A quality improvement project on empowerment in chronic kidney care
- an interactive research approach

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Abstract

One way of improving health care has been conceptualized as person-centred care. In person-centred care the concept of empowerment is crucial. This thesis aims to explore the meaning of empowerment from the perspective of persons with chronic kidney disease (CKD) and their family members and to evaluate the outcomes of an improvement intervention (QI) for the persons with CKD. Furthermore, to explore the implementation of an QI for empowerment in the context of chronic kidney care from a professional perspective. The research was based on an interactive approach in which the findings relating to the experiences of empowerment by persons with CKD and their family members in chronic kidney care were used in developing the QI. The methods of data collection were both qualitative and quantitative. In all, 20 persons with CKD (Study I) and 12 family members (Study II) participated in the interviews. In the quasi-experimental evaluation of the QI, 25 individuals took part in the intervention group and 21 persons in the comparison group (Study III). Twelve healthcare professionals participated in the case study of the QI (Study IV). Empowerment in chronic kidney care for the persons with CKD was described in terms of creation of trust and learning through encounters. The family members of the persons with CKD described empowerment as having the strength to assume responsibility. The outcomes of the QI after 2 years showed significantly higher scores for individualized care in the intervention group than in the comparison group. The facilitators in the QI were the healthcare professionals' moving spirit and encouragement from involved persons. As a barrier, the healthcare professionals referred to the limitation of the organization. In conclusion, the individual’s perspective of empowerment is important, both for quality of care and as a facilitator for QI in chronic kidney care.
Original studies

The thesis is based on the following studies, which are referred to by their Roman numerals in the text:

**Study I**


**Study II**


**Study III**


**Study IV**


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"Knowing is not enough, we must apply.
Willing is not enough, we must do" (Goethe, 1833)
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Annette Nygårdh
Introduction

Quality of care is an issue that has always been present in the author’s clinical work. Before the start of this doctoral study, the author was clinically engaged as a nurse anesthetist and dealt with issues about quality of care in relation to outpatient surgery from the individual’s perspective. This doctoral thesis is part of a larger inter-professional project called Bridging the Gaps (BTG). The overall aim of the BTG project is to contribute to improving healthcare by better system performance and professional development to increase the health of the general population. In this thesis, quality of care is illuminated by means of persons with chronic kidney disease (CKD) and their family members. According to the National Board of Health and Welfare (Socialstyrelsen, 2009), quality of care is accomplished when the care is safe, efficient, timely, equal, evidence-based, and person-centred. This thesis emphasizes two of the above indicators of quality of care—evidence-based and person-centred care. The gold standard of evidence is research findings from randomized controlled trials (RCTs) (Polit & Beck, 2012). However, in recent years, the concept of evidence has expanded to include the staff’s clinical experience, the experience of individuals with long-term diseases and their family members, and local context data (Socialstyrelsen, 2012; Rycroft-Malone et al., 2004; Willman, Stoltz, & Bahtsevani, 2011).

Professionals often plan care without acknowledging the needs of persons with disease and their family members (Ponte et al., 2003). One way of improving healthcare organizations to emphasize individual needs, values, and preferences has been conceptualized as person-centred care (Beach, Saha, Cooper, & Fund, 2006; Saha, Beach, & Cooper, 2008; Wolfe, 2001). Person-centred care is based on a dialogue among the persons with disease, their relatives, and healthcare professionals (Socialstyrelsen, 2009). The concept of person-centred care is used interchangeably with that of patient-centred care, and the variance depends on the context in which the care is
provided. Furthermore, the intent of the two concepts is congruent: it means that the care should be individualized around the person (Morgan & Yoder, 2012). The knowledge and changes needed to bring about person-centred care in healthcare are an organizational issue, not just an individual problem (Batalden & Davidoff, 2007; Grol, Bosch, Hulscher, Eccles, & Wensing, 2007; Jones & Meleis, 1993; Kaplan et al., 2010; Rycroft-Malone, 2008). In Sweden, there is still a lack of person-centred care in healthcare organization (The Swedish Agency for Health and Care Services Analysis, 2012). In person-centred care, the concept of empowerment is crucial. Without the empowerment of the persons with disease, person-centred care would be defined simply from the healthcare professionals’ perspective (Ekman et al., 2011; Funnell & Anderson, 2003; Holmstrom & Roing, 2010; Morgan & Yoder, 2012). Hence, empowerment of the person with CKD needs to be emphasized in chronic kidney care (Iles-Smith, 2005; Sijpkens, Berkhout-Byrne, & Rabelink, 2008).

In this thesis, toward accomplishing improved quality of care, the empowerment experience of persons with CKD and their family members’ will be applied in the context of chronic kidney care. Using an interactive research approach may assist healthcare professionals in using evidence as a basis for QI (Aagaard Nielsen & Svensson, 2006; Rolfe, 2001; Rycroft-Malone, 2012). Integrating evidence into clinical practice is a process that has been scarcely researched (Rycroft-Malone & Burton, 2010). Furthermore, there is a need for knowledge about what is essential in the process of transforming evidence into practice—particularly of what is important in the role of leaders (Sandstrom, Borglin, Nilsson, & Willman, 2011).
Background

Being afflicted with CKD has an impact on both the person with the disease and their family members. The individual’s physical, psychological, and psychosocial life is affected (Ekelund & Andersson, 2007; Tong et al., 2009). In the following sections, these three dimensions related to the disease will be examined in terms of findings in the literature.

Chronic kidney disease

The incidence and prevalence of CKD are increasing worldwide (Zhang & Rothenbacher, 2008). CKD is a progressive disease, and it has an unpredictable trajectory, which may necessitate life-sustaining treatment. Within 5 years of being diagnosed as having CKD, 80% of patients progress to end-stage renal disease, requiring renal replacement therapy by dialysis or renal transplantation. Persons with CKD have an increased risk of chronic heart disease, which increases the mortality risk. The mortality risk is eight times higher in this group of patients than in the general Swedish population (Evans et al., 2005). The term “pre-dialysis” has not been officially defined, but the majority of persons with CKD start their pre-dialysis care when their creatinine clearance is <30–15 ml/min (Sijpkens, et al., 2008). Decreased creatinine clearance results in increased serum urea levels, which is known to impair the ability to concentrate as well as the cognitive functions, for example with memory (Iles-Smith, 2005). Elias et al. (2009) claimed that the relationship between CKD and neuropathological changes is similar to the mechanism underlying cardiovascular disease, e.g., atherosclerosis. Having CKD in the pre-dialysis phase also involves such physical symptoms as tiredness, anemia, changes in body shape, and sexual dysfunction (Ekelund & Andersson, 2007). These symptoms develop and increase as the renal function becomes increasingly impaired. In many cases, persons with CKD suffered from such comorbidities as diabetes and cardiovascular diseases (Swedish Renal Registry, 2012).
In Sweden, 9210 persons with CKD in the pre-dialysis phase were recorded in the national CKD register in 2011. Since 1999, 15,503 persons have been included in the register, of whom 63.9% were men and 36.1% women, with a mean age of 67 years (SD 15.4), (Swedish Renal Registry, 2012).

