condition had problems remembering information about the planned tests and their treatment upon hospital admission. A few patients were frustrated. One 81-year-old man with an upper femur fracture waiting to be examined by the admitting doctor said to the researcher: 'I miss information. What has happened and what is going to happen?'

Upon discharge, patients received information about the medical treatments they received, as well as further treatment and decisions about discharge, often with several professionals standing around the bed. Patients often struggled to understand and remember the information provided to them on the day of discharge. An 85-year-old man with pneumonia said to the researcher:

'It was easy to understand the oral information from the doctor, but in the written documents, professional medical language was used, and it was hard to understand. The doctor did not explain the content of the written paper and I am not sure about further treatment, but I think I'm supposed to take antibiotics at home'.

Table 2 Extractions from the analysis of participant observations during hospital admission and discharge

Preliminary themes	Meaning units and code-groups	Sub-groups	Categories
The older patient	<p>Admission</p> <p><i>Observation:</i></p> <p>The triage area was full, the nurses did not have time to stay at the patient's bedside, and the older woman received minimal information in the triage area (83-year-old woman, dehydration)</p> <p>The triage area was crowded and the older woman was lying unattended, with no information from the nurses (86-year-old woman, reduced health condition)</p> <p>Minimal information was provided in the triage area to a patient who was tired and had nausea (83-year-old woman, dehydration)</p> <p>In the treatment area of the ED in the patient rooms, the nurse and doctor stayed at the patient's bedside</p> <p>The patient received information about routines and plans for the hospital stay from the nurse and the training doctor in the treatment room (86-year-old man, cerebral apoplexia)</p> <p>The nurse provided information to the patient while caring for him. The doctor provided information to the patient during the examination. The patient was asked about his medical history and current health problems (93-year-old man, fracture)</p> <p>The patient was informed about the medical examination in the treatment room (86-year-old man, syncope)</p> <p><i>Patient statements:</i></p> <p>The doctor examined and informed me about treatment simultaneously. (93-year-old man, chest pain)</p> <p>I did not miss any information in admission; I felt very ill. (81-year-old woman, pneumonia)</p> <p>I was well informed and was heard. (85-year-old man, FCF)</p> <p>I was well informed and they cared for me. (83-year-old woman, FCF)</p> <p>'I miss information on facts. What has happened and what is going to happen?' he asked when waiting for the medical examination in the ER. (81-year-old man, hip fracture)</p> <p>I got enough information, but I do not remember much. (83-year-old woman, dehydration)</p> <p>I do not remember what I was informed about, but I do not miss any information. (85-year-old man, urinary infection)</p> <p>I was very well informed about what and when things should happen on the day of admission. (83-year-old woman, hip-fracture)</p>	<p><i>Information</i></p> <p>Admission</p> <p>Crowded triage area, minimal information to the patient</p> <p>Unattended, no information in the triage area</p> <p>Minimal information, health challenges</p> <p>Professionals stayed with the patient in the treatment room</p> <p>Received information on routines and plans from the nurse and doctor</p> <p>Examination and information simultaneously, asked about his health problems</p> <p>Informed about medical examination</p> <p>Received information from professionals</p> <p>Did not miss any information, felt ill</p> <p>Well informed and heard</p> <p>Well informed and cared for</p> <p>Missed information about medical examination</p> <p>Satisfied with information in the treatment room</p> <p>Did not remember information given</p> <p>Did not miss information</p> <p>Well informed</p>	<p>Older patients' experiences with integration of information</p>

Table 2 (continued)

Preliminary themes	Meaning units and code-groups	Sub-groups	Categories
	<p>Discharge <i>Observation:</i> The doctor was sitting at the patient's bedside, while asking questions about her health conditions. He told her that she was going to be discharged the same day (87-year-old woman, malnutrition)</p> <p><i>Patient statement:</i> It was easy to understand the oral information, but the written documents used medical terminology and it was hard to understand. The doctor did not explain the content of the written paper and I am not sure about further treatment, but I think I am supposed to take antibiotics at home. (85-year-old man, pneumonia)</p>	<p>Discharge: The patient was informed by the doctor about decision on discharge Easy to understand oral information Written information was difficult to understand The doctor did not explain</p>	
	<p>No, I do not need any information; it is home care professionals' responsibility to take care of that. (91-year-old man, reduced health condition)</p>	No need for information	
	<p>'There are angels working here', he said, although he did not have the opportunity to speak much with the doctor (85-year-old man, pneumonia)</p>	Very satisfied with the healthcare personnel	
	<p>Admission <i>Observation:</i> The patient told the nurse that he had asked the doctor in the municipality to delay the admittance until the next morning, because days at home were very valuable to him, because of his cancer diagnosis. This wish was granted (73-year-old man, pneumonia)</p>	<p><i>Decision-making</i> Admission Patient influenced admission. Managed to delay the admission</p>	Older patients' preferences for involvement in decision-making
	<p>The old man was investigated if he had personal preferences, but he had none (86-year-old man, syncope)</p>	No personal preferences	
	<p>The man told the doctor what was important to him, that he was hard of hearing so they had to talk loudly and clearly. He agreed to admission, which was important for him to influence (81-year-old man, FCF)</p>	<p>The patient was heard and agreed to admission. Trusted the professionals</p>	
	<p><i>Patient statement:</i> They know everything; I have been here several times and they know what is best. One cannot interfere in the doctors' job, they find the truth. (81-year-old woman, pneumonia)</p>	<p>Felt safe and heard and had full confidence in the healthcare workers</p>	
	<p>I feel safe, since I have been here on several occasions. I feel heard and have full confidence in the healthcare workers. (93-year-old man, chest pain)</p>		
	<p>Discharge <i>Observation:</i> The woman wanted to stay longer at the hospital; the painkillers she was provided after surgery did not work and she had a stiff neck (90-year-old man, reduced health condition)</p>	<p>Discharge Additional problems, wanted a longer hospital stay</p>	

Table 2 (continued)

Preliminary themes	Meaning units and code-groups	Sub-groups	Categories
	The old man had trouble with standing and walking while being discharged following surgery for his fractured hip, but was discharged on schedule (87-year-old man, pleural drainage)	Discharged on schedule, despite physical challenges.	
	The charge nurse made it possible for her to stay a couple of days extra at the hospital until another nursing home was available (85-year-old woman, reduced health condition)	Managed to delay discharge	
	One specific nursing home was unpopular and the patient refused to transfer there (80-year-old man, COPD)	Got choice of nursing home.	
	<i>Patient statement:</i> I have been very well taken care of and I am confident here at hospital. (86-year-old woman, fall tendency)	Patient refused transfer	
	'There are so many patients there, they lack systems of care and I don't feel safe there' the old man said. (80-year-old man, COPD)	Felt well taken care of	
	Wherever you send me, let it not be to the specific rehabilitation unit, please! (80-year-old man, COPD)	Many patients, no systems, felt unsafe.	
	It goes too fast, but do I have to get discharged today? You must not discharge me today, I need to relax and improve my walking, I have trouble walking, so I am not ready yet to be discharged. (97-year-old woman, hip fracture)	Refused discharge to a specific nursing home	
	Everything goes too quickly. (87-year-old woman, malnutrition)	Discharge came too soon	
		Hospitalisation ended too soon	
		Not prepared for discharge	

COPD, chronic obstructive pulmonary disease; ED, emergency department.

### Older patients' preferences for involvement in decision-making

Patients had a range of preferences for participation in decision-making about transitional care. On admission, most patients were confident in, and trusted, the healthcare system and the healthcare professionals. Several were satisfied with the admission and said that they had had the opportunity to describe their symptoms, what had happened and how. Some said that it was not important for them to have any say in the decisions and they were comfortable letting the staff make the decisions for them. An 81-year-old woman with pneumonia said to the researcher: 'They know everything. I have been here several times and they know what is best. One cannot interfere in the doctors' job; they find the proper treatment'.

Several observed patients had been hospitalised many times, so they were familiar with the routines and the hospital system. Patients were most often not prepared for and

able to plan an acute hospital admission. One patient said to the researcher that he had asked the general practitioner to delay admission until the next morning, as staying at home was very important to him in this stage of his life.

On discharge, some patients were satisfied and one 85-year-old patient with urinary infection reported that he was very well taken care of. 'There are angels working here', he said to the researcher, although he said he had not had many opportunities to speak with the nurses and doctors during the hospital stay.

Some healthcare professionals respected the patients' preferences. Some patients were allowed a longer hospital stay, for example, if they needed an x-ray. A few patients were able to transfer to the nursing home of their choice. Several patients said to the researcher that the day of discharge came upon them suddenly and unexpectedly. They often were unprepared, as decisions were made by healthcare professionals without consulting them. A 97-year-old woman with a hip fracture said to the doctor:

It goes too fast. Do I have to get discharged today already? You must not discharge me today, I need to relax and improve my walking, so I am not ready yet to be discharged.

Some of the patients were worried about further treatment and follow-up care and therefore wanted to prolong their hospital stay. Healthcare professionals often responded to the patients' stories or requests by telling that they would receive rehabilitation or a short stay in a nursing home in the municipality. The patients were often told that physiotherapy was included in a rehabilitation programme after hospital discharge and that additional health problems would be solved in the municipality, so a prolonged hospital stay was unnecessary. Some doctors told patients that there was a shortage of beds on the ward and that they needed to make room for incoming patients. Despite patients' objections and arguments of poor health, the decision to discharge patients was most often made by the professionals, with the patients being transferred to follow-up care in the municipality.

#### Next of kin advocacy

The patient's next of kin were advocates for their family members in hospital admission. They played an important role in providing and receiving information, to support the older patient's participation in admission and discharge.

In admission, the next of kin provided valuable information about the patient's medications, health conditions, level of care and living conditions prior to admission. The patients' next of kin could be of vital support to the older patients in the ED, given the understaffing and the nurses' heavy workloads. A daughter had to take care of her 86-year-old mother, because too many patients were in the triage area. She provided her mother her medication, as she was accustomed to doing when her mother got epileptic seizures. One 90-year-old woman admitted for medication delirium said to the researcher: 'It is very good having my daughter present when information is given; it makes me feel safe. When my daughter receives the same information she is able to repeat it to me'.

The next of kin also received information from the healthcare personnel about the patient's health status and the decision-making. An 92-year-old woman with an upper femur fracture said to the researcher: 'My son received the necessary information and explained the treatment plan to me'.

A particular challenge for healthcare professionals in admission appeared in some instances when the patient arrived in the ED without their next of kin and were unable to describe their symptoms, health problems, and/or medica-

tions. One 91-year-old woman could not even state her name or date of birth to the healthcare personnel. Such a situation made staff dependent on the written transfer documentation from the doctors and nurses in the municipality.

It was observed that older patients with their family members present during the admission were satisfied with their care. An 83-year-old woman with an upper femur fracture said to the researcher, 'It feels good having a hand to hold. My daughter can be my voice, which is vital to me'.

Upon discharge, there were no routines to invite family members to stay with the patient on the doctor's rounds. Their next of kin were usually informed on the day of discharge about the decisions made during the ward rounds at the hospital. Some family members said that they had to seek information about the decision-making by calling the hospital. One son said (to the researcher on the phone): 'The discharge came very soon. They could have called a day before discharge'.

The next of kin also picked up medications from the pharmacy; family members were sometimes observed to drive the discharged patient from the hospital to the nursing home, as they did not want the patient to take a taxi. According to one son of an 87-year-old woman with malnutrition, 'Cognitively impaired or not makes no difference. To include family is important. The older patients often do not remember and cannot answer questions about their own health conditions' (on the phone to the researcher).

#### Discussion

The objective of this study was to explore older patients' participation in hospital admission and discharge. The findings indicate that patient participation is not systematically incorporated into the hospital admission and discharge planning. This was shown by variable degrees of information exchanges between healthcare professionals and patients, and a lack of involvement of the patient in decision-making (in admission and discharge), as observed and experienced by patients and their next of kin. The data suggest that patient participation in admission and discharge is influenced by time constraints and heavy workloads on healthcare professionals, together with patients' health conditions, disabilities and preferences for participation.

The level of patient participation was found to vary significantly. Some professionals were sitting at the bedside of each patient, providing information to them, while speaking with and listening to the patients explain their health challenges during admission and discharge. At times, patients talked about their health problems to doctors and nurses who were respectful of their patients' needs and values, which is in



accordance with the Institute of Medicine's quality standards (IOM, 2001, Coulter 2005, Storm *et al.* 2014).

During discharge, some patients were generally passive recipients of information from professionals about the decision-making to transfer to a community healthcare facility. This is consistent with the findings of Foss and Askautrud (2010), in their review of older patients' participation in hospital discharge. Their emphasis was placed on the transmission of information from the professional to the patient. Information from healthcare professionals to the patients is a prerequisite for patient participation in healthcare decision-making, but it is not sufficient enough for patients to truly participate in the decision-making (Thompson 2007, Heggland & Hausken 2012).

Patients had different preferences for involvement in decision-making during admission and discharge; some patients wanted to be involved, while others did not. The older patients in this study were found to have several health challenges, which seemed to reduce their capacity to integrate information and participate in decision-making.

The integration of information was reported to be important for patient participation by Heggland and Hausken (2012). Older people with complex health conditions can face particular challenges when adapting to new situations, like a hospital stay (Foss & Askautrud 2010, Enderlin *et al.* 2013). This implies that the level of participation needs to be based on patients' preferences and capacity.

Older patients may easily assume a passive role upon hospital admission and discharge (Foss 2011, Heggland & Hausken 2012). In our study, several patients often appeared to show their trust in the healthcare system by letting the nurses and doctors decide upon their treatment during the admission, as well as when and where they were to be discharged. Some patients seemed hesitant to ask clarifying questions to the doctor when they did not understand the information provided.

Dilworth *et al.* (2012) reported that older patients readmitted to hospitals at times felt 'left out', unheard and ignored by healthcare professionals, because they were not given information and not provided with an opportunity to participate in the decision-making. Foss and Hofoss (2011) reported that older patients preferred to be involved in hospital discharge. A few patients in our study were able to delay admission to the hospital and discharge themselves by negotiating an agreement with their family and their professionals. This might be seen as participation in a shared decision-making process (IOM 2001, Naylor & Sochalski 2010, Enderlin *et al.* 2013).

Healthcare professionals in this study did not routinely involve patients in decision-making about their treatment

and care when they were admitted to or discharged from the hospital. This might be an important restriction on patient participation and suggests that the paternalistic model of care is still an integrated part of the hospital system, and in particular, in transitional care (Coulter 1999, Heggland & Hausken 2012).

During the discharge, healthcare professionals often focused on the patients' medical problems (e.g., checking wounds, prescribing medication and scheduling a discharge). Healthcare professionals spent a minimal amount of time at the patient's bedside with face-to-face communication, resulting in minimal chances for the patients to discuss their health problems. Procedurally driven care is in contrast to patient-centred care, where professionals spend time listening to their patients' stories, trying to understand their patients' concerns and taking these concerns into account in the decision-making (Wiman & Wikblad 2004, Berwick 2009).

