

Continuity of care from hospital to municipal health care. Experiences of older patients, next of kin and nurses

by

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Summary

Background: A successful care transition from hospital to municipal health care involves coordination and management of multiple factors tied to the patient's treatment and care. Due to a fragmented health care system in the western world, several health care levels, with different areas of competence and financial systems, together provide treatment and care to older patients. At the same time, recent research finds that patients aged 80 years or older have different needs during care transition than younger older patients. Next of kin report that they want to help their older relative but receive little support from health care. Norwegian health authorities have a consistent focus on increased continuity across health care levels. Nurses are considered central during care transitions, due to their competence and their position on both hospital and municipal health care levels.

Aims: The overall aim of this thesis is to explore and describe how patients aged 80 years or older, their next of kin, and nurses from hospital and municipal health care, experience care transition from hospital to municipal health care. The aims of the three sub-studies were: I. to explore how patients, ≥ 80 years of age, experience the care transition from hospital to municipal health care services; II. to understand how next of kin experience the care transition of an older relative from hospital to municipal health care; III. to gain increased knowledge about nurses' experiences of care transitions of older patients from hospital to municipal health care.

Methods: Inductive exploratory and descriptive design, using semi-structured individual interviews, was used to capture the experiences of older patients and their next of kin in study I and II. A total of 14 patients aged 80 years or older, and 13 next of kin, named by the patient, participated in the study. Study III, exploring the experiences of hospital and municipal nurses, used step-wise focus group interviews.

A total of 30 nurses were recruited, 16 from hospital care and 14 from municipal health care. Findings from study I were used as evocative material in the focus groups' second meeting. All interviews in the three studies were analysed with content analysis.

Results: Older patients (Paper I) and their next of kin (Paper II) experienced several challenges during care transition. Lack of participation, as well as reduced information and vague areas of responsibility were identified as issues which led to worries for the patients. The next of kin worked hard to obtain and share information between all involved parties. They considered themselves responsible for their older relative's welfare during their care transition, and put efforts into helping them to get back to daily routines and activities. The period of care transition was emotionally difficult for them, as they tried to come to terms with what help they could provide, in addition to feeling grief for their older relative coming to their end of life. Nurses (Paper III) identified how collaboration was considered important in care transitions. However, administrative routines and altered methods of communication due to technological developments influenced the collaborative relationship between hospital and municipal nurses. Patient participation and the creation of long-term goals for the older patients' recovery was discussed to optimise care transitions.

Conclusion: Older patients, next of kin and nurses experienced multiple areas of discontinuity during care transitions from hospital to municipal health care. Collaboration between hospital and municipal health care nurses is considered essential due to their first-hand contact with older patients and next of kin, as well as their prominent role in both arenas of health care. Continuity of care for older patients and next of kin should be based on an approach with older patients' needs at the centre.

Errata

Due to an error during the procedure of publishing, the columns in Tables 3 and 4 do not reflect the correct chronological order of the analytical abstraction process, as implied in the Table heading.

Abbreviations

FOUSAM	Joint research and development unit for collaboration, established in Helse Fonna health enterprise, which includes relevant municipalities and the Western Norway University of Applied Sciences.
RN	Registered Nurse.
Care transition	Refers to the transition from hospital to municipal health care, with a fluent timespan, from planning the transition to the time when the older patient feels settled at home or in a municipal institution.
Next of kin	The caregiver, named by the older patient, who provides support during the period of care transition. Next of kin do not have to be blood relatives of the older patient, despite this being the case in the examples in this thesis.

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1 Introduction

It is well known that older people often suffer from co-morbidity as well as deteriorating health related to increased age (Christensen, Doblhammer, Rau, & Vaupel, 2009; Clegg, Young, Iliffe, Rikkert, & Rockwood, 2013; Statistics Norway, 2013). In Norway, more than half of the population aged 80 years or older receive municipal health care (Statistics Norway, 2016). The organization of hospitals and municipal health care causes older patient to be transferred between different health care levels. Care transitions have been associated with increased risks as well as diverse experiences for involved stakeholders (Allen, Hutchinson, Brown, & Livingston, 2017). Older patients' needs during care transitions are suggested to be related to age, where the oldest old patients report different experiences than younger older patients (Bobay, Jerofke, Weiss, & Yakusheva, 2010).

Next of kin offer substantial help and support to their older relatives and are considered an important resource (Official Norwegian Reports, 2011:17). However, previous research finds that next of kin who take on multiple roles during their older relative's care transition struggle to gain influence in planning the treatment and care (Bragstad, Kirkevold, & Foss, 2014). Next of kin want to support their older relatives but are largely unsupported by health care staff and describe it as difficult to identify how they can best help (Giosa, Stolee, Dupuis, Mock, & Santi, 2014; Hansen & Slagsvold, 2014).

Care transitions across health care levels involve collaboration between health care staff with different perspectives, different financial systems as well as diverse professional cultures, which together should provide care for the older patient (Coleman & Boulton, 2003; Romøren, Torjesen, & Brynjar, 2011; Røsstad, Garåsen, Steinsbekk, Sletvold, & Grimsmo, 2013). In previous research hospital and municipal health care nurses experienced different challenges during care transitions, however,

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improved understanding of each other's contributions could possibly contribute to increased collaboration (Kirsebom, Wadensten, & Hedström, 2013; Røstad et al., 2013).

Norwegian health authorities use the patient perspective as a basis for its amendments of hospital and municipal healthcare services, describing how different stakeholders, with different objectives for their activity, together should provide treatment care for the older patient (Hagen & Johnsen, 2013; Report No. 47 to the Storting, 2008-2009). This has led to an increased focus on vertical transitions across health care levels.

I was first introduced to the cooperation challenges across health care levels in 2009, as the hospital and municipalities, along with the local college, prepared for the implementation of the Coordination Reform (Report No. 47 to the Storting, 2008-2009) through establishing Helsetorgmodellen (later named FOUSAM, see 2.1.1). All researchers in the present study are nurses: however, none have direct experience of care transitions. Despite this, their professional background led to a preconception of designing a study which was clinical applicable, derived from the older patient and their next of kin's experiences and needs during this important period of their treatment and care. In addition, the present thesis is based on the preconception that care transitions must involve both hospital and municipal health care as equal contributors providing for the older patient, addressing the perspectives of both health care levels. As such, the thesis emphasises practical aspects important for the continuous improvement of older patients care transitions, in light of the Coordination Reform (Report No. 47 to the Storting, 2008-2009).

The overall aim of the present thesis is to explore and describe how patients aged 80 years or older, their next of kin, and nurses from hospital and municipal health care, experience care transition from

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hospital to municipal health care. The thesis consists of three papers presented in Table 1.

Table 1 – Schematic overview Paper I, II, III and aims

Paper	Aim
I Rustad EC, Furnes B, Cronfalk BS, Dysvik E (2016). Older patients' experiences during care transition. <i>Patient Preference and Adherence</i> .10:769-779. DOI: https://doi.org/10.2147/PPA.S97570	Explore how patients' \geq 80 years of age experience the care transition from hospital to municipal health care services
II Rustad EC, Cronfalk BS, Furnes B, Dysvik E (2016) Next of kin's experiences of information and responsibility during their older relatives' care transition from hospital to municipal health care. <i>Journal of Clinical Nursing</i> . 26 (7-8), 964-974. DOI: http://dx.doi.org/10.1111/jocn.13511	Understand how next of kin experience the care transition of an older relative from hospital to municipal health care
III Rustad EC, Cronfalk BS, Furnes B, Dysvik E (2017). Continuity of care during care transition: Nurses' experiences and challenges. <i>Open Journal of Nursing</i> . 7(2), 277-293. DOI: https://doi.org/10.4236/ojn.2017.72023	Gain increased knowledge about nurses' experiences of care transitions of older patients from hospital to municipal health care

1.1 Outline of the thesis

This thesis consists of two parts. Part I gives the overview and background for the research. Part II consists of three original research papers, and appendices.

Part I is divided into sections 1-8. Section 1 and 2 provide a broad introduction to care transitions and its background, as well as information about the Norwegian health care system. In addition, a description is provided of cooperative initiatives that are specific for the region where the studies have been conducted. Section 2 presents research on care transitions that has been conducted from the perspectives of the different stakeholders represented in this thesis: older patients, next of kin and nurses from hospital and municipal health care. The thesis is grounded in conceptual and theoretical perspectives, which are outlined in section 3, presenting the concept of continuity of care, and an overview of the theory of person-centred practice, followed by a presentation of the aims and research questions of the three papers that constitutes this thesis. Section 4, methodology, gives a description of the study design and the methods that have been used, in addition to describing data analysis, ethics and an outline of trustworthiness, all of which have been taken into consideration throughout the research process. Section 5 provides a brief summary of the findings. In section 6, the findings are discussed both in relation to conceptual and theoretical perspectives as well as related to recent research. The section ends with an outline of possible implications of the research findings. Section 7 is a summarizing conclusion; followed by section 8, list of references.

2 Background

The following section will describe the framework and development of the Norwegian health care system, in light of the Coordination Reform (Report No. 47 to the Storting, 2008-2009) as well as describing contextual conditions in the region where research was conducted. In addition, the section presents research on the experiences and perspectives of older patients, next of kin and hospital and municipal health care nurses during care transition. Comprehensive literature searches have been done continuously, related to publication of papers and writing of the thesis.

2.1 Norwegian health care system

The Norwegian health care system is divided into two health care levels. The hospitals are responsible for all specialist care and are financed by the Norwegian health authorities. The municipalities have responsibility for all long-term care, home care and primary care (general practitioners), and are largely financed by the municipalities themselves and through additional governmental funding (Romøren et al., 2011). The Coordination Reform, introduced in 2008, and implemented in 2012, follows a series of restructurings of the Norwegian health care during the last decades. Through reorganizing the responsibilities of hospital and municipal health care, the reform aims to make health care more efficient, sustainable and to create more continuous treatment and care for patients. Norwegian health authorities use a top-down approach through financial incentives, reorganization and administration to implement the warranted changes (Report No. 47 to the Storting, 2008-2009; Romøren et al., 2011). Even so, the Coordination Reform continues the trend by which the patient and their next of kin are given a clearer position through increased participation. The reform also addresses the importance of holistic and

continuous care not only intra-sectorially but also across health care levels (Report No. 29 to the Storting, 2012-2013; Report No. 47 to the Storting, 2008-2009; Official Norwegian Reports, 1997).

The focus of the Norwegian health authorities on coordination resembles what is seen in other northern and western countries; however the policy strategies to bridge the challenges across health care levels are different (Wadmann, Strandberg-Larsen, & Vrangbæk, 2009). Similarly to Denmark, the Norwegian health authorities have implemented cooperation agreements between each specialist health care region and the municipals they are serving. The Norwegian Directorate of Health (Helsedirektoratet) administers the agreements, and the responsibility and initiative to formulate and follow up the agreements are with the specialist health care region (Gautun, Martens, & Veenstra, 2016; Rudkjøbing, Strandberg-Larsen, Vrangbæk, Andersen, & Krasnik, 2014; The Norwegian Specialised Health Care Act, 1999; Wadmann et al., 2009). In Sweden, The ÄDEL Reform was introduced in 1992 when the state handed over responsibility for all long-term care to the municipalities (Socialstyrelsen, 1996). As such, each municipality is accountable for coordination policies, implementation of care pathways and strategies to attend their residents' needs (Åhgren & Axelsson, 2011). In Norway the creation of diagnosis-specific clinical pathways has been found to be challenging, as treatment and care in the municipals are more generic, serving patients with multiple diagnoses (Grimsmo et al., 2016).

The Coordination Reform targets earlier discharge of older patients who have had a prolonged hospital stay and are waiting for municipal health care, or who have received treatment that could have been performed within municipal health care services (Report No.47 to the Storting, 2008-2009). In Norwegian municipalities, a purchaser-provider model, closely linked to New Public Management ideology, was implemented during the late 1990s (Vabø, 2012). This reorganization marked an increasing focus on quality in municipal

health care – as part of a move to a more transparent health care services (Vabø, 2012). However, the reorganization also led to fragmentation of the health care services, and there are extensive municipal differences in how the purchaser-provider organization is conducted as well as variations in levels of professional flexibility experienced by the health care staff (Wollscheid, Eriksen, & Hallvik, 2013). During the same period there have also been changes in the kind of health care services provided by the municipalities, where home care has increased, on behalf of institutional care and domiciliary help (Otnes, 2015). Several municipal institutions have also been reorganized to provide acute medical care instead of long-term care, as patients are being discharged from hospital still in need of treatment (Grimsmo, 2013; Otnes, 2015). As such, these patients, admitted from hospital to a short term stay in nursing homes before being discharged to home care, often experience additional care transitions and fragmented health care, which is the opposite of the aim of the Coordination Reform (Grimsmo, 2013).

The Coordination Reform has been described as providing directions for future health care. The reform is evaluated and followed by new proposals to further improve the identified challenges (The Norwegian Directorate of Health, 2016b). The most evident effect of the Coordination Reform is the reduced number of days the patient is admitted to hospital. However, this must be seen in comparison with an increase in readmissions in the same period, which is associated with early discharge and with whether the patient has previously received municipal health care after a previous discharge (The Norwegian Directorate of Health, 2016a). Norwegian municipalities are diverse, in terms of number of inhabitants, demography and financial preconditions for establishing proper health care for their inhabitants. Future directions indicate a need to ensure a more equal health care service across municipalities (Report No.26 to the Storting, 2014-2015). The gap between hospital and municipal health care is still

evident, and strategies to create more continuous patient care are described through further developing standardized patient pathways. Hospitals are in particular responsible for extending their standardized care pathways to include municipal health care. An additional concern is the altered need for competence as the patient flow is redirected across health care levels, which requires structures for exchange of necessary competences between health care staff (Report No.11 to the Storting, 2015-2016; Åm, 2015).

2.1.1 Local cooperation strategies concerning health care

The present research took place in the local region of Helse Fonna health enterprise, which is constituted by three local hospitals, providing specialist health care to 170,000 citizens, in 19 urban or rural municipalities. The region has a long tradition of cooperation across health care levels. As a result a joint collaboration was initiated between Helse Fonna specialist health care, all municipalities in the region, and the local university college (Western Norway University of Applied Sciences) (<http://www.helsetorgmodellen.net>). An important decision within the Helsetorgmodellen was to establish a joint Research and Development unit (www.FOUSAM.no) inviting representatives from all three stakeholders (Figure 1).

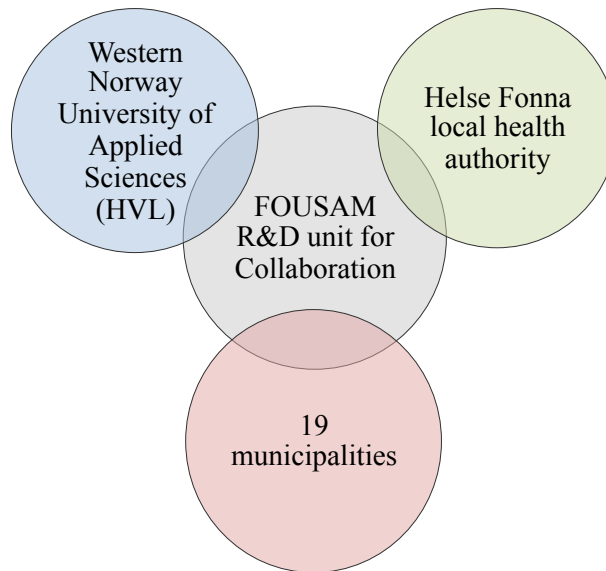


Figure 1 – FOUSAM. Research and development unit for collaboration

The main objective of FOUSAM was to facilitate research and development across health care levels, creating a platform for cooperation and project management. The purpose was therefore to identify areas of special importance and relevance for the region's population and, as such, people older than 65 and with poor health or at risk of poor health were identified as important target groups. In addition, professional networks had been established by hospital and municipal health care staff to gain increased knowledge about different aspects of care regarding various diagnosis and groups of patients. Within FOUSAM, dialogue meetings between hospital and municipal health care staff were arranged to draw up health care plans for patients across health care levels and to create a mutual understanding of each other's contributions (Helsetorgmodellen.net). This unique model of collaboration has been defined as pioneering in Norway, and FOUSAM

has been described as a model for replication in several public reports (Cronfalk et al., 2017; Report No.18 to the Storting, 2012-2013).

2.2 Care transition

During recent decades, the distinctive treatment and care that patients receive at separate health care locations has been given comprehensive attention within research in order to counteract its unwarranted consequences for patients (Coleman & Boulton, 2003; Enderlin et al., 2013; Naylor et al., 1994). Models such as the Transitional Care Model (Naylor et al., 2009) and the Care Transitions Program (Coleman et al., 2004) are examples of well-known nurse-led models expanding the follow-up of the patient across health care settings. Both models are based on a conceptual understanding of transitional care, defined as “*a set of actions designed to ensure the coordination and continuity of healthcare as patients transfer between different locations or different levels of care within the same location*” (Coleman & Boulton, 2003). In addition, transitional care underlines the importance of enabling the older patient to be involved in decisions during planning of their transitional care, as they are often the only thread that ties the health care levels together (Coleman, 2003).

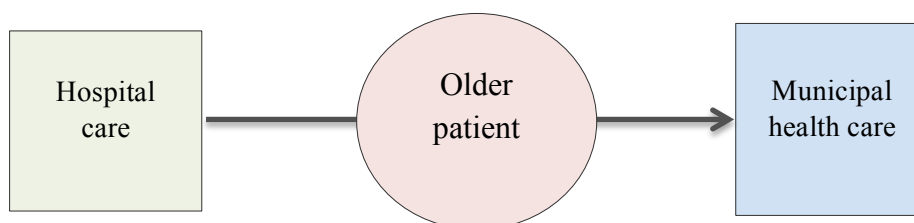


Figure 2 – Overview of care transition from hospital to municipal health care of older patient

Of importance, and in contrast to other frameworks, transitional care emphasises a change of settings. However the definition of transitional care does not mark a timely start or end-point of the process (Holland & Harris, 2007), as shown in Figure 2. There is an important conceptual distinction between transitional care which addresses the actions of coordination during care transition, and the concept of care transition, which is used as an indicator of the actual transfer from one location to another (Coleman & Boulton, 2003). Care transition, as defined by Coleman & Boulton (2003) is the conceptual foundation for the present thesis. Recent research from the perspectives of the older patients, next of kin and hospital and municipal health care nurses will be presented below.

2.2.1 Older patients

Research addressing characteristics of older patients often finds that patients express concerns about this time-limited, yet important period of their treatment and care and the often altered life situation that follows (Gabrielsson-Järhult, 2016). Old age is associated with increasing physical disorders as well as psychological strain due to ageing and alterations of life conditions (Clegg et al., 2013; Holm & Severinsson, 2013). Older patients are also found to take on a personal role characterised by modest requests, rather than being active consumers demanding their participatory rights (Foss, 2011). In addition, what we know is largely based on patients who are 65 years or older (Allen et al., 2017). To our knowledge, fewer studies have focused on care transition for patients aged 80 years or older. This is despite previous studies that have identified age-related differences of care transitions (Allen et al., 2017; Bobay et al., 2010; Coffey & McCarthy, 2013). Age-related differences are also supported by Norwegian statistics (Otnes, 2015).

Care transitions of older patients have been widely investigated in recent decades (Naylor et al., 1994). However, previous research has often targeted isolated parts, which has not allowed for a depiction of the entire care transition experience of the older patient. Care transitions are associated with older patients experiencing lack of information and participation (Bångsbo, Dunér, & Lidén, 2014; Dyrstad, Laugaland, & Storm, 2015; Foss & Hofoss, 2011), compromised safety, such as increased risks of medication errors (Knight, Thompson, Mathie, & Dickinson, 2011), as well as unmet needs and practical obstacles (Andreasen, Lund, Aadahl, & Sørensen, 2015). Recent developments in care transitions of older patients are described in a larger meta-synthesis by Allen et al (2017), who identify older patients striving for independence and, as such, being in need of self-management preparations and support. Older patients are found to actively use strategies such as questioning and negotiation to understand what is going to happen during and after the care transition.

In their paper, Bragstad et.al (2012) found that patients aged 80 years or older described how having someone present when arriving home, together with receiving adequate formal help, was important for a successful care transition from hospital to home. It has also been argued, by Hvalvik & Dale (2015) that older patients often feel a lack of dialogue during care transition and, as such, experience dehumanization which in turn might make it more challenging to master the alterations in their life situation.

2.2.2 Next of kin

In this thesis, the next of kin is defined as the caregiver, named by the older participants, who had regular, informal and non-paid supportive contact prior to, and during the care transition. This is in line with Norwegian law (The Norwegian Patients' Rights Act, 1999), which

states that caregivers do not need to be a blood relative of the patient, despite this being the case in the examples in this thesis.

Previous research on next of kin's caregiving has dealt with various perspectives. One major issue has been how next of kin are affected by the strain and impact on their well-being that follows their caregiver role. It has been identified that despite the strain and stress, most next of kin simultaneously report well-being and that the efforts are worthwhile. Caregiving by next of kin has in previous research been found to vary with cultural differences and family norms as well as political context and type of welfare system. It is suggested that countries with developed welfare systems reduce the expected responsibilities of next of kin to care for their older relatives, and they are given a role of agent between the older patient and the formal health care services (Blomgren, Breeze, Koskinen, & Martikainen, 2012; Daatland, Herlofsen, & Lima, 2011). In addition, an increased level of impairment is related to increased caregiver burden (de Almeida Mello et al., 2016). Previous research also identifies gender differences, where women tend to provide more care and emotional support to their older relatives compared to men, who offer more practical help. Daughters are also found to take on a protective role that is burdening: however sharing responsibilities with other family members is experienced as positive (Hansen & Slagsvold, 2014; Hartmann et al., 2016). There are slightly different findings in regard to whether the next of kin is living in the same household as the older patient and/or whether the next of kin has full-time employment, which is found to have positive effect on their experienced stress. (Bastawrous, 2013; Hansen & Slagsvold, 2014; Toljamo & Laukkala, 2012).

Previous research has also focused on next of kin roles in the process of discharge from hospital. Different preferences are described about taking part in decision-making and discharge planning on behalf of their older relative: however, next of kin describe their role as advocating on their older relative's behalf if needed. This is

experienced as a heavy responsibility to carry during a stressful period of hospitalization (Digby & Bloomer, 2014; Popejoy, 2011). Research on participation during care transitions across health care levels has found that next of kin take on an active role when the older patients are unable to do so. However, to gain influence and take part in the decision-making on behalf of their older relative is experienced as difficult (Bragstad et al., 2014). These findings resemble other studies where older patients describe their next of kin role changing from being in charge to having minimal influence when the older patient was hospitalized (Lowson et al., 2013). A similar outcome is found when older patients are admitted to nursing homes (Eika, Espnes, Söderhamn, & Hvalvik, 2013). Next of kin's continuous perception of being responsible for the patient during different trajectories of treatment and care is also identified in other studies (Plank, Mazzoni, & Cavada, 2012). Few studies have focused on next of kin's more general experiences during older relatives' care transition across health care levels. In the important study by Giosa et al (2014), using a grounded theory approach, it was identified that next of kin feel capable of helping their older relatives during care transitions, however, given the stressors in the situation, they experience it as difficult to identify how they should contribute, and describe a need for support and education from health care staff. More recently, Hvalvik & Reiersen (2015) argue that next of kin experience vulnerability at the same time as they take responsibility on behalf of their older relative. In addition, the care transition process was found to influence the next of kin's life in both existential and emotional ways.

2.2.3 Nurses

This thesis has a nursing professional perspective. Multiple professions are involved in care transitions, however, previous research finds that nurses are “front” figures and collaboration usually takes place between nurses across health care levels, leaving out physicians,

physiotherapists and other professions (Johannessen & Stehaug, 2014). This is in spite of the challenging nature of intra-professional collaboration between nurses across health care levels and therefore we need more knowledge about their perspectives. From the viewpoint of home care nurses, Eija and Marja-Leena (2005) found that timely and adequate information, along with cooperation across health care levels, were important success factors during hospital discharges. Transfer of information across health care levels is seen as an important service during care transitions, and has been widely investigated, finding that poor information quality compromises patient safety (King et al., 2013). In addition, information transfer across health care levels is dependent on several barriers related to the individual nurse, cooperation between involved health care staff, as well as organizational factors (Olsen, Østnor, Enmarker, & Hellzén, 2013).

There is a considerable amount of research from the hospital perspective, addressing various aspects of the discharge process. However, discharge planning is found to consist of several different functions, and is not always associated with an increase in older patients' self-reported readiness for discharge, as discharge planning to a larger extent involves organizational factors. Nurses are also found to have low adherence to discharge planning procedures, due to competing tasks (Graham, Gallagher, & Bothe, 2013; Laugaland, Aase, & Waring, 2014; Mabire, Büla, Morin, & Goulet, 2015).

Electronic messaging is found to reduce patient risks during care transition: however, nurses do not yet take full advantage of the technological benefits (Melby, Brattheim, & Hellesø, 2015). In line with the Norwegian government's future directions, the Norwegian study by Røsstad et al. (2013) attempted to develop standardized care pathways across hospital and municipal health care levels. However, disease-based care pathways that are the usual approach in hospital care, were not found to be a sufficient tool for municipal care due to the comorbidity that the older patients suffered from. The differences

between health care levels have consequences for the cooperation between hospital and municipal nurses. Kirsebom et al. (2013) identified nurses' needs and willingness to collaborate. However, hospital and municipal nurses addressed different challenges of care transitions as hospital nurses found it difficult to decide when the patient had finished his/her treatment. Municipal nurses often received patients late and with a lack of information and inaccurate medications. Importantly, Hellesø and Melby (2013) discovered how care transitions in Norway are largely influenced by negotiations between the health care staff from hospital and municipal health care levels during care transitions. These negotiations are seen as a parallel process to the formalized discharge procedures, described as a result of different perspectives as well as professional cultures between hospital and municipal health care.

