

Person-centred care
Possibilities, barriers and effects in hospitalised patients

Axel Wolf



UNIVERSITY OF GOTHENBURG

2012

© Axel Wolf 2012
axel.wolf@gu.se

ISBN 978-91-628-8497-0
<http://hdl.handle.net/2077/29206>

Printed in Gothenburg, Sweden 2012
Printer's name

*To my mother Barbro, who convinced me of the
power and vitality of "homo capax":*

ABSTRACT

The need for a person-centred rather than disease-centred approach to care is considered an important part of care today. However, healthcare professionals still tend to focus on the disease within the person rather than on the person with the disease. Envisioning care tailored to each patient's capabilities and needs, the perspective of this thesis places the person with a long-term illness at the centre of the care process. The core concept of person-centred care (PCC), as defined in this thesis, is a partnership between the patient (and often relatives) and healthcare professionals that is based on respect and dignity. The patient's narrative is a prerequisite for this relationship, which also must be safeguarded through documentation.

The overall aim of this thesis was to investigate the possibilities, barriers and effects of a PCC in the everyday hospital setting focusing on persons with chronic heart failure (CHF). Ethnographic fieldwork, a patient-reported care experience questionnaire and interviews were used to explore the possibilities and barriers of PCC. The effects of PCC were investigated using a quasi-experimental before and after design.

In a national sample of patients hospitalised in Sweden during 2010, patients with poor self-rated health and physical dependence reported significantly less positive care experiences regarding communication of care and participation than patients with good self-rated health and without physical dependence ($p < 0.0001$). Ethnographic fieldwork in a university hospital ward revealed a care environment with structures that either promoted or impeded both the patients' and healthcare professionals' different actions and relationships. The design of the hospital environment, focus on biomedical routines and limited opportunities for dialogue, restricted the choices available to both patients and healthcare professionals. The healthcare professionals, primarily registered nurses, felt that the structures restricted their ability to provide optimal care for the patient, which in turn made them feel guilty. The patients seemed to accept the prerequisites of the hospital structures and routines and assumed a role of passive recipients of care. However, patients with CHF often have untapped personal resources (e.g., independence and vitality) prior to hospitalisation that may potentially be exploited to engage the patient and improve care. Levels of self-rated independence (Activities of Daily Living - ADL) and beliefs in one's ability to achieve/attain goals in life (self-efficacy) were high. However, when patients were grouped by functional impact of symptoms on everyday life, a significant negative correlation between poor functional status and low self-efficacy ($r = -0.27$, $p < 0.001$) was found. Patient interviews strengthened the quantitative findings that patients were independent prior to hospital admission, and described a pattern wherein patients increasingly restricted their social spaces to areas nearby their homes during illness deterioration. In the PCC intervention group ($n = 125$) length of indexed hospital stay (LOS) was one day shorter ($p = 0.16$) and ADL was better ($p = 0.07$) than in the conventional treatment group ($n = 123$). When the PCC intervention was fully implemented by the healthcare professional during the entire hospital stay (per protocol analysis, $n = 74$) LOS was reduced by 2.5 days ($p = 0.01$) and ADL level was preserved ($p = 0.04$). Despite reduced LOS, health related quality of life (HRQoL) and time-to-first readmission did not differ between groups.

Implementation of PCC in the hospital setting requires increased equality and awareness of the capabilities and resources of both patients and healthcare professionals. The care environment with its almost hegemonic focus on the biomedical explanatory model and routine-based structures restricts the choices available to both patients and healthcare professionals, hence counteracting PCC. The findings suggest that a fully implemented PCC approach shortens hospital stay and maintains functional performance in patients hospitalised for worsening CHF, without increasing risk for readmission or jeopardising patients' HRQoL. The use of patient narratives in combination with simple instruments to uncover the inherent resources of the patient as a starting point for initiating the partnership may serve as a basis for and facilitate collaboration between professionals and patients in setting common care/treatment goals.

Keywords: patient-centered care, care experience, chronic heart failure, care management

ISBN: 978-91-628-8497-0

LIST OF PAPERS

This thesis is based on the following studies, referred to in the text by their Roman numerals.

- I. Wolf A, Olsson LE, Taft C, Swedberg K, Ekman I. Impacts of patient characteristics on hospital care experience in 34,000 Swedish patients. *BMC Nursing* 2012, 11:8. (Epub ahead of print. Open Access)
- II. Wolf A, Olsson LE, Swedberg K, Ekman I. Self-efficacy and functional status in patients with heart failure. *Manuscript*
- III. Wolf A, Ekman I, Dellenborg L. Everyday practice at a medical ward. A 16-month ethnographic field study. *BMC Health Services* 2012, 12:184. (Open access)
- IV. Ekman I, Wolf A, Olsson LE, Taft C, Dudas K, Schaufelberger M, Swedberg K. Effects of person-centred care in patients with chronic heart failure: the PCC-HF study. *Eur Heart J.* 2012;33(9):1112-9. (Open access)

Permission to reproduce and use content from the above articles was obtained from the publisher.

CONTENTS

| | |
|---|----|
| INTRODUCTION | 11 |
| History and structures of the hospital clinic | 11 |
| What constitutes a person | 12 |
| Person vs. Individual and ethics | 12 |
| Health and vitality | 13 |
| Illness and disease | 13 |
| Person-centredness | 14 |
| Person-centred care | 14 |
| Partnership and participation | 15 |
| Illness narrative | 16 |
| Documenting the partnership | 16 |
| Chronic Heart Failure | 16 |
| CHF symptoms, signs and everyday resources | 17 |
| CHF care management programs | 18 |
| Effects of PCC | 18 |
| Rationale of the study | 18 |
| AIM | 20 |
| Overall aim | 20 |
| Specific aims | 20 |
| METHOD | 21 |
| Overall research methodology perspective | 21 |
| Study population | 21 |
| Study design | 22 |
| Questionnaires and assessment scales | 26 |
| Text analysis and statistical methods | 27 |
| Text analysis | 27 |
| Statistical methods | 28 |
| Ethics | 29 |
| RESULTS | 30 |
| Possibilities and barriers of PCC | 30 |
| Paper I | 30 |
| Paper II | 30 |
| Paper III | 31 |
| Effects of PCC | 32 |
| Paper IV | 32 |

| | |
|---|----|
| DISCUSSION | 34 |
| THEORETICAL AND METHODOLOGICAL CONSIDERATION | 39 |
| CONCLUSION | 41 |
| FUTURE PERSPECTIVE | 42 |
| SAMMANFATTNING PÅ SVENSKA | 43 |
| ACKNOWLEDGEMENT | 44 |
| REFERENCES | 46 |
| APPENDIX 1 | 56 |
| APPENDIX 2 | 57 |
| PAPER I-IV | |

ABBREVIATIONS

| | |
|-------|---|
| ADL | Activities of Daily Living |
| AN | Assistant nurse |
| CHF | Chronic Heart Failure |
| GSES | General Self-Efficacy Scale |
| HRQoL | Health Related Quality of Life |
| KCCQ | Kansas City Cardiomyopathy Questionnaire |
| LOS | Length of hospital stay |
| NYHA | New York Heart Association classification |
| PCC | Person-centred care |
| RN | Registered nurse |
| SRH | Self-rated health |

PREFACE

During my journey in writing this thesis I have learnt the importance of reflection, maybe mostly about the essence of being a clinician, and the importance of storytelling. It has been said that our understanding always grows, but that it progresses in an upward spiral (Germaine De Staël, 1813). Arthur Kleinman (1973), inspired by a text by Ludvig Wittgenstein, wrote that human stories can be seen as a city, a maze of little streets and squares, of old and new houses, surrounded by growing numbers of new impersonal suburbs with identical streets and high-rise buildings. In today's conventional healthcare settings, the unique story of a person seems to vanish amongst standardised medical language and routines. The question is how we will combine these stories, and when (not if) we will allow ourselves to build our future in a more personal rather than professional manner.

Cover illustration: Design by Sanna Wieslander

INTRODUCTION

History and structures of the hospital clinic

The Encyclopaedia Britannica defines a hospital as: *"an institution that is built, staffed, and equipped for the diagnosis of disease; for the treatment, both medical and surgical, of the sick and the injured; and for their housing during this process. The modern hospital also often serves as a centre for investigation and for teaching."* (Encyclopaedia Britannica Online, 2012). During the last 300 years, healthcare settings have evolved from houses of mercy for the care of dying and wounded soldiers and centres to prevent the spread of infectious outbreaks to medical institutions also engaged in academic teaching and conducting leading-edge research and technology (Risse, 1999 pp. 675-677). The hospital clinics have become the spearhead of modern medicine and as such also have significant influence in society. The hospital was the first attempt to organize and implement medical science based on positivistic principles in clinical work (Foucault, 1975 p. 89). The hospital clinic was also the birthplace for modern nursing education. In the 1850s, during the Krim war, Florence Nightingale implemented a care organisation and educational curriculum for nursing care (Moberg, 2007 pp. 108-119). Numerous followers in the nursing fields were inspired by Florence Nightingale, trying to evolve nursing into a healthcare profession that supported the patient by individualising care to the patients' needs (Henderson, 1967 p. 31). Yet, as Virginia Henderson (1967 p. 31) has suggested, the biomedical structures of the hospital impose limits to the nurse's abilities to provide such care.

Michel Foucault (1975 pp. 54-85) argued that the hospital is an institution where medicine as a positivistic science is applied based on objective observations and categorisations of signs. Hospital structures are therefore still based upon the assumptions of reductionism and ocular inspection of pathological location is the primary working tool (Foucault, 1975 pp. 88-89; Jewson, 2009). Similarly, objectivism affected attitudes to patient care, as exemplified by the tendency to refer to patients as cases (Jewson, 2009). The nursing profession has often been influenced by these structures and have organised their work accordingly into task-oriented and performance-driven routines (McCormack, Karlsson, Dewing & Lerdal, 2010). The care environment, that is the particular wards, clinics or entire hospitals in which care is delivered, has developed certain cultural characteristics, such as language, technology, clothing, symbols, myth and stories, as well as espoused values and basic assumptions which together define and nourish the everyday structures of the care environment (Berlin & Carlstrom, 2010). While the management in the hospital clinic often embraces the notion of multi-disciplinary competency, ethnographic studies suggest that biomedical knowledge takes precedence in care procedures (Ekman & Segesten, 1995). This perspective may lead to feelings of invisibility and inferiority in patients (Ekman, Lundman & Norberg, 1999; Penney, 2007; Bridges, Flatley & Meyer, 2010; Nordgren, Asp & Fagerberg, 2007).

What constitutes a person

The French philosopher Emmanuel Mounier is often cited as one of the early founders of the French branch of personalism, a philosophy that deals with the concept of person (Bengtsson, 2006 p. 1). According to Mounier (1970 pp. 19-25), a person is unique, creative and curious, with feelings, thoughts and beliefs that are shared and nourished through interactions with others. It is in the encounter with others that a person grows, evolves and finds his/her identity. A person is defined by other persons he/she interacts with and grows within a social context characterised by mutuality, trust and respect (Kitwood, 1997 pp. 8-9). Each person constitutes a meaning maker in interactions with others, and is imbued with resources learned from past engagements as well as a capacity to reflect about oneself (Kitwood, 1997 pp. 15-17).

Person vs. Individual and ethics

Martin Buber (1994 p. 18) divides this view into the “I-You” and the “I-It”. The “I-It” perspective is characterized by the fact that the meeting is pre-focused on one thing or object/character, i.e. the individual and its context is established in time or space. In contrast, “I-you” is an immediate and free meeting where the dialogue becomes a way to see the other person and, in doing so, also to make apparent one’s own identity. A concept in Mounier’s “personalism” is the “decentralization” of the person, in contrast to the centralization of an individual (Mounier, 1970 pp. 19-25). By decentralisation of the person, Mounier means that a person is curious and strives to communicate and interact with others, and hence does not need to be centralised and be the center of focus in order to be part of the group. In comparison, an individual is one in the group, which does not imply an active part by the individual; instead, the individual must be placed in the centre in order to be recognised. The individual can be looked upon with objective eyes, because there is more monolog than dialog between the beholder and the individual.

The French philosopher Paul Ricoeur (1994 p. 169-202), describes the capable person, i.e. “homo capax”, as a person with awareness, meaning, self-respect and self-esteem. The capable person is in constant interaction with others, and in these interactions is always aware and exposed to existential aspects, such as human action and vulnerability (Kristensson Uggla, 2009 pp. 15-16). An important notion in Ricoeur’s definition of the capable person is that of personal responsibility for one’s own actions, where responsibility is exercised by remembering and reflecting upon one’s actions (Kristensson Uggla, 2009 p. 24). According to Ricoeur (1994 p. 172), personal growth and self-esteem is dependent on establishing a point of reference about the “good life” that is worth living, a reference that is only found in the dialog with another person. Ricoeur posits that this relationship is also defined by the context, or as he calls it “just institutions”. Together these three define a person’s ethical intentions: “aiming at the good life with and for others in just institutions”. According to Ricoeur (1994 p. 172), “ethics” is the *aim* of achieving a good life, and “morality” is the articulated *way or agency* to attain this aim. As such, the ethical aim is superior to the moral obligations, and if the norm is not consistent with the ethical aim, the ethical aim should be super-

imposed (Ricoeur, 1994 p. 170). Accordingly, a person is defined by his/her constant interactions with others as well as the surrounding context, hence we cannot define a person as an isolated entity or as an individual.

Health and vitality

The World Health Organization (2005) defines health as "a state of complete physical, mental, and social well-being and not merely the absence of disease or infirmity." It is however questionable if health should be seen as an absolute state of something, as suggested by the definition. According to Dahlberg and Segesten (2010 p. 62), health is a balanced feeling of freedom and vulnerability, that constitutes a person's well-being and capacity to pursue minor and major life projects that he/she values. This feeling of equilibrium may be summarised by the word vitality, i.e. a zest for life that constitutes a personal resource that balances needs and motivation with personal resources and capacity (Olsson, Nystrom, Karlsson & Ekman, 2007b). It is the constant interaction with others and the ability and perception of movement that is central to health and personal vitality, because movement (physical, spiritual, cognitive, such as personal growth, etc.) is a prerequisite to perceiving one's ability to fulfil planned life projects (Dahlberg, Todres & Galvin, 2009). Vitality is an important personal resource in everyday life and it may be seen as the patient's belief in his/ her ability to overcome the hurdles of everyday life with his/her own set of mental and physical resources, e.g. self-efficacy. The concept of self-efficacy (SE) was first used by Bandura (1978) and encompasses both locus of control and self-esteem. The concept focuses on a person's beliefs in his/her capacity to perform a task or specific behaviour that can lead to a desired outcome, rather than the actual execution of the task (Bandura, 1978). SE is a dynamic state that is influenced by both external and internal factors. Studies have shown that the level of SE as well as changes in the level of SE are important ingredients in successful self-management (Lorig & Holman, 2003).

Illness and disease

When an imbalance occurs in a person's health and vitality, a perception of illness arises. Illness is often described as a subjective feeling that there is something wrong, that one's health is affected, while disease is an objective classification of pathological processes (Eisenberg, 1977). Illness represents a "dis-ability" to engage the world as desired, something that becomes most evident in illness that limits the person in performing normal daily activities through loss of usual function (Toombs, 1987 pp. 62-63). In this sense, illness is intimately connected to the concept of health and one's perception and/or ability to accomplish small and large life projects. However, it is important to acknowledge that there is no straight, upward path from illness to health. In long-term illness, it is the balancing act that sometimes puts illness in the foreground and at other times health (Paterson, 2003). Many patients admitted to hospital may, during this balancing act between health and illness, manifest some sort of vulnerability that may occur because of decreased independence or feelings of imbalance in the health state. Vulnerability is a broad and complex concept with many defini-

tions, often included in a preconceived and stigmatised picture of the elderly patient (Gilleard & Higgs, 2010; Fried, Ferrucci, Darer, Williamson & Anderson, 2004). The common stereotype of the elderly patient as a vulnerable and physically dependent person can be misleading, and result in healthcare professionals treating patients in a paternalistic manner (Picco, Santoro & Garrino, 2010; Bridges *et al.*, 2010). Such paternalistic behaviour could have an impact on patient-professional interactions regarding decision-making, communication and information.