**Experiences of persons living with CKD**

In the early stage, the person with CKD has difficulties in accepting the diagnosis in the face of vague symptoms (Thomas-Hawkins & Zazworsky, 2005). This is related to the initial failure to understand and accept the diagnosis (Jansen et al., 2010). Comprehending the diagnosis takes time, as does being able to cope with the uncertainty that is involved with CKD (Tong, et al., 2009). Persons with CKD describe themselves as having little control over their disease and traumatic experiences when they suddenly become aware of its severity (Jansen et al., 2010). They also speak of a lack of knowledge and no clear expectations concerning dialysis treatment related to the unpredictable trajectory of their condition (Iles-Smith, 2005). Living with CKD involves modifications to lifestyle and to handling physical aspects of the person’s life (Ekelund & Andersson, 2007). There is also a need to deal with emotional aspects, such as a sense of weakness, insecurity, sadness, and dependency (Ekelund & Andersson, 2007; Thomas-Hawkins & Zazworsky, 2005).

**Experiences of family members living with persons with long-term disease**

In recent years, there has been increased recognition of family members’ importance in providing psychological support for persons with long-term disease (Pitceathly & Maguire, 2003). If family members are closely engaged with persons with long-term disease, this has a great impact on their
relationship, and it leads to a life characterized by challenges and uncertainty about the future (Bostrom, Ahlstrom, & Sunvisson, 2006; Mishel, 1999; Morton, Tong, Howard, Snelling, & Webster, 2010; Walsh, 2004; Ziegert, Fridlund, & Lidell, 2009; Årestedt, Persson, & Benzein, 2013). Those challenges include the transformation from partners to carers, a reduced sense of individual freedom, responsibility for caring for the ill person, and a lack of insight in the disease (Eriksson & Svedlund, 2006; Esbensen & Thome, 2010; Ohman & Soderberg, 2004; Paulson, Norberg, & Soderberg, 2003). There is also evidence of a lack of support from healthcare professionals (Paulson, et al., 2003).

Chronic kidney care

The person with CKD has to manage medical, psychological, and psychosocial issues in their everyday life—something that can be distressing and experienced as powerlessness over their situation (Aujoulat, Luminet, & Decache, 2007). In the project presented in this thesis, the persons with CKD received treatment and support from an outpatient unit, and the frequency of visits was two to four times per year for follow-up of medical and physiological parameters of kidney function. The persons with CKD had telephone access to healthcare professionals between their visits to the outpatient unit. In addition, the healthcare professionals invited the persons with CKD to participate in patient education related to the physical impact, different medical treatments, and self-management of the disease as well as preparatory discussions about renal replacement therapies at the dialysis ward. This education was organized as two sessions for each individual. When necessary, the person with CKD included in this project was treated at the medical ward. However, the staff at the clinic were unaware of the persons with CKD having experienced empowerment in their encounters with the chronic kidney care professionals. Furthermore, the family members of the persons with CKD were not involved in the care.
Empowerment

Empowerment is not a new concept in facilitating an individual’s opportunity to take control over their lives. In the seventies, educational approaches were undertaken to increase empowerment for oppressed individuals to decrease power imbalances in society (Freire, 1970). In theories of empowerment, the concept is defined as both a process and an outcome. Clearly, individuals’ activities or organizational structures can be measured in terms of the individuals’ experiences of the empowerment process (Freire, 1970; Perkins & Zimmerman, 1995; Rappaport, 1984). Empowerment is a complex process, and it can occur at three levels—the individual, organizational, and community level. At an individual level, empowerment refers to the willingness to participate and exert control as well as the individual’s feeling of efficacy (Zimmerman, 1990). Zimmermann and Rappaport argue that self-efficacy (Bandura, 1977) and locus of control (Rotter, 1966) are linked to the concept of empowerment; such individual differences as personality and cognition broaden the construct of empowerment (Zimmerman & Rappaport, 1988). The process of empowerment can take on various forms of control—from the individual’s sense of control to an actual, practical control that has an effect on the person’s life (Rappaport, 1984). The individual’s capacity and interaction with contextual factors, such as organizational routines and attitudes, are both critical components of empowerment (Rappaport, 1984; Zimmerman, 1990). Qualitative research on empowerment is needed to facilitate an understanding of the construct (Zimmerman, 1990), though empowerment takes different forms depending on the individuals and the context. Therefore, empowerment needs to be described by the individuals it concerns (Rappaport, 1984; Zimmerman, 1995). This thesis is grounded in empowerment at an individual level with respect to the persons with CKD and their family member’s experience of empowerment in chronic kidney care.
**Empowerment in healthcare**

Empowerment is a prerequisite for an individual’s health and wellbeing (Jones & Meleis, 1993). As described above, empowerment at the individual level involves complex issues related to achieving empowerment in healthcare encounters. Empowerment also emphasizes the responsibility of healthcare professionals in attending to the individual needs and preferences of the person with disease (Gibson, 1991; Rodwell, 1996). In nursing, empowerment has been conceptualized as a combination of attributes related to the person with disease: attributes that relate to the nurse and those that relate to both the person with disease and the nurse (Gibson, 1991). Furthermore, empowerment contributes to the individual’s control and freedom to make their own choices over the factors that affect their lives (Gibson, 1991; Rodwell, 1996). This means that the process of empowerment involves healthcare professionals relinquishing some of their control and power (Ellis-Stoll & Popkess-Vawter, 1998). In addition, it has been argued that empowerment involves a paradigm shift in the relationship between the persons with long-term disease and healthcare professionals: this is the shift from the person with long-term disease being a passive consumer of healthcare to becoming an active partner in the management of their condition (Aujoulat, d'Hoore, & Deccache, 2007; Andersson & Funell, 2005; Funnell & Anderson, 2003).

Empowerment for persons with long-term diseases has been studied in a literature review covering 27 research papers (Aujoulat, d'Hoore, et al., 2007). The concept was mostly applied to outcomes in terms of self-management or self-efficacy. Most of the studies were quantitative and related to patient education. Furthermore, empowerment was mostly described from the professionals’ perspective. The meaning of empowerment from the perspective of persons with long-term diseases has mostly concerned individuals with diabetes, cancer, or those in need of professional home care. From the perspective of the person with disease in long-term care, the main conditions for empowerment are continuity,
patient-centeredness, mutual acknowledgement, and relatedness (Aujoulat, d'Hoore, et al., 2007).

