From the Department of Neurobiology, Care Sciences and Society,
Division of Social Work,
Karolinska Institutet, Stockholm, Sweden

PATIENTS' POSITION IN CARE TRANSITIONS
- AN ANALYSIS OF PATIENT PARTICIPATION AND PATIENT-CENTEREDNESS

Maria Flink

Karolinska Institutet

Stockholm 2014

ABSTRACT

Introduction: Patients with chronic diseases need care transitions between primary and hospital care when facing severe exacerbation or acute illness. Such transitions are associated with risks, potentially adverse events and patient suffering. To improve care transitions, patients' and healthcare professionals' experiences and perspectives of patient participation and patient-centeredness need to be explored.

Aim: The general aim of this thesis is to improve the knowledge and understanding of patient participation and patient-centeredness in handovers between primary and hospital care.

Methods: The thesis comprises four papers about patients with chronic diseases (asthma, diabetes mellitus I or II, chronic heart failure, chronic obstructive pulmonary disease) and/or polypharmacy, and the healthcare professionals who treated the patients in the hospital and the primary healthcare. The study was conducted in five European countries: the Netherlands, Spain, Poland, Italy and Sweden. Both qualitative (papers I, II, and III) and quantitative (paper IV) methodology are used. Paper I is a content analysis of individual interviews with 23 Swedish patients. Paper II is a secondary analysis of both individual and focus group data of 90 patients from the five countries. Paper III is a meta-synthesis of both individual and focus group data of 90 patients and 258 healthcare professionals from the five countries. Paper IV includes medical records of 22 Swedish patients by review and assessment of their handover records.

Results: Patients participated through both verbal activities (information exchange) and non-verbal activities (e.g. transfer of medication lists, referrals, and discharge notes). Patients' activity varied from taking responsibility for handover, via shared responsibility, to being passive. The patients' capacity for participation was reduced by health condition and health illiteracy, and strengthened by personality, experience and social network. Patients felt empowered by the knowledge they received through participation. Patients and healthcare professionals experienced both patient-centered handovers (patient needs addressed and discussed; responsive relations in which personalized information was provided; having continuity of care) as well as non patient-centered handovers. Organizational factors such as lack of time; emergent needs of other patients; and shift work forced the healthcare professionals to discharge patients without needs properly assessed; in discharge encounters held in a rush or without encounters; and by healthcare professionals who had not treated the patient at the ward.

Conclusions: Based on the findings, improved handovers – ensuring that information reaches the next setting – would mean having formal discharge encounters, and empowering patients with information, education and clarification of the handover process. In such cases, the patients can participate in handovers through exchange of information about their self-management, care and treatment in the present encounter, the next encounter and the handover between those. Organizational factors contribute to healthcare professionals' patient-centeredness, and patient-centeredness seems to increase patients' participation in handovers. The interactive aspects should be encouraged, an organization providing allocated time and recourses, and a following patient-centered attitude of the healthcare professionals could benefit all involved stakeholders resulting in patient-centered handovers with participating patients.

LIST OF PUBLICATIONS

I. Maria Flink, Gunnar Öhlén, Helen Hansagi, Paul Barach, Mariann Olsson.
    Beliefs and experiences can influence patient participation in handover between primary and secondary care - a qualitative study of patient perspectives.
    BMJ Quality and Safety, 2012;21:i76-83

II. Maria Flink, Gijs Hesselink, Loes Pijnenborg, Hub Wollersheim, Myrra Vernooij-Dassen, Ewa Dudzik-Urbaniak, Carola Orrego, Giulio Toccafondi, Lisette Schoonhoven, Petra J Gademan, Julie K Johnson, Gunnar Öhlén, Helen Hansagi, Mariann Olsson, Paul Barach.
    The key actor: a qualitative study of patient participation in the handover process in Europe.
    BMJ Quality and Safety, 2012;21:i89-96

III. Gijs Hesselink, Maria Flink, Mariann Olsson, Paul Barach, Ewa Dudzik-Urbaniak, Carola Orrego, Giulio Toccafondi, Cor Kalkman, Julie K Johnson, Lisette Schoonhoven, Myrra Vernooij-Dassen, Hub Wollersheim.
    Are patients discharged with care? A qualitative study of perceptions and experiences of patients, family members and care providers.
    BMJ Quality and Safety, 2012;21:i39-49

IV. Maria Flink, Susanne Bergenbrant Glas, Fanny Airosa, Gunnar Öhlen, Paul Barach, Helen Hansagi, Mats Brommels, Mariann Olsson.
    Poor patient-centeredness during handovers in Sweden? – findings from a medical record review.
    Manuscript.

CONTENTS

LIST OF ABBREVIATIONS

WHO	World Health Organization
GP	General Practitioner
CN	Community Nurse
PHC	Primary Healthcare, including the primary healthcare center, advanced home care service, nursing home or occupational health service
ICF	International Classification of Functioning, Disability and Health
IOM	Institute of Medicine
COPD	Chronic Obstructive Pulmonary Disease
MESH	Medical Subject Headings
ER	Emergency Room

PREFACE

My pathway to writing this thesis started already during my first job as a medical social worker at the University Hospital in Malmö just after graduation from School of Social Work, Lund University. Even though I enjoyed the clinical work, I pretty soon found myself longing for deepening my knowledge about social work theory. This led me into further studies to a Master's degree in Social Work and a chance to work part-time at Arbetslivsinstitutet Syd.

In connection to the parental leave, my husband and I moved to Stockholm with our daughter. I started to work at Karolinska University Hospital where I met Mariann Olsson, the head of R&D at Department of Social Work. She introduced me to the HANDOVER-project: a qualitative, multi-national project on care transitions in the Netherlands, Spain, Poland, Italy and Sweden. The project focused on barriers and facilitators for effective handovers between primary and hospital care, with the overall aim of improving patient handovers.

Immersing me into a new area of research with brilliant colleagues from so many countries, backgrounds and professions was indeed a contrast to the parental leave. Finding my own focus in this rich research environment was however not a challenge. Based on my work as medical social worker, the patients – their perspectives, participation and opportunities – were an obvious focus to me.

1 INTRODUCTION

Patients with chronic diseases, who receive care in the primary healthcare, need specialist hospital care in case of exacerbation or acute illness/trauma. In such cases a handover – a care transition – between the primary healthcare provider and the hospital care provider is needed. This handover is a transfer of responsibility for patient care and a transfer of information about the patient to ensure continuity of care. Unfortunately, handovers are associated with deficits, possessing a risk for patients potentially leading to adverse events, re-hospitalization and patient suffering.

This thesis focuses on patients' and healthcare professionals' experiences and perspectives of patient participation and patient-centeredness in handovers between the primary healthcare and hospital. Two interfaces – primary healthcare to hospital by the time of hospital admission, and hospital to primary healthcare by the time of hospital discharge – are hence studied.

1.1 KEY CONCEPTS

The introduction starts with definitions of the studied key concepts: patient participation, patient-centeredness, continuity of care and handover. This is followed by an overview of patients with chronic diseases, handovers between primary and hospital care, and the theoretical framework of the thesis.

Several of the thesis' key concepts have synonyms used more or less interchangeable in literature: patient participation (e.g. patient engagement, patient involvement); patient-centeredness (e.g. client-centered, person-centered, family-centered); continuity of care (e.g. coordination of care, integrated healthcare, care management) and handover (e.g. handoff, care transition, transitional care). To add to the confusion, patient-centered care is sometimes used interchangeable with both integrated healthcare, and continuity of care [1].

1.1.1 Patient participation

The focus on patient participation was started about the time for the civil right movement in 1960's and 1970's [2]. Patients' rights, just as citizens' rights overall, were increased and former power relations shifted. The World Health Organization (WHO) declared in 1978 that "people have the right and duty to participate individually and collectively in the planning and implementation of their health care" [3] (page 1). Following this, Swedish healthcare legislation was renewed aiming to stress patients' rights in the beginning of the 1980's [4]. The legislation is currently once again rewritten to further strengthen patient rights and participation [4].

Patient participation is a concept without clear definition [5-7] that has been studied and applied in several different research areas, e.g. patient safety [6 8 9], nursing [7 10], and medical encounters/consultations [11 12] – to mention a few.

The database Pub Med of the National Library of Medicines in the USA [13] uses the definition "patient involvement in the decision-making process in matters pertaining to health". However, in a recent report on patient safety, WHO consider this definition too narrow [9]. The editors suggest that participation can both take place on a macrolevel when patients are part of advisory boards/committees and on a microlevel when patients participate in decision-making, self-management activities, and/or safety management in encounters and interventions. This argument is in line with other researchers who consider patient participation occurring on three different levels: in direct care, organizational design and policy making [14].

In another WHO publication, International Classification of Functionality, Disability and Health (ICF), participation is defined as "involvement in a life situation" [15 16], a definition which has shown coherence with patients' own views on participation [17]. Participation and activity are considered parts of the same component, and activity is defined as a person's "execution of a task or action" [16] (page 14). The assessment of participation and activity consists of performance (what a person is doing) and capacity (a person's ability to perform a task or action) [15 16].

One early definition in the nurse setting was made in a concept analysis by Cahill in 1996 [10]. She suggests that the defining attributes of patient participation are an existing relationship; a narrowing of the gap of information, knowledge, competence; surrendering of power/control; engagement in intellectual or physical activity and that this activity has a positive benefit. Cahill also arranged patient participation in a hierarchy with the related concepts "patient involvement/collaboration" and "patient partnership". Patient involvement/collaboration is seen as a simpler version of participation and is hence subordinate to it – patients perform basic tasks without the intellectual activities required in e.g. decision-making. Patient partnership is considered superior to participation and as a goal to strive for. It is described as an established, ongoing healthcare relation between a nurse and a patient. Swedish nurses have, following Cahill, also examined the concept [7 17]. Sahlsten et al define patient participation as "an established relationship between nurse and patient, a surrendering of some power or control by the nurse, shared information and knowledge, and active engagement together in intellectual and/or physical activities" [7] (page 9). The definition by Eldh et al follows part of this stating in that patients understanding of the concept corresponds to "sharing knowledge and sharing respect" [17] (page 31).

Other researchers have also followed Cahill's hierarchal definition with three different levels of participation: consultation, involvement and finally partnership and shared leadership [14]. Similar levels of participation are also found in the research area of children and social work. Shier [18] further developed a ladder of participation in decision-making. The ladder included five levels: the children 1) are listened to, 2) are supported in expressing their perspectives, 3) have their perspectives taken into account, 4) are involved, 5) share power and responsibility [18].

A review of interventions to improve patient participation in medical consultations showed that participation most often was considered as "question-asking, raising concerns, and requesting clarification or checking understanding" [11] (page 9). In another review, patient participation is considered as an interaction between patient and/or healthcare professionals/healthcare systems "in which the patient is active in providing information to aid diagnosis and problem-solving, sharing his/her preferences and priorities for treatment or management, asking questions and/or contributing to the identification of management approaches that best meet his/her needs, preferences or priorities" [12] (page 13). A taxonomy of patient participation in consultations describes participation also as a co-determination between patient and healthcare professionals [19]. The level of participation is determined in the relation between the patient and the professional and through the patient's willingness to participate and the healthcare professionals' communicational behavior.

To summarize, the above definitions and analyzes of patient participation focus on the
1) patient-professional relationship: relationship [7 10 14], co-determination [19], and share of power [7 10 14 18];
2) exchange of information/shared activity: shared decision-making [9 13], and sharing/exchanging info [5 7 10 12 17];
3) patient own activity: asking questions [11 12], self-management [9], and execution of tasks [15].

In this thesis, focus is on patients' exchange of information and patients' own activity in handovers. Therefore, patient participation is defined as the patients' execution of and capacity for own verbal and/or non-verbal activities in information exchange with healthcare professionals and in handovers. This is in line both with the ICF definition where participation includes the activities a person is doing and his/her capacity to perform this activity [15], as well as with other researchers' definitions [17 20-22]. The patient-professional relationship will therefore be part of the patient-centered aspect of the interaction.

1.1.2 Patient-centeredness

Patient-centeredness is the term for a care that is not centered on healthcare or the patient's disease, but around the whole patient. The notion that care needs to be adjusted to the individual patient is not new. Carl Rogers published his book on "client-centered" therapy already in 1951, and in 1970 "patient-centered medicine" was used as a contrast to "illness-centered medicine" [23]. Since the introduction to the field of medicine the interest for the topic has increased tremendously. A simple search in Pub Med using the MESH-term "Patient-centered Care" (defined as "design of patient care wherein institutional resources and personnel are organized around patients rather than around specialized departments" [13]) shows that the term was first used in 1993 and that the number of publications increase largely, see table 1.

Table 1 Pub Med publications on patient-centeredness

Year	Publications
1993-1997	1084
1998-2002	1417
2003-2007	2340
2008-2012	4466

Despite, or perhaps because of, the common use of the term there is no global definition of patient-centeredness. One well-known definition is the one used by the Institute of Medicine (IOM), a non-profit organization in the USA, in its often cited book Crossing the Quality Chasm [24]. IOM focuses on the need to change the healthcare system to meet new challenges, and one of its suggested solutions is to have a patient-centered care. The IOM definition is a care that is "respectful of and responsive to individual patient preferences, needs, and values, ensuring that patient values guide all clinical decisions" [24] (page 40).

The National Board of Health and Welfare in Sweden uses the same wording as in the IOM definition, but also adds that a patient-centered (or patient-focused as it translates) healthcare must take into consideration the equal value of all people, and the individual's dignity, autonomy and integrity [25].

The definition by IOM is adopted from the book of 1993 "Trough the patient's eyes" by Gerteis et al from the Picker/Commonwealth program for patient-centered care [26]. Gerteis et al states that modern healthcare "by its very nature depersonalize" the encounter between a patient and healthcare professionals [26] (page 4). This is especially so in the hospital setting with the use of institutional clothes (both of the patient and the healthcare professional); new epithets as "patient" instead of those the patient might be used to (e.g. "mother", "daughter", "student"); as well as absence of familiar persons and the presence of strangers with whom the patient shares the room. Patient-centered care is defined as a set of dimensions: 1) respect for patients' values, preferences and expressed needs; 2) coordination and integration of care; 3) information, communication and education; 4) physical comfort; 5) emotional support and alleviation of fear and anxiety; 6) involvement of family and friends; 7) transition and continuity. Later, when renamed the "Picker Principles of Patient-centered Care" an eight dimension was added: access to care [27].

Mead and Bower [28] suggested in their conceptual literature review that patient-centered care differs from traditional "biomedical" care in five perspectives: 1) bio-psychosocial perspective, i.e. the healthcare professionals are involved in all aspects and parts of a patient's problem; 2) patient-as-a-person, i.e. all patients experience their disease and illness differently due to for example social, behavioral, or economical circumstances; 3) sharing power and responsibility, i.e. inequality exists in traditional healthcare but in the patient-centered care patients are encouraged to increased involvement; 4) the therapeutic alliance, i.e. the relation between the patient and

healthcare professional; 5) the doctor-as-a-person, i.e. the focus on the interaction between patient and healthcare professional means that the personal characteristics of the professionals need to be considered.

Another often cited (more than 200 citations in Web of Science, 2013-10-13) definition was proposed by Moira Stewart [29] and based on the patient-centered clinical method [23]. "Patients want patient-centered care which (a) explores the patients' main reason for the visit, concerns and need for information; (b) seeks an integrated understanding of the patients' world – that is, their whole person, emotional needs, and life issues; (c) finds common ground on what the problem is and mutually agrees on management; (d) enhances prevention and health promotion; and (e) enhances the continuing relationship between the patient and the doctor" [29] (page 445). In the patient-centered clinical method is also the component "being realistic about personal limitations and resources" part of patient-centeredness [23]. The first three components (exploring both disease and illness; understanding the whole person; and finding common ground) are seen as a process between patient and healthcare professionals. The remaining components (incorporating prevention and health promotion; enhancing patient-doctor relationship; and being realistic) are seen as the context in which the process occurs [23].

From a patient perspective, the International Alliance of Patients' Organizations (http://www.patientsorganizations.org/index.pl) conducted a review of definitions and principles resulting in a declaration on patient-centered healthcare [30]. This states that healthcare must be based on: 1) respect for patients' needs, preferences, values, autonomy and independence; 2) choice and empowerment, i.e. patients' right and responsibility to participate in their care which requires responsive healthcare system; 3) patient involvement in health policy, i.e. patients and patient organizations should share the responsibility of policy making; 4) access and support to safe, qualitative and appropriate healthcare; 5) information that enables patients to informed decisions must be provided [30].

From a Swedish perspective the Gothenburg Centre for Person-Centered Care (www.gpcc.gu.se) advocates the relationship between patient and healthcare professional [31-33]. The healthcare professional is to initiate the relationship by inviting the patient to share her/his story, maintain the relationship by involving the patient (e.g. shared decision-making), and to guard the relationship by documenting the patient's perspective in the medical record [31].

Patient-centeredness has been suggested to be both a goal [34] of the encounter, a value in itself [35] as well as a process [23 34]. Epstein et al [36] also follows the suggestion that patient-centered care is a process and conclude that for achieving patient-centered care patients and families need to be informed/involved, healthcare professionals need to be receptive and responsive and the healthcare environment needs to be well-coordinated and integrated. Stewart [29] states that a truly patient-centered care is open

and responsive to what the patient wants; even when the answer may be that this specific patient wants an "old-fashioned" paternalistic approach.