Person-centredness

In a literature review of the concept person-centredness, McCormack (2004) identified several focal points in person-centredness: the social world of the person, context and environmental aspects of the person's everyday life, relationships and interactions with others, and inner beliefs about one's own values, goals and motivations. Edvardsson (2010b p. 15) describes person-centredness as having a lifeworld perspective, which includes exploring/understanding the everyday life, motivation and driving force of the person. A lifeworld according to Edmund Husserl is the way we acknowledge ourselves, others and the world (Smith, 2007 p. 182), comprising the everyday life of the person. The lifeworld becomes the point of view and the point of departure in understanding oneself and the world. Thus, the lifeworld is a process and is under constant development. The concept is suggested to consist of a combination of one's personal identity, self-efficacy, self-consciousness, dreams, values, as well as interactions with others and the surrounding environment (Dahlberg & Segesten, 2010 p. 188).

Person-centred care

Person-centred care (PCC) stresses the importance of seeing the patient as a dignified and capable person who together with the health professional designs a care plan (Ekman & Norberg, 2012; Ekman *et al.*, 2011). The term person shifts focus from the disease to the uniqueness of the person experiencing illness (Hobbs, 2009; Leplege, Gzil, Cammelli, Lefevre, Pachoud & Ville, 2007). A large body of research on PCC is found in the areas of elderly care and dementia care (Edvardsson, Winblad & Sandman, 2008; Kitwood, 1997). In the hospital setting, PCC is still vague and mostly practiced if time permits (Picker, 2004). There is an array of different concepts and terms for PCC that are often used interchangeably, e.g., patient-centred care, individual-focused care and person-centred care (Stewart, 2001; Mead & Bower, 2000; Edvardsson *et al.*, 2008; Leplege *et al.*, 2007). The conceptual difference between the terms *patient-centred care* and *person-centred care* lies in the eye of the beholder, meaning that in acknowledging the person merely as a patient, the professional's focus is the disease, its impact on the body and the individual patient's needs. Central aspects in patient-centred care are to find a common ground and shared responsibilities between the patient and the healthcare professional in the therapeutic alliance (Mead & Bower, 2000), and to acknowledge the realities of the environment and structures in which health care is delivered (Stewart, Brown, Donner, Mcwhinney, Oates, Weston & Jordan, 2000). As outlined in the conceptual framework by Mead and Bower (2000), the healthcare professional's focus is on identifying the biopsychosocial needs of the pa-

tient, in order to tailor care and information thereafter. The concept of PCC is the core concept in this thesis since patient-centred care is a broader, vague concept including all care related to the individual patient's needs and suffering. PCC implies not just interaction and communication but also mutuality in relations with others.

Although the theoretic knowledge about PCC is increasing, the lack of consensus about the components and concepts comprising PCC jeopardises the ability to operationalise the concept within care settings (Edvardsson, 2010a). Recently, Ekman *et al.* (2011) have delineated a set of core PCC components in an attempt to operationalise the concept for use in care settings. To carefully structure and listen to the patient's illness narrative provides an opportunity to become aware of each person's knowledge of himself and his capabilities and obstacles to achieve health. Central is the establishment of a partnership characterised by mutual respect between the patient as a capable person with expert knowledge from a lifeworld perspective and the healthcare professional's generic expert knowledge (Ekman *et al.*, 2011). The emphasis on a person being interdependent, rather than independent, can manifest itself as a partnership between healthcare professionals and the patient, for example, in a jointly formulated rehabilitation or care plan.

Partnership and participation

In this thesis, partnership is viewed as the primary core component of PCC. Partnership in PCC focuses on shared decision-making which is constituted by a mutual agreement (Ekman *et al.*, 2011; Ekman & Norberg, 2012). The term "partner" derives from the Latin *parcere*, meaning "A person who shares, or has a part in, something with another or others; a partner; a sharer, a partaker" (OED, 2005). Partnership is defined as "the condition of being a partner". According to Cahill's (1996) conceptual analysis of patient participation, being a partner constitutes the highest level of participation, above both patient involvement and/or collaboration. Tutton (2005) describes partnership and participation not in terms of a hierarchy, but instead as a dynamic process that changes over time.

Participation is often described as involvement in decision making (Sahlsten, Larsson, Sjoström & Plos, 2008). Shared decision making has been described as the shift from a beneficence-based ethical perspective, where the healthcare professional is responsible for making decisions, to a more autonomous-based ethical view, where the patient is seen as an autonomous stakeholder who knows what suits his/her wellbeing best (Will, 2011a; Will, 2011b). Research has shown that there are patients who do not want to participate in decision-making about their treatment (Eldh, Ekman & Ehnfors, 2008), and that willingness to participate declines with age and disease severity (Schneider, Korner, Mehring, Wensing, Elwyn & Szecsenyi, 2006). In one study, over 60% of the patients wanted a more passive role in decisions about their medical treatment; however, a majority wanted more extensive information and knowledge about the treatment process (Wilkinson, Khanji, Cotter, Dunne & O'keeffe, 2008). Hence, patient participation in decision making does not necessarily imply choosing treatments or drugs, but rather it should be seen in more existential terms as self-confidence, sense of control and responsibility (Eldh, Ehnfors & Ekman, 2004). It

has been suggested that non-participation should instead be seen as a protective step by the patient (Eldh *et al.*, 2008), taken because the health care professional does not acknowledge and respect the patient as a person. This could suggest that although patients want to take an active role in their care, their level of engagement will depend on the success in establishing a true partnership with the patient. The healthcare professionals' responsibility is to combine their expert knowledge (e.g. evidence-based guidelines) about how to support patients in achieving health with the patient's personal resources in order to arrive at a care plan in collaboration with the patient.

Illness narrative

Patients' illness experience, obtained through the narrative, has always been a central point of interest in nursing and caring science (Ekman & Skott, 2005; Eriksson, 1988 p. 57; Norberg *et al.*, 1997). It is also considered in clinical medicine to be a fundamental part of clinical practice (Charon, 2001; Kleinman & Benson, 2006). During the past century the illness narrative has been increasingly replaced with objective measurements. While the disease begins at the point at which it is diagnosed, the illness begins earlier when the person becomes aware of distress and symptoms (Kleinman, Eisenberg & Good, 1978). The illness experience is interwoven in everyday life, not added on to life itself (Toombs, 1987 p. 81). Therefore, the healthcare professional must use his/her competence to be intentional and curious when listening to the patient narrative and the way a person describes his/her everyday life with the illness (Skott, 2002). To be curious implies having an intentionality toward the other, a concept often connected to the phenomenological theories of Edmund Husserl (Smith, 2007 pp. 191-192). It refers to a consciousness and awareness toward a person or thing, with the ambition to embrace the actions, beliefs and expectations of others (Watson, 2002).

Documenting the partnership

As proposed by Ekman *et al.* (2011), the documentation of patients' resources, goals and motivations, as well as of their involvement in shared decision-making gives legitimacy to PCC, produces transparency and a structure for assessing clinical outcomes. According to Cahill (1996), being a partner requires not only active participation in care, but also represents a joint venture between two people based upon a verbal or written contract that they have agreed upon. This contract distinguishes partnership from participation as it obligates mutuality throughout the entire continuum of care (Cahill, 1996). Including patient-defined goals in a care plan has been shown to be effective in improving quality of life, especially in patients with complex care needs with recurring hospitalisations, as shown in the primary care setting-based SA-Health study (Battersby *et al.*, 2007).

Chronic Heart Failure

Noncommunicable diseases (NCD), also known as chronic diseases or long-term illnesses without an infectious component (World Health Organization, 2011), generally progress slowly and are lifelong. NCD, such as coronary disease, stroke, cancer,

chronic respiratory diseases and diabetes, are the leading cause of mortality worldwide, representing 63% of all deaths (World Health Organization, 2011). One of the most common NCDs is chronic heart failure (CHF). CHF is a periodically disabling, progressive and lifelong condition (McMurray *et al.*, 2012), with a high mortality rate (Tribouilloy *et al.*, 2008). The prevalence of CHF in Europe is about 1-2%, increasing to above 10% among those over 70 years old (McMurray *et al.*, 2012). Patients with CHF commonly require periodic hospital care (McDonagh *et al.*, 2011; Tavazzi *et al.*, 2006; Westert, Lagoe, Keskimaki, Leyland & Murphy, 2002). Although advances have been made in the diagnosis and treatment of CHF, patients are still often diagnosed and treated for acute exacerbation in the hospital setting (McDonagh *et al.*, 2011), and the hospital readmission rates for worsening CHF is high (Tavazzi *et al.*, 2006; Cleland *et al.*, 2003). The average care time in Europe is 9 days (Harjola *et al.*, 2010).

CHF symptoms, signs and everyday resources

CHF is classified as a syndrome including both symptoms and signs compatible with CHF in combination with objective evidence of a structural or functional abnormality of the heart at rest. These abnormalities are mostly caused by a previous myocardial infarction or hypertension (McMurray *et al.*, 2012). CHF is a complex syndrome, involving many different organ systems. This multi-system effect could explain the many and diverse symptoms (more than 30) commonly associated with this syndrome (Clark, 2006). The most common symptoms are breathlessness, fatigue, diffuse pain and symptoms of depression, symptoms that have shown to impact the patient's health-related quality of life (HRQoL) (Zambroski, Moser, Bhat & Ziegler, 2005).

The diagnostic evaluation of CHF is initiated with the investigation of the patient's symptoms and signs. The patient's symptoms represent one of the most important tools for the clinician; however, the mechanisms behind them are often not clearly understood. The workup includes imaging of cardiac function mostly by electrocardiography, echocardiography and blood samples to assess biomarkers associated with left ventricular dysfunction (McMurray *et al.*, 2012). While the treatment focus in CHF is on symptom relief, the diagnosis and treatment are driven by the presence of signs, which serve as the basis for risk assessment and as a guide in treatment decisions for prolonging life. This is troublesome, because little evidence suggests that signs and symptoms always correlate (Clark, 2006). This poor relationship between signs and symptoms observed during the diagnostic stage is also seen in treatment outcomes, where improved objective signs of, for example pulmonary pressure, do not necessarily translate into symptom relief (Shah, Hasselblad, Stinnett *et al.*, 2002). It is also important to note that persons with CHF act upon the severity and distress of symptoms, not the medical signs. Everyday life may be impacted by CHF symptoms (Norberg, Boman & Lofgren, 2010; Falk, Granger, Swedberg & Ekman, 2007). It has also been observed that the persons adapt to and cope with the symptoms' impact on everyday life (Falk, Wahn & Lidell, 2007). Patients with worsening symptoms of CHF seek medical help because they feel that their symptoms need to be discussed and perhaps treated (Ekman, Cleland, Andersson & Swedberg, 2005).

CHF care management programs

Care for persons with CHF is complex (McDonagh *et al.*, 2011), and as suggested in the European Society of Cardiology Guidelines for care of patients with heart failure, a multi-professional care management program is highly recommended, including specially trained healthcare professionals (physicians, RNs, occupational therapists, physiotherapist) in both the primary care setting, outpatient clinics and the hospital (McMurray *et al.*, 2012). There is a difference between multi-disciplinary attitudes, wherein different professionals work independently towards common goals, and interdisciplinary or inter-professional attitudes, wherein different professionals work as partners towards the same goal (MacIntosh & McCormack, 2001). Yet, there seem to be boundaries, such as legitimacy of expertise, competence and clinical efficiency, between the different healthcare professionals that could inhibit effective care and partnership (Sanders & Harrison, 2008). In addition, the patient is seldom considered as a natural member of either multi-professional or inter-professional teams.

Effects of PCC

Most research in PCC seems to be found within care settings other than the hospital, such as care for persons with dementia. Nevertheless, research evaluating the clinical effects and outcomes of PCC by means of controlled intervention studies is scarce (Edvardsson *et al.*, 2008; Olsson, Jakobsson, Swedberg, Ekman, 2012). The lack of a consensus definition of PCC and the array of different concepts used in research about PCC is also problematic. Studies evaluating the effects of PCC (operationalised in terms of the personal illness narrative and partnership in developing the care plan) in the hospital setting have shown positive outcomes, reducing hospital mortality (Mudge, Laracy, Richter & Denaro, 2006), LOS (Olsson, Karlsson, Ekman, 2006) as well as improving ADL function (Olsson, Karlsson, Ekman, 2007a). Other studies have, however, reported neutral results regarding length of hospital stay (Wolf *et al.*, 2008).

Rationale of the study

Over the last 200 years hospital mortality rates have markedly decreased while costs have dramatically increased, particularly during the latter half of the last century. Today hospital costs continue to rise sharply, while little appreciable improvement may be seen in hospital mortality. (Meyer, Demehin, Liu & Neuhauser, 2012). It would appear that the primarily biomedical explanatory model has lost its momentum; hence we need to find different care models for more effective care. A person consists of more than the sum of his/her parts, a statement important in the world of medical reductionism. When a person becomes ill and seeks hospital care, the patient enters the institutional world of the hospital. A person with a long-term illness, such as CHF, must not only live with the illness for the rest of his/her life, but must also have a lifelong relation with the healthcare provider. Hospitalised patients with CHF are often elderly with comorbidities, have a history of previous hospitalisation and present some physical impairment due to their symptoms of breathlessness and fatigue. Hence, these patients may be acknowledged by healthcare professionals as complex and vulnerable instead of capable partners. Political, professional and patient inter-

est groups have argued that increased patient participation in care decision making is needed for improved quality of care (Washington & Lipstein, 2011; Committee on Quality of Health Care in America, Institute of Medicine & The National Academies, 2001). The patient's role as an active and important participant in care and treatment decisions has been highlighted as a requirement for good care in Sweden (SOU, 2007:12). The Swedish Health and Medical Services Act (SFS, 1982:763) stipulates that care should be built upon respect for the patient and for his/her personal integrity, equality, patient involvement in care and treatment decision making and rights to individually adapted information about their health and treatment. Nevertheless, governmental policy still states that patients' rights to involvement in decisions should always be balanced against and subordinate to the needs of the collective group, i.e. society in general. Hence, patient participation in care decision is desirable as long as it does not impact outcome variables in healthcare. It is therefore important to explore if increased collaboration and shared decision making between the person with the illness and the healthcare professional is more effective than usual care.

In a recent report sponsored by the Commonwealth Fund, Swedish and Norwegian patients with complex care needs had some of the lowest self-rated levels of shared decision making and patient engagement compared to other countries, such as the UK and Switzerland (Schoen *et al.*, 2011). PCC places the capable person/patient in the care team and on equal terms with the rest of the care team, and thereby promotes increased collaboration that may lead to more effective care. PCC involves the patient, relatives and healthcare professional but also gives importance to the design and structures of the care environment where PCC is provided. To explore the possibilities and barriers of PCC requires that one must try to grasp the complex interplay of dialog and interaction that occurs within the healthcare setting.

AIM

Overall aim

The main purpose of this thesis is to explore the possibilities, barriers and effects of person-centred care in the hospital setting. By describing 1) the patients' care experience of communication and care participation; 2) their personal resources in everyday life; 3) everyday hospital practices (healthcare professionals relationship, shared belief system, ward design and organisation), the possibilities for and barriers to PCC will be explored within usual care. The clinical outcomes of a PCC intervention in usual care will be evaluated in order to describe the possible effects of PCC.