3 Conceptual and theoretical framework

Within qualitative research, theories offer comprehensive explanations and descriptions of complicated phenomenon and problems (Reeves, Albert, & Hodges, 2008). This research has been guided by the concept of continuity of care, as well as the theory of person-centred practice during the creation of the study design, and these concepts also provided perspectives for the interpretation of findings. The concepts and theories described in the following sections are intended to highlight different facets of the experiences of older patients, their next of kin and nurses from hospital and municipal health care during care transition. Continuity of care refers to a more patient-focused coordination of health care services, however, it goes beyond the direct experience of the patient (Gulliford, Naithani, & Morgan, 2006), while person-centred practice describes qualities of care, provided holistically and based on each individual persons' needs and aspirations (McCormack & McCance, 2017).

3.1 Continuity of care

Continuity of care is a multi-dimensional concept (Figure 3), which is often used and associated with quality of treatment and care within both nursing and medicine (Freeman & Hjortdahl, 1997; Haggerty et al., 2003; Hellesø & Lorensen, 2005; Sparbel & Anderson, 2000b; van Servellen, Fongwa, & D'Errico, 2006). Continuity of care is also described in the Coordination Reform as a goal for holistic health care (Report No.47 to the Storting, 2008-2009). The concept has been defined and measured in different ways, within different health care services and contexts, and is related to other concepts such as coordination of care and transitional care (Crilly, Chaboyer, & Wallis, 2006; Holland & Harris, 2007; Sparbel & Anderson, 2000a, 2000b; van Servellen et al., 2006). Continuity of care is also argued to hold

different dimensions in municipal health care and hospital care where the latter often describe continuity of care as seamless health care services, involving coordination and communication through complex treatment and care trajectories, either intra-organizationally or through planning discharge. In municipal health care continuity of care is often described as a relational quality within the general practitioner-patient-relationship, as well as within service provision (Crilly et al., 2006; Freeman & Hjortdahl, 1997; Gulliford et al., 2006). Haggerty (2003) argues that the concept involves two core dimensions that are viable in all contexts; continuity of care is provided individually to each patient, and continuity of care is provided over time. Continuity of care, defined as *“the degree to which a series of discrete healthcare events is experienced as coherent and connected and consistent with the patient’s medical needs and personal context”* (Haggerty et al., 2003, p. 1221) is the conceptual perspective of this thesis. The definition comprises organisational elements as well as professional practice, but its core component is the patient’s experience of the health care services they receive. Continuity of care is, as such, seen as an outcome as well as a value in itself (Gulliford et al., 2006). Four different types of continuity of care are presented in the following (Figure 3); management continuity, informational continuity and relational continuity, as described by Haggerty et al. (2003), and inter-organizational continuity as described by Hellesø and Lorensen (2005).

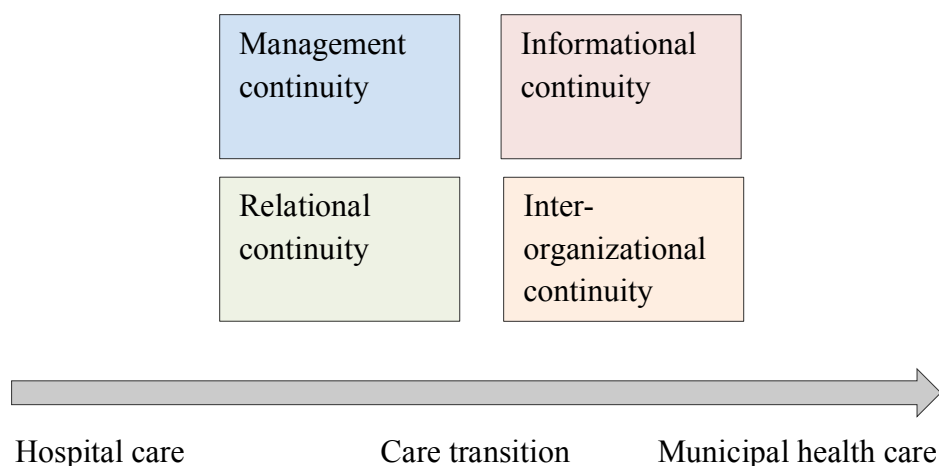


Figure 3 – Overview of different dimensions of continuity of care

The management dimension of continuity of care comprises the coordination of health care illnesses that require several health care providers (Haggerty et al., 2003). Management continuity is sometimes described as unperceived by the patient, as long as the coordination and collaboration between health care staff is working properly, for instance through care plans or other professional tools (Haggerty, Roberge, Freeman, & Beaulieu, 2013). However, from the patient's perspective, availability of health care services and seamless care transitions are identified as important attributes of management continuity (Waible, Henao, Aller, Vargas, & Vázquez, 2012). In addition, management continuity is sometimes perceived as a prerequisite for informational and relational continuity to occur (van Servellen et al., 2006).

Informational continuity refers to the use of information to link previous episodes of treatment and care to the present and the future, as well as linking different providers to each other. Information refers both to written documentations about treatment and care, as well as the health care providers' memorized personal knowledge of the patient (Haggerty et al., 2003). However, in later research, information is

described as a tool for enabling the patient to take an active part in their own treatment and care. The importance of informational continuity is particularly evident as informational discontinuity is found to be burdensome for the patient (Haggerty et al., 2013). Informational continuity has been a focus for a vast amount of research, in particular looking at concerns about care transitions across health care levels (Hellesø, Lorensen, & Sorensen, 2004).

Relational continuity is defined as “*an on-going therapeutic relationship between a patient and one or more providers*” (Haggerty et al., 2003, p. 1220). Relational aspects between the health care provider and the patient are highly valued by the patients and are often described as trust (Haggerty et al., 2013). The definition highlights two elements, namely the quality of the relationship between the patient and the health care staff, and predictability and consistency in the group of health care staff who are caring for the patient (Haggerty et al., 2003; Waible et al., 2012).

Inter-organizational continuity, developed by Hellesø & Lorensen (2005), addresses continuity across health care levels and different health care organizations, which adds an additional dimension to the continuity of care described above. The concept is pictured as both a process and as a targeted outcome of a care transition (Hellesø & Lorensen, 2005). Inter-organizational continuity consists of an individual as well as organizational perspective, where the latter in particular is concerned with formal and informal structures that coordinate and systematize complex care transitions where many health care providers are involved (Hellesø & Lorensen, 2005). The individual perspective targets relational aspects between the patient as well as health carers, and the quality of provision of continuity of care (Hellesø & Lorensen, 2005).

3.2 Person-centred practice

A growing body of literature within research, politics and health care organisations has recognized the approach of person-centred practice (Edvardsson, Sandman, & Rasmussen, 2008; McCormack et al., 2015; O'Dwyer, 2013; World Health Organization, 2015). It has in particular won great influence in nursing older patients (McCormack, 2003). There is broad agreement in the literature about the underpinning value of treating the person as an individual, positioning the patient at the centre of health care (Kitson, Marshall, Bassett, & Zeitz, 2013). Individualized care should be based on thorough knowledge and understanding of the patient's life situation, aspirations and abilities (McCormack & McCance, 2017). The present thesis is based on person-centred practice, as described by McCormack and McCance (2017): the term has recently been changed from person-centred care, to sustain a more inter professional approach (McCormack & McCance, 2010). The framework addresses four constructs of person-centred practice (Figure 4): prerequisites for delivering care; the environment or context of the care; person-centred processes in terms of activities for delivering the proper care; and finally person-centred outcomes referring to the expected consequences of the care. The constructs are mutually dependent as each one is a necessary prerequisite for the others fulfilment, which will ultimately lead to person-centred outcomes for the patient (McCormack et al., 2015). An additional supplement has been made to the person-centred practice framework in suggesting macro context as an influential prerequisite. Macro context involves four components; health and social care policy, strategic frameworks, workforce developments and strategic leadership (McCance & McCormack, 2017).

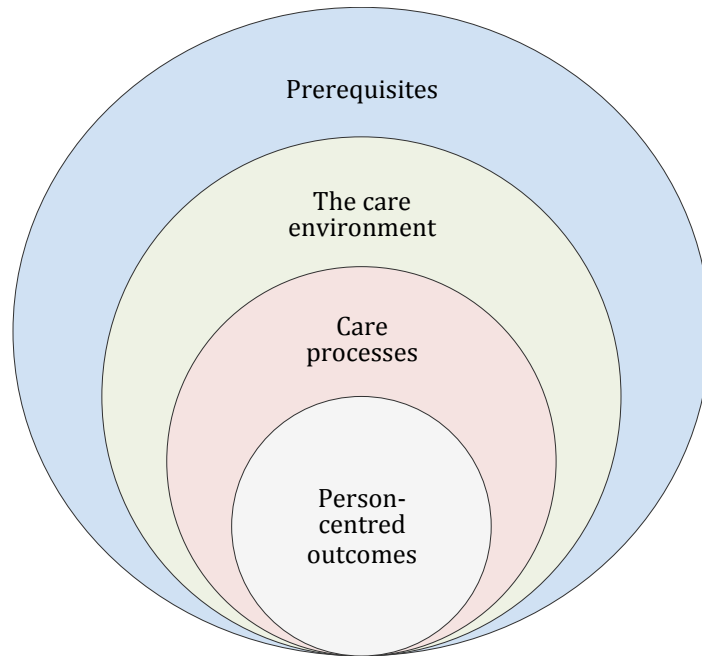


Figure 4 – Framework of person-centred practice based on McCormack and McCance (2017)

Despite the eminent and influential position of person-centred practice in recent years, the approach has received criticism for being too philosophical and diffuse, which makes person-centred practice difficult to use in a clinical setting (Berghout, van Exel, Leensvaart, & Cramm, 2015; Scholl, Zill, Härter, & Dirmaier, 2014). More recent initiatives within the field of person-centred practice have been to develop models and care pathways to implement and measure effects on continuity of health care services (Røstad et al., 2013; Ulin, Olsson, Wolf, & Ekman, 2016). Person-centred practice is suggested to promote a different psycho-social position of the patient to the consumerism which has been influential in health care services in recent decades (O'Dwyer, 2013). Through delivering health care services, across health care levels, in agreement with patients' needs, instead of focusing on organizational provisions, person-centred

practice is argued to improve continuity across health care levels (Juhnke & Mühlbacher, 2013).

3.3 Aims and research questions

The overall aim of the present thesis is to explore and describe how patients aged 80 years or older, their next of kin, and nurses from hospital and municipal health care, experience care transition from hospital to municipal health care.

3.3.1 Paper I

The aim of this study was to explore how patients who are ≥ 80 years of age experience the care transition from hospital to municipal health care services, based on two research questions:

- How do older patients experience participation in planning the care transition from hospital to municipal health care?
- How do older patients experience continuity in treatment and care during care transition from hospital to municipal health care?

3.3.2 Paper II

The aim was to understand how next of kin experience the care transition of an older relative from hospital to municipal health care.

3.3.3 Paper III

The aim of this study was to gain increased knowledge about nurses' experiences of care transitions of older patients from hospital to municipal health care, based on two research questions:

Conceptual and theoretical framework

- How do nurses experience continuity during care transition of older patients from hospital to municipal health care?
- How would nurses describe an optimal care transition?

4 Methodology

This chapter will describe the reasoning and underpinnings of the chosen study design and methods followed by an outline of the analysis, considerations of trustworthiness and ethics of the research presented in this thesis.

This study is qualitative in nature. In general, qualitative methodology provides tools for exploring social phenomena and human experiences (Polit & Beck, 2012). Interaction between researcher and participants is essential to build the trust and mutual understanding needed to clarify and conceptualize the perspectives (Kvale & Brinkmann, 2010). Within the qualitative methodological approach, this study employs an inductive exploratory and descriptive design, using individual interviews to capture the experiences of older patients and their next of kin. Exploratory research is often used when little is known about how an issue is experienced, to bring forth a clearer understanding (Blaikie, 2010). The current study is explorative because of the novelty of bringing together patient, next of kin and nurses. The descriptive part of the study seeks to accurately present the topic at stake. The differences between explorative and descriptive approaches are vague: however, there might be a preconception of descriptive as more rigorous (Blaikie, 2010).

4.1 Study design

The overall aim of this thesis is to explore and describe how patients aged 80 years or older, their next of kin and nurses from hospital and municipal health care experience care transition from hospital to municipal health care. Compared to quantitative methods, which aim at rigorously measuring causes and effects, a qualitative approach intends to get an in-depth understanding (Polit & Beck, 2012). Previous

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research on discharge planning finds varying values and priorities between older patients, next of kin and health professionals (Denson, Winefield, & Beilby, 2013) which suggest that care transitions should be explored and described from a multiple stakeholder perspective. The conceptual framework of the study encourages care transitions to be judged by the patient (Haggerty et al., 2003). In addition, health reforms in recent years have initiated a change of perspective where the patient comes first (See chapter 2.1). At the time when the study was planned, there had been little research attention on how care transition was experienced by the oldest patients and their next of kin. We developed the design with the intention of foregrounding their voices, which made older patients and next of kin the natural starting point of the study. Based on previous descriptions of cooperative initiatives in the health enterprise established under FOUSAM (see 2.1.1), we decided that Study A would be conducted within the FOUSAM region. A schematic of the study design is presented in figure 5.

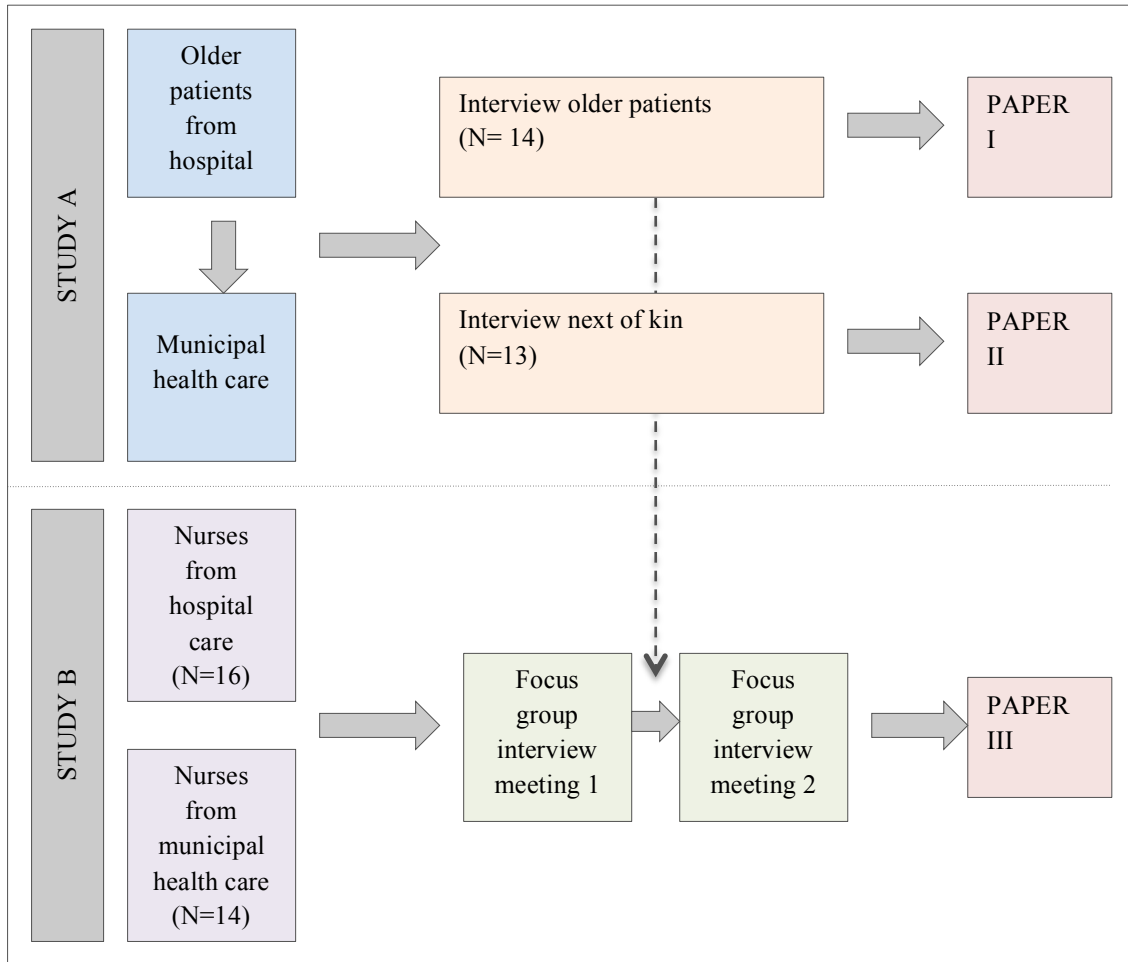


Figure 5 – Schematic of study design

4.1.1 Paper I and II

Based on the aims and research questions a descriptive and explorative design was chosen to capture the experiences of older patients and their next of kin. Semi-structured interviews were conducted to gather data. Within social research, interview is reckoned to be the most frequently used method (Aase & Fossåskaret, 2014). Described as an intentional

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conversation following a pre-decided structure and topic, research interviews aim to construct new knowledge (Kvale & Brinkmann, 2010). Semi-structured interviews follow a thematic question guide, structured to such an extent that the main topics are discussed, but loose enough to further discuss experiences described by the informant that might surface during the interview (Kvale & Brinkmann, 2010). Aase & Fossåskaret (2014) argue that each interview is a singular meeting between researcher and participant, shaped by cultural, emotional and cognitive preconditions: this implies that each interview must be adapted to the participant and the specific situation. In relation to the topics in the present thesis, care transition might not be a situation where patients have reflections and meanings other than the actual transportation between locations. In addition, we assumed that care transition might be experienced differently if the patient was discharged healthy and well, compared to patients being discharged with a deteriorating health and worsened sickness. As such, a semi-structured interview-guide was developed on the basis that the interviews would largely take shape from the older patients' stories about what had happened during their admission to hospital and following discharge to municipal health care (See Paper I, page 86 and Appendix 1, page 136).

4.1.2 Paper III

When the study was designed, there was increasing attention on the advantages of dialogue across health care levels, and in the Helse Fonna region, initiatives such as FOUSAM (see 2.1.1), which encouraged cooperation across health care levels, were established. To our knowledge, minimal research had been conducted to obtain the perspectives of municipal health care. Therefore we wanted to utilize the window of opportunity and the willingness of the municipalities in the region to design a study that safeguarded the perspectives of nurses on both health care levels. To explore the experiences of nurses from hospital and municipal health care, focus groups were perceived to be

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an appropriate way of gathering data in addition to facilitating the reflective dialogue between hospital and municipal health care nurses. Our intentions were to encourage discussion of the different frameworks of understanding that might exist between nurses representing different health care levels, and to gain further insight into the care transition process that might not have been highlighted through individual interviews, in line with Kitzinger descriptions of the advantages of focus groups (1995). Malterud (2012) describes using facilitating material in focus group research, steering the group discussions in a wanted direction. Such an approach would take advantage of focus groups' pedagogic function (Kamberelis & Dimitriadis, 2011), and contribute to valuable insights for participants (Malterud, 2012). The research questions in Paper III are twofold. Based on the practical limits of conducting a focus group, for example the range of topics to discuss within a given timeframe, and the intention of creating a reflective process for the participants, it was decided to conduct two meetings per focus group. According to Hummelvoll (2008) multi-stage focus groups can reach a higher level of abstraction, to create knowledge that goes beyond the specific situation. In addition, through asking questions concerning future care transitions, we aimed to stimulate an expression of ideas for improvement and debates between participants from both health care levels, in line with Kitzingers descriptions (1995). Findings from the patient study were used as evocative material for the focus group study, and were in addition an opportunity to bring forth the voices of the older patients (See Appendix 2, page 138).

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Table 2 – Overview participants and data collection

Paper	Participants	Data collection	Data analysis
1. Older patients' experiences during care transition	14 older patients	Individual interview	Content analysis
2. Next of kin's experiences of information and responsibility during their older relatives' care transitions from hospital to municipal health care	13 next of kin	Individual interview	Content analysis
3. Continuity of care during care transition: Nurses' experiences and challenges	30 nurses, 16 working in hospital and 14 from municipal health care	Focus-group interviews	Content analysis

4.2 Methods

4.2.1 Participants

4.2.1.1 Paper I

Recruitment and data collection for Paper I and Paper II were done simultaneously. The papers address care transition of older patients and their next of kin from hospital to municipal health care. Within qualitative research an important aim is to select a sample that can provide rich descriptions of the phenomena studied and provide a proper answer to the research question (Polit & Beck, 2012). As such, Registered Nurse (RN) at a medical, surgical and geriatric ward at a local hospital prior to discharge recruited a “convenience sample” of older patients, with a planned care transition to municipal health care. Convenience sampling means recruiting participants that are available and willing to participate. The recruitment was done in accordance with predetermined criteria (Table 3). To ensure enough participants in the study, one inclusion criterion was set to ≥ 80 years of age. After the patient and their next of kin had signed the informed consent (Appendix 4, page 148 and Appendix 5, page 151), their contact information was given to ECR. The older patients participating in our study represented a varied selection with different characteristics and paths of care transition. They were recruited from a local hospital. A total of 18 older patients agreed to participate. However, 4 participants withdrew prior to the interviews, due to deteriorated health after discharge from hospital. The older patients belonged to 5 different municipalities of different sizes and organization of health care services. When 1 of the older patients was contacted to schedule the interview, she withdrew the name of the next of kin that she had previously stated. Due to the assumed contributions of this patient to share her valuable experiences with the research study, it was decided

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to go forward with the interview even though she no longer fitted the inclusion criteria. During the interview it came up that the next of kin she had named was a neighbour and friend, as she did not have relatives. She did not want to burden them any further than the assistance they had contributed when she was hospitalized and discharged. All interviews with the older patients were done at their location, either at their home or in a municipal service apartment, or at a nursing home if the participant was admitted to a short-term stay (Rustad, Furnes, Cronfalk, & Dysvik, 2016).

Table 3 – Inclusion criterions Paper I, II and III

Older patients	Next of kin	Hospital and municipal nurses
Older patients \geq 80 years of age	Be related to older, admitted patients agreeing to participate in the study	Work as a registered nurse
Admitted to medical, surgical or geriatric ward	Have regular contact with the older patient	Be employed in hospital or municipal health care
Planned discharge to municipal health care	Speak and understand Norwegian	Work with care transition of older patients on a daily basis
Being able to understand and answer questions about their care related experiences		
Having next of kin agreeing to participate in the study		
Speak and understand Norwegian		

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4.2.1.2 Paper II

Next of kin were recruited through the older patient, who named the relative or person that they felt closest to during this period of treatment and care. All next of kin were family, related to the older patient. The adult children consisted of 7 daughters and 4 sons (Table 4). A total of 7 adult children lived in the same municipality as their older parent, 2 adult children lived in the neighbouring municipality while 2 adult children lived on the opposite side of the country or in a foreign country (Rustad, Cronfalk, Furnes, & Dysvik, 2016). Next of kin were interviewed at location by choice, participant's office (n=1), at ECR's office (n=3), or at the older patients' or their own home (n=9).

Table 4 – Background data of participants (Paper I and II)

Patient	Age	Next of kin	Age	Municipal health care
Female	87	Daughter	55	New user home care
Female	89	Daughter	62	Short term nursing home and home care
Female	87	Daughter	*	Home care
Male	88	Son	64	Home care
Female	89	**		Home care
Male	86	Wife	> 80	Rehabilitation in nursing home and home care
Female	94	Son	58	Home care
Female	81	Daughter	47	New user home care
Female	84	Daughter	63	Home care (service apartment)

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Female	92	Daughter	62	Home care (service apartment)
Male	87	Wife	> 80	Home care
Female	90	Daughter	65	Nursing home
Male	91	Son	60	Home care
Male	88	Son	62	Home care

* Age unknown, ** No next of kin

4.2.1.3 Paper III

Nurses attending a postgraduate course at a local University College were recruited to the study. The selection of participants by convenience sampling had great potential to illuminate the research questions (Malterud, 2012). To bypass the hindrance of nurses often working busy schedules in large municipal geographical areas, or being tied to a hospital ward during their shift, postgraduate students were seen as a convenient way of gathering enough participants with sufficient experience. In addition, a few participants were recruited from a local hospital in order to ensure equal distribution of participants' affiliation. After being given information about the study (Appendix 6, page 153), volunteers for participation signed a list and were later contacted by ECR with practical information. Participants were divided into five focus groups (A-E) by ECR (Rustad, Cronfalk, Furnes, & Dysvik, 2017), with the intention of creating groups with 5-7 participants each, with equal numbers of participants from hospital and municipal health care. This is in line with the literature's recommendations for group dynamics (Malterud, 2012). However, some of the participants chose to attend different focus groups from where they were assigned which contributed to a certain variation in the group sizes. The sample represented different municipal health care

services, as well as different municipalities organized with different administrative approaches to assigning health care. A total of 30 RN participated in the study. 16 nurses represented hospital care, being employed in medical or surgical wards in 5 different hospitals from 2 different regional health authorities. In addition, 14 nurses were recruited, employed in home care, nursing homes or rehabilitation centres in 9 different municipalities from 5 different counties in 3 different regional health authorities (Rustad et al., 2017). Participants' experiences as RN ranged from 0,5 -26 years (average 10 years). The gender distribution was skewed with more women (n=28) than men (n=2) participating in the study. All focus group interviews were conducted at the campus of the participants' University College, during their lunch break or in the afternoon, using an appropriate meeting room.