To summarize, the definitions and principles above span from a
1) macrosystem perspective taking the whole healthcare system into consideration: access to care [26 27 30]; participation in policy making [26 27]; care transitions and coordination [26 27]; considering the organizational settings with the doctor-as-a-person and being realistic [23 28 29]
2) to a microsystem perspective with the interaction between patient and healthcare professionals: considering each patient as an individual [23-30]; providing information [23 26 27 29 30]; relationship/therapeutic alliance/common ground [23 28 29 31 32]; patient/family participation [26 28 30 31].

In common for all definitions and principles of patient-centeredness is that the patient is to be considered as an individual whole person, healthcare professionals must view the patient holistically, and the professionals must be responsive to the patient. Several also focus on the relation between patient and the healthcare professional, sharing of power, and patient/family participation. This focus also takes the professional as an individual into consideration.

In this thesis, patient-centeredness is considered in all its dimensions since a patient-centered healthcare is one that acknowledges the patient in his/her individualistic differences across all settings – from the person-to-person encounter to the overall need of a responsive system. Patient-centeredness is therefore defined as the patient 1) being respected and treated as an individual, whole person, 2) receiving treatment/care in a responsive relationship with healthcare professionals, and 3) having access to care and continuity of care.

1.1.3 Comparing patient participation and patient-centeredness

The difference between patient participation and patient-centeredness can seem somewhat confusing, and the concepts may seem partly interchangeable. For example, patient and/or family participation is mentioned as one defining aspect of patient-centeredness [26 28 30 31] and the patient-professional relationship (sometimes seen as the core of patient-centeredness [31]) is one defining aspect of patient participation [7 10 19]. In this thesis, the concepts are however separated with patient participation as patients' own activity and patient-centeredness as professional activity, patient-professional relationship and patient access to care/continuity of care.

1.1.4 Continuity of care

Continuity of care is often referred to as a concept of two, or three, dimensions: management, relational and, in some studies also informational continuity [37]. The review by Haggerty et al concludes that continuity of care holds all three aspects [38]. Management continuity refers to the "consistent and coherent approach" used to

manage the patients' disease [38] (page 1220). Relational continuity refers to the "ongoing therapeutic relationship between a patient and one or more providers" [38] (page 1220). Informational continuity refers to the information shared between, and used by, professionals in different care settings and information is seen as the "common thread linking care from one provider to another" [38] (page 1220).

In this thesis, the definitions by Haggerty et al are used with focus on informational and management continuity due to their close relation to handovers.

1.1.5 Handover

Handovers in this thesis are care transitions between healthcare settings. Handover has been 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" [39] (page 556). The National Library of Medicines in the USA [13] defines patient handoff as "transferring of patient care responsibility from one health-care professional to another". A handover is not to be seen as a specific moment, but rather as a process without a clear start or endpoint. For example, the broad spectrum of suggested best time to start discharge planning spans from pre-hospital discharge planning for planned admissions [40], and ends at the actual discharge, with optional starting points at hospital admission or during hospitalization [41].

In this thesis, handovers between primary healthcare and hospital care are studied. Primary healthcare (PHC) includes the primary healthcare center, advanced home care service, nursing home or occupational health service. A handover is defined as the transfer of patient care responsibility and of patient information between the PHC and the hospital in either direction.

1.2 PATIENTS WITH CHRONIC DISEASES

There is no consensus of the exact diagnoses that are to be included under "chronic diseases". According to WHO, chronic diseases (sometimes also referred to as non-communicable diseases) are defined as "diseases of long duration and generally slow progression" [42]. The term is often referred to as the diagnoses cardiovascular disease, diabetes, asthma, and chronic obstructive pulmonary disease [43].

Chronic diseases are one of the largest challenges of healthcare. Two thirds (63%) of all global deaths in year 2008 were due to chronic diseases – especially cardiovascular diseases, diabetes, respiratory diseases and cancer [44]. Within Europe, chronic diseases are the most common diseases and the leading cause of death [43]. Unfortunately, it does not seem like the challenge of chronic disease will decrease by time. A large register study in UK revealed that half of all 50 year olds and about 80% of all 65 year olds have at least one chronic condition [45]. Hence, patients with one chronic disease often have other chronic diseases as well, and the number of chronic

diseases increases by age [45 46]. With the increase of older people in the western world, a following increase of people with chronic conditions can be expected [43].

Patients living with chronic diseases face many day-to-day obstacles which need to be addressed, for example fatigue and lost abilities [47 48]. Another obstacle is the management of care. Most of the management is performed in the patients' own home in self-management activities such as taking the daily medicine, exercising, and keeping track of blood sugar [49]. The coordination of care between levels of care is another management task. Healthcare in many western countries is characterized by a fragmented system [50-52], that have high level of specialization and is organized mainly around management of acute illness instead of chronic disease [50 53]. In case of exacerbation or acute illness, patients therefore need to seek and receive care at another setting than their usual primary healthcare provider; in severe and/or acute cases this means the hospital.

1.3 HANDOVER BETWEEN PRIMARY AND HOSPITAL CARE

For every hospitalization, two handovers occur between care settings: between PHC and hospital at admission, and between hospital and PHC at discharge. During such handovers informational continuity, in terms of information transfer, is needed to ensure management continuity, so that care providers are working towards the same goals [38 54]. The information can be transferred by healthcare professionals, by patients or both either in writing, for example referrals or discharge notes, or verbal. Most often multiple stakeholders are involved in the handover: e.g. patient, families/close-ones, community nurses (CN), general practitioners (GP), social workers, hospital nurses and/or physicians.

Most studies of handovers have focused on the discharge handover and most of them are US-based. One possible explanation is the relatively new Patient Protection and Affordable Care Act in the USA which encourages hospitals to reduce re-hospitalization rates with economical incitements and also to enhance patient-centeredness [55 56].

1.3.1 Quality deficits in handovers

Despite how common handovers are, several deficits have been shown to follow these transitions both in connection to admission and discharge.

Medication errors are common during handovers from the PHC to the hospital [57]. A systematic review from 2005 identified discrepancies between prescribed medications and medications recorded in the hospital's medication history in up to 67% of the reviewed cases [57]. Other, more recent, studies have found discrepancies in 35.9% of admitted patients in US [58] and 59% in Sweden [59], and simpler errors (e.g. not signing medication list) in 94% of studied medication charts for admitted patients in Australia and New Zeeland [60]. Several barriers towards accurate medication history

taking at hospital admission has been identified: patients' health condition, patients' low knowledge about their medications, and hospital physicians' lack of access to PHC's medical records [57]. Another barrier is the time needed for complete medication history taking; studies have found that 9-30 minutes are needed [57 58], which can be difficult to manage e.g. in a stressful emergency room (ER) environment.

Unwanted outcomes in terms of adverse events, re-hospitalizations and visits to emergency departments are also common deficits during handovers from hospital at discharge [61-65]. About one in five (ranging from 19% [63] to 23% [62]) recently discharged patients experience adverse events (i.e. injury caused by medical management and not by patient's original disease) following their hospitalization. Another study found that 42% of patients experienced errors in medication continuity [66], 8% experienced errors in follow-up of test results [66] and 12% experienced errors in follow-up of suggested tests or procedures [66]. A mixed methods study found that 42% of discharged patients reported at least one of the following problems two weeks after their discharge: problems with follow-up appointments or tests, re-admission/visit to ER, medication problems, un-preparedness for discharge and ongoing problems/questions [61]. Studies of healthcare use following discharge show that between 12% and 20% (12.3% [65]; 14% [67] and 19.6% [64]) of the studied hospitalizations resulted in re-hospitalization within 30 days, and more than one third of the studied hospitalizations resulted in re-hospitalization within 90 days [64]. In addition, 7.5% of the hospitalizations resulted in an ER visit within 30 days after discharge [65]. A Swedish study also found that high hospital use is a predictor for future hospitalizations; indicating that in-patients are likely to return to the hospital within a near future [68].

Handovers have also been studied from patients, families and healthcare professionals' perspectives in qualitative studies. Patients' and families' experiences of handovers are both positive and negative. Planned admissions to hospital are considered as ideal due to the possibility of being prepared, and unplanned admissions are experienced as more problematic [69]. Healthcare professionals identified a proper discharge planning to start already at admission hence ensuring decent time getting to know and prepare the patient for post-discharge care [70]. Most studies showed that unfortunately this was uncommon. Discharges often happened in a rush leaving little time for questions or clarification, resulting in patients being unprepared for post-discharge care [69 71]. Also, patients and families overall lacked receiving information about their treatment and illness [71 72], even though some reported receiving enough information [73]. Additionally, patients did not know whereas their PHC had been informed about their discharge, and thereby felt responsible for self updating their healthcare professionals about treatment changes [72]. Patients and family caregivers described being excluded from decision-making [71 73-75], also in settings meant to facilitate patients' active involvement such as discharge planning conferences [74]. Patients' resources, such as cognition and social support, were not taken into consideration by the healthcare professionals leading to patients not being actively involved [76]. Healthcare

professionals on their side described problems in shift work that caused confusion of what information had been given to patients [71].

Several studies have sought answer to why adverse events and hospital care use follow discharge. Possible contributors to adverse events were insufficient or lacking communication between physicians in hospital and PHC [63 77], as well as between hospital physician and patient [63 78]. Arora et al found that 30% of the GPs were unaware of their patients' hospitalization and that patients, whose GPs were unaware, twice as often reported problems after discharge [61]. Other contributing factors are low availability of discharge summaries at PHC and the absence of information in discharge summaries [77].

Multiple interventions have been designed to improve handovers in terms of reduced re-hospitalization, ER visits and improved patient medical status [77 79 80]. The interventions focus on the communication between settings (electronic vs. dictated discharge summaries; timing and mode of delivery of information; medication reconciliation) [77 80] and coordination of care (enhanced discharge planning and follow-up services; early assessment of needs; patient education) [77 79 80]. Several interventions included multiple components and actors such as patients, nurses, physicians, pharmacists and/or social workers [80]. Patients' participation and a patient-centered approach has been suggested [57 78 81 82] and found effective [77 83 84] to improve handovers.

1.3.2 Patient participation in handovers

Patients, and sometimes their families, have been considered the "only common thread" between healthcare settings [85] (page 550) and identified as a partner-in-care who could contribute to decreased errors in handovers to and from the hospital [57 58 78 81 82]. Hence, patient participation has been suggested to improve handovers when patients participate in discharge planning [81]; give information about medication history [57 58]; transfer written information between settings [57 58] and receive information [82]. Additionally, patient participation through transferring discharge summaries lead to improvements in information reaching the PHC [77]. However, a newer intervention examining patients as couriers found that discharge summaries reached PHC in 24% of the studied cases, compared to almost 74% for email delivery and 70% for fax delivery [86]. Few studies have focused on patient participation solely; whereas several interventions have focused on improving education and information to patients in the discharge process [84 87] and empowering patients to take a pro-active role in encounters [83 84] with reduced re-hospitalizations as outcome. Interestingly, studies suggesting patient participation to improve handovers focus either on non-specified participation [81] or on single actions as giving or transferring information [57 58 82] whereas interventions proven effective combine patient participation with enhanced support from healthcare professionals [83 84 87]. Therefore it is not clear what the exact contribution of patient participation per se is to improve handovers.

A survey among Swedish healthcare professionals showed that 90% considered it "very important" to involve patients as much as possible at discharge; nurses rated patient participation more important than physicians did [88]. Despite this, studies have shown that patients experience low level of participation in discharge planning [73-75 89] and they also have difficulties to navigate the healthcare system [24 43 51 52 85].

1.3.3 Patient-centeredness in handovers

As stated in chapter 1.1.2, patient-centeredness is a well-used concept, which also has received attention in the field of handovers. Following the definition of patient-centeredness in this thesis (i.e. the patient 1) being respected and treated as an individual, whole person, 2) receiving treatment/care in a responsive relationship with healthcare professionals, and 3) having access to care and continuity of care) all interventions should be considered as at least partly patient-centered due to their focus on continuity of care. Hence, the below referred interventions do also focus on the two first aspects of patient-centeredness.

A review of interventions to reduce re-hospitalization [41] found 8 studies that included patient-centered discharge instructions. Such instructions were adjusted to the patients' individual needs, circumstances and literacy level and used both for education of patients at the hospital and for instructions at discharge [41]. (Worth to notice, these 8 studies included 3 studies [83 90 91] that were based on the same intervention: the care transition intervention, http://www.caretransitions.org/.) Four of the interventions resulted in a statistically significant reduction in re-hospitalization rates [83 84 87 92]. A Cochrane review concluded that discharge plans that are customized to the individual patient (hence being patient-centered in one aspect) showed reductions in hospital length of stay and re-hospitalization rates [93]. A Swedish study of patient-centered care pathways found a cost reduction of 40% for patients whose individual resources and motivation were acknowledged [94].

Most studies focus on the handover at discharge (starting either during hospitalization or at discharge, and in some studies also following the patient post-discharge) [41]. Only a few interventions focused on handovers at admission. In a Swedish study patients' needs and social circumstances were addressed and a personalized program to meet patients' medical and care needs was developed during their admission to ER with decreased use of hospital care as result [95].

1.4 HEALTHCARE SYSTEM – PATIENT RIGHTS IN THE FIVE STUDIED COUNTRIES

Patient rights are regulated in the five countries addressed in this thesis (the Netherlands, Spain, Poland, Italy and Sweden), and examples of patient participation and patient-centeredness legislations are presented here.

All countries encourage patient participation on a citizen level; meaning, patient organizations' and/or patient councils' involvement in healthcare policy and development [96-100]. In the Netherlands, patients have the right to participate in the choice of healthcare providers and health insurance as well as in the direct encounter [100]. Patients have a law stipulated right to receive information about treatment and health condition [100]. In Spain, patients' rights to informed consent, to refuse treatment, and to choose among available healthcare professionals are stipulated in the general care act [97]. Patients have the right to receive information about healthcare and treatment [97]. In Poland, patients have the right to choose among healthcare professionals, right to refuse treatment, to informed consent and to receive information about their condition and treatment [99]. In Italy, patients have the right to informed consent as part of the code of practice [98].

1.4.1 Legislation and regulation in Swedish healthcare

In the Swedish Health and Medical Services Act [101], several paragraphs are directly connected to patient participation and especially patient-centeredness. The legislation stipulates that patients' autonomy and integrity should be respected; patient and healthcare professional relations are to be encouraged; and patients' need for continuity of care and safety are to be met. Care and treatments are also to be performed in collaboration with the patient, and patients should be given information about their health condition, treatment options and possibility to choose healthcare provider [101]. Further, regulation of the National Board of Health and Welfare [102] states that patients are to be consulted about the discharge planning; the patients must be shown respect; and their participation, if any, are to be documented in the medical record. If no other legislation hinders it, patients should receive written information at discharge, and information about discharge planning are to be documented in the medical record. Information about the patient's need for healthcare is to be transferred to the PHC and/or community healthcare at the day of discharge [102].

As mentioned in chapter 1.1.1, a commission has proposed a change in the healthcare legislation to strengthen patient participation and patient-centeredness [4]. The commission for example suggests that it should be added in the new patient legislation that patient participation must be based on patients' own preferences and capacity [4].

1.4.2 Comparisons between countries

International comparisons of patient participation and patient-centeredness show that 30% of the Swedish patients does not consider their physician to spend enough time with them, compared to 13% in the Netherlands [51]. In Sweden, 41% of the patients consider their physician to explain things clearly and encourage questions, compared to 54% in the Netherlands and between 69% - 77% for UK, USA, Switzerland and Australia [51]. Further, 48% of the Swedish patients reported shared decision-making, compared to 67% in the Netherlands and nearly 80% in Switzerland and UK [51]. In an older comparison, Swedish, Italian and Polish patients scored their doctors listening

skills as the lowest among the studied 8 countries, whereas the Spanish patients gave the highest scores for their doctors [103]. On the other hand, Swedish patients gave the second highest scores regarding experiences on how often they were involved in healthcare decisions, followed by the Italian patients, with the Spanish and Polish patients giving the lowest scores [103].

All countries but Sweden have a gate-keeping function of the general practitioner [96-100]. This means that for access to specialist care patients are obliged to first contact the PHC to get a referral from their GP [97-100], whereas patients in Sweden have the right to contact a specialist directly, without consulting their GP [96].

1.5 THEORETICAL FRAMEWORK: SYSTEMS THEORY

The care levels, in which the patients perform their self-management and receive care/treatment, can also be studied as different levels in a system. The relation of the different levels is often illustrated as connected circles, with the person (here a patient) in the inner circle and the outer circles illustrating parts of the system, see figure 1.