Several issues seemed to constrain patient participation in hospital admission and discharge in this study. These issues included crowded hospital wards, ward routines and a tight schedule for healthcare professionals to attend to all the patients at the ward. This resulted in pressure to discharge patients to prevent 'bed blocking' (occupy a bed needlessly). When effectiveness is prioritized in healthcare, it could be at the expense of patient participation, and hence, may lead to the exclusion of patients from the decision-making (Thompson 2007). The study results indicate that routines for patient participation were not sufficiently implemented at the hospital wards. Patients seemed to be even less involved in decisions when healthcare professionals were busy.

Having their next of kin present during hospital admission and discharge is important in articulating the older patients' needs and to keep patients feeling safe (Bragstad *et al.* 2014). In this study, next of kin was important in admission as they were providing hospital personnel with key information about the patients. They were important receivers and retainers of information about their family members' health situations. Family members appeared as advocates when they stayed at the patients' bedside during admission and when they provided practical support, during both admission and discharge.

Coulter (2005) found that patients wanted involvement from their family and their carers. Roberts (2002, p. 416) reported that family or friends act as representatives for the patient 'to articulate on their behalf or otherwise help or provide support in their contacts with care professionals'. In this study, the next of kin seemed to be an unused information source upon discharge. They were rarely present and not invited to the doctor's rounds, just appraised of the decisions of the healthcare professionals. Some patients did not

have any next of kin, which sometimes became an impediment to information dissemination. In these cases, written and verbal information, as well as asking the patients about their health problems and wishes was even more important.

To support the participation of older patients in hospital admission and discharge, a stronger awareness and competency in healthcare professionals' of older patients' capacity and preferences for participation can be useful. In addition, changes in the admission and discharge procedures to include measures focusing on information, involvement and the preparation of older patients for upcoming transitions is needed.

### Study limitation

A potential challenge of participant observation is the observer's influence on the research participants' behaviours (DeWalt & DeWalt 2011) (e.g. some healthcare professionals strive to do a better job). To limit observer effects, the researchers wore nurse's uniforms. Patients in discharge were not the same as those in admission. The first author of this article observed admission and the second author observed discharge. To avoid observer bias, the observations were conducted at the same point in time. The observers and the research team met regularly to debrief, discuss and validate the observation summaries and preliminary impressions. No tape-recording was conducted during the observations, due to the complexity of the situations and because of the presence of other patients, staff and noise. Thus, short field notes were taken discreetly during the observations; summaries were written immediately after each observation.

### Conclusions

This study explored participation of older patients by applying participant observations of hospital admission and discharge. The study reveals that patient participation during the transitional care of the older patients varies, but is generally limited. Decisions during discharge were most often made by healthcare professionals without consultation of the patients and their family members. Healthcare professionals rarely investigated patients about their preferences for follow-up care.

Patient preferences and capacity for involvement in decision-making in admission and discharge varied. Next of kin were advocates in admission and provided practical support

to patients during admission and discharge. Patient participation during hospital admission and discharge is influenced by a heavy workload, time pressure and healthcare professionals' limited awareness.

To develop older patients' participation in hospital admission and discharge, the findings indicate that more attention needs to be paid to issues that constrain participation. In addition, increased competencies in healthcare professionals about patient participation and the implementation of measures focusing on information, involvement and the preparation of older patients for upcoming transitions is necessary.

### Relevance to clinical practice

This study explored older patients' participation in hospital admission and discharge. The study reports on the discrepancies in the involvement of older people and their next of kin and in the need to increase and support older patients' participation in hospital admission and discharge.

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### Disclosure

The authors have confirmed that all authors meet the ICMJE criteria for authorship credit ([www.icmje.org/ethical\\_1author.html](http://www.icmje.org/ethical_1author.html)), as follows: (1) substantial contributions to conception and design of, or acquisition of data or analysis and interpretation of data, (2) drafting the article or revising it critically for important intellectual content, and (3) final approval of the version to be published.

### Conflicts of interest

There are no conflicts of interest in this study.

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## **Paper III**



RESEARCH ARTICLE

Open Access



# Older patients' participation in hospital admissions through the emergency department: an interview study of healthcare professionals

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## Abstract

**Background:** Patient participation is an important aspect of healthcare quality and may be one way to improve the quality of transitional care for older patients. Research reveals minimal awareness about patient participation in hospital admissions. Hospital admissions require attention to individuals' specific needs beyond patient frailty, and to involve patients and their families in shared decision-making. The aim of this study was to identify factors influencing patient participation by exploring healthcare professionals' views on patient participation during the hospital admission of older patients through the emergency department (ED).

**Methods:** The study used a qualitative and descriptive design with face-to-face interviews. A total of 27 interviews were conducted with 15 healthcare professionals from one hospital and 12 from another. The data were analyzed using systematic text condensation.

**Results:** Healthcare professionals thought that patient participation in hospital admissions was influenced by five main factors: 1) routine treatment and care during hospital admission, and in particular certain procedures such as medical examinations; 2) the frail and thankful older patients, and the overall picture of their medical needs; 3) hospital resources, such as available staff and beds; 4) healthcare professionals' attitude towards finding out about older patients' experiences; and 5) the presence of a supportive and demanding next of kin acting as an advocate for the patient.

**Conclusions:** Patient participation in hospital admissions of older patients is dependent on the way the service is organized, the patients' condition, hospital resources, healthcare professionals' attitudes, and support from patients' next of kin. Some of the participants had high expectations of themselves and actively involved patients, but others did not find patient participation relevant in the emergency department. Some used crowded wards as a reason not to engage older patients in their own care.

**Keywords:** Patient participation, Views of healthcare professionals, Interviews, Hospital admission, Older patients

## Background

Patient participation is one way to improve healthcare quality [1–3]. It can be viewed as a response to the paternalistic healthcare model, in which the patient has a passive, dependent role and the physician or healthcare professional is the expert on treatment and care [4–6]. Patient participation includes the patient's right to participate in decision-making about treatment and care,

level of care, and living conditions [7]. During hospital admissions, providing information to patients about planned tests and treatment, and the planned stay in hospital, and giving them opportunities to describe their symptoms (what has happened and how) are important to ensure patient involvement [8]. Transitional care, which includes hospital admission, was defined by Coleman and Bolt [9] as a set of actions to ensure the quality and continuity of healthcare as patients transfer between hospital and community healthcare services [10].

Older people with multiple diseases and medication have complex care needs and often transfer between community and hospital healthcare services [11–13]. These

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patients are a vulnerable group at the point of hospital admission and may have difficulties self-advocating owing to illness, confusion, or deterioration of health [13]. Research shows that older patients in the emergency department (ED) often do not remember whether they have received information about treatment or been involved in decision-making about treatment and hospital admission [8, 14, 15]. Patients who are admitted as an emergency also report receiving less information about the results of their medical treatment and care [16]. A lack of information exchange between healthcare professionals and gaps in the documentation about patients' cognitive function, mental orientation, medication charts, and advance directive status can also complicate the transfer of older patients to the ED [13]. Such gaps will require healthcare professionals to spend more time to ensure that adequate and individualized care is provided to the patient in the ED.

Studies report that healthcare professionals do not always focus on patient participation. Some are aware of involving patients in decisions concerning their treatment and care, while others lack competencies in this area [15, 17–21]. In particular, at the point of hospital admission, with time pressure and a strong emphasis on efficiency, clinicians can easily focus on medical problems and not patients' individual preferences and opinions [19, 20, 22].

It can be challenging for healthcare professionals to look beyond the frailty, complex medical history and multiple medications of older people in the ED, and instead focus on the individual's preferences and views [23]. A common and important screening tool used by healthcare professionals in the ED is the emergency severity index triage system, which scores patients from 1 (most urgent) to 5 (least resource-intensive) [24–26]. The triage system provides timely clinical observations, tests, and examinations to support decisions about treatment and care. It does not, however, automatically include patient involvement in decision-making and can result in failure to see the patient as a whole person. The aim of our study was to identify factors influencing patient participation by exploring healthcare professionals' views on patient participation during the hospital admission of older patients through the ED.

## Methods

### Design

The study applied a qualitative and descriptive design. The descriptive approach is rooted in Giorgi's phenomenological research, which focuses on individual experiences in their natural context [27]. A descriptive design aims to provide an "accurate portrayal of the characteristics of persons, situations, or groups and/or the frequency with which certain phenomena occur" [28]. We conducted face-to-face individual interviews to gather descriptions of

the diversity and nuances in healthcare professionals' views on patient participation, to increase understanding of this complex phenomenon [29].

### Participants and study setting

We held individual interviews with ambulance workers, nurses, and doctors in two hospitals in the same Regional Health Authority in Norway, one hospital with 595 patient beds and one hospital with 206 patient beds. The reason for choosing two hospitals was to explore different contexts [30].

All the participating nurses worked in the ED (triage unit and treatment rooms), providing nursing care for incoming patients. The ambulance workers were from the ambulance station connected to the hospital. Their work tasks included responding to emergency calls, transporting patients to the hospital, and triaging patients based on the severity of their illness. The medical doctors in the study were based in either medical or orthopedic hospital wards, serving the ED in their specialist area. The interns had a schedule that rotated between medical and orthopedic wards while they were working in the ED.

### Data collection

The leader of each of the three professional groups (ambulance workers, nurses, and doctors) gave approval for the interviews to be conducted with staff members. A total of 29 healthcare professionals were invited to participate in individual interviews during work hours between March and October 2012, and 27 agreed to do so. The remaining two cited high workloads and change of work schedule as their reasons for not participating. The interviews with nurses and interns took place in an office in the ED, ambulance workers were interviewed in an office at the ambulance station, and medical doctors were interviewed in their own offices. Table 1 shows information about the participants.

**Table 1** Interviews with hospital healthcare professionals

Profession	Gender, age	Professional work experience in field
8 ambulance workers	2 females, 6 males Mean age 41	Mean 15 years
9 nurses	9 females Mean age 46	Mean 8 years
4 medical doctors	1 female, 3 males Mean age 36	Mean 5 years
6 interns	4 females, 2 males Mean age 28	Mean 6 weeks



A semi-structured interview guide was developed based on the study protocol of the main study [30] and four previous studies [10, 19, 31, 32]. This included the following main topics: (1) coordination/interaction among care providers (experiences, success, problems, and improvements), (2) multidisciplinary collaboration, (3) information exchange, (4) knowledge sharing, (5) quality and safety, (6) patient and family involvement/education, (7) structure/planning, and (8) challenges/barriers. Each interview lasted approximately 1 h and was audio-taped.

#### Ethical considerations

The Western Norway Regional Ethics Committee for Medical Research approved the study (REC, no.2011/1978). Participation was based on informed oral and written consent. The interview participants received an information letter from their professional lead describing the project's aims and focus. The researcher contacted the healthcare professionals after they had been informed about the study and agreed to participate.

#### Data analysis

The audiotaped interview data material was transcribed to text format (274 pages) by a professional editor and by the first author of this article (half each). The first author then read all of the text transcripts to validate the written interview data. The interview data were analyzed using a systematic text condensation approach [33]. To ensure trustworthiness in the analysis, the three authors met to discuss, analyze, and code the interview data [28]. The researchers performed a four-step analysis, in part together and partly individually, before and after meeting:

- 1) The authors separately read the data material several times to obtain an overall impression before they met, and each presented their preliminary themes at the meeting.
- 2) Meaning units, or "text fragment[s] containing some information about the research question" (p. 797) [33]—in this case patient participation in hospital admission—were identified by all three authors beforehand and agreed upon during the meeting [33].
- 3) After the meeting, the first author continued to work on identifying meaning units related to the agreed themes. The meaning units were coded into code groups, which were sorted into subgroups by the first author, reducing and condensing the data but maintaining the original terminology as much as possible.
- 4) Finally, descriptions and concepts were discussed, and five categories were agreed upon [33].

Table 2 illustrates how the analysis proceeded using a selection of "meaning units" from the interview transcripts.

#### Results

Healthcare professionals' views on patient participation during hospital admission of older patients were influenced by five factors, shown in Fig. 1:

1. Routine treatment and care during hospital admission;
2. The frail and thankful older patient;
3. Hospital resources: available staff and beds;
4. Healthcare professionals' attitude towards exploring older patients' experiences; and
5. Presence of a supportive and demanding next of kin

#### Routine treatment and care during hospital admission

The first priority in the treatment and care of older patients on hospital admission is, according to the study participants, to save the patient's life. The participants stated that all patients are triaged when they arrive in the ED, based on the severity of their illness. According to several ambulance workers, observations of the patients' vital functions were necessary to provide correct and effective treatment and care both during the ambulance journey and in the ED. In the ED, one intern reported that medical examinations involve checking the patient's physical functions using a top-to-toe checklist. One nurse suggested that leaving patients in bed can easily lead to them feeling vulnerable. She said:

*"We are not forcing the patients, but we have to do our procedures and routines; ...undressing the patients, getting them into hospital clothing, performing the medical examination, establishing a diagnosis, and then we ask the patients if they have any questions."*

Several of the interview participants, particularly interns and nurses, talked about how and why they provided information to their patients. They considered information was necessary for patients to understand their medical problem and agree to the planned treatment, and for them to feel safe and well cared-for. The amount and content of the information provided to patients varied, depending on the interviewee's profession and whether the patient was in the ambulance or the ED. Ambulance workers said that they told the patient how long it would take to reach the hospital and explained the care that would be provided during the journey and at the hospital. They asked questions about the patients' symptoms and current health condition so that they could meet patient needs. At the hospital, patients were often given minimal information by nurses

**Table 2** Extracts from the interview analysis process

Preliminary themes	Codes/meaning units and code groups	Subgroups	Categories
Prerequisites for patient participation	Patient treatment and care	Necessary treatment of the patient	Routine treatment and care during hospital admission
	We observe the patient's vital functions to provide correct treatment and care. (ambulance worker)	Take care of vital functions	
	We are not forcing the patients, but we have to do our procedures and routines; undressing the patients, getting them into hospital clothing, performing the medical examination, establishing a diagnosis and then we ask the patients if they have any questions (ED nurse)		
	Information	Information to and from the patient	
	Informing the patient is important so that he understands the medical problem and agrees to the planned treatment (intern)		
Barriers to patient participation	Competence	Variable competence	
	Interns are unexperienced and need supervision (ED nurse)		
	Older patients' health status	Frail health status	The frail and thankful older patient
	Small changes in the older patients' health condition lead to severe consequences (ambulance worker)		
	The challenge with older patients is the compound medical picture (medical doctor)	A compound medical picture	
Barriers to patient participation	Belonging to another generation		
	Older patients never complain and tolerate pain very well, they do not want to bother anyone (medical doctor)	Older patients are thankful	
	The time aspect	Time is limited	Hospital resources; available staff and beds
	We have limited time for the patients, so when older patients want to explain what is wrong, we sometimes have to stop them (medical doctor)	High workload	
	One has to prioritize, if you spend much time on one of the older patients, then there is less time for other patients in the ED (intern)	Priority of time	
How to conduct older patients' participation	Respect	Involving the patient in practice	Healthcare professionals' attitudes towards exploring older patients' experiences
	I like working together with the patient (medical doctor)		
	I think it is of high importance that we show we care (ambulance worker)	Show that we care	
	The patients say what they want if you sit down and ask them (medical doctor)		
	I think it is important that the patient feel he has a right to decide himself and [to feel] that we do not just overrule him by our procedures, which we easily can (medical ED nurse)	Older patients want to stay at home	
	Preference for participation	Patient involvement in ED not relevant	
	Older people want to stay at home as long as possible if they know help will come when needed (ED nurse)	Multiple transitions	
	I don't think patient participation is very relevant in the ED (ED nurse)		
	It is important to not treat the older patient as a packet and transfer him from place to place (ambulance worker)		
	How to conduct older patients' participation	Next of kin	The next of kin role
Older people often call the next of kin instead of the doctor or the emergency services (ambulance worker)		Next of kin is first priority	
It is not easy to get any information from the older patient in a bad health condition; then next of kin supports with useful and necessary information (intern)		Next of kin, an information source	

**Table 2** Extracts from the interview analysis process (Continued)

Patients are more heard if the next of kin is present in the admission situation (ED nurse)	Patients heard if next of kin present
Next of kin can be challenging, having their own interests, which are not always the same as the patient's (medical doctor)	Next of kin's interests unlike the patient's
For a nurse it is good to know that the patient is not alone in the room, he has his family present, especially when I am busy with other patients. Then I ask them to tell me when they are leaving (ED nurse)	Family, safety for patient and nurse

in the triage part of the ED, because the patients were waiting for a medical examination. In the treatment part of the ED, the doctors (interns) usually provided information, often repeated by the nurses. Information focused on the possibilities and risks of surgery, medical treatment, and plans.