4.2.2 Data collection

4.2.2.1 Paper I and II

Prior to the interviews with the older patients and their next of kin, a thematic interview guide was developed (Rustad, Furnes, et al., 2016) (See Paper I, page 87 and Appendix 1, page 137). A pilot interview was carried out with 1 older patient not included in the final material. In agreement with the patient, the interview was carried out to test the interview-guide, as she did not fit the inclusion criteria. The interviews were carried out a few weeks after the patient was received in municipal health care. The interviews with older patients and their next of kin were attempted to be done separately, however 2 interviews were, by the patient's request, done simultaneously. Due to these patients' hearing impairment or physical limitations 1 wife and 1 daughter was asked to be present, which underlined these patients' vulnerability. In addition, due to geographical distance, 1 next of kin was interviewed by phone. All interviews were done by ECR and tape

recorded in agreement with the participants. Interviews with older patient lasted from 27-96 minutes, and interviews with next of kin lasted from 18 until 82 minutes.

4.2.2.2 Paper III

The interviews were carried out with one moderator (ECR) and one trained observer, following an interview-guide (See Paper III, page 115). An interview-guide balances the need to support the interview through standardizing the questions, whilst being flexible enough to underpin the discussions that might surface during the interviews (Malterud, 2012). In our study, using multiple focus groups (A-E), the interview-guide was used to ensure that the same questions were asked across the focus groups, but still allowed the groups to thoroughly discuss each topic (Rustad et al., 2017). At the beginning of each focus group it was underlined that all participants would be given time to have their say. Prior to focus-group interview 1, all participants received the interview-guide by email. Between focus-group meeting 1 and 2, all participants were emailed a summary of the main impressions of interview 1, which was written based on the tape-recorded interviews and the agreements of the moderator and the observer. In addition, they received quotations from the patient-study (Appendix 2). The quotations were condensed into meaning units selected from the various sub-themes in the analysis in Paper I. The quotations were read through at the end of focus group meeting 1, to familiarize the participants with its contents. They also received the interview-guide for focus-group meeting 2, along with practical information about time and place for the interview.

4.3 Data analysis paper I, II and III

The analysis in all three papers was based on qualitative content analysis as described by Graneheim and Lundman (2004). Historically,

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content analysis can be traced back to the 17th century and has been described as a research method as well as an analytical approach (Downe-Wamboldt, 1992; Graneheim & Lundman, 2004). In the seminal work of Berelson (1952) content analysis was mainly used numerically and often referred to as quantitative. Due to its broad applicability in describing and interpreting characteristics of a text, content analysis has become one of the most common analyses in social research during the last decades, and is found in a large body of literature. The article of Hsieh and Shannon (2005) is considered a major advance addressing the usual distinction within content analysis between the quantitative and qualitative approach and they sort qualitative content analysis in three different classifications. Content analysis can, as such, be performed differently in accordance with the epistemological underpinnings of the study (Hsieh & Shannon, 2005; Krippendorff, 2013; Patton, 2015). Within qualitative content analysis there is broad agreement that the initial steps of the analysis are inductive. However, the later analytic steps are described variously as inductive and deductive approaches (Elo & Kyngäs, 2008; Hsieh & Shannon, 2005; Patton, 2015). As such, the flexibility of content analysis, and the lack of a shared stepwise agreement about how the analysis should be performed, can also be argued to make the approach imprecise and complex.

All three data sets represent variations in narrations and linguistic characteristics and qualities which somewhat influence the data analysis. According to Krippendorff (2004), research questions are the targets for the content analysis. In Paper I, given the nature of the patient-interviews that were narrations of the older patients' experiences of their care transition, often reflected upon through previous life incidents, the research questions in the study became important tools to demarcate the answers in the text that corresponded to the aim of the study. In Paper II, next of kin gave more precise answers to the interview questions, which allowed for the usage of

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technological assistance during the analysis, and NVIVO version 10.1.1 was used on the first 5 steps of the content analysis, followed by Office Word on the latter steps of the analysis. In Paper III, the focus group interviews with nurses, focus group meeting 1 (group A-E) was analysed separately from focus group meeting 2 (group A-E). No technological assistance was used in the analysis of Paper III. All researchers took part in the analyses in all three papers. In cases of ambiguity, the transcribed text or the recorded interviews were consulted, and the interpretations represent the most plausible interpretation based on agreements among the researchers. The analyses was performed in the following steps:

1. Transcription of the interviews
2. Read through the text several times to get a sense of the whole
3. Identify meaning units
4. Condense the meaning units to make the large material more manageable
5. Code the meaning units
6. Create categories by grouping content by similarities
7. Interpret theme, underlying meanings

4.4 Ethics

All participants were informed about the study orally and in writing, and had to sign a written form of consent (Appendix 4, 5 and 6). They were assured of full confidence and could withdraw from the study at any time. The study was approved by Norwegian Social Science Data Service and The Regional Committees for Medical and Health Research Ethics, project number 2010/3342 (Appendix 3).

4.5 Research quality

One major question rooted in qualitative research is how one can establish trust or confidence in the results so that others feel safe acting upon them (Lincoln & Guba, 1985). The criteria to establish this kind of judgement varies between different research traditions, however, in the following, and in accordance with Graneheim and Lundmans suggestions (2004), the conceptual approach of trustworthiness by Lincoln and Guba will be used. Several initiatives were taken throughout to ensure the quality of the study findings.

4.5.1 Credibility

The concept of credibility refers to the process of conducting the study to enhance the trust of the interpretations and findings (Lincoln & Guba, 1985). Initially, the interview guide for Paper I was tested on one older patient whose response was not included in this study. In addition, the interview guide for Paper III was tested on one focus group constituted by academically employed nurses with long clinical experience as well as research experience.

In Paper I and II, we included participants of different backgrounds, different paths of treatment and care and various relations to their next of kin in order to produce rich descriptions of care transition experiences. In Paper III, about nurses' experiences of care transition, the sampling approach contributed to participants representing a wide selection of hospitals as well as municipalities, nationwide. Through triangulation of different sources of experiences of care transition across the three Papers that constitute the thesis, broad descriptions are provided, which also give the opportunity to compare the appositeness of the interpretations and findings. The studies have also used multiple investigators as well as different methods of data collections.

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One other approach to increase credibility is to identify meaning units, codes and categories that fit the data during the analytic process. In Paper I, focusing on the older patients, the data consisted of a large body of material where the patients often put the care transition experiences within a larger framework as they evaluated their lifetime experiences. Through a prolonged process of getting to know the data and the stories of the participants, the research questions were used as guidance to illuminate the aim of the study. In Paper II and Paper III, about the next of kin and nurses, the interviews were concise and the selection of analytical framework proved easier.

Member checks, where the data and findings are presented to the stakeholders of the phenomenon being researched, were carried out for Paper III. Each focus group interview was followed by a discussion between moderator and observer of the main impressions. In addition to the transcripts, these were written in a report that was sent to the participants, for additional comments or corrections. The report was also addressed in the beginning of the second focus group interviews, where the participants' opinions were requested about the previous interview as well as about the report.

4.5.2 Dependability and confirmability

Dependability refers to reliability within the quantitative research tradition, holding judgements about the stability of the study findings based on its potential for replication (Lincoln & Guba, 1985). Confirmability is understood as the consistency of the data and findings of the study (Lincoln & Guba, 1985). An underlying assumption of our analysis is the acknowledgement that a text can be read from several perspectives and does not possess a single meaning (Krippendorff, 2013). To strengthen confirmability of the studies, all analysis was done separately and discussed in the research group. In cases of ambiguity, the quotations were discussed by the authors until consensus

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was reached. Presenting quotations from the interviews to illustrate both diversities and similarities in the participants' experiences ensured transparency.

The data material that laid the ground for this thesis was produced during the period 2011-2015. The Coordination Reform was introduced in 2008-2009, and implemented in 2012 (Report No.47 to the Storting). The interviews of older patients and their next of kin were conducted in 2011, at the very beginning of the Coordination Reform. As such, one might anticipate that the consequences were not evident for the patients at this point. Older patients today might experience the care transition differently. However, Paper I and II find that the care transition is partly influenced by formalized circumstances where the Coordination Reform might have had a positive influence during later years. At the same time, experiences of care transition also affect personal dimensions, that from a lifetime perspective might be applicable today. The focus group interviews for Paper III were conducted in 2014/15, and were therefore after the implementation of the Coordination Reform. Implementation of structural changes as proposed in the reform is time consuming. Based on our findings, large municipal variations in care transitional procedures indicate that this implementation process is time consuming, which might suggest that similar findings as ours might also be applicable today. The focus group interviews were performed with one moderator and one observer who had long experience in conducting focus group interviews. To ensure dependability, the same written interview-guide was used in all focus groups (A-E).

4.5.3 Transferability

The concept of transferability holds a different meaning from generalizability, as it refers to the researchers openly putting forward the necessary information for others to judge whether the findings

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could be transferred (Lincoln & Guba, 1985). In all papers, methods are clearly described. The findings are presented with quotations from the participants' descriptions, giving the reader access to the data as well as the abstraction process of the analyses. Transferability should be decided by the reader judging the culture and context of the study and, as such, its applicability (Graneheim & Lundman, 2004). Care transitions from multiple stakeholders address a challenge of international relevance. Exchange of experiences in these matters is of importance, and we suggest our findings are relevant for all health care providers working with these issues.

5 Findings

In the following, a brief presentation of the findings in each Paper is given.

5.1 Paper I

The analysis resulted in two themes: “Participation depends on being invited to plan the care transition” and “Managing continuity of care represents a complex and challenging process”. Only a few of the older patients described formal participation in planning their care transition and future care needs. One patient was invited to an interdisciplinary meeting, and described being well prepared and informed. An informal bedside question about their future needs was the most common experience. In addition some of the participants described that their family had taken part in this process on their behalf. A few patients also described not participating in planning their care transition at all.

All participants were very concerned about information and communication between all stakeholders during their care transition. Their concerns were related to whether the information was transferred properly between hospital and municipal health care and some expressed insecurity about their obligations concerning the written documentation they were given at hospital, what information it held and if they supposedly should have passed it on to municipal health care. In addition several participants described how they could get in contact with health care if needed, through informal as well as formal channels of communication. All participants described experiences of varying responsibilities during care transition. Some of them were relieved, as the care transition was followed by an increase in the health care they received, while others wanted to restore their situation, returning to life as it was prior to being admitted to hospital

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with only minor help from municipal health care. In addition participants were concerned with their own responsibilities for their health and rehabilitation, describing efforts ranging from rehabilitation training to taking care of medications.

5.2 Paper II

The analysis resulted in one main theme; “Next of kin balance multiple tasks during older relatives’ care transitions”, which was abstracted from two sub-themes; “Next of kin strive to fulfil informational needs”, and “Next of kin take responsibility for the older relative”. Our participants’ stories described their efforts to balance their care in a way that they found appropriate for their older relative, while still being considerate of the older relatives’ integrity and autonomy. Their position as bystander to the care transition was in particular evident concerning the informational flow during care transition. The necessity of knowing how the health care system works, and especially municipal health care, was emphasized. Many next of kin lacked this knowledge. Receiving information about their older relative’s health status was also described as challenging. The older patient informed some relatives, while others had to trace information about their health status themselves; often because the older patients’ misunderstood the information they received. Next of kin also provided information, being an intermediary between the older patient and health care. Sometimes this was motivated by themselves or the older patient, at other times it was requested by health care staff either at hospital or municipal health care services. One common concern was how to get hold of health care staff when they wanted to provide information about their older relative.

Next of kin described taking responsibility for their older relative during care transition. One major task was described as helping the older relative restore the disruption of hospitalization through

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motivating them to continue daily activities and routines. All next of kin also had reflections about what kind of health care and assistance they perceived their older relative needed. Most of our participants shared their responsibilities with other family members. They made arrangements to overlap each other's contributions, and described the older patient as in charge themselves, but the family role was to oversee the situation making sure that everything worked out satisfactorily. Only a few next of kin described health care as a sharer of their responsibilities. In addition to taking care of their older relative, next of kin also had to accommodate changes in their own daily living. The responsibilities were described as heavy, and in particular the two wives had to balance managing their role as a caregiver with not compromising their own health and situation. In addition, the hospitalization and the deterioration of their older relatives' health status led next of kin to reflect around life inevitably coming to an end, which by some was experienced as a grieving process.

5.3 Paper III

The first research question was analysed within the theme "Administrative demands challenge terms for collaboration". The second research question was analysed within the theme "Essentials for nursing determine optimal care transition for older patients". Hospital nurses described care transitions as stressful when many of the arrangements were made during the last few hours prior to sending the patient to municipal health care. On the contrary, municipal nurses described care transition as being dependent on the preparations done by hospital nurses. If something were forgotten, they had to invest considerable time in making necessary arrangements, for example if medications were wrong. Nurses on both health care levels missed the opportunity of dialogue by phone to request or provide necessary information, and to get a broader understanding of the patients' situation as well as offering training in situation where needed. Many

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participants described being directed to a case manager who was holding a more administrative perspective and often could not sufficiently carry forward nurses' professional judgements. As such, care transition was framed by administrative routines, and limited professional collaboration between hospital and municipal nurses.

During the focus group interview, hospital and municipal nurses discussed their differences of perspective of older patients' health status and the levels of care and assistance that they were in need of. Hospital nurses usually considered the patient as being too frail for home care, while municipal nurses experienced that older patients often managed very well as soon as they were back in their own home. Agreeing upon levels of assistance should to a much greater extent involve the patients' opinions and it was suggested that this was explicitly requested in the nursing documentation system. In addition, collaboration about one common, long-term goal for the patient, could extend the perspectives of the patient's treatment and care, ensuring collaboration and commonalities also if the patient was readmitted to hospital. Administrative routines, such as short notices about the patients being discharged, often led to frustrations for both hospital and municipal nurses as well as the patient who was not given time to digest their situation. In addition, preferably all involved should have access to all written information. Large variations were described among the different municipalities about their preconditions for receiving patients from hospital care.

6 Discussion

The overall aim of this thesis is to explore and describe how patients aged 80 years or older, their next of kin, and nurses from hospital and municipal health care, experience care transition from hospital to municipal health care. In this section, the main findings as well as methodological considerations will be discussed.

6.1 Discussion of main findings

The discussion of the main findings is guided by the notion that different stakeholders have different perspectives, needs and challenges during the care transition. In the following section our findings, which support existing knowledge and add to the body of research on this topic, will be highlighted.

6.1.1 Older patients' challenges with participation during care transition

The older patients (Paper I) experienced minimal participation in planning their care transitions. This finding was supported by hospital nurses (Paper III), who described reduced times of admission, busy schedules, and extensive administrative duties, as priorities. Both nurses and the older patients described indirect ways of participation, through the engagement of next of kin. In Norway, patients' participation is a legal right, strongly promoted by health authorities (Report No.47 to the Storting, 2008-2009; The Norwegian Patients' Rights Act of 2 July, 1999). Similarly to our findings, older patients' lack of participation is known from previous research, despite their value of autonomy and independence, and wanting to take part in decisions (Denson et al., 2013; Dyrstad et al., 2015; Foss & Hofoss, 2011).

Implicit in the definition of continuity of care is the depiction of the patient in a twofold role: taking an active part in health-related decision making, as well as having opinions about the continuity of care by reporting experienced discontinuity and suggestions for improvements (Armitage & Kavanagh, 1998; Aspinal, Gridley, Bernard, & Parker, 2012; Crilly et al., 2006; Haggerty et al., 2013; van Servellen et al., 2006; Waible et al., 2012). Two of the older patients in the present study experienced situations where lack of participation left them in danger, which compromised their safety. However, the older patients had nowhere to report their incidents. Only a few of them described a level of participation that could correspond with the consumer role in continuity of care (Armitage & Kavanagh, 1998; Waible et al., 2012). Previous research has found that older patients position themselves differently in relation to participation in discharge planning, and their position is influenced by themselves as well as multiple external factors (Bångsbo et al., 2014).

In the concept of continuity of care the patient's proactive involvement and the patient's personal agency is an important attribute (Aspinal et al., 2012; Haggerty et al., 2013). However, patients must be enabled by health care staff to undertake such a position during their treatment and care (Haggerty et al., 2013). Based on our findings, this raises a question of how this relates to more vulnerable and sick patients, who are not able to have proactive involvement. In addition, the concept of continuity of care stands in stark contrast to our findings where older patients lack opportunities and communication channels to evaluate the care transition. We suggest that older patients' opinions should be formalized and requested in the written documentation system, to enhance their participation and bring to the forefront their valuable opinions to the relevant nurses in hospital as well as municipal health care. This is in line with findings in previous research where nurses have an important role in encouraging and facilitating patient

participation (Tobiano, Bucknall, Marshall, Guinane, & Chaboyer, 2015).

In addition, an active patient role should also involve the opportunity to evaluate the care transition afterwards with the relevant nurse. The ideological underpinnings of the Norwegian health care services are described as putting the older patients in a consumer role (Vabø, 2012). However, a change of focus towards person-centred practice might represent a shift of values, giving the patient a different position in relation to active involvement (McCormack & McCance, 2017). Providing care in accordance with older patients' needs during care transition implies more formalized channels for the patient to express their opinions as a documented statement followed by all involved health care staff.

6.1.2 Older patients' and next of kin's challenges with information during care transition

The older patients wanted information about care transition, and information about which health care staff they could contact if needed. Our findings support recent research on informational needs of adult hospitalized patients (Sefcik et al., 2016). Previous research has often focused on health care staff transfer of information across health care levels (Allen, Ottmann, & Roberts, 2013; Kirsebom et al., 2013). From the perspective of older patients, information is frequently seen as part of a broader preparation for hospital discharge prior to the care transition (Gabrielsson-Järhult, 2016). The older patients in our study expressed, *inter alia*, confusion about the medical reports given at discharge, because they did not understand their content and intention. On the other hand, next of kin lacked information about how health care services work, whom they could contact if they had questions, and how they could give and receive information about their older relative. The present findings clearly highlight that information should be adapted to the receiver and their particular needs. In a meta-synthesis

Allen et al. (2017) found that older patients and next of kin use active strategies like questioning, information seeking and negotiation to get the necessary knowledge about the care transition.

The older patients in our study were concerned about the information that was communicated between nurses from hospital and municipal health care about their treatment and care. This information is usually transferred electronically, and does not involve the older patient (Kirsebom et al., 2013). As a measurement of quality, continuity of care has been found to be associated with patient satisfaction (van Servellen et al., 2006). Patients' experiences of continuity of care are described as emotions, in terms of feelings of safety and confidence rather than seamless coordination (Haggerty et al., 2013). Related to our findings, the older patients' worries might be seen as an expression of their lack of control and vulnerability, as inadequate information could compromise their treatment and care. The present findings underline the importance of providing adequate and continuous information that is highlighted within continuity of care. (Haggerty et al., 2013).

Next of kin often lacked important information about their older relative's medical situation, as they did not have proper channels for communication. Similarly to our study, Denson et al. (2013) found that protecting older patients' autonomy without compromising their safety is important. Next of kin in our study described this as a delicate matter where thorough knowledge about the older patients' capabilities of giving and receiving information about their own treatment and care is crucial. In person-centred practice, next of kin have a central role in guiding nurses based on their familiarity with the patient (McCormack & McCance, 2017). Research on discharge preparation has found that older patients have reduced capability of receiving and understanding information while hospitalized (Palonen, Kaunonen, Helminen, & Åstedt-Kurki, 2015). This underlines the importance of using next of

kin as an additional resource for the patient when conveying information or in decision-making.

The older patients and their next of kin used informal sources of information while relying on friends and their extended network if they were unsure. In Norway, preventive home visits are suggested as one way of providing information about municipal health care to older persons, preparing them for future disease-related incidents which might occur (Tøien, Heggelund, & Fagerström, 2014). Clearly, lack of information about how the health care system works hampers next of kin's opportunity to assist the older patient during their care transition. Municipals should make such information easily available for next of kin, well in advance of medical incidents, to enable them to take an active part in the care of their older relative. In addition, many next of kin described how information about the municipal health care system was only available on the Internet, which was not a preferred source of information for many of them. We suggest that in addition to the online information, brochures about municipal health care, next of kin's legal rights, as well as contact information, should be automatically sent out to the next of kin named by the older patient, prior to -or parallel with- the older relatives' discharge to municipal health care.

6.1.3 Older patients' and next of kin's challenges with responsibility during care transition

Older patients were worried about who was responsible during their care transition. Coordination of care transitions involves tasks for hospital and municipal health care nurses where the older patient is not involved, described as management continuity of care (Haggerty et al., 2003). In a meta-summary, Haggerty et al. (2013) found that patients were not aware of these mechanisms, and therefore assumed that

everything was organized and coordinated, as long as everything worked out and no errors were experienced. In relation to the present study, it seems plausible that the older patients are not feeling safe during the care transition, rather they are alert and feeling unsafe, worried if anything goes wrong, and planning for what to do if it happens. In addition, Norwegian municipal health care has extensive interpersonal discontinuity as older patients receive care from different nurses (Gjevjon, Eika, Romoren, & Landmark, 2014). Related to our findings revealing older patients' lack of information and their confusions about nurses' areas of responsibility, this might be a supplementary explanation for their concerns.

The older patients considered that their own responsibility was to take care of their own health on a level they could manage. These findings provide additional nuance, suggesting that their energy and resources are focused on what they feel to be manageable. Next of kin felt a general responsibility for their older relative's welfare and offered major assistance, helping them regain their health and independence. Older patients' independence is considered important in preventing their institutionalization (Denson et al., 2013). In addition, some next of kin said it was difficult to decide on the appropriate extent of their help and support. None of them was given help and guidance by health care staff in this process, which seemed personal and guided by feelings of guilt. Several studies describe cultural differences in how next of kin experience responsibility towards their older relatives. However, few studies focus on the details of deciding the level of assistance. (Hartmann et al., 2016).

Importantly, next of kin in our study described care transition as a period of grief as they observed their older relative becoming increasingly unwell. They provide extensive help and support to their older relatives, preserving and reflecting their identity. This requires increased recognition of next of kin and acknowledgement of their need to be in the centre of care in stressful situations (Morhardt & Spira,

2013). Involved nurses should assist next of kin in clarifying their role and contributions, as well as understand and support their needs for care during care transition.

The present findings suggest that next of kin need enablement and support in order to sustain their contributions towards their older relatives. This might be of particular importance during the period of changes that care transitions represent. Next of kin's contributions and care are essential, and their interaction with health care services is necessary in creating a sustainable health care services that reflects the needs of the older patient (Report No.26 to the Storting, 2014-2015). Nurses are expected to collaborate with next of kin, being familiar with the patients' personal needs in the situation (McCormack & McCance, 2017). However, Morhardt and Spira (2013) argue that this might lead to a polarization between the older patient and their next of kin. In recent years, the Norwegian health authorities have increased recognition of next of kin's responsibilities and efforts leading to an increased obligation on municipalities to provide extended support to next of kin with heavy caregiving burdens (The Norwegian Directorate of Health, 2017; Report No.26 to the Storting, 2014-2015).

6.1.4 Hospital and municipal health care nurses` challenges and proposals during care transition

Our findings provide insight into care transitions as a hectic period largely influenced by extensive administrative routines, taking nurses' focus away from the older patient and their needs. There was agreement that short notice of older patient's discharge hindered the opportunity to provide proper care for and preparation of the older patient and their next of kin. In addition, short notice led to limitations on the collaborative opportunities between hospital and municipal health care nurses. Norwegian health authorities have increased cooperation between hospitals and municipal health care through

statutory health care agreements, providing detailed information about responsibilities (The Norwegian Municipal Health Care Services Act, 2011; The Norwegian Specialised Health Care Act, 1999). This approach provides an expedient framework for cooperation on an organisational and administrative level, but has less influence on collaboration between provider levels (Gautun et al., 2016; Martens & Veenstra, 2015). Clearly, our study suggests that in order to advance care transitions, health care agreements must safeguard functional aspects sustaining clarity of responsibilities while enhancing the opportunity of making professional judgements based on each older patient's needs.

Electronic transfer of information was considered an important advance, protecting patients from risks, and making information more available. Previous research has similar findings (Melby et al., 2015; Olsen et al., 2013). However, nurses lacked the opportunity for professional dialogue. Municipal case managers were perceived as intermediaries that put further limitations on hospital and municipal health care nurses' collaborative communication. Care transitions are guided by the goals of the different participating stakeholders (Hellesø & Melby, 2013). Norwegian municipalities are often organized with case managers that coordinate and administrate available health care services (Vabø, 2012). However our findings reveal that case managers were often asked to provide additional information between hospital and municipal health care nurses or discuss concerns which did not fit in the electronic documentation systems. This was explained as being performed poorly and inconsistently as the municipal case managers lacked the perspectives and insight of the caring nurses. This finding is of importance as, to our knowledge, there is limited research on the influence of New Public Management organization on nurses' planning of care transitions. One possible explanation could be that in recent years electronic developments and administrative agreements have led to modification of informational flow and altered collaborative

partnerships between nurses. When transfer of information was strictly electronic, nurses were concerned about the limited opportunity to invite municipal nurses to hospital for tutoring when needed. Exchange of competence and necessary tutoring was explained to come about through polite inquires, often through a verbal invitation. Care transitions apparently involve additional qualities that are not fully attended to in electronic transfer of information, leading the nurses' collaborative efforts in a different direction.

Inter-organizational continuity of care as described by Hellesø and Lorensen (2005) contains an individual dimension referring to the person-to-person relationships, and an organizational level pointing at the coordination of the many-to-many provisions. Related to the present findings, nurses' experiences of extensive administrative routines as well as collaborative challenges between hospital and municipal health care services, might point to situations where individual and organizational levels are incongruent. This corresponds with the Norwegian Health Authorities' particular efforts on the organizational level in improving the coordination of Norwegian health care (Romøren et al., 2011). Future initiatives should attend to both organizational dimensions and individual dimensions, to ensure continuity between hospital and municipal health care.