Figure 1 Systems theory according to Bronfenbrenner
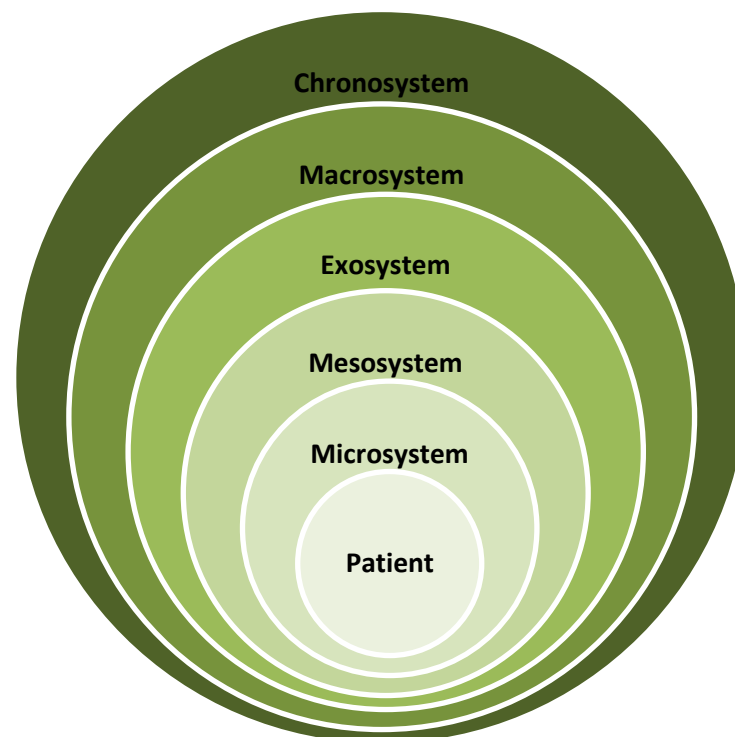
This systematic way of organizing interplaying parts can be applied in different areas: from an individual's body as a system with interacting organs, to society as a system with interacting individuals, to the world as a system with interacting societies. The system parts' relation to each other, their communication and interplay is in focus [104 105]. Healthcare with its many shapes from family physicians and primary healthcare centers, to rural hospitals and moving on to the large urban university hospitals can be described as a system with interconnections and links [24]. Healthcare systems are regarded as complex systems since they consist of individuals who act on free will and whose actions not always can be predicted (such as with biological phenomena) [106]. The actions and interactions of the individuals in the system also affect other individuals in the system, as well as the system as a whole [106].

1.5.1 Ecological systems theory

Urie Bronfenbrenner, a Russian-American psychologist, developed his theory of human development in the late 1970's [107]. His theory first focused mainly on the child's development, but in later work the theory itself developed. His new model, sometimes referred to as the "bio-ecological model", focuses on the life course development of individuals [108]. The bio-ecological model involves four components 1) the person with his/her individual characteristics, 2) the processes that the person is involved in, i.e. the person-context relation, 3) the context of the developing person, i.e. the system levels micro, meso, exo, macro, 4) the time aspect, i.e. the chronosystem [109]. During a lifetime a person undergoes what Bronfenbrenner refers to as "ecological transitions", i.e. a change of position in the context [110]. Examples are getting sick, having a child, being admitted to the hospital – such ecological transitions change both the person's position in his microsystem and his/her position in the other system levels.

1.5.1.1 Microsystem

A microsystem in Bronfenbrenner's terms is defined as the "patterns of activities, roles, and interpersonal relations" that a person is experiencing [110] (page 22). The microsystem consists, at a minimum, of a dyad – two people engaged in the other one's activity. The dyad, can take three different functional forms: observational dyad, joint activity dyad and primary dyad.

In the observational dyad, one person is observing the other one's activity, for example the patient observing the nurse washing her hands [110]. In the joint activity dyad two persons are engaged in the same activity, for example the patient lifting her arm so that the nurse can take the blood pressure. In the joint activity there is usually some form of reciprocity [110]. In the example above the patient must wait for the nurse to come to the bedside/chair with the instrument, and the nurse must wait for the patient to lift her arm. Bronfenbrenner compares this with a ping-pong game with the participants improving their abilities to play with each other, and therefore improving both pace and skills, and perhaps moving on to a more advanced form of the game [110]. The joint activity also includes some sort of power balance. As in the ping-pong game one part

could have advantage over the other, but it may also shift during the play of the game. The third dyad form, the primary dyad, is an extension of the joint activity resulting in an affective relationship [110]. Bronfenbrenner states that persons engaged in the joint activity for a longer period of time tend to start having feelings, either of affection or dislike, towards each other and names this affective relation [110].

Hence, the activities that persons perform are considered to be partly defined by the roles the persons have in the microsystem. The individual, the patient, is not a passive object but a part of and co-worker in the microsystem.

1.5.1.2 *Mesosystem*
The mesosystem is defined as "the interrelations among two or more settings in which the developing person actively participates", i.e. a "system of microsystems" [110] (page 25). When the person engages in new activities, new microsystems are added to the mesosystem; for example during handovers, new microsystems at the ER and the ward is added. The links between microsystems are not consistent; same persons can occur in several microsystems (for example the patients' GP might play tennis at the same club as the patient, or the physician at the ER is also a physician at the ward). The interrelations between microsystems, i.e. the mesosystem, can be of various types. For example the patient's participation in both the hospital ward setting and the PHC setting, the community nurse discussing the patient with the hospital nurse, or a discharge note being sent to the PHC after the hospitalization. Another form of interconnection is the knowledge and experience that the microsystems have about each other [110].

1.5.1.3 *Exosystem*
The exosystem is defined as "one or more settings that do not involve the developing person as an active participant, but in which events occur that affect, or are affected by, what happens in the setting containing the developing person" [110] (page 25). That is, the exosystem is the context in which the micro- and mesosystem exist. The exosystem does not have a direct effect on the patient, compared to the direct activities in the microsystem, but an indirect [110]. For example, the county council decides, based on governmental decisions, that the patient's PHC should be a private instead of public provider. This causes the patient's GP to leave her position due to ideological reasons, and the patient experience a loss of relational continuity and have to find a new GP.

1.5.1.4 *Macrosystem*
The macrosystem is the culture, beliefs and values, the "overarching patterns of ideology and organization of social institutions" [110] (page 8). Imbedded in our culture are, for example, expectations on how a patient, and a healthcare professional, is to act towards each other [110]. A person's role and his/her actions are affected by the expectations, beliefs and values that our surrounding society has. On the same time the person is also a part of the society and his/her expectations, beliefs and values affect other persons' behavior [110].

1.5.1.5 Chronosystem

The chronosystem is the dimension of time, which Bronfenbrenner added in his later work. Time has an impact on the person's development both during the life course but also as a historical time, i.e. the time the person grows up and lives in [111]. The "prior life events and experiences" [109] (page 83) in the life course development may either be internal factors (such as getting the chronic disease) or external factors (parents' divorce). Historical time – the time era and the paradigms of our time – have an impact on the person's life [109 111]; for patients living with a chronic disease the possibility of getting sickness benefit have a major impact on their life course or for women the entrance to the workforce have had a major impact on their life course.

1.5.2 Clinical microsystem

A systems theory approach used in the healthcare setting is the clinical microsystem model. A clinical microsystem is "the place where patients, families, and caregivers meet" [106] (page 2) and "a group of people (including healthcare professionals and care-receiving patients and their families) who work together in a defined setting on a regular basis (or as needed) to create care for discrete subpopulations of patients" [106] (page 3). The microsystem is considered being the "building blocks" of healthcare [112]. Like other systems theories, the clinical microsystem is seen in a context of a larger system, i.e. the healthcare system with the microsystems nested, embedded, within the healthcare system [106 112].

Where Bronfenbrenner used his theory to explore a person's development in its context [107], the clinical microsystem model uses systems theory to understand how healthcare is organized aiming for healthcare improvement [113]. Bronfenbrenner's theory has the person – in this thesis: the patient – as the focus. Other systems theorists in the area of healthcare have the healthcare system in itself as the main focus – with the patient as an important part of the clinical microsystem. Since this thesis has as its main aim to explore patient's participation and patient-centeredness the further analysis will primarily emanate from Bronfenbrenner's theory.

1.6 STUDY RATIONALE

Patients with chronic diseases need to seek care at both primary and hospital level and are therefore often experiencing handovers. For these, and other, patients it is important to have safe care transitions to ensure continuity of care. Unfortunately, handovers are associated with several quality deficits that may result in patients experiencing re-hospitalization, adverse events and suffering.

As well as gaps in continuity of care, there are also gaps in the knowledge about several handover aspects. First, patients' and healthcare professionals' perspectives of patient participation and patient-centeredness are not sufficiently studied in both handovers to and from the hospital. Second, the facilitators and barriers for patient participation and patient-centeredness need to be further addressed for finding optimal ways of

improving these aspects. Third, it is not clear what patients' participation consist of in the handovers between settings. Additionally, most of the interventions to improve handovers are from the US. Since healthcare system as well as societal systems differ between USA and Europe, it is important to understand how patients and healthcare professionals in the studied European settings perceive and experience patient-participation and patient-centeredness.

2 GENERAL AIM

The general aim of this thesis is to improve the knowledge and understanding of patient participation and patient-centeredness in handovers between primary and hospital care.

2.1 SPECIFIC AIMS

The specific aims are to:

I: improve the knowledge and understanding of patients' perspectives about their participation in handover communication between primary and hospital care at the time of hospital admission and at discharge.

II: explore the experiences and perspectives of patients with chronic diseases in regards to their participation in handover communication between primary and hospital healthcare in five European countries.

III: explore the barriers and facilitators to patient-centered care in the hospital discharge process.

IV: explore patient-centeredness in handovers between primary and hospital care for patients with chronic diseases.

3 METHODS

To answer the overall aim of the thesis – improved knowledge and understanding – both qualitative (I, II, III) and quantitative (IV) methodology were used. Paper I and II both had a descriptive design using qualitative content analysis (I) and qualitative content analysis in a secondary analysis (II). Paper III had a grounded theory design using meta-synthesis of grounded theory analyzes. Paper IV had a prospective quantitative design using both descriptive and analytical statistics.

The data in the thesis' papers were collected for the HANDOVER- project [114]; an international, multi-setting study performed in the Netherlands, Spain, Poland, Italy, and Sweden. Swedish data were analyzed in paper I and IV, and data from all five countries were analyzed in paper II and III. Paper I and II include patient interview data, paper III patient and healthcare professional interview data, and paper IV include patient medical record data.

In section 3.2 "Participants" and section 3.3 "Data collection" papers I, II and III are described under the same headings. In section 3.4 "Data analysis", the papers are described separately.

Table 2 Paper overview

	Country setting	Study population	Sample	Data collection	Analysis
Paper I	Sweden	Patients with chronic diseases from Sweden	23 patients	Individual interviews	Qualitative content analysis
Paper II	The Netherlands, Spain, Poland, Italy and Sweden	Patients with chronic diseases from five European countries	90 patients	Individual interviews and focus group interviews	Secondary analysis using Qualitative content analysis
Paper III	The Netherlands, Spain, Poland, Italy and Sweden	Patients with chronic diseases and healthcare professionals from five European countries	90 patients and 258 healthcare professionals	Individual interviews and focus group interviews	Meta-synthesis of analyzes using Grounded Theory
Paper IV	Sweden	Medical records of patients with chronic diseases from Sweden	98 records of 22 patients	Medical record collection from primary healthcare and hospital	Descriptive and analytical statistics (Fisher's exact test)

3.1 SETTINGS

The interfaces between PHC and hospital at hospital admission and discharge were studied using nine European hospitals and the included patients' PHC.

The five countries were chosen to reflect different regions, with the assumption that handover processes may differ in the regions across Europe. All countries but Sweden

included two hospitals and the nine hospitals span from university and regional hospitals to rural hospitals. The foci on the national level were: general medical care (the Netherlands), cultural minorities/health illiteracy (Spain), geriatric care (Poland) and emergency care (Italy and Sweden), see table 4. These foci were the result of a convenience sample due to the interest and research areas of the research groups in each country. The following hospitals, used for recruiting of patients and hospital healthcare professionals, were included:

- The Netherlands: The University Medical Center Utrecht (UMCU) and The Diakonessenhuis

- Spain: Germans Trias i Pujol Hospital and Hospital de la Esperanca

- Poland: The Good Brothers' Hospital and The Specialist Hospital of Stefan Zeromski

- Italy: Nuovo San Giovanni di Dio and Nuovo Ospedale del Mugello

- Sweden: The Karolinska University Hospital Huddinge

All countries used electronic medical record systems. At the point of data collection, in the Netherlands and Spain a shared medical record system between hospitals and PHC was under development but not implemented. In Poland and Italy, a shared system was neither in use nor in process. In Sweden, some but not all PHC had reading access to the hospital's medical record system and the hospital had reading access to medical records of two patients in the advanced home care service.

3.2   PARTICIPANTS

We studied patients with chronic diseases and each patient's treating healthcare professional in both the hospital and PHC. Patients with chronic diseases were chosen as participants due to their expected experience of handovers between hospital and PHC, and because continuity of care is important in the management of their disease (see also chapters 1.2 and 1.3).

In paper I, 23 individual patient interviews were analyzed. In paper II, 53 individual patient interviews and 37 focus group patient interviews were analyzed. In paper III the same patient individual and focus group interviews (53+37) and 139 individual and 119 focus group healthcare professional interviews were analyzed, see table 3. In paper IV medical records of 22 patients were analyzed.

Table 3 Data overview

	Paper I (n=23)	Paper II (n=90)		Paper III (n=348)												Paper IV (n=22)
	Patient ind. inter-view	Patient ind. inter-view (n=53)	Patient focus group (n=37)	Patient ind. inter-view (n=53)	Patient focus group (n=37)	Healthcare professional individual interview (n=139)				Healthcare professional focus group interview (n=119)				Medical records of patients
						HP	HN	GP	CN	HP	HN	GP	CN	
The Netherlands	-	8	7	8	7	8	8	8	0	8	5	5	6	-
Spain	-	8	3	8	3	6	5	7	4	8	6	9	7	-
Poland	-	23	5+5	23	5+5	16	10	13	3	4	7	4	7	-
Italy	-	5	9	5	9	7	6	5	4	4	8	7	0	-
Sweden	23	9	8	9	8	9	9	6	5	6	6	6	6	22
SUM	**23**	**53**	**37**	**53**	**37**	**46**	**38**	**39**	**16**	**30**	**32**	**31**	**26**	**22**

HP= hospital physician HN= hospital nurse GP= general practitioner CN=community nurse

3.2.1 Patients

The inclusion criteria were both country specific and general (i.e. the same for all countries), see table 4.

Table 4 Country specific and general inclusion and exclusion criteria

	Country specific inclusion criteria	General inclusion criteria	General exclusion criteria
The Netherlands	Patients admitted to internal medicine, pulmonary disease, cardiology or vascular surgical wards	Patients ≥18 years of age, with any of the diagnoses: asthma, diabetes mellitus (type 1 or 2), chronic heart failure, chronic obstructive pulmonary disease (COPD), and/or polypharmacy (prescribed ≥ 6 drugs)	Patients who, prior to the discharge, were referred to another care setting within the hospital
Spain	Patients belonging to cultural minority groups and/or with limited capacity to read, write, and/or understand healthcare information		
Poland	Patients ≥ 60 years of age		
Italy	Patients admitted to emergency room	Admitted to hospital care and discharged to PHC (i.e. under the responsibility of primary/community care)	
Sweden	Patients admitted to emergency ward from emergency room; if the patient lived at a nursing home facility, the home must be within a specific geographical area. Enough understanding of Swedish for interview participation		

In each country, purposive sampling [115] was used to get variation and representation of patients regarding age, gender, and diagnoses. In the countries that included patients from several hospitals and/or hospital wards, variation was also considered for the hospital settings and wards. In Spain, a screening tool (developed by the Spanish research group) with questions about e.g. country of origin, language barrier, level of education was used to identify patients from minority groups and/or with limited health literacy. We did not specifically include any family members/close-ones, but in all countries family members/close-ones accompanied the patients to interviews and participated in the interviews.

3.2.2 Healthcare professionals

The general inclusion criterion for healthcare professionals was a professional contact with the included patients either at the hospital (emergency room or hospital ward) or in the PHC. The sample of healthcare professionals at the hospital were either responsible for the admission or the discharge of the patient. The healthcare professionals at the PHC were either listed as the patient's CN or GP, or otherwise performed the follow-up of the patient.

3.3 DATA COLLECTION

3.3.1 Paper I, II and III - interviews

3.3.1.1 Interview guide

Data was collected using both individual interviews and focus group interviews. The interview guides (one for patients, one for healthcare professionals, one for patient focus groups, and one for healthcare professional focus groups) were developed within the HANDOVER project. The guides were developed in English; each country translated the guides, piloted them in a pilot interview and refined them based on the experiences. The interview guides were semi-structured and allowed for follow-up questions and prompts.

All interview guides covered the following topics:
- Experiences from the included patients' most recent handover – e.g. handover performance of the stakeholders in the specific care episode, own and/or families'/close-ones' participation in the handover (patient interviews).

- Experiences of the most recent handover with the included patient – e.g. satisfaction and experience with handover performance, roles/tasks/responsibilities of involved professionals and patients, methods used to transfer information (healthcare professional interviews).

- Previous experiences of handover – roles/tasks/responsibilities of the involved healthcare professionals and the patients, standard performance of a handover, improvement suggestions.

- Examples of positive and/or negative experience of handover.

- Barriers and facilitators for effective handovers.

During the data collection, new questions – e.g. experienced hospital/PHC differences in handover habits – were added to the guides across the countries, based on the preliminary results from the first interviews. The interviews were conducted in the native language of each country, audio-taped and transcribed verbatim according to a jointly decided format [116]. All interviewers had experience of healthcare, either from working as healthcare professionals or as healthcare researchers.