Accordingly, the nature of empowerment is poorly described and often restricted to such outcomes as self-management or self-efficacy (Aujoulat, d'Hoore, et al., 2007). Furthermore, it has been argued that empowerment takes different forms in different people and in different contexts. This may imply that empowerment needs to be described by the individuals it concerns (Rappaport, 1984). Empowerment-related research on the CKD population is limited and has emphasized educational programs focused on helping patients develop skills and self-awareness related to the disease (Tsay & Hung, 2004). Moreover, the World Health Organization (WHO) has argued that the empowerment of persons with long-term disease is a challenge for the current healthcare system. New strategies for and attitudes of healthcare professionals will be necessary to shift both healthcare professionals and persons with disease from a hierarchical mindset toward one based on dialogue and equal partnership (WHO, 2012).

Consequently, interviewing persons with CKD and their family members about their experiences of empowerment in areas of involvement, self-determination, and awareness of the care process appears to be highly relevant toward improving evidence-based person-centred care (Rycroft-Malone, et al., 2004). In addition, the experiences of persons with CKD and their family members related to empowerment in chronic kidney care may facilitate the implementation of QI (Bate & Robert, 2006).
Quality improvement

In this thesis the quality improvement intervention (QI) was initiated and performed by healthcare professionals to improve person-centred care, i.e., empowerment in chronic kidney care. The healthcare professionals invited the research group to support the QI exploring the evidence related to persons with CKD and their family members’ empowerment in chronic kidney care. There are many potential challenges with evidence-based QI (Dixon-Woods, McNicol, & Martin, 2012; Øvretveit et al., 2012). One of the most important challenges is the complexity of clinical practices (Rycroft-Malone, 2012).

The complexity of QI interventions in the healthcare context needs a clear theoretical standpoint if they are to provide improvement, (Grol, et al., 2007; Rycroft-Malone, 2004). In this thesis, the QI introduced and performed by the healthcare professionals is based on the theoretical thinking of QI (Figure 1) defined as “the combined and increased efforts of everyone—healthcare professionals, patients and their families, researchers, payers and educators—to makes the changes that will lead to better patient outcomes (health), better system performance (care) and better professional development” (Batalden & Davidoff, 2007). QI comprises systematic, data-guided activities designed to improve healthcare quality in particular settings (Lynn et al., 2007). The most used QI methodology involves the stepwise approach of data collection, problem description, generation and selection of changes, and then the implementation and evaluation of those changes (Walshe, 2009). The stepwise approach to QI involves plan-do-study-act (PDSA) cycles (Langley, 2009). The use of PDSA cycles emphasizes the healthcare professionals’ experiential learning by examining data within their own clinical setting, and it makes use of an approach that was previously applied to improve person-centred care in individuals with long-term diseases (Knight, Ford, Audehm, Colagiuri, & Best, 2012; Wagner et al., 2001).
There is a body of literature that examines the relationship between the effectiveness of QI in healthcare and contextual factors (Kaplan, et al., 2010). However, no clear evidence exists regarding the healthcare professional’s desired improvement and successful outcomes in healthcare (Scott, 2009; Øvretveit et al., 2011b). There is, though, enthusiasm among QI professionals and managers regarding QI methodologies toward improving care. Therefore, the need exists for empirical evidence related to methods and approaches used in healthcare (Walshe, 2009).

Improvement science deals with exploring means of undertaking QI and how to narrow the gap between research and practice. Applying research methods toward understanding the QI and the approaches adopted to facilitate the use of evidence may contribute to an understanding of evidence-based QI (The
Health Foundation, 2011). To study QI in healthcare, there is a need of the following: (1) scientific knowledge from generalizable empirical studies; (2) knowledge about the specific context, i.e., the habits and processes of care; (3) knowledge about the impact of the QI; (4) knowledge of the attitudes for applying and adapting generalizable evidence to particular contexts; and (5) knowledge of the drivers for change. The nature of these five fields of knowledge and the ways in which they work together in practice are essential to enhancing improvements in healthcare settings (Batalden & Davidoff, 2007). Furthermore, small-scale QI in a specific context can provide important knowledge for both those undertaking a particular project and researcher into the QI intervention (Harvey & Wensing, 2003). Consequently, inductive methods that capture the process and quantitative methods that evaluate an evidence-based QI for empowerment will be useful for healthcare professionals toward improving healthcare (Davidoff & Batalden, 2005; Øvretveit, et al., 2011a).
Rationale for the thesis

QI is being increasingly adopted in healthcare, both in Sweden and internationally. From the scant empirical research into QI in general, and chronic kidney care in particular, there is a need to study how this theoretical approach, as translated into Swedish practice, can contribute to empowerment for persons with CKD and their family members. The QI project in this thesis was initiated and performed by healthcare professionals to increase the empowerment of persons with CKD and their family members in chronic kidney care. Empowerment in healthcare for persons with disease is often a professional construct. Person-centred care that takes the needs, values, and preferences of the person with disease into account implies that empowerment has to be described by the individual in question. As noted above, there has hitherto been a lack of empowerment-related research concerning the CKD population.
Aims of the thesis

This thesis aims was to explore the meaning of empowerment from the perspective of persons with CKD and their family members and to evaluate the outcomes of an QI for the persons with CKD. Furthermore, to explore the implementation of an QI for empowerment in the context of chronic kidney care from a professional perspective. These aims took the form of four specific research questions and four different studies:

How do persons with CKD in the pre-dialysis phase and their family members experience empowerment in outpatient chronic kidney care? (Studies I and II)

What is the outcome of an QI in terms of quality of care based on empowering interactions between healthcare professionals and outpatients with CKD in the pre-dialysis phase? (Study III)

How do demographic variables correlate with assessments of empowerment by persons with CKD? (Study III)

What are the facilitators and barriers in the implementation process of an QI in chronic kidney care? (Study IV)
Method