Specific aims

- to explore the impacts of various socio-demographic and health characteristics, such as self-rated health and physical dependence, on patients' hospital care experiences.
- to describe personal resources and vitality during everyday life among patients hospitalised for worsening CHF.
- to observe and interpret the everyday acts and intentions of healthcare professionals and patients in a coronary care unit in order to gain an understanding of how the care environment, with its routines, structures and architecture, influences the actions and relationships of both patients and healthcare professionals.
- to evaluate the effects of a PCC intervention on clinical and patient-reported outcomes.

METHOD

Overall research methodology perspective

A multi-method approach was adopted, including a quasi-experimental before and after design along with ethnographic fieldwork and patient-reported outcomes questionnaire. The use of several methods to investigate the same phenomena is referred to as methodological triangulation. Methodological triangulation is used to improve the credibility and validity of research results and provides a nuanced view of the phenomena under investigation (Sandelowski, 2003). Two papers were quantitative (Papers I & IV), one paper was qualitative (Paper III) and one paper had a mixed-method design (Paper II) (Table 1).

Table 1. Patient population. *Same patient samples in Papers II and IV

| Study | Population (n) | Method | Analysis |
|-----------|--|--|---|
| Paper I | 32 517 | National care-experience questionnaire | Statistical comparison and correlation between care experience and patient characteristics |
| Paper II | 248* | Mixed method design (QUAN + qual design) | Descriptive statistics regarding ADL, NYHA and Self-efficacy combined with admission interviews |
| Paper III | Patients and staff on a coronary care ward | Ethnographic field study | Hermeneutic analysis of everyday life on a hospital ward |
| Paper IV | 248* | Quasi-experimental design | Between group comparison of length of hospital stay, ADL HRQoL and rehospitalisation |

Study population

Paper I was a retrospective, cross-sectional study examining selected parts of the 2010 national hospital patient survey. During spring of 2010, the survey was sent to a random national sample of over 56 000 patients, 16 years and older, who had been admitted to hospital for at least one night. The response rate was 66% (n=34603). Reasons for non-response could be established in 5126 cases: refusal (n=941), severe illness (n=1281), death (n=1951), language problems (n=25), wrong postal address (n=590) and screening failure (n=338).

Resources of patients with CHF (Paper II) and effects of a PCC intervention (Paper IV) were studied in five wards comprising the majority of the internal medicine department at a university hospital. All patients admitted for worsening symptoms of CHF between February 2008 and April 2010 at these wards were screened. Inclu-

sion to the study took place in two stages: between February 2008 and April 2009, a total of 712 patients were eligible for the conventional care group; and between May 2009 and April 2010, 732 patients were eligible for the intervention group. The CHF diagnosis was made according to ESC guidelines (Dickstein *et al.*, 2008) and a separate committee adjudicated the diagnosis. Pre-specified exclusion criteria were: acute myocardial infarction, chest pain and age <50 years, primary valvular disorder, severe concomitant illness (e.g. cancer), survival expectancy <3 months, planned surgical intervention, cognitive impairment or reluctance to participate. All patients in both groups were included using the same inclusion and exclusion criteria. In total, 589 patients were excluded from the conventional care group and 607 patients from the intervention group, leaving 123 patients in the conventional care group and 125 patients in the interventional care group.

The ethnographic part of this thesis (Paper III) is based on fieldwork conducted during 2009-2011 at a coronary care unit that was one of the five included wards in the intervention study. Common diagnoses for the patients admitted to the ward were acute or chronic heart failure, atrial fibrillation, acute coronary syndrome such as angina pectoris or myocardial infarction. The ward staff consisted of 60 RNs, 40 ANs and 35 physicians.

Study design

Paper I reports results from parts of the 2010 national patient survey. The questionnaire is an adapted version of the international 40-item Picker “in-patient” questionnaire (Jenkinson, Coulter & Bruster, 2002). The Swedish version has been further developed during the last 10 years and currently contains 63 items. The questionnaire was sent together with a cover letter explaining the purposes of the study to a national sample of hospital admittals within 4 weeks after discharge. After three weeks, a reminder consisting of a replacement questionnaire and follow-up letter was mailed to non-respondents only. After seven weeks, a second follow-up letter and questionnaire was sent to the remaining non-respondents. The 15 items comprising the Picker Patient Experience Questionnaire (PPE-15) (Jenkinson *et al.*, 2002) (Appendix 1) were extracted from the Swedish version. Derived from the original Picker in-patient questionnaire, the PPE-15 consists of a core set of items that provide a meaningful picture of the patient’s care experiences. In order to analyse the impact of patient characteristics on PPE-15 scores, all patient characteristics included in the national patient survey were used: gender, functional impairment during hospital admission (need for assistance from healthcare professional to and from the bathroom or bedpan), native language (Swedish/other), age (≤ 44 years, 45-64 years, 65-74 years, ≥ 75 years), education level (elementary/ high school/university), healthcare utilisation within the previous six month (never, once, 2-3 times, ≥ 4 times) and self-rated health (SRH; excellent/very good/good/fair/bad). In a sub-group analysis, patients were grouped according to their SRH and their ability to independently go to the toilet or use a bedpan. Patients who rated their health status as excellent, very good or good and reported no dependency when toileting were coded as non-vulnerable, whereas those with SRH ratings fair or bad and who reported dependency when toileting were classified as vulnerable patients.

In Papers II-IV, the research population consisted of patients from 5 internal medical wards at a university hospital. A randomised control study was deemed unfeasible as this would have meant that the same healthcare professional would at times have been forced to practise two different types of care (PCC and conventional) (Polit & Beck, 2004 pp. 186-188). Hence, a quasi-experimental before and after design with a control group was chosen (Shadish, Cook & Campbell, 2002 pp. 135-148). In order to determine if changes in treatment regime or organisational changes that could influence the primary clinical outcome variable (LOS) had occurred during the study period (February 2008-April 2010), another ward within the department of medicine was used as an external reference (Figure 1). Because patients were not randomised, comparability between the conventional care group and intervention group was assured by comprehensively assessing baseline variables regarding pre-specified medical, psychological and sociodemographic variables, and differences were controlled for in the statistical analysis.

The initial stage of the intervention study (February 2008 - April 2009) involved a careful mapping of the patients enrolled in the conventional care group (Figure 1) (Paper II & IV). During this stage a group of designated research nurses managed all data collections, whereas during the PCC intervention data was collected by the ordinary ward staff. However, patients in both the conventional care group and the intervention group received the same battery of instruments and the same protocol for the admission interview was followed (Figure 1). Within 24 hours after admission, the study nurses approached eligible patients with information about the study. Consenting patients signed consent forms and baseline data (Figure 1) was gathered using a semi-structured interview guide and questionnaires. The interview guide was designed to be used as a clinical admission interview guide for the RNs in the intervention stage of the study (Paper IV). The interview began with two open-ended questions concerning 1) patients' perceptions of how symptoms and signs of CHF impacted on their daily life and 2) patients' expectations and goals while in hospital. The guide followed standard nursing documentation nomenclature and terms used in common nursing documentation, such as health history, physical function, nourishment, elimination, medication, bodily pains, need for walking aids and for assistance at home and in social situations (Ehrenberg, Ehnfors & Thorell-Ekstrand, 1997).

The quantitative data from the baseline assessment of all patients was used in Paper II to describe the resources of patients. A mixed method design by Morse (2007) was chosen, with a quantitative core and a simultaneous qualitative supplementary component, a QUAN + qual design. The quantitative component comprised the General Self-Efficacy Scale (GSES), the Functional Recovery Scale (FRS), the New York Heart Association (NYHA) classification, and selected items (items 1 & 15) from the Kansas City Cardiomyopathy Questionnaire (KCCQ), as described below. The qualitative supplementary component consisted of patient admission interviews, which were used to enhance the description of the patients' personal resources in daily life. Interviews from the patients enrolled during the period between February 2008 and April 2009 were chosen (n=32). Although the aim of the supplementary component is to enhance and enrich the understanding of the phenomena investigated, in a mixed method design it cannot stand on its own (Morse, Niehaus, Wolfe & Wilkins, 2006).

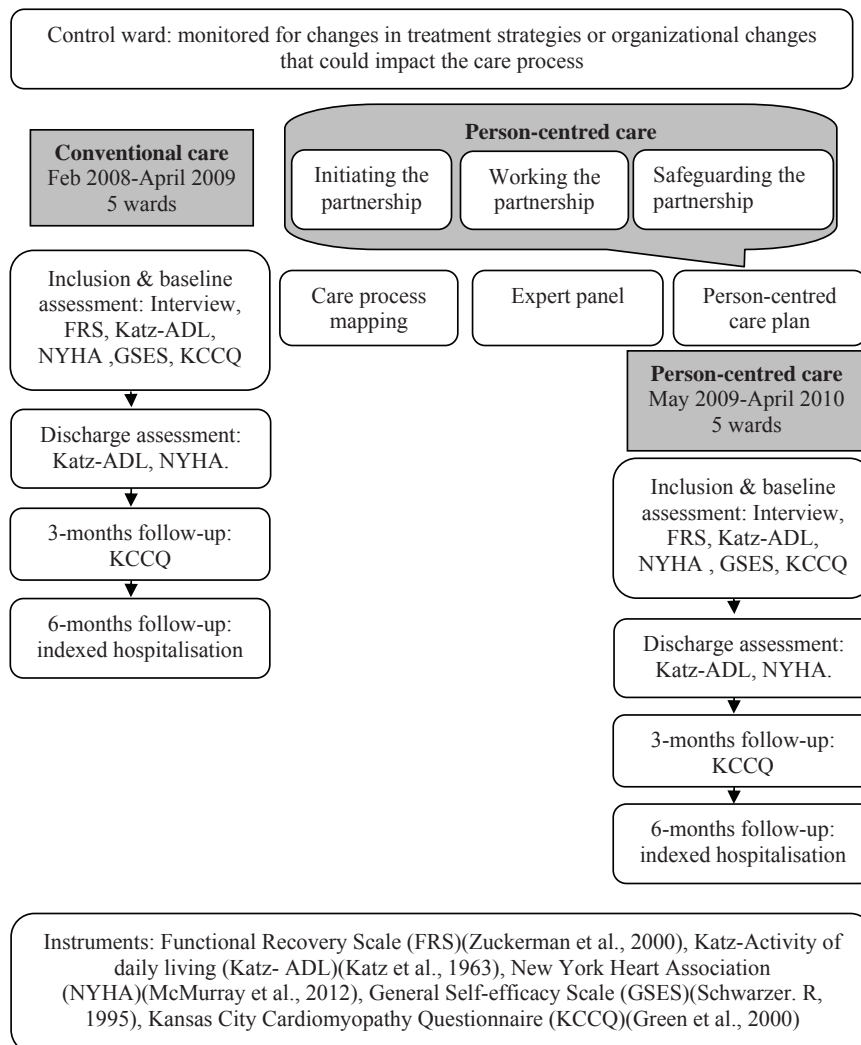


Figure 1. Schematic overview of the study design showing care mapping (conventional care), steps in the development of the intervention and the intervention. Modified from the original article (Ekman *et al.*, 2012).

The PCC intervention

The structured PCC methodology was specifically designed to identify each patient's resources for and barriers to recovery and to guide the planning and performance of care. The methodology was refined from that used in previous research by Olsson (2006). The intervention was developed by a group of experienced RNs, physicians, physiotherapists, occupational therapists, a patient representative from the local heart failure patient association and researchers/clinicians. The expert group met approximately ten times during a two month period. Thereafter, all physicians, RNs, ANs, physiotherapists and occupational therapists on all five wards (approx. 300 persons)

participated in an afternoon educational program given by researchers involved in the study. The program included an introduction to the philosophies underpinning person-centred care and instruction in the practice of the structured person-centred care methodology.

The structured PCC methodology consisted of three steps:

Initiating the partnership. By means of semi-structured interviews conducted by an RN, comprehensive narratives were obtained from the patients upon arrival to the ward. The narrative included information regarding everyday life prior to the worsening of their condition, symptoms and motivations/goals. The purpose of the patient narrative was to identify patients' own views of their goals, needs, preferences, values and resources, as well as their perception of their own role in their care. While performing the interview, the RNs listened carefully and documented the illness narrative and asked the patient about his/her views about his/her condition. The information from the narrative was used to guide and help formulate the care plan, in combination with patient assessments, such as the FRS, symptom severity of breathlessness and fatigue using a 5-scale Likert scale (Ekman, Cleland, Swedberg, Charlesworth, Metra & Poole-Wilson, 2005), and frequency of social contacts with relatives/friends (dichotomised into often, sparse or none). This information was synthesised in a protocol in order to provide an easily accessible and comprehensive overview of the patient's situation. On the next medical round all information gathered by the RNs, ANs, physicians, occupational therapists and physiotherapists was reviewed and a tentative care plan was developed. The care plan included all planned investigations, treatments, treatment goals and estimated length of hospital stay. The care plan was discussed with the patient and finalised when the patient agreed. According to study protocol, the care plan was to be finalised within 24 hours but that period could be extended to 48 hours in special situations.

Working the partnership. Additional or new information that could affect the PCC plan was checked for 72 hours after admission and every 48 hours thereafter in order to evaluate and adjust the PCC plan in collaboration with the patient. Patients were encouraged to be as active as possible and nurses were encouraged to avoid certain procedures, such as the use of urine catheter. Patients rated their symptoms of dyspnoea and fatigue on a daily basis using a 5-step Likert scale. These ratings were used as a process indicator for the medical treatment.

Safeguarding the partnership (documentation). The PCC plan stipulated that decisions and assessments be documented throughout the care process in the assessment record form. On the day of discharge the patients were given the opportunity to take part in a discharge-debriefing and to receive a written summary of the care period.

Ethnographic fieldwork

Two researchers observed and conducted informal interviews with patients and staff at a ward in a large university hospital to gain insight into perceptions, experiences and daily routines of the ward and staff responsibilities. Moreover, formal interviews with eleven staff members (6 RNs, 3 ANs, 2 physicians) and three patients were per-

formed. The formal interviews comprised only a few questions (e.g., everyday work on the ward, rounds, working relations with other healthcare professionals and patients, etc.) The fieldwork was performed during weekdays, nights and weekends. Observations and thoughts were documented in fieldnotes. An inductive approach was applied to gain an understanding of the complex context of the ward, everyday aspects of the staff's working experience, and the relationships between colleagues and with patients. Such relationships, structures within the group and common belief systems are suggested to emerge for the researcher's interpretation only with "time in the field", and therefore a long-term commitment is recommended (Wolcott, 2008 p. 61).

Questionnaires and assessment scales

Picker patient experience questionnaire

The Picker in-patient questionnaire was originally developed in the USA in cooperation with the Commonwealth Fund and Harvard Medical School (Gerteis, 1993 pp. 11-13), using research data from patient survey (n=8000), field observations from 20 hospitals and focus groups with patients, family members, physicians and management. The original Picker in-patient questionnaire consists of 40 items, that together comprise 8 dimensions: "Respect for patients' values", "Preferences and expressed needs", "Coordination and integration of care", "Information, communication and education", "Physical comfort", "Emotional support", "Involvement of family and friends" and "Transition and continuity" (Jenkinson *et al.*, 2002). Unlike patient satisfaction questionnaires, questions in the Picker questionnaire do not enquire about satisfaction with received care but rather ask if a specific process was performed adequately, such as "Did you want to be more involved in decision made about your care. Response alternatives are Yes, often; Yes, sometimes; and No." (Jenkinson *et al.*, 2002). In 2002, the Picker Institute developed the PPE-15 (Jenkinson *et al.*, 2002). Response alternatives are coded (0=problem, 0.5 slight problem and 1=no problem) and summarized into a total and dimension scores ranging from zero (scoring all items as problems) to 100 (no problems). Internal consistency has been shown to be good in international samples (Cronbach's alpha=0.80-0.87) (Jenkinson *et al.*, 2002).