Views on how to involve patients to secure optimal treatment and care varied between the interview participants. One nurse held that a challenge to patient involvement was that the interns needed to focus on patients' basic medical treatment before prioritizing their involvement. The interns held that they were inexperienced and needed supervision around procedures and medical examination from medical doctors, who were often not present in the ED.

**The frail and thankful older patient**

Ambulance workers, nurses, and doctors all commented that the older patients in the ED were often frail, and had several chronic diseases and different sets of medication. They were therefore a challenging patient group to involve in their own treatment and care. According to the interview participants, these patients were often in

need of help in many areas because of their hearing difficulties, trouble walking, or spells of dizziness and cognitive impairment. One medical doctor commented that the deterioration in the medical condition that had resulted in the hospital visit could exacerbate existing problems, and that older patients could often be very confused when admitted to the hospital.

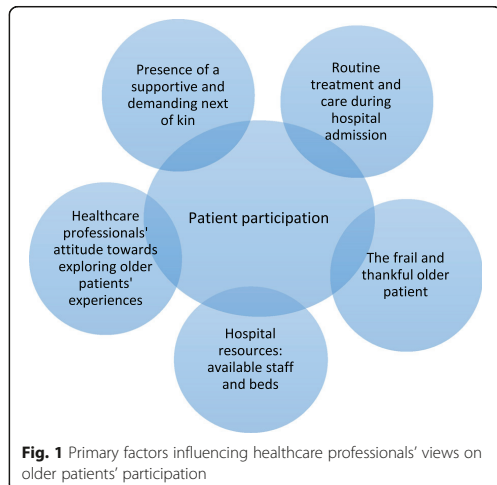
The medical examination of frail older patients was described by participants as "complex". One medical doctor commented that patients may have an acute medical problem combined with other conditions, which can make it difficult to find the medical reason for the problem on admission. Older patients were also characterized by one nurse as grateful for help. A medical orthopedic doctor agreed that they may seek help too late, and tend not to ask questions, but wait patiently to be seen by the doctor or nurse. This means that they are not involved in decisions on treatment and care. Participants felt that combination of a complex medical picture and the tendency to accept, and not complain, can lead older patients to be assessed as having simpler care needs than is actually the case.

Some nurses and doctors emphasized the importance of hearing from the patient. Some doctors said that they asked the patients to explain their health challenges and current problems during the medical examination:

*"The older patient has important information that is not documented by healthcare professionals, but the patient is at risk of not being heard. Sometimes there is a difference between the content of the written medical information from healthcare professionals in the municipality and what the patient says."* (intern)

**Hospital resources: available staff and beds**

Findings suggest that having sufficient staff and beds available constituted a challenge to patient participation for both hospital and municipality healthcare services. Several ambulance workers and an intern said that during the nights and weekends, staffing in nursing homes and home healthcare services is reduced. In their view, this could lead to patients being admitted to the hospital without adequate information about their medical history or medication.



**Fig. 1** Primary factors influencing healthcare professionals' views on older patients' participation

A medical doctor said that this shortage of staff in the municipality meant that patients often had to be admitted to the hospital, rather than sent home. The number of available staff at the hospital, however, was also said to be lower during weekends and nights. One nurse suggested that the combination of an over-crowded ED and hospital wards, and the lack of staff could influence staff capacity to care for patients. Mondays were often busy because patients waited until after the weekend to contact the doctor.

The participants reported that obtaining a medical history from older patients could be time-consuming. One intern said that this could be because of complex medical status, multiple types of medication, and older patients' difficulties explaining their health problems.

*"We have limited time for the patients, so when the older patients want to explain what is wrong, we sometimes have to stop them."* (medical doctor)

Nurses in the ED also talked about time pressure, working effectively, and not having much time to ask the patients about their preferences. They mentioned that they sometimes tell patients to talk to the doctor after transfer to the ward instead. Time pressure was a common issue:

*"One has to prioritize, if you spend much time on one of the older patients, then there is less time for the other patients in the ED."* (intern)

Several participants said that older patients were prioritized during hospital admission, but shortages of staff and beds in the ED and on hospital wards can cause long waits for medical examinations. An optimistic nurse in the ED said that the ideal situation would be no waits in the triage part of the ED admission process.

#### **Healthcare professionals' attitude towards exploring older patients' experiences**

The attitude and understanding of the healthcare professionals towards older patients' participation varied. Several participants emphasized that they tried to explore older patients' experiences, ask about their health problem, provide explanations, and respect their wishes.

An ambulance worker stated that one of his intentions during the journey to the hospital was to give patients an optimal experience and to help them feel respected and cared for. One nurse said that it was important to be professional and provide patient-centered care. This might include actions as simple as welcoming patients with a smile. Several of the medical doctors said they

asked their patients about their experiences and views of their medical problem.

One medical doctor preferred to sit at the bedside, to improve the quality of the interaction. He said:

*"The patients say what they want if you sit down and ask them."*

Some doctors and nurses also said that they tried to involve the patients in treatment and care by asking about their health challenges, but found that some older patients did not understand. One medical doctor emphasized the importance of patience in communicating with older patients.

Despite many positive statements, not all the participants could see how to involve older patients. One nurse felt that patient participation was not relevant in the ED. She was not familiar with the concept and held that the decision to admit the patient was made by the doctor in the municipality. An intern said that involvement depends on the patients and whether they are capable of making decisions.

Some nurses and doctors were concerned that there was a shortage of patient participation, with a medical nurse saying:

*"I think it is important that the patient feel he has a right to decide himself. It is good for the patient to be seen and heard and [to feel] that we do not just overrule him by our procedures, which we easily can."*

There were differences in views on involvement in decision-making about medical treatment. One nurse said that medical treatment is decided by the doctor and is often conducted without asking and involving the patient in the decision-making. A medical doctor pointed out, however, that the final decision about whether to treat is made by the patient, who must be informed of the alternatives.

Several participants focused on avoiding unnecessary hospital admission of older patients. One nurse doubted whether hospital admission was the best alternative for older patients, saying:

*"Older people want to stay at home as long as possible if they know help will come when needed."*

The study participants emphasized adjustment for end-of-life care, and letting older patients stay at home for as long as possible, and decide for themselves whether they should be admitted to the hospital. One ambulance worker stressed that communication between healthcare professionals, and proper documentation of

patients' functions, statements, and wishes are important to avoid unnecessary transfers.

#### Presence of a supportive and demanding next of kin

The interviewees considered patients' next of kin to be a good source of support when older patients were admitted to the hospital. One ambulance worker commented:

*"Older people often call the next of kin instead of the doctor or the emergency services."*

He had found that family members were often present when the ambulance arrived at the patient's home, and provided support with information and practical tasks. According to both doctors and nurses, having the next of kin present during hospital admission is valuable, in particular when providing information to older patients. The interview participants also considered the next of kin as a valuable information source. They know the patients well, can remember better what has been said, and are listened to by healthcare professionals.

Several of the interview participants considered next of kin to be a practical support for older patients. One nurse commented that the presence of someone familiar made older patients feel safe.

*"For a nurse, it is good to know that the patient is not alone in the room, he has his family present, especially when I am busy with other patients. Then I know that next of kin are staying with their loved one, and I ask them to tell me when they are leaving."* (nurse)

Although next of kin were a valuable source of support and help for healthcare professionals, the nurse emphasized that responsibility for care in the ED lay with the professionals.

Clinicians had several opinions about next of kin. Two nurses felt that patients were taken more seriously if their next of kin was present at admission. According to some of the interview participants, however, next of kin could sometimes be a challenge as their opinions and proposals might not be consistent with the patient's needs or wishes. Both an ambulance worker and a medical doctor emphasized that patients' needs and preferences take priority, although the views of next of kin were important.

#### Discussion

Our study has identified factors influencing patient participation by exploring healthcare professionals' views on patient participation during the hospital admission of older patients through the ED. Results indicate that the participation of older patients in the hospital admission process is influenced by five factors.

During hospital admission, routine treatment like assessing the patient's vital functions is the first priority for clinicians, and they use a medical triage system to prioritize patients who need emergency care [34]. Meeting patients' physical needs is vital and healthcare professionals need to have good clinical skills to ensure that patients feel safe and receive the right care and treatment in the ED [35]. In this study, the majority of physicians in the ED were interns. This is a challenge and can lead to procedure- and symptom-oriented care [22], with limited involvement of patients in their treatment and care. Andersson et al. [35] reported that medical competencies were valued more than caring competencies in everyday work in the ED, but clinicians in that study agreed that caring competencies were necessary to build a relationship with the patients. Our results support the idea that both medical and caring competencies are important in hospital admission to ensure the involvement of older patients [36].

Participants in the study reported that older patients' physical frailty and complex health condition may present a challenge to patient participation. The characteristics of older patients reported in earlier studies included being patient, tolerating pain well, hesitating to ask questions, and never complaining [8, 37]. Older patients might therefore become passive recipients of treatment and care, which is typical in the initial stage of illness [38]. Interview participants in our study said that wearing standard hospital clothing and staying in bed may also decrease patients' willingness to report pain or explain their preferences for treatment and care. There is a risk of less awareness among healthcare professionals of older patients' needs and preferences, as this group is perhaps not seen as capable of participating in their own care [38]. Older patients might end up being triaged as having more straightforward care needs than is actually the case, because they do not like to ask questions or complain [8].

Availability of hospital resources such as staff and beds influence patient participation in hospital admission, and were reasons given by clinicians in this study for not involving older patients. In a study by Storm et al. [15], some older patients in the ED waited between 3 and 7 h before being admitted to a hospital ward because of a crowded ED. The results in our study also suggest that healthcare professionals seem to prioritize aspects of work other than involving older patients in their treatment and care. The registration of ED patients is time-consuming but it is important to record vital patient information [39]. Research has identified several strategies for handling overcrowding, lack of care efficiency and provision of high-quality emergency care in the ED [8, 14, 15, 36, 39, 40]. Eitel et al. [39] suggested that the emergency severity index triage

system could help to prioritize patient needs. A protected time plan for clinicians also can help them plan for changes in patient flow in the ED [15, 39]. The use of nursing care plans in the ED can contribute to increased nurse/patient contact and improve communication between patients and nurses [38].

The interviewees all seemed to have high expectations of themselves and aimed to give high-quality treatment and care during the hospital admission process. The clinicians talked about taking the time to listen to patients' stories and to talk with them and their next of kin. Allowing patients to provide information about their health challenges, and giving them information about their treatment and care are necessary to involve them in decision-making and for truly informed choice [41, 42]. This is a fundamental value of patient-centered care [1, 42]. Older people want to be informed, heard, and involved in transitional care [8, 15, 21]. Storm et al. [15] found that older patients were dissatisfied with the long wait time for hospital admission and wanted to participate in decision-making about their level of care. A study by Dyrstad et al. [8] showed that patients and family members were not particularly involved in decisions about medical treatment and care during hospital admission. This contrasts with the intentions of clinicians in our study, who aimed to inform patients and involve them in decisions. This might be because of a lack of either time or established routines that involve patients in their treatment and care.

In increasing older patients' participation, we have to consider whether we want genuine participation, or merely to inform patients about decisions already made by healthcare professionals [43]. Many clinicians in our study seemed to want to provide patient-centered care, respecting patients and taking the time to listen to them. Berwick [42] referred to a patient statement: "They give me exactly the help I need and want, exactly when and how I need and want it" (p. 558), which seemed to be the general ambition in our study. We found that clinicians perceived that older patients could be overwhelmed by the hospital on arrival. They therefore made decisions based on what they perceived as the patients' best interests. Clinicians should focus on older patients' views and resources, rather than their frailty, and identify those who are capable of explaining their health challenges and participating in decisions about their treatment and care [44]. Taking a few moments to ask for patients' stories can be enough to identify their preferences and views [22, 23, 45].

Next of kin were described by the interview participants as fulfilling several roles, including receiving and providing information, and helping the patient to feel safe. This has also been reported in other studies, which

found next of kin were important in articulating older patients' needs and supporting their participation by advocating on their behalf [8, 15, 46]. In our study, next of kin were also perceived as demanding by healthcare professionals. These individuals often advocate for both themselves and the patient. Several of the participants in our study noted that it was important to take patients' wishes and needs into consideration before those of their next of kin.

We suggest it is important to increase healthcare professionals' knowledge of the factors influencing the participation of older patients in hospital admission, educate staff to handle complex situations, and facilitate continuity of treatment and care. Dyrstad et al. [8] reported that healthcare professionals need better awareness and knowledge of how to support older patients' participation. Measures that focus on information and participation of older patients in forthcoming transitions would be helpful. Training to improve provider-patient communication, especially sharing information with patients and their families, talking to patients, and involving them in care planning, would also be useful. Other useful measures include standardizing routines for information exchange, organizing meetings with next of kin to plan follow-up care, and encouraging the next of kin to stay with patients during hospital admission [15].

## Conclusion

This study explored healthcare professionals' views on patient participation in the hospital admission of older patients through the ED. We found that patient participation is influenced by five factors: routine treatment and care in hospital admission, the patients themselves, availability of hospital resources, especially staff and beds, the healthcare professionals' attitude towards exploring older patients' experiences, and the presence of a supportive and demanding next of kin. Some of the participants wanted to involve patients and emphasized that they kept patients constantly informed during hospital admission. A crowded ED ward, time pressure, lack of resources, and procedure-driven care, however, adversely affect the involvement of patients in their treatment and care. Next of kin were considered important in helping older patients to feel safe during hospital admission.