There was agreement between hospital and municipal health care nurses that their care should extend across the actual care transition and one suggestion from this thesis is to form a collaborative relationship between hospital and municipal health care nurses and the older patient to create a long-term goal for the older patients' recovery. A shared long-term goal for nursing across health care levels would be consistent with patient-centred practice, with an improved opportunity to preserve the older patients' authenticity. Authenticity is described as a person's aspirations, goals and unique set of values, where the nurses' task would be to help the older patient to realize their full potential in the situation (McCormack & McCance, 2017). The theory of person-

centred practice has been criticised for not describing clear activities when the patient is in the centre of care (Morgan & Yoder, 2012). In relation to care transitions from hospital to municipal health care, one preconception for person-centred practice is that all nurses coincide in their perception of the care that should be provided. In addition, all involved nurses should be familiar with the older patients' values, personal goals for their treatment and care, and potential for recovery. As such, a person-centred approach challenges health care services beyond the mere coordination of care transition.

In the region where this study is carried out, FOUSAM has been a facilitator of dialogue-meetings between health care staff in hospital and municipal health care, to enhance knowledge about the opposite health care levels and affect collaborative initiatives that might strengthen professional cooperation. Similar understanding was observed in our focus groups, where differences of perspectives changed to a common concern for the older patient. Our observations are in line with previous research (Dyrstad & Storm, 2016).

6.1.5 Summarizing portrayal of challenges

The complexity of challenges during care transitions involves several health care levels, multiple stakeholders with different goals, as well as a vulnerable group of older patients.

The present study finds that older patients have worries during care transition from hospital to municipal health care concerning lack of participation, reduced information and vague areas of responsibility between hospital and municipal health care nurses. Many next of kin experienced being left on the side-line during care transition, despite their important contributions helping and supporting the older patient, and their legal rights (The Norwegian Patients' Rights Act, 1999). The Norwegian Directorate of Health has recently published guidelines about next of kin's legal rights and their own needs (The Norwegian

Directorate of Health, 2017). Next of kin are essential in meeting future challenges providing health care to an increasing ageing population. Care transitions for the older patient and their next of kin should be of mutual concern for both hospital and municipal health care nurses, as equal partners. This requires different professional cultures to intertwine across health care levels and together contribute to strengthen the older patient and their next of kin's positions in hospital and municipal health care to ensure proper treatment at the right place and time, as stated in the Coordination Reform (Report No.47 to the Storting, 2008-2009). Norway, compared to other countries, scores lower on information and coordination between health care services (Skudal, Sjetne, Bjertnæs, Lindahl, & Nylenna, 2016).

A theoretical approach to the vertical challenges can be seen in continuity of care and expected outcomes for the patient in person-centred practice. The patient is expected to experience a proper continuity of care as a feeling of security, safety and confidence, and to have a role as an active agent (Haggerty et al., 2013). In person-centred practice the patient is expected to be satisfied with their care, to be involved, have a feeling of well-being, and create a therapeutic alliance (McCormack & McCance, 2017). Person-centred practice mainly addresses care from the provider-perspective. However Marshall, Kitson and Zeitz (2012) identify three qualities that older patients considered important; improved participation and communication, having an attentive staff and being connected through relationship. Their findings resemble our findings of older patients' experiences during care transition, concerning participation, information and responsibilities (Figure 6).

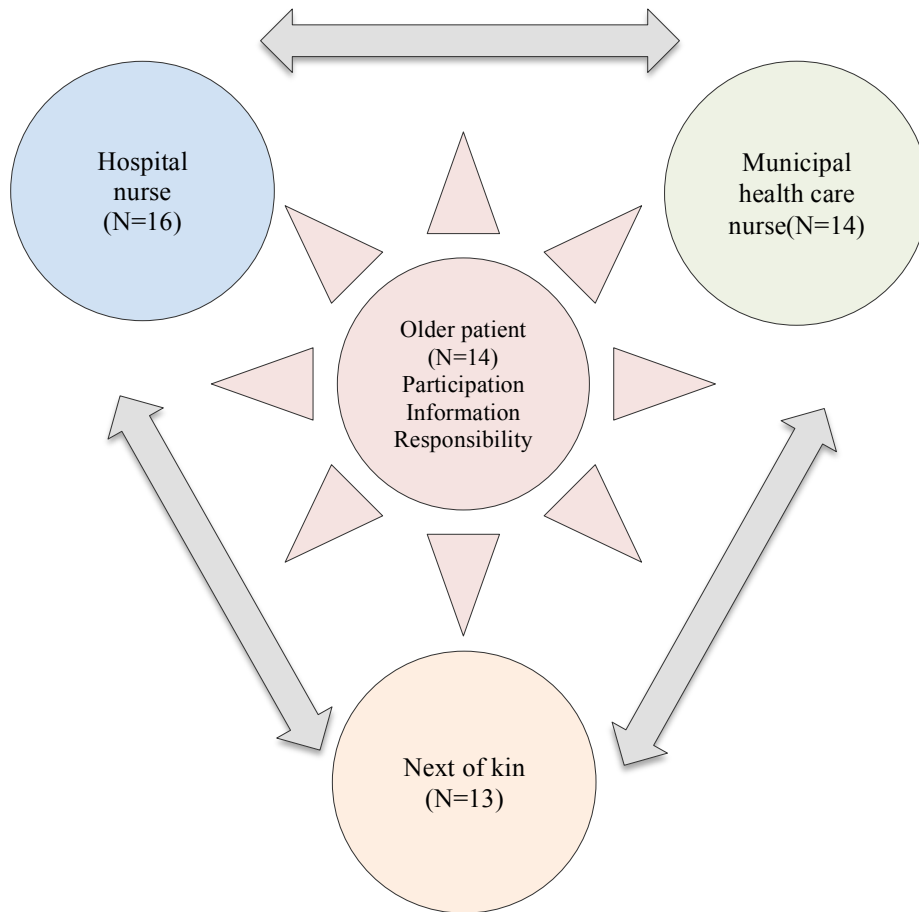


Figure 6 – Overview of stakeholders with the patient in centre

6.2 Methodological considerations

Several strengths and limitations must be taken into consideration in relation to the findings of this thesis. Hospital nurses, in accordance with the inclusion and exclusion criteria, recruited older patients and their next of kin. As such, the nurses' used their professional experience and judgment to decide if the patient was well enough to participate. The inclusion and exclusion criteria might have influenced

the findings, as older patients and next of kin who do not speak Norwegian possibly might experience care transitions differently. In addition, next of kin were recruited through the older patient, excluding older patients who did not have the support of next of kin. Having a relational support system is an important personal resource in distressed situations (Giosa et al., 2014), and older patients without next of kin might experience care transitions differently. All the older patients said that they had next of kin who supported them. However, during the interviews it turned out that one older participant did not have any relatives at all; she was relying on neighbors and friends. Two older patients had relatives living in a foreign country or in a far off region of Norway. One might anticipate that our understanding of help from next of kin on a regular basis has a different meaning for older patients who have limited personal resources. The different relations to the next of kin contributed to variations and width in our findings.

Four older patients, who were recruited to participate, chose to withdraw after care transition. They reported deteriorating health after discharge as their reason not to participate. Older patients at this age are often diagnosed with multiple diseases and frailty (Clegg et al., 2013), which was also apparent in our study. Hospital treatment for older patients is not always followed by recovery (Hvalvik & Reiersen 2011) after care transition. In addition, previous research finds that unresolved issues during planning of the care transition might influence the patient after discharge (Holland, Mistiaen, & Bowles, 2011). We contacted the older patient within a timeframe of 1-4 weeks after care transition. As such, the older patient might still have experienced their situation as challenging and unsettled, which led them to decline participation. Their experiences could have made valuable contributions to better understand older patients' experiences during care transitions.

Most of the older participants were female, which might have led to bias in the findings. However, the gender distribution is representative of the older population in Norway where women live longer than men

(Statistics Norway, 2013). Furthermore, the findings are in accordance with similar studies (Allen et al., 2017), and the participants represent variations in age, diagnosis and life situation, suggesting both depth and breadth in the experiences. Uneven gender distribution also occurred in the study of next of kin, where more females than males participated. In Norway, despite having less of a traditional role in family structures compared to other European countries, more women than men are actively providing care for their older relatives (Daatland et al., 2011). However, adult sons and daughters are found to provide different kinds of care. Also, the effect of being a caregiver is different on relatives living with the older patient than on relatives who are not living with the older patient (Hansen & Slagsvold, 2014). The participants represented adult sons and daughters, as well as wives living with the older patient, and it seems reasonable to anticipate that the study provides a breadth of experiences of next of kin during care transitions.

In Paper I, the interviews were semi-structured, which is understood to mean that an interview is in the shape of a conversation but still guided by pre-set themes (Kvale & Brinkmann, 2010). The interviews followed an interview-guide but were, as such, largely directed by the older patients' story. In retro-perspective, the questions concerning different aspects of the care transition seemed to initiate reflections around the older patients' lives, their past, present and future. This was particularly the case for the older participants, compared to their next of kin. Balancing the ethics of a research interview (Kvale & Brinkmann, 2010) and the exploration of the older participants' experiences of care transition, the interviews largely focused on their overall experiences of the past weeks, from hospitalization to home-coming. The interviewer ensured that the specific topics were answered through follow up questions. Persons of this age often experience transitions in many areas of their lives (Meleis, Sawyer, Im, Hilfinger Messias, & Schumacher, 2000) which was also evident in the interviews.

According to Krippendorff (2013) research questions are the targets for the content analysis. In Paper I, given the nature of the patient-interviews that were narrations about the older patients' experiences of their care transition, often reflected upon through previous life incidents, the research questions became important tools to demarcate the answers in the text that corresponded to the aim of the study. Interviewers' influence interacts with their respondents and can, as such, influence the narration of their experiences (Polit & Beck, 2012). The older patients described experiences, which on some points coincided with the experiences of their next of kin. However both the older patient and their next of kin also described situations that they experienced as difficult and had not explained to others during the care transition. This led to the assumption that the participants' descriptions of the care transition was based on their experiences and not what they assumed that the interviewer wanted to hear. Two interviews were carried out with the older patient and their next of kin simultaneously. Their close relationship and the older patients' dependence on their relative might have influenced their telling of their experience (See section 6.2.1).

In Paper III it was decided to recruit a convenience sample of nurses studying at a postgraduate class. Convenience sampling, which has been criticized by Patton (2015) for the risk of being an easy and information-poor way of recruiting participants, is an approach to recruit participants willing to share their experiences concerning the research topic (Malterud, 2012). In Paper III, the sampling was convenient in regard to time and location. However, students on a higher educational level with an extensive practical experience might be more motivated to take part in research, and they might also possess more knowledge about the topic (Kvale & Brinkmann, 2010). The recruitment ensured inclusion of participants from all over the country, representing both larger and smaller municipalities with different organizations of their health care services, as well as nurses from both

regional and local hospitals, nationwide. Their contributions might be seen as adding variation to the findings. In addition, the study had a minimal dropout, probably as the interviews were done during lunch break. Sample-sizes in all three papers meet criteria of information power as described by Malterud (2016). Information power advises that sample size should be decided by the amount of information that the sample holds, considered by the aim, sample specificity, theoretical approach, quality of dialogue and analytical approach.

The focus groups were gathered twice. Multi-stage focus groups are suggested if the intention is to evoke reflections that can contribute to further elaboration of the research topic (Hummelvoll, 2008; Malterud, 2012). In between focus group meeting 1 and focus group meeting 2, the participants were given quotations to reflect upon from the study of older patients. Usage of evocative material could be seen as a task of balance, where we wanted to initiate but not control the discussions and reflections of focus group meeting 2. During their second meeting, the quotations from the older patients were discussed and commented upon. However, the nurses took the discussions further, referring to their own reflections, and a few also brought notes from their own preparation for the interview, where they suggested and discussed improvements from a nurses' professional perspective. As such, one might imply that the evocative material fulfilled its intentions.

One additional limitation of our study is concerned with translation into English. To prevent misunderstandings of the meaning conveyed during the interviews (Kitzinger, 1995), all analysis was done in Norwegian, and the translation to English was done after the analysis process.

Care transition is sought to be described from the experiences of the older patient, their next of kin and nurses from both health care levels, in order to give a broad picture of the experiences during this important period of treatment and care. In all three papers, data analysis was

based on the stepwise guidance of Graneheim & Lundman (2004). One of the major debates within the field of qualitative content analysis is concerned with describing the final step of analysis, which is the level of interpretation and theming (Elo & Kyngäs, 2008; Hsieh & Shannon, 2005; Krippendorff, 2013; Patton, 2015). To our knowledge, few stepwise procedures of content analysis exist. Graneheim and Lundman's article is one of few offering a detailed guide of how to perform content analysis (2004), which, as such, has won major attention. They differentiate between manifest analysis, which is the initial step of sorting and categorizing the data on a descriptive level, and latent analysis that is described as interpretation of the underlying meaning of the text. However, based on the study design, and the intention of using findings from the patient interviews as facilitating material in the focus group interviews with hospital and municipal health care nurses, we do agree with Krippendorff's (2013) argument of conceptual similarity for comparison across research studies. Based on the above, we aimed at interpretation of a low latent level of content across the three papers.

6.2.1 Ethical considerations

In addition to the formalized ethical permits, ethical considerations can be seen as more fluent within qualitative health research. Qualitative research is defined as a situated activity studying phenomena in their natural settings (Denzin & Lincoln, 2011). As argued by Øye and colleagues (2016), ethical issues cannot always be planned for in advance, as they often occur when data are constructed in real life situations. In the present study, the interviews with the older patient and their next of kin were intentionally to be done individually, due to a presumption of preventing the participants from influencing each other's stories. However, on location, two of the older patients decided to do the interview with the next of kin present due to hearing impairment and other more practical issues. As such, balancing the

integrity of the research interview, the patients' autonomy and the ethics of doing no harm, the interviews were done simultaneously. Throughout the interview session, some of the emotional strain and the inelible relational dependency between the older patient and their next of kin became visible, making it necessary to adopt a sensitized role as an interviewer, weighing which follow-up questions seemed reasonable to ask. However, regarding the validity of the study, the main topics were discussed and answered which gave valuable contributions to the overall findings of the study.

Kvale (2006) addresses the ethics of power dynamics in research interviews, where the interviewer is in a dominant position. This was also of concern in the present study. In the interviews of older patients, it appeared that their experiences of decreasing health in old age, when recently discharged from hospital, evoked emotions and experiences of more existential concerns. As such, the interview questions were often answered through sharing lifetime experiences. The research group had thorough discussions about the ethics, and which parts of the interviews should be included in the study, to ensure the older patients' privacy. Meaning units were, as such, extracted from the transcripts following the research questions of Paper I, which were further analysed as described in the methods section. The ethical principles of the Declaration of Helsinki are applied (2013).

6.3 *Implications for nursing*

The three papers in the present study provide different perspectives and experiences of care transitions from hospital to municipal health care. Several implications for future research, politics, education and clinical practice can be suggested.

To facilitate patient participation in planning care transition, their perspectives should permeate all levels and layers of health care. We suggest that an underpinning in line with patient-centred practice could

promote increased participation. On a provider level, older patients' opinions should be requested and documented electronically during planning care transition. Based on continuity of care older patients' evaluation of their care transition should be highlighted, which requires systems and channels for exchange of information.

Information should be better adapted to the receiver, and based on their needs. This, in particular, involves information about who is responsible for their care during their care transition, and how they can be contacted. We suggest that this "grey area" of responsibility is clarified through health care agreements, leading to specific routines on provider levels that accommodate older patients' needs.

Next of kin should, from the beginning, have easily available information about how the health care system works. This goes beyond municipal information on the Internet, focusing on more structured and formalized approaches. In addition, the next of kin's role and rights should be clarified in order to safeguard their position in the informational flow. Next of kin's need for help and support should be mapped and provided by hospital as well as municipal health care nurses.

Future developments should ensure more equal conditions across municipalities to safeguard the quality of the care transition and standardize routines. Hospital and municipal health care nurses should take part in designing and revising health care agreements, to ensure that they underpin and facilitate a person-centred approach of nursing.

6.4 *Implication for research*

More knowledge about the experiences of older patients is needed. We suggest research should focus on how person-centred practice could influence older patients' experiences during care transitions.

Future research should focus on next of kin`s experiences, in addition to identifying how their needs could best be met by health care. The interface between nurses and next of kin`s caregiving is vague, and interventions addressing such a collaborative relationship could be suggested.

Future research should explore the role of multiple stakeholders, including municipal case managers in care transitions, as well as the implications of new public management organisation of Norwegian municipals.

Clearly our findings emphasise that electronic documentation does not communicate all dimensions of the collaborative activities between hospital and municipal health care nurses. This is of particular concern in regard to hospitals` role providing instructive support and transfer of knowledge. Interventions should be made to identify how use of technological developments could sustain transfer of knowledge and facilitate a collaborative relationship.

Much research has been done on care transitions, particularly from the hospital perspective. We suggest that future studies focus on municipals` requirements for receiving older patients, on organizational as well as provider levels.

To ensure improvement of care transitions across health care levels, for all stakeholders and within all dimensions of this complex process, initiatives and developments must be evaluated and revised continuously, and quantitative evaluation and implementation-studies could be suggested.

7 Conclusion

In accordance with the main objectives this study provides new and extended knowledge about care transitions. Older patients and their next of kin experience multiple areas of discontinuity during their care transitions. Continuity of care for older patients and their next of kin should be based on a more patient-centered approach to the older patients' needs. In addition, next of kin should have a clearer role during care transition, acknowledged as resources for the older patients as well as having their own needs for support. Better collaboration between hospital and municipal health care nurses is needed to facilitate and continue patient care as well as to exchange knowledge. This implies a need for establishing systems enhancing professional exchange and dialogue. We suggest that care transitions should be based on a common theoretical perspective, ensuring a joint prospect for the overarching goals. In addition, this would lay a common ground for further research, clinical developments and building further on existing theoretical provisions. Nurses have a central position in care transitions due to their education and competence, their first hand contact with older patients and next of kin and their prominent role in both arenas for health care. They are in a central position and should play a key function in health authorities' continuous improvement of continuity of care for older patients across health care levels to meet current and future needs for health care services.

Conclusion

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Paper I

Older patients' experiences during care transition

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Background: A fragmented health care system leads to an increased demand for continuity of care across health care levels. Research indicates age-related differences during care transition, with the oldest patients having experiences and needs that differ from those of other patients. To meet the older patients' needs and preferences during care transition, professionals must understand their experiences.

Objective: The purpose of the study was to explore how patients ≥ 80 years of age experienced the care transition from hospital to municipal health care services.

Methods: The study has a descriptive, explorative design, using semistructured interviews. Fourteen patients aged ≥ 80 participated in the study. Qualitative content analysis was used to describe the individuals' experiences during care transition.

Results: Two complementary themes emerged during the analysis: "Participation depends on being invited to plan the care transition" and "Managing continuity of care represents a complex and challenging process".

Discussion: Lack of participation, insufficient information, and vague responsibilities among staff during care transition seemed to limit the continuity of care. The patients are the vulnerable part of the care transition process, although they possess important resources, which illustrate the importance of making their voice heard. Older patients are therefore likely to benefit from more intensive support. A tailored, patient-centered follow-up of each patient is suggested to ensure that patient preferences and continuity of care to adhere to the new situation.

Keywords: care transition, older patients, continuity of care, participation, communication

Introduction

People ≥ 80 years of age constitute the fastest growing age group in the western world. In addition to general age-related functional impairment, older people are at increased risk of diseases such as dementia, cancer, and cardiovascular diseases.¹ In the current health care system, several health care providers, with different financial systems and areas of competence, are offering acute and long-term treatment and care.^{2,3} The complexity of the cooperation between different health care levels makes the process of moving across these levels challenging.^{4,5} Care transition is understood as the continuity of health care when the patient is transferred across different health care levels.³ Older people are large consumers of health care services, which leave them vulnerable to adverse incidents and make them a target for alterations to reduce medical costs.⁶⁻⁹ To meet the needs and preferences of older patients better, research has altered focus from a health-administrative perspective on care transition to the patients' experiences of the continuity of care during care transition.^{10,11} Theories such as person-centered care, based on values of mutual respect, self-determination, and understanding, have been widely acknowledged.¹² A successful care transition of older patients, across health care levels, forms the basis of well functioning and continuous residential treatment and care.^{3,13}

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In Norway, as in many other western countries, the health care system is organized vertically in two sectors; primary health care, run by the municipalities, are responsible for nursing homes, home care and general practitioners, while the hospital sector is run by the national health authorities.¹⁴ The Norwegian Government proposed The Coordination Reform, to be gradually implemented.¹⁵ The reform aimed at improving coordination across health care levels, and the patient's experience of continuity of care, through increased treatment and care of patients at primary care level and earlier discharge from hospitals and specialist care. The strategies of the Norwegian reforms are comparable to reforms in other Scandinavian countries.¹⁴ Evaluations indicate that The Coordination Reform has unintentionally led to an increase in care transitions, as primary care more often receives sicker patients, leading to readmissions in hospital, and the reform seems to have led to a fragmented health care service for the older patient.^{16–18} Based on this, there is an urgent need to explore the present situation more closely from the older patients' perspective, looking for actions and improvements.

The older generation themselves tend to meet their situation with an attitude of acceptance and a denigration of their own needs, which masks their vulnerability in the care-transition process.^{19,20} Notwithstanding, recent research suggests that there should be more focus on age-related differences among older patients during care transition. Bobay et al²¹ found no association between discharge preparation and discharge readiness among patients ≥ 85 years of age. The oldest patients reported being given less information than elder patients ≥ 65 years of age. Further, Allen et al²² show how lack of communication systems across health care levels negatively affects older patients care transition, indicating the importance of proper information not only between multiprofessional health carers but also to the older patient. In a large study by Holland et al,²³ a considerable amount of unmet needs after discharge of patients from hospital to home and self-care was identified. An incongruence was found between health care staff's impression of the patient's capacity and what they actually were capable of performing, and the patient was often dependent on informal assistance to cope immediately after discharge. As such, the challenge to create a safe environment that meets the expectations and needs of the oldest old patients across health care levels still remains.

Given these considerations, the aim of this study was to explore how patients ≥ 80 years of age experience the care transition from hospital to municipal health care services. To identify various aspects of the care-transition process, the following research questions were formulated: How

do older patients experience participation in planning the care transition from hospital to municipal health care? How do older patients experience continuity in treatment and care during care transition from hospital to municipal health care?

Methods

The present study used a qualitative approach with a descriptive and explorative design. Individual and semistructured interviews were conducted with 14 participants. Content analysis of the interviews was performed to capture the individual's experiences during the care transition.²⁴

Sampling and participants

Older patients ≥ 80 years of age were recruited from a local hospital in Norway. Registered nurses selected the participants using the following inclusion criteria: ≥ 80 years and admitted to medical, surgical, or geriatric wards with a planned discharge to municipal health care services.

Eighteen patients (eleven women and seven men, aged 81–94 years) with various diagnoses, such as cancer, stroke, and pneumonia, agreed to participate. Four patients (two women and two men) later withdrew from the study because of deteriorating health after being discharged from hospital. Background data, including the participants' different transitions across the health care levels and to different health care providers, are described in Table 1.

Interviews

All interviews were conducted by the first author (ECR). The participants were contacted (ECR) by telephone 1–2 weeks after discharge from hospital to schedule an appointment for the interview. The interviews were semistructured, with open questions (as described in Supplementary material 1) and lasted for 27–96 minutes. The participants were given the opportunity to speak freely about their experiences, and their stories and statements directed the conversation. However, an interview guide ensured that the main topics were addressed (Supplementary material 1). Three participants were interviewed at a nursing home where they had a short-term stay, and eleven participants were interviewed in their own home or at a residential service apartment. Two of the interviews were conducted in the presence of family at the participants' request, for convenience and because of hearing impairment. The participants agreed to have the interviews tape recorded.

Data analysis

The interviews were transcribed verbatim and analyzed using qualitative content analysis inspired by Graneheim and

Table 1 Background data of participants, n=14

Patient	Age (years)	Cause for admission to hospital	Care transition
Female	87	Unknown to the patient ^a	Home – hospital – home
Female	89	Unknown to the patient ^b	Home – hospital – nursing home – home
Female	87	Fall	Home – hospital – home
Male	88	Fall	Home – hospital – home
Female	89	Fall	Home – hospital – home
Male	86	Only the primary diagnosis known to the patient ^c	Home – hospital – rehabilitation at the nursing home – hospital – nursing home – home
Female	94	Infection	Home – hospital – home
Female	81	Paralyzed bowel	Home – hospital – home
Female	84	Wrong medication	Service apartment – hospital – service apartment
Female	92	Cancer	Service apartment – hospital – service apartment – hospital – service apartment
Male	87	Infection	Home – hospital – home
Female	90	Stroke	Service apartment – hospital – nursing home
Male	91	Stroke	Home – hospital – home
Male	88	Pneumonia	Home – hospital – home

Notes: ^aReduced general condition, ^bfall, ^ccomplications following elective surgery, pneumonia, heart attack, and reduced general condition.

Lundman,²⁴ through the following steps: the interviews were transcribed verbatim. The transcriptions were read through several times to gain a sense of the whole. Meaning units were then identified and extracted from the transcriptions and further condensed, ensuring that the meaning was maintained while shortening the text. The condensed meaning units were labeled, and based on their similarities, coded for further assortment. The codes were sorted based on their similarities into categories to preserve the diversity of the participants' experiences. To ensure the diversity of the content, the analysis (presented in Table 2) includes subthemes in addition to the overall theme. The analysis was guided by the research questions to ensure that the participants' experiences during care transition were captured. Data analysis was an active process, going back and forth between different steps of the

analysis. In cases of any ambiguity, the transcribed text or audiotape was used to clarify the participant's expression. Each author performed the analysis independently, and the findings were discussed until agreement was reached.