General Self-Efficacy Scale

The General Self-Efficacy Scale used in Paper II is a 10-item, unidimensional scale developed by Jerusalem and Schwarzer (2005) to assess self-efficacy (Appendix 2). Self-efficacy refers to the belief that one has the ability to achieve a desired goal. Items are rated on a Likert scale ranging from 1(not all true) - 4 (exactly true), with a total score ranging from 10 (low self-efficacy) to 40 (high self-efficacy). Psychometric properties of the Swedish version of the GSES have been evaluated (Cronbach's alpha=0.90) (Love, Moore & Hensing, 2011).

Functional status

Functional status was evaluated in Paper II using the FRS (Zuckerman, Koval, Aharonoff, Hiebert & Skovron, 2000), which consists of the Basic Activities of Daily Living scale (B-ADL), Instrumental Activities of Daily Living (I-ADL) and the patient's ability to walk independently. The total FRS score (100%) indicates complete independence, and is calculated by combining the B-ADL score (four items comprising

44% of the total score), I-ADL score (six items comprising 23% of total score) and the patient's ability to walk independently (a single item comprising 33% of total score). In Paper IV, the Katz Personal Activities of Daily Living index (Katz-ADL) (Katz, Ford, Moskowitz, Jackson & Jaffe, 1963) was used. The Katz-ADL evaluates functional dependence or independence in six daily activities: bathing, dressing, toileting, movement, continence and eating. The Katz-ADL has a hierarchical structure and uses ADL gradings A-F.

Severity of symptoms

The New York Heart Association (NYHA) classification was used to assess CHF symptom severity in Papers II & IV. NYHA is a widely used and clinically useful classification system of functional status in CHF (Dickstein *et al.*, 2008; Holland, Rechel, Stepien, Harvey & Brooksby, 2010). The NYHA classifications consist of an ordinal scale that is divided into NYHA I (no limitation in physical activity), NYHA II (slight limitation in physical activity), NYHA III (marked limitation in physical activity) and NYHA IV (unable to perform any physical activity without discomfort).

Health Related Quality of Life

Health related quality of life (HRQoL) is a complex concept, involving the patient's expectations and experience of the physical, emotional and social aspects of life (Rosenberg, 1995). The Kansas City Cardiomyopathy Questionnaire (KCCQ) is a validated 23 item, disease-specific HRQoL instrument (Green, Porter, Bresnahan & Spertus, 2000) (Paper II & IV). KCCQ ratings are aggregated using standardised scoring procedures into an overall summary score (general health status) and a clinical summary scale (symptom impact). The Swedish version of the KCCQ was shown to have good internal consistency (Cronbach's alpha) for both the overall summary score (0.87) and the clinical summary score (0.84) (Patel, Ekman, Spertus, Wasserman & Persson, 2008). The KCCQ has also been shown to be sensitive for detecting clinically significant changes in HRQoL (Green *et al.*, 2000).

Text analysis and statistical methods

Text analysis

A hermeneutic approach was used in analysing the qualitative data. The analytical approach was influenced by Paul Ricoeur's (1976 p. 72) hermeneutic ideas of a circular movement between 'understanding' and 'explaining' the text. In Paper II, admission interviews (n=32) were selected and analysed. The interviews were selected on the basis of richness of content about resources in everyday life activities at home, hobbies, training activities, social activities or traveling. The interviews were transcribed verbatim. The analysis focused on content in the text pertaining to the patient's confidence in managing everyday life, their resourcefulness and how they dealt with the current deterioration of the illness. Each interview was read "one by one" and meaning units (MU) of sentences or phrases that touched upon the research question of personal resources were identified. The MUs were condensed into subcategories which were subsequently compared with other subcategories and consolidated into various categories after discussion between the co-authors (Graneheim & Lundman, 2004).

According to Geertz (Geertz, 1973 p. 7-14), ethnography implies thick descriptions of social phenomena that illuminate people's similarities without reducing their particularity. In order to analyse the discrepancy between the intentions of healthcare professionals and those of patients (what they say and what they do in the everyday activities) (Paper III), the fieldnotes and transcribed interviews were structured into five categories: The Scene (the ward environment), the Act, the Agent (patient, RN, AN, physician), the agent's purpose and agency. This approach was influenced by Kenneth Burke's dramatism method (1969), which aims to explore how the care environment with its daily routines (the tools used to support and evaluate care), physical design, and social structures (the proceedings and relationships within the shared belief system) influence the patients and healthcare professionals (Geertz, 1973 p. 145).

Statistical methods

The sample size in Paper I was 32 517 respondents. The internal validity of the Swedish PPE-15 was evaluated with Cronbach's alpha. The half-scale method was applied to impute missing PPE-15 item values in all analyses of associations between patient characteristics and the PPE-15 total score. Using this method PPE-15 total scores were available for 29 882 respondents. Analyses of associations between patient characteristics and PPE-15 total scores were examined with the chi-square test for dichotomised variables and the Spearman correlation coefficient for ordinal variables. Multiple linear regression analyses were performed to determine the influence of patient characteristics (dependent variables) on PPE-15 scores. To estimate the effect size of the differences in the PPE-15 total score between groups (vulnerable vs. non-vulnerable), Cohen's *d* was calculated. In Papers I, II and IV basic descriptive statistics (mean, standard deviation, median, min and max values) were used for continuous variables and categorical data was described using frequencies and percentages. Between-group differences were tested using Fisher's Exact test for dichotomous variables, Mantel-Haenszel Chi-2 test for ordered categorical variables and Mann-Whitney U-test for ordinal variables. In Paper II, Spearman's correlation coefficient was used for analysing the relationship between NYHA class and self-efficacy (GSES).

In Paper IV, sample size estimates were based on a two day reduction in LOS from 8.5 days (based on hospital audit records), with $\alpha=0.05$ and $1-\beta=0.80$. Accordingly, at least 91 patients were needed in each of the two groups. To compensate for withdrawals, 120 patients per group were targeted.

In Paper IV, analyses were performed both on an intention-to-treat (ITT) and a per-protocol (PP) basis. The ITT analyses included all patients in the comparison groups irrespective of whether or not they actually completed the allocated treatment, whereas PP analyses included only those patients who fully adhered to treatment as stipulated in the protocol. Protocol non-adherence occurred if the PCC plan was not evaluated either within the first 72 hours or within the succeeding evaluations of the PCC plan every 48 hours until discharge. Hence, protocol non-adherence was more associated with the care structures and behaviours of the staff rather than with patient factors.

Important variables that differed significantly at baseline (NYHA class and Dyspnoea score) were included in an adjusted model. In addition, age was included in the adjusted model in the ITT analysis. All statistical tests were two-sided with a significance level of $p \leq 0.05$.

Ethics

Ethical approval was obtained from the Regional Ethical Review Board in Gothenburg, Sweden, and the investigation conforms to the principles outlined in the Declaration of Helsinki. Consent was obtained from all patients. The staff received written and verbal information about the study at various staff meetings, and were asked for their consent to be interviewed (Paper III).

RESULTS

Possibilities and barriers of PCC

Paper I

Most respondents used in the analysis of the national patient survey (n=32517) were 65 years or older (61%), females (54%), and native Swedish speakers (92%) and half had attended either high school (32%) or university (19%). The mean PPE-15 score was 81.1 (SD=17.6). The PPE-15 yielded a Cronbachs' alpha of 0.87. Self-rated health correlated positively with the total PPE-15 score ($r=0.24$, $p<0.0001$). Statistically significant but weak correlations were found with age ($r=-0.03$, $p<0.0001$) and healthcare utilisation ($r=-0.06$, $p<0.0001$). Level of education was not significantly correlated with PPE-15 scores. Respondents who were dependent for help when toileting (functional impairment), non-native speakers and female reported less satisfaction with care ($p<0.0001$). Nonetheless, patient characteristics could explain only 7% of the variance in PPE-15 scores ($R^2=0.07$, $p<0.0001$). In a sub-group analysis, PPE-15 scores were compared between patients who were classified as vulnerable vs. non-vulnerable. Vulnerable patients were those who had poor self-rated health and needed help when toileting (physical impairment) (n=7103). These patients had significantly poorer PPE-15 total scores (M=75, SD=19.8) than non-vulnerable patients (n=9551) (M=85, SD=15.0, $p<0.0001$). The effect size of this difference was moderate (Cohen's $d = 0.58$).

Paper II

The mean age of the patient sample (n=248) was 79 years. The personal resources, i.e. self-efficacy (GSES) and functional independence (FRS), were high. The mean GSES score was 29.5 (SD=7.3, median=31). GSES scores were negatively correlated with NYHA class ($r_s=-0.27$, $p<0.001$). Between-group comparisons revealed a significant difference in GSES scores between NYHA II and III ($p<0.05$) and II and IV ($p<0.05$); however, the difference between patients in NYHA III and IV was not significant ($p=0.42$). Functional independence as assessed with the FRS was high (M=86%, median=96%). The interviews (n=32) revealed that patients generally lived their daily lives in an active and independent way. Analyses of the interviews yielded four categories: social spaces, reduced social spaces, feeling at home and returning to my previous life. A central theme in the interviews was that the patients continually modified and adapted their behaviours and lifestyles to their increasing functional limitations as their condition worsened. For example, the patients reported that they performed daily activities, such as shopping, gardening or doing housework, at a slower pace, and as symptoms deteriorated, patients progressively reduced their social zones to areas closer to their homes. During the period of deterioration prior to the hospitalisation, the patients tested their functional abilities in different social activities and adapted their life accordingly. Some patients started to test their physical function regularly directly after hospital admission, and sought assurance and confirmation that they would be able to manage at home and in their different social spaces (e.g., the shopping mall or the garden).

Paper III

Opportunities for testing one's personal resources and gain reassurance were however limited for patients admitted to the hospital ward. The ethnographic fieldwork at a coronary care unit revealed a care environment that was poorly adapted to the needs and usual activities of patients, and not conducive to dialog between healthcare professionals and patients. These conditions tended to make the patients passive and to affect healthcare professionals' daily decisions and care practices. The situation on the ward was further aggravated by high admission and discharge rates and daily staff rotation, which the staff managed by adhering to strict routines (Table 2).

Table 2. The different actors: acts, agencies and purposes. Modified table from the original publication (Wolf, Ekman & Dellenborg, 2012)

| Agents | The Act | Agency | The purpose |
|----------------------|---|---|---|
| The patient | The patients spent almost all their time sitting or lying in their bed, waiting for a decision concerning their treatment. Occasionally, patients walked back and forth along the corridors for physical exercise; watched TV, or chatted with other patients in the public areas of the ward. | In general, the patients were eager to act as a "good patient", and live up to the professionals' picture of an ideal patient who is compliant and cooperative. Many patients described the hospital stay as filled with waiting: waiting for the round to come, for the physician's decision, for examinations and results. | <ul style="list-style-type: none"> To understand why and how the disease and treatment will affect him/her. To get good care |
| The assistant nurse | The AN was in charge of taking blood samples and helping the patient with his/her morning routines. They spent most of their time caring for the patient and reported back to the RN. For the past few years the ANs have participated in the morning rounds. The ANs argued that they are the one's who spend most time with the patients, supporting them in their daily needs and reflections. The ANs seldom stayed a whole week in the same subunit. | The ANs joined the morning rounds to get a more comprehensive picture of the patient. Many were silent during the round and only answered questions that were directed to them. When ANs did not have the time to attend the round, the RNs filled them in afterwards. | <ul style="list-style-type: none"> To support the patient. To have a comprehensive picture of the patient's well-being. To be seen as a competent, professional part of the care team. |
| The registered nurse | The RN was responsible for distributing medicine, executing the physician's ordination and coordinating the nursing tasks. Relatives, patients and the physician/AN constantly interrupted the RN to ask questions about prescriptions, tasks, etc. that had to be performed. This meant acting in a task oriented, day-to-day basis, often moving to different patients throughout the day. Nurses expressed frustration and experienced themselves as sometimes more of an administrator or secretary than an RN. The RNs seldom stayed a whole week in the same subunit. | RNs' main focus was on vital signs and medical knowledge. They made efforts to assist the ANs in their work in order to spend more time with the patients but administrative tasks seemed to be a heavy burden. They often ate breakfast in front of the computer. | <ul style="list-style-type: none"> To proficiently perform the physician's medical ordination. To learn how to manage acute situations. To give good nursing care. |
| The physician | The physician had the overall responsibility for the treatments of the patients on the ward. Besides being responsible for the patients on the ward, the physicians had other duties, such as consultations at other wards or outpatient clinics. This meant spending the afternoon outside the ward, being reachable primarily over the phone if the nurses needed advice or consultation. The physicians stayed a whole week in the same subunit. | The morning rounds were described by physicians as their main "working tool" to get to know the patient's pathology and medical status. They relied on the computer journal and the information from the RN for information about the patient. During the rounds, they were keen to ask the patients about their symptoms and often asked them for a short anamnesis. | <ul style="list-style-type: none"> To provide and coordinate suitable care and to coordinate his/her duties inside and outside the clinic. |

The ward structure and architecture also constrained the patients' ability to partake in normal everyday activities. For example, the kitchen/TV room was often used for staff meetings, and a smaller TV room was frequently used as an extra patient room at times of overcrowding.

Routine-based care on the ward revolved around three time periods: mornings, evenings and nights. During the mornings, treatment and care decisions were discussed and made, and the medical round was the principal activity. In contrast, the evening, night and weekend shifts' primary responsibility was monitoring and observation. For the patient, the morning round was often the only time that they could meet or even see the physician. Generally, the patient had a only few minutes with the physician, and sometimes even less time, depending on the amount of information and the level of inquiry on the part of the physician and the patient. The patients expressed the importance of being friendly and pleasant to the healthcare professional: *"It depends on the patient too. 'You are always happy in the morning', they say [referring to the staff]. Sometimes I'm not, but I give them a smile anyway. It has such great importance... those small things...."*

The physicians spent more time during the rounds reading the patients' records than talking to the patients. For the healthcare professional, the routines, often performed under time constraints, gave little opportunity for the healthcare professionals to reflect on their actions and the decisions they made. For example, although the RNs and ANs considered the rotating schedule to be advantageous for their private lives, the downside was that the RNs often found themselves with a whole set of new patients, constantly feeling one step behind. One RN said: *"I only have about five minutes with every patient during my shift, so I have to make the best of it. I read the nurses' and physicians' documentation in the patients' records to get the whole picture."* The patients sympathised with the healthcare professionals' work situation.

By creating clearly defined routines, the care structures both promoted and counteracted different healthcare professionals' intentions. The RNs related that it was difficult to apply principles of good nursing care in clinical practice, hence such principles were deprioritised. They felt trapped between demands for status achieved through biomedical knowledge, technical skills and adhering to routines, and their professional perception of good care. In particular, the RNs reacted to these restrictions with feelings of guilt and inadequacy.