Design

This thesis is based on a naturalistic paradigm under the assumption that human activity is not context free and that reality is a social construct, i.e., no phenomena can be understood isolated from their time and context (Lincoln & Guba, 1985). Different designs are used in this thesis to address the research questions (Table 1). An explorative design was chosen in Studies I, II, and IV because of its appropriateness in capturing phenomena from the individual’s perspective in natural settings (Denzin & Lincoln, 2005; Lincoln & Guba, 1985). Furthermore, an explorative design was suitable if the phenomena had not previously been studied in this group of participants or this context. In Study III, a quasi-experimental design was used to evaluate the impact of an QI in chronic kidney care based on empowerment. This design was appropriate because the participants were not randomly assigned to the two study groups, and there was an inability to fully control the experimental stimuli (Shadish, Cook, & Campbell, 2002). A single intrinsic qualitative case study (Study IV) was chosen to generate knowledge about a real-life situation (Stake, 1995) so as to capture the circumstances and conditions of implementation of the QI (Creswell, 2007; Lincoln & Guba, 1985; Yin, 2009). In contrast to an instrumental case study, an intrinsic case study is not undertaken to make generalizations, but it can provide insights that lead to further theoretical development (Denzin & Lincoln, 2005).
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Interactive research approach

An interactive research approach was chosen to support the planning and evaluation of the QI (Aagaard Nielsen & Svensson, 2006). Interactive research, or participatory action research (Aagaard Nielsen & Svensson, 2006; Reason, 2001; White, Suchowierska, & Campbell, 2004; Whyte, 1991), developed from action research (Greenwood & Levin, 2007; Lewin, 1946). Historically, action research was developed to respond to social problems in which the researcher played an active role in informing and improving behavior as well as encouraging social change by bridging the gap between theory and practice (Dickens & Watkins, 1999). This means that the researcher had a strong organizing role, and there was a risk of the practitioners becoming objectified (Aagaard Nielsen & Svensson, 2006).

However, there is a continuum within action research—from the researcher adopting an outside perspective (as described above) to an inside perspective, which is characterized by problem solving from the specific perspective of the practitioner (Dickens & Watkins, 1999; Hughes, 2008). Both action research and interactive or participatory action research have the same core aim, i.e., developing knowledge and improving practice. The difference lies in the emphasis that interactive or participatory action research places on the practitioners’ participation in the research process (Hughes, 2008). Interactive research (Figure 2) is described as the interaction between the researcher and practitioners during the research process; it is based on an equal partnership (Aagaard Nielsen & Svensson, 2006), in which the researcher and practitioners maintain their professional identities. Interactive research has the aim of conducting research in a collaborative effort that benefits both parties in the process. The core concern in knowledge production through interactive research is practical usefulness and theoretical insights; these are accomplished by emphasizing theoretical and practical knowledge as complementary elements within a joint learning process. This means that the practitioners in the research project play an important role in defining the research question, in the analysis phase, and in disseminating the research findings (Aagaard Nielsen & Svensson, 2006).
Interactive research in this thesis (Figure 3) is based on the partnership between the researcher and healthcare professionals, in which mutual learning and reflection are essential during the QI (Aagaard Nielsen & Svensson, 2006). The initiative for the collaboration was taken by a project group (director of a medical clinic, one ward manager, and two nurses) in an outpatient unit and dialysis ward to increase the quality of care based on empowerment. The researcher's role was to establish a respectful, confident relationship with the healthcare professionals. This relationship was achieved by the researcher making several visits to the three units involved in the study and being reachable when necessary by the healthcare professionals. The role of the researcher included obtaining support at the start of the QI by interviewing the persons with CKD and their family members about their experiences of empowerment so as to form a basis for the QI. To study and evaluate the process of the QI from the perspectives of

![Figure 2](image-url)
the persons with CKD and healthcare professionals was also the role of the interactive researcher (the author). Together with the healthcare professionals, the research group determined suitable instruments for the study participants. The author was available as a discussion partner for the project group with regard to questions and concerns related to the intervention and research process. In this way, mutual learning and reflection were able to function.

**Improvement intervention**

The QI (Studies III and IV) involved three care units: one medical ward, one dialysis ward, and one outpatient unit at a county hospital in the south of Sweden. The QI was based on the results of discussions held between the author and staff members using findings from the author’s interviews about empowerment in chronic kidney care from the perspective of persons with CKD (Study I) and their family members (Study II). The QI included interventions for the staff members as well as the persons with CKD and their family members (Table 2). To facilitate the QI, support was provided by the local center of improvement knowledge (Qulturum). Training in improvement knowledge for healthcare professionals was carried out there free of charge.
Interactive research approach performed by the researchers

Planning the project and methods to use, in collaboration with the project group

Project start

Pre-intervention data collection: questionnaires and interviews for patients, interviews of family members and staff

Learning seminars for presentation and reflections of preliminary results

Learning seminars for presentation and reflections of research findings

Post-intervention data collection: questionnaires for patients and interviews for staff.

Recorded projectgroup meetings

2008

2009

"Taste of water", (anthology) reflection groups

Training in Improvement knowledge

Reflectiongroups (cases)

Ethics, ethical values as guidelines for empowerment

Information and explicit invitation of the family members

Workshop on empowerment

2010

2011

Learning meetings for persons with CKD

Learning meetings for family members

Improvement intervention planned and performed by the healthcare professionals

Figure 3. Interactive research approach in the Improvement intervention process.
Table 2. Improvement interventions aimed at increasing empowerment for persons with CKD and their family members in chronic kidney care

<table>
<thead>
<tr>
<th>Goal of the intervention</th>
<th>Procedure</th>
</tr>
</thead>
<tbody>
<tr>
<td>Create a joint value system to guide the healthcare professionals’ encounters with persons with CKD and their family members</td>
<td>All staff members read an anthology about personal experience with healthcare. All staff members participated in a half-day workshop to discuss the value system they wanted to create. This workshop took place with a representative from the hospital ethics board. The discussions resulted in a written handy pocket card detailing the created value system as a useful reminder.</td>
</tr>
<tr>
<td>Increase staff competence in working with QI</td>
<td>Training the staff about QI took place over a period of 4 months (1 day per month); one group made up of healthcare professionals from each of the three units participated.</td>
</tr>
<tr>
<td>Introduce evidence about the concept of empowerment.</td>
<td>Workshops for all staff members and the managing director of the medical clinic were held; these included presentations of research findings and the thoughts of staff members about current approaches for persons with CKD and their family members with regard to empowerment in care.</td>
</tr>
<tr>
<td>Increase the staff awareness about empowerment in chronic kidney care; increase their understanding of how work processes in different wards are related to one another</td>
<td>Reflection meetings, each lasting 1 hour, were held. They included staff members from the medical ward, the chronic kidney outpatient unit, and dialysis ward. The focus was on case descriptions for persons with CKD and the staff members’ encounters in care. The cases also gave the staff members opportunity to reflect on their different perspectives about how they worked and how that was related to experiences of empowerment by the persons with CKD and their family members.</td>
</tr>
<tr>
<td>Invite the family members’ participation in healthcare.</td>
<td>Family members were specifically invited to participate in chronic kidney care of persons with CKD’s by means of a letter. A brochure containing information requested by family members was produced. In addition, staff members invited the family members to participate in the patient’s discharge from hospital.</td>
</tr>
<tr>
<td>Adopt the perspective of persons with CKD and their family member regarding their life situation.</td>
<td>Persons with CKD and their family members invited different healthcare professionals depending on which professional would be able to answer their questions to take part in separate meetings (lärcafé). These meetings lasted 2.5 hours and were held once a month over a period of 4 months for each group. The lärcafé was a place where interchanges could take place with the persons with CKD and their family members regarding everyday-life concerns.</td>
</tr>
</tbody>
</table>
Sampling and participants