Ethics

The study was approved by the Regional Committees for Medical and Health Research Ethics (Project number 2010/3342) and was reported to Norwegian Social Science Data Services. Based on instructions, a registered nurse at each ward provided information about the study, both verbally and in writing. Participants were assured anonymity and confidentiality and informed that they could withdraw from participation in the study at any time without any consequences for treatment and care. Participants signed a

Table 2 Examples of the abstraction process of the content analysis, n=14

Category	Subtheme	Theme
Was asked to participate in discharge meeting	Formal and informal participation in planning the care transition	Participation depends on being invited to planning the care transition
Was asked their opinion about future care needs	Partial participation in planning the care transition	
The family helped in planning the care transition	No participation in planning the care transition	
Don't remember being asked to participate in planning the care transition		
Was not asked to participate in planning care transition		
Information from hospital to home-care staff and patient	Communication during care transition takes place on different levels	Managing continuity in care represents a complex and challenging process
Experiences with written documentation		
Communication from patient to health care staff	Responsibility during care transition varies	
Unresolved responsibility		
Handing over the responsibility		
Obligated responsibility		
Personal responsibility		

written informed consent form before contact information was given to the first author.

Findings

The data comprised extensive and detailed descriptions of the participants' experiences during care transition from hospital to municipal health care. Our findings represent both similarities and diversities in the participants' experiences. The main findings were developed and formulated in two complementary themes. The theme "Participation depends on being invited to plan the care transition" encompassed the subthemes of "Formal and informal participation in planning the care transition", "Partial participation in planning the care transition", and "No participation in planning the care transition". The second theme formulated was "Managing continuity in care represents a complex and challenging process", abstracted from the subthemes: "Communication during care transition takes place on

different levels" and "Responsibility during care transition varies". Examples of the abstraction process of the content analysis are presented in Table 2. The results will now be presented, with selected quotations from the participants used to illustrate each subtheme and allow the reader to assess the evidence directly.

Participation depends on being invited to plan the care transition

Hardly any participant described taking part in organized formal meetings to plan their future care needs. Examples of abstraction process of participation when planning the care transition are presented in Table 3.

One older patient was invited to participate at an interdisciplinary meeting, and the patient's family was asked to join in the discharge meeting. The patient seemed well prepared and mentioned several questions that he wanted to ask if given the opportunity.

Table 3 Examples of abstraction process of participation when planning the care transition, n=14

Theme	Category	Subtheme	Condensed meaning unit
Participation depends on being invited to plan the care transition	Was asked to participate in discharge meeting	Formal and informal participation in planning the care transition	There is supposed to be a final meeting here before I go home. The staff will recommend the home services that I will need when I am discharged. And if we want something we can let them know tomorrow at the meeting.
	Was asked their opinion about future care needs		I could have home care for as long as I felt I needed it, and it has not ended yet. I think I was asked several questions about my needs of care when I was discharged.
	The family helped in planning the care transition	Partial participation in planning the care transition	I wasn't asked if I wanted to be discharged home to my apartment when I was at the hospital. I believe it was my daughters who applied for the nursing home. With me, they only discussed more general stuff, but I said that I have my wife at home, and she can help me with almost everything.
	Don't remember being asked to participate in planning the care transition	No participation in planning the care transition	I can't remember that I was asked in hospital about what help I would need at home after discharge. I told them that I was alone. And all the aids were already in my apartment when I arrived at home. I was probably asked about my home situation at the hospital, but I don't remember now. And I don't remember my answer either.
	Was not asked to participate in planning care transition		I knew there was no reason for me to stay there any longer. I can't remember being asked about the discharge and home care. I don't remember that I was asked directly about what I wanted, but they didn't do anything against my will.

There is going to be a meeting here before I'm discharged (from a short-term municipal institution). They will recommend for home service the things that I need. And if we want something, we could let them know tomorrow at the meeting. And both my wife and my son will participate, and probably the nurses who has cared for me.

However, the most common experience when planning the care transition was the informal "bedside" question about the participants' health care preferences after being discharged.

The nurses asked me if I wanted to be transferred to the nursing home, but I didn't believe that it was necessary.

Some of the participants believed that their family was involved in the process and had communicated with the health care staff. This was experienced differently; for some participants, not having to deal with planning the discharge seemed to be a relief, whereas others perceived it negatively and had been left feeling dissatisfied.

No, I wouldn't know because I didn't have anything to do with that. It is the girls who have arranged it. They don't believe I could manage anything any longer. But it is okay, I put up with it.

A few participants reported that they could not recall any influence on the care transition at all. One participant was not sure when he was to be discharged but guessed that he was supposed to leave hospital because his physical condition had improved.

I didn't take part in the discussion about my care needs. I don't remember that I was asked directly about what I wanted, but they didn't do anything against my will, that's for certain.

Thus, not being invited to participate in planning the care transition was not explained as a totally negative experience.

Managing continuity of care represents a complex and challenging process

The participants described the care transition from hospital to municipal health care as a complex experience comprising many elements. Examples of abstraction process of patient experiences during care transition are presented in Table 4.

All of the participants described experiences related to information and communication during their interviews, and the statements reflect the multitude of communication channels that the participants faced during care transition.

Several of the participants mentioned the communication between hospital staff and home-care staff in their interviews. A few participants expressed confusion about not knowing what information had been sent from the hospital and received by the municipal health care staff.

I've been receiving a new kind of medication since I was in hospital. I don't know if it is because of directions from the hospital or [...] I just take them and keep quiet (...).

A few of the participants commented on the written documentation they were given when discharged. The participants expressed insecurity about their obligations in relation to the documents and frustration because the written terminology was difficult to understand. At risk of not receiving the help he needed, one participant made a real effort to ensure that the written information about his medical condition reached the municipal home-care office.

I received a letter from the hospital addressed to the municipal health care services with no stamps on it. So, I had to take my walker and walk to the kiosk down the street to buy a stamp and post the letter to the municipal health care services. I don't want to say anything but I have my own opinion about that.

Almost all of the participants felt secure knowing that they were going to be well looked after by the health care providers and their general practitioner.

Yes, I felt safe when leaving the hospital. I knew that I had my general practitioner next to where I live, and I also have a safety alarm.

Several of the participants talked about how they could contact the home-care staff if needed, by using a safety alarm or by talking to the nurses who visited them daily. Some participants possessed informal lines of communication to feel secure, as exemplified in next quotation.

If my general practitioner couldn't help me, I know the chief of home care. She used to work in my store, so she could probably take care of most things. And also my grandson's wife is a home-care nurse. It is not a problem for me to get in contact with the right person if I need to.

All of the participants described several views of responsibilities during care transition, and some of the older patients described handing over the responsibility as a positive experience. One of the participants felt relieved.

But it has worked out. I get my medication delivered now, so I am, so to speak, free from it all.

Table 4 Examples of abstraction process of patient experiences during care transition, n=14

Theme	Category	Subtheme	Condensed meaning unit
Managing continuity in care represents a complex and challenging process	Information from hospital to home-care staff and patient	Communication during care transition takes place on different levels	Yes, they had contact, so everything worked just fine. The hospital told the municipal home care, who said that they would come in the evening. At the same time as we came home, we called the nurse from home care who took the papers I was given at the hospital. They had called from hospital as well, but I don't know what they said.
	Experiences with written documentation		Someone gave me a piece of paper and, I suppose, no [...] I guess I should just keep it. I don't think I should even deliver it. I don't receive enough help. I have a letter from the municipal home-care service, but I can't sign that I am satisfied with their services. I'll just leave it until they send a reminder, and then I get to tell them what I think about the aid they are not providing.
	Communication from patient to health care staff		I've been receiving a new kind of tablet since I was in hospital. I don't know if it is because of directions from the hospital, I just take them and keep quiet. If I need more help, I just contact the home-care office because I can get more help if needed.
	Unresolved responsibility	Responsibility during care transition varies	There is a nurse from home care saying that she is my primary contact. I didn't catch her name, but that doesn't matter. Then, I at least know that someone is responsible for me. I don't know if I am taking too much medicine because there is no one in charge of that now. I believe I have to go to my general practitioner to give a blood sample, but nobody has told me to do that.
	Handing over the responsibility		He (his son) has taken care of it all from the beginning. He called the Municipal Decision Office and made sure that they came from the municipal health care. A safety alarm has been applied for, but it is a long wait. This was applied for when I was still in hospital.
	Obligated responsibility		And then I thought I should call the municipal home care and check with them. I think that gradually I will be able to manage on my own. You don't open the book of law to read all these paragraphs. And you don't go to the municipal home-care office either to ask what it means. So, I don't think many people would make a complaint about the resolutions. This is simply just a waste of paper.
	Personal responsibilities		I started to use a walking stick today, and I stopped using the walker. I will start to exercise. You know, I got tired really fast, but I can't give up. In the hospital, the physiotherapist gave me an exercise description, and I have used it all by myself as much as I have been able to. So, my condition has improved a lot, from sitting in a wheelchair to using a walking stick.

Other participants described how they tried to withhold responsibility for their own situation themselves, expressing optimism about their ability to be in charge of their own situation.

I will at least try to go home because if it doesn't work out, I can apply for a short-term stay here at the nursing home. I really think that's what's best for me.

Almost all of the interviewees noted that they made a huge effort to take personal responsibility for their own health and rehabilitation.

At hospital, I was working out by walking up and down the stairs, holding heavy things in my hands. And I walked in the parallel bars. I exercised every day as much as I could manage, just to improve my mobility, and I recovered. I got help from the physiotherapist and the occupational therapist. And I noticed that the power and mobility in my left arm and foot improved.

The participants described responsibilities ranging from physical rehabilitation to being responsible for their own medication in accordance with their perceived functional abilities.

Discussion

The aim of this study was to explore how people ≥ 80 years of age experienced the transition from hospital to municipal health care services. Two complementary themes, which greatly affected the older patient's experiences during care transition, were developed through the analysis: "Participation depends on being invited to plan the care transition" and "Managing continuity in care represents a complex and challenging process". The discussion was arranged according to these themes to highlight different aspects of the care transition process of older patients.

Participation depends on being invited to plan the care transition

In our study, only one participant experienced formal participation, being invited to take part in a discharge meeting. The participant felt well-informed about who would attend the meeting and what questions and problems he could address. This is in agreement with the findings by Bångsbo et al,²⁵ who indicate that patient participation is affected by the patient's level of preparation. However, the actual influence that older patients may exercise in such discharge meetings might be limited by the professionals' perception of opportunities for postdischarge arrangements.^{26,27}

Most of the older patients in our study experienced a more informal bedside approach, being asked about their preferences after discharge. Previously, older patients' preference about being actively involved in decision making was questioned.²⁸⁻³⁰ However, more recent research argues that older patients do want to participate in decision making about their care transition, but because of the inequity in power between the patient and the professionals, the patients are left in a vulnerable position and may therefore be reluctant to communicate their preferences.³¹⁻³⁴ This might explain our finding that patients were waiting to be asked for their opinions instead of taking an active approach to participating in planning their care transition. Some of our participants indicated that the family took part in planning the care transition. A few of them did not totally agree with their family even though they accepted the decisions made on their behalf. Extended support from either family or professionals has been shown to facilitate patient participation and give older patients a stronger position from which to influence the decisions.^{32,35,36}

In our study, some patients described that they could not recall any participation at all. Some of them made firm statements that they were not asked for their opinion at all when planning the care transition. Horwitz et al³⁷ found that one-third of the older patients were given less than a day's notice in advance of the discharge. In addition to the professionals spending limited time with the patient, the opportunities for proper patient participation in the discharge planning might be reduced.^{37,38} One of the patients in our study expressed that the nurses did not do anything against his will. As such, our findings might also illustrate the complexities of patient participation due to relational elements, which may impede the possibilities for participation. Similarly, Foss³⁴ found that older patients identified themselves with a cultural understanding of age as being old and slow. As such, older patients took responsibility for the lack of participation, which reflects the tensions surrounding the conflicting holistic needs of the patient and the hospital.³⁴

Our findings can also be understood by characteristics specific to older people in general, as individuals of this generation often have lifelong experience of a paternalistic health care system.³¹ In addition, older patients seem to experience feelings of powerlessness, lack of knowledge, and being disempowered and pacified.^{31,32,39,40} These circumstances contrast with proactive involvement in the process of planning the care transition from hospital to home. As such, the minimal participation found in our study might

be interpreted as influenced by the attitudes of the professionals in a health care system practice where participation is not properly established.^{17,33,38} However, like our findings indicate, Bynum et al²² found that some barriers to participation, such as lack of communication during medical decisions for older patients, can be modifiable, although this research needs further attention.

Because our findings varied from formal and informal participation to no participation, we suggest that professionals must take the initiative to invite and facilitate older patients' participation in the planning of care transition. More focus on older patient's values and right to self-determination are emphasized to minimize the identified deficits.

Managing continuity in care represents a complex and challenging process

All the older patients in this study had experiences with communication and information exchange. The findings show that some participants described being well informed while others were worried because of lack of understanding of the information. We interpret our findings as pointing out two important elements of the older patients' experiences during care transition. Without confirmation that the information has been communicated across the health care levels, older patients are left to trust that the home-care nurse is informed about their homecoming and is given enough detailed information to maintain the continuity of the hospital care. Similar to our findings, several studies report a lack of information continuity across health care levels, and lack of information exchange has proven to compromise patient safety.^{8,22,41-43} Communication skills, in terms of speaking directly to the patient, or "above the patients head", have been shown to affect participation negatively in discharge meetings.²⁵ As such, our findings might indicate that older patients experience a lack of control and feel unsafe when they are talked about but do not know what is being said.

Some of the older patients in our study explained that the written summary of their treatment and care was difficult to understand and they expressed uncertainty about its intentions. Two of the participants could not remember their diagnosis and did not understand why they were admitted to hospital. Previously, health care literacy, mild cognitive impairment, and not being given a thorough explanation in words that they can understand are identified as barriers to older patient's understanding of their own treatment and care during care transition.^{39,44,45}

Most of our participants stated that they could contact a health care provider if necessary, using several different

channels of communication. Knowledge of whom to contact if necessary has been described as an important part of older patient's satisfaction with quality of care.⁴⁶ As identified in our data, the lines of communication in the health care system are complex and difficult to navigate, involving older patients and their family, the general practitioner, and health care staff on both health care levels. Clearly, there is a need to establish a communicative relationship with older patients, allowing them to bring forth their questions and worries in a safe environment.

Our findings indicate that allocation of responsibility could be experienced in several ways. This might reflect a health care system often experienced as fragmented, with ambiguous areas of responsibility that fail to meet older people's expectations and needs. Like in our study, Altfeld et al⁴⁷ found that a majority of the informants reported altered and new needs emerging shortly after discharge, which might explain contribution to the older patients' experience of insecurity regarding responsibilities.

A different kind of responsibility is seen in the participants' expressions about their own efforts to regain health and be actively involved. These efforts were directed by their physical strength and their perceived abilities to face the challenges that they experienced. Such personal values and self-efficacy are shown to be important resources for older patients for maintaining responsibility for their own rehabilitation after discharge, but they seem to be overlooked.⁴⁸

The clarification of information and responsibilities is identified as different but important experiences in the transition from hospital to municipal health care. These aspects may also be seen as intertwined because insufficient information seems to limit the older patient's understanding and feelings of being properly taken care of. On the other hand, the notion of being taken care of is of less value if one does not possess the information of how to get in touch with the right health care worker when needed. These findings could also be seen as a partial explanation of why older patients participate to a limited extent in planning their care transition. Obviously, to secure continuity of care, the communicative relationship with older patients as well as between health care staff across health care levels must be improved. This in turn would lead to better information flow, and hopefully the voice and resources of the older patient will be more in focus.

Methodological considerations

The strength of our study is that 14 older people with various health problems provided extensive descriptions of the phenomena of the study. The sex imbalance in the present

study mirrors the sex distribution in the older population in Norway, where women tend to live longer than men.⁴⁹ Several steps were taken to ensure the credibility of the study. The interview guide was pretested by one older person who was not included in the study. Judgments were made about follow-up questions and when to end the data collection. Transparency was sought through distinct descriptions of the analytical steps and presentation of quotations. The similarities and differences in the content that surfaced during the interview process were discussed within the research team. Each author carried out the analyses independently, followed by a shared process to reach consensus. As such, our interpretation highlights the most probable meaning of care transitions from a particular perspective. We suggest that our findings may be transferable to other professionals or people in similar situations by considering the culture and context, as well as methods of data collection and analysis.

Implications for practice

The findings of this study suggest important implications for the formation of the patients' rights and opportunities for participation. Well in advance of their discharge from hospital, older patients should be invited to share their opinions and concerns about the care transition. To secure continuity of care, they should be given the necessary information to be able to participate in planning the care transition in accordance with their preferences. Moreover, throughout the hospital stay and the transition to municipal health care, older patients should be kept thoroughly informed about all the initiatives and communications made on their behalf. The professionals who are responsible during the transition should be referred to by name so that older patients receive legitimate confirmation of who is responsible for them and the continuity of their care. In addition, older patients should know whom to contact and who is responsible for their care. It is important to map the patients' prerequisites in order to tailor the care individually. Continuously mapping older patient's needs and preferences in the first weeks after discharge will enable the accommodation of challenges not foreseen before discharge from hospital. Our approach might also create a basis for improving care transition for cognitively impaired patients.

Conclusion

Our study identified various aspects of the care transition process, and our findings clearly indicate that it is a complex process with many challenges for, and requirements of, older patients, professionals, and the health care system. To secure

continuity of care, a specific focus should be directed toward older patient's participation in planning care transition, how communication and responsibilities can be organized to formulate better policies, and the development of better practice in serving older patients. Older patients are the vulnerable part in the transition process, and it is important to make their voices heard and equip professionals with the necessary insight to meet their needs best and secure continuity of care. Further research is needed to achieve more detailed knowledge about older patient's worries and preferences during this important period of their treatment and care to adhere to their new situation.

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Disclosure

The authors report no conflicts of interest in this work.

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Supplementary material I

Interview guide

Introduction

- How are you feeling today?

The patient's experiences of treatment and care

- Why were you admitted to hospital?
- Can you explain how you experienced being patient in the hospital?
- Can you describe in what way you participated in planning the transfer from hospital and home/to nursing home?
- How would you describe the process of being transferred from hospital to home/nursing home?
- How did you experience the first period of being at home/ in nursing home?

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Paper II

ORIGINAL ARTICLE

Next of kin's experiences of information and responsibility during their older relatives' care transitions from hospital to municipal health care

Else Cathrine Rustad, Berit Seiger Cronfalk, Bodil Furnes and Elin Dysvik

Aims and objectives. To gain an understanding of how next of kin experience the transition of their older relatives from hospital to municipal health care.

Background. During the care transition of their older relatives, next of kin experience a period of ill-defined roles and expectations. Successful transition lays the ground for postdischarge treatment and care, in which next of kin have important roles.

Design. A descriptive, exploratory design was used to gain a greater understanding of the experiences of next of kin during their older relatives' care transitions.

Methods. We conducted qualitative interviews of 13 next of kin of patients aged ≥ 80 years who had been discharged from the hospital to municipal care. Qualitative content analysis was used to analyse interviews.

Results. The main theme, 'Next of kin balance multiple tasks during older relatives' care transitions', emerged from two subthemes: 'Next of kin strive to fulfil informational needs during care transition' and 'Next of kin take responsibility for the older relative during care transition'.

Conclusions. Next of kin have the challenging role of letting their older relative manage self-care during transition, when able, while being prepared to act on behalf of their relative as needed. Insufficient information and significant responsibilities contribute to unnecessary concerns and worries among next of kin.

Relevance to clinical practice. Nurses in both hospitals and municipal health care will benefit from knowing more about the experiences of next of kin; this may ensure continuity of care during transitions and diminish unnecessary worries and concerns. Clinical nurses should be sensitive to the next of kin's need for support so the next of kin can better manage their older relatives' care after homecoming.

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

- Next of kin experience complex information streams and their efforts contribute largely to informational continuity.
- Next of kin take responsibility for safeguarding and thus protecting their older relative from discontinuity during care transition.
- To ensure continuity of care and support, nurses should facilitate clarity and consistency between the care that they provide and the roles of the next of kin.

Key words: care transition, continuity of care, next of kin, older patients

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Introduction

Successful care transition is described as the period planning discharge from hospital to the next healthcare level and forms the basis of well-functioning continuity of residential treatment and care (Coleman & Berenson 2004, Bauer *et al.* 2009). Older adults receive substantial assistance and support from both public health care and their next of kin during care transitions, which have been a recent research and policy focus (Gitlin & Wolff 2011, Toljamo *et al.* 2012, Giosa *et al.* 2014). Within health care, the next of kin is the individual designated by a patient as their most important caregiver (Hautsalo *et al.* 2013). Next of kin provide a different kind of care than do formal healthcare services; however, the interface between the two is diffuse (Hautsalo *et al.* 2013, Lowson *et al.* 2013).

As in many Western countries, the Norwegian government has launched extensive healthcare reforms (White Paper No. 47 2008 2009) with the intention of creating more continuous care transitions across healthcare levels and prevent further fragmentation of healthcare services (Romøren *et al.* 2011). The healthcare system in Norway is organised in two sectors: primary health care, run by the municipalities, is responsible for nursing homes, home care and general practitioners (GPs); and specialist health care and the hospital sector are run by the national health authorities (Romøren *et al.* 2011). However, recent evaluations of the current model indicate that discharge of seriously ill patients places additional demand on municipal institutional care, which may lead to even more care transitions (Grimsno 2015). As such, transition of older patients, some with severe health conditions, from hospital to municipal health care is a challenge for both formal healthcare services and the patient's next of kin (Hautsalo *et al.* 2013, Grimsno 2015).

Background

In a large, cross-national study investigating family norms in Europe, Daatland *et al.* (2011) identified that next of kin want to support and help their older relatives. Previous research has mainly identified discrete areas of challenge in care transition (Gitlin & Wolff 2011) such as next of kin report receiving inadequate information (Knight *et al.* 2011, Dossa *et al.* 2012, Hautsalo *et al.* 2013) and lack of influence during their older relatives' treatment and care (Bragstad *et al.* 2014). Consequently, there is a need to obtain a broader picture of the experiences among next of

kin during care transition to further facilitate their strengths and to accommodate their needs for support during this vulnerable time. Next of kin maintain a flexible continuity to ensure their older relatives' well-being across healthcare levels (Bridges *et al.* 2010, Lowson *et al.* 2013, Giosa *et al.* 2014). Moreover, they offer important support and assistance to their older relatives both during hospitalisation and after discharge (Bridges *et al.* 2010, McLennon *et al.* 2010, Knight *et al.* 2011).

In addition, next of kin are often expected to cooperate with healthcare professionals on different healthcare levels (Digby & Bloomer 2014). Olsen *et al.* (2013) argue that barriers to information exchange between nurses may negatively affect older patients' care transition. Poor collaboration among healthcare workers may lead to increased use of next of kin as information providers (Bökberg *et al.* 2014). However, this is in contrast to the finding by Plank *et al.* (2012) that next of kin need emotional support to cope with challenges during care transition. As such, there is a need for greater understanding about the informal contributions by next of kin to the transition of their older relatives across healthcare levels. This is needed to better support the next of kin with their needs and to create a more continuous collaboration between healthcare staff across healthcare levels.

Continuity of care is understood as the extent to which the patient experiences treatment and care that meet their perceived needs (Haggerty *et al.* 2003), where needs refers to both medical requirements and personal circumstances. Continuity of care can be divided into three areas: informational continuity, which links one healthcare event to another; management continuity, which is the extent to which services are delivered accurately and on time; and relational continuity, which addresses the extent to which the patient can expect to be cared for by staff that they know (Haggerty *et al.* 2003). Gulliford *et al.* (2006) indicate that the specialist and municipal healthcare sectors have different understandings of care continuity. Such conceptual differences may contribute to transitional care challenges.

Aim

Despite the contributions described above, to our knowledge few studies have focused on continuity of care experiences among next of kin during their older relatives' hospitalisations and care transitions. Our aim was to understand how next of kin experience the care transition of an older relative from hospital to municipal health care.

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Methods

We conducted a qualitative study with semi-structured, individual interviews. Exploratory design was chosen to capture the experiences of next of kin during their older relatives' transition from hospital to municipal health care.

Inclusion and participants

Next of kin of inpatients at a hospital in Norway were informed about the study and invited to participate. A registered nurse on each ward selected and recruited participants based on convenience and in accordance with the following inclusion criteria: adult next of kin, named by the older relative prior to hospital discharge; the older relative should be aged ≥80 years and discharged to municipal health care at home or in institution; have regular contact with the older relative; and speak and understand Norwegian.

A total of 13 next of kin participated, representing both genders and different relations to their older relatives, as well as possessing varied life situations: seven were daughters, four were sons, and two were wives of hospitalised older adults. Next of kin ranged in age from 47 to >80 years (see Table 1). Only the wives resided with the hospitalised patients after discharge.

Data collection

One to two weeks after discharge, the older patients' next of kin were contacted by phone to schedule an interview. The first author conducted all of the interviews, following a semi-structured guide to ensure that all topics were addressed. The interview questions were as follows: 'Can you please describe your experiences during hospital visit and discharge to home care/nursing home?' and 'Can you please describe your part during this process?' Interviews were largely directed by the next of kin's stories and follow-up questions were used, such as 'Can you tell me more about this experience?' and 'What does this mean to you?' The interviews were carried out at the participants' location of choice. One interview was conducted via phone, by the informant's choice, because the next of kin lived in a different part of the country. All participants agreed to have their interview recorded. The mean duration of the interviews was 48 minutes, ranging from 18 minutes until 82 minutes.

Data analysis

The data were transcribed verbatim. The analysis was explorative searching for latent content referred to 'what is

Table 1 Participants' (N = 13) background information

Patient	Relation	Age	Location	Occupation
P1	Daughter	55	Living in the same municipality	Employed full time
P2	Daughter	62	Living in the same municipality	Retired
P3	Daughter	*	Living in a foreign country	Homemaker
P4	Son	64	Living in the same municipality	Employed full time
P5	Wife	88	Living in the same municipality	Retired
P6	Son	58	Living in the same municipality	Employed full time
P7	Daughter	47	Living in the same municipality	Employed full time
P8	Daughter	63	Living in a neighbouring municipality	‡
P9	Wife	†	Living in the same house	Retired
P10	Son	62	Living in the same municipality	Employed full time
P11	Daughter	65	Living in the same municipality	Retired
P12	Son	60	Living on the opposite side of the country	Employed full time
P13	Daughter	62	Living in a neighbouring municipality	Homemaker

*Age unknown, estimated 55–60 years.