Effects of PCC

Paper IV

The intervention study compared patients receiving conventional care (n=123) with patients receiving PCC (n=125). Fifteen patients in each group died during the study and ten patients withdrew during follow-up. The study groups were similar regarding all baseline characteristics, e.g., age, sex, comorbidities, etc. (Table 3). Patients in the PCC group were significantly more symptomatic (NYHA; p=0.002) and reported worse dyspnoea (p=0.03). PP-analyses included 74 patients from the PCC group and all patients in the Conventional care group. The patients in the PP analysis did

Table 3. Selected baseline patient characteristics. Modified from the original publication (Ekman *et al.*, 2012)

| Characteristics | Conventional care (n=123) | PCC (n=125) | P-value Conventional vs. PCC | PCC-PP* (n= 74) |
|------------------------|---------------------------|-------------|------------------------------|-----------------|
| Female (%) | 41 | 42 | 1.0 | 49 |
| Age at inclusion | 80 ±9 | 77 ±11 | 0.08 | 78±10 |
| NYHA class | | | | |
| Class I (%) | 4 | 0 | | 0 |
| Class II (%) | 41 | 31 | | 30 |
| Class III (%) | 52 | 58 | 0.002 | 64 |
| Class IV (%) | 3 | 11 | | 6 |
| Medical history | | | | |
| Comorbidities (SD) | 4±2 | 4±2 | 0.7 | 4±2 |
| CHF medication | | | | |
| ACE-I/ARB (%) | 69 | 66 | 0.7 | 66 |
| Beta-blockers (%) | 72 | 82 | 0.07 | 86 |

*Per-protocol analysis

not differ from Conventional care patients on any baseline variables except NYHA class ($p=0.03$). The mean indexed LOS in the Conventional care group was 9.22 days ($SD=7.4$, median=7, range 2-44 days) compared to 8.22 days ($SD=4.4$, median=8, range 2-31 days) in the PCC group ($p=0.16$). In the PP analysis, LOS was significantly shorter (2.5 days) in the PCC group (6.77 days, $SD=3.2$, median=6.5, range 2-25; $p=0.01$). At discharge, ADL levels were better in the PCC group (all patients, $p=0.07$; PP group, $p=0.04$) (Figure 2). Time-to-first readmission as well as readmission frequency within 6 months did not differ significantly between the groups. There were no differences in the KCCQ Overall Summary Score or the Clinical Summary score after 3 months.

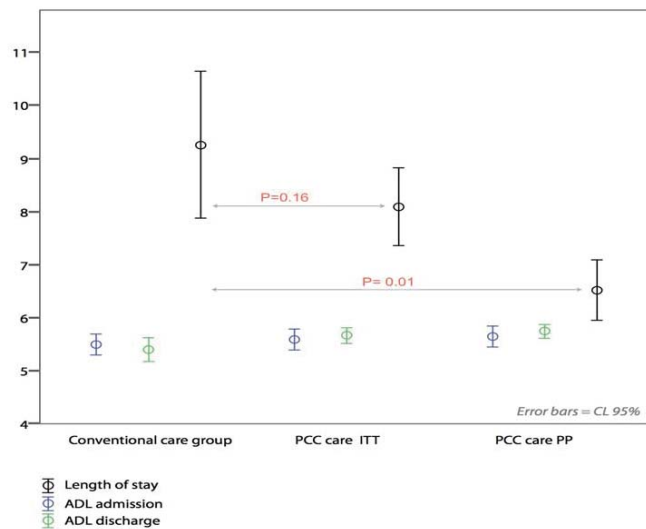


Figure 2. LOS and Katz-ADL between the Conventional care group and PCC group.

DISCUSSION

In this thesis, PCC is conceived as the operationalisation of person-centeredness. Patients admitted for worsening CHF presented a high capacity for independent living and vitality prior to the hospital admission (Paper II). They tended to adapt to their illness and maintain their independence by choosing different strategies, such as decreasing their social spaces to manage their daily activities as their condition worsened. In a recent cohort study from the USA, the Cardiovascular Health study (n=5511) (Bowling *et al.* 2012), impairment in ADL ability (such as shopping) in community dwelling elderly was found to be a strong risk predictor for developing CHF. Similarly, we found that patients actively adapted and restricted their daily activities as their condition worsened prior to hospitalisation. Changes in behaviour patterns, such as reducing and confining social spaces to areas near the home and performing daily activities (shopping, gardening, etc.) less frequently and at a slower pace (Paper II), may constitute patterns that are important to acknowledge in preventing acute decompensation and rehospitalisation. Such behavioural changes should then not be seen as mere physical impacts/manifestations of symptoms such as breathlessness or fatigue on physical performance. A recent study by Moser *et al.* (2011) showed that variability in the symptom breathlessness in patients with CHF (n=71) is a predictor of hospitalisation regardless of the physical impact of symptoms on everyday life (NYHA). Fluctuating symptoms could therefore increase a person's uncertainty about his/her illness and hence impact on self-efficacy.

The perception of being able to achieve life projects is an important part of one's self-identity (Bandura & Locke, 2003), and this may help to explain our finding of a negative correlation between symptom severity during CHF deterioration and self-efficacy level (Paper II). This could also explain why patients increasingly restricted their activities to areas nearby their homes (Paper II). Home comprises a contextual feeling of security, control and power (Zingmark, Norberg & Sandman, 1995), and is perceived as an integrated part of one's life (Gillsjo, Schwartz-Barcott & Von Post, 2011). The patients decreased their social spaces in order to stay independent, yet they seemed to test their abilities/functioning during the period when they experienced worsening in their symptoms and on the ward, suggesting a desire and eagerness to return to their everyday life.

The prevailing attitudes, beliefs and social roles on the ward hampered healthcare professionals from acknowledging and supporting the patients' resources and abilities. These social structures, reinforced by the physical design of the care environment may pose barriers to the patients by inhibiting them from using their own resources and by limiting them in their normal daily activities (Paper III). We observed that the patients spent much of their time in their beds patiently waiting for the healthcare professional. According to Toombs (1987 p. 65), confinement to a hospital bed will increase feelings of vulnerability and dependency. Yet, in the present study, patients had few alternatives other than to remain waiting in their beds. In a recent observational study of hospitalised medical patients (n=76), Kuys *et al.* (2012) reported that the patients spent approximately 88% of their time in their rooms, and less than 20% of their time was spent with a healthcare professional.

The CCU ward (Paper III) had very few physical attributes that could promote everyday activities. However, the physical design of a ward, such as availability of a TV room, etc., is just one aspect of a care environment. In fact, in a recent interview study (n=12) about the ward architecture on a ward specialised in oncology, the patients always returned to the importance of the staff and their ability to communicate and interact (Rowlands & Noble, 2008). Previous studies in the Scandinavian countries have pointed out the importance of environments that promote activity, are aesthetic (Hansen, Tjørnhøj-Thomsen & Johansen, 2011) and facilitate social interaction with others. Such attributes form a crucial part in a person's perception of independence, identity, and feeling of security and being acknowledged (Edvardsson, Sandman & Rasmussen, 2005).

Hospital structures and clinical routines seem to be organised primarily to supervise and monitor patients rather than to support the patients' independence, resources and partnerships in care (Paper III). According to McCormack *et al.* (2010), the health-care professional's competence, beliefs and conviction about person-centredness are important factors in PCC, however the context where care is delivered will have an impact on the above mentioned factors. The ward structures seem to have a dominant impact on the overall delivery of care, and even if there were elements of care that resembled PCC, PCC was not conducted consistently throughout the admission (Paper III). Social structures are created and maintained by their members (Geertz, 1973 p. 145) and in the hospital ward, structures such as the daily routines, professional hierarchies and perceived ideals of professional competence reflected the biomedical supremacy. In the present study, only 60% of the patients received the structured PCC intervention throughout their hospitalisation (Paper IV), indicating the challenges of trying to implement PCC in the conventional care environment.

Healthcare professionals struggled with their own moral beliefs about how care should be provided, yet they in fact sometimes depersonalised the patient (Paper III). According to Ricoeur (1994 p. 179), a person goes back and forth between his/her ethical intention of having a good life and the obligations perceived in the given context. In hospital structures today, the ethical intentions of aiming at the good life with others (reciprocity) and for others (solicitude), in just institutions (equality) (Ricoeur, 1994 p. 172) seem to be subordinate to the present social structures of the hospital ward. Healthcare professionals tend to see the patient as an individual with needs that can be fragmented into different patient characteristics and disease pathologies, rather than as a capable and resourceful person with an identity that is developed and nourished in his/her relationships with other persons. As such, the combination of social structures, its routines and the physical design of the ward act as barriers to the practice of PCC.

It has been suggested that healthcare professionals' authoritarian attitudes toward the patient, which undermine patient involvement in decision-making, stem from a lack of knowledge about the patient's own beliefs, values and capacities (Zomorodi & Foley, 2009). According to Bandura (1997 p. 17), structures that shape passivity through paternalistic behaviours could influence a person's self-efficacy negatively, something that Bandura calls "proxy control". This may explain why patients became so passive in the examined ward structures (Paper III). Increased proxy control by the

healthcare professionals may produce passive patient behaviours, which in turn may have a negative impact on self-efficacy because a person constantly compares his/her competence and performance with others (other patients or healthcare professionals) (Bandura, 1997 p. 17). As observed in the ethnographic study (Paper III), patients were referred to as room and bed numbers, and although the staff occasionally considered this practice to be necessary for reasons of confidentiality, it was sometimes used routinely without reflection. This may lead to a care structure that promotes staff behaviours that Kitwood (1997 p. 46-47) calls depersonalisation of the person, such as labelling, disempowering, stigmatization or withholding information. The practice of referring to patients as, for example room numbers, may result in the objectification of patients, and may ultimately pose a barrier for PCC.

The failure of hospital structures to acknowledge patients' resources and preference could also explain the finding that vulnerable patients were less satisfied with their care (participation and communication) and wanted to receive more information and improved communication about their condition and treatment/discharge strategies, as well as increased participation in clinical decision-making (Paper I). The vulnerable patients (poor/fair SHR and dependency when toileting) were older and had a history of higher healthcare utilisation compared to the non-vulnerable patients. In a recent study, only 54% of elderly patients (n=214) with a serious form of chronic illness reported that they had been informed by their physician of the seriousness of their condition, and only 20% agreed with their physician that they had discussed or been informed about the severity of the disease (Fried, Bradley & O'Leary, 2003). Hence, it may be presumed that patients who perceive themselves as severely ill or vulnerable need and want more comprehensive information about their disease and its treatment and seek greater involvement in the decision-making process. Our findings are strengthened by a recent study of care experience in over 10 000 patients with complex care needs (defined as patients with fair/poor health with a history of previous healthcare utilisation within the last year) conducted in 11 countries, including Sweden and Norway (Schoen *et al.*, 2011). Sweden and Norway had some of the least positive care experiences regarding care participation and communication amongst the participating countries. Together, the above studies indicate that patients, especially vulnerable patients, judge their care experiences in conventional care settings to be sub-optimal and that they want to be more involved in shared decision making about the care plan.

In Paper III, healthcare professionals were shown to often complain about having too little time in their clinical encounters with patients. Westbrook *et al.* showed that RNs spend less than about 40% of their time with the patient (Westbrook, Duffield, Li & Creswick, 2011) and that physicians spend less than 15% of their time communicating with patients (Becker *et al.*, 2010). Yet, time spent with the patient does not necessarily mean that the meeting is focused on the patient as a person. Bolster and Manias (2010) showed in an observational study that the time spent with the patient was driven by routines and professional perceptions of what the patient needs instead of actually inviting the patient to participate. When asked about their failure to spend sufficient time with patients (Paper III), most RNs were very self-critical and distressed by their inability to provide optimal care due to time constraints, increasing administration

and care routines. The present study indicates that the care environment with its social structures in Sweden can lead to feelings of guilt amongst the RNs, that may lead to moral stress. Moral stress or the closely related concept of stress of conscience, surfaces when the care structures and organisational aspects present values that conflict with healthcare professionals ethical and moral convictions (Corley, Minick, Elswick & Jacobs, 2005; Juthberg, Eriksson, Norberg & Sundin, 2007).

In the current ESC guidelines, multi-disciplinary care management programmes have received the highest recommendation class (Class 1, Level A) (McMurray *et al.*, 2012). Interestingly, the patient is not clearly considered as an active expert member in multi-disciplinary teams and interventions. Our study was the first to evaluate the effects of including the patient as a central partner in a structured care management team targeting patients with CHF (Paper IV). An important focus point in that study was the initiation of the partnership through the patient narrative, which was summarised in a care plan. Critical aspects covered in the narratives were the impact of the patient's illness experience on everyday life, aspects of the patient's life prior to the deterioration as well as the patient's current resources, motivation and goals. The results seemed consistent with other studies in hospitalised patients who used the illness narrative for goal setting in care planning namely, shortened LOS (Olsson *et al.*, 2006), decreased hospital mortality (Mudge *et al.*, 2006) and improved ADL capacity (Mudge *et al.*, 2006; Olsson *et al.*, 2007a).

A mere reduction of LOS should not be considered an end in itself if it compromises care quality or increases hospital readmission. The PCC intervention (Paper IV) led to less variation in the distribution of LOS (SD PCC PP 3.2 vs. Usual care 7.4). It has been argued that short LOS (2 days) as well as lengthy LOS (above 10 days) negatively impact on the quality of care and medical treatment of patients with CHF (Kossovsky *et al.*, 2002). While the PCC intervention decreased LOS overall, it in fact seemed to reduce the shortest LOS found in the conventional care group. The current ESC guidelines in CHF (McMurray *et al.*, 2012) include a recommended minimum of diagnostic procedures and interventions, which would be difficult to perform during an extremely short LOS. On the other hand, prolonged LOS seems also to impact hospital care quality (adherence to guidelines) negatively (Svendsen, Ehlers, Andersen & Johnsen, 2009). Predictors of prolonged LOS for CHF includes e.g. acute worsening of vital signs/symptoms, co-morbidities, in hospital treatments (e.g., intravenous diuretics) and social barriers (need for home services, etc.) (Wright, Verouhis, Gamble, Swedberg, Sharpe & Doughty, 2003). Most of the above mentioned aspects that may lead to prolonged LOS could be reduced by early identification and care planning. The present study's effect in reducing both LOS, the spread in LOS and preserved ADL level (Paper IV) could imply an increased level of quality care for the patients. In addition, while the present study was not designed to investigate patient-reported care satisfaction during the intervention, other studies suggest that shorter LOS has a positive (Nguyen Thi, Briancon, Empereur & Guillemin, 2002; Quintana *et al.*, 2006) or non-inferior impact (Borghans, Kleefstra, Kool & Westert, 2012) in terms of patient satisfaction compared to longer LOS. In the present study, reduced LOS did not have any negative impact on readmission. However, in agreement with the above mentioned study by Mudge *et al.*, (2006), the 6-month rehospitalisation rate did not

improve in the present study (Paper IV). It may be speculated that the effects of PCC are transitory, dissipating with time, and that PCC must be extended to other care settings outside the hospital in order to improve long-term outcomes, such as 6-month rehospitalisation or HRQoL.

Patients acquiesce and adapt to ward regimens. Care satisfaction and experiences are complex phenomena determined by both previous experience and future expectations (Williams, 1994). The low explanatory value of different patient characteristics found in Paper I may reflect the complexity in evaluating care experiences, something that has previously also been shown by Bleich *et al.* (2009). This raises the question about what and how future research and benchmarking endeavours should measure PCC outcomes in the future. As governments, patient organisations and other interest groups strive to increase patient participation, self-reported care satisfaction or care experience questionnaires have been increasingly used to benchmark care (Garratt, Solheim & Danielsen, 2008). The Swedish national patient care satisfaction survey used in Paper I assesses care experience on a hospital or ward level rather than on an individual level. In order to gain a richer picture of the partnership that constitutes PCC, it may be feasible to merge patients' assessments of their current care experience with their previous experiences/future expectations of care combined with healthcare professionals' perceptions and expectations of the care provided. Patient and staff assessments have already been combined in surveys for evaluating the care environment, such as the Patient-centred Climate Questionnaire (Edvardsson, Koch & Nay, 2010), and should be further developed for assessing other areas of PCC, such as the partnership and documentation.

THEORETICAL AND METHODOLOGICAL CONSIDERATIONS

This thesis has tried to enrich and expand our understanding of PCC by exploring usual care and the effects of a PCC intervention. The philosophical point of departure in this thesis is that a person is unique, capable and reflective and that he/she wants to be engaged in and nourished by dialog and interaction with others and his/her surroundings. In conceptualising the person as capable, person-centredness highlights the importance of understanding the person's resources and vitality in everyday life in order to support health. This thesis does not deal with the concept of becoming a person, an ethical issue that is still heavily debated in relation to, for example, abortion (Giubilini & Minerva, 2012).