To integrate patient participation as an important element in healthcare, participants suggested that inter-professional meetings and educational programs would be helpful.

## Competing interests

The authors declare that they have no competing interests.

## Authors' contributions

DND designed the study, developed tools for and carried out the data collection, performed the qualitative analysis, and drafted the manuscript. IT contributed to the data analysis, manuscript preparation, and revision. MS



designed the study and contributed to the development of tools for the data collection, data analysis, manuscript preparation, and revision. All authors read and approved the final manuscript.

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## **Paper IV**

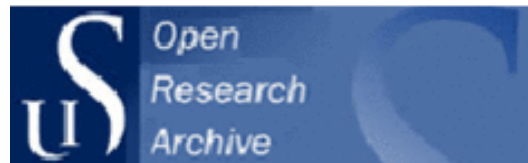


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# Interprofessional simulation to improve patient participation in transitional care

Dagrunn Nåden Dyrstad, Marianne Storm

## Abstract

### Background

Educating and training healthcare professionals is known to improve the quality of transitional care for older adults. Arranging interprofessional meetings for healthcare professionals might be useful to improve patient participation skills in transitional care.

### Aim

To describe the learning activities used in The Meeting Point programme, focusing on patient participation in transitional care, and assess whether they increase healthcare professionals' awareness of and competencies relating to patient participation in the transitional care of older patients.

### Design

Data were collected as part of an educational intervention programme, The Meeting Point, including three seminars on 'Patient participation in the transitional care of older patients' and four follow-up meetings. Participants were nurses, care assistants, doctors, physiotherapists, patient coordinators and administrative personnel from hospital, nursing homes and home-based care services.

### Method

The Meeting Point was organised around four pillars: introduction, teaching session, group work activity and plenary discussion. Qualitative data included log reports, summaries of meetings, notes from group work activities, and reports from participants and from follow-up meetings.

### Results

Feedback from participants shows that they were satisfied with meeting healthcare professionals from other units of care. A film scenario was perceived relevant for group work activity and useful in focusing participants' attention to patient participation. Follow-up meetings show that some nursing home wards, the emergency department and one medical ward at the hospital continued with ongoing work to improve quality of care. Efforts included implementation of an observational waiting room with comfortable chairs, planning for discharge in hospital admission, a daily patient flow registration system and motivational interviewing during admission to nursing home.

## Conclusions

The description of the learning activities used at The Meeting Point seminars shows that they were useful to increase awareness of and competencies on patient participation in transitional care.

## Introduction

The education and training of healthcare professionals is recognised as one way to improve the quality of transitional care given to older patients [1, 2]. Older patients are often transferred between different locations (e.g. from hospital to a nursing home) or between different levels of care within the same location (e.g. from an emergency department [ED] to a hospital ward) [2, 3]. Transitional care can be understood as a set of actions designed to ensure the coordination and continuity of health care as patients transfer between locations [4]. In this study, transitional care refers to transition from home with home care services or from nursing homes in the municipality to a hospital and vice versa.

Healthcare quality involves the following dimensions: safety, effectiveness, patient centredness, timeliness, efficiency and equitability [5]. Patient-centred care encourages patient participation in healthcare decisions [6]. According to Cahill [7], patient participation involves a power transfer from health professionals to the patient, the sharing of information between healthcare professionals and patients and patient involvement in decision-making about treatment and care [6]. Patient participation is regulated in the Norwegian Patient Rights Act [8]. The patient has a right to be informed and to participate in the decision-making about his or her treatment and care. Several studies report that healthcare professionals do not always acknowledge patients' preferences for involvement in treatment and care and that patients want to be involved in treatment and decisions [2, 9-12]. A lack of information to the patient and next of kin is a main barrier to patient participation during transitions. Dyrstad et al. [3] reported several studies where older patients received little information and were not involved in decisions about hospital discharge and the level of care after hospitalisation. Research on improvements in healthcare quality emphasises the education and training of healthcare professionals to provide patient-centred care [13] and ensure shared decision-making in clinical encounters [2, 14]. Training programmes for healthcare professionals that focus on the patient's perspective are suggested to improve the quality and safety of transitional care [3]. Meetings between healthcare professionals from different units and levels of care can develop professionals' competencies about patient participation in transitional care, and improve their understanding of involved personnel's work situation and the quality of transitional care [2, 15, 16]. Competencies include specific behaviours and skills as well as both attitudinal and cultural disposition [17].

The World Health Organization [18] developed a framework focusing on interprofessional education and collaborative work practices focusing on team members' understanding of their own role, responsibility and expertise in the team; communication within the team; relationship with the patient and recognising the patient's needs; and critical reflection of one's own clinical work. To achieve a healthcare team that is competent and possesses necessary behaviours, attitudes and skills, simulation training and learning are considered useful approaches [15, 19-21]. Simulation can be defined as 'activities that mimic the reality of a clinical environment and are designed to demonstrate procedures, decision-making and critical thinking through techniques such as role playing and the use of devices such as interactive videos or mannequins' (p. 97) [22]. Simulation in the training of healthcare

professionals can be used to engage clinicians from different organisational cultures in interprofessional collaboration (p. 27) [23]. Jeffries [23] identified five characteristics to successful simulation: clear objectives, fidelity, problem-solving, participant support and reflective thinking (debriefing). From a sociocultural perspective, knowledge and learning is constructed via participants interacting in social practices in, for example, a team-oriented simulation [21, 24]. Dieckmann [25] created a simulation model including a facilitator, theory input, a clinical scenario, simulation-based training and debrief. Simulation training has been used in different clinical areas and nursing education [15, 21] and has been reported to be a useful way to learn, acquire new skills and behaviours and suggest improvements in own units.

In this study, we report the results from The Meeting Point, a cross-level educational programme to improve the quality and safety of transitional care [26].

## Aims

This study has two key aims: (i) to describe the details of the learning activities used at The Meeting Point, focusing on the patient's perspective and participation in transitional care, and (ii) to assess whether the learning activities were useful to increase healthcare professionals' awareness of and competencies about the patient's perspective and participation in the transitional care.

## Methods

### Study design and setting

We used a qualitative research design [27]. Interprofessional meetings were held with healthcare professionals (nurses, nursing assistants, physicians, physiotherapists, administrative personnel) from the emergency department (ED), medical wards and an administration unit at hospital, and from nursing homes, home-based services and patient coordinating units in the municipality (Table 1). The Meeting Point consisted of an educational part and a discussion platform [26]. Three half-day seminar meetings were arranged over a 1-month period (November 2013), focusing on 'Patient participation in the transitional care of older patients'. Four follow-up meetings were conducted addressing the implementation of the measures suggested at The Meeting Point. The study was performed in one Norwegian Regional Health Authority. The meetings were conducted at a simulation centre.

Table 1. Summary of participants at The Meeting Point

<i>Healthcare services</i>	<i>Participants from healthcare units</i>	<i>Nurses</i>	<i>Nursing assistants</i>	<i>Physio-therapists</i>	<i>Physicians</i>	<i>Leaders</i>	<i>Adm. personnel</i>
Hospital	One Adm. unit						2
	One Emergency Department (ED)	9				2	3
	Two Medical wards	16			2	1	
	Summary hospital (35)	25			2	3	5
Municipality	Two patient coordinating units						16
	Four nursing homes	16	2	1	3	4	
	Four home-based services	7				1	
	Summary municipality (50)	23	2	1	3	5	16
In total	85 participants	48	2	1	5	8	21

## Recruitment and participants

A formal invitation to participate in the study was made to the leaders of hospital wards and in the municipality. The invitation contained information about The Meeting Point, including location, thematic focus, group work activity and information about lunch on arrival. This was followed by information meetings in each ward held by the research team. It was important to ensure leader support and willingness from the staff to participate in the study [26]. The hospital wards and departments in the municipality were selected based on their similarities regarding the number of patient beds, duties and their involvement in the transitional care of older patients and aimed to include the whole healthcare team involved in transitional care [26]. Participant information is presented in Table 1.

## Organising The Meeting Point

Before each Meeting Point seminar, the research team divided participants into five groups, which varied in size from five to eight members and were mixed across professional groups from the region's hospital, nursing homes and home care services. The seminars started with lunch, to best fit in the daily medical and caring activities at the hospital and in the municipality. Meeting for lunch was also an opportunity for participants to get to know each other in an informal setting, before the structured programme of the seminar [26].

The learning activities at The Meeting Point are presented as a simulation model [25, 28] in Table 2.

## Seminar introduction and theory input – a teaching session

While participants were sitting in their groups, the research team welcomed the participants and introduced the seminar theme and objectives [26]. A 1-hour teaching session held by a research team member was conducted with the theme 'Patient perspectives in transitional care'. The session presented an overview of relevant research, health-political documents [29] (the Coordination Reform), and the legal requirements of healthcare professionals to involve patients and users of healthcare services in their own treatment and care [8, 9, 26].

## Scenario briefing and simulation scenario – film

A film called *The patient's perspective in transitional care* was used as a simulation scenario. It focused on the hospital admission and discharge of an older patient. The film manuscript was based on anonymised field note data from observations of an older patient in transitional care [9, 26]. The field note data enabled the research team to develop a film scenario presenting realistic patient situations and work practices in transitional care. The film was recorded in the simulation laboratory at the university using a professional cinematographer who also prepared the layout. Before showing the film, a member of the research team gave a brief outline of the film, its purpose and setting.

Table 2 Simulating patient participation at The Meeting point (Dieckmann, 2009) and conducting follow-up meetings

November 2013, The Meeting Point, three meetings		March - August 2014, four follow-up meetings (two meetings hospital, two meetings nursing homes)				
Seminar introduction	Theory input	Scenario briefing	Simulation scenario – film	Debriefing – group work	Seminar ending	Summary The Meeting Point discussion
15 minute thematic area: The patient perspective Objectives: Increased knowledge, competence, patient participation Identify measures	45 minute Teaching session: “The patient perspective in transitional care”	5 minute Introduction of the film: Setting: Hospital admission (triage and treatment areas) and discharge (medical ward) of an older patient Objectives: To illustrate the patient perspective during the hospital admission and discharge of older patients To stimulate individual reflection on current transitional care practices To engage participants in group discussions about current practices, existing challenges, and the identification of improve-ment measures	10 minute Showing the film: The patient perspective in transitional care Manuscript based on anonymized field notes from observations (Dyrstad et al. 2014)	1 hour 5 groups (6–7 participants per group). Guided group discussion regarding film scenario Questions: 1 How were the patient’s care needs taken care of in the film during hospital admission and discharge? 2 What could be done to involve the patient in a larger degree during admission and discharge? 3 How are patients’ needs and preferences attended to in your unit? 4 Note the three most important measures that can be implemented at your ward to support the patient’s perspective in the transitional care of older patients between hospital and municipality 5 Agree on three measures and present these in the plenary session	45 minute Plenary discussion and summary by facilitator: Identify measures for implementation in the wards	1 hour Questions: 1 Have your ward initiated or participated in measures related to quality and safety in transitional care (admission to or discharge from the ward)? In case which? 2 Have any of the measures identified at the Meeting Point been initiated at the ward? 3 Can the research group assist with implementing measures to improve transitional care? 4 Has any changes occurred at the ward after participation at The Meeting Point?

### *A brief outline of film*

An older man lies in his bed after arriving at the ED, with pre-existing epilepsy and diabetes. He seems to be in pain. In the triage area, nobody talks to him, but soon his daughter arrives and sits at his bedside. He asks for his medication and she looks in her purse to find it. After 2.5 hours he is transferred to a treatment room in the ED. A nurse takes care of him, taking vital signs and informing him about the planned examination and tests, after which an intern comes into the room. At discharge, the patient is lying in his bed when a doctor comes in on her rounds. The doctor stands by the end of the bed, informing the patient that other patients need his place and that he is going to have a short stay at a nursing home from today. The nurse states that he has to leave very soon, before lunch. No next of kin is present at discharge.

### Debriefing – group work

Group work activities were a central part of The Meeting Point. The film was followed by a debrief and group work activity where the seminar participants answered five questions (presented in Table 2). A facilitator from the research team guided each work group through the questions.

### Seminar ending – plenary discussion

A plenary discussion followed the group work activities and a short coffee break. The discussion was planned to last for 45 minute and was led by members of the research team. The aim was to generate a discussion, identify different perspectives and reach some agreement regarding measures to implement in the wards [26]. One member from each group then presented the work group's suggestions for improvement measures. All participants were encouraged to take the key measures back to their own ward and take further action.

### Follow-up meetings

The researchers conducted follow-up meetings with participants from the nursing homes and hospital wards some months after The Meeting Point [26]. The aim was to identify drivers and barriers to implementing measures to improve the quality of transitional care. The follow-up meetings started with a summary of The Meeting Point seminar, the plenary discussion and the written feedback from participants. Four key questions, presented in Table 2, were used to assess whether and how improvement measures had been implemented in the wards [26].

### Data material

The data gathered at The Meeting Point and used in this study were written feedback from participants on the key components of the cross-level educational programme, minutes from the plenary sessions, the log reports of group work facilitators and study participants' written notes from the group work activities. The follow-up meetings were tape-recorded and transcribed to electronic text format by a research assistant in the research group.



## Ethical considerations

Approval for the study was obtained from the Western Norway Regional Ethics Committee for Medical Research (REC, no. 2011/1978). To ensure the appropriate use of data and confidentiality, all data related to the meetings; the seminars and the film were anonymised, as well as statements from participants during the meetings. Data were stored on a protected server only accessed by selected members of the research team.

## Data analysis

Data were analysed using thematic analysis, which is a method for identifying, analysing and reporting patterns (themes) in qualitative data [30, 31]. The method is descriptive, as the data has been organised to show patterns in the semantic content. In this study, a modified version of Braun and Clarke's [31] thematic analysis model was used. The written data material collected at The Meeting Point and from the follow-up meetings were transcribed into electronic text format and were read by both authors several times. The first author made codes by marking important features in the text transcripts and sorting data relevant to each code. The authors met to discuss the codes and identified themes. We used a semantic approach as we identified themes that were explicit or recognised the surface meanings of the data. Thus, we did not look for anything beyond what participants expressed, as shown in Table 3 [31].

## Results

The analysis identified four themes: *Lack of information during hospital admission and discharge in the film scenario; Lack of care from healthcare professionals in the film scenario; Information dissemination to/from the patient and next of kin is vital; and Let the patient decide*. The themes covered the aims of the study, which were to describe and assess whether the learning activities at The Meeting Point were useful in increasing healthcare professionals' awareness of and competencies related to the patient's perspective in transitional care.