†Age unknown, estimated 80–85 years.

‡Occupation unknown.

the text talking about' (Graneheim & Lundman 2004, p. 111). Two of the authors initiated the analysis by carefully reading and discussing the transcribed interviews in chronological order to get a sense of their whole. Two broad content areas, understood as parts of the text dealing with the same issues (Graneheim & Lundman 2004), were found during the initial reading: experiences related to communication with health care and experiences related to helping the older relative. Based on these, meaning units were extracted from the text and condensed, with the intention of shortening the text while preserving its content. The condensed meaning units were then coded according to their content. Through a process of comparing the codes, sorting them based on similarities and periodically cross-comparing the transcripts and codes, they were divided into six tentative categories (Table 2). Based on their content, the categories were then abstracted into two subthemes and finally a main theme was formulated to capture the participants' overall experiences.

Table 2 Schematic of categories, subthemes and main theme, for next of kin's experiences during their older relatives' care transitions

Main theme	Next of kin balance multiple tasks during older relatives' care transition					
Subtheme	Next of kin strive to fulfil informational needs during care transition			Next of kin take responsibility for the older relative during care transition		
Category	Obtain information about how the healthcare system works	Receive information about medical treatment and care	Provide information to healthcare service and the older relative	Help to regain level of self-management	Share responsibility with family and health care	Try to accommodate to changes in own daily living

Ethical considerations

The participants were informed verbally and in writing about the study by a registered nurse at the ward that admitted their older relative; signed consent was administered before participants' contact information was given to the first author. All participants were assured full confidentiality and could withdraw from participation at any time. The Regional Committees for Medical and Health Research Ethics (Project number 2010/3342) and Norwegian Social Science Data Services approved the study.

Results

Next of kin described a multitude of experiences related to continuity during care transition of their older relatives. Our main theme, 'Next of kin balance multiple tasks during older relatives' care transitions', describes our participants' overall experience during this period. This main theme consists of two subthemes: 'Next of kin strive to fulfil informational needs during care transition' and 'Next of kin take responsibility for the older relative during care transition'. Each subtheme was derived from three categories presented in the following section (Table 2). Selected quotes are used to illustrate both diversities and similarities in participants' experiences.

Next of kin strive to fulfil informational needs during care transition

All next of kin described a variety of experiences regarding the continuity of information during care transition, and additional episodes when they received inadequate information. This subtheme was derived from three categories, with each describing a different area of information experience:

'Obtain information about how the healthcare system works', 'Receive information about medical treatment and care' and 'Provide information to healthcare service and the older relative'.

Obtain information about how the healthcare system works

Next of kin described the importance of knowing how the healthcare service works, and that they lacked this knowledge. Obtaining such information seemed difficult and they did not know where to turn. Their lack of knowledge was typically described in relation to the municipal healthcare system. Informal information sources such as friends and family who work in health care were considered important resources. Some next of kin requested additional information, including brochures about the healthcare system and available services. Understanding 'the system' was seen as crucial towards fulfilling tasks on behalf of their older relatives, as exemplified by the following quote:

P1: I have a very good acquaintance working within home care, and I have of course phoned her, simply because I know nothing about this. I don't know what dementia is or deterioration of old age, and I don't know what to do and where to start. So I had some concrete tips. And then it was said that those who scream loudest get what they ask for; that's how the system works.

Health care, and specifically municipal health care, was sometimes referred to as 'the system' and described by next of kin as something they are either inside or beyond. For example:

P 2: The mother of a friend of ours was in need of help, and they were in complete despair because it was so difficult. But like I said, 'you must get in the system first', because once you're in, then all the arrangements will be made for you.

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Receive information about medical treatment and care

Next of kin received information about their older relatives' treatment and care from the relative. Some found this adequate. Others, because of their relatives' health condition, found that the information they were given was incomplete:

P 7: It was difficult to find out a lot because the doctor talks to her but she does not always understand what he means because of medical terms and such, and then she is going to tell us, and then it is... So a few times I had to go out there and visit by myself and I tried to wait until the doctor came but it took so long that I had to leave. Because it would be nice to talk to the doctor myself... Understand things a bit differently than she does.

The participants explained that they were not in a clear-cut position to receive information about their older relatives' treatment and care during transition. They portrayed an unclear partition between healthcare services, ensuring that they were properly informed and having to find the information they felt they lacked. A few next of kin described how this led to adverse incidents:

P 7: When I was at the hospital to pick her up I didn't talk to anyone, they just said, 'yes, she is ready'. And she was handed a letter that she should give to the municipal home care. And when she came home she phoned them and was told that they would come and see her on Monday. So from Friday until Monday they didn't visit her, and I didn't think that I could open the letter. (...) And I didn't know anything about the wound, and neither did she. And they could have made changes on her medications as well. (...) I felt kind of insecure that weekend about what to do, what could happen and go wrong... was there... So I would have wanted more information when we left the hospital, yes. But if we had stopped by the municipal health care office on our way home and delivered this (letter from hospital), we would probably be given some more information... but we didn't because at that point she was so tired...

Provide information to healthcare services and the older relative

Next of kin provided information during care transition: to healthcare staff about their relatives' health conditions; to their older relatives about their treatment and care on behalf of the healthcare staff; and across levels of healthcare staff. A common experience and concern was how to get in contact with healthcare staff. During hospitalisation, next of kin could easily access the ward, but it was more difficult to access the nurse who was familiar with their older relative. After care transition, next of kin could talk to the home care nurse when he or she arrived but getting in touch with home care at other times was sometimes difficult, as one wife explained:

P 9: The contact with home care could perhaps be better. I don't know when... they are so many and some of them are out working and such... so there has to be a leader at the office I think. Why can't they just have a board where they can put messages and such so that everyone receives them during lunch break or something because then they're all gathered. (...) It is practically impossible to phone home care. And they're not there after a certain time, and if something happens in the evening for example... Then they just say, 'Phone the medical emergency'.

Conversely, some next of kin described how being close to the healthcare services made it easy to get in contact and to cooperate with healthcare staff if necessary. A few had more informal points of contact within health care. For example, sharing a GP with the older relative became a link to health care:

P 10: So I go to my GP, and then we talk about this and that, and he always asks about my dad. And that has made things easier, you know. So it is much easier for us to contact him if we feel that he needs to get something checked out. And I have made appointments for him and stuff. And I wouldn't have done all of this if I had a different GP, because you touch a private sphere. But it is a huge advantage, so it has worked very, very well for us.

Next of kin take responsibility for the older relative during care transition

The participants described a variety of responsibilities during care transition. These experiences were sorted into three categories: 'Help to restore level of activity and daily routines', 'Shared responsibility between family and health care' and 'Try to accommodate to changes in own daily living'.

Help to regain level of self-management

Next of kin described the importance of helping their older relative recover from the period of sickness and they put extra efforts in assisting the older relative to regain to prior level of self-management. Their motivational activities seemed to be a task they perceived as part of their duty during the transitional period. And after the care transition, next of kin had daily contact with their older relative so they could solve practical issues or just be available for help when needed:

P 1: Well, I have more frequent contact, and I have made a lot of arrangements by phone. I have consciously tried to hold back, not to take over too much at an early stage... Mother has been capable of doing her groceries and warming dinner if she has bought something, make some toast, and she has done some of the laundry herself. She has been going for a walk and... I have asked her control

questions, checking up on her and been thinking that I will not take over too much too early.

All participants stated their opinions about the best level of health care for their older relatives. This was understood as a balance between giving their older relative needed help with certain tasks, while compromising about levels of activity and daily routines so they could support their relatives' independence as long as possible:

P 13: I tried to (get home care to do the medications), but then the nurse from home care told her 'this you can easily take care of yourself. You have always done it so you can do it'. 'Yes' she said, and then... I don't know... but it seems like she can take care of it herself too, but not the first couple of days. Because she should take some Paracet (pain medication) when she felt in pain, and so the next day she phoned me because 'You know those Paracets, what is it good for?' she said. 'What will I do with them and when am I supposed to take them?'

Some incidents were depicted in which the next of kin found that their older relative did not receive needed health care immediately after the care transition, but by a few weeks after the care transition most reported that their older relative was being well cared and this was a positive and safe experience.

Shared responsibility between family and health care

All but one next of kin, who was an only child, shared responsibility for their older relative with other family members. Those who had siblings made family arrangements for sharing the tasks of caring for their older relative during care transition. The older relative was seen as being in charge of their own situation, but next of kin oversaw care so that everything worked well:

P 6: Sort of, she has the main responsibility herself, this little old lady, I think, and then her closest family has a responsibility to... we phone her... someone phones her every day, and we do her groceries, and she has come with us to do the shopping, but recently we have done her groceries once or twice a week and we take turns. And we make sure that she has enough food and house-keeping, this is private, for her, so we probably do feel a main responsibility for her welfare.

Sharing responsibilities with health care made next of kin feel secure and that they could relax. When their older relative was admitted to the hospital, they felt at ease trusting that their relative was well cared for. Only a few next of kin described making contact with municipal home care to discuss care arrangements when the situation warranted

changes. Those who had such contact with health care described it as positive:

P 2: If I have stopped by her in the evening and have had an impression that she is a bit messy or something... That I... not have been quite right... then I have phoned home care and asked if they could check on her during the night, just to make sure she is asleep or if she is totally off, you know... And they say 'yes, of course we will do that'. And that is so good, you know, instead of me, lying awake and thinking about it all night, wondering if I should drive over to her house to check on her. I do have a key, so it has happened that I have driven over there to see if she is asleep.

P 1: So homecare phoned me asking for an appointment for a home visit, I answered that I unfortunately was going on vacation the next week and I thought that it at least would take a couple of weeks to make the arrangements. But then they said 'how about this week?' 'This week?' (laughing), 'Yes, how about Thursday?' And I was really taken by surprise.

Try to accommodate to changes in own daily living

Hospital admission and consequent care transition of their older relative led to alterations to the next of kin's lives as well. All next of kin described how their responsibilities for their older relative had to fit in and balance with other responsibilities for children, grandchildren and other obligations. They often experienced these responsibilities as a heavy weight, as explained by one daughter:

P 1: Well, right now I think so much has happened in such a short period of time, that I have removed bricks from my sack, its been a relief. Just the last week. It's amazing. I think I am fairly down to earth saying that at the age of 86, anything might happen. We will be busier in the time to come. We are mentally prepared for that and we talk a lot about it. It limits our spare time; it limits our freedom in every way. But I will not quit my job, and I will not give up on my spare time activities or anything. I won't sacrifice that. She is well taken care of and has home care in the morning and evening, and dinner is delivered to her door.

The two wives who participated in our study each described how they had to balance their perceived responsibilities for their husband with what they thought they could manage, without having to compromise their own deteriorating health:

P 9: I recently had an operation and I was supposed to be admitted for rehabilitation afterwards, but I couldn't. I was offered to, but I couldn't be away for that long period of time. But... I need to take care of myself, as you well know. Go outside, move around and... I can't just be stuck here in the house. Because if I fall apart, then there is nothing! Then we will be admitted to hospital. Both of us! So that's quite important I think.

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P 5: So I just hope that everything will work out fine. And now when he comes home he might receive some help... a little perhaps, at least in the beginning. Then we will see how it goes.

The period of hospitalisation followed by care transition and municipal health care resulted in next of kin focusing a huge amount of attention on health-related issues and their changing roles:

P 6: I'm supposed to be her son, not health carer, and I should be her next of kin and sit down with her and have good conversations about this and that. Usually about grandchildren and great grandchildren, whom she is very interested in. She is very concerned about literature and a lot... so I think that the role comes with responsibilities, but we also have a responsibility as next of kin and as her closest family, and then the health care services will take its course.

Next of kin reflected on how this period of treatment and care made the inevitable end of life feel closer. This was especially a concern whether the hospitalisation and following transition to municipal health care was seen as a result of worsened health condition for the older relative:

P 2: It is sort of a grieving process as you see they become more and more helpless. You know... mama who used to be... You know...

P 12: Yes. I have never been so close to my dad as I have been during this phase... So we have talked about anything, from death and funeral and...

Based on these descriptions and experiences, the main theme 'Next of kin balance multiple tasks during older relatives' care transitions' emphasises next of kin's sensitive care for their older relatives in the manner they found most proper and balanced with the older relatives' capabilities. Next of kin aimed their efforts towards the older relative as well as both healthcare levels, which sometimes were challenging to keep up with.

Discussion

The aim of this study was to further understand next of kin's experiences with the transition of their older relatives from the hospital to municipal health care. The main theme 'Next of kin balance multiple tasks during older relatives' care transitions' was developed from two subthemes: 'Next of kin strive to fulfil informational needs during care transition' and 'Next of kin take responsibility for the older relative during care transition'. The following sections are organised based on these subthemes.

Next of kin strive to fulfil informational needs during care transition

Our analyses show that next of kin invest a large amount of time and effort in informational matters. They actively obtain, perceive and provide information during care transition of their older relative. However, their efforts varied in accordance with the older relatives' abilities to manage self-care. In Haggerty *et al.*'s (2003) review of continuity of care, informational continuity is described as linking the past and the present, towards patient-appropriate care. Most next of kin in our study seemed to lack informational continuity and in particular knowledge about how the municipal healthcare system works. Such informational discontinuity led them to frequently use informal sources to get answers to their questions. Similar findings have been described in previous research (Plank *et al.* 2012). Based on our findings, it seems reasonable to believe that some worries among next of kin could be avoided if they had sufficient information about the healthcare system. Another limitation was that next of kin seemed unfamiliar with online information and a few lacked Internet access. We argue that the responsibility rests with the municipalities to ensure that their citizens possess baseline knowledge about the healthcare system prior to acute health incidents. To improve the situation, nurses on both healthcare levels should map and supplement knowledge among next of kin to link and ensure continuity of information about care for their older relative.

It was a common perception among next of kin that capable older relatives should share information regarding their own treatment and care. However, this was challenging when they doubted their older relatives' understanding of the situation. Further, there seemed to be frustration about whether obtaining information should be the next of kin's initiative or if healthcare staff had an obligation to make contact. As such, our findings indicate how next of kin struggle to balance between the older relatives' autonomy, and their own need for information. Previous research has shown that next of kin who are uninformed are more frustrated, compared with those who are well informed (Condelius & Andersson 2015). In Norway, next of kin are entitled by law to healthcare information with the patient's consent (Norwegian Patient Rights' Act of 2 July 1999). In our study, next of kin's experiences of informational continuity during the care transition can be described as fractured. Similar discontinuity has been found in the informational transfer between nurses during care transition of patients (Olsen *et al.* 2013). As such, informational

discontinuity is a challenge on the system level. However, the initiative should lie with the healthcare professionals, and we recommend nurses take the initiative to develop clear agreements about information dissemination between each other, the older patient and the patient's next of kin. This may prevent adverse incidents and avoid next of kin feeling unsafe. As we see it, the obligation for informational continuity lies primarily with the nurses, on both healthcare levels, not with the patient or their next of kin.

Providing information to healthcare services on behalf of their older relative caused worry as some next of kin lacked knowledge about how to get in touch with healthcare staff for any reason. Haggerty *et al.* (2003) point out that an important aspect of relational continuity is the link to future care. According to our analyses, next of kin who had relations with the healthcare staff involved felt safe in the event of future needs arising. Moreover, they experienced concern about passing on information on behalf of healthcare staff, as they lacked sufficient medical skills. Similar to our findings, Bökberg *et al.* (2014) identified that next of kin are used as a resource between healthcare levels with low professional cooperation. This is also supported by studies identifying incomplete informational continuity across healthcare levels (Olsen *et al.* 2013).

Next of kin take responsibility for the older relative during care transition

Perceived responsibilities were of great concern for next of kin in our study. Their nuanced descriptions depicted different dimensions of responsibility, such as fulfilment of their older relatives' needs, sharing responsibility with others and adapting to their own changed roles.

Our study reveals next of kin's feelings of responsibility during care transition and how this required extra time and effort. However, despite the strains and additional tasks in their everyday living, taking care of their older relative seemed to be a wanted responsibility. This is supported by Toljamo *et al.* (2012) and Hansen *et al.* (2013) who argue how the Nordic healthcare services give next of kin a complementary role. Their main responsibility was motivating their older relative to regain prehospitalisation activities and encouraging their independence. This is an important indicator of admission into long-term care (Verbeek *et al.* 2015). In the present study, experiencing a lack of established health care after discharge made the next of kin expand their efforts and responsibility to accommodate the patient. This has been reported in previous studies (Plank *et al.* 2012, Bökberg *et al.* 2014). Despite that our findings not directly relate to management continuity, which refers

to chronological delivery of services (Haggerty *et al.* 2003), the results clearly indicate the importance of next of kin buffering the discontinuity in order to safeguard the patient. In addition, we emphasise how next of kin's familial understanding of their older relative stood in a sharp contrast to their lack of insight and knowledge about healthcare services. As such, this is closely connected to informational continuity, as lack of knowledge made it difficult to consider suitable healthcare services and create a smooth and continuous care transition for their older relative.

Responsibility during this period was perceived as comprehensive. In our study, next of kin usually shared responsibilities with other family members. In addition, the daily follow-up with the older relative was carried out by municipal health care. Interestingly, in spite of this, only a few next of kin described being in contact with healthcare nurses or discussing their joint care contributions. Those next of kin who had a cooperative relationship with health care saw this as positive, had fewer concerns and experienced their responsibility as more bearable. Conversely, previous research finds that lack of cooperation between next of kin and health care might contribute to an extended sense of responsibility (Plank *et al.* 2012) and may contribute to discontinuity of care. Based on our findings, we recommend involved nurses take the initiative to create an open and cooperative environment to improve continuity between formal and informal assistance.

In our study, next of kin expressed feeling responsible for helping their older relatives through the process of ageing. Their role shift and its effect on their relationship with their relative were considered an additional strain but one that came with a renewed understanding about ageing process challenges. Valuable moments of just being a son or a daughter were scattered through their experiences. As such, care transition was also a gentle reminder of responsibility and that the future could no longer be taken for granted. A few next of kin expressed loss and grief as they observed their spouse or parent going through disease and ageing. DeCaporale *et al.* (2013) discovered that active next of kin also experience grief prior to the loss of their older relative. Therefore, nurses should recognise grief among next of kin and sensitively map their needs and offer necessary support.

Obviously, next of kin balance multiple tasks during their older relatives' care transitions, including a multitude of chores they take on to ensure their relatives' continuous and smooth care transition. In addition, they balance acting on their relatives' behalf in some circumstances and withdrawing in others based on a sensitive assessment of their older relatives' capabilities to manage independently. The

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traditional understanding of care transition involves the timeline until the patient is received on the next healthcare level (Coleman & Berenson 2004). However, our participants described experiences from a period lasting until the older relative were well settled at home or in municipal institution. As such, our study might defend a broader conceptual understanding of care transition. Such an approach will profit positively to previous challenges found in research arguing that many patients experience unmet needs during the first period after care transition (Holland *et al.* 2011). The concept of continuity of care puts healthcare services in charge of delivering treatment and care in accordance with the patients' opinions of their own needs and circumstances (Gulliford *et al.* 2006). Professional care, delivered by nurses on both healthcare levels, and the personal understanding of next of kin seem to contribute to a more continuous care for the older patient in care transition.

Methodological considerations

Research should be evaluated by the procedures used to generate the findings (Graneheim & Lundman 2004); several steps have been taken herein to ensure trustworthiness. The strength of our study is that the participants represent different age groups and different relations to the older relative going through care transition. Various experiences contributed to a broad understanding of the next of kin's experiences during this period of treatment and care. Two interviews were conducted in the presence of the older relative, which may have reduced these participants' opportunities to address more complicated aspects of their relationship. However, the next of kin and their relative also supplemented each other's stories, resulting in tensions, agreements, sadness and laughter, which also contributed important insight into their common experiences.

According to Graneheim and Lundman (2004), an important aspect of latent content analysis is balancing between interpretations of the underlying meaning of the data. To ensure the interpretation process, all authors took an active part in the abstraction process and alternative interpretations were discussed until consensus was reached. One limitation might be the translation of the participants' statements from Norwegian to English. However, in cases of ambiguity the quotes were discussed by the authors to ensure that our English translation retained the original meaning. Our findings represent the most probable interpretation of next of kin's experiences during actual care transition. However, through detailed

descriptions of our analysis and inclusion of representative quotes, the presentation allows the reader to search for alternative interpretations. We submit that these study results may be transferable to comparable cultural and circumstantial settings and that these findings might be useful to both professionals and others in similar situations.

Conclusion

Our study describes experiences among next of kin during their older relatives' care transitions from hospital to municipal health care. These participants have the challenging role of letting their older relative manage their own care transition when capable, but being ready to act on behalf of their relative when necessary. Insufficient information and vast responsibilities lead to unnecessary concerns and worries. In addition, next of kin are in a vulnerable position, facing relational and generational changes that largely affect their own lives. To improve continuity of care, we encourage nurses on both healthcare levels to recognise and take into consideration the next of kin's complex and challenging positions and their valuable contributions during older patients care transition. Further research should focus on the interface between formal and informal health care, and initiatives to make positive changes should be tested.

Relevance to clinical practice

This study emphasises the importance of nurses having knowledge about next of kin's experiences during care transition. Perceiving next of kin's needs as both carers and care recipients, and identifying proper strategies for support are important for diminishing unnecessary worries and concerns. Safeguarding and supporting next of kin's needs might positively influence their abilities to support and care for their older relative after care transitions. We recommend that nurses on both healthcare levels work to create safe spaces for dialogue and cooperation with next of kin. Clarifying the interface between nurses' formal and next of kin's informal care, on the basis of older patients' ability for self-care, could lead to greater care continuity during transitions and improved experiences for patients and their next of kin.

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Contributions

Study design: ECR, BSC, BF, ED; data collection and analysis: ECR, BSC, BF, ED and manuscript preparation: ECR, BSC, BF, ED.

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Paper II

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Paper III



Continuity of Care during Care Transition: Nurses' Experiences and Challenges

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Abstract

The aim of this study was to gain increased knowledge about nurses' experiences of care transition of older patients from hospital to municipal health care, based on two research questions: How is nurses' experience continuity during care transition of older patients from hospital to municipal health care? How would nurses describe an optimal care transition? Nurses have a pivotal role during care transitions of older patients. More knowledge about their experiences is necessary to develop favorable improvements for this important period in the older patient's treatment and care. The study has a qualitative explorative design with follow-up focus group interviews. Nurses (N = 30) working in hospital (n = 16) and municipal (n = 14) health care were organized in five mixed focus groups during the period October-January 2014/2015. The focus groups met twice, answering the research questions following a previously circulated semi-structured interview guide. The interview analysis was inspired by content analysis. The analysis resulted in the themes "Administrative demands challenge terms for collaboration" and "Essentials for nursing determine optimal care transitions for older patients". Administrative demands may prevent nurses' professional dialogue and collaboration across health care levels. Older patients' best interests should be ensured through a collaborative relationship between hospital and municipal nurses, to form continuous care across health care levels. Clinical practice should be aware of essentials for nursing, which could influence and facilitate a more individualized and continuous transition for older patients.

Keywords

Care Transition, Municipal Health Care, Hospital Care, Continuity of Care, Focus Groups

1. Introduction

A successful care transition from hospital to municipal health care is understood as the coordination of multiple factors to ensure continuity of the patient's treatment and care [1]. Due to a fragmented health care system in western countries, several health care levels, with different areas of competence and financial systems, together provide for the older patients [2]. As such, improvement of care transitions has been a stated goal both politically and within health care research [3]. Comparable to many other countries, Norwegian authorities have implemented the Coordination Reform [4]. By using incentives to skew treatment and care to municipal level, responsibilities and demands for nurses involved in care transitions of older patients are consequently altered [5]. Both hospital and municipal nurses play a key role during this important period of treatment and care, and they also have first hand contact with the older patients and their next of kin [6] [7].

Background

Norway has organized health care services in a New Public Management model, with the intention of making health care more efficient [8]. In this model the patient requests health care services from municipal health care through a purchaser-provider model. Municipalities organized in such a manner have separated nursing care from making decisions about the level of health care service the older patient are assigned [8].

Continuity of care can be understood as the extent that the patient perceives health care as coherent, connected and consisted with their needs [9]. Continuity of care includes three concepts: continuity of information, continuity of relation between patient and provider, as well as continuity of management—which is particularly important with complex chronic illness [9]. Adding to the conceptual descriptions, Hellesø & Lorensen [10] suggest inter-organizational continuity of care, which addresses individual and organizational perspectives of continuity of care across health care levels.

In previous research, municipal nurses experience different professional challenges compared to hospital nurses [11]. Furthermore, municipal nurses experience low quality of discharge communication to be a major threat to patient safety [12]. As in other countries, and regulated by law, routines for discharging and receiving patients across health care levels are framed by cooperation agreements between hospital regions and associated municipalities [13]. Nevertheless, hospital nurses planning long-term care for the older patient often described it to be stressful when different stakeholders hold different values [14]. Obstacles such as patients' immediate needs and their limited preconditions to participate are found to explain nurses' low adherence to discharge routines [15]. In addition, multiple barriers are found to complicate nurses' continuity of information across health care levels (Olsen *et al.* 2013). Handover documents are often found incomplete regarding both medical and person-centered information about the patient [16] [17]. Electronic documentation systems are ex-

pected to accommodate some of the instrumental challenges of information exchange [18]. However, within nursing practice, the synergism of collaboration is described as a core element [19] [20] [21]. Nevertheless, differences of perspectives, organizational structures and cultures might be important obstacles for collaboration across health care levels [21]. As such, improved communication and understanding of the opposite health care level could possibly contribute to increased collaboration between nurses during care transition [11].