An important aspect, and possibly a critique of the philosophy of personalism is that it originated and initially developed in the Western world, mainly Europe and America. Personalism as such is therefore often associated with the moral and ethical foundations of the Western world and of Christianity (Bengtsson, 2006 p. 69). However, while many Western philosophers, such as Martin Buber or Paul Ricoeur had a theological background in Christianity, the principal tenet of personalism concerns the interaction and acknowledgment of the other person (Mounier, 1970). Hence, PCC may well be applicable in other countries and other religious belief systems. In fact, the ideology of personalism runs somewhat contrary to the Western conception of the absolute autonomy of the individual, which in its extreme tries to separate the individual from the impact of culture and society (Lock & Gordon, 1988 p. 34).

In intervention studies within the healthcare setting, complexity often implies multiple causes (Craig *et al.*, 2008). The purpose of science is to describe, explain or predict phenomena; however, in healthcare the phenomena are often so complex that different investigative methods are required (Persson & Sahlin, 2009). The structure of the care environment where the intervention is implemented as well as the patients and healthcare professionals' attitudes and beliefs have to be acknowledged when trying to understand complex interventions (Campbell *et al.*, 2007). Using both qualitative and quantitative methods within the same paradigm has been argued to diminish the gap between different methodological assumptions (Barbour, 1998). There are ontological and epistemological differences in different research methods, such as instruments and interviews, and combining different methods is often a balancing act (Morse *et al.*, 2006). According to Morse *et al.* (2006), mixed-methods designs (using different methods within the same study) as well as multi-method designs (multiple studies within a project or thesis) should have a theoretic drive of either a qualitative or quantitative nature in order to assure validity. The overall epistemological perspective in this thesis is hermeneutical, that is, trying to understand and explain complexity, rather than establishing causality. The present thesis shows that a multi-method approach may help to understand a complex care phenomenon. Although the randomised controlled trial design is considered the "gold standard" in evaluating interventions, its use may be limited by practical concerns in complex interventions that target both patients' and the healthcare professionals' attitudes, performance and the everyday working tasks (Shepperd *et al.*, 2009; Kaplan, Giesbrecht, Shannon &

McLeod, 2011; Bird, Arthur & Cox, 2011). As the type of method used will have implications for the observations and conclusions that can be made, complexity needs to be tackled in different ways and with different designs. In a complex intervention, it is often impossible to blind participants (both patients and healthcare professionals) with respect to the intervention and consequently the question arises as to what care/treatment the controls have received. Oftentimes, controls will in fact receive better care, which could result in the effects of the interventions being underestimated. In short, one strength of this thesis was that a multi-method design was used, including a quasi-experimental design in the intervention study and fieldwork performed to understand the context of usual care.

CONCLUSION

The possibilities for applying PCC in the hospital setting exist, from the perspective of both the patient and the healthcare professional. Patients who are hospitalised for worsening CHF have personal resources and vitality that can be used to facilitate PCC. Furthermore, patients in general wish to be more involved in their care and desire better communication with healthcare professionals.

The barriers to PCC are found in the care environment of the hospital, which seems poorly designed to support the patient's resources and vitality, and which through demarked routines compels the staff to deliver care based on organisational needs. In addition, the social structures do not value the RNs moral intentions toward person-centredness, producing feelings of guilt that resemble moral stress.

The benefits of adopting a PCC approach may also be considerable from a healthcare management perspective. By supporting the development of a partnership between the patient and the healthcare professionals through a structured PCC approach, a reduction in hospital LOS by 30% was achieved. The greatest effects of PCC were seen when the partnership and care plan were established within the first 48 hours and maintained throughout the patients' entire hospital stay. To ensure effective and satisfactory care in Sweden, the healthcare system must learn to rely upon and exploit both the patient's resources, vitality and motivation as well as the experience and knowledge of healthcare professionals.

FUTURE PERSPECTIVES

A growing number of research studies, including those in this thesis, indicate that a structured PCC approach is effective in improving clinical outcomes. Future studies should evaluate the efficiency and scalability of PCC in other settings. In order to implement PCC, the structures of the care environment and the multi-professional team must be adapted to PCC. It will be necessary to make changes in the care environment and the multi-professional team's ability to provide care consistent with their moral conviction. This change needs to target the architectural design of the hospital, organisational aspects of the delivery system, such as the healthcare professionals' schedules and shift rotation, as well as social structures, i.e., attitudes and common belief systems that regard the patient as a capable person and partner. Redesigning the hospital clinics requires educating healthcare professionals as well as patients and their relatives about the prerequisites and effects of PCC. In addition, the implementation of PCC and its effects should be benchmarked in order to evaluate the quality and acceptance of PCC in the hospital setting.

SAMMANFATTNING PÅ SVENSKA

Är personcentrerad vård effektiv och inte bara moraliskt eftersträvansvärd? Personcentrerad vård bygger på ett partnerskap mellan experter; patienten som expert på sin livssituation samt den professionella vårdaren med generiska expertkunskaper. I denna avhandling presenteras analys av en vårdavdelnings kultur och strukturella förutsättningar för personcentrerad vård, patientrapporterade data om sjukhusvård samt en utvärdering av personcentrerad vård.

På gruppnivå rapporterar sjukhusinlagda patienter att kommunikation och delaktighet i vården är otillräcklig. I synnerhet bedömer patienter som upplever sin hälsa som dålig samt behöver assistans från sjukvårdspersonalen kommunikation och delaktighet mera bristfällig än patienter med god hälsa och hög fysisk oberoendegrad. Patienter som sjukhusvårdas för försämring av kronisk hjärtsvikt har trots sin höga medelålder samt symptom i form av bland annat andfåddhet och trötthet många personliga resurser i vardagen så som tillit till sin egen förmåga att lösa problem och en hög vardaglig oberoendegrad. Patienter anpassar gradvis sin vardag till försämringen. Vardagens fokusering till trygghetsfären i och omkring hemmet kan utgöra ett tidigt varningsstecken på en försämring av patientens symptom. Jämfört med traditionell vård av patienter som sjukhusvårdas för försämring av kronisk hjärtsvikt innebär personcentrerad vård en signifikant 30% (2.5 dagar) reduktion i vårdtid samt en bibehållen daglig aktivitetsförmåga. Den kortare sjukhusvårdtiden ledde inte till lägre livskvalitet eller högre återinläggningsfrekvens efter 6 månader.

Enbart 60% av interventionsgruppens patienter fick personcentrerad vård under hela vårdtiden. Detta pekar på den troligtvis största utmaningen för implementeringen av personcentrerad vård, nämligen de traditionella och rigida strukturer inom sjukvården som inte tillvaratar patientens resurser. Istället observerades en rutindriven vårdmiljö som var uppbyggd kring sjukvårdens fokus på patientens biomedicinska behov. Denna struktur kan i sin tur leda till att vårdpersonal, framförallt sjuksköterskor känner maktlöshet och skuld känslor.

Dagens konventionella vård uppvisar en diskrepans mellan patientens vilja och mål och vårdgivarnas bedömning och behandling, vilket tyder på en brist i den konventionella vårdens sätt att vårda patienter. Därför bör den aktuella studien ses som ett första steg i det paradigmskifte som nu börjar ta form i den praktiska vården, vilken kombinerar medicinsk evidensbaserad vård med patientens sjukberättelse och kunskap om sitt tillstånd. Detta skifte kommer att kräva förändring i vårdmiljön och dess strukturer, utbildning till sjukvårdspersonal, patienter och anhöriga kring personcentrerad vård samt verktyg för utvärdering av personcentrerad vård.

ACKNOWLEDGEMENT

My experiences and feelings during the last four years with this thesis can best be summarised by Aloe Blacc's lyrics "Something special happened today, I got green lights all the way, with no big red sign to stop me, no traffic jam delay...." (Aloe Blacc, Green Lights). You have to get stuck in traffic jams or at red lights in order to really appreciate the feeling of total happiness you get when you hit a stretch of road with green lights all the way. Many people have helped to make this ride to my thesis a smooth one, even though the road was bumpy at times, it was a very memorable ride and something that I forever will remember and be grateful for. Even if I drove into a few ditches along the way, you all helped me out of them and back onto the road. Thanks.

To my supervisors *Inger, Karl* and *Lars-Eric*, who even during the most stressful times always had time for my questions, thoughts and ideas.

Inger Ekman; When we first met in 2008, you said that once you get hooked on being a researcher, you will have a hard time letting it go. I didn't really believe you then, but I think I've got it now. Thanks for enabling me to "get hooked", not only on clinical research, but also for looking at philosophy, arts and entrepreneurship in a different way.

Karl Swedberg; All the pages and articles in my thesis combined still don't come close to the numbers of articles that you have published. Thanks for sharing your experience in clinical trials and clinical medicine with me. Your stories and experiences have helped me to develop as a researcher, but also as a clinical nurse and in tech support.

Lars-Eric Olsson; The Swedish rapper Looptroop sings about the long-distance runner's persistency in reaching his/her goal. Implementing PCC feels sometimes like a marathon, but it is so much easier when you have someone that leads the way. Thanks for being my running coach for the last four years.

Lisen Dellenborg; While some anthropologists visit the wide spaces of Africa or the inaccessible jungles in Asia to explore human structures, our fieldwork required a tram ticket to Östra Sjukhuset. But what a ride and adventure it was. Thanks for all your guidance and support in the ethnographic fieldwork and the world of anthropology.

Charles Taft; Thanks for all your guidance in patient-reported outcome instruments, statistics as well as your language editing.

Kerstin Dudas; I'm thankful for your support and guidance in good clinical practice and study implementation, but also for taking it easy on me during our morning jogs.

Kerstin Frid; Your insight into both the professional and patient perspective of the clinic was an important part in the development of the PCC intervention and in my understanding of PCC.

I am obliged to my colleagues at Östra Hospital who worked with me during this thesis. I would especially like to thank *Eva-Lena Andersson, Annika Hilding, Jenny Bergstrand, Karin Johansson Schultz* and *Maria Schaufelberger* for your support during the PCC intervention.

Lars Fallberg; Thanks for all the help and guidance in the world of patient-reported care experience.

Nils-Gunnar Pehrsson; Thanks for the statistical guidance and help during this thesis.

Eva Thydén and *Christine Forssell*; This dissertation would not have been possible without your help with the preparation and layout of this thesis.

Sanna Wieslander; Thanks for helping me visualise my thoughts of PCC with your artistic qualities.

My fellow PhD-students *Lilas Ali, Malin Berghammar, Sara Wallström, Andreas Fors* and *Tariq Saleem Alharbi* for providing me with a well needed sounding board during the last years.

My family; Even if we are sometimes far apart geographically, your support and love have made my journey so much easier.

Finally but not least, a special thanks and gratitude to all the patients and healthcare professionals who shared their time and thoughts with me.

Funding for this thesis was provided by the Swedish Research Council and the Sahlgrenska Academy.

REFERENCES

- Bandura, A. 1978. Reflections on Self-Efficacy. *Advances in Behaviour Research and Therapy*, 1, 237-269.
- Bandura, A. 1997. *Self-efficacy : the exercise of control*, Basingstoke, W. H. Freeman.
- Bandura, A. & Locke, E. A. 2003. Negative self-efficacy and goal effects revisited. *Journal of Applied Psychology*, 88, 87-99.
- Barbour, R. S. 1998. Mixing qualitative methods: quality assurance or qualitative quagmire? *Qualitative Health Research*, 8, 352-61.
- Battersby, M., Harvey, P., Mills, P. D., Kalucy, E., Pols, R. G., Frith, P. A., McDonald, P., Esterman, A., Tsourtos, G., Donato, R., Pearce, R. & McGowan, C. 2007. SA HealthPlus: a controlled trial of a statewide application of a generic model of chronic illness care. *Milbank Quarterly*, 85, 37-67.
- Becker, G., Kempf, D. E., Xander, C. J., Momm, F., Olschewski, M. & Blum, H. E. 2010. Four minutes for a patient, twenty seconds for a relative - an observational study at a university hospital. *BMC Health Services Research*, 10, 94.
- Bengtsson, J. O. 2006. *The Worldview of Personalism Origins and Early Development*, Oxford, Oxford University Press.
- Berlin, J. M. & Carlstrom, E. D. 2010. From artefact to effect: the organising effects of artefacts on teams. *Journal of Health Organization Management*, 24, 412-27.
- Bird, L., Arthur, A. & Cox, K. 2011. "Did the trial kill the intervention?" experiences from the development, implementation and evaluation of a complex intervention. *BMC Medical Research Methodology*, 11, 24.
- Bleich, S. N., Ozaltin, E. & Murray, C. K. 2009. How does satisfaction with the health-care system relate to patient experience? *Bulletin of the World Health Organization*, 87, 271-8.
- Bolster, D. & Manias, E. 2010. Person-centred interactions between nurses and patients during medication activities in an acute hospital setting: qualitative observation and interview study. *International Journal of Nursing Studies*, 47, 154-65.
- Borghans, I., Kleefstra, S. M., Kool, R. B. & Westert, G. P. 2012. Is the length of stay in hospital correlated with patient satisfaction? *International Journal for Quality in Health Care*.
- Bowling, C. B., Fonarow, G. C., Patel, K., Zhang, Y., Feller, M. A., Sui, X., Blair, S. N., Alagia-krishnan, K., Aban, I. B., Love, T. E., Allman, R. M. & Ahmed, A. 2012. Impairment of activities of daily living and incident heart failure in community-dwelling older adults. *European Journal of Heart Failure*, 14, 581-7.
- Bridges, J., Flatley, M. & Meyer, J. 2010. Older people's and relatives' experiences in acute care settings: systematic review and synthesis of qualitative studies. *International Journal of Nursing Studies*, 47, 89-107.
- Buber, M. 1994. *I and thou*, Edinburgh, T&T Clark.
- Burke, K. 1969. *A grammar of motives*, Berkeley, University of California Press.

- Cahill, J. 1996. Patient participation: a concept analysis. *Journal of Advanced Nursing*, 24, 561-71.
- Campbell, N. C., Murray, E., Darbyshire, J., Emery, J., Farmer, A., Griffiths, F., Guthrie, B., Lester, H., Wilson, P. & Kinmonth, A. L. 2007. Designing and evaluating complex interventions to improve health care. *British Medical Journal*, 334, 455-9.
- Charon, R. 2001. The patient-physician relationship. Narrative medicine: a model for empathy, reflection, profession, and trust. *Journal of the American Medical Association*, 286, 1897-902.
- Clark, A. L. 2006. Origin of symptoms in chronic heart failure. *Heart*, 92, 12-6.
- Cleland, J. G., Swedberg, K., Follath, F., Komajda, M., Cohen-Solal, A., Aguilar, J. C., Dietz, R., Gavazzi, A., Hobbs, R., Korewicki, J., Madeira, H. C., Moiseyev, V. S., Preda, I., Van Gilst, W. H., Widimsky, J., Freemantle, N., Eastaugh, J. & Mason, J. 2003. The EuroHeart Failure survey programme-- a survey on the quality of care among patients with heart failure in Europe. Part 1: patient characteristics and diagnosis. *European Heart Journal*, 24, 442-63.
- Committee on Quality of Health Care in America, Institute of Medicine & The National Academies 2001. Crossing the Quality Chasm: A New Health System for the 21st Century. 1. Print ed. Washington, DC.: The National Academies Press.
- Corley, M. C., Minick, P., Elswick, R. K. & Jacobs, M. 2005. Nurse moral distress and ethical work environment. *Nursing Ethics*, 12, 381-90.
- Craig, P., Dieppe, P., MacIntyre, S., Michie, S., Nazareth, I. & Petticrew, M. 2008. Developing and evaluating complex interventions: the new Medical Research Council guidance. *British Medical Journal*, 337, a1655.
- Dahlberg, K. & Segesten, K. 2010. *Hälsa och vårdande : i teori och praxis*, Stockholm, Natur & kultur.
- Dahlberg, K., Todres, L. & Galvin, K. 2009. Lifeworld-led healthcare is more than patient-led care: an existential view of well-being. *Medicine, Health Care and Philosophy*, 12, 265-71.
- Dickstein, K., Cohen-Solal, A., Filippatos, G., McMurray, J. J., Ponikowski, P., Poole-Wilson, P. A., Stromberg, A., Van Veldhuisen, D. J., Atar, D., Hoes, A. W., Keren, A., Mebazaa, A., Nieminen, M., Priori, S. G. & Swedberg, K. 2008. ESC guidelines for the diagnosis and treatment of acute and chronic heart failure 2008: the Task Force for the diagnosis and treatment of acute and chronic heart failure 2008 of the European Society of Cardiology. Developed in collaboration with the Heart Failure Association of the ESC (HFA) and endorsed by the European Society of Intensive Care Medicine (ESICM). *European Journal of Heart Failure*, 10, 933-89.
- Edvardsson, D. 2010a. Commentary on McCance T, Slater P & McCormack B (2009) Using the caring dimensions inventory as an indicator of person-centred nursing. *Journal of Clinical Nursing*, 19, 592-3.
- Edvardsson, D. (Ed.) 2010b. *Personcentrerad omvårdnad i teori och praktik*, Lund, Studentlitteratur.
- Edvardsson, D., Koch, S. & Nay, R. 2010. Psychometric evaluation of the English language Person-centred Climate Questionnaire--staff version. *Journal of Nursing Management*, 18, 54-60.