3.3.1.2 Individual interviews

Individual patient interviews were performed to receive the patients' experiences and perspectives both of a specific handover situation and of the patients' handovers in general. For all countries, the research groups collaborated with the included hospitals and received information about patients that fulfilled both the general and the country specific inclusion criteria. These patients were approached at the hospital before the discharge and received both written and verbal information about the project. The interviews were performed 1- 4 weeks after the discharge. They were conducted either at the hospital, the patients' home or at any other place the patient preferred.

Individual interviews with the healthcare professionals were performed in order to receive their experiences of both patient specific and general handovers. The interviews with hospital professionals were performed as soon as possible after the included patient's discharge, but varied from 1-95 days after discharge. Interviews with the PHC professionals were performed after approximately two weeks to allow for follow-up, the range was 9-122 days after discharge. In some cases the healthcare professionals were not able to remember the included patient and/or their handover, either because too long time had passed since the handover or because of the intense flow of patients at their setting. In these cases, only the general part of the interview guide was performed.

3.3.1.3 Focus group interviews

Patient focus group interviews were performed to get patients' general attitudes and perceptions of handovers, based on their own experiences. The patients were recruited from the included hospitals except from the Swedish focus group in which the patients were recruited from the patient organizations of Diabetes Mellitus and Heart/Lung Diseases. Each country performed one focus group, except in Poland where two patient focus groups were performed. Hence, six patient focus groups were performed. The focus groups consisted of three to nine patients, see table 3, and were led by an experienced moderator with one or two observers. The moderator summarized the session at its end, for the patients to add or clarify their statements. The observer(s) added questions and prompts when needed.

Healthcare professional focus group interviews were performed to get healthcare professionals general attitudes to handovers. The interviews were performed with healthcare professionals in profession specific groups (hospital physicians, hospital

nurses, general practitioners, community nurses), except in Italy were two groups were profession specific (hospital nurses and general practitioners) and two groups consisted of a mix of professionals from both hospital and PHC. Hence, 20 healthcare professional focus groups were performed: four groups per country. The focus groups consisted of four to nine professionals, see table 3. The groups were led by an experienced moderator and had one or two observers who could add questions and prompts when needed. At the end, the moderator summarized the session for the professionals to add or clarify their statements.

3.3.2 Paper IV - medical record data

In Sweden, all hospital and PHC record notes relevant to the handover were collected after the patients' discharge: CN and GP notes within 2 weeks prior to the hospitalization, referrals from the PHC to the hospital, paramedic notes during transportation, physician and nurse discharge notes, referrals from the hospital to the PHC, the hospital nurses' web-care notes, as well as CN and GP notes up to 3 months after discharge. The chosen time frame of the PHC allowed for visits prior to hospitalization and follow-up afterwards. The sub-study of paper IV was divided in two parts: one part assessing patient-centeredness in handover records in which 51 records were assessed and one part assessing continuity of care in which 80 records were assessed. Some records were assessed for both patient-centeredness and for continuity of care, see table 5.

Table 5 Patient records reviewed: all records and in each part of the sub-study

	All records	Records assessed for	
		Patient-centeredness in handover records	Continuity of care
PHC records prior hospitalization	22	-	22
Written referrals to hospital	5	5	-
Paramedic notes	13	13	-
Discharge notes	31	31	31
Written referrals to the PHC	2	2	2
PHC records following hospitalization	25	-	25
SUM	**98**	**51**	**80**

In the first part, a template based on the patient-centeredness model described by Stewart et al [23] was developed for assessing patient-centeredness in the records. The original model by Stewart consists of three components (exploring both disease and illness, understanding the whole person, and finding common ground) and was developed for patient-professional communication observation. For assessing medical records, the last component was modified to "information to patients" and "shared understanding/agreement".

The template hence consisted of four patient-centeredness components containing 4-5 aspects each:

- Component 1 "Exploring both the disease and the illness experience" (aspects: reason for visit, feelings, ideas, effects on function, and expectations).

- Component 2 "Understanding the whole person" (aspects: family, life cycle, social support, personality, and context).

- Component 3 "Information to patients" (aspects: problem definition, goals of treatment/management, patient roles, and healthcare professional roles).

- Component 4 "Shared understanding/agreement" (aspects: problem definition, goals of treatment/management, patient roles, and healthcare professional roles).

In the second part, records were reviewed to explore continuity of care. Patients' continuity of care was assessed by tracing their records from handovers to the hospital prior admission: PHC records prior to hospitalization; as well as their records from handovers from hospital to PHC: hospital discharge notes, hospital referrals to PHC, and PHC records following hospitalization. Continuity of care was assessed as 1) interface continuity (encounters with PHC prior to and/or following hospitalization), 2) informational continuity (documented knowledge about hospitalization at PHC following discharge) and 3) follow-up continuity (medical/nursing follow-up of hospitalization at PHC).

3.4   ANALYSIS
Data were analyzed using four different methods, see table 2.

3.4.1 Paper I – qualitative content analysis
The 23 individual Swedish patient interviews were analyzed using qualitative conventional content analysis as described by Hsieh and Shannon [117]. Content analysis is a method that can be used for describing themes and characteristics in communication, and patterns/beliefs [118]. Conventional content analysis is applicable when "existing theory or research literature on a phenomenon is limited", and used when aiming to describe phenomena [117] (page 1279).

The interviews were read in their whole, and thereafter inductively coded by two authors. Only data related to the patients' own participation and interaction with healthcare professionals at handovers was used; that is, no data about for example their experience of care in general. The coding process was continuously discussed among the two coders, and new codes led to re-reading and re-coding of interviews. Based on content links and relations the codes were sorted into 9 categories; e.g. the codes

"patient brings medication list", "patient gives information" and "patient contacts PHC" were sorted into the category "actively participating". The categories were thereafter sorted into two themes: "Experience of participation" and "Enablers for participation". The results were structured after the two interfaces (PHC to hospital and hospital to PHC) to facilitate the reading of the results. Along the process, the findings and analysis were continuously discussed among the authors. The software ATLAS.ti [119] was used to aid the structuring of data.

3.4.2 Paper II – secondary analysis

The 90 international patient interviews (53 individual and 37 focus group interviews) were analyzed in two steps: one national grounded theory analysis and one international, secondary analysis using content analysis.
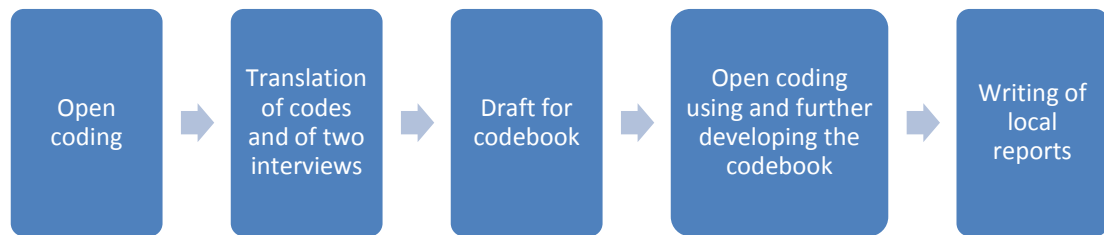
3.4.2.1 Step one: national analysis

The first step of analysis was performed using a Grounded Theory approach according to Corbin and Strauss [120]. In this first step, only open coding was performed and due to the design of the study no theoretical sampling was performed.

Since all interviews were performed in the respective language of each country a translation to English was needed for the development of a joint codebook. Two researchers in each country coded two interviews as open coding in their own language. Thereafter interviews and codes were translated to English. Research members from all five countries brought their translated codes and interviews to a face-to-face meeting to discuss and develop a joint codebook. At this first meeting a draft was developed, including a first attempt to categorize the codes, and to each code and category a definition was included. The draft was continuously revised during numerous telephone-conferences, email correspondence and another face-to-face meeting as more interviews were coded, see figure 2. Comparisons were hence constantly made between and within the countries. The open coding and data collection was parallel until conceptual saturation was reached in each country. All countries used the software Atlas.ti [119] to structure the data.

In the national analysis, researchers in each country analyzed the interviews using the codebook. Each country reported their analysis in three local reports. The three local reports had three different research foci: 1) barriers and facilitators for effective handover; 2) patient roles and responsibilities; 3) patient-centeredness, patient participation and facilitators/barriers for patient-centeredness/patient participation. This resulted in a total of 15 reports, i.e. three reports per country. The local reports were written in English and included quotes.

Figure 2 National data analysis of data to paper II and III

Open coding → Translation of codes and of two interviews → Draft for codebook → Open coding using and further developing the codebook → Writing of local reports

3.4.2.2   Step two: international analysis

In the international analysis for paper II, a secondary analysis of these local reports was performed. Secondary analysis is described by Thorne [121 122] as using already collected data to answer new research questions. In this study, analyzed reports from all countries were analyzed to answer the research question of patient experiences and perspectives of patient participation. The altogether 15 reports were analyzed using qualitative conventional content analysis [117]. The local reports were read one by one, thereafter merged to one text per country to facilitate the reading. The merged reports were coded inductively. The codes were sorted into ten categories; for example the codes "patient delivers discharge report to PHC", "no communication hospital-GP" and "patient as medical secretary" were sorted into the category "patients as the key actors in the handover process". Thereafter the categories were sorted into three themes based on their content relations. The coding and sorting were performed by authors from Sweden and the Netherlands. To ensure that no information was missing or misunderstood the authors of the local reports in Spain, Poland and Italy reviewed the drafts and checked with their original data.

3.4.3   Paper III – meta-synthesis

Paper III used meta-synthesis based on grounded theory analyzes. Both patient and healthcare professional individual and focus group interviews were analyzed. For patients, 53 in individual interviews and 37 in focus group interviews, and for healthcare professionals 139 in individual interviews and 119 in focus group interviews, see table 3 for details.

As with paper II, the analysis needed to be performed in two steps due to the multilingual data. The same codebook as described under paper II was used. Each country analyzed their data using the joint codebook with the focus on patient-centered care, patient participation and barriers/facilitators for patient-centered care. The analyses were reported in one English-written local report per country and included quotes, see figure 2.

In the international analysis, a meta-synthesis [123] of the five reports (one per country) was conducted. The local reports were read one by one, and the categories of the local

reports were synthesized based on their content relations to new categories. The sub-categories of the meta-synthesis hence consist of the categories of the local reports. For example, the sub-categories "Completeness of information", "Understandable/ Clarity of information" and "Too much information" was synthesized to the category "Quality of information provided to patients and relatives". The synthesized 15 categories were sorted into four themes. Hence, no new coding was performed. The sorting was performed by authors from Sweden and the Netherlands. The findings were checked with the authors of reports from Spain, Poland and Italy, and additional quotes that illustrated the findings were provided.

3.4.4 Paper IV – descriptive and analytical statistics

Data in medical records were reviewed [124] and analyzed for 22 Swedish patients. The analysis consisted of two parts: patient-centeredness in handover records and patient-centeredness implying continuity of care. For the analysis of patient-centeredness in handover records, records pertaining to the handover were studied: referrals to and from the hospital, paramedic notes and discharge notes. For the analysis of continuity of care, records that contained information about continuity of care were studied: PHC records prior to and after hospitalization, discharge notes, and referrals to PHC.

The software SPPS Statistics 20 was used for the statistical calculations: descriptive and analytical statistics. For descriptive statistics conventional methods were used to calculate percentages, means, and medians. For the analytical statistics the patient-centeredness components were dichotomized to poor (0-1 aspects covered) and good (more than 2 aspects covered), continuity of care to having and not having continuity of care, discharge information send to having and not having information sent, and having request for follow-up and not having request for follow-up. Due to the small sample size, Fisher's exact test [125] was used to calculate associations between patient-centeredness in the handover records and patient age groups (≤ 67 years, > 67 years), male-female patients, male-female healthcare professionals, and nurses-physicians. Fisher's exact test was also used to calculate associations between patient-centeredness in handover records and continuity of care; associations between having discharge information sent and continuity of care; and associations between request for follow-up in sent discharge information and continuity of care.

3.5 ETHICAL CONSIDERATIONS

Patients signed a consent stating that they could withdraw their participation in the project at any time without any consequences. This consent was signed after the patients had received both written and verbal information about the project.
Each country received ethical approval for the study, in accordance with the EU Grant Agreement (No. 223409). The Swedish part of the study was approved by the Regional Ethics Review Board in Stockholm, Sweden (No. 2008/1933-31/2).

4 RESULTS

The findings from the papers are presented under the two main foci of research in this thesis: patient participation and patient-centeredness. The findings are structured according to the definitions in the thesis, with the addition of facilitators and barriers towards patient participation and patient-centeredness.

The number within brackets refers to the papers I, II, III, and IV.

4.1 PATIENT PARTICIPATION

Patient participation is defined as the patients' execution of and capacity for own verbal and/or non-verbal activities in information exchange with healthcare professionals, and in handovers.

4.1.1 Execution of verbal and non-verbal activities

Patients participated in the exchange of information with the healthcare professionals by verbal activities: sharing information about past and present acute conditions, care episodes and medications (I, II); conveying their needs (I); asking questions (I, II); specifying to which PHC the discharge information should be sent (I, II); and participating in the choice of rehabilitation centers (III). Patients also participated through non-verbal activities: collecting and storing information from their encounters with healthcare professionals to present at the next level of care (II) and by bringing medication list from home, referrals from the PHC to the hospital and discharge notes from the hospital to PHC (I, II). Patients also contacted the PHC to schedule an appointment for the follow-up (I), and to ensure continuity of care by conveying information between the hospital and PHC (I, II).

The level of activity varied from passive to active. Passive participants were those who assumed that healthcare professionals performed the handovers (II) or those who did not consider participation a patient task (I). Active participants were those who took tasks and responsibility upon themselves for the transfer of information (I, II), functioned as the key actors in the handover process (II) and left the hospital before the discharge encounter when getting tired of waiting for the professionals to appear (I). Patients' participation was also found in shared collaboration with healthcare professional when asked (I, II) or advised (III) to contact their PHC after the discharge. In paper IV statements about patient roles were lacking in all the studied records.

4.1.2 Capacity for verbal and non-verbal activities

Patients' capacity for participation was reduced by their frail health condition (I), or low health literacy (II). On the other hand the capacity was strengthened by their personality (I), discipline (II), previous experiences (I) or their family/social network that could replace the patient as an active participant (I, II). Patients also felt

empowered by taking own responsibility in the handover process; by participating in the transferring of information they received knew knowledge and could ascertain information (II).

4.1.3 Facilitators and barriers to patient participation

Patients' execution of verbal and non-verbal activities was not only affected by their capacity but also by other factors.

Facilitators for patient participation were the healthcare professionals' attitudes (I, II). When patients perceived a positive, open atmosphere (I, II) with healthcare professionals who sat down by the bed (I); had a relaxed and personal manner (I, II); gave personal adjusted information (I); encouraged the patients to share their information (II); and responded to the patients' information (I) they were more willing to communicate (I, II). Another facilitator was formal discharge encounters; meetings between the patient and the healthcare professional in order to get information about the discharge (I, II).

Barriers for participation were a negative communicative climate (I, II, II) with healthcare professionals questioning (I), neglecting (II), or not acting upon (I) patients' information. Patients also limited the information they shared at the ER during admission and at PHC during follow-up when they perceived that the healthcare professionals had all information in the computer/medical record (I), asked few questions (I), or when the situation was perceived as stressful (I, II). They wanted to communicate with healthcare professionals they felt comfortable with and limited information to those they distrusted (I). Patients needed information about their situation for participation in handovers (II); participation was hence hindered when information was provided in a medical jargon (III), without time for questions (III), and in between other activities instead of in discharge encounters (I, II, III).

Patients expressed that their participation was an important part of their continuity of care; they had experienced that no information was conveyed unless they did it themselves (I, II). They preferred to take responsibility since it improved the handover (II). Patients were guided in their participation by their beliefs; those who believed that there was an instant transfer of medical record information between settings limited their participation (I). Other patients had a preference for healthcare professionals being responsible since they experienced such handovers to be more effective (II).

4.2 PATIENT-CENTEREDNESS

Patient-centeredness is defined as the patient 1) being respected and treated as an individual, whole person, 2) receiving treatment, care and information in a responsive relationship with healthcare professionals, and 3) having access to care and continuity of care.

4.2.1 Patient as individual whole person

Patients and healthcare professionals stated the importance of addressing and discussing patients' preferences and social/emotional needs at discharge (III). Patients had both positive experiences of treatment on a personal level (II), as well as negative experiences with little awareness of and neglected needs (II, III). They acknowledged more focus on the medical/caring needs than on emotional needs (III). This was also found in paper IV, the medical reason for visit was documented in 98% of the records, but none documented anything about patients' reflections about the illness/disease or about social support (IV). Healthcare professionals valued preparing patients with complex care needs for the discharge; but at the same time both patients and CNs expressed that patient resources and self-management skills were often overestimated (III). Professionals also described abrupt discharges without time to prepare patients for post-discharge care (III).

4.2.2 Responsive relationship

Patients experienced responsive and non-responsive relationships in the handover process. Patients found that healthcare professionals responded to and understood their information/situation (I), adjusted the communicated information (I), showed respect (II) and encouraged patients to share their information (II). Patients had positive experiences of receiving information about handover arrangements (I), and hospital nurses described approaches to enhance clarity of information; e.g. checking understanding, involving family/close-ones, demonstration of self-management tasks (III).