Based on these considerations, we need more knowledge about both hospital and municipal nurses' collaborations to ensure favorable working conditions and continuity of care for older patients across health care levels. The aim of this study was to gain increased knowledge about nurses' experiences of care transitions of older patients from hospital to municipal health care, based on two research questions: how do nurses experience continuity during the care transition of older patients from hospital to municipal health care? How would nurses' describe an optimal care transition?

2. Methodology

2.1. Study Design

An explorative qualitative design with focus group interviews was chosen because care transition involves nurses from hospital and municipal health care with different perspectives and experiences. Focus group interviews are a common method within health care research, and are particularly productive given their multiple benefits within pedagogy, politics and research [22]. It was anticipated that through discussion among participants representing similar and dissimilar health care levels, new knowledge could emerge to illuminate the aim of the study. In addition, exchange of perspectives and experiences could contribute to valuable insight for our participants. Due to the scope of the study, the focus groups were gathered in two meetings (Figure 1). According to Malterud [23], arranging multiple meetings of focus groups is an option to initiate a reflective process in the participants that can be elaborated and clarified. As such, the first research question was addressed in the first focus group meeting, while the second research question was addressed in the second focus group meeting (Figure 1). In addition, based on the second research question, the participants were given quotations from a previous study exploring the experiences of patients aged 80 years or older during care transition [7]. The quotations highlighted topics concerning experiences of participation and continuity in terms of communication and responsibility during care transition [7], and were intended to be evocative, contributing to the participants' opportunity for reflective preparation prior to the second focus group meeting.

2.2. Participants

As nurses often busily work schedules, and as the intention was to bring nurses from different health care levels together in the same focus groups, a convenient sample of nurses was recruited to the study, because they were available with re-

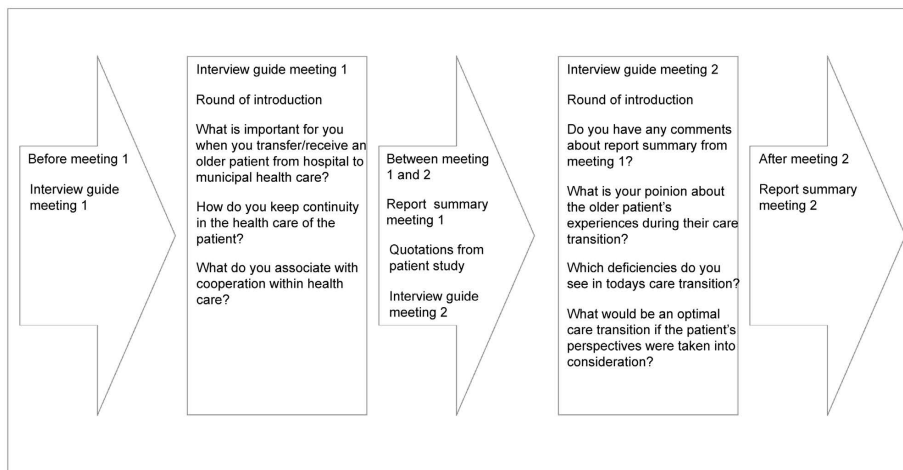


Figure 1. Schematic overview of focus group interviews, interview guides and participant confirmation, all documents sent participants by email.

gard to access, location, time and willingness. Nurses attending a postgraduate education at a local University College and nurses at a local hospital were informed about the study orally and in writing by the first author or by a Professional Development nurse staff at the hospital ward. Sample size was based on the focus group interviews information power as described by Malterud *et al.* [24] which indicates that the aim, sample specificity, theory, quality of dialogue and analysis strategy must be considered. The participants were divided into five focus groups, A-E, attempting equal distribution of nurses representing hospital and municipal health care in each focus group. Participants were contacted by email with the time and place of their first meeting. All participants were offered free lunch. A total of 30 nurses, 28 female and 2 male, participated in the study. All participants were attending a postgraduate education during the period of the focus group interviews. In addition, most of the participants had prior experiences as RN from other health care locations than the present. Background information is described in Table 1. From hospital care there were 16 nurses, representing 5 different hospitals, both larger university hospitals and smaller local hospitals nationwide. Municipal health care was represented by 14 nurses, from 9 different municipalities nationwide. The municipalities were of different sizes measured by number of citizens, and both towns and smaller villages were represented.

2.3. Data Collection

The focus group interviews were performed October/January, 2014/2015. All interviews were conducted at the University College of the participants' postgraduate education, during their lunch break or in the afternoon. The focus group

Table 1. Participants' (N = 30 RN) background information.

Focus group	Background information				
	Gender	Age (years)	Employment	Experience as RN (years)	Participation in focus group 1 and 2
A	Female	28	Municipal health care	a	1 and 2
	Female	29	Hospital	4	1 and 2
	Female	31	Municipal health care	3	1 and 2
	Female	28	Hospital	3	1 and 2
	Female	35	Municipal health care	10	1 and 2
B	Male	29	Hospital	a	1 and 2
	Female	23	Hospital	0,5	1 and 2
	Female	34	Municipal health care	11	1 and 2
	Female	26	Hospital	3	1 and 2
	Female	42	Hospital	9	1 and 2
	Female	27	Hospital	4	1 and 2
	Female	33	Municipal health care	11	1 and 2
	Female	29	Municipal health care	3	1 and 2
	Female	25	Hospital	2	1 and 2
	C	Female	50	Municipal health care	24
Female		44	Municipal health care	25	1
Female		25	Hospital	1	1 and 2
Female		48	Hospital	21	1 and 2
Female		36	Municipal health care	6	1 and 2
Female		25	Hospital	0,5	1 and 2
Female		34	Hospital	12	2
D	Female	25	Hospital	1	1 and 2
	Female	23	Hospital	1,5	1 and 2
	Female	46	Municipal health care	10	1 and 2
	Female	50	Municipal health care	26	1 and 2
E	Female	52	Municipal health care	10	1 and 2
	Female	53	Hospital	29	1
	Female	26	Hospital	1,5	1 and 2
	Male	43	Municipal health care	16	1
	Female	a	Hospital	a	1

a. Unknown; b. Was prevented from participating in 2. Meeting, sent answers to interview guide in writing.

interviews were carried out with one trained moderator and observer. The moderator led the focus group interview following a pre-tested interview guide covering the main topics. The interview questions are presented in Figure 1. The interview guide gave opportunity to follow issues that surface during the focus

group interviews. In the beginning of each focus group interview it was emphasized that all participants were given time to describe their experiences. The observer took notes and asked additional follow-up questions if necessary. The focus group interviews lasted from 45 m until 1 h 31 m, with a mean duration of 1 h 4 m. After each focus group interview the moderator and observer discussed the dialogues and group dynamics. Finally, the moderator wrote a report summary from the focus group interview, which was approved by the observer before being sent to participants for validation.

2.4. Ethical Considerations

All participants had to sign a written consent prior to the focus group interview. They were assured of full confidentiality and could withdraw from the study at any time. The Norwegian Social Science Data Service and The Regional Committees for Medical and Health Research Ethics (Project number 2010/3342) have approved the study.

2.5. Analysis and Interpretation

Data from focus group meeting 1 (A1-E1) and data from focus group meeting 2 (A2-E2) were analysed separately as they address different topics of the aim of the study. Based on Graneheim and Lundman's [25] approach to content analysis the study was aiming for interpretation of its latent content;

1. The focus group interviews were transcribed verbatim and read carefully several times to get a sense of their whole.
2. Meaning units were identified in the text.
3. The meaning units were condensed to shorten the text without reducing its content.
4. Condensed meaning units were coded in accordance with their content.
5. The codes were compared based on their differences and similarities and sorted in sub-categories and thereafter grouped in categories.
6. Categories were abstracted in two themes.

3. Results

The analysis resulted in two main themes and four categories. In the following, the results will be organized in categories and clarified in selected quotations to illuminate the analysis and bring forward the voice of the participants.

3.1. Administrative Demands Challenge Terms of Collaboration

Analysis of data from meeting 1 (A1-E1) resulted in the theme "Administrative demands challenge terms of collaboration", interpreted from two categories; "Care transition rests on extensive routines" and "Professional collaboration is prevented by external conditions" (Table 2).

3.1.1. Care Transition Rests on Extensive Routines

Hospital nurses discussed care transition as stressful when many factors were

Table 2. Theme, categories and sub-categories of “Administrative demands challenge terms for collaboration”.

Theme	Administrative demands challenge terms for collaboration			
categories	Care transition rests on extensive routines		Professional collaboration is prevented by external conditions	
sub-categories	Hospital nurses perform extensive preparations prior to care transition	The preliminary municipal care rests on hospital preparations	Misses the opportunity for professional dialogue by phone	Case manager experienced as intermediaries

considered during the final hours. Detailed agreements between hospital and municipal health care were followed, and the older patient’s needs had to be taken into consideration, all within a limited period of time. Municipal nurses explained that they depended on preparations by hospital nurses. They often struggled with problems not always foreseen by hospital nurses, for example providing medications during weekends. The focus groups gave the opportunity to discuss the range of hospital care:

- B1:
- (Hospital nurse) Usually, we end our care initiatives when the patient is discharged. And then you have the nursing summary for further follow up of the patient. But of course, I have special education in wounds, so sometimes I have sent along procedures from the Nursing Plan...or at least tried to...
 - (Municipal nurse)It is very good with that kind of... you know, if not we just receive a patient with a wound, and it is sometimes frustrating when you receive a wound grade two or three you know, and there is no information about it
 - (ECR) So what do you do then?
 - (Municipal nurse) Well, we have to make a procedure ourselves. And we have a lot of qualified personnel on wound care (...) so we are fortunate. But what might happen is that it is overlooked, and if they come home during the weekend and there are a lot of nursing assistants, there might not be a nurse with the patient at that point and the patient is laying with a wound where the bandage should have been changed two days ago and they might develop....

3.1.2. Professional Collaboration Is Prevented by External Conditions

The participants unanimously missed using the telephone to talk to the nurse on the opposite health care level. Passing on information electronically was positive, improving the older patients’ safety during care transition. Professional collaboration was understood to offer training if needed in the municipalities, often by inviting municipal nurses in to the hospital, which was easily done by telephone. In addition, verbal dialogue was sometimes necessary to make sure all concerns were understood and to exchange information that fell out of the electronic documentation system.

C1:

- (Hospital nurse) (...) Sometimes we make a phone call to homecare if it is something very... or they are sick and there are things that they should pay extra attention to. And often this is due to next of kin feeling unsafe, that they find it scary and frightening or they feeling insecure, they don't feel safe and need additional information and that... well, that is the kind of thing that we discuss by phone instead of document in the sense of, for example, that the next of kin have said that they are not happy about the patient going home, for example.

In those care transitions where it was seen necessary to have a dialogue with the nurses on the opposite health care level, the participants usually had to communicate with the case manager. However, this was perceived to be insufficient due to their differences of perspectives. The case manager was described as having an administrative perspective, estimating older patients' right to assistance, and as not assessing older patients' needs from a nursing perspective.

A1:

- (Hospital nurse) But like us we have patients being admitted... and it is home care that knows and is familiar with the patient that they take care of on a daily basis. They talk to a case manager who maybe reads from the computer... perhaps a report... then it would help to call the nurse directly and talk... because that intermediary it is kind of...
- (Municipal nurse) We notice that a lot at the nursing home. When we receive the written documentation, after they have made the decision about the patient being admitted or having home care, the assessments are not correct in comparison with the patient when she arrives.

The theme "Administrative demands change terms for collaboration" was interpreted from the described categories. Care transition was experienced as a complex procedure in which nurses should fulfill extensive administrative duties. However, routines were framed by administrative agreements between health care levels, which sometimes limited the opportunities for professional exchanges and dialogue.

3.2. Essentials for Nursing Determines Optimal Care Transitions for Older Patients

Analysis of data from meeting 2 (A2-E2) resulted in the theme "Essentials for nursing determine optimal care transitions for older patients", interpreted from two categories; "Collaboration to identify older patients' best interest" and "Important elements for nursing practice" (Table 3).

3.2.1. Collaboration to Identify Older Patients' Best Interest

Findings indicate the older patient should be more involved during planning of the care transition. Often the nurses, along with next of kin, had suggestions for care that were presented to the older patient. The findings suggested that patient participation increased when documentation systems explicitly requested patients' opinions about their treatment and care. Agreeing about patients' needs for treatment and care after care transition was described as a difficult and ex-

Table 3. Theme, categories and sub-categories of “Essentials for nursing determines optimal care transitions for older patients”.

Theme	Essentials for nursing determines optimal care transitions for older patients					
categories	Collaboration to identify older patients best interest			Important elements for nursing practice		
sub-categories	Patient participation prior to care transition	Professionals have different perceptions of patients needs	Professional agreement about long term goals	Predictability for involved nurses and patients	Written documentation available for all involved	Municipal nurses flexibility and competence

tensive process. Hospital nurses often found the patient’s health status too poor for home care, while municipal nurses argued that patient’s health most often improved in his or her own home.

D2:

- (Hospital nurse) But then I feel at the hospital that sometimes someone gets really poor health when they are in our ward and then, all they need is to be sent home and they function very well. But then it is difficult to know “is home care enough or do they need something more or what do they really need?” (...)
- (ECR) It is complex to consider the patients’ real needs for assistance?
- (Municipal nurse) But it is very important to be open to...when the patient comes home that we come and visit and be a bit generous in the beginning, nor reduce the level of assistance afterwards.
- (Municipal nurse) We need to reassure the patient when he comes out (of hospital)...we are maybe told by the hospital that needs are the same as previously and so on but we need to discuss the things around technical utilities and make sure that they really do manage. But usually they are always better than we think they are.

Nurses across health care levels should share long-term goals for the older patient. All involved professionals should take part in creating the long-term goals, along with the older patient and their next of kin. As such, care transition should be done through shared professional planning:

A2:

- (Municipal nurse) I have been thinking about...I work at a nursing home and we see patients being admitted and coming back, and we do have sort of plans for the continuing treatment and care. We are not always updated on what has come forward in hospital, but have a more long-term and health-promoted plan for the patients who need it...who have chronic illnesses and are being cared for by different health personnel. It is in use but it is not the kind of...if one thinks of the good coordination in a good plan. It can be quite heavy and...
- (Nurse) We lack a shared goal.
- (Municipal nurse) Yes! The goal that is set by the patient and that we all are going to work towards. And why isn’t it like that? You know, it would have been...I have often thought that it would be ok if we had sort of a template

for... Now almost everybody has a care plan but still. It is missing so much.

3.2.2. Important Elements for Nursing Practice

Short notice of patient care transition was frustrating. Older patients weren't given time to digest their situation, and nurses had to fulfill the care transition within a short period of time. Predictability would give all involved parties time to prepare properly, in addition to bringing a feeling of safety and control to the older patients.

A2:

- (Hospital nurse) It would have been a bit better if we knew, perhaps one day in advance, when the patient will be offered care assistance, or where he is going to be transferred to, rather than one hour before we are off duty. I thought last time that we probably should phone them to let them know, but I don't have the time...or to tell them about the patient. But in other municipalities where they might know that the patient has been given a place in a nursing home several days in advance, then I have scheduled the time, during the day, to phone and update the place about his condition. That is absolutely the optimal way.
- (Municipal nurse) The most optimal for us...often when the case manager has...sometimes there are a lot of things that are not right, so it is not until we receive the PLO (Electronic documentation), and the medical summary and the nursing report are sent prior to the arrival of the patient, that we have the opportunity to check if we have the correct medications and equipment...do we need extra, e.g. oxygen, do we need to find a thermometer to hang on the wall, be more prepared. If not, we are suddenly taken by surprise, the decision office hasn't been aware that the patient needs oxygen, you know, and then we have to run to find it because the ambulance is waiting, and this should have been prepared a long time in advance. Because then you would have more direct contact between the nursing home and the hospital. If we do get the report in advance, we can make a phone call and ask "what do you mean by what is written?" Instead the patient arrives at ours at four o'clock, and then at eight o'clock we still haven't made his pill organizer, and then we have to call, and new staff are on duty, and there we are, going in circles.
- (Several participants) And you feel like a fool. You do not feel like a professional.

Written electronic documentation was important for patient safety. All those involved should have access to all documentation and preferably use the same data program. In addition, all documentation should be available prior to patient's care transition. There were extensive variations in municipalities' preconditions for treatment and care. Flexibility, where the nurse on site could decide the level of care needed in dialogue with the older patient was described as optimal. Municipal nurses needed to possess the necessary competence to receive complex and severely sick older patients.

4. Discussion

The analysis resulted in two themes, “Administrative demands change terms for collaboration” and “Essentials for nursing determine optimal care transitions for older patients”, which will structure the following section.

4.1. Administrative Demands Challenge Terms for Collaboration

Our findings indicate that nurses experienced care transition demanding, having to fulfill extensive administrative duties in addition to taking care of the needs of older patients and next of kin. Planning and completing care transition is regarded as a nursing responsibility [20]. It seems that a substantial part of preparations for care transition are done during the final working hours, which might result in a work overload for the responsible nurses. Prior findings indicate that nurses prioritize between several important responsibilities during preparations for care transition, which might result in reduced compliance with discharge routines [15]. Our nurses described cooperation agreements between hospital and municipal health care as giving a clear regulation of responsibilities of each health care levels. However, they directed their attention to administrative tasks, often on behalf of the older patients’ needs. The municipal nurses described receiving the patient in accordance with the cooperation agreements. Nursing-specific objectives such as providing medications for weekends and afternoons were often not fulfilled. Norwegian hospital regions and their associated municipalities are required by law to develop cooperation agreements, to provide a concrete division of duties and responsibilities between hospital and municipal health care [5] [26]. This agreement is similar to those in other Scandinavian countries [13]. As such, we argue that the organizational structures during care transitions appear to be insufficiently appropriate to nurses’ working agenda.

Another finding was that nurses’ initiatives for collaborative dialogue were often directed through case managers. This was experienced to be inadequate given their differences of perspectives. The initial purpose of a New Public Management organization of municipal care, was to divide the contractor role within municipal health care service from that of the provider of health care [8]. It appears that attempting to direct nurses’ to intra-professional collaborations through liaising with the contractor is a challenging use of organizational structures. Previous research has often targeted communication and informational structures on an organizational level [27]. However, nurses have a long tradition of verbal reports, establishing common ground and continuity of care through two-way informational exchange [27] [28]. Recent research has focused largely on improvement of informational continuity across health care levels [16]. However, our findings clearly indicate the necessity of safeguarding essential features of nurses’ collaboration, ensuring proper channels for alliance and dialogue in care transitions when needed.

Inter-organizational continuity of care consists of two perspectives: individual continuity of care in terms of provider-to-provider, and organizational continu-

ity of care understood as structural coordination of care [10]. Similarly, our findings show how different perspectives of continuity of care contradict each other. Demands on an organizational level seem to be given priority at the expense of other nursing-specific tasks, possibly due to financial incentives adding weight to the priority of duties. Summing up, we suggest establishing organizational structures across the health care levels that facilitate nurses' collaboration, in order to improve continuity of care.

4.2. Essentials for Nursing Determine Optimal Care Transition for Older Patients

Hospital and municipal nurses in our study discussed patient participation in the process of planning the destination for the care transition. Patient participation is a formalized value that permeates all levels of health care [29]. Even so, patient participation is still found to be complex and insufficient [7] [30]. Some of our participants described it as a paradox that older patients' opinions about their treatment and care were not a fully formalized rubric in the electronic documentation system, which could be a way to optimize patient participation. Compared to the municipal nurses, the hospital nurses often had an impression of the older patient as frailer. The discussions underline the differences of perspectives and opinions of care in hospital and municipal health care. Exchange of views and opinions provided additional insight, which is also found in previous studies [21] [11] [31]. Our nurses suggested that to create long-term goals for patient treatment and care could optimize patients' experience of continuity, including in any subsequent admissions. The goals should stem from the older patient's motivation and perception of her own situation in combination with the professional assessment by hospital and municipal nurses. This perspective is in line with Haggerty *et al.* [9], who emphasises continuity of care where the patient's perceives whether care is experienced as continuous. We argue that a long-term aim could optimize and improve patient participation as well as lead to a joint effort in tailoring the care to older patients needs across health care levels.

In our focus groups, essentials for nursing were discussed as important for an optimal care transition. Following a timeline where all involved nurses, as well as the older patient, were prepared well in advance of the care transition was highlighted. A care transition that was not properly prepared seemed to compromise involved nurses' professionalism, and led to a poor start of the older patients' long-term municipal health care. Temporal aspects have previously been identified as influencing the quality of discharge of older patients [32].

There was agreement in the focus groups about the role of electronic documentation systems in safeguarding and improving care transitions, in line with previous studies [18]. Hospitals and municipals should optimally use the same documentation systems, and the information should be available for all involved well in advance of the care transition. Some of our nurses indicated that medical information from the medical doctor was often delayed until after the municipal

nurses received the patient. In addition, there was no consensus in the focus groups about whether the electronic documentation should be supplemented with written documentations. There seem to exist parallel-varied routines, with different assumptions and practices in different municipalities. This might be explained by the historical evolution of municipal health care [8]. The approach should be standardized and not left to each individual nurse to anticipate what to do. There was a need for verbal dialogue if there was particularly sensitive information or exchange of competence. This was discussed as an important supplementary to the electronic documentation. The professional benefits of verbal dialogue are also found in previous research [33]. We argue that care transition does not just involve the passing of the patient from one point to another. Based on our findings it should, optimally, comprise the creation of a professional environment covering eventualities in the patients' treatment and care that might surface during and immediate after the care transition. In addition, through the focus groups it became clear that there are no communication channels known by the nurses where care transitions in themselves can be discussed and evaluated. We suggest that to ensure further continuity of treatment and care across health care levels there should be regular evaluation on a provider-to-provider level, in addition to the organizational level.

4.3. Recommendations for Clinical Practice

Clinical practice should be aware that a continuous care transition is influenced on an organizational level as well as a provider level. Clinicians are recommended to take into consideration the described essentials for nursing which could contribute to a more optimal care transition from both a nursing perspective as well as for older patients. Hospital and municipal nurses along with the older patient should create shared long-term goals for treatment and care during care transition. Important elements for nursing were experienced as influencing the possibilities of facilitating an optimal care transition. Cooperation agreements are suggested to clarify hospital and municipal health care responsibilities, but be flexible enough to facilitate nurses' professional judgements during care transitions. We recommend that hospital and municipal nurses should have open communication channel for discussing and evaluating care transitions.

4.4. Methodological Considerations

The group distribution ensured that participants representing the same municipality or hospital participated in the same groups, which increased the possibility of having some acquaintances with whom they were familiar. In addition, participants' different backgrounds contributed to depth and variation in their contributions. One limitation was that fewer male nurses participated in the study. However, that might reflect the gender distributions of nurses in Norway. In addition, the groups had approximately equal representatives from hospital and municipal health care, to facilitate a positive group dynamic. A balance between homogeneity and heterogeneity of the focus groups can reveal the diversity of

experiences of participations [23]. Another possible limitation of the study might be the introduction of patient quotations as evocative material, which negotiates between steering and outlining the group dialogues [23]. All participants expressed recognition of older patients' experiences and built on this further with their own complementary reflections, and some participants brought hand-written notes of reflections to meeting 2. As such, the patient quotations seemed to give the participants room for elaboration of the topics they found most important. In addition, arranging two meetings of each focus group gave an opportunity to address different features of care transition and follow up the discussions further, leading to a vast data material illuminating the aim. The analysis was done separately by the authors and discussed within the research team. Detailed descriptions of analysis and presentation of quotations seeks to ensure transparency. As we see it, these considerations might strengthen information power as an important aspect of internal validity [24]. Taking into consideration culture and context in an international perspective, as well as described methodological and analytical concerns, our findings might be transferable to similar situations.

5. Conclusion

Our study explores hospital and municipal nurses' experiences of continuity during care transition of older patients. Administrative demands sometimes limited the nurses' opportunities for establishing collaborative alliance and dialogue across health care levels. Care transitions should be continuous in accordance with the patients' best interests, provided through a collaborative relationship involving nurses from both health care levels. Essentials for nurses' practice should be taken into consideration when establishing administrative routines for care transition, in order to ensure collaboration across health care levels and provide continuous treatment and care for the older patient. When making improvements to care transitions, all dimensions of continuity of care should be taken into considerations.

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Appendices

Appendices

Appendix 1 – Interview guide next of kin

29.08.11 ECR

INTERVJUGUIDE PÅRØRENDE

Hensikten med intervjuet er og få mer kunnskap om hvordan pårørende erfarer overføring av deres eldre slektning fra sykehus til kommunal omsorgstjeneste.

INTRODUKSJON

Vi skal nå prate om hvordan du har erfart de siste uker hvor din mor/far/ektefelle mm har vært syk. Kan du fortelle hva som har skjedd de siste ukene?

PÅRØRENDE SIN OPPLEVELSE AV INNFLYTELSE/ DELAKTIGHET I PASIENTENS PLEIEFORLØP

- Kan du fortelle hvilken funksjon/ rolle du har hatt overfor din mor/far etter at vedkommende ble syk?
- Kan du beskrive på hvilken måte du har vært delaktig i planleggingen av hva som skulle skje når din mor/far skulle utskrives fra sykehus?

PÅRØRENDE SIN OPPLEVELSE AV DEN PLEIE OG BEHANDLING PASIENTEN HAR FÅTT PÅ SYKEHUS OG VED KOMMUNAL OMSORGSTJENESTE

- Hvordan vil du beskrive den pleie og behandling som din mor/far har fått ved sykehuset
- Hvordan vil du beskrive den pleie og behandling som din mor/far har fått ved sykehjem/kommunal omsorgstjeneste
- Har du vært enig/ uenig i den pleie/behandling som din mor/far har fått i denne perioden?