- Edvardsson, D., Winblad, B. & Sandman, P. O. 2008. Person-centred care of people with severe Alzheimer's disease: current status and ways forward. *Lancet neurology*, 7, 362-7.
- Edvardsson, J. D., Sandman, P. O. & Rasmussen, B. H. 2005. Sensing an atmosphere of ease: a tentative theory of supportive care settings. *Scandinavian Journal of Caring Sciences*, 19, 344-53.
- Ehrenberg, A., Ehnfors, M. & Thorell-Ekstrand, I. 1997. The VIPS model--implementation and validity in different areas of nursing care. *Studies in Health Technology and Informatics*, 46, 408-10.
- Eisenberg, L. 1977. Disease and illness: Distinctions between professionals and popular ideas of sickness *Culture Medicine and Psychiatry*, 1, 9-23.
- Ekman, I., Cleland, J. G., Andersson, B. & Swedberg, K. 2005. Exploring symptoms in chronic heart failure. *European Journal of Heart Failure*, 7, 699-703.
- Ekman, I., Cleland, J. G., Swedberg, K., Charlesworth, A., Metra, M. & Poole-Wilson, P. A. 2005. Symptoms in patients with heart failure are prognostic predictors: insights from COMET. *Journal of Cardiac Failure*, 11, 288-92.
- Ekman, I., Lundman, B. & Norberg, A. 1999. The meaning of hospital care, as narrated by elderly patients with chronic heart failure. *Heart Lung*, 28, 203-9.
- Ekman, I. & Norberg, A. 2012. Personcentrerad vård - teori och tillämpning. *Omvårdnadens höjder*. Lund. Studentlitteratur. (Unpublished)
- Ekman, I. & Segesten, K. 1995. Deputed power of medical control: the hidden message in the ritual of oral shift reports. *Journal of Advanced Nursing*, 22, 1006-11.
- Ekman, I. & Skott, C. 2005. Developing clinical knowledge through a narrative-based method of. *European journal of cardiovascular nursing*, 4, 251.
- Ekman, I., Swedberg, K., Taft, C., Lindseth, A., Norberg, A., Brink, E., Carlsson, J., Dahlin-Ivanoff, S., Johansson, I. L., Kjellgren, K., Liden, E., Ohlen, J., Olsson, L. E., Rosen, H., Rydmark, M. & Sunnerhagen, K. S. 2011. Person-centered care-ready for prime time. *European Journal of Cardiovascular Nursing*, 10, 248-51.
- Ekman, I., Wolf, A., Olsson, L. E., Taft, C., Dudas, K., Schaufelberger, M. & Swedberg, K. 2012. Effects of person-centred care in patients with chronic heart failure: the PCC-HF study. *European Heart Journal*, 33, 1112-9.
- Eldh, A. C., Ehnfors, M. & Ekman, I. 2004. The phenomena of participation and non-participation in health care-experiences of patients attending a nurse-led clinic for chronic heart failure. *European Journal of Cardiovascular Nursing*, 3, 239-46.
- Eldh, A. C., Ekman, I. & Ehnfors, M. 2008. Considering patient non-participation in health care. *Health Expect*, 11, 263-71.
- Encyclopædia Britannica Online. 2012. *Hospital*. Available: <http://www.britannica.com.ezproxy.ub.gu.se/EBchecked/topic/272626/hospital> [Accessed May 2012].
- Eriksson, K. 1988. *Vårdprocessen*, Stockholm, Nordstedts Förlag AB.

- Falk, K., Granger, B. B., Swedberg, K. & Ekman, I. 2007. Breaking the vicious circle of fatigue in patients with chronic heart failure. *Qualitative Health Research*, 17, 1020-7.
- Falk, S., Wahn, A. K. & Lidell, E. 2007. Keeping the maintenance of daily life in spite of chronic heart failure. A qualitative study. *European journal of cardiovascular nursing : journal of the Working Group on Cardiovascular Nursing of the European Society of Cardiology*, 6, 192-9.
- Foucault, M. 1975. *The birth of the clinic : an archaeology of medical perception*, New York, Vintage books.
- Fried, L. P., Ferrucci, L., Darer, J., Williamson, J. D. & Anderson, G. 2004. Untangling the concepts of disability, frailty, and comorbidity: implications for improved targeting and care. *Journals of Gerontology. Series A, Biological Sciences and Medical Sciences*, 59, 255-63.
- Fried, T. R., Bradley, E. H. & O'Leary, J. 2003. Prognosis communication in serious illness: perceptions of older patients, caregivers, and clinicians. *Journal of the American Geriatrics Society*, 51, 1398-403.
- Garratt, A., Solheim, E. & Danielsen, K. 2008. National and cross-national surveys of patient experiences: a structured review. Report nr 7-200.
- Geertz, C. 1973. *The interpretation of cultures : selected essays*, New York, Basic Books.
- Germaine De Staël, A. 1813. De l'Allemagne. *Wikiquote*.
- Gerteis, M. 1993. *Through the patient's eyes : understanding and promoting patient-centered care*, San Francisco, Jossey-Bass.
- Gilleard, C. & Higgs, P. 2011. Frailty, disability and old age: A re-appraisal. *Health*, 15, 475-90.
- Gillsjo, C., Schwartz-Barcott, D. & Von Post, I. 2011. Home: the place the older adult can not imagine living without. *BMC Geriatrics*, 11, 10.
- Giubilini, A. & Minerva, F. 2012. After-birth abortion: why should the baby live? *Journal of Medical Ethics*.
- Graneheim, U. H. & Lundman, B. 2004. Qualitative content analysis in nursing research: concepts, procedures and measures to achieve trustworthiness. *Nurse Education Today*, 24, 105-12.
- Green, C. P., Porter, C. B., Bresnahan, D. R. & Spertus, J. A. 2000. Development and evaluation of the Kansas City Cardiomyopathy Questionnaire: a new health status measure for heart failure. *Journal of the American College of Cardiology*, 35, 1245-55.
- Hansen, H. P., Tjornhoj-Thomsen, T. & Johansen, C. 2011. Rehabilitation interventions for cancer survivors: The influence of context. *Acta Oncologica*, 50, 259-64.
- Harjola, V. P., Follath, F., Nieminen, M. S., Brutsaert, D., Dickstein, K., Drexler, H., Hochadel, M., Komajda, M., Lopez-Sendon, J. L., Ponikowski, P. & Tavazzi, L. 2010. Characteristics, outcomes, and predictors of mortality at 3 months and 1 year in patients hospitalized for acute heart failure. *European Journal of Heart Failure*, 12, 239-48.
- Henderson, V. 1967. *The nature of nursing*, New York. Macmillan Publishers Ltd.

- Hobbs, J. L. 2009. A dimensional analysis of patient-centered care. *Nursing Research*, 58, 52-62.
- Holland, R., Rechel, B., Stepien, K., Harvey, I. & Brooksby, I. 2010. Patients' self-assessed functional status in heart failure by New York Heart Association class: a prognostic predictor of hospitalizations, quality of life and death. *Journal of Cardiac Failure*, 16, 150-6.
- Jenkinson, C., Coulter, A. & Bruster, S. 2002. The Picker Patient Experience Questionnaire: development and validation using data from in-patient surveys in five countries. *International Journal for Quality in Health Care*, 14, 353-8.
- Jewson, N. D. 2009. The disappearance of the sick-man from medical cosmology, 1770-1870. *International Journal of Epidemiology*, 38, 622-33.
- Juthberg, C., Eriksson, S., Norberg, A. & Sundin, K. 2007. Perceptions of conscience in relation to stress of conscience. *Nursing Ethics*, 14, 329-43.
- Kaplan, B. J., Giesbrecht, G., Shannon, S. & Mcleod, K. 2011. Evaluating treatments in health care: The instability of a one-legged stool. *BMC Medical Research Methodology*, 11, 65.
- Katz, S., Ford, A. B., Moskowitz, R. W., Jackson, B. A. & Jaffe, M. W. 1963. Studies of Illness in the Aged. The Index of Adl: A Standardized Measure of Biological and Psychosocial Function. *Journal of the American Medical Association*, 185, 914-9.
- Kitwood, T. M. 1997. *Dementia reconsidered : the person comes first*, Buckingham; Bristol, Pa., Open University Press.
- Kleinman, A. 1973. Medicine's symbolic reality. *Inquiry: An Interdisciplinary Journal of Philosophy*, 16, 206-213.
- Kleinman, A. & Benson, P. 2006. Anthropology in the clinic: the problem of cultural competency and how to fix it. *PLoS Medicine*, 3, e294.
- Kleinman, A., Eisenberg, L. & Good, B. 1978. Culture, illness, and care: clinical lessons from anthropologic and cross-cultural research. *Annals of Internal Medicine*, 88, 251-8.
- Kossovsky, M. P., Sarasin, F. P., Chopard, P., Louis-Simonet, M., Sigaud, P., Perneger, T. V. & Gaspoz, J. M. 2002. Relationship between hospital length of stay and quality of care in patients with congestive heart failure. *Quality & Safety in Health Care*, 11, 219-23.
- Kristensson Uggla, B. 2009. *Ricoeur, hermeneutics, and globalization*, London, Continuum.
- Kuys, S. S., Dolecka, U. E. & Guard, A. 2012. Activity level of hospital medical inpatients: An observational study. *Archives of Gerontology and Geriatrics*.
- Leplege, A., Gzil, F., Cammelli, M., Lefevre, C., Pachoud, B. & Ville, I. 2007. Person-centredness: conceptual and historical perspectives. *Disability and Rehabilitation*, 29, 1555-65.
- Lock, M. & Gordon, D. 1988. *Biomedicine Examined: Culture, Illness and Healing*, Netherlands, Kluwer Academic Publishers.
- Lorig, K. R. & Holman, H. 2003. Self-management education: history, definition, outcomes, and mechanisms. *Annals of Behavioral Medicine*, 26, 1-7.
- Love, J., Moore, C. D. & Hensing, G. 2011. Validation of the Swedish translation of the general self-efficacy scale. *Quality of Life Research*, Epub ahead of print.

- Luszczynska, A., Scholz, U. & Schwarzer, R. 2005. The general self-efficacy scale: multicultural validation studies. *Journal of Psychology*, 139, 439-57.
- MacIntosh, J. & McCormack, D. 2001. Partnerships identified within primary health care literature. *International Journal of Nursing Studies*, 38, 547-55.
- McCormack, B. 2004. Person-centredness in gerontological nursing: an overview of the literature. *Journal of Clinical Nursing*, 13, 31-8.
- McCormack, B., Karlsson, B., Dewing, J. & Lerdal, A. 2010. Exploring person-centredness: a qualitative meta-synthesis of four studies. *Scandinavian Journal of Caring Sciences*, 24, 620-634.
- McDonagh, T. A., Blue, L., Clark, A. L., Dahlstrom, U., Ekman, I., Lainscak, M., McDonald, K., Ryder, M., Stromberg, A. & Jaarsma, T. 2011. European Society of Cardiology Heart Failure Association Standards for delivering heart failure care. *European Journal of Heart Failure*, 13, 235-241.
- McMurray, J. J., Adamopoulos, S., Anker, S. D., Auricchio, A., Bohm, M., Dickstein, K., Falk, V., Filippatos, G., Fonseca, C., Gomez-Sanchez, M. A., Jaarsma, T., Kober, L., Lip, G. Y., Maggioni, A. P., Parkhomenko, A., Pieske, B. M., Popescu, B. A., Ronnevik, P. K., Rutten, F. H., Schwitter, J., Seferovic, P., Stepinska, J., Trindade, P. T., Voors, A. A., Zannad, F., Zeiher, A., Bax, J. J., Baumgartner, H., Ceconi, C., Dean, V., Deaton, C., Fagard, R., Funck-Brentano, C., Hasdai, D., Hoes, A., Kirchhof, P., Knuuti, J., Kolh, P., McDonagh, T., Moulin, C., Popescu, B. A., Reiner, Z., Sechtem, U., Sirnes, P. A., Tendera, M., Torbicki, A., Vahanian, A., Windecker, S., McDonagh, T., Sechtem, U., Bonnet, L. A., Avraamides, P., Ben Lamin, H. A., Brignole, M., Coca, A., Cowburn, P., Dargie, H., Elliott, P., Flachskampf, F. A., Guida, G. F., Hardman, S., Iung, B., Merkely, B., Mueller, C., Nanas, J. N., Nielsen, O. W., Orn, S., Parissis, J. T. & Ponikowski, P. 2012. ESC Guidelines for the diagnosis and treatment of acute and chronic heart failure 2012: The Task Force for the Diagnosis and Treatment of Acute and Chronic Heart Failure 2012 of the European Society of Cardiology. Developed in collaboration with the Heart Failure Association (HFA) of the ESC. *European Heart Journal*, 33, 1787-847.
- Mead, N. & Bower, P. 2000. Patient-centredness: a conceptual framework and review of the empirical literature. *Social Science and Medicine*, 51, 1087-110.
- Meyer, G. S., Demehin, A. A., Liu, X. & Neuhauser, D. 2012. Two hundred years of hospital costs and mortality--MGH and four eras of value in medicine. *New England Journal of Medicine*, 366, 2147-9.
- Moberg, Å. 2007. *Hon var ingen Florence Nightingale : människan bakom myten*, Stockholm, Natur & kultur.
- Morse, J. & Niehaus, L. 2007. Combining Qualitative and Quantitative Methods for Mixed-Method Designs. In: Munhall, P. (ed.) *Nursing Research. A Qualitative Perspective*. 4 ed. Massachusetts: Jones & Bartlett Publisher.
- Morse, J., Niehaus, L., Wolfe, R. & Wilkins, S. 2006. The role of the theoretical drive in maintaining validity in mixed-method research. *Qualitative Research in Psychology*, 3, 279-291.
- Moser, D. K., Frazier, S. K., Worrall-Carter, L., Biddle, M. J., Chung, M. L., Lee, K. S. & Lennie, T. A. 2011. Symptom variability, not severity, predicts rehospitalization and mortality in patients with heart failure. *European Journal of Cardiovascular Nursing*, 10, 124-9.