Patients and healthcare professionals also experienced non-responsive relations. Patients had experienced healthcare professionals questioning or not acting upon their information (I), making decisions against their will (I), being too busy to communicate (II), or communicating in a medical-technical jargon (III). Healthcare professionals on their side experienced both giving overload of non-prioritized information (III) as well as patients receiving insufficient information at discharge (III). The majority of the healthcare professionals did not document information to patients (92%) or shared understanding/agreement (98%) (IV).

Discharge encounters were overall experienced as important but non-prioritized (I, II, III). Patients expressed the importance of discharge encounters as a forum for information exchange and communication (II, III). The discharge encounters were held in a rush or between other activities and at times convenient for the professionals but not for the patients' families/close-ones (III). The daily work with emergent admissions and other patients' medical and caring needs were given priority over discharge encounters (III).

4.2.3 Access to care and continuity of care

Patients stated that continuity of care relied on their own effort and responsibility (I, II). Patients also described faith in a handover system that usually ensured them continuity of care (I).

The healthcare professionals described organizational problems with few hospital beds resulting in earlier discharges and patients risking both lacking access to care and re-admissions (III). The professionals found coordination of care difficult to handle during discharges at weekends (III).

Two thirds of the patients had continuity of care at the PHC-hospital interface at admission. At the interface-out after discharge 82% of the patients had an encounter with their PHC within 3 months, 68% of the patients' PHC professional had documented knowledge of the patients' hospitalization, and 55% of the patients received a follow-up of the problems causing the hospitalization (IV). The follow-up continuity was not associated with either sent discharge information (referrals or discharge notes sent to the PHC) or with a documented request for follow-up in the sent discharge information (IV).

4.2.4 Facilitators and barriers to patient-centeredness

Overall, healthcare professionals identified lack of time as the main barrier for patient-centeredness at handovers (III). The shortage of time forced them to prioritize medical and nursing care to other patients rather than on the discharge encounters with patients about to be discharged (III). Another barrier for discharge encounters was the interruptions by emergent cases, and the shift work which lead to healthcare professionals discharging patients without knowledge about them or their specific needs (III). The non-prioritized discharge encounters on their hand were a barrier for patients' informational needs. Patients did not receive as much information as needed to be well-prepared for the post-discharge follow-up (II), and without sufficient information from the healthcare professional the handover responsibility was more difficult to handle (II). In some cases the patient left the hospital before the discharge encounter after they had been waiting in vain for the professionals to show up (I).

5 DISCUSSION

This chapter includes a general discussion of results and interpretation of results following systems theory, a methodological discussion, conclusions and implications for practice.

5.1 DISCUSSION OF RESULTS

Our result shows that patients participated in handovers both verbally by information exchange as well as non-verbally by transferring information. Prerequisites for participation were patients' own capacity; healthcare professionals' attitudes and behavior; and organizational factors such as allocated time. Patients and professionals experienced patient-centered handovers with needs addressed and discussed; responsive relations in which personalized information was provided to patients; and with patients receiving continuity of care. Non patient-centered handovers were also experienced: patients' skill/resources were overestimated; professionals gave unadjusted, insufficient or overload of information; and discharge encounters were non-prioritized. Organizational factors such as lack of time; emergent needs of other patients; and shift work resulted in non patient-centered handovers. Patient-centeredness was overall lacking in the medical records.

5.1.1 Patient participation and patient-centeredness

From the patients' perspectives, transferring information gave insights in care and treatment, and patients felt empowered by the increased knowledge. From a continuity of care perspective, patients had a role as couriers in handovers both to and from the hospital: few referrals reached ER at admission, and neither sent discharge information nor request for follow-up could guarantee patients a follow-up at the PHC. Patients' verbal and non-verbal participation could hence make a difference for their continuity of care. Even though a randomized controlled trial found that using the geriatric patients as deliverer of discharge summaries were significantly less effective than fax or email [86], the authors add that giving patients a copy might serve as a back-up and that younger patients might gain better results [86]. Patient participation may not serve as *the* solution to quality chasms in handovers; rather the contribution should be sought in patients' positive experiences of participation, their increased knowledge and their additional function as an extra safety net combined with healthcare professionals' handovers. However, when involving patients in a shared handover, the question of responsibility must be addressed. Patients who are willing and capable should have the possibility to *take* responsibility for handovers; the healthcare professionals on the other hand should *have* the overall responsibility for patient handovers. Hence, there is a difference between patients taking responsibility for their own health by adding information to the professionals' handovers, and patients taking overall responsibility for the handover. This is in line with several studies that define patient participation not as patient responsibility but as sharing power [7 10], knowledge [5 17], leadership [14] and responsibility [18] with the professionals.

In order to manage being the extra safety net, patients must get the information needed to be transferred from the healthcare professionals. Information about the handover process – how information is transferred and by whom – must also be made visible for the patients. Our findings show that patients had false assumptions about the process that affected their participation. Experiences from a Swedish collaboration project where community social workers worked at a hospital geriatric ward to inform and educate patients about the discharge planning has shown an increase in patients' participation, preparedness and understanding of the discharge process, as well as their feeling of security for the return home [126]. Based on our results, patients had learned about the handover process through their own experiences as patients. This knowledge should not have to be learned by doing, but preferably through either written or verbal information. One way would be to further improve, and use, the Patient Handbook by the National Board of Health and Welfare [127].

Despite the possible advantages of a shared handover system, the patients expressed preferences for either being key actors themselves or for healthcare professionals being responsible. These preferences could be caused by patients preferring a handover system with clarity about patient and healthcare professional roles and responsibilities. These preferences are interesting in Sweden, since Swedish patients described most experiences with a shared collaboration. The possible preference for a clear handover system could be emphasized due to the past years changes in healthcare structure with healthcare providers in both private and community healthcare [128] which has led to a more fragmented system [52]. Further, Sweden is the only of the studied countries without a gate-keeping general practitioner for the hospital access. Busse et al stated that patients receiving care in non gate-keeping systems have to take more responsibility and organize their own care pathways [43]: following the absence of a non gate-keeping function is the absence of a function with overall responsibility of the patients' care transitions.

Besides patient experience and knowledge, patient participation and patient-professional communication also seems to follow cultural [103 129], socio-economic [130 131] and illness characteristics [8]. In our studied countries, patients had positions as key actors, actors with shared responsibility or actors without responsibility in the handover process. The patterns were most distinct in Poland (key actor), Sweden (shared) and the Netherlands (without) even though descriptions of the patients' different positions were found across countries. Patients expressed preferences either for being key actor or actor without responsibility. We have not found any studies on country differences for participation in handovers, but on decision-making; patients in Spain and Poland preferred healthcare professionals to be responsible for decision-making, whereas Italian and Swedish patients preferred shared decision-making [103]. This partly contradicts our findings where several Italian and Swedish patients preferred healthcare professionals as the key actors, while the Spanish patients were the only ones *not* mentioning any preferences regarding responsibility. This may be related to contextual factors of our study – the Spanish patients having health illiteracy, and the

Italian and Swedish patients suffering acute conditions. This interpretation is confirmed in a review by Davis et al [8] who found that patients who are admitted to emergency care have fewer opportunities for participation and patients who are severely ill are more passive. However, patients with limited health literacy in other studies preferred their healthcare professionals to be responsible for decisions [8 130] and preferred a more passive role in decision-making [132].

Patient-centeredness in our definition is closely related to the facilitators and barriers for patient participation. The facilitators were positive attitudes, open atmosphere, personally adjusted information, formal encounters, and healthcare professionals encouraging patients to share information and responding to patients' information. The barriers were distrust, stressful situations, professionals' use of medical jargon, and healthcare professionals questioning, neglecting or not acting upon patient information. These facilitators and barriers are all part of the definition "patient being respected and treated as an individual, whole person and receiving treatment/care in a responsive relationship" [23-32 133]. Findings from discharge planning and rehabilitation processes have also shown that the behavior of healthcare professionals affect patients' participation [74 134]. In this interaction, patient participation is often considered as a shift in power – from the professionals to the patients [5 7 10]. Such sharing of power seems unlikely to appear when the professionals encounter the patient with a non patient-centered attitude. Studies of healthcare professional-patient interaction have found that the influence not only flows from the professional to the patient, but also the other way around. Physicians had more patient-centered communication with patients who the physicians perceived as good communicators [135] and who participated actively verbally by asking questions and expressing concerns [20 136].

Additionally, the identified barriers to patient-centeredness were related to organizational factors: lack of time, interruptions by emergent cases and shift work. In the same way as the healthcare professionals' attitude and behavior were prerequisites for patient participation, the organizational factors were the prerequisites for patient-centeredness. The organizations hence can influence not only patient-centeredness but also patient participation by creating an environment that facilitates patient-centered encounters. Examples of such facilitators are organizations promoting a patient-centered culture by making patient-professional communication and responsive relationships part of organizational policy [36]. A comparison of our finding of patient-centeredness to the patient-centered interventions proven effective for improving handovers shows that several interventions [83 84 87 137] have added an extra working resource for performing the handover tasks and interacting with patients at discharge. The healthcare professionals' identification of time and work processes as barriers towards patient-centered handovers therefore seems relevant, even though one study had positive outcomes despite no additional professionals [138].

5.1.2 Theoretical application of systems theory

5.1.2.1 Microsystem

Healthcare is a system of both patients and of healthcare professionals; in the microsystem they meet and form a dyad. Their interaction – in form of both patients' participation and the patient-centeredness of healthcare professionals – appears on the stage of the microsystem. In this thesis, the dyadic interaction includes both aspects of observation and joint activities, as well as examples of primary dyads [110]. Examples of observational dyads were patients' experiences of healthcare professionals asking few questions and patients' beliefs that the professionals had all information in the computer. This resulted in passive patients not giving any information and hindered a joint activity and reciprocity to appear [110]. Joint activities were also found, both at the ER, at the wards, and in PHC. One example is healthcare professionals' patient-centered behavior that encouraged patients to share information. The metaphor (previously used in the theoretical framework chapter 1.5.1.1) with a ping-pong game can here illustrate the professionals adjusting pace and level to the patients, resulting in reciprocity and enhanced information exchange. Bronfenbrenner consider reciprocity to follow the joint activity, and that the reciprocity can improve over time [110]. It seems however that our studied patients not only increased the reciprocity with specific healthcare professionals in dyads but also with the different microsystems. Previous experiences had taught them when they needed to be active, and this was applied within similar microsystems. The dyadic relation may especially in the hospital setting have few possibilities of advancing from the joint activity dyad to the primary dyad due to the short hospital stays. Even though relational continuity [38] was not in focus for this thesis, patients gave examples of preferences for such continuity and described preferring to share information with professionals they knew and trusted, i.e. in a primary dyad. In that aspect, relational continuity seem to increase informational exchange and in the extension also informational continuity.

During the handovers, patients enter several different microsystems: at the ER, the ward and PHC. Some microsystems may be familiar since previous encounters, but others may be new. For some patients, the care transition is hence also an ecological transition involving a change in their position and a change of role. According to Bronfenbrenner "roles have a magiclike power to alter how a person is treated, how she acts, what she does, and thereby even what she thinks and feels" [110] (page 6). The same patient is entering different microsystems with different – and altering – needs and values [106 110], that the healthcare professionals must meet. Patient-centeredness is hence not a static concept but included in the term is that the healthcare professionals in each and every microsystem have to acknowledge the patient in that specific situation. This means that professionals must have an attentive approach. The need for patients' (and/or their families/close-ones') information about their self-management, previous care episodes and current emotional situation etc is obvious. Professionals may risk missing important information about the patient by only following standardized assessments without close interaction with the patients [139].

The microsystem is, as stated, also the microsystem of the healthcare professional. The professionals' involvement in the patients' participation process is emphasized in Shier's ladder of participation [18]. On the microlevel, the professionals' openness or willingness to involve the patient is one of the steps towards increased participation. In this thesis, the professionals' attitude was an often stated and important part of the prerequisites for patient participation

5.1.2.2 Mesosystem

Patients' handovers includes by definition a mesosystem of interrelated microsystems [140]. Clinical microsystems are considered as the "building blocks" of healthcare systems [112]. This would then make the mesosystem the cement that holds the blocks together, building a gap free healthcare. Based on our findings, there are four different interconnections that link the microsystem either alone or in combination with each other: 1) the patients or their family/close-ones are the interconnection through their verbal participation; 2) the patients or their family/close-ones through their transfer of written information; 3) the healthcare professionals through their verbal communication; or 4) the professionals through exchange of written information. In our studies, the interconnections between microsystems seemed to follow from the interaction within the microsystems. For managing the transfer of information, patients had to receive understandable and, preferably personally adjusted, information. Healthcare professionals' ability to assess patients' skills and resources also echoed on the patients' opportunities for self-management at home. Patient and healthcare professional activities within the microsystem both affected the patient in the home setting as well as the interrelated microsystems. This is in line with Nelson et al's statement that patients' self-management and the healthcare professionals' ability to assess patient self-management affects not only the microsystem but also the surrounding systems [141].

Our findings revealed that healthcare professionals had to prioritize care for patients at the ward, instead of discharge encounters. The prioritization of the own part of the system instead of collaboration between the parts were also found in a study of chain of care for new mothers [142]. The studied midwives were aware of the importance of collaboration between settings, but they did not consider collaboration to benefit their daily work [142]. Priorities on the own microsystem instead of on the mesosystem – regardless of the reason for the decisions – may unfortunately boomerang back to the own microsystem with re-hospitalization of the patient [61-65].

It has been suggested that patients consider their way through handovers as horizontal and seamless whereas it in reality is a vertical way through hierarchal levels [106] and far from seamless [57-66]. According to communications theory, communication between two parts is not possible without meta-communication, i.e. communication about the communication like questions "can you explain this?" [105]. Following this, the written information exchange between healthcare professionals that is the basis for most handovers [77] does not meet the standards for well-functioning communication if not the involved parts writes/calls back to check their understanding. This is in line with

our findings of a non-association between continuity of care and sent discharge information, and patients' experience that no handover occurred if the patients themselves did not take responsibility.

5.1.2.3 Exosystem

Both patients and healthcare professionals gave examples of organizational factors that either hindered or facilitated patient participation and patient-centeredness. The organizational hinders left the patients experiencing stressed healthcare professionals without sufficient time for their interaction, and it also left the healthcare professionals in a vulnerable situation between their employer and their patient. A similar situation of the healthcare professionals was also found in a qualitative study of discharges in UK where the healthcare professionals described being "in the midst of competing internal and external pressures" [143]. Organizational support has also previously been identified as an important factor for healthcare professionals' sharing of power and responsibility with patients [6].

According to Shier's theory of participation [18], the healthcare professionals must have allocated time, knowledge and skills to facilitate the patients' participation. Following our findings, the professionals' opportunity for involving the patients and having patient-centered approach may hence have to be facilitated by added resources (e.g. time and re-organization of work) from the organization. Obligation is Shier's third level of commitment for professionals and organizations striving for patient participation [18]. Obligation refers to the organization having a policy that professionals must work in a specific way that enables participation [18]. This level of commitment was not found in this thesis. On a macrolevel, legislations are promoting patient participation and patient-centeredness, but we did not find any statements about the organization enabling or demanding a specific way of work on the exolevel. Enabling participation is not the sole work of the individual patient or professional but also of the context in which they interact.

5.1.2.4 Macrosystem

The macrosystem consist of the culture, beliefs and values in the setting, as well as expectations on how patients and healthcare professionals are to act towards each other [110]. As exemplified in chapters 1.1.1 and 1.1.2 patient participation and patient-centeredness have received major recognition. Our studied countries have also, either on macrolevel or microlevel, legislations that encourage patient participation and patient-centeredness [96-100]. Patients and healthcare professionals hence enter the encounter with expectations on the other ones behavior. Several of our studied patients, especially those in Poland, were older patients who grew up in a different era, politically, culturally and socially. The Spanish patients could also be considered belonging to sub-cultures of the Spanish society due to their minority background. Their expectations may differ from patients in their own countries with different backgrounds. For healthcare professionals, each encounter with patients must hence include an assessment of that particular patient's beliefs, values and expectations.

A paradox seems to have been built into the macrosystem of healthcare in Sweden. Legislations and regulations are promoting patient-centeredness and collaboration [101 102] whereas other legislation [144] promote both competition between healthcare providers as well as patients' changes of healthcare providers. PHC and hospitals are addressing partly different needs of patients, and may not be competitors of the same patients. Still, a system encouraging competition among healthcare providers encourages focus on the healthcare professional's own hospital or PHC, not on collaboration. Such focus was also, as stated in chapter 5.1.2.2, identified with the healthcare professionals [142].

5.1.2.5 Chronosystem

This thesis has not specifically focused on the historic time in which the patients and professionals interact and how it affects participation and patient-centeredness. As stated above in chapters 1.1.1 and 1.1.2, patient participation and patient-centeredness is a product of the second half of the 1900's [2-4 23]. This shift in power, from the traditional paternalistic era, is acknowledged in legislations as well as in research and could have affected patients' and professionals' attitudes and behavior. However, this was not mentioned by either patients or professionals. Instead patients considered time as an aspect in their individual life course. Patients' experiences during their life course with chronic disease had taught them how to communicate and be active. The events of earlier handovers had also changed the patients' awareness to PHC knowledge about hospitalization.