All participants were selected using purposeful and cluster sampling. Purposeful sampling was employed (Studies I, II, and IV) to increase understanding about the phenomena of interest; it is a sampling strategy often used in qualitative research (Creswell, 2007). In accordance with Shadish et al. (2002), cluster sampling was applied (Study III) for the intervention and comparison groups. Cluster sampling was used because random sampling was not possible owing to the small sample size and the predetermined places of treatment for the study groups. Assignment to the intervention group was based on self-selection: the participants in the intervention group were treated at the hospital where the QI was initiated (Shadish, et al., 2002).

Participants of persons with CKD (Studies I and III)

The inclusion process of participants began with individual telephone contact with each of the 197 people with CKD who were treated at one county hospital and two district hospitals in the same county in the south of Sweden. Individuals who had undergone any dialysis treatment or transplantation were excluded since the QI was specifically directed at the pre-dialysis phase. After providing information about what participation would involve, individuals received a letter by post, which included details about the purpose of the study, contact information, and a document for providing written informed consent. Those willing to participate answered four coded questionnaires and returned the questionnaires free of charge in a single envelope. Those individuals who were selected for interviews (Study I) were contacted by telephone within 2 weeks of receipt of the letter. At that time, they were given further explanations and offered the opportunity to ask any questions they might have prior to agreement to participate in the study.
In Study I, 20 persons with CKD participated: six women and 14 men, 38–86 years old (median age 69). A maximal variation strategy was used to reflect differences in perspectives (Creswell, 2007); this resulted in variations in sex, age, marital status, education, duration of disease, and place of residence (rural or urban).
In Study III, 25 persons with CKD in the intervention group and 21 persons with CKD in the comparison group participated (Figure 4). Most aspects of the baseline demographics were similar in the two groups. The exceptions were that significantly more individuals were living alone \((p=0.045)\) and had no problem with usual activities \((p=0.048)\) in the intervention group than in the comparison group.

**Participants of family members (Study II)**

The persons with CKD were asked to give the name and address of a family member they thought would be interested in taking part in the interviews. As a result, the names, addresses, and phone numbers of 20 family members were obtained; all of them were then contacted individually by phone. During the call, information was provided about the purpose of the study, and the family members were asked if they wished to receive more information about the study. Eight of them declined because of lack of knowledge about chronic kidney care, lack of time, or lack of interest. A letter was sent to those who wanted to receive more information; it included a written invitation to participate, information about the study, and a document for providing written informed consent.

In Study II, 12 family members to persons with CKD participated; they were 32–67 years old (median 61), and there were variations in the relationship to the person with CKD, sex, education, employment status, and place of residence. Two family members could not be interviewed a second time: one of them (wife, age 56) because of lack of time and the other (daughter, age 63) because she was unreachable.
**Participants of healthcare professionals (Study IV)**

The healthcare professionals were recruited from the county hospital that performed the QI. All 12 healthcare professionals who were asked to participate in the study indicated their willingness to do so. They received information about the purpose and content of the study as well as a document for providing their written informed consent before deciding about participation.

In Study IV, among the 12 healthcare professionals who participated, seven were members of the project group for the QI, and five were not; this was done to obtain maximum variations in perspectives regarding the implementation of the QI. The 12 professionals included variations in age, professional position, academic degree, and work experience.

**Qualitative data collection**

Qualitative methods were used to explore the persons with CKD and their family members experiences of empowerment in chronic kidney care from the perspectives (Studies I and II). This was carried out using qualitative semi-structured interviews (Kvale & Brinkmann, 2009). Implementation of the QI (Study IV) was explored using multiple qualitative sources of data relating to the particular case (Creswell, 2007; Stake, 1995; Yin, 2009). In this case study, the data collection included the participants, their activities, the physical setting, and context in which the QI could be known (Denzin & Lincoln, 2005).

The interviews were carried out at a place chosen by the participants as being the most convenient (Studies I, II, and IV). To obtain comprehensive data, an attempt was made to create a dialogue that was designed to capture the participant’s experience of the phenomena of interest (Kvale &
Brinkmann, 2009). All interviews (Studies I, II, and IV) adopted a semi-structured interview guide and began with an open-ended question. The number and formulation of follow-up questions depended on the richness of the participant’s answer to the open-ended question. The final question in all the interviews was the following: “Is there anything else you want to tell me?” (Kvale & Brinkmann, 2009).

In Study I, data on the persons with CKD were collected during the period April–August 2009; this was done on one occasion for each participant. The participants were interviewed at their home (n = 12), in the author’s office (n = 5), at the hospital (n = 2), or at their workplace (n = 1). The interviews lasted 30–60 minutes and started with the following open-ended question: “Could you please tell me about your experiences with all the chronic kidney care you’ve received?”

In Study II, the data on family members were collected on two occasions for each participant, from April 2009 to May 2011, with approximately 2 years between the two interviews. The first interview lasted 20–45 minutes and started with the following open-ended question: “Could you please tell me about your experiences related to your sick relative’s chronic kidney care?” The procedure before the second interview included listening to the first interview and making notes (Graneheim & Lundman, 2004) in an effort to obtain more comprehensive data in particular areas during the follow-up interview. This preparatory step was performed directly before the second interview. The second interview lasted 35–90 minutes and started with the same open-ended question as in the first interview.

In Study IV, the period of data collection on the healthcare professionals lasted from March 2009 to June 2011; it included digitally recorded project group meetings, field notes about the project meetings during the study period, and individual interviews before and after the study period related to the QI. The field notes included unstructured observations during the project
group meetings. Details relating to the number and professions of the participants, the meeting environment, the positions the participants took when they sat around the table, and whether someone arrived late or left before the meeting ended were noted.

The first interview took place before the QI was started. The interviews lasted 23–45 minutes and started with the following open-ended questions: “Can you please tell me about your expectations of the improvement intervention?”; “What is the purpose of the improvement intervention?”; “How do you see your role in this intervention?”; “How do you imagine the improvement intervention will be carried out?”; and “What are your thoughts about the possible success or failure of the improvement efforts?”