### Lack of information during hospital admission and discharge in the film scenario

A film scenario was used to create a learning activity and introduction to the group work. The film emotionally affected several participants. Log reports show that participants commented on the lack of information provided to the patient and his daughter, both in the triage area of the ED and later in the ward during discharge. During the admission process, the participants were surprised that no information was given to the patient regarding the long waiting time before being examined by the physician. They reported good information and a high care level in the treatment area of the ED. During discharge, participants commented how the doctor stood at the end of the bed while informing the older patient about the decision to transfer him to a short stay in nursing home, that very day. One participant stated: 'The film was very realistic. As a ward leader from a short stay ward, I was shocked by the comment 'you have to go before lunch'. Participants commented that decisions about hospital discharge were made before the doctor's rounds and that the doctor and nurse simply informed the patient about the decision afterwards. A participant (a nurse) said that time pressures were no excuse for not informing the patient. Another participant commented, 'If the patient and next of kin are well informed, they can handle many challenges'.

Lack of care from healthcare professionals in the film scenario

The participants identified several deficits and lack of care during the hospital admission and discharge depicted in the film. They were particularly concerned about the lack of care and clinicians not attending to the patient's preferences, care and medical needs. In the ED, the older patient was only taken care of by his daughter who was sitting at his bedside. The patient had epilepsy and diabetes but was not given any food or medication. The participants were surprised that the daughter had to take care of the medication. They also remarked in the plenary discussion that the patient was in the ED for a total of 5.5 hour, and he was hungry, tired and in pain. The patient's basic needs and wishes were not met, neither during admission nor during discharge. The healthcare professionals made decisions for a short stay (without asking the patient) and did not acknowledge the patient's preferences. A nurse from a home care service commented that the healthcare professionals in the film displayed a top-down attitude, nobody asked about the patient's needs and there was no involvement. A nurse from an intermediate care provider in the municipality said that 'healthcare professionals were talking above the patient's head, not seeing the patient as a person'. Participants also viewed the next of kin as vital in hospital admission and missing at discharge.

A nurse from a medical ward advised that the film presented common work practices. Several participants were inspired to make improvements, and one said, 'Unfortunately it showed a busy day at work and I got many ideas for improvements'. Seminar participants discussed in the plenary session the importance of providing sufficient and relevant information to the patient and next of kin, at both hospital admission and discharge. It was suggested that the information included waiting hours, ward routines, common tests, procedures and treatment, and plans for follow-up care after hospital discharge. Examples included giving the patient information early in their stay, plans for discharge and communicating with the patient (e.g. 'I have not forgotten you' when the patient is waiting for examination in triage).

Information dissemination to/from the patient and next of kin is vital

The second learning activity, which incorporated group work, focused on increasing healthcare professionals' awareness of and competencies related to the patient perspective in their own wards. Log reports show that, during the group work, participants focused on the needs of patients and next of kin during hospital admission to the ED and hospital wards or at a nursing home in the municipality. In addition, some of the staff from hospital wards focused on discharge strategies.

The log reports from the group work show that all groups were concerned about providing sufficient information to the patient and their next of kin. They emphasised that information during hospital admission needs to focus on tests and examinations, the expected stay at the specific ward and plans for transfer to another ward at the hospital. A short-stay ward connected to the ED had developed a patient information brochure describing daily routines at the ward. Recently, the ED had installed an electronic information screen in the waiting room with information on routines and expected waiting time. Information on medical treatment and level of care given by the physician was considered very important during hospital discharge. Although nurses and physicians focused on information, a nurse from the medical ward said in the plenary session that 'unfortunately there is not much time to give information to older patients'. In contrast, a participant reported that a nursing home rehabilitation ward had arranged structured admission meetings with new patients to ensure essential information was given to patients and their next of kin. This was also mentioned by some patient coordinators in the municipality.

The log reports show that some healthcare professionals were concerned about the opportunity for patients to inform healthcare professionals about their views, concerns, experiences and preferences during hospital discharge. A nurse from the medical ward said she usually asks patients whether they want to go home or have a short stay in a nursing home. It was customary for geriatric ward staff to talk with patients during hospital admission about their needs after discharge. Nevertheless, healthcare professionals from the municipality placed a stronger emphasis on patients' perspectives. For example, during admission meetings at a nursing home, staff usually spoke with both the patient and next of kin, to determine the patient's level of functioning, expectations and wishes for future care and services. A nurse from a nursing home commented in the plenary session, 'Everything has to do with talking together'. She stated that communication is the key to collaboration between healthcare workers, the patient and next of kin to give optimal treatment and care to older patients.

Let the patient decide

Log reports from the group work show that involving patients in treatment, care and discharge planning varied among wards. Some wards had procedures to involve patients and family, and others had no such routines.

The medical hospital ward had no procedures in place to involve patients, but the patient's home situation was explored using a specific dialogue technique, 'motivational interviewing' where the primary goal for clinicians is to let the patient manage the conversation. Staff would typically ask a patient, 'What is important to you?' and 'What are your wishes?' In other words, staff would let the patients tell their story. This technique was also used in the community.

A nurse at a medical hospital ward commented that, 'At hospital the patient's needs and wishes are taken care of as much as possible, but at times it is difficult to do so'. To prepare for discharge, the patient and next of kin are encouraged to make an application to the coordinating unit in the municipality about the level of care required after discharge. Participants reported that the patient coordinator sometimes visits the patient at hospital or makes home visits and telephone calls to establish proper community-based services. The possibility of a readmission should also be addressed and discussed with the patient before hospital discharge.

Log reports also show that in community healthcare services (according to a home care nurse), the acute hospital admissions of older patients are usually unplanned. Furthermore, a transfer report is written and the patient is not involved in the decision. In contrast, network meetings with the patient, family, patient coordinator, nurse, physician, physiotherapist and others are arranged 1–3 day after admission to rehabilitation wards at nursing homes. If the patient is not cognitively impaired, he/she (according to a nurse at a nursing home) should be asked whether they wish their next of kin to be involved. To identify the patient's needs and resources, checklists and structured questions are used to formulate the specific aims of the stay. According to staff at a rehabilitation ward at a nursing home, it is also important to plan for the home situation, new medication and care needs, supporting remedies/materials and whether the patient wants to go home after the short stay. A patient coordinator from the municipality also mentioned that a nursing home stay is expensive, and the patient needs to be informed about this when planning the discharge. A patient coordinator stated that if necessary, the patient should be able to choose between several alternatives (e.g. nursing homes, home care services).

## Suggested measures and written feedback from The Meeting Point

The measures, the written feedback and the follow-up meetings were useful to assess healthcare professionals' awareness of and competencies related to participation in transitional care (aim 2). Measures suggested to enable patient participation are outlined in Table 4.

Table 4 'To-do-list' for healthcare professionals illustrating awareness and competencies in facilitating patient participation

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Relevant measures for patient participation identified at the Meeting Point
Treatment: <ul style="list-style-type: none"><li>• Consider the following question: Could treatment be conducted at the nursing home?</li></ul>
Patient-centred care: <ul style="list-style-type: none"><li>• Information brochure in ED presenting routine treatment and procedures in ED</li><li>• Sit at the patient's bedside, have a face-to-face talk, focus on the older patient's resources and ask about his/her views, concerns and wishes/expectations</li><li>• An admission meeting using a motivational interviewing, focusing the patient's personal goals for the stay; involve the patient from the first day</li><li>• Checklist for the patient to tick off when examinations, treatment and plans have been conducted</li><li>• Repeat information about opportunities for rehabilitation and follow-up care in the municipality and the patient's own resources to improve health and rehabilitation</li><li>• What is the patient's personal situation and living conditions ahead of the hospital stay?</li><li>• Apply for health care in the municipality at an early stage during the hospital stay</li><li>• Municipality healthcare services call the patient to ask 'how are you, what are your specific needs upon hospital discharge?'</li><li>• Regular network meetings/interprofessional meetings focusing the patient's views and needs</li></ul>
Involving next of kin: <ul style="list-style-type: none"><li>• Call next of kin during the hospital stay/nursing home stay; ask for a contact person in the family</li><li>• Family/network meetings; involve next of kin at an early stage (during admission about discharge)</li><li>• Invite next of kin to the doctor's rounds in hospital</li><li>• Make a discharge plan together with the patient and next of kin</li></ul>
The healthcare system: <ul style="list-style-type: none"><li>• Include a user representative in revision of the agreements between hospital and municipality regarding hospital admission and discharge</li></ul>

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In total, 70 of the 85 participants gave written feedback at the end of each of the three meetings. Participant comments included:

1. It was satisfying to meet and learn about 'patient participation', as well as discussing with involved professionals across units and level of care.
2. It increased my awareness of informing the patient for him/her to feel safe after hospital discharge.
3. I have learnt more about the patient perspective and challenges in transitional care of older patients.
4. The Meeting Point should become a regular interprofessional arena across specialist and community healthcare services to discuss challenges and keep focus on patient participation in transitional care.

## Results of the follow-up meetings

Follow-up meetings were conducted some months after the final seminar. Results show that some wards at the hospital and in the municipality had continued their work to improve quality in transitional care.

At the hospital, participants from the ED said that they have prepared an observational waiting room (where patients wait for a medical examination) for older patients; they are given a comfortable chair to sit in and remain in their own clothing. If they are not admitted, they are ready to be transported home. Observation ward staff (connected to the ED) said that they now plan discharge during the hospital admission process by checking the patient's history and asking the patient and next of kin about medical conditions and care needs ahead of admission. The ED has implemented a daily registration system to obtain an overview of how many medical and surgical patients are present. This is to ensure a faster transfer to the respective wards and to avoid any unnecessary hospitalisation. The head of the ED also plans to ensure that older patients with upper hip fractures undergo a medical examination at the ward to avoid meeting too many different professionals in ED: 'For older patients, it would result in less waiting hours in the ED and less confusion in new surroundings'.

In the municipality, participants from a short-stay nursing home stated that they planned to start using admission dialogues and 'motivational interviewing' with the patient, next of kin, nurses, doctors, physiotherapists and others, to let/help the patient set goals for the stay. One nursing home ward, which practiced goal setting, said that goals set by patients were usually realistic: practice walking, recuperate or go home.

## Discussion

Results from the Meeting Point show that the film scenario, the group work and plenary discussions were useful learning activities to focus attention and increase competencies about patient participation in transitional care. Results from follow-up meetings show that some wards had started improvement work in this area.

Conducting interprofessional meetings between healthcare professionals in hospital and community healthcare services is one way to increase the understanding of each other's work situation [16]. It was expected that the use of interprofessional groups at the Meeting Point seminars would encourage dialogue between group participants, foster engagement and stimulate discussion on the scenario depicted in the film [26]. The Meeting Point has contributed to increased understanding between the participants' work situation, with healthcare professionals from both hospital and municipality [32]. During the work groups and plenary discussion, the participants discussed with enthusiasm the importance of and challenges with informing the patient and next of kin during hospital admission and discharge.

Group work with participants from different interprofessional groups can serve as a useful platform for learning via different learning activities [33]. Sitting together in groups, discussing familiar themes, sharing experiences and working through key issues can lead to transformation of an interprofessional group into an effective and well-functioning team [34]. Sjøvold and Hegstad [35] conducted an observational study on group dynamics in interprofessional teams and reported that physicians with their medical knowledge and skills can play a dominant role in the hospital setting compared with nurses with their caring competencies. The authors suggested that physicians should expand their role from that of medical expert to one where they take greater responsibility in the team. At The Meeting Point, few doctors were present and the nurses were particularly engaged in the discussions.

According to the first aim, we used a film scenario as a learning activity and an introduction to the group work activity. The film depicted a realistic scenario to draw the participants' attention to the patient's perspective and patient participation in transitional care. Participants found the film scenario relevant as it was familiar to them and showed everyday clinical practice. The use of a briefing, film scenario, debriefing and a facilitator who encourages participant contemplation can be a useful approach to learning [25, 36]. From a sociocultural perspective, learning occurs when participants interact and work together in teams [24]. A common role of facilitators in debriefing is to guide participants through a description of the patient's situation in the scenario, analyse the actions of the role players, suggest improvements and highlight what can be transferred into clinical practice [37]. Questions from the participants about the simulation scenario are also important to enhance constructive comments and learning instead of criticism [38]. We used a guide with questions addressing the film scenario and patient participation in the participants' own wards, and a facilitator in each group to guide the group work activity. The film and questions were useful to initiate discussion about how to involve the patient in decisions and transitional care, and the participants were able to suggest possible improvements in their respective wards.

The use of a film scenario is also frequently used in the training of health professionals and in patient education to improve communication [39]. The simulation model in Dieckmann et al. [28] featured healthcare professionals playing the relevant roles in a clinical case. In a film scenario, the film actors play these roles. Meeting Point participants simply observed the film, and their thoughts about the film were discussed in the debriefing and group work. The participants were affected by the lack of care and patient participation during admission and discharge. Bålint et al. [40] also used film-aided simulation to stimulate role modelling and identity formation in healthcare professionals. Results showed that the negative role models in the films triggered more reflective thinking compared with positive role models. Hartland et al. [41] used short video simulations showing a variety of complex healthcare delivery situations associated with patient injury. They reported that using videos to visualise patient situations in combination with oral explanations could enhance learning and positively affect participants' work life. During group work and in the plenary discussion, the participants talked about how healthcare professionals in the film were talking above the patient's head, not seeing the patient as a person and informing and involving him in decisions. This suggests that the film scenario was useful to increase participants' awareness and the competencies of patient participation.

Two themes emerged from the group work activity to identify patient participation in their own wards: 'Information dissemination to/from the patient and next of kin is vital', and 'Let the patient decide'. Information was considered vital for the patients as was a focus on planning the length of and routines for the stay as well as treatment in hospital admission and options for level of care in the municipality after hospital discharge. Information about options for treatment and care is essential to ensure that older patients and their families are involved in decisions during and after hospitalisation [9, 16]. Good communication with patients is characterised by information dissemination between patients and health professionals, transparency, individualisation, recognition, respect, dignity and choice in all matters related to the patient and their personal situation [42]. Studies report that patients and their families often are not informed and involved in decision-making in transitional care because of negative attitudes and healthcare professionals that do not acknowledge patients as active players in their own care [43, 44].

Some of the participants at The Meeting Point said that there is minimal time to inform and involve the patients. Time pressure has been reported as a barrier to patient participation both in municipal healthcare services and in hospitals [2, 9, 45]. According to the participants in our study, patients in community healthcare services were somewhat more involved in decisions about their care than hospital patients. Patients have their permanent community residence and according to healthcare professionals in the municipality, a more active role in their own care. When older patients are hospitalised, they commonly experience deteriorating health and a reduced ability to participate in their own treatment and care [46].

In this study, the participants suggested measures to improve quality in transitional care in their own ward environment. We arranged follow-up meetings to assess possible changes and initiatives in clinical practice. This approach can be viewed as an extension of the simulation model [25, 37] to assess whether the simulation led to action and improvements in clinical practice. The film scenario was based on anonymised field notes from the observations of an older patient in transitional care [2, 9]. The film scenario illustrates key aspects of transitional care of older patients, which along with the large and varied written data material from The Meeting Point might have contributed to validate the study findings. We did not arrange follow-up meetings with all participants and wards represented at The Meeting Point due to the small number of participants from some of the wards. Some initiatives to improve patient participation in transitional care may not have come to our knowledge.