5.2   DISCUSSION OF METHODS
The qualitative papers I-III are first discussed, and thereafter the quantitative paper IV.

5.2.1 Qualitative papers: papers I, II and III
The patient studies, papers I and II, used partly similar but substantially different methods of analysis. In paper I, patient interviews were analyzed using conventional qualitative content analysis [117]. In paper II, a secondary analysis [121 122] was used merging local reports with three different foci to one and thereafter coding these merged reports. We choose this approach since aspects of patient participation were present in all these three local reports and we risked missing elements by not including all three. The merged reports were analyzed using conventional qualitative content analysis [117]. The findings from paper I are overall more detailed than in paper II. The design of paper II hence resulted in fewer details, but a broad spectrum of patients' perspectives in different countries and settings.

In paper III, we used meta-synthesis [123] of local reports which were analyzed using a grounded theory approach [120]. The major modification of grounded theory is that no axial coding was performed in the national analysis of the local reports; the reports included only open coding. In the synthesis of local reports axial coding was conducted

linking the categories to their subcategories and into themes. However, no core category was identified; instead, a hypothesis was derived based on the four themes.

It can be discussed whether the secondary analysis in paper II is not to be considered as a meta-synthesis as used in paper III, since the data analyzed are not primary data but findings of the local reports. The reasons for labeling the analysis secondary analysis are that a new research question was to be answered and a new analysis (content analysis) was performed. In paper III, the meta-synthesis included axial coding of the open codes but not a new coding process.

5.2.1.1 Methodological issues in the multinational studies

The international papers II and III emanates from the HANDOVER-project [114]. Performing qualitative studies in different countries is accompanied by linguistic challenges [145]. A limitation of the papers II and III is that no formally trained translators/interpreters were used. The translations of the interview guides were conducted by the researchers in the countries, not by professional translators, and not by using a forward-backward method. However, in qualitative semi-structured interview guides, the exact wording is not crucial [146]. The interviewers must be aware that the aims of the study are clear and achieved within the interviews, but the wording of the questions changes from interview to interview. The interviewers were involved either, or both, in the local research groups and the HANDOVER-project meetings and therein discussed aim of the studies thoroughly. Another translation issue was that the secondary analysis and meta-synthesis was performed by Dutch and Swedish speaking researchers on data written in English by authors from the five countries. The risk of linguistic misinterpretations has however been minimized since the authors of the local reports read the secondary analysis and meta-synthesis, gave feedback and co-authored the papers.

Despite the standardized approach in data collection [116], there were differences among the countries. First, in the Netherlands no individual interviews were performed with community nurses. Second, in Spain only three patients participated in the patient focus group. Third, in Poland a larger amount of interviews was analyzed but only a few with community nurses. Fourth, Italy had a mix of healthcare professionals in two focus groups and did not perform a focus group interview with community nurses. Fifth, Sweden only included one hospital instead of two as in the other countries and recruited patients from patient organizations instead of from the hospital for the focus group interview. There was also a wide variation within countries regarding number of days between day of discharge and interview performance. Most differences between countries were due to practical reasons. The obstacles were also spread over the countries and over professionals/patients, which could level out the differences.

Multinational studies present an opportunity to access both perspectives from within-countries (as in papers I and IV) and from across-countries (as in papers II and III). In papers II and III findings showed differences among the countries, as well as within countries, but overall most findings were addressed across countries. In multinational

qualitative studies, as in all studies, a sampling must be performed. This sampling naturally includes more participants in multinational studies. In papers II and III the descriptions of the participants were less thick than what is normally preferred for qualitative studies, and the findings may be considered too general. On the other hand, the sampling of patients from different contexts may also add variation that enhances the credibility. The findings also present an overview of perspectives that can improve the understanding of patient participation and patient-centeredness in different contexts.

5.2.1.2 Trustworthiness

Credibility, the intern validity, of a study refers to if it measures what it intends to measure [147 148]. Data triangulation – aiming to capture multiple perspectives – was used both as person, researcher and space triangulation [125 147]. For person triangulation, papers II and III included both individual and focus group interviews and in paper III also data from both patients and healthcare professionals. In papers I, II and III triangulation of researchers [147] was used: two researchers per country performed the interviews. In Sweden, the interviewers had different professional backgrounds (registered nurse and medical social worker). However, in Sweden the interviewers were hospital based in their profession, which may have caused too much focus on the hospital setting. In the other countries the interviewers' backgrounds were more varied (hospital nurse, midwife, general practitioner, healthcare researcher). In Spain, with focus on cultural minorities/health literacy, the interviews and analysis were performed by a registered nurse and a midwife, living in Spain, but born and raised in other countries. For space triangulation, the design of papers II and III involved data from multiple countries and also from different hospitals within the countries, except for Sweden. A modified version of member-checks [147] was used in papers II and III; the researchers who conducted the local reports were asked to review, revise or confirm the findings in the secondary analysis (paper II) and in the meta-synthesis of findings (paper III). Peer-debriefing [147] was also used in all papers to get perspectives, ideas and critic from colleagues not involved in the research project.

Transferability, external validity, or applicability refers to if findings can be transferred to or applicable on other settings than in the ones studied [125 147]. It has been suggested that the level of transferability lies in the eye of the beholder, hence it is the readers who must judge whether the findings can be transferred/applicable in their setting [147]. For being able to make this judgment a thick description of the research is needed [125 147]. For papers II and III, the multi-component design including patients and healthcare professionals from nine hospitals and their surrounding PHCs in five countries in both individual and focus groups have resulted in fewer details about the interviewed persons and in the findings. Data (for example age, number of years in profession) about all analyzed persons were not obtained in all countries which lead to an absence of a thick description of the interviewed persons' characteristics. This makes the transferability of the findings more difficult. At the same time, the multi-setting design of the study could at least to some extent compensate for this.

Dependability, reliability, refers to how well the findings are comparable to findings in similar settings and with similar participants [125 148], and can be achieved through clear descriptions that allows other researchers to follow the "decision trail" used by the authors [147 148]. The decision trails in paper I, allows the reader to follow the analysis process with descriptions and examples of the coding process. In paper II and III the descriptions of the coding process is not exemplified, but is shown in the quotes representing the categories. The decision trails regarding the data collection and analysis in papers II and III were audited by senior researchers in the HANDOVER-project using a standardized approach [116] based on qualitative research criteria [115 149].

Confirmability refers to the objectivity of the research [147], and that the findings reflect the perspectives of the patients and healthcare professionals interviewed and not of the researchers [125]. The use of triangulation of researchers [125 147] in all papers – during both data collection and analysis, and especially the constant discussions among the researchers during the analysis – was done to minimize the risk of findings emerging from the researcher instead of from the data.

5.2.2 Quantitative paper: paper IV

The modification and transfer of the patient-centeredness model by Stewart et al [23] to a medical record review makes it more difficult to assess validity. The original model was tested for validity [23 133], but in paper IV the model was modified: the component "finding common ground" was divided into two components "information to patients" and "shared understanding/agreement". No construct validity test was performed within paper IV. The original component "finding common ground" however included both "information to patients" as well as "shared understanding/agreement" aspects and the validity can therefore be considered as remaining. Another obstacle is the transfer from patient-professional communication to professional documentation. The aspects of patient-centeredness were however assessed as not being specific for verbal communication, but applicable in written documents.

Also, data is lacking about the verbal handovers that might have occurred between professionals at hospital and in PHC. This makes the internal validity – knowing if other factors may have caused the observed relationship [125] – more difficult to assess. For this, we had to rely on unpublished data from the HANDOVER-project which revealed that the Swedish healthcare professionals rarely spoke with each other over telephone. For reliability, the data was assessed using inter-rater reliability [124] with two researchers assessing the data and comparing their assessment with each other's.

5.3 CONCLUSIONS

This thesis highlights that patient participation during handovers occurs both in form of verbal and non-verbal activities. Patient participation depends on patients' own capacity in form of e.g. health condition, previous experiences and available proxies. Facilitators for participation are the presence of formal encounters in which the patients and professionals could exchange information, and healthcare professionals' positive and encouraging attitude and behavior. Barriers are related to healthcare professionals' attitudes; patient beliefs about handover systems; stressful environment and lack of formal discharge encounters.

Patients as well as healthcare professionals in this study acknowledge that considering the patient as a whole person with different needs/values and having responsive relations are important. At the same time, patients and professionals also express that these aspects of patient-centeredness are not always a reality. Discharge encounters which should ensure information exchange between patients and professionals are often lacking, as is documentation about patients' views or about dialogues with the patients. Half of the studied patients received follow-up after discharge, though the follow-up was not associated with having referrals or discharge notes sent to the PHC. Barriers for patient-centeredness are shift work, interruptions by emergent cases and lack of time since it caused the professionals to not focus on the patients but on other patients needing acute care.

Based on the findings in this thesis, improved handovers – ensuring that information reaches the next setting – would mean having formal discharge encounters, preferable with a professional the patient has met during the hospitalization. It would also mean empowering patients and family/close-ones with information, support and education as well as with clarification of the handover process. In such cases, the patients can participate actively through exchange of information about their self-management, care and treatment in the present encounter, the next encounter and the handover between those. A truly patient-centered attitude [29] would also let the patients themselves decide the level of preferred or possible participation. Though it must be made clear for patients that handovers are not their responsibility, but their contribution is important and valued.

Changes to improve handovers by increasing patient-centeredness and patient participation must be addressed at all levels within the healthcare system. Patient participation, patient-centeredness and organizational factors seem to follow each other like a horse and carriage. Even though you could have one without the other, to paraphrase the song by Frank Sinatra, the found facilitators and barriers for patient participation are very similar to our definition of patient-centeredness and the found barriers for patient-centeredness are related to organizational factors. The interactive aspects should be encouraged, an organization providing allocated time and recourses, and a following patient-centered attitude of the healthcare professionals could benefit all involved stakeholders resulting in patient-centered handovers with participating patients.

The findings from this thesis include not only barriers and negative experiences, but also several well-functioning interactions. Improved patient safety has previously focused on misses but is now increasingly paying attention to what works, and the systems' resilience towards adverse events [150]. Enhancing the positive examples and not only diminishing the negative can be applied on the findings of this thesis. This means, from a patient perspective to continue and enhance their verbal and non-verbal participation, and from a professional perspective to continue and strengthen the many positive examples of patient-centered attitude and behavior.

5.4   IMPLICATIONS FOR PRACTICE

The findings of this thesis have several implications for practice.

Firstly, handovers are not to be seen as negotiable parts of the care, but as care. It is as important to have a formal discharge encounter in which the patient and healthcare professionals can discuss and address the needs of the patient, as it is to deliver care to the other patients at the ward. For this to happen, the healthcare organization must provide a facilitating environment with enough resources. Further, the healthcare professionals need to raise their awareness that their specific encounters with the patient are of importance and that all encounters together form the patients' healthcare. Healthcare professionals, both from hospital settings and PHC, could benefit from an extended contact between the levels of care. Such contact – in form of professional exchange, joint meetings, or extended periods at different settings during education – could strengthen the interconnections between microsystems and form a common understanding that the healthcare is one system and that all parts of the system count.

Secondly, patients are strengthened by feelings of empowerment through knowledge and information. Such empowerment should not have to be learned from own experience, but from the healthcare organization. Information about the handover process, the healthcare professionals' roles and responsibilities, as well as patients' possible roles and responsibilities are all factors that could be addressed either through written information in a leaflet, or in encounter with the professionals. The extra resources that such educational effort consumes have been shown to pay back with decreased healthcare usage.

Thirdly, it needs to be further addressed if patient participation and patient-centeredness are to be documented in the medical records and transferred to the next setting. In a healthcare system aiming for integration, ways of ensuring that patients' resources as well as their needs and values are taken into account over the boundaries of today's healthcare must be found.

6 SWEDISH SUMMARY/SVENSK SAMMANFATTNING

BAKGRUND

Patienter som har kroniska sjukdomar har oftast sin ordinarie vårdgivare inom primärvården. När dessa patienter blir akut sjuka, eller sjukdomen förvärras, kan de behöva uppsöka sjukhus. För att sjukhuset ska få information om patientens omsorg, behandling och medicinering inom primärvården behöver information föras över från primärvården till sjukhuset. När patienten skrivs ut från sjukhuset behöver information föras tillbaka från sjukhuset till primärvården. En sådan överföring – där både patienten och informationen om patienten flyttas mellan olika nivåer inom sjukvården – kallas för vårdöverföring. Vårdöverföringar är förenat med risker: studier visar att både vårdskador (såsom förvärrat sjukdomstillstånd och återinläggning på sjukhus) och tillbud (såsom felaktig medicinering som kunnat medföra vårdskada) inträffar vid vårdöverföringar såväl vid inläggningen på sjukhus, som vid utskrivningar.

I vetenskapliga studier har det föreslagits att ökad patientdelaktighet och ökad patientcentrerad vård skulle kunna bidra till att förbättra vårdöverföringar. Med förbättrade vårdöverföringar menas att tillräcklig mängd information når nästa vårdgivare snabbare och att negativa konsekvenser såsom återinläggningar på sjukhus minskar. Interventionsstudier har även funnit att återinläggning på sjukhus kan minskas om patienter ges individuell, personligt anpassad information och vård. Det finns otillräcklig kunskap om både patienters och vårdpersonals erfarenheter av och uppfattning om patientdelaktighet och patientcentrerad vård vid vårdöverföringar till och från sjukhus, samt om vad som är underlättande respektive hindrande faktorer för delaktighet och patientcentrerad vårdöverföring.

SYFTE

Syftet med denna avhandling är att fördjupa kunskapen om och förståelsen för patienters och vårdpersonals erfarenheter och perspektiv på patientdelaktighet och patientcentrerad vård vid vårdöverföringar.

METOD

Avhandlingen innehåller fyra delstudier: tre med kvalitativa metoder och en med kvantitativ metod. Data samlades in i Nederländerna, Spanien, Polen, Italien och Sverige.

Vuxna patienter med kroniska sjukdomar – astma, diabetes mellitus typ I eller II, hjärtsvikt, kronisk obstruktiv lungsjukdom (KOL) – samt patienter med sex eller fler läkemedel inkluderades i studien i samband med att de skulle skrivas ut från sjukhus. Samtidigt inkluderades även patientens läkare och/eller sjuksköterska som skrivit in patienten på sjukhuset eller skrivit ut patienten från sjukhuset samt den distriktsläkare och/eller distriktssköterska som behandlade patienten inom primärvården. Patienter och

vårdpersonal intervjuades både individuellt och i fokusgrupper. Journaldata om patienternas vårdöverföringar (t.ex. remisser, epikriser, journalanteckningar från primärvården) samlades in.

Studie I: individuella intervjuer med 23 patienter från Sverige analyserades med kvalitativ innehållsanalys.
Studie II: individuella intervjuer och fokusgruppsintervjuer från 90 patienter i Nederländerna, Spanien, Polen, Italien och Sverige analyserades i två steg: först i varje land med grounded theory sedan för samtliga länder genom sekundär analys med kvalitativ innehållsanalys.
Studie III: individuella intervjuer och fokusgruppsintervjuer med 90 patienter och 258 vårdpersonal i Nederländerna, Spanien, Polen, Italien och Sverige analyserades i två steg: först i varje land med grounded theory sedan för samtliga länder med metasyntes.
Studie IV: journaldata från 22 svenska patienter bedömdes utifrån hur patientcentrerad journalinformationen var, samt om det fanns kontinuitet vid vårdöverföringarna till och från sjukhuset.

RESULTAT
Patientdelaktighet
Patienters delaktighet bestod av både verbala och icke-verbala aktiviteter. Patienterna gav information om sitt nuvarande tillstånd, tidigare liknande tillstånd, vart information skulle skickas och de ställde frågor. Patienter förde även själva över skriftlig information mellan primärvården och sjukhuset, såsom remisser och epikriser. Vid vårdöverföringen till sjukhuset så tog patienter med sig sina medicinlistor hemifrån. Patienternas delaktighet varierade från aktiv till passiv. Patienter beskrev sig som aktiva och huvudansvariga för vårdöverföringen; det hade inte blivit någon vårdkontinuitet om patienterna själva inte fört över information. Patienter beskrev att de delade ansvaret med vårdpersonal, till exempel genom överenskommelse att patienten själv skulle ringa primärvården efter utskrivningen och boka en tid för uppföljning. Andra patienter beskrev att vårdpersonalen skötte all informationsöverföring och att de som patienter inte behövde göra något.

Patienterna beskrev att deras delaktighet dels berodde på deras aktuella hälsotillstånd, men även på deras förmåga att förstå informationen som vårdpersonalen gav. Patienterna beskrev även att deras delaktighet stärktes av deras egen personlighet, deras erfarenheter och av den hjälp/stöd som de fick av familj och andra anhöriga. De kände sig stärkta av den information och kunskap som de fick del av genom att ge/få information samt genom att föra över skriftlig information mellan vårdpersonal.

Hinder för delaktighet bestod av att vårdpersonalen var stressad och inte hade tid för samtal. Ett annat hinder låg i den uppfattning som patienterna hade av hur vårdöverföringen gick till: patienter kunde bedöma att de inte behövde föra över information eller ge information på grund av den direktöverföring som man trodde skedde genom primärvårdens och sjukhusets datorer. Denna missuppfattning stärktes

även av att vårdpersonalen inte ställde så många frågor. Patienterna uppfattade att detta berodde på att vårdpersonalen redan hade all information om dem som behövdes för vårdtillfället.