The second interview was performed after 2 years and lasted 35–90 minutes. It started with the following open-ended question: “Can you please tell me about your experiences regarding work with the improvement intervention?” Follow-up questions were asked regarding the process for initiating and running the QI. The questions were based on the phases of the QI, i.e., PDSA (Langley, 2009).

**Qualitative data analysis**

In the inductive qualitative studies (Studies I, II, and IV), content analysis was chosen as an appropriate method for identifying what something is called or belongs to (Krippendorff, 2004). Content analysis may be manifest, i.e., involve the obvious meaning of a text, or latent, i.e., involve the underlying meaning of a text. Both involving interpretation, but there is variation in the level of abstraction (Graneheim & Lundman, 2004). In this thesis, qualitative latent content analysis was used for systematic reading of transcribed text or listening to recorded data to answer the research questions (Krippendorff, 2004). The qualitative software NVIVO 8 (QSR International, 2008) in (Study IV) was chosen because it provides a means for easily locating, assessing, and storing codes, categories, subthemes, and
themes (Creswell, 2007) when analyzing large volumes of data (Krippendorff, 2004). The clearly described content analysis procedure of Graneheim and Lundman (2004) was chosen to guide the analysis process.

**Data analyses of interviews (Studies I and II)**

The inductive analysis was performed in several steps. In the first step, several open readings of the interviews were performed to gain an overall impression of the content. Second, meaning units with reference to the study aims were identified. Third, the meaning units were condensed (closely adhering to the text). Fourth, the interpretation of the underlying meaning in each of the meaning units was expressed in terms of codes. Fifth, the codes were inductively analyzed and labeled by the first author in terms of subthemes. Sixth, themes were developed from the subthemes, expressing the main thread or main latent content of the text. Throughout the analysis, the interviews in their entirety served as a point of reference when deeper understanding was required relating to the meaning units, codes, and subthemes. Furthermore, all steps in the analysis were subjected to discussion and comparison within the research group, and certain modifications were made as a result.

**Data analyses of the case study (Study IV)**

Data from the interviews and project group meetings were imported into the qualitative data analysis program NVIVO 8 (QSR International, 2008). Inductive analysis of the data was performed in several steps. First, there were several open readings of the interviews and transcriptions of the critical meeting discussions about the QI to obtain an overall impression of the content. Second, meaning units representing the facilitators and barriers in implementing the QI were identified and marked with plus or minus signs. Third, the meaning units were labeled into preliminary codes representing the underlying meaning of each unit. Fourth, the preliminary codes were verified by moving back and forth between the codes and the meaning units.
Fifth, the codes were then abstracted and merged into categories. Sixth, the analysis focused on representation of the categories in the phases (Initiating/Planning phase, Implementation phase, and Integrated implementation). These phases emerged in the text analysis of implementing the QI. Seventh, the categories were then abstracted and merged into subthemes representing the underlying meaning of the categories. Finally, the subthemes were merged into three themes describing features for facilitators and barriers in QI. The data were reviewed and organized by all members of the research group, and alternative interpretations were continually discussed during the analysis (Graneheim & Lundman, 2004). Field notes were used as an additional source of data to gain a more comprehensive understanding of the project group meetings.

Quantitative data collection

Data were collected for the baseline in February 2009 and follow-up in February 2011 for Study III.

Questionnaires

Three instruments were used to describe and monitor the QI regarding empowerment: empowerment (SWE-DES-23); the participant’s management of stressful situations (WCQ-S); and individualized care (ICS-A and B). A fourth instrument monitoring health status was employed as a background variable: EQ-5D was used because of the impact of health status on empowerment (Wallerstein, 1992) and empowerment offers potential approaches for improving health and wellbeing (Woodall, Raine, South, & Warwick-Booth, 2010). Participants also filled in background questions about their sex, age, marital status, education level, duration of disease (CKD), and employment status.
Swedish Version of the Diabetes Empowerment Scale

The Swedish version (SWE-DES-23) (Leksell et al., 2007) of the American Diabetes Empowerment Scale (US-DES) (Anderson, Funnell, Fitzgerald, & Marrero, 2000) contains 23 statements concerning the following four subscales of empowerment: identification of problems and problem solving (10 items); self-awareness (four items), stress management (four items); and willingness to change (five items). The respondents answered the items on a five-point Likert scale ranging from 1 (definitely do not agree) to 5 (agree entirely). Higher mean values indicated stronger empowerment. The US-DES has previously been used to measure empowerment in persons with CKD (Cronbach’s alpha = 0.93) (Tsay & Hung, 2004). The reliability of the Swedish version has been tested: Cronbach’s alpha coefficient = 0.90 (Leksell, et al., 2007), and it was 0.93 in the current study.

Ways of Coping Questionnaire-Swedish Version

The Ways of Coping Questionnaire-Swedish version (WCQ-S), (Lazarus, 1993; Lundqvist & Ahlström, 2006) was used to assess the stress management and problem-solving aspects of empowerment. This questionnaire measures the thoughts and actions of an individual when managing stressful situations. The revised WCQ-S has 45 statements divided into the following eight scales: confrontive coping (six items); distancing (five items); self-controlling (five items); seeking social support (five items); accepting responsibility (four items); escape/avoidance (eight items); planful problem solving (six items); and positive reappraisal (six items). The respondents answered the items on a four-point Likert scale to indicate the extent to which they used each strategy. The options were from 0 (does not apply or not used) to 3 (used a great deal). The Swedish version, comprising 50 items, has been used in several studies (Ahlstrom & Wenneberg, 2002; Gustafsson & Ahlstrom, 2006). The WCQ-S total score has good internal consistency: Cronbach’s alpha coefficient = 0.86 (Lundqvist & Ahlström, 2006), and it was 0.91 in the current study.
Individualized Care Scale

The Individualized Care Scale (ICS) (Suhonen, Leino Kilpi, & Välimäki, 2005) measures a person’s perspectives on individualized care. The questionnaire consists of 34 statements divided into two sections: the ICS-A and ICS-B. The ICS-A assesses the person’s perspective on how specific nursing interventions support and promote individuality; the ICS-B assesses how persons perceive individuality in the care they receive. The ICS-A and ICS-B have the same subscales: clinical situations (seven items); personal life situation (four items); and decisional control over care (six items). The participants evaluated their individual care on a Likert scale from 1 (absolutely do not agree [worst]) to 5 (absolutely agree [best]). The ICS-A and ICS-B have good internal consistency: Cronbach’s alpha coefficient = 0.94 and 0.93, respectively (Berg, Suhonen, & Idvall, 2007), and they were 0.91 and 0.93 in the current study.