## Conclusion

The Meeting Point represents a promising arena for interprofessional simulation focusing on patient participation in transitional care. The learning activities contributed to awareness of the importance to inform and involve patients and next of kin. Follow-up meetings show that some wards have continued their work with quality improvement in transitional care. Examples of initiatives are an observational waiting room with comfortable chairs for the patients during hospital admission, planning discharge in hospital admission, a daily patient flow registration system, motivational interviewing and patients setting their own goals for their stay and admission to a nursing home. It was also suggested that The Meeting Point should be implemented as a regular interprofessional arena across the specialist and community healthcare services.

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## Author contribution

DND designed the study, developed tools for and carried out the data collection, performed the qualitative analysis and drafted the manuscript. MS designed the study protocol for the cross-levelled intervention 'The Meeting Point', was responsible for conducting the intervention including developing tools for the data collection, contributed to the data analysis, manuscript preparation and revision. Both authors read and approved the final manuscript.

## Ethical approval

Approval for the study was obtained from the Western Norway Regional Committee for Medical and Health Research Ethics (REC, no. 2011/1978).

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## **Appendices**



## **Appendix I: Ethical approval**



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<b>Region:</b> REK sør-øst	<b>Saksbehandler:</b> Katrine Ore	<b>Telefon:</b> 22845517	<b>Vår dato:</b> 11.11.2011	<b>Vår referanse:</b> 2011/1978/REK sør-øst B
			<b>Deres dato:</b> 27.09.2011	<b>Deres referanse:</b>

Vår referanse må oppgis ved alle henvendelser

karina.aase@uis.no  
Institutt for helsefag

#### **2011/1978 B kvalitet og sikkerhet knyttet til overføring av eldre pasienter**

Vi viser til søknad om forhåndsgodkjenning av ovennevnte forskningsprosjekt. Søknaden ble behandlet av Regional komité for medisinsk og helsefaglig forskningsetikk i møtet 19.10.2011.

**Forskningsansvarlig:** Einar Marnburg  
**Prosjektleder:** karina.aase@uis.no

#### **Prosjektomtale (revidert av REK):**

Formålet med prosjektet er å synliggjøre kjennetegn på god overføring og samhandling mellom sykehus og kommunehelsetjenesten i forbindelse med utskrivelse av eldre pasienter, samt utvikle en praktisk guide for sikre overføringer. Studien har fokus på pasientsikkerhet og hvordan denne blir ivaretatt når eldre pasienter skrives ut fra sykehus til kommunehelsetjenesten (sykehjem eller egen bolig). Studien vektlegger helsepersonells, pasienters og pårørendes erfaringer og opplevelser knyttet til slike overføringsprosesser. Denne studien inngår i et større forskningsprosjekt (Quality and safety within elderly health and care services – the role of transitions and interactions) ved Universitetet i Stavanger. Forskningsprosjektet er finansiert av Norges Forskningsråd, Helse Vest og UiS. Det er planlagt å inkludere 640 personer som er pasienter, pårørende eller helsepersonell. Studien er samtykkebasert.

#### **Forskningsetisk vurdering**

Komiteen har ingen forskningsetiske innvendinger til studien.

#### **Vedtak**

Komiteen godkjenner at prosjektet gjennomføres, jf helseforskningsloven § 10.

Godkjenningen er for øvrig gitt under forutsetning av at prosjektet gjennomføres slik det er beskrevet i søknaden, og de bestemmelser som følger av helseforskningsloven med forskrifter.

Forskningsprosjektets data skal oppbevares forsvarlig, se personopplysningsforskriften Kap. 2, og Helsedirektoratets veileder for "Personvern og informasjonssikkerhet i forskningsprosjekter innenfor helse- og omsorgssektoren".

Dersom det skal gjøres endringer i prosjektet i forhold til de opplysninger som er gitt i søknaden, må prosjektleder sende endringsmelding til REK.

Opplysningene skal ikke oppbevares lenger enn det som er nødvendig for å gjennomføre prosjektet, deretter

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<b>Besøksadresse:</b> Gullhaug torg 4 A, Nydalens, 0484 Oslo	<b>Telefon:</b> 22845511 <b>E-post:</b> post@helseforskning.etikkom.no	All post og e-post som inngår i saksbehandlingen, bes adressert til REK sør-øst og ikke til enkelte personer	Kindly address all mail and e-mails to the Regional Ethics Committee, REK sør-øst, not to individual staff
	<b>Web:</b> http://www.rek.no		



skal opplysningene anonymiseres eller slettes.

Godkjenning gjelder til 31.12.2015

Prosjektet skal sende sluttmelding på eget skjema, senest et halvt år etter prosjektslutt, jf. helseforskningsloven § 12.

Komiteens avgjørelse var enstemmig

Godkjenningen av prosjektet gjelder til 31.12.2015.

Forskningsprosjektets data skal oppbevares forsvarlig, se personopplysningsforskriften kapittel 2, og Helsedirektoratets veileder for «Personvern og informasjonssikkerhet i forskningsprosjekter innenfor helse- og omsorgssektoren».

Prosjektet skal sende sluttmelding til REK sør-øst på fastsatt skjema senest 30.06.2016.

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

Dersom det skal gjøres endringer i prosjektet i forhold til de opplysninger som er gitt i søknaden, må prosjektleder sende endringsmelding til REK. Vi gjør oppmerksom på at hvis endringene er "vesentlige", må prosjektleder sende ny søknad, eller REK kan pålegge at det sendes ny søknad.

Vi ber om at alle henvendelser sendes inn via vår saksportal: <http://helseforskning.etikkom.no> eller på e-post til: [post@helseforskning.etikkom.no](mailto:post@helseforskning.etikkom.no).

Vennligst oppgi vårt referansenummer i korrespondansen.

Med vennlig hilsen,

Stein Opjordsmoen Ilnér (sign.)  
Overlege dr. med. professor  
Komiteens leder

Katrine Ore  
Rådgiver

**Kopi til:** einar.marnburg@uis.no, einar.marnburg@uis.no

## **Appendix II: Information to healthcare professionals**





## INFORMASJONSSKRIV TIL HELSEPERSONELL

Forespørsel om deltakelse i forskningsprosjekt knyttet til eldre og samhandling mellom primær- og spesialisthelsetjenesten!

### Bakgrunn

Vi vil med dette invitere deg til å delta i forskningsprosjektet "Kvalitet og sikkerhet knyttet til overføring av eldre pasienter". Forskningsprosjektet har fokus på kvalitet og sikkerhet i behandling, pleie og omsorg av eldre i grensesnittet mellom primær- og spesialisthelsetjenesten. Studien har fokus på hvordan kvalitet og pasientsikkerhet blir ivaretatt når eldre pasienter *legges inn og skrives ut* til/fra sykehus og kommunehelsetjenesten (sykehjem eller egen bolig med hjemmesykepleie). I dette informasjonsskrivet redegjør vi for hvorfor denne forskningen utføres og hva den innebærer for deg, som mulig deltaker i studien.

### Hva er formålet med prosjektet?

Hovedformålet med prosjektet er å synliggjøre kjennetegn på god overføring og samhandling mellom sykehus og kommunehelsetjenesten i forbindelse med innleggelse og utskrivelse av eldre pasienter, samt utvikle praktiske løsninger til beste for pasient, pårørende og helsepersonell.

### Hvem er de eldre pasientene som inkluderes i forskningsprosjektet?

Forskningsprosjektet inkluderer eldre pasienter (>75 år) som legges inn eller skrives ut med ortopediske tilstander som hoftebrudd (FCF/FPF) akutte medisinske tilstander i forbindelse med kronisk sykdom, herunder KOLS, hjerte/kar problemer, diabetes og andre akutte medisinske tilstander, eksempelvis infeksjoner i kombinasjon med polyfarmasi (>5 medikamenter daglig). I tillegg inkluderes demente pasienter som innlegges eller utskrives med de nevnte diagnoser.

### Hvem finansierer og er ansvarlig for prosjektet?

Forskningsprosjektet gjennomføres ved Universitetet i Stavanger (UiS) av to doktorgradsstudenter, Kristin Alstveit Laugaland (ansatt i Helse Førde), Dagrunn Nåden Dyrstad (ansatt ved UiS), post doktor Marianne Storm (ansatt ved UiS) og prosjektleder professor Karina Aase ved UiS. Forskningsprosjektet er finansiert av Norges Forskningsråd, Helse Vest og UiS. Helse Førde og Regionalt senter for eldremedisin og samhandling (SESAM) er formelle samarbeidspartnere i forskningsstudien. Studien har fått tilslutning fra Regionale komiteer for medisinsk og helsefaglig forskningsetikk (REK) den 19.10.11 – referansenummer 1978.

### **Hvorfor blir jeg invitert til å delta?**

Ditt sykehus eller kommune har takket ja til å delta i studien, og vi inviterer noen av de ansatte til å delta på flere måter (se under).

### **På hvilken måte kan jeg bli involvert?**

Dersom du ønsker å delta i forskningsprosjektet innebærer det å dele dine synspunkter og erfaringer om gjeldende praksis knyttet til samhandling ved innleggelse og utskrivelse mellom primær og spesialisthelsetjenesten. Du kan bli invitert til å delta på 2 ulike måter:

*Observasjon:* Deltakelse i studien innebærer at vi får følge/observere deg og din samhandling med pasient og øvrig helsepersonell den dagen pasienten legges inn eller skrives ut fra sykehuset til kommunehelsetjenesten (sykehjem eller egen bolig). Hvis du takker ja til dette, vil vi be deg om å signere et samtykkeskjema hvor du aksepterer å bli observert.

*Intervju:* Vi kommer til å invitere et antall ansatte til intervju, med medlemmer av forskningsteamet. Dersom du får en slik invitasjon og takker ja til å delta i et intervju, vil dette ta ca 45 min. Vi vil gjerne ta opp intervjuet på bånd, slik at vi får en nøyaktig oversikt over det du forteller oss. Vi vil be deg om å signere et samtykkeskjema hvor du aksepterer deltakelse i intervjuet.

### **Deltakelse er frivillig og vil være konfidensielt**

All deltakelse i denne forskningsstudien er frivillig og en har full mulighet til å trekke seg underveis om det skulle være ønskelig. Alle innsamlede opplysninger håndteres konfidensielt. Alt som vedrører observasjon, samtaler og intervju blir gitt en kode for å sikre konfidensialitet og vil lagres i et låst arkivskap eller på en passordbeskyttet datamaskin som er sikret mot uautorisert tilgang. Når datamaterialet presenteres i forskningsarbeidet er forskerteamet forpliktet til å overholde taushetsplikten slik at din anonymitet ivaretas. Alt datamaterialet vil bli anonymisert ved all rapportering fra studien. Forventet prosjektslutt er 31. Desember 2015.

### **Hvorfor delta - hva kan du bidra med?**

Å bedre samhandlingen mellom primær- og spesialisthelsetjenesten blir oppfattet som en stor og viktig oppgave. I dette arbeidet er det helt nødvendig å få kunnskap om helsepersonells egne erfaringer knyttet til samhandling mellom sykehus og kommunehelsetjenesten. Vi håper det kan være av interesse for deg å delta og håper på positiv tilbakemelding. Det er imidlertid helt opp til deg om du ønsker å delta eller ikke. Om du takker ja ber vi deg om å fylle ut vedlagt samtykkeerklæring.

### **Mer informasjon**

Takk for at du leste denne informasjonen. Dersom noe er uklart eller du ønsker mer informasjon om dette prosjektet kan du ringe eller sende e-post til:

Kristin Alstveit Laugaland (Stipendiat)  
(prosjektleder) [kristin.a.laugaland@uis.no](mailto:kristin.a.laugaland@uis.no)  
Tlf: 51834141 Mob: 98486261

Karina Aase  
[karina.aase@uis.no](mailto:karina.aase@uis.no)  
Tlf: 51831534

Dagrunn Nåden Dyrstad (Stipendiat)  
[dagrunn.n.dystad@uis.no](mailto:dagrunn.n.dystad@uis.no)  
Tlf: 51834258 Mob: 93676824

Marianne Storm (post doktor)  
[marianne.storm@uis.no](mailto:marianne.storm@uis.no)  
Tlf: 51834158

# SAMTYKKEERKLÆRING

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## OBSERVASJON OG INTERVJU MED ANSATTE

Navn på forskere fra Universitetet i Stavanger som kan utføre intervju: Dagrunn Nåden Dyrstad, Kristin Laugaland, Lene Schibevaag, Heidi Nedreskår, Marianne Storm, Karina Aase.

Jeg bekrefter at jeg har mottatt, lest og forstått skriftlig informasjon om forskningsprosjektet "Kvalitet og sikkerhet knyttet til overføring av eldre pasienter" og takker ja til å delta i prosjektet.

**JA**

Jeg aksepterer å bli observert:

Jeg aksepterer å bli intervjuet:

Navn på deltaker: .....

Dato:.....

Sign:.....

Navn på forsker: .....

Dato:.....

Sign:.....



### **Appendix III: Information to patients and next of kin**







## INFORMASJONSSKRIV TIL PASIENTER OG PÅRØRENDE

Forespørsel om deltakelse i forskningsprosjekt

### Bakgrunn

Vi vil med dette invitere deg til å delta i forskningsprosjektet "Kvalitet og sikkerhet knyttet til overføring av eldre pasienter". Forskningsprosjektet har fokus på kvalitet og sikkerhet i behandling, pleie og omsorg av eldre på tvers av kommune og sykehus. Studien har fokus på hvordan kvalitet og pasientsikkerhet blir ivaretatt når eldre pasienter *legges inn og skrives ut* til/fra sykehus og kommunehelsetjenesten (sykehjem eller egen bolig med hjemmesykepleie). I dette informasjonsskrivet redegjør vi for hvorfor denne forskningen utføres og hva den innebærer for deg, som mulig deltaker i prosjektet.

### Hva er formålet med prosjektet?

Hovedformålet med prosjektet er å synliggjøre kjennetegn på god overføring og samhandling mellom sykehus og kommunehelsetjenesten i forbindelse med innleggelse og utskrivelse av eldre pasienter, samt utvikle praktiske løsninger til beste for pasient, pårørende og helsepersonell.

### Hvem er de eldre pasientene som inkluderes i forskningsprosjektet?

Forskningsprosjektet inkluderer eldre pasienter (>75 år) som legges inn eller skrives ut med: akutte medisinske tilstander eller lårhalsbrudd i kombinasjon med polyfarmasi (>5 medikamenter daglig). I tillegg inkluderes pårørende til demente pasienter som innlegges eller utskrives med de nevnte diagnoser.