Faktorer som underlättar för delaktigheten var att vårdpersonalen hade en positiv attityd mot patienterna. Det vill säga, vårdpersonalen satte sig ner hos patienten, hade ett avslappnat och personligt bemötande, gav personligt anpassad information, uppmuntrade patienterna att ge information samt lyssnade på patienten och agerade utifrån hens information. Patienterna beskrev även att det var lättare att ge och få information vid formella utskrivningsmöten än om utskrivningen skedde snabbt och oplanerat.

Patientcentrerade vårdöverföringar

Patienter och vårdpersonal hade erfarenheter av både patientcentrerade vårdöverföringar och av vårdöverföringar som inte var patientcentrerade. Patientcentrerade vårdöverföringar kännetecknades av att patienternas behov uppmärksammades och diskuterades, att mötet mellan patient och vårdpersonal skedde i en relation där det fanns ömsesidigt förtroende, att individuellt anpassad information gavs, samt att patienterna hade vårdkontinuitet.

Journalgranskningen visade att majoriteten, 92 %, av vårdpersonalen inte dokumenterar något om vilken information patienter har fått på sjukhuset. Majoriteten, 98 %, dokumenterade inte något om gemensam förståelse mellan patient och personal avseende till exempel patientens roll efter utskrivningen. Det fanns inte heller något samband mellan att vårdpersonalen hade skickat utskrivningsinformation till primärvården, eller att sjukhuspersonalen begärde en uppföljning, och att patienterna fick uppföljning inom primärvården efter utskrivningen.

Vårdöverföringar som inte var patientcentrerade kännetecknades av att patienternas information inte togs tillvara, att personalens fokus enbart låg på de medicinska behoven och inte på patienten som person, att beslut fattades utan patientens medverkan, att information gavs på ett medicinskt språk som var svårt för patienterna att förstå och att antingen för mycket eller för lite information gavs. Både patienter och vårdpersonal ansåg att det var viktigt att patienterna var väl förberedda för vårdöverföringen från sjukhuset till primärvården och att det fanns formella utskrivningssamtal i vilka information kunde utbytas. Vårdpersonalen förklarade den bristande patientcentreringen med att det fanns lite tid för utskrivningssamtal då man var tvungen att prioritera övriga patienter på vårdavdelningen framför de patienter som skulle skrivas ut. Vårdpersonal beskrev även att skiftarbetet medförde att patienter skrevs ut av någon annan än den personal som träffat patienten under vårdtiden.

SLUTSATSER

Avhandlingen visar att patienter har en roll att fylla som medaktörer vid vårdöverföringar både till och från sjukhus genom överföringar av såväl muntlig som

skriftlig information. Patienternas delaktighet ska dock inte förväxlas med ansvar för vårdöverföringar – ett sådant övergripande ansvar hör till vårdpersonalen. Patienternas delaktighet ska snarare ses som ett komplement, som ett extra säkerhetsnät, till vårdpersonalens överföring. Förbättrade vårdöverföringar – i betydelsen att information når nästa vårdgivare – skulle kunna möjliggöras av följande faktorer: patienters utskrivningar genomförs i formella utskrivningssamtal tillsammans med en vårdpersonal som patienten har träffat kontinuerligt under vårdtiden, patienter stärks genom information, stöd och utbildning, samt förtydligande information om hur vårdöverföringsprocessen går till. Patienten stärks då till ökad delaktighet och kan utbyta information med vårdpersonal om sjukdomstillståndet, vård och behandlingar i såväl det pågående mötet, vid nästa vårdinstans samt vid vårdöverföringen mellan dessa.

Vårdöverföringar ska inte ses som en del av vården, utan som vård. Det är därför lika viktigt att prioritera utskrivningssamtal med patienter som att ge vård till andra inneliggande patienter. Avhandlingen visar även att de underlättande faktorerna för delaktighet har stora likheter med det som beskrivs som patientcentrerad vård och att organisatoriska faktorer (tid för samtal, vårdpersonalens arbetsbelastning och arbetsorganisation) i sin tur påverkar möjligheterna för patientcentrerad vård. Hälso- och sjukvården behöver därför organisera vårdpersonalens arbete så att det finns utrymme för ett patientcentrerat arbetssätt. Detta skulle i sin tur kunna öka patienternas möjlighet till delaktighet både i det direkta mötet med vårdpersonalen och vid vårdöverföringarna.

7 ACKNOWLEDGEMENTS

Some time ago, I read that a thesis had been written about acknowledgements in theses, and I then realized the importance that can be attributed this small part of my own thesis. Regardless of such possible added value, my thesis would not have been written if it were not for all professionals, friends and my family that have supported me and believed in me. To all of you, my warmest and most sincere thank you!

There are however some persons who has contributed more than others, and therefore my especial thanks go to:

The patients and professionals:
The patients and healthcare professionals who took their time to participate in interviews and share their experiences, thoughts and ideas of patient participation and patient-centeredness in the handover process.

The financiers:
The institutions that financially as well as practically made it possible to conduct this thesis: the 7th Framework Programme of the European Union, the Department of Social Work and the Department of Emergency Medicine, Karolinska University Hospital and the Division of Social Work, Department of Neurobiology, Care Sciences and Society, Karolinska Institutet.

My supervisors:
Mariann Olsson, my main supervisor, for your endless patience, experience, curiosity, for your deep knowledge in social work in healthcare, and for always having the patient in focus. I am grateful that you had me in mind when you got involved in the HANDOVER-project and that you with such an ease accepted my struggle to find my own way. It has been a fantastic experience to share this journey – literally around Europe but even more so in my scientific development – with you. I cannot thank you enough.

Helen Hansagi, my co-supervisor, for your everlasting carefulness in all steps of research, from data collection to manuscript drafting. You taught me the importance of checking and re-checking, and about clarity. Your hard work with coordinating the data collection of the European countries gave me insights in the importance of being sensitive to the needs of all involved, but not compromising on scientific values.

Gunnar Öhlén, my co-supervisor, for your guidance in critical episodes, and for your inspiring ways of tackling all obstacles that follow a project: your calm and firm way of discussing, educating and listening is a role model. Your experience of the settings in which our research took place has been invaluable, as well as your ability to see the "bigger picture" and draw conclusions.

Mats Brommels, my co-supervisor, for your work and input especially with the last paper. I do hope that we will have the chance to work together in other projects in the future.

The HANDOVER-team:
Paul Barach, for your hard work with the HANDOVER-project and with my papers. This thesis would not have happened if you had not been.

Gijs Hesselink, for accompanying me as a PhD-student through the HANDOVER - project. It was always a great time discussing, analyzing, writing and discussing again with you. I learned a lot during our co-authorship for paper II and III, especially during the intense week of your stay here in Stockholm. I hope to see you back in Sweden soon!

Fanny Airosa, for your role as project nurse for the HANDOVER-project, for conducting half of all interviews and for always adding new perspectives. You were brilliant in your calm way of coordinating our project, and for being open to all suggestions and ideas. But most of all, thank you for all our talks and laughter about research, being a PhD-student, and about life in general.

Susanne Bergenbrant-Glas, for your energy and enthusiasm during the HANDOVER-project, and co-work with the last paper. It was always fun and inspiring having you on board during the travels through Europe.

All members of the HANDOVER Research Collaborative, for all your contributions – from minor to major – that helped me develop as a researcher and to understand the differences that exist between countries in healthcare settings as in research methods.

Colleagues at the Department of Social Work:
B44 colleagues, for all the discussions and laughter that flow around the lunch room. A special thanks to Malin, my former room-mate, for all the fun we have had sharing these years – it sure has happened a lot! And to Linda, my present room-mate, for research as well as life discussions. A conversation that I hope has only started.

Tina and Charlotte, friends, colleagues and fellows as PhD-students, for finding our way from medical social workers to being PhD-students together.

My former and present employers at Department of Social Work Karolinska University Hospital: Britt Strand, Kerstin Fugl-Meyer, Marianne Jakobsson, for believing in me and for financial as well as emotional support during these years.

My PhD-fellows and the senior colleagues at Doktorandgruppen: Lena, Marie, Lill, Liisa, Mette, Catharina, Ann-Sofie, Aina, Ulla, Pelle.

8 REFERENCES

1. Nolte E, McKee L. Integration and chronic care: a review. In: Nolte E, McKee L, eds. Caring for people with chronic conditions - a health system perspective. Berkshire: Open University Press, 2008.
2. Rothman DJ. The origins and consequences of patient autonomy: A 25-year retrospective. Health Care Analysis 2001;**9**(3):255-64
3. World Health Organization. Primary Health Care - Report of the International Conference on Primary Health Care Alma Ata. International Conference on Primary Health Care. Alma Ata, USSR, 1978.
4. SOU. Patientlag - delbetänkande av patientmaktsutredningen. 2013:2, 2013.
5. Eldh AC. Patient participation – what it is and what it is not. Örebro University, 2006.
6. Longtin Y, Sax H, Leape LL, et al. Patient Participation: Current Knowledge and Applicability to Patient Safety. Mayo Clinic Proceedings 2010;**85**(1):53-62.
7. Sahlsten MJM, Larsson IE, Sjostrom B, et al An analysis of the concept of patient participation. Nurs Forum 2008;**43**(1):2-11.
8. Davis RE, Jacklin R, Sevdalis N, Vincent CA. Patient involvement in patient safety: what factors influence patient participation and engagement? Health Expectations 2007;**10**(3):259-67.
9. Delnoij D, Hafner V, editors. *Exploring patient participation in reducing health-care-related safety risks*. Copenhagen: WHO Regional Office for Europe, 2013.
10. Cahill J. Patient participation: a concept analysis. J Adv Nurs 1996;**24**(3):561-71
11. Harrington J, Noble LM, Newman SP. Improving patients' communication with doctors: a systematic review of intervention studies. Patient Education and Counseling 2004;**52**(1):7-16.
12. Haywood K, Marshall S, Fitzpatrick R. Patient participation in the consultation process: A structured review of intervention strategies. Patient Education and Counseling 2006;**63**(1-2):12-23.
13. National Library of Medicines Database. Secondary 2013. http://www-ncbi-nlm-nih-gov.proxy.kib.ki.se/mesh.
14. Carman KL, Dardess P, Maurer M, et al. Patient and family engagement: a framework for understanding the elements and developing interventions and policies. Health Aff (Millwood) 2013;32(2):223-31.
15. World Health Organization. *Klassifikation av funktionstillstånd, funktionshinder och hälsa* Stockholm: Socialstyrelsen, 2003.
16. World Health Organization. *International Classification of Functioning, Disability and Health: ICF*. Geneva, 2001.
17. Eldh AC, Ekman I, Ehnfors M. A comparison of the concept of patient participation and patients' descriptions as related to healthcare definitions. Int J Nurs Terminol Classif 2010;**21**(1):21-32.
18. Shier H. Pathways to Participation: Openings, Opportunities and Obligations. A New Model for Enhancing Children´s Participation in Decision-making, in line with Article 12.1 of the United Nations Convention on the Rights of the Child. Children & Society 2001;**Volume 15**:107-17
19. Thompson AGH. The meaning of patient involvement and participation in health care consultations: A taxonomy. Social Science & Medicine 2007;**64**(6):1297-310.

20. Cegala DJ, Street RL, Clinch CR. The impact of patient participation on physicians' information provision during a primary care medical interview. Health Communication 2007;**21**(2):177-85

21. Street RL, Gordon HS, Ward MM, et al. Patient participation in medical consultations - Why some patients are more involved than others. Medical Care 2005;**43**(10):960-69

22. Zandbelt LC, Smets EMA, Oort FJ, et al. Patient participation in the medical specialist encounter: Does physicians' patient-centred communication matter? Patient Education and Counseling 2007;**65**(3):396-406.

23. Stewart M, Brown J, Weston W, et al. *Patient-centered Medicine - Transforming the Clinical Method*. Oxon: Radcliffe Medical Press Ltd, 2003.

24. Institute of Medicine. Crossing the quality chasm: a new health system for the twenty-first century. Washington: National Academies Press, 2001.

25. Socialstyrelsen. God vård - om ledningssystem för kvalitet och patientsäkerhet i hälso- och sjukvården. Stockholm, 2006.

26. Gerteis M, Edgman-Levitan S, Daley J, Delbanco TL. *Through the patient's eyes - understanding and promoting patient-centered care*. San Francisco: Jossey-Bass Publishers, 1993.

27. Picker Institute. http://pickerinstitute.org/about/picker-principles/ [Access date: 2013-08-16].

28. Mead N, Bower P. Patient-centredness: a conceptual framework and review of the empirical literature. Social science & medicine (1982) 2000;**51**(7):1087-110

29. Stewart M. Towards a global definition of patient centred care. BMJ 2001;**322**(7284):444-5

30. International Alliance of Patients Organizations. What is Patient-Centred Healthcare - a review of definitions and principles London, UK, 2007.

31. Ekman I, Swedberg K, Taft C,et al. Person-centered care--ready for prime time. European journal of cardiovascular nursing : journal of the Working Group on Cardiovascular Nursing of the European Society of Cardiology 2011;**10**(4):248-51.

32. Ekman I, Wolf A, Olsson LE, et al. Effects of person-centred care in patients with chronic heart failure: the PCC-HF study. European heart journal 2012;**33**(9):1112-9.

33. Wolf A. Person-centred care - Possibilities, barriers and effects in hospitalised patients. University of Gothenburg, 2012.

34. Holmstrom I, Roing M. The relation between patient-centeredness and patient empowerment: a discussion on concepts. Patient Educ Couns 2010;**79**(2):167-72.

35. Berwick DM. What 'patient-centered' should mean: confessions of an extremist. Health Aff (Millwood) 2009;**28**(4):w555-65.

36. Epstein RM, Fiscella K, Lesser CS, Stange KC. Why the nation needs a policy push on patient-centered health care. Health Aff (Millwood) 2010;**29**(8):1489-.

37. Cowie L, Morgan M, White P, Gulliford M. Experience of continuity of care of patients with multiple long-term conditions in England. Journal of Health Services Research & Policy 2009;**14**(2):82-87.

38. Haggerty JL, Reid RJ, Freeman GK, et al. Continuity of care: a multidisciplinary review. BMJ 2003;**327**(7425):1219-21.

39. Coleman EA, Boult C. Improving the quality of transitional care for persons with complex care needs. J Am Geriatr Soc 2003;**51**(4):556-7

40. Merriman ML. Pre-hospital discharge planning: empowering elderly patients through choice. Critical care nursing quarterly 2008;**31**(1):52-8.

41. Hansen LO, Young RS, Hinami K, et al. Interventions to reduce 30-day rehospitalization: a systematic review. Ann Intern Med 2011;**155**(8):520-8.
42. World Health Organization. http://www.who.int/topics/chronic_diseases/en/. [Access date: 2013-10-23]
43. Busse R, Blümel M, Scheller-Kreinsen D, Zentner A. Tackling chronic diseases in Europe - strategies, interventions and challenges The European Observatory on Health Systems and Policies, 2010.
44. World Health Organization. Global status report on noncommunicable diseases 2010. In: Alwan A, ed., 2011.
45. Barnett K, Mercer SW, Norbury M, et al. Epidemiology of multimorbidity and implications for health care, research, and medical education: a cross-sectional study. Lancet 2012;**380**(9836):37-43.
46. Salisbury C, Johnson L, Purdy S, et al. Epidemiology and impact of multimorbidity in primary care: a retrospective cohort study. British Journal of General Practice 2011;**61**(582).
47. Ek K. Livet med mycket svår kronisk obstruktiv lungsjukdom. In: Andershed B, Ternestedt BM, Håkansson C, eds. Palliativ vård - begrepp och perspektiv i teori och praktik. Lund: Studentlitteratur, 2013.
48. Brännström M. Livet med svår hjärtsvikt. In: Andershed B, Ternestedt BM, Håkansson C, eds. Palliativ vård - begrepp och perspektiv i teori och praktik. Lund: Studentlitteratur, 2013.
49. Clark NM. Management of chronic disease by patients. Annu Rev Public Health 2003;**24**:289-313.
50. Mur-Veeman I, van Raak A, Paulus A. Comparing integrated care policy in Europe: does policy matter? Health policy (Amsterdam, Netherlands) 2008;**85**(2):172-83.
51. Schoen C, Osborn R, Squires D, et al. New 2011 survey of patients with complex care needs in eleven countries finds that care is often poorly coordinated. Health Aff (Millwood) 2011;**30**(12):2437-48.
52. Wadmann S, Strandberg-Larsen M, Vrangbaek K. Coordination between primary and secondary healthcare in Denmark and Sweden. Int J Integr Care 2009;**9**:e04
53. Nolte E, McKee M. Caring for people with chronic condition - an introduction. In: E N, McKee M, eds. Caring for people with chronic conditions - a health system perspective. Berkshire: Open University Press, 2008.
54. Ham C. The ten characteristics of the high-performing chronic care system. Health Economics Policy and Law 2010;**5**(1):71-90.
55. Davis K. A New Era in American Health Care: Realizing the Potential of Reform. The Commonwealth Fund, 2010.
56. Naylor MD, Aiken LH, Kurtzman ET, et al. The care span: The importance of transitional care in achieving health reform. Health Aff (Millwood) 2011;**30**(4):746-54.
57. Tam VC, Knowles SR, Cornish PL, et al. Frequency, type and clinical importance of medication history errors at admission to hospital: a systematic review. Canadian Medical Association Journal 2005;**173**(5):510-15.
58. Gleason KM, McDaniel MR, Feinglass J, et al. Results of the Medications at Transitions and Clinical Handoffs (MATCH) study: an analysis of medication reconciliation errors and risk factors at hospital admission. J Gen Intern Med 2010;**25**(5):441-7.
59. Hellstrom LM, Bondesson A, Hoglund P, Eriksson T. Errors in medication history at hospital admission: prevalence and predicting factors. BMC clinical pharmacology 2012;**12**:9.

