

## 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	No	Daughter by telephone	6	Short-time stay nursing home
		(cognitively impaired)				
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	No	Wife by telephone	2	Nursing home
		(cognitively impaired)				
Female, age 89	Fracture collum femoris	Yes	No	Son by telephone	5	Short-time stay nursing home
Female, age 86	Fracture collum femoris	No	No	Sister by telephone	5	Short-time stay nursing home
		(cognitively impaired)				
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	Admission <i>Observation:</i> 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)	<i>Information</i> Admission Crowded triage area, minimal information to the patient	Older patients' experiences with integration of information
	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)	Unattended, no information in the triage area	
	Minimal information was provided in the triage area to a patient who was tired and had nausea (83-year-old woman, dehydration)	Minimal information, health challenges	
	In the treatment area of the ED in the patient rooms, the nurse and doctor stayed at the patient's bedside	Professionals stayed with the patient in the treatment room	
	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)	Received information on routines and plans from the nurse and doctor	
	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)	Examination and information simultaneously, asked about his health problems	
	The patient was informed about the medical examination in the treatment room (86-year-old man, syncope)	Informed about medical examination	
	<i>Patient statements:</i> The doctor examined and informed me about treatment simultaneously. (93-year-old man, chest pain)	Received information from professionals Did not miss any information, felt ill	
	I did not miss any information in admission; I felt very ill. (81-year-old woman, pneumonia)	Well informed and heard	
	I was well informed and was heard. (85-year-old man, FCF)	Well informed and cared for	
	I was well informed and they cared for me. (83-year-old woman, FCF)	Missed information about medical examination	
	'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)	Satisfied with information in the treatment room	
	I got enough information, but I do not remember much. (83-year-old woman, dehydration)	Did not remember information given	
	I do not remember what I was informed about, but I do not miss any information. (85-year-old man, urinary infection)	Did not miss information	
	I was very well informed about what and when things should happen on the day of admission. (83-year-old woman, hip-fracture)	Well informed	

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> <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>	<p>No need for information</p> <p>Very satisfied with the healthcare personnel</p>	
	<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>The old man was investigated if he had personal preferences, but he had none (86-year-old man, syncope)</p> <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><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>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><i>Decision-making</i> Admission Patient influenced admission. Managed to delay the admission</p> <p>No personal preferences</p> <p>The patient was heard and agreed to admission. Trusted the professionals</p> <p>Felt safe and heard and had full confidence in the healthcare workers</p>	<p>Older patients' preferences for involvement in decision-making</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	
		Not prepared for discharge	
		Hospitalisation ended too soon	

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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