## Hvorfor blir du invitert til å delta og hva vil deltakelse innebære?

Du inviteres til deltakelse i dette forskningsprosjektet da du er:

- Pasient over 75 år som innlegges eller utskrives med en akutt medisinsk tilstand eller lårhalsbrudd og bruker mer enn 5 medisiner daglig
- Pårørende til demente pasienter over 75 år som innlegges eller utskrives med akutte medisinske tilstander eller lårhalsbrudd og bruker mer enn 5 medisiner daglig

Deltakelse i studien vil innebære at medlemmer fra forskerteamet får følge deg og din samhandling med helsepersonell enten *ved innleggelse* eller *den dagen du skrives ut fra sykehuset*. Deltakelse innebærer at du aksepterer at forskerteamet får innsyn og kopi av innleggelse og utskrivelseskriv. Vi understreker at ingen personidentifiserbare data vil registreres eller benyttes.

Vi ønsker også å besøke deg på *sykehjemmet* eller *hjemme 1-2 dager etter utskrivelse* for å samtale med deg om den aktuelle utskrivelsesprosessen. Sentrale temaer i samtale med deg som pasient eller pårørende er dine opplevelser knyttet til medvirkning, involvering, og informasjonstilgang i forbindelse sykehusoppholdet og utskrivelse. Samtalen vil ha en varighet på ca 30-60 min. For å kunne gjengi samtalen korrekt, vil denne tas opp på bånd. Samtalen vil deretter skrives ned og bearbeides til anvendelse for studien.

### Deltakelse i forskningsprosjektet er frivillig

Deltakelse i denne forskningsstudien er helt frivillig og en har full mulighet til å trekke seg underveis om det skulle være ønskelig. Alle innsamlede opplysninger håndteres konfidensielt. Det som vedrører observasjon og samtaler blir gitt en kode for å sikre konfidensialitet og vil lagres i et låst arkivskap eller på en passordbeskyttet datamaskin som er sikret mot uautorisert tilgang. Når datamaterialet presenteres i forskningsarbeidet er forskerteamet forpliktet til å overholde taushetsplikten slik at din anonymitet ivaretas. Alt datamaterialet vil bli anonymisert ved all rapportering fra studien. Forventet prosjektslutt er 31. Desember 2015.

### **Hvorfor delta og hva kan dere bidra med?**

Å bedre samhandlingen mellom sykehus og kommune blir oppfattet som en stor og viktig oppgave. I dette arbeidet er det helt nødvendig å få kunnskap om pasienters og pårørendes egne erfaringer knyttet til samhandlingene mellom sykehus og kommunehelsetjenesten.

Om du takker ja til deltakelse i forskningsprosjektet ber vi deg om å fylle ut vedlagt samtykkeerklæring.

### **Mer informasjon**

Takk for at du leste denne informasjonen. Dersom noe er uklart eller du ønsker mer informasjon om dette prosjektet kan du ringe eller sende e-post til:

Kristin Alstveit Laugaland (Stipendiat)  
(prosjektleder) [kristin.a.laugaland@uis.no](mailto:kristin.a.laugaland@uis.no)  
Tlf: 51834141 Mob: 98486261

Karina Aase  
[karina.aase@uis.no](mailto:karina.aase@uis.no)  
Tlf: 51831534

Dagrunn Nåden Dyrstad (Stipendiat)  
[dagrunn.n.dystad@uis.no](mailto:dagrunn.n.dystad@uis.no)  
Tlf: 51834258 Mob: 93676824

# SAMTYKKEERKLÆRING

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## OBSERVASJON OG SAMTALE MED PASIENTER OG PÅRØRENDE

Navn på forskere fra Universitetet i Stavanger som kan utføre observasjon/samtale: Dagrunn Nåden Dyrstad, Kristin Laugaland, Lene Schibevaag, Heidi Nedreskår, Marianne Storm, Karina Aase.

Jeg bekrefter at jeg har mottatt, lest og forstått skriftlig informasjon om forskningsprosjektet "Kvalitet og sikkerhet knyttet til overføring av eldre pasienter" og takker ja til å delta i prosjektet.

JA

Jeg aksepterer å delta i forskningsprosjektet:

Navn på deltaker: ..... Dato:..... Sign:.....

Navn på forsker: ..... Dato:..... Sign:.....

## **Appendix IV: Observation guide**





## OBSERVASJONSGUIDE

KONTEKST	PASIENT	HELSEPERSONELL	HELSEPERSONELL
Dag/dato:	Kode: Alder: Kjønn:	Stilling:	Stilling:
Tidspunkt på dagen:	Diagnose: Tilleggsdiagnoser: Dement: Funksjonsnivå: (Før/Etter)	Arbeidserfaring:	Arbeidserfaring:
Anvendt tid:	Antall medikamenter:	Kjønn, alder:	Kjønn, alder:
Sted for observasjon (avdeling):	Sosialt nettverk(pårørende):	Stilling:	Stilling:
Forsker:	Innlagt med: Utskrives til:	Arbeidserfaring:	Arbeidserfaring:
Medobservatør:	Lengde på sykehusopphold:	Kjønn, alder:	Kjønn, alder:

\*Beskriv det som skjer ikke legg tolkninger I det som observeres



## DEL 1: OBSERVASJON PÅ SYKEHUS INNLEGGELSESDAGEN I AKUTTMOTTAK/UTSKRIVELSESDAGEN PÅ SENGEPOST

- Strukturer/planer ansatte jobber med – (ta evt. kopi)
- Beskrivelse av mottakssituasjonen/utskrivelsessituasjonen
- Min evaluering av innleggelsesforløpet/utskrivelsesforløpet

Foreligger det egen innleggelses/utskrivelsesprosedyre?	
Benyttes denne? (grad av etterlevelse)	
Svikt i rutiner?	

- Grad av samhandling med kommunehelsetjenesten

Er det kontakt mellom sykehus og kommune innleggelsesdagen/utskrivelsesdagen? Hvem er i kontakt med hvem?	
--	--

- Innleggelsesundersøkelsen/utskrivelse/samtalen/samhandling med pasient

Hvordan er denne organisert? (tid, sted, rom)	
Hvem er med?	
Har pårørende fått tilbud?	
Hvilken informasjon får pasienten?	
Er informasjonen tilpasset pasientens tilstand? (bruk av faguttrykk, tydelig, utydelig.)	
Blir pasienten informert om eventuell behandling/ medikamentendringer og begrunnelse for disse? (Bivirkninger, administrasjon etc.)	
Blir pasienten informert om det videre behandlingsforløpet i sykehuset? Etter utskrivelsen? Hvilken informasjon blir gitt?	
Hvor informert fremstår pasienten knyttet til sykehusoppholdet, diagnoser, medikamenter	
Har pasienten anledning til å fortelle om forhold de mener er viktig i forbindelse med innleggelsen/utskrivelsen? Få fram fortellingen fra pasienten.	
Blir det tatt hensyn til pasientens vurderinger i beslutninger som tas ved innleggelsen/utskrivelsen?	

### Tverrfaglig samarbeid – helhetlig tilnærming

Hvilke faggrupper er involvert i forbindelse med innleggelse/utskrivelse?	
Hvordan er samspillet mellom dem? (hvor mye dialog, hva er innholdet i dette)	
Hvilken rolle har hjelpepleier i forbindelse med innleggelse/utskrivelse?	
Hvilken rolle har sykepleier i forbindelse med innleggelse/utskrivelse?	
Hvilken rolle har legen i forbindelse med innleggelse/utskrivelse?	
Hvilken rolle har ambulanspersonellet i forbindelse med innleggelse/utskrivelse?	
Er det planlagt vurdering av geriater i løpet av sykehusoppholdet?	

- Dokumentasjon og informasjonsoverføring (ta kopi av innleggelseskriv/utskrivelsesnotater)

Foreligger innleggelses/utskrivelsespapirer ved innleggelse/utskrivelse?	
Sendes denne elektronisk og/eller med pasient ved innleggelse/utskrivelse?	
Foreligger det eget notat fra hjemmebaserte tjenester/sykehjem? (ta kopi)	

Har sykepleieprosessen blitt ivare tatt under sykehusinnleggelsen/utskrivelsen? Kartlegging av sykepleiebehov og tiltak Helhetlig bilde av pasientens situasjon (ernæringstilstand, kognisjon/delirium, legemidler, smerter, infeksjon, fallrisiko, aktivitet, eliminasjon etc.)	
Har pasienten fra før en sykepleieplan eller individuell plan? Blir denne tatt med til sykehuset og tatt til etterretning? Blir pasienten involvert i utarbeidelse av sykepleieplan eller Individuell plan?	

• Samhandling med pårørende

Har pasienten pårørende, sosialt nettverk? Hvem består disse av?	
Blir pårørende involvert/kontaktet ved innleggelse/utskrivelse? Hvem tar kontakt med pårørende?	
Hvilken informasjon får pårørende? Hvem informerer?	
Blir pårørende informert om eventuelle medikament endringer ved innleggelse/utskrivelse?	
Har pårørende anledning til å fortelle om forhold de mener er viktig i forbindelse med innleggelsen/utskrivelsen?	
Blir det tatt hensyn til pårørendes vurderinger i beslutninger som tas ved innleggelsen/utskrivelsen?	
Virker pårørende tilfreds?	

- Tidsfaktorer og stresserelementer som påvirker innleggelses-/utskrivelsesprosessen (ressursmangel, ansvar for flere pasienter, ekstraordinære hendelser etc.)

## Resultat

- Går innleggelses/utskrivelsesprosessen som planlagt?
- Suksesskriterier og barrierer

Hvor lenge ble pasienten liggende i akuttmottak/sengepost før overflytting til sengepost/kommunen? Forsinkelser? Fikk pas. mat? Ble pårørende kontaktet?	
Fremstår pasienten tilfreds med innleggelsen/utskrivelsen?	
Barrierer og forbedringsmuligheter i innleggelses/utskrivelsesprosessen	
Risikoelementer/svikt i rutiner Uønskede hendelser?	

## Oppsummering fra ansvarlig sykepleier/hjelpepleier

Hvordan opplevde de denne innleggelses/utskrivelsesprosessen? (Svakheter/styrker)

Var de ansatte forberedt?

## Oppsummering fra ansvarlig lege

Hvordan opplevde de denne innleggelses/utskrivelsesprosessen? (Svakheter/styrker)

Var de ansatte forberedt?

---

## Samtale med pasient

---

Kode:	
Intervjuer:	
Tid og sted:	
Anvendt tid:	

NB: Spør om det samme flere ganger

1. INNLEGGELSE/UTSKRIVELSESPROSESSEN
  - **Be pasient om å fortelle om sine opplevelser i løpet av innleggelses/utskrivelsesprosessen og sykehusoppholdet så langt – kartlegg grad av tilfredshet (hvorfor/hvorfor ikke) (Legg stor vekt på deres egen fortelling)**
  - Forberedt/uforberedt (engstelse/frykt)?
2. PASIENT INVOLVERING
  - Fikk du informasjon om hva som skulle skje på sykehuset/kommunen da du ble innlagt/utskrevet? Var denne informasjonen lett å forstå?
  - Fikk du anledning til å fortelle personalet hva du mente var viktig ved innleggelsen/utskrivelsen?
  - Tok de hensyn til det du sa (dine meninger/vurderinger)?
  - Var det viktig for deg å få lov til å påvirke de beslutningene som ble tatt om din behandling da du ble innlagt/utskrevet?
3. TVERRFAGLIG SAMARBEID
  - Hvilken opplevelse hadde du av samarbeidet mellom helsepersonell og involverte faggrupper i løpet av innleggelsen/utskrivelsen din?
4. INFORMASJONSOVERFØRING
  - Hvilken informasjon fikk du?
    - ✓ Savnet du informasjon om noe, for mye for lite, tilstrekkelig?
    - ✓ Hvilken informasjon var viktig for deg?
  - Ble du informert om behandling, medikament endringer (bivirkninger, administrasjon etc.), oppfølging, rehabilitering, trening, prøver etc. ved innleggelsen/utskrivelsen?
5. UØNSKEDE HENDELSER
  - Var det noe etter din oppfatning som gikk galt som kunne vært unngått?
6. ØNSKER OG FORBEDRINGER
  - Hva var bra?
  - Hva kunne vært bedre?

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## Samtale med pårørende

---

Pårørende:	
Kode:	
Intervjuer:	
Tid og sted:	
Anvendt tid:	

### 1. INNLEGGELSE/UTSKRIVELSESPROSESSEN

- **Be pårørende fortelle om sine opplevelser i løpet av innleggelsen og sykehusoppholdet så langt –**
- **Er de tilfreds? kartlegg grad av tilfredshet (hvorfor/hvorfor ikke) (Legg stor vekt på deres fortelling)**

Forberedt/uforberedt (engstelse/frykt)- når ble du informert om innleggelsen/utskrivelsen?

### 2. PÅRØRENDE INVOLVERING

- Ble du som pårørende involvert/kontaktet ved innleggelse/utskrivelse?
- Hvem tok kontakt med deg som pårørende?
- Har du hatt anledning til å fortelle om forhold du mener er viktig i forbindelse med innleggelsen/utskrivelsen?
- Ble det tatt hensyn til dine vurderinger i beslutninger som ble tatt ved innleggelsen/utskrivelsen?

### 3. TVERRFAGLIG SAMARBEID

Hvilken opplevelse hadde du av samarbeidet mellom helsepersonell og involverte faggrupper i innleggelsen/utskrivelsen?

### 4. INFORMASJONSOVERFØRING

- Hvem informerte dere?
- Hvilken informasjon fikk du/dere som pårørende,
  - ✓ Var denne lett å forstå?
  - ✓ Savnet dere informasjon om noe, for mye for lite, tilstrekkelig?
  - ✓ Hvilken informasjon var viktig for deg som pårørende at spesialisthelsetjenesten hadde kunnskap om?
- Ble du/dere informert om behandling, medikament endringer, oppfølging, rehabilitering, trening, prøver etc.

### 5. UØNSKEDE HENDELSER

- Var det noe som etter din oppfatning gikk galt som kunne vært unngått?

### 6. ØNSKER OG FORBEDRINGER

- Virker pårørende tilfreds? Hva var bra? Hva kunne vært bedre?