EuroQol-5D

EuroQol-5D (EQ-5D) is a non-specific disease measure of self-perceived health status. It is divided into five dimensions: mobility; self-care; usual activities; pain/discomfort; and anxiety/depression. Each domain is divided into three levels, and this produces a self-rating from 1 to 3: 1 = extreme problems; 2 = some or moderate problems; and 3 = no problems with overall health. The questionnaire also includes a visual analogue scale (VAS) anchored at zero; this indicates an overall valuation of the current state of health from 1 to 100. Validity and reliability for EQ-5D-VAS have been tested in different countries and populations with satisfactory results (Brooks, 1996; Hurst, Kind, Ruta, Hunter, & Stubbings, 1997).
Quantitative data analyses (Study III)

The data were at the nominal and ordinal level and not normally distributed or of equal size; thus, statistics for non-parametric data was used. For non-parametric data, statistics are normally given in terms of medians and range (Brace, Kemp, & Snelgar, 2009). In this thesis, statistics are given as means and standard deviations to facilitate comparison with other studies using mean values.

Internal missing values in each of the instruments of ≤30% were imputed with the mean value of the person’s assessment of the index using the compute variable function in SPSS (SPSS, Chicago, IL, USA) (Brace, et al., 2009). Mean values for all the indexes and the total scale were used for summation of the scores in each instrument. Statistical comparison was also performed between the non-responders (regarding sex, age), dropouts (regarding demographics and baseline of questionnaires), and with the participants in the study. Accepted internal consistency of Cronbach’s alpha was considered lowest at 0.70 and highest at 0.95 (Brace, et al., 2009). Data were analyzed with SPSS 19.0. The level of significance was set at $p < 0.05$. 

**Ethical considerations**

Because of the involvement of human subjects, the intervention to improve chronic kidney care was guided by research-ethical principles (Lynn, et al., 2007; Northern Nurses' Federation, 2003; World Medical Association Declaration of Helsinki, 2002). The research project was approved by the Research Ethics Committee of Linkoping University in Sweden (Dnr: M205-08).

The researcher contacted all participants in the national register of persons with CKD who were treated at one of the three hospitals involved in the QI. Furthermore, in the study involving the family members (Study II), the persons with CKD gave the name and phone number of one family member. This sampling strategy may have had an effect on the participants’ autonomy. However, the researcher contacted the family members individually to inform them about participation being voluntary and what that implied for them. In accordance with respecting the participants’ autonomy, all the participants were informed that they had the right to withdraw from the study at any time without suffering any consequences for their future care. The participants gave their written informed consent before the study was undertaken. In the interviews, the author was aware of power issues, in that an interview is not a conversation between two equal individuals. The researcher has control over the situation. This power issue was treated with respect, and the participants were able to choose the place where the interview was held. In addition, during the course of the interview, the participant was asked if the author’s interpretation was correct. In accordance with the participants’ autonomy, the healthcare professionals were asked individually for their permission to use recordings of the project group meetings. There was no dependency between the participants and any of the researchers. The researchers were not members of the organization and not involved in the delivery of care. In an attempt to maintain the autonomy of the participants in the project group; the author also clarified the role as interactive researcher, i.e., not being actively involved in the organization or management of the QI intervention.
To maintain the principle of non-maleficence, the participants were guaranteed their confidentiality. The author was the only person to possess the names and addresses of the participants (Studies I, II, and III), and the personal information was kept secure. Confidentiality was increased by using codes in the correspondence between the researcher and participants and when the transcriptions and analyses of the qualitative data were performed. The confidentiality of the participants was also taken into account when reporting the findings. The findings were abstracted and presented at the group level, and the place where the study was undertaken remained confidential so as to minimize the disclosure of recognizable information. When reporting a case study, the literature recommends a detailed description of the case to enhance the trustworthiness of the study. Cases and participants should be described to allow transferability and the possibility for interested parties to search for additional information in specific areas (Yin, 2009). However, this is not a preferable option in terms of Swedish research ethics in the field of health care. Therefore, cases and participants (Study IV) were described in accordance with the ethical principle of confidentiality.

In the interviews, there was an attempt to obtain beneficial knowledge while minimizing harmful consequences (Kvale & Brinkmann, 2009). The interviewer was aware of the consequences when the situation may involve private concerns. If a person with CKD or a family member in the study was undergoing emotional difficulties or stress, the researcher offered help in contacting healthcare professionals. The interview time was also taken into careful consideration. The researcher made all efforts to be sensitive to participants’ signs of tiredness, which are part of the symptoms in CKD. The researcher gave the participants opportunity to reflect on what they had said in the interviews, and time was also available for the participants to ask questions.
All persons with CKD in the pre-dialysis phase who had been entered on the regional part of the national register were invited to take part in the study. However, not all participants received the treatment based on the QI as those did in the intervention group. The comparison group received ordinary treatment. In accordance with the principle of justice, it will be important to send the findings of this study to the hospitals involved in the comparison group. The interactive research process is based on equal partnership and mutual learning in the process of knowledge creation.
Findings

Experiences of empowerment in chronic kidney care (Studies I and II)

Empowerment in chronic kidney care was described by the persons with CKD as encounters that support the creation of trust and learning (Study I); the family members described empowerment as the strength to assume responsibility (Study II). Accessibility to chronic kidney care was essential for the experience of empowerment: it facilitates access to knowledge and information (Studies I and II) and allows person-centred care (Study I). Access to chronic kidney care was also essential toward being prepared for the future (Studies I and II) and for clarifying the supportive role of family members (Study II). Confirming encounters plays an important role in the experience of empowerment: when healthcare staff recognized them and addressed them by name, the persons with CKD and their family members experienced empowerment. Furthermore, personal relationships on equal terms and a sense of genuine interest provided a feeling of confirmation for those in a vulnerable situation (Studies I and II). This was also provided by the possibility of sharing knowledge with healthcare professionals (Study II) and others in a similar situation (Study I). The need for participation in care decisions received a range of response—from little need to being considered essential for empowerment. Having appropriate knowledge was taken to be important in this respect (Studies I and II). Furthermore, it was felt that participation in decision making was affected by the staff’s attitude to this type of responsibility. The experience of empowerment was related to such treatment as well as to lifestyle changes fitting in with habits and routines (Study I). Trust in the competence of the healthcare staff was described as empowerment (Studies I and II), and it was based on the feeling that the care being given was of the best possible kind and that the ultimate responsibility for care was taken by the healthcare professionals.
The sense of collaboration of different healthcare professionals was emphasized by the persons with CKD and their family members as providing empowerment. Empowerment was related to understanding one’s illness (Studies I and II) and maintaining one’s health for as long as possible (Study I). The knowledge associated with this gave a sense of control. Learning was facilitated through informal meetings as well as through sharing knowledge and experience with others (Study I). Persons with CKD and their family members sought knowledge outside the chronic kidney care environment with regard to the disease itself (Studies I and II), preventive activities, or diet (Study II).