- Mounier, E. 1970. *Personalism*, Notre Dame,, University of Notre Dame Press.
- Mudge, A., Laracy, S., Richter, K. & Denaro, C. 2006. Controlled trial of multidisciplinary care teams for acutely ill medical inpatients: enhanced multidisciplinary care. *Internal Medicine Journal*, 36, 558-63.
- Nguyen Thi, P. L., Briancon, S., Empereur, F. & Guillemin, F. 2002. Factors determining inpatient satisfaction with care. *Social Science and Medicine*, 54, 493-504.
- Norberg, A., Axelsson, K., Hallberg, I-L., Lundman, B., Athlin, E., Ekman, S-L., Engström, B., Jansson, L., Kihlgren, M. 1997. *Omvårdnadens mosaik - En modell*, Stockholm:Liber AB.
- Norberg, E. B., Boman, K. & Lofgren, B. 2010. Impact of fatigue on everyday life among older people with chronic heart failure. *Australian Occupational Therapy Journal*, 57, 34-41.
- Nordgren, L., Asp, M. & Fagerberg, I. 2007. An exploration of the phenomenon of formal care from the perspective of middle-aged heart failure patients. *European Journal of Cardiovascular Nursing*, 6, 121-9.
- Oed 2005. Partner. *Oxford English Dictionary*. Third ed.
- Olsson, L.E. 2006. *Patients with acute hip fractures motivation, effectiveness and costs in two different care systems*. (Doctoral thesis). Gothenburg: Acta Universitatis Gothoburgensis.
- Olsson, L.E., Jakobsson, E., Swedberg, K., Ekman, I. 2012. Efficacy of person-centred care in interventional trials – a systematic review. *Journal of Clinical Nursing* (submitted)
- Olsson, L. E., Karlsson, J., Ekman, I. 2006. The integrated care pathway reduced the number of hospital days by half: a prospective comparative study of patients with acute hip fracture. *Journal of Orthopaedic Surgery*, 1, 3.
- Olsson, L.E., Karlsson, J., Ekman, I. 2007a. Effects of nursing interventions within an integrated care pathway for. *Journal of Advanced Nursing*, 58, 116.
- Olsson, L. E., Nystrom, A. E., Karlsson, J. & Ekman, I. 2007b. Admitted with a hip fracture: patient perceptions of rehabilitation. *Journal of Clinical Nursing*, 16, 853-9.
- Patel, H., Ekman, I., Spertus, J. A., Wasserman, S. M. & Persson, L. O. 2008. Psychometric properties of a Swedish version of the Kansas City Cardiomyopathy Questionnaire in a Chronic Heart Failure population. *European Journal of Cardiovascular Nursing*, 7, 214-21.
- Paterson, B. L. 2003. The koala has claws: applications of the shifting perspectives model in research of chronic illness. *Qualitative Health Research*, 13, 987-94.
- Penney, W. 2007. Hearing what older consumers say about participation in their care. *International Journal of Nursing Practice*, 13, 61-68.
- Persson, J. & Sahlin, N. E. 2009. A philosophical account of interventions and causal representation in nursing research. *International Journal of Nursing Studies*, 46, 547-56.
- Picco, E., Santoro, R. & Garrino, L. 2010. Dealing with the patient's body in nursing: nurses' ambiguous experience in clinical practice. *Nursing Inquiry*, 17, 39-46.
- Picker, I. 2004. *Patient-Centered Care 2015: Scenarios, Vision, Goals & Next Steps*. Camden: Picker Institute.

- Polit, D. F. & Beck, C. T. 2004. *Nursing research : principles and methods*, Philadelphia, Lippincott Williams & Wilkins.
- Quintana, J. M., Gonzalez, N., Bilbao, A., Aizpuru, F., Escobar, A., Esteban, C., San-Sebastian, J. A., De-La-Sierra, E. & Thompson, A. 2006. Predictors of patient satisfaction with hospital health care. *BMC Health Services Research*, 6, 102.
- Ricoeur, P. 1976. *Interpretation theory : discourse and the surplus of meaning*, Fort Worth, Tex., Texas Christian Univ. Press.
- Ricoeur, P. 1994. *Oneself as another*, Chigago, University of Chicago Press.
- Risse, G. B. 1999. *Mending bodies, saving souls : a history of hospitals*, New York, Oxford University Press.
- Rosenberg, R. 1995. Health-related quality of life between naturalism and hermeneutics. *Social Science and Medicine*, 41, 1411-5.
- Rowlands, J. & Noble, S. 2008. How does the environment impact on the quality of life of advanced cancer patients? A qualitative study with implications for ward design. *Palliative Medicine*, 22, 768-74.
- Sahlsten, M. J., Larsson, I. E., Sjostrom, B. & Plos, K. A. 2008. An analysis of the concept of patient participation. *Nursing Forum*, 43, 2-11.
- Sandelowski, M. 2003. *Tables or Tableaux? The challange of writing and reading mixed methods studies*, Thousand Oaks, Calif., SAGE Publications.
- Sanders, T. & Harrison, S. 2008. Professional legitimacy claims in the multidisciplinary workplace: the case of heart failure care. *Sociology of Health & Illness*, 30, 289-308.
- Schneider, A., Korner, T., Mehring, M., Wensing, M., Elwyn, G. & Szecsenyi, J. 2006. Impact of age, health locus of control and psychological co-morbidity on patients' preferences for shared decision making in general practice. *Patient Education and Counseling*, 61, 292-8.
- Schoen, C., Osborn, R., Squires, D., Doty, M., Pierson, R. & Applebaum, S. 2011. New 2011 survey of patients with complex care needs in eleven countries finds that care is often poorly coordinated. *Health Affairs*, 30, 2437-48.
- SFS 1982:763. Hälso och sjukvårdlag. In: Socialdepartementet (ed.). Stockholm.
- Shadish, W. R., Cook, T. D. & Campbell, D. T. 2002. *Experimental and quasi-experimental designs for generalized causal inference*, Boston, Houghton Mifflin.
- Shah, M. R., Hasselblad, V., Stinnett, S. S., Kramer, J. M., Grossman, S., Gheorghiad, M., Adams, K. F., Jr., Swedberg, K., Califf, R. M. & O'connor, C. M. 2002. Dissociation between hemodynamic changes and symptom improvement in patients with advanced congestive heart failure. *European Journal of Heart Failure*, 4, 297-304.
- Shepperd, S., Lewin, S., Straus, S., Clarke, M., Eccles, M. P., Fitzpatrick, R., Wong, G. & Sheikh, A. 2009. Can we systematically review studies that evaluate complex interventions? *PLoS Medicine*, 6.
- Skott, C. 2002. Expressive metaphors in cancer narratives. *Cancer Nursing*, 25, 230-5.

- Smith, D. W. 2007. *Husserl*, London, Routledge.
- SOU 2007:12. Hälso- och sjukvården. *In: Socialdepartementet* (ed.). Stockholm.
- Stewart, M. 2001. Towards a global definition of patient centred care. *British Medical Journal*, 322, 444-5.
- Stewart, M., Brown, J. B., Donner, A., McWhinney, I. R., Oates, J., Weston, W. W. & Jordan, J. 2000. The impact of patient-centered care on outcomes. *Journal of Family Practice*, 49, 796-804.
- Svendsen, M. L., Ehlers, L. H., Andersen, G. & Johnsen, S. P. 2009. Quality of care and length of hospital stay among patients with stroke. *Medical Care*, 47, 575-82.
- Tavazzi, L., Maggioni, A. P., Lucci, D., Cacciatore, G., Ansalone, G., Oliva, F. & Porcu, M. 2006. Nationwide survey on acute heart failure in cardiology ward services in Italy. *European Heart Journal*, 27, 1207-15.
- Toombs, S. K. 1987. The meaning of illness: a phenomenological approach to the patient-physician relationship. *Journal of Medicine and Philosophy*, 12, 219-40.
- Tribouilloy, C., Buiciuc, O., Rusinaru, D., Malaquin, D., Levy, F. & Peltier, M. 2008. Long-term outcome after a first episode of heart failure. A prospective 7-year study. *International Journal of Cardiology*.
- Tutton, E. M. 2005. Patient participation on a ward for frail older people. *Journal of Advanced Nursing*, 50, 143-52.
- Washington, A. E. & Lipstein, S. H. 2011. The Patient-Centered Outcomes Research Institute-promoting better information, decisions, and health. *New England Journal of Medicine*, 365, e31.
- Watson, J. 2002. Intentionality and caring-healing consciousness: a practice of transpersonal nursing. *Holistic Nursing Practice*, 16, 12-9.
- Westbrook, J. I., Duffield, C., Li, L. & Creswick, N. J. 2011. How much time do nurses have for patients? A longitudinal study quantifying hospital nurses' patterns of task time distribution and interactions with health professionals. *BMC Health Services Research*, 11, 319.
- Westert, G. P., Lagoe, R. J., Keskimaki, I., Leyland, A. & Murphy, M. 2002. An international study of hospital readmissions and related utilization in Europe and the USA. *Health Policy*, 61, 269-78.
- Wilkinson, C., Khanji, M., Cotter, P. E., Dunne, O. & O'keeffe, S. T. 2008. Preferences of acutely ill patients for participation in medical decision-making. *Quality & Safety in Health Care*, 17, 97-100.
- Will, J. F. 2011a. A brief historical and theoretical perspective on patient autonomy and medical decision making: Part I: The beneficence model. *Chest*, 139, 669-73.
- Will, J. F. 2011b. A Brief Historical and Theoretical Perspective on Patient Autonomy and Medical Decision Making: Part II: The Autonomy Model. *Chest*, 139, 1491-7.
- Williams, B. 1994. Patient satisfaction: a valid concept? *Social Science and Medicine*, 38, 509-16.

- Wolcott, H. F. 2008. *Ethnography : a way of seeing*, Lanham, MD, Altamira Press.
- Wolf, A., Ekman, I. & Dellenborg, L. 2012. Everyday practices at the medical ward: a 16-month ethnographic field study. *BMC Health Services Research*, 12, 184.
- Wolf, D., Lehman, L., Quinlin, R., Rosenzweig, M., Friede, S., Zullo, T. & Hoffman, L. 2008. Can nurses impact patient outcomes using a patient-centered care model? *Journal of Nursing Administration*, 38, 532-40.
- World Health Organization. 2005. Constitution of the world health organization. Available: <http://apps.who.int/gb/bd/PDF/bd47/EN/constitution-en.pdf> [Accessed April 2012].
- World Health Organization. 2011. Noncommunicable Diseases Country Profiles 2011. Available: www.who.int/nmh/publications/ncd_profiles_report.pdf [Accessed May 2012]
- Wright, S. P., Verouhis, D., Gamble, G., Swedberg, K., Sharpe, N. & Doughty, R. N. 2003. Factors influencing the length of hospital stay of patients with heart failure. *European Journal of Heart Failure*, 5, 201-9.
- Zambroski, C. H., Moser, D. K., Bhat, G. & Ziegler, C. 2005. Impact of symptom prevalence and symptom burden on quality of life in patients with heart failure. *European Journal of Cardiovascular Nursing*, 4, 198-206.
- Zingmark, K., Norberg, A. & Sandman, P. O. 1995. The experience of being at home throughout the life span. Investigation of persons aged from 2 to 102. *International Journal of Aging and Human Development*, 41, 47-62.
- Zomorodi, M. & Foley, B. J. 2009. The nature of advocacy vs. paternalism in nursing: clarifying the 'thin line'. *Journal of Advanced Nursing*, 65, 1746-52.
- Zuckerman, J. D., Koval, K. J., Aharonoff, G. B., Hiebert, R. & Skovron, M. L. 2000. A functional recovery score for elderly hip fracture patients: I. Development. *Journal of Orthopaedic Trauma*, 14, 20-5.
- Zuckerman, J. D., Koval, K. J., Aharonoff, G. B. & Skovron, M. L. 2000. A functional recovery score for elderly hip fracture patients: II. Validity and reliability. *Journal of Orthopaedic Trauma*, 14, 26-30.

Appendix 1: The Swedish PPE-15

- Item 1 När du frågade en läkare om något som var viktigt för dig, fick du då svar som du förstod?
Ja, alltid, Ibland, Nej, Jag vågade inte, Jag hade inget behov att fråga.
- Item 2 När du frågade en sjuksköterska om något som var viktigt för dig, fick du då svar som du förstod?
Ja, alltid, Ibland, Nej, Jag vågade inte, Jag hade inget behov att fråga.
- Item 3 Hörde det att du fick olika besked från sjuksköterskor och läkare?
Ja, alltid eller nästan alltid, Ibland, Nej.
- Item 4 Om du kände oro eller ängslan över ditt tillstånd eller din behandling, hade du möjlighet att prata med en läkare om det?
Ja, helt och hållet, Delvis, Nej, Jag kände ingen ångest, Jag ville inte prata om det.
- Item 5 Talade personalen med varandra i din närvaro som om du inte var där?
Ja, alltid eller nästan alltid, Ibland, Nej.
- Item 6 Kände du dig delaktig i beslut om din vård och behandling, så mycket som du önskade?
Ja, helt och hållet, Delvis, Nej.
- Item 7 Kände du att du blev bemött med respekt och på ett hänsynsfullt sätt?
Ja, helt och hållet, Delvis, Nej.
- Item 8 Om du kände oro eller ängslan över ditt tillstånd eller din behandling, hade du möjlighet att prata med en sköterska om det?
Ja, helt och hållet, Delvis, Nej, Jag kände ingen ångest, Jag ville inte prata om det.
- Item 9 När du behövde tala med en läkare/sjuksköterska, fick du då möjlighet till det?
Ja, alltid eller nästan alltid, Ibland, Nej, Jag hade inget behov.
- Item 10 Upplevde du att personalen gjorde allt de kunde för att lindra din smärta?
Ja, helt och hållet, Delvis, Nej, Nej, det behövdes inte.
- Item 11 Om dina närstående ville tala med personalen om ditt tillstånd och din vård, fick de då möjlighet till det?
Ja, helt och hållet, Delvis, Nej, Ej aktuell, Jag ville inte.
- Item 12 Har den/de som ger dig fortsatt behandling fått information om din sjukdom och behandling från sjukhuset?
Ja, helt och hållet, Delvis, Nej, Jag vet inte, Ej aktuellt.
- Item 13 Förklarade någon läkare varför du skulle ta de läkemedel du fått på ett sätt som du förstod?
Ja, helt och hållet, Delvis, Nej, jag förstod inte, Nej, jag fick ingen förklaring, Ej aktuellt.
- Item 14 Berättade någon läkare för dig om eventuella biverkningar av läkemedel som du skulle uppmärksamma?
Ja, helt och hållet, Delvis, Nej, Jag behövde inge information, Jag behövde inga läkemedel.
- Item 15 Berättade någon ur personalen för dig om vilka eventuella varningssignaler som du skulle vara uppmärksam på beträffande din sjukdom eller behandling
Ja, helt och hållet, Delvis, Nej.

Appendix 2: The Swedish GSES

- Item 1 Jag lyckas alltid lösa svåra problem om jag bara anstränger mig tillräckligt.
- Item 2 Även om någon motarbetar mig hittar jag ändå utvägar att nå mina mål.
- Item 3 Jag har inga svårigheter att hålla fast vid mina målsättningar och förverkliga mina mål.
- Item 4 I oväntade situationer vet jag alltid hur jag skall agera.
- Item 5 Till och med överraskande situationer tror jag mig klara av bra.
- Item 6 Tack vare min egen förmåga känner jag mig lugn även när jag ställs inför svårigheter.
- Item 7 Vad som än händer klarar jag mig alltid.
- Item 8 Vilket problem jag än ställs inför kan jag hitta en lösning.
- Item 9 Om jag ställs inför nya utmaningar vet jag hur jag skall ta mig an dem.
- Item 10 När problem uppstår kan jag vanligtvis hantera dem av egen kraft.

1=Tar helt avstånd, 2=Tar delvis avstånd, 3=Instämmer delvis,
4=Instämmer helt.

(Love et al., 2011)