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## Samtale med pasientansvarlig ambulanspersonell

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Ambulansesjåfør:	
Kode:	
Arbeidserfaring:	
Alder/kjønn:	
Intervjuer:	
Tid og sted:	
Anvendt tid:	

**NB: La de fortelle!**

### 1. INNLEGGELSESPROSESSEN

- Be ambulanspersonell fortelle om den bestemte innleggelsen av pasient NN

### 2. INFORMASJONSOVERFØRING/SAMHANDLING MED SYKEHUS –

- Hvordan var informasjonsoverføringen fra kommunen/hjem til ambulanspersonellet?
  - Hvor ble informasjonen overført?
  - Ble informasjonsoverføringen foretatt over sengen til pasienten?
  - Hvordan vil du beskrive kommunikasjonen mellom pasient og helsepersonell – sykepleier, lege, hjelpepleier, ambulanspersonell?
  - Er du tilfreds med informasjonsoverføringen?
- ✓ Informasjonsoverføringen – ta utgangspunkt i den faglige dokumentasjonen som foreligger ved innleggelse
- ✓ Hvilken informasjon mener du som ambulanspersonell er viktig å få om en pasient som skal innlegges – forelå denne informasjonen ved innleggelsen av NN?
- ✓ Kunne du som ambulanssjåfør/-personell identifisere/vurdere pasientens behov basert på innleggelsesskriv og den faglige dokumentasjonen som fulgte med ved innleggelse?
  1. Ga denne informasjonen et helhetlig bilde av pasientens situasjon?
  2. Var pasientens tilstand tilstrekkelig beskrevet?
  3. Fantes informasjon om ivaretagelse av pasientens grunnleggende behov?
  4. Fantes informasjon om medikamenter - endringer etc.?
- Hvordan var informasjonsoverføringen fra ambulanspersonellet til helsepersonell på sykehus?
  - Hvor foregikk denne informasjonsoverføringen?
  - Hvem fikk informasjon?
  - Hva ble informert?

### 3. PASIENT OG PÅRØRENDE INVOLVERING

- Opplevde du at pasient og pårørende var tilstrekkelig informert om innleggelsen?
- Fikk de/Gav du informasjon om hva som skulle skje på sykehuset ved innleggelse?
- Fikk pasienten og pårørende anledning til å fortelle hva de mente var viktig i forbindelse med innleggelsen?
- Ble de involvert i beslutninger og ble det tatt hensyn til?

#### 4.TVERRFAGLIG SAMARBEID

- Samhandling mellom lege, sykepleier og ambulanspersonell etc.
- Hvordan opplevde du samarbeidet med helsepersonell (lege, sykepleier, ambulanspersonell) som var involverte i innleggelsen?
- Kan du si noe om samhandlingen mellom de ulike faggruppene involvert i innleggelsen?
- Hvor koordinert var samhandlingen?

#### 5.UØNSKEDE HENDELSER

- Var det noe etter din oppfatning som gikk galt ifm. innleggelse som kunne vært unngått?

#### 6.ØNSKER OG FORBEDRINGER

- Hva var bra?
- Hva kunne vært bedre?

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## Samtale med pasientansvarlig sykepleier

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Sykepleier:	
Kode:	
Arbeidserfaring:	
Alder/kjønn:	
Intervjuer:	
Tid og sted:	
Anvendt tid:	

### 1. INNLEGGELSES/UTSKRIVELSESPROSESSEN

- Be sykepleier fortelle om sin opplevelse av innleggelses/utskrivelsesprosessen til pasient NN

### 2. INFORMASJONSOVERFØRING/SAMHANDLING MED SYKEHUS

- Tilfredshet med informasjonsoverføringen
- ✓ Ta utgangspunkt i den sykepleiefaglige dokumentasjonen som foreligger ved innleggelse/utskrivelse
- ✓ Hvilken informasjon mener du er viktig å få om en pasient? Forelå denne informasjonen da NN ble innlagt/utskrevet?
- ✓ Hvilken informasjon om tidligere sykehistorie mener du er viktig å bli informert om – forelå denne informasjonen om pasient NN?
- ✓ Kunne du vurdere pasientens behov for sykepleie basert på innleggesskriv og den sykepleiefaglige dokumentasjonen som fulgte med ved innleggelse?
  1. Gav informasjonsskrivene et helhetlig bilde av pasientens situasjon?
  2. Gav informasjonsskrivene tilstrekkelig informasjon om pasientens grunnleggende behov og ivaretagelse av disse?
  3. Var det tilstrekkelig informasjon om medikamenter - endringer?

### 3. PASIENT OG PÅRØRENDE INVOLVERING

- Opplevde du at pasient og pårørende var tilstrekkelig informert om innleggelsen/utskrivelsen og pasientens tilstand?
- Fikk pasient og pårørende informasjon om hva som skulle skje på sykehuset ved innleggelse/utskrivelse og videre i forløpet?
- Fikk pasienten og pårørende anledning til å fortelle hva de mente var viktig i forbindelse med innleggelse/utskrivelse?
- Ble de involvert i beslutninger og ble det tatt hensyn til?

### 4. TVERRFAGLIG SAMARBEID

- Hvilken erfaring hadde du med samarbeidet med annet helsepersonell som var involverte i innleggelsen/utskrivelsen?
- Kan du si noe om samhandlingen mellom de ulike faggruppene? Samhandling mellom lege, sykepleier, fysioterapeut, ambulanspersonell etc.
- Hvor koordinert var samhandlingen?

#### 5.UØNSKEDE HENDELSER

- Var det noe etter din oppfatning som gikk galt ifm. innleggelse som kunne vært unngått?

#### 6.ØNSKER OG FORBEDRINGER

- Hva var bra?
- Hva kunne vært bedre?



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## Samtale med pasientansvarlig lege

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Lege:	
Kode:	
Arbeidserfaring:	
Alder/kjønn:	
Intervjuer:	
Tid og sted:	
Anvendt tid:	

### 1. INNLEGGELSE/UTSKRIVELSESPROSESSEN

- ✓ Be lege fortelle om sine opplevelser i løpet av innleggelses/utskrivelsesprosessen til pasienten
  - Ble legen kontaktet før og under sykehus innleggelsen/utskrivelsen?
  - Var det en kvalitetssikret innleggelse/utskrivelse? Forklar.

### 2. INFORMASJONSOVERFØRING/SAMHANDLING MED SYKEHUSET

Tilfredshet med informasjonsoverføringen

- ✓ Ta utgangspunkt i innleggelses/utskrivelsesskriv som foreligger
- ✓ Hvilken informasjon mener du er viktig å få om en pasient som skal innlegges/utskrives– forelå denne informasjonen da pasient NN ble innlagt/utskrevet?
- ✓ Kunne du vurdere pasientens behov for medisinsk behandling, og oppfølging basert på innleggelses/utskrivelsesskrivet om pasienten?
  - Inneholdt innleggelses/utskrivelsesskrivet relevante opplysninger om sosialmedisinske forhold, tidligere sykdommer, tidligere innleggelser, aktuell sykehistorie, funn ved innleggelse og initiale tiltak?
  - Inneholdt innleggelses/utskrivelsesskriv relevante opplysninger om behov for supplerende undersøkelser (lab, røntgen, andre)?
  - Inneholdt innleggelses/utskrivelsesskriv relevante opplysninger om forløpet før innleggelsen/utskrivelsen og de vurderinger som ble foretatt under innleggelsen/utskrivelsen?
  - Framgikk det av innleggelses/utskrivelsesskriv hvem som er innleggende lege?

### 3. TVERRFAGLIG SAMARBEID – MED AMBULANSEPERSONELL OG SYKEPLEIER

- Hvordan opplevde du samarbeidet med helsepersonell som var involverte i innleggelsen/utskrivelsen?
- Kan du si noe om samhandlingen mellom de ulike faggruppene som var involvert i innleggelsen/utskrivelsen? Samhandling mellom lege, sykepleier, fysioterapeut, ambulanspersonell etc.
- Hvor koordinert var samhandlingen?

### 4. PASIENT OG PÅRØRENDE INVOLVERING

- Opplevde du at pasient og pårørende var tilstrekkelig informert om innleggelsen/utskrivelsen og pasientens tilstand ved innleggelsen/utskrivelsen?

- Fikk de informasjon om hva som skulle skje på sykehuset ved innleggelse og videre i forløpet?
  - Fikk pasienten og pårørende anledning til å fortelle hva de mente var viktig for det videre behandlingsforløpet?
  - Ble pasient og pårørende involvert i beslutninger og ble det tatt hensyn til?
5. UØNSKEDE HENDELSER
- a. Var det etter legens oppfatning noe som gikk galt ifm. Innleggelse/utskrivelse som kunne vært unngått?
6. ØNSKER OG FORBEDRINGER
- Hva var bra?
  - Hva kunne vært bedre?



## **Appendix V: Interview guide**





# Intervjuguide: Helsepersonell

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## Innledende spørsmål:

Alder:

Kjønn:

Stilling:

Arbeidserfaring/praksis:

Hvor lenge har du jobbet på denne avdelingen?

## Pasientinnleggelse

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1. Hvilke kriterier legges til grunn ved innleggelse av pasient i spesialisthelsetjenesten?
2. Opplever du at sykehus og kommunehelsetjenesten er enige om kriterier for innleggelse av pasienter?
3. Hvordan involveres pasientens fastlege/tilsynslege i forbindelse med innleggelse?

## Samhandling mellom sykehus og kommune

---

1. Hvordan vil du generelt beskrive samhandling mellom sykehus og kommunen i forbindelse med innleggelse av eldre pasienter
  - a. Hva fungerer bra/hva fungerer mindre bra?
  - b. Hvis du skulle velge en utfordring, ut fra ditt ståsted som hindrer/svekker samhandling – hva ville det vært? Er det noe som kunne fungert bedre?
2. Hva mener du er suksesskriterier for god samhandling mellom sykehus og kommune i forhold til innleggelse?
3. Er du kjent med om det foreligger etablerte prosedyrer som skal sikre god samhandling ved innleggelse av eldre pasienter.
  - a. Hvordan opplever du at disse evt. fungerer i praksis?
  - b. Hvordan vil du evaluere innleggelsesprosedyren – på hvilken måte opplever du at denne har bidratt til å bedre samhandlingen med kommunen?

4. Har du kjennskap til samhandlingsarenaer som er etablert mellom sykehus og kommune – kjenner du til om det er formaliserte, jevnlig møter på ledernivå mellom sykehuset og kommunen?
  - a. Har du deltatt på slike møter?
5. Hvordan opplever du at rammebetingelser støtter opp om god samhandling (strukturelle og økonomiske)?
6. Hvilke tanker har du omkring samhandlingsreformen?
  - a. Hvordan mener du den vil bidra til å fremme/bedre samhandling mellom primær- og spesialisthelsetjenesten?
  - b. Har du opplevd endringer i samarbeidet/samhandlingen mellom sykehus og kommune etter at samhandlingsreformen trådte i kraft i januar i år?

### **Innleggelse og pasientsikkerhet**

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1. Er du kjent med begrepet pasientsikkerhet og kan du med egne ord beskrive hva du legger i dette begrepet?
2. I lys av det du nå har sagt – hva mener du er viktig for å ivareta pasientsikkerhet ved innleggelse?
3. Hvordan vil du beskrive en trygg og god pasientoverføring?
  - a. Hvordan vil du beskrive en mangelfull/risikofylt pasientoverføring? Opplever du at innleggelse av eldre er forbundet med risiko?
4. Forskning antyder at eldre pasienter er en pasientgruppe med økt risiko for uønskede hendelser ved overføringer? Deler du den samme opplevelsen – og hvorfor tror du evt at det er slik?
5. Opplever og tror du at eldre blir nedprioritert som pasientgruppe? (og da evt noe som kan medføre økt risiko for denne pasientgruppen)
6. Har du selv opplevd at eldre pasienter har blitt utsatt for uønskede hendelser som følge av mangelfull samhandling?
  - a. Kan du si litt om denne hendelsen og hvilke faktorer som var medvirkende til at hendelsen inntraff?
7. Vil du si at det er situasjoner/dager som er mer risikofylte enn andre knyttet til innleggelse av eldre pasienter? (hvilke og hvorfor?)
8. Spiller størrelse på kommunene og geografiske avstander noen rolle i forhold til risiko?

### **Sykepleiedokumentasjon og Informasjonsoverføring ved innleggelse**

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1. Er det etablert gode rutiner/system som sikrer god informasjonsutveksling mellom sykehus og kommune ved innleggelse? Kan du beskrive hvordan dette foregår?
2. Hvilken verdi anser du at den skriftlige dokumentasjonen har ved innleggelse?
3. Hvilken dialog har dere med kommunehelsetjenesten før innleggelse?
  - a. Opplever du at det er lett å kontakte kommunehelsetjenesten for dialog rundt innleggelse?
4. Hvilken informasjon anser du er viktig å overføre til sykepleier (som skal overta det sykepleiefaglige ansvaret) ved sengeposten?
5. Forskning avdekker at informasjonsoverføringer kan være mangelfulle ved innleggelse?

- a. Hvilke tanker har du om det?
  - b. Hvilke fokus har dere på sykepleiefaglig dokumentasjon ved innleggelse?
  - c. Har du tanker om hvordan vi kan sikre bedre informasjonsoverføring?
6. På hvilken måte tror du at elektroniske løsninger kan bedre samhandlingen?

### **Brukermedvirkning og pårørende involvering**

---

1. Hvordan vil du beskrive samarbeidet med pasient og pårørende i prosessen knyttet til innleggelse?
  - a. Kan du fortelle om dine erfaringer, opplevde du utfordringer?
  - b. Opplever du at de involveres i tilstrekkelig grad? (evt hvorfor ikke?)
  - c. Kan du si noe om årsaken til at du anser det viktig/mindre viktig å involvere pasient og pårørende og gi rom for medvirkning?
2. Hvilken informasjon anser du det er viktig å gi pasient ved innleggelse?
  - a. Hvem informerer pasienten ved innleggelse?
  - b. Hvordan blir pasienten informert – ved direkte kommunikasjon? via lege/sykepleier/pårørende? sammen med andre pasienter?
3. Hvilken informasjon mener du det er viktig at pårørende får ved innleggelse i sykehuset?
  - a. Hvem informerer pårørende ved innleggelse?
  - b. Hvordan blir pårørende informert – ved direkte kommunikasjon? Via lege/sykepleier?
4. Har pasient og pårørende anledning til å fortelle om forhold de mener er viktig i forbindelse med innleggelsen?
5. Opplever du at pasientens og pårørendes vurderinger blir tatt hensyn til ved innleggelse?

### **Tverrprofesjonelt samarbeid**

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1. Hvilke faggrupper/profesjonsgrupper er ofte involvert i forbindelse med innleggelse av eldre pasienter (KOLS/lårhalsbrudd) fra kommunehelsetjenesten?
  - a. Hvordan opplever du at kommunikasjonen og samhandlingen mellom de ulike fag-/profesjonsgruppene fungerer på din avdeling? (hva fungerer bra/dårlig?)
  - b. Har du opplevd at kommunikasjonen mellom ulike fag-/profesjonsgrupper har sviktet i forbindelse med innleggelse? (kom gjerne med eksempler). Hva tror du er grunnen til kommunikasjonssvikten?
2. Hvilken betydning anser du at den tverrfaglige samhandlingen har ved innleggelse av eldre pasienter?
3. Hvordan legges det til rette for et godt tverrfaglig samarbeid på din avdeling?

**Til slutt: Hva ser du for deg som viktig for en kvalitetssikret og trygg innleggelse med helhetlige pasientforløp og god samhandling? Er det andre viktige spørsmål som du mener er viktig å få belyst i denne sammenheng/studien som vi ikke har vært inne på/ eller noe du vil tilføye det vi allerede har snakket om?**

**Har du forslag til tiltak? (mtp en intervensjon)**