PÅRØRENDE SIN BESKRIVELSE AV EGEN FUNKSJON

- Hvilken funksjon har du hatt overfor din mor/far i perioden fra innleggelse i sykehus til overføring til hjem/sykehjem?
- Hvordan har din mor/far sin sykdom, pleie og behandling påvirket deg?

AVSLUTNING/ OPPSUMMERING

- Nå når din mor/far er overført til sykehjem/ hjem, hvordan ser du for deg din funksjon på veien videre?

Appendices

Appendix 2 – Patient quotations and demographic information nurses

PASIENTUTSAGN

Brukermedvirkning:

"In the hospital I was asked if I wanted to be transferred to the nursing home but I didn't believe that it was necessary"

"I wasn't asked if I wanted to be discharged home to my apartment when I was at the hospital. I believe it was my daughters who applied for nursing home"

"I don't remember that I was asked directly about what I wanted, but they didn't do anything against my will"

Erfaringer fra overføringsprosessen:

Kommunikasjon:

"At the same time as we came home, we called the nurse from home care who took the papers I was given at the hospital. They had called from hospital as well, but I don't know what they said"

"Someone gave me a piece of paper and, I suppose, no ... I guess I should just keep it. I don't think I should even deliver it"

Ansvar:

"There is a nurse from home care saying that she is my primary contact. I didn't catch her name, but that doesn't matter. Then, I at least know that someone is responsible for me."

"I started to use a walking stick today, and I stopped using the walker. I will start to exercise. You know, I got tired really fast, but I can't give up"

Appendices

Demografiske opplysninger

Alle personidentifiserbare opplysninger vil slettes i etterkant av studien. Opplysningene samles inn for å vise hvor mange kommuner og sykehus som er representert i studien samt deltakernes alder og yrkeserfaring.

..... Kvinne

..... Mann

Årstall født:.....

Utdanning:.....

Antall år yrkeserfaring:

Nåværende arbeidsplass:.....

Har du tidligere yrkeserfaring fra andre helsetjenestenivå enn der hvor du er ansatt per i dag?

.....

Appendix 3 – Ethical approval



UNIVERSITETET I OSLO
DET MEDISINSKE FAKULTET

Høgskolelektor Else Cathrine Rustad
Høgskolen Stord/Haugesund
Bjørnsonsgate 45
5528 Haugesund

**Regional komité for medisinsk og helsefaglig
forskningsetikk Sør-Øst C (REK Sør-Øst C)**
Postboks 1130 Blindern
NO-0318 Oslo

Telefon: 22 84 46 67

Dato: 18.02.2011
Deres ref.:
Vår ref.:2010/3342 (oppgis ved henvendelse)

E-post: post@helseforskning.etikkom.no
Nettadresse: <http://helseforskning.etikkom.no>

Eldre pasienter, pårørende og sykepleieres erfaringer med overføring mellom ulike helsetjenestenivåer. En studie om samhandling

Vi viser til søknad mottatt til frist 14.12.2010 om forhåndsgodkjenning av ovennevnte forskningsprosjekt. Søknaden er blitt vurdert av Regional komité for medisinsk og helsefaglig forskningsetikk i henhold til lov av 20. juni 2008 nr. 44, om medisinsk og helsefaglig forskning (helseforskningsloven) kapittel 3, med tilhørende forskrift om organisering av medisinsk og helsefaglig forskning av 1. juli 2009 nr 0955.

Prosjektleder: Else Cathrine Rustad
Forskningsansvarlig: Universitetet i Stavanger

Internasjonalt har forskning rettet et kritisk blikk på helsetjenestetilbudet til eldre pasienter, hvor flere helsetjenesteytere, med ulike finansieringsystem, ulikt kompetansebelegg og til dels mangelfull samhandling sammen skal gi et helhetlig pleie- og behandlingstilbud til den eldre pasientgruppen. Særlig oppleves overføring mellom ulike helsetjenestenivåer som stress og belastning for pasienten, på grunn av manglende kontinuitet i helsetjenestene. Samtidig viser forskning at også pårørende til eldre pasienter har en sentral rolle gjennom og pleie og støtte den eldre. Få norske undersøkelser kartlegger eldre pasienters erfaringer og behov for samhandelnde helsetjenester. Den overordnede hensikten med studien er derved og få økt kunnskap om hvordan den eldre pasient, deres pårørende og sykepleiere ved spesialist og kommunal omsorgstjeneste opplever overføringen fra pleie og behandling på sykehus til kommunale omsorgstjenester i hjemmet eller ved kommunal institusjon.

Forskningsetisk vurdering

REK sitt mandat og helseforskningslovens saklige virkeområde er medisinsk og helsefaglig forskning på mennesker, humant biologisk materiale eller helseopplysninger. Formålet med forskningen må være å skaffe til veie ny kunnskap om helse og sykdom.

Komiteen uttrykker tvil om pasienters, deres pårørende og sykepleiere ved i spesial- og kommunalhelsetjenesten sin erfaringsbaserte kunnskap om opplevelser knyttet til overføringer fra ulike tjenestelinjer i helsesektoren skaffer til veie ny kunnskap om helse og sykdom. Det opplyses videre at data vil være selvformidlende erfaringer som ikke vil påvirke det enkelte pasientforløp eller behandling.

Fenomenet det skal forskes på er hvordan samhandlingstjenestene innenfor helsesektoren fungerer for en gruppe pasienter. Forskningsprosjektet må etter komiteens syn ses i sammenheng med *Samhandlingsreformen* og hvor formålet er å undersøke hvordan organiseringen av helsetjenesten oppleves. På den annen side vil et skifte mellom tjenestenivåer etter komiteens syn representere en

potensiell fare for svikt i omsorg for den enkelte. Spesielt hvis beslutninger er blitt tatt på feilaktig eller sviktende grunnlag. Sett i denne sammenheng kan forskningsprosjektets overordnede hensikt mer relateres til enkeltpersoner enn forskning på systemnivå.

Komiteen er av den oppfatning at å dra lærdom av fremgangsmåten som er benyttet når pasienter eller brukere har fått helsehjelp og assistanse på det beste effektive omsorgsnivå, eller avdekke eventuell feilsått plassering, vil kunne generere ny kunnskap om helse og sykdom.

Deltakelse i prosjektet er basert på et informert, skriftlig samtykke.

Komiteen har ingen forskningsetiske innvendinger mot at prosjektet gjennomføres.

Vedtak

Prosjektet godkjennes.

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.

Tillatelsen gjelder til 31.12.2014. Av dokumentasjonshensyn skal opplysningene likevel bevares inntil 31.12.2019. Opplysningene skal lagres avidentifisert, dvs. atskilt i en nøkkel- og en opplysningsfil. Opplysningene skal deretter slettes eller anonymiseres, senest innen et halvt år fra denne dato.

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

Komiteens avgjørelse var enstemmig.

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

http://www.helsedirektoratet.no/samspill/informasjonssikkerhet/norm_for_informasjonssikkerhet_i_helsesektoren_232354

Komiteens vedtak kan påklages til Den nasjonale forskningsetiske komité for medisin og helsefag, jf. Forvaltningslovens § 28 flg. Eventuell klage sendes til REK Sør-Øst. Klagefristen er tre uker fra mottak av dette brevet.

Med vennlig hilsen

Arvid Heiberg (sign.)
professor dr. med.
leder


Øyvind Grønlie Olsen
jurist/ rådgiver

Appendices

UNIVERSITETET I OSLO
Det medisinske fakultet

Side 3 av 3

Kopi: Universitetet i Stavanger v/ universitetsdirektøren, 4036 Stavanger

Vi ber om at alle henvendelser sendes inn via vår saksportal:
<http://helseforskning.etikkom.no> eller på e-post til: post@helseforskning.etikkom.no. Vennligst
oppgi vårt saksnummer/referansenummer i korrespondansen

Appendices



Region: REK sør-øst	Saksbehandler: Tor Even Svanes	Telefon: 22845521	Vår dato: 03.10.2012	Vår referanse: 2010/3342
			Deres dato: 05.09.2012	Deres referanse:

Vår referanse må oppgis ved alle henvendelser

Else Cathrine Rustad
Høgskolen Stod/Haugesund
Bjørnsonsgate 45
5528 Haugesund

2010/3342 Eldre pasienter, pårørende og sykepleieres erfaringer med overføring mellom ulike helsetjenestenivåer. En studie om samhandling

Forskningsansvarlig: Universitetet i Stavanger
Prosjektleder: Else Cathrine Rustad

Vi viser til søknad om prosjektendring datert 05.09.2012 for ovennevnte forskningsprosjekt. Søknaden er behandlet av leder for REK sør-øst på fullmakt, med hjemmel i helseforskningsloven § 11.

Endringen består i en forlengelse av prosjektperiode, som et resultat av svangerskapspermisjon. Endringen består videre i at man vil videreføre resultater fra studiens del A over i studiens del B. Kvantitative spørreskjema utgår fra prosjektet.

Del B omfatter fokusgruppeintervjuer med sykepleiere fra kommunal- og spesialisthelsetjeneste, samt dokumentanalyse av overføringsdokumentasjon samlet inn i del A.

Vedtak
Prosjektendringssøknaden godkjennes.

Tillatelsen er gitt under forutsetning av at prosjektendringen gjennomføres slik det er beskrevet i prosjektendringssøknaden og endringsprotokoll, og de bestemmelser som følger av helseforskningsloven med forskrifter.

Tillatelsen gjelder til 31.12.2015. Av dokumentasjons- og oppfølgingshensyn skal opplysningene likevel bevares inntil 31.12.2020. Opplysningene skal lagres avidentifisert, dvs. atskilt i en nøkkel- og en opplysningsfil. Opplysningene skal deretter slettes eller anonymiseres, senest innen et halvt år fra denne dato.

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

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

Klageadgang
Du kan klage på komiteens vedtak, jf. forvaltningslovens § 28 flg. Klagen sendes til REK sør-øst.

Besøksadresse:
Nydalens allé 37 B, 0484
Oslo

Telefon: 22845511
E-post: post@helseforskning.etikkom.no
Web: <http://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 members

Appendices

Klagefristen er tre uker fra du mottar dette brevet. Dersom vedtaket opprettholdes av REK sør-øst, sendes klagen videre til Den nasjonale forskningsetiske komité for medisin og helsefag for endelig vurdering.

Med vennlig hilsen

Arvid Heiberg
prof. dr.med
leder REK sør-øst C

Tor Even Svanes
seniorrådgiver

Kopi til: *Universitetet i Stavanger* v/ Elin Dysvik: elin.dysvik@uis.no

Appendices



Region:	Saksbehandler:	Telefon:	Vår dato:	Vår referanse:
REK sør-øst	Tor Even Svanes	22845521	27.11.2015	2010/3342/REK sør-øst C
			Deres dato:	Deres referanse:
			12.11.2015	

Vår referanse må oppgis ved alle henvendelser

Else Cathrine Rustad
Høgskolen Stord/Haugesund
5528 Haugesund

2010/3342 Eldre pasienter, pårørende og sykepleieres erfaringer med overføring mellom ulike helsetjenestenivåer. En studie om samhandling

Forskningsansvarlig: Universitetet i Stavanger
Prosjektleder: Else Cathrine Rustad

Vi viser til søknad om prosjektendring datert 12.11.2015 for ovennevnte forskningsprosjekt. Søknaden er behandlet av sekretariatet i REK sør-øst på delegert fullmakt fra REK sør-øst C, med hjemmel i helseforskningsloven § 11.

Endringen består i at man ønsker å forlenge prosjektperioden, til og med 31.12.2016.

Vedtak

Endringsøknaden godkjennes.

Tillatelsen er gitt under forutsetning av at prosjektendringen gjennomføres slik det er beskrevet i prosjektendringsmeldingen og endringsprotokoll, og de bestemmelser som følger av helseforskningsloven med forskrifter.

Tillatelsen gjelder til 31.12.2016. Av dokumentasjonshensyn skal prosjektopplysningene likevel bevares inntil 31.12.2021. Opplysningene skal lagres avidentifisert, dvs. atskilt i en nøkkel- og en opplysningsfil. Opplysningene skal deretter slettes eller anonymiseres, senest innen et halvt år fra denne dato.

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

Klageadgang

Du kan klage på komiteens vedtak, jf. forvaltningsloven § 28 flg. Klagen sendes til REK sør-øst. Klagefristen er tre uker fra du mottar dette brevet. Dersom vedtaket opprettholdes av REK sør-øst, sendes klagen videre til Den nasjonale forskningsetiske komité for medisin og helsefag for endelig vurdering.

Med vennlig hilsen

Knut W. Ruyter
avdelingsdirektør
REK sør-øst C

Tor Even Svanes

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Appendices

Kopi til: elin.dysvik@uis.no

seniorrådgiver

Appendices



Region: REK sør-øst	Saksbehandler: Henriette Snilsberg	Telefon: 22845531	Vår dato: 20.01.2017	Vår referanse: 2010/3342/REK sør-øst C
			Deres dato: 27.12.2016	Deres referanse:

Vår referanse må oppgis ved alle henvendelser

Else Cathrine Rustad
Universitetet i Stavanger

2010/3342 Eldre pasienter, pårørende og sykepleieres erfaringer med overføring mellom ulike helsetjenestenivåer. En studie om samhandling

Forskningsansvarlig: Universitetet i Stavanger
Prosjektleder: Else Cathrine Rustad

Vi viser til søknad om prosjektendring datert 27.12.2016 for ovennevnte forskningsprosjekt. Søknaden er behandlet av sekretariatet på delegert fullmakt fra REK sør-øst C, med hjemmel i helseforskningsloven § 11.

Vurdering

Endringen består i ny dato for prosjektlutt: 28.02.2018.

Vedtak

Endringsøknaden godkjennes, jf. helseforskningslovens § 11. Tillatelsen er gitt under forutsetning av at prosjektendringen gjennomføres slik det er beskrevet i prosjektendringsmeldingen og endringsprotokoll, og de bestemmelser som følger av helseforskningsloven med forskrifter.

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

Komiteens vedtak kan påklages til Den nasjonale forskningsetiske komité for medisin og helsefag, jf. Forvaltningslovens § 28 flg. Eventuell klage sendes til REK Sør-Øst. Klagefristen er tre uker fra mottak av dette brevet.

Med vennlig hilsen
Knut Ruyter
avdelingsdirektør REK sør-øst

Henriette Snilsberg
førstekonsulent

Kopi til:

elin.dysvik@uis.no

Universitetet i Stavanger ved øverste administrative ledelse: post@uis.no

Besøksadresse:
Gullhaugveien 1-3, 0484 Oslo

Telefon: 22845511
E-post: post@helseforskning.etikk.no
Web: <http://helseforskning.etikk.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

Appendix 4 – Information to older patients

Samtykkeerklæring pasient

Forespørsel om deltakelse i forskningsprosjekt

”En studie om samhandling. Eldre pasienter, pårørende og sykepleieres erfaringer med overføring mellom ulike helsetjenestenivåer.”

Bakgrunn og hensikt

I Norge har vi, per i dag, relativt lite forskningsmessig kunnskap om hvordan eldre pasienter over 80 år, og deres nærmeste pårørende, erfarer overføringen av pasienten fra sykehus til kommunale omsorgstjenester. For at vi som helsepersonell skal kunne tilrettelegge denne prosessen best mulig for våre eldre pasienter ønsker vi og gjennomføre en større studie hvor inneliggende pasienter ved Haugesund sykehus og Stord sykehus, og deres nærmeste pårørende, inviteres til å bidra med deres erfaringer. Dette er et spørsmål til deg om du vil delta i vår studie. Studien inngår i et doktorgradsarbeid tilknyttet Høgskolen Stord/Haugesund og Universitetet i Stavanger, som utføres av stipendiat Else Cathrine Rustad. Studien er godkjent av Regional Etisk Komité og er meldt Norsk Samfunnsfaglig Datatjeneste.

Hva innebærer studien?

Studien innebærer at du vil intervjues om hvordan du har erfart overføringen fra sykehus til kommunale omsorgstjenester. Vi vil også be deg om å navngi den som du regner for å være din nærmeste pårørende og støttespiller gjennom dette sykdomsforløpet slik at vedkommende kan forespørres om deltakelse i studien. Også din nærmeste pårørende, som du selv peker ut, vil bli intervjuet. Intervjuene vil gjennomføres av stipendiat Else Cathrine Rustad, 2-3 uker etter at du er utskrevet fra sykehuset. Intervjuet av deg og din nærmeste pårørende vil gjennomføres hver for seg. Intervjuet av deg vil vare ca 1 time og vil gjennomføres i ditt hjem eller på sykehjemmet hvor du er innlagt. Intervjuet av din nærmeste pårørende vil også vare ca 1 time og gjennomføres i hans/hennes hjem eller et annet egnet sted hvis ønskelig. For at jeg lettere skal få dokumentert samtalen vår er det ønskelig og ta denne opp på lydbånd. I tillegg til intervjuet vil jeg be om å få innsyn i den overføringskurven som sykepleierne på sykehuset vil sende til sykepleierne ved den kommunale omsorgstjeneste hvor du skal overføres. Din deltakelse i studien vil ikke få noen konsekvenser for ditt videre pasientforløp eller som mottaker av helsetjenester.

Appendices

Samtykkeerklæring pasient

Mulige fordeler og ulemper

Ulempen ved deltakelse i studien kan være den tiden du må avse for å gjennomføre intervjuet. Samtalen vil også tas opp på lydbånd som noen kan oppleve som ubehagelig.

Hva skjer med informasjonen om deg?

Informasjonen som registreres om deg skal kun brukes slik som beskrevet i hensikten med studien. Alle opplysninger vil bli behandlet uten navn og fødselsnummer eller andre direkte gjenkjenner opplysninger. En kode knytter deg til dine opplysninger gjennom en navneliste. Det er kun prosjektleder som har adgang til navnelisten og som kan finne tilbake til deg. Alle opplysninger vi har samlet inn vil slettes i løpet av våren 2014 når vi har fått analysert svarene og studien i sin helhet er gjennomført. Det vil ikke være mulig å identifisere deg i resultatene av studien når disse publiseres.

Frivillig deltakelse

Det er frivillig å delta i studien. Du kan når som helst og uten å oppgi noen grunn trekke ditt samtykke til å delta i studien. Dette vil ikke få konsekvenser for din videre behandling. Dersom du ønsker å delta, undertegner du samtykkeerklæringen på siste side. Om du nå sier ja til å delta, kan du senere trekke tilbake ditt samtykke uten at det påvirker din øvrige behandling. Dersom du senere ønsker å trekke deg eller har spørsmål til studien, kan du kontakte:

Else Cathrine Rustad

**Høgskolen Stord/ Haugesund
Bjørnsonsgate 45
5528 Haugesund.
Tlf.: 52 70 27 73 / 402 401 22**

Appendices

Appendix 5 – Information to next of kin

Samtykkeerklæring pårørende

Forespørsel om deltakelse i forskningsprosjekt

”En studie om samhandling. Eldre pasienter, pårørende og sykepleieres erfaringer med overføring mellom ulike helsetjenestenivåer.”

Bakgrunn og hensikt

I Norge har vi, per i dag, relativt lite forskningsmessig kunnskap om hvordan eldre pasienter over 80 år, og deres nærmeste pårørende, erfarer overføringen av pasienten fra sykehus til kommunale omsorgstjenester. For at vi som helsepersonell skal kunne tilrettelegge denne prosessen best mulig for våre eldre pasienter og deres nærmeste pårørende, ønsker vi og gjennomføre en større studie hvor inneliggende pasienter ved Haugesund sykehus og Stord sykehus, og deres nærmeste pårørende, inviteres til å bidra med deres erfaringer. Dette er et spørsmål til deg om du vil delta i vår studie. Studien inngår i et doktorgradsarbeid tilknyttet Høgskolen Stord/Haugesund og Universitetet i Stavanger, som utføres av stipendiat Else Cathrine Rustad. Studien er godkjent av Regional Etisk Komitè og er meldt Norsk Samfunnsfaglig Datatjeneste.

Hva innebærer studien?

Vi har tillatt oss og forespørre sin deltakelse i studien ettersom en av våre inneliggende pasienter har oppgitt deg som sin nærmeste pårørende i vedkommendes sykdomsforløp. Hvis du samtykker til deltakelse vil dere vil begge inngå i studien vår. Studien innebærer at du vil intervjues om hvordan du har erfart overføringen av din eldre pårørende fra sykehus til kommunale omsorgstjenester. Intervjuene vil gjennomføres av stipendiat Else Cathrine Rustad, 2-3 uker etter at din pårørende pasient er utskrevet fra sykehuset. Intervjuet av deg og din pårørende vil gjennomføres hver for seg. Intervjuet av deg vil vare ca 1 time og gjennomføres i ditt hjem eller et annet egnet sted hvis ønskelig. For at jeg lettere skal få dokumentert samtalen vår er det ønskelig og ta denne opp på lydbånd. Intervjuet av din pårørende pasient vil også vare ca 1 time og vil gjennomføres i vedkommendes hjem eller på sykehjemmet hvor han/ hun er innlagt. Din deltakelse i studien vil ikke få noen konsekvenser for pasientens videre behandlingsforløp eller som mottaker av helsetjenester.

Appendices

Samtykkeerklæring pårørende

Mulige fordeler og ulemper

Ulempen ved deltakelse i studien kan være den tiden du må avse for å gjennomføre intervjuet. Samtalen vil også tas opp på lydbånd som noen kan oppleve som ubehagelig.

Hva skjer med informasjonen om deg?

Informasjonen som registreres om deg skal kun brukes slik som beskrevet i hensikten med studien. Alle opplysninger vil bli behandlet uten navn og fødselsnummer eller andre direkte gjenkjennende opplysninger. En kode knytter deg til dine opplysninger gjennom en navneliste. Det er kun prosjektleder som har adgang til navnelisten og som kan finne tilbake til deg. Alle opplysninger vi har samlet inn vil slettes i løpet av våren 2014 når vi har fått analysert svarene og studien i sin helhet er gjennomført. Det vil ikke være mulig å identifisere deg i resultatene av studien når disse publiseres.

Frivillig deltakelse

Det er frivillig å delta i studien. Du kan når som helst og uten å oppgi noen grunn trekke ditt samtykke til å delta i studien. Dette vil ikke få konsekvenser for din videre behandling. Dersom du ønsker å delta, undertegner du samtykkeerklæringen på siste side. Om du nå sier ja til å delta, kan du senere trekke tilbake ditt samtykke uten at det påvirker din øvrige behandling. Dersom du senere ønsker å trekke deg eller har spørsmål til studien, kan du kontakte:

Else Cathrine Rustad

**Høgskolen Stord/ Haugesund
Bjørnsonsgate 45
5528 Haugesund.
Tlf.: 52 70 27 73 / 402 401 22**

Appendix 6 – Information to nurses

Samtykkeerklæring delstudie B

Forespørsel om deltakelse i forskningsprosjekt

”En studie om samhandling. Eldre pasienter, pårørende og sykepleieres erfaringer med overføring mellom ulike helsetjenestenivåer.”

Bakgrunn og hensikt

I Norge har vi lite forskningsmessig kunnskap om hvordan eldre pasienter over 80 år, pårørende og involverte sykepleiere erfarer å overføre pasienter fra sykehus til kommunale omsorgstjenester. På denne bakgrunn ønsker vi og gjennomføre en større studie hvor sykepleiere fra spesialisthelsetjeneste og sykepleiere fra kommunal omsorgstjeneste inviteres til å bidra med sine erfaringer. Dette er et spørsmål til deg om du vil delta i vår studie.

Studien inngår i et doktorgradsarbeid tilknyttet Høgskolen Stord/Haugesund og Universitetet i Stavanger, som utføres av stipendiat Else Cathrine Rustad. Studien er godkjent av Regional Etisk Komité og er meldt Norsk Samfunnsfaglig Datatjeneste.

Hva innebærer studien?

Dataene vil samles inn ved hjelp av fokusgruppeintervju. Dette vil si at du, sammen med 6-8 kollegaer intervjues i gruppe hvor dere blir bedt om å fortelle om og diskutere ulike erfaringer knyttet til å overføre eldre pasienter fra sykehuset og til kommunal omsorgstjeneste. Der vil være to fokusgruppesamlinger hvor samling nummer to er en oppfølging til den første samlingen. Stipendiat Else Cathrine Rustad vil utføre intervjuet og også en medforsker vil være tilstede. Fokusgruppeintervjuet vil gjennomføres ved Høgskolen Stord/ Haugesund i lunsjpauzen og samlingen vil vare 1 time. Der vil bli servert mat. For at jeg lettere skal få dokumentert samtalen i fokusgruppen vil denne bli tatt opp på lydbånd.

Hva skjer med informasjonen om deg?

Informasjonen som registreres om deg skal kun brukes slik som beskrevet i hensikten med studien. Alle opplysninger vil bli behandlet uten navn og fødselsnummer eller andre direkte gjenkjennende opplysninger. Alle opplysninger vi har samlet inn vil slettes i løpet når vi har fått analysert svarene og studien i sin helhet er gjennomført. Når resultatene publiseres vil det ikke være mulig å identifisere deg.

Appendices

Samtykkeerklæring delstudie B

Frivillig deltakelse

Å delta i studien er frivillig. Du kan når som helst og uten å oppgi noen grunn trekke ditt samtykke til å delta i studien. Dersom du ønsker å delta, undertegner du samtykkeerklæringen nedenfor.

Dersom du har spørsmål til studien, kan du kontakte:

Else Cathrine Rustad
Prosjektleder

Høgskolen Stord/ Haugesund
Bjørnsonsgate 45
5528 Haugesund.
Tlf.: 52 70 27 73 / 402 401 22

Samtykke til deltakelse i studien

Jeg har mottatt skriftlig informasjon om studien og sier meg villig til å delta:

Dato: *Signatur:*

v/ utdanning:



2

Appendices