60. Barton L, Futtermenger J, Gaddi Y, et al. Simple prescribing errors and allergy documentation in medical hospital admissions in Australia and New Zealand. Clinical medicine (London, England) 2012;**12**(2):119-23

61. Arora VM, Prochaska ML, Farnan JM, et al. Problems after discharge and understanding of communication with their primary care physicians among hospitalized seniors: a mixed methods study. Journal of hospital medicine: an official publication of the Society of Hospital Medicine 2010;**5**(7):385-91.

62. Forster AJ, Clark HD, Menard A, et al. Adverse events among medical patients after discharge from hospital. Canadian Medical Association Journal 2004;**170**(3):345-49

63. Forster AJ, Murff HJ, Peterson JF, et al. The incidence and severity of adverse events affecting patients after discharge from the hospital. Annals of Internal Medicine 2003;**138**(3):161-67

64. Jencks SF, Williams MV, Coleman EA. Rehospitalizations among patients in the Medicare fee-for-service program. The New England journal of medicine 2009;**360**(14):1418-28.

65. Vashi AA, Fox JP, Carr BG, et al. Use of hospital-based acute care among patients recently discharged from the hospital. JAMA : the journal of the American Medical Association 2013;**309**(4):364-71.

66. Moore C, Wisnivesky J, Williams S, McGinn T. Medical errors related to discontinuity of care from an inpatient to an outpatient setting. Journal of General Internal Medicine 2003;**18**(8):646-51

67. Oduyebo I, Lehmann CU, Pollack CE, et al. Association of self-reported hospital discharge handoffs with 30-day readmissions. JAMA internal medicine 2013;**173**(8):624-9.

68. Stack P, Forsberg B, Hogberg M, et al. Risken för akut återinläggning kan förutsägas. Läkartidningen 2012;**109**(48):2211-5

69. Fuji KT, Abbott AA, Norris JF. Exploring care transitions from patient, caregiver, and health-care provider perspectives. Clinical nursing research 2013;**22**(3):258-74.

70. Bull MJ, Roberts J. Components of a proper hospital discharge for elders. Journal of Advanced Nursing 2001;**35**(4):571-81

71. Toscan J, Manderson B, Santi SM, Stolee P. "Just another fish in the pond": the transitional care experience of a hip fracture patient. Int J Integr Care 2013;**13**:e023

72. Jackson K, Oelke ND, Besner J, Harrison A. Patient journey: implications for improving and integrating care for older adults with chronic obstructive pulmonary disease. Canadian journal on aging = La revue canadienne du vieillissement 2012;**31**(2):223-33.

73. Almborg A, Ulander K, Thulin A, Berg S. Patients' perceptions of their participation in discharge planning after acute stroke. Journal of Clinical Nursing 2009;**18**(2):199-209

74. Efraimsson E, Sandman PO, Hydén L, Rasmussen BH. Discharge planning: 'fooling ourselves?' -- patient participation in conferences. Journal of Clinical Nursing 2004;**13**(5):562-70

75. Huby G, Brook JH, Thompson A, Tierney A. Capturing the concealed: Interprofessional practice and older patients' participation in decision-making about discharge after acute hospitalization. J Interprof Care 2007;**21**(1):55-67.

76. Rydeman I, Tornkvist L. The patient's vulnerability, dependence and exposed situation in the discharge process: experiences of district nurses, geriatric nurses and social workers. Journal of Clinical Nursing 2006;**15**(10):1299-307.

77. Kripalani S, LeFevre F, Phillips CO, et al. Deficits in communication and information transfer between hospital-based and primary care physicians - Implications for patient safety and continuity of care. Jama-Journal of the American Medical Association 2007;**297**(8):831-41.

78. Kripalani S, Jackson AT, Schnipper JL, Coleman EA. Promoting effective transitions of care at hospital discharge: a review of key issues for hospitalists. Journal of hospital medicine : an official publication of the Society of Hospital Medicine 2007;**2**(5):314-23.

79. Brock J, Mitchell J, Irby K, et al. Association between quality improvement for care transitions in communities and rehospitalizations among Medicare beneficiaries. JAMA: the journal of the American Medical Association 2013;**309**(4):381-91.

80. Hesselink G, Schoonhoven L, Barach P, et al. Improving patient handovers from hospital to primary care: a systematic review. Ann Intern Med 2012;**157**(6):417-28.

81. Carroll Ã, Dowling M. Discharge planning: communication, education and patient participation. British Journal of Nursing (BJN) 2007;**16**(14):882-86

82. Halasyamani L, Kripalani S, Coleman E, et al. Transition of care for hospitalized elderly patients - Development of a discharge checklist for hospitalists. Journal of Hospital Medicine 2006;**1**(6):354-60.

83. Coleman EA, Parry C, Chalmers S, Min SJ. The care transitions intervention - Results of a randomized controlled trial. Archives of Internal Medicine 2006;**166**(17):1822-28

84. Jack BW, Chetty VK, Anthony D, et al. A Reengineered Hospital Discharge Program to Decrease Rehospitalization A Randomized Trial. Annals of Internal Medicine 2009;**150**(3):178-+

85. Coleman EA. Falling through the cracks: challenges and opportunities for improving transitional care for persons with continuous complex care needs. J Am Geriatr Soc 2003;**51**(4):549-55

86. Chen Y, Brennan N, Magrabi F. Is email an effective method for hospital discharge communication? A randomized controlled trial to examine delivery of computer-generated discharge summaries by email, fax, post and patient hand delivery. Int J Med Inform 2010;**79**(3):167-72.

87. Koehler BE, Richter KM, Youngblood L, et al. Reduction of 30-day postdischarge hospital readmission or emergency department (ED) visit rates in high-risk elderly medical patients through delivery of a targeted care bundle. Journal of hospital medicine : an official publication of the Society of Hospital Medicine 2009;**4**(4):211-8.

88. Arnetz JE, Winblad U, Arnetz BB, Hoglund AT. Physicians' and nurses' perceptions of patient involvement in myocardial infarction care. European journal of cardiovascular nursing : journal of the Working Group on Cardiovascular Nursing of the European Society of Cardiology 2008;**7**(2):113-20 doi.

89. Foss C, Hofoss D. Elderly persons' experiences of participation in hospital discharge process. Patient Educ Couns 2011;**85**(1):68-73.

90. Coleman EA, Smith JD, Frank JC, et al. Preparing patients and caregivers to participate in care delivered across settings: the Care Transitions Intervention. J Am Geriatr Soc 2004;**52**(11):1817-25.

91. Parry C, Min SJ, Chugh A, et al. Further application of the care transitions intervention: results of a randomized controlled trial conducted in a fee-for-service setting. Home health care services quarterly 2009;**28**(2-3):84-99.

92. Naylor M, Brooten D, Jones R, et al. Comprehensive discharge planning for the hospitalized elderly. A randomized clinical trial. Ann Intern Med 1994;**120**(12):999-1006

93. Shepperd S, Lannin NA, Clemson LM, et al. Discharge planning from hospital to home. Cochrane Database Syst Rev 2013;**1**:CD000313.

94. Olsson LE, Hansson E, Ekman I, Karlsson J. A cost-effectiveness study of a patient-centred integrated care pathway. J Adv Nurs 2009;**65**(8):1626-35.

95. Reinius P, Johansson M, Fjellner A, et al. A telephone-based case-management intervention reduces healthcare utilization for frequent emergency department visitors. Eur J Emerg Med 2013;**20**(5):327-34.

96. Anell A, Glenngård AH, S. M. Sweden: Health system review: Health Systems in Transition, 2012.

97. García-Armesto S, Abadía-Taira MB, Durán A, et al. Spain: Health system review.: Health Systems in Transition, 2010.

98. Lo Scalzo A, Donatini A, Orzella L, et al. Italy: Health system review: Health Systems in Transition, 2009.

99. Sagan A, Panteli D, Borkowski W, et al. Poland: Health system review: Health Systems in Transition, 2011.

100. Schäfer W, Kroneman M, Boerma W, et al. The Netherlands: Health system review: Health Systems in Transition, 2010.

101. Hälso- och sjukvårdslag. SFS 1982:763, 1982.

102. Socialstyrelsens föreskrifter om samverkan vid in- och utskrivning av patienter i sluten vård. SOSFS 2005:27 2005.

103. Coulter A, Jenkinson C. European patients' views on the responsiveness of health systems and healthcare providers. European Journal of Public Health 2005;**15**(4):355-60.

104. Forsberg G, Wallmark J. *Nätverksboken - om mötets möjligheter*. Stockholm: Liber, 2001.

105. Schjodt B, Egeland TA. *Från systemteori till familjeterapi*. Lund: Studentlitteratur, 1994.

106. Batalden PB, Nelson EC, Godfrey MM, Lazar JS. Introducing clinical microsystems. In: Nelson EC, Batalden PB, Godfrey MM, eds. Value by Design: Developing Clinical Microsystems to Achieve Organizational Excellence. Hoboken: Jossey-Bass, 2011.

107. Andersson G. Utvecklingsekologi och sociala problem In: Meeuwisse A, Swärd H, eds. Perspektiv på sociala problem Stockholm: Natur och Kultur, 2002.

108. Bronfenbrenner U. Ecological systems theory. In: Kazdin AE, ed. Encyclopedia of Psychology, Vol. 3. Washington: American Psychological Association/Oxford University Press, 2000.

109. Bronfenbrenner U. *Making human beings human: bioecological perspectives on human development*. Thousand Oaks, California, USA: Sage Publications, 2005.

110. Bronfenbrenner U. *Ecology of Human Development: Experiments by Nature and Design*. Cambridge: Harvard University Press 1979.

111. Bronfenbrenner U, Morris PA. The Bioecological Model of Human Development. Handbook of Child Psychology. John Wiley & Sons, Inc, 2007.

112. Nelson EC, Godfrey MM, Batalden PB, et al. Clinical microsystems, part 1. The building blocks of health systems. Jt Comm J Qual Patient Saf 2008;**34**(7):367-78

113. Mohr JJ, Batalden P, Barach P. Integrating patient safety into the clinical microsystem. Quality & Safety in Health Care 2004;**13**:34-38.

114. Improving the continuity of patient care through identification and implementation of novel patient handover processes in Europe. Secondary Improving the continuity of patient care through identification and implementation of novel patient handover processes in Europe. www.handover.eu.

115. Tong A, Sainsbury P, Craig J. Consolidated criteria for reporting qualitative research (COREQ): a 32-item checklist for interviews and focus groups. International Journal for Quality in Health Care 2007;**19**(6):349-.

116. Johnson JK, Barach P, Vernooij-Dassen M. Conducting a multicentre and multinational qualitative study on patient transitions. BMJ quality & safety 2012;**21** Suppl 1:i22-8.

117. Hsieh HF, Shannon SE. Three approaches to qualitative content analysis. Qualitative Health Research 2005;**15**(9):1277-88.

118. Downe-Wamboldt B. Content analysis: method, applications, and issues. Health care for women international 1992;**13**(3):313-21.

119. ATLAS.ti Scientific Software Development Company, GmbH, Berlin, Germany. Secondary ATLAS.ti Scientific Software Development Company, GmbH, Berlin, Germany. http://www.atlasti.com/.

120. Corbin J, Strauss A. Grounded theory research: Procedures, canons, and evaluative criteria Qualitative Sociology 1990;**13**(1):3-21

121. Thorne S. Secondary analysis in qualitative research: Issues and implications. In: Morse J, ed. Critical issues in qualitative research methods: Thousand Oaks, Sage Publications, 1994:263-79.

122. Thorne S. Ethical and representational issues in qualitative secondary analysis. Qualitative Health Research 1998;**8**(4):547-55

123. Zimmer L. Qualitative meta-synthesis: a question of dialoguing with texts. Journal of Advanced Nursing 2006;**53**(3):311-.

124. Epstein I. *Clinical data-mining - Integrating practice and research*. New York: Oxford University Press Inc, 2010.

125. Polit DF, Beck CT. *Nursing research: generating and assessing evidence for nursing practice*. 8th ed. Philadelphia: Lippincott Williams & Wilkins, 2008.

126. Österman J, Karp A. Att få inflytande över sin egen vårdplanering: Äldrevägledare i Nacka kommun - en modell för att förbereda den äldre inför samordnad vårdplanering: Äldrecentrum - Forskning och utveckling. 2012.

127. Socialstyrelsen. *Min guide till säker vård*. Västerås: Edita Västra Aros, 2011.

128. Assarsson J, Zetterberg Ferngren P, Barrbrink L, et al. Ansvarsfull hälso- och sjukvård. Slutbetänkande av Patientmaktsutredningen. SOU 2013:44. Stockholm: Elanders Sverige AB., 2013.

129. Meeuwesen L, van den Brink-Muinen A, Hofstede G. Can dimensions of national culture predict cross-national differences in medical communication? Patient Education and Counseling 2009;**75**(1):58-66.

130. Ishikawa H, Yano E. Patient health literacy and participation in the health-care process. Health Expectations 2008;**11**(2):113-22.

131. Verlinde E, De Laender N, De Maesschalck S, et al. The social gradient in doctor-patient communication. International journal for equity in health 2012;**11**:12.

132. Say R, Murtagh M, Thomson R. Patients' preference for involvement in medical decision making: A narrative review. Patient Education and Counseling 2006;**60**(2):102-14.

133. Stewart M, Brown JB, Donner A, et al. The impact of patient-centered care on outcomes. Journal of Family Practice 2000;**49**(9):796-804

134. Wohlin Wottrich A, Stenstrom CH, Engardt M, et al. Characteristics of physiotherapy sessions from the patient's and therapist's perspective. Disability and rehabilitation 2004;**26**(20):1198-205.

135. Street RL, Gordon H, Haidet P. Physicians' communication and perceptions of patients: Is it how they look, how they talk, or is it just the doctor? Social Science & Medicine 2007;**65**(3):586-98.

136. Cegala DJ, Chisolm DJ, Nwomeh BC. Further examination of the impact of patient participation on physicians' communication style. Patient Educ Couns 2012;**89**(1):25-30.

137. Naylor MD, Brooten DA, Campbell RL, et al. Transitional care of older adults hospitalized with heart failure: a randomized, controlled trial. J Am Geriatr Soc 2004;**52**(5):675-84.

138. Balaban RB, Weissman JS, Samuel PA, Woolhandler S. Redefining and redesigning hospital discharge to enhance patient care: a randomized controlled study. J Gen Intern Med 2008;**23**(8):1228-33.

139. Tistad M, Ytterberg C, Tham K, von Koch L. Poor concurrence between disabilities as described by patients and established assessment tools three months after stroke: a mixed methods approach. J Neurol Sci 2012;**313**(1-2):160-6.

140. Godfrey MM, Nelson EC, Batalden PB. Starting the patient's care in clinical microsystems. Value by Design: Developing Clinical Microsystems to Achieve Organizational Excellence. Hoboken, NJ, USA Jossey-Bass 2011.

141. Nelson EC, Lazar JS, Godfrey MM, Batalden PB. Partnering with patients to design and improve care. Value by Design: Developing Clinical Microsystems to Achieve Organizational Excellence. Hoboken, NJ, USA: Jossey-Bass, 2011.

142. Barimani M. Bridging the gap in the chain of care for expectant and new mothers. Karolinska Institutet, 2012.

143. Connolly M, Grimshaw J, Dodd M, et al. Systems and people under pressure: the discharge process in an acute hospital. J Clin Nurs 2009;**18**(4):549-58.

144. Lag om valfrihetssystem. SFS 2008:962, 2008.

145. Larkin PJ, Dierckx de Casterle B, Schotsmans P. Multilingual translation issues in qualitative research: reflections on a metaphorical process. Qual Health Res 2007;**17**(4):468-76.

146. Kvale S, Brinkmann S. *Den kvalitativa forskningsintervjun*. Lund: Studentlitteratur, 2009.

147. Dahlgren L, Emmelin M, Winkvist A. *Qualitative methodology for international public health*. Umeå: Print and Media, 2007.

148. Sandelowski M. The problem of rigor in qualitative research. ANS. Advances in nursing science 1986;**8**(3):27-37

149. Mays N, Pope C. Qualitative research in health care. Assessing quality in qualitative research. BMJ 2000;**320**(7226):50-2

150. Nemeth C, Wears R, Woods D, et al. *Minding the Gaps: Creating Resilience in Health Care Advances in Patient Safety: New Directions and Alternative Approaches (Vol. 3: Performance and Tools)*. Rockville MD, 2008.