The persons with CKD and their family members also related experiences that illustrated the absence of empowerment, such as being met with nonchalance on the part of healthcare professionals when their care was being planned and not allowing them to have their say (Study I). Insufficient involvement and empathy on the part of healthcare professionals had a negative effect on the care relationship and resulted in an apparent nonchalance on the part of such professionals toward chronic kidney care. The lack of dialogue and personal influence in encounters with healthcare professionals was described as leading to difficulties in understanding the seriousness of the illness (Studies I and II). The lack of dialogue derived to some extent from the fact that persons with CKD and healthcare professionals did not speak the same language and did not have the same view of what was important or when individuals were left to their own interpretations and imaginings (Study I). Finally, not being regarded as a natural partner in chronic kidney care was also considered a factor behind the lack of dialogue and influence (Study II).
Evaluation of an improvement intervention based on empowerment (Study III)

When the QI was evaluated (Study III), the difference between the groups after 2 years of QI was evident in personal life situation (ICS-A): the intervention group scores were significantly higher than in the comparison group ($p = 0.044$). When comparing baseline with follow-up scores, only within-group differences were found in the intervention group. At follow-up, the WCQ-S scores of the intervention group were significantly higher on escape/avoidance ($p=0.011$), which included wishful thinking and efforts to avoid problems. The intervention group also had significantly higher scores in terms of support of individuality (ICS-A) by staff members ($p=0.013$) and with personal life situation (ICS-A, $p=0.001$; ICS-B, $p=0.030$) and decisional control over care (ICS-A, $p=0.019$).

Analysis at the item level showed that the intervention group had more significant differences in follow-up scores than the comparison group. When comparing baseline and follow-up in the intervention group, the item concerning goal achievement (SWE-DES-23) was scored significantly higher in the intervention group ($p=0.046$). Regarding WCQ-S, there were significantly higher scores in confrontive coping ($p=0.026$), escape/avoidance ($p=0.021$, $p=0.023$), seeking social support ($p=0.040$), and self-controlling ($p=0.047$) in the intervention group. Significantly higher scores were also found with the following items: ICS-A—personal life situation ($p=0.000$, $p=0.002$, $p=0.012$); ICS-B—personal life situation ($p=0.005$, $p=0.009$). Furthermore, there were significantly higher scores with ICS-A for decisional control over care ($p=0.006$). There were also significant lower scores at follow-up in the intervention group with regard to decisional control over care (ICS-B) for the item “I have followed received instructions in care.”
Correlation between demographics and empowerment (Study III)

When analyzing the correlation between the demographics of persons with CKD and their assessments of empowerment, the following results were found. In the intervention group, there were moderate correlations between the WCQ-S index of escape/avoidance (\(rs= -0.48, p=0.034\)) and the ICS-A index of decisional control over care and also with the pain/discomfort of persons with CKD (\(rs=0.47, p=0.039\)). In the comparison group, significant correlations were found between escape/avoidance and usual activities (\(rs = -0.61, p=0.010\)) and between ICS-B personal life situation and anxiety/depression (\(rs=0.69, p=0.009\)).
Facilitators and barriers in implementing an improvement intervention (Study IV)

In exploring the QI, two themes emerged that described the facilitators and one theme that described the barrier (Table 3).

Table 3. Analysis from sub-themes to themes.

<table>
<thead>
<tr>
<th>Themes</th>
<th>Sub-themes</th>
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<tbody>
<tr>
<td>Facilitators</td>
<td>Improve the individualization of care</td>
</tr>
<tr>
<td></td>
<td>Motivation through the family perspective</td>
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<tr>
<td></td>
<td>Willingness to increase professional collaboration</td>
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<td></td>
<td>Learning from one another</td>
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<td></td>
<td>Possibilities for professional development</td>
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<tr>
<td>Moving spirit</td>
<td>Reinforcement from involved persons</td>
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<tr>
<td></td>
<td>Energy from the group</td>
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<tr>
<td></td>
<td>Different personas</td>
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<td>Encouragement</td>
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**Moving Spirit**

The healthcare professionals described a positive attitude toward improving the individualization of care. They expressed a readiness for implementing QI. The healthcare professionals described the potential of a joint value system of empowerment in individualized care: this facilitated the healthcare professionals’ work and was a reminder of the bottom-up perspective of quality of care. The motivation through the family perspective was clearly described by all healthcare professionals: turning the perspective from that of the healthcare professionals to that of the person with CKD and their family members yielded energy and clarify the focus of the intervention. The
healthcare professionals described a willingness to increase professional collaboration: they wanted to increase collaboration among themselves and between different units. They indicated that the QI promoted this opportunity and that they regarded it as essential toward achieving empowerment for persons with CKD and their family members. Learning from one another was regarded as a driving force in the QI: learning opportunities were facilitated by sharing perspectives with the researcher, healthcare professionals, the persons with CKD, and their family members. The healthcare professionals stated that the QI would provide possibilities for professional development: they stated that it would present an opportunity for personal development, i.e., a driving force not to remain stationary within their profession. In addition, the QI provided them with a feeling of satisfaction and pride regarding their work.

Encouragement

Reinforcement from involved persons was provided using external and internal sources of support. The researcher was an external facilitator with respect to the collection and translation of evidence and as a source of knowledge and positive energy. The local center of improvement knowledge was an external support for education and training for the intervention. The internal reinforcement from the managing director of the medical clinic and the project manager was vital—especially in terms of resource endorsements and organization as well as spread and vitality of the QI. The healthcare professionals significantly commented about the energy of the group: they were comfortable with one another and they felt respected. The healthcare professionals talked about the confirming atmosphere and the positive attitude with respect to one another’s efforts. They described themselves as different personas who adopted different roles: organizers, flexible participants and inspirers in the QI. These different roles were facilitated for the implementation of the activities. Furthermore, front-line healthcare professionals had the opportunity to follow up on the impact of the QI from a bottom-up perspective. This was related to their close involvement with persons with CKD and their family members as well as with other staff members. The project manager, manager of the medical ward, and managing
director of the medical clinic provided an overview of the organization of the QI.

Limitations of the Organization

Obstacles were also encountered in the course of the QI. The healthcare professionals described a lack of cooperation among the different care units because of different statuses and resources. They were also aware of the challenges with the persons with CKD and their family members when the QI had to be implemented in accordance with daily routines. In the course of the QI, the project leader had no authority over other levels of the healthcare organization or medical ward involved in the QI: that ward was under the control of its own manager. The organizational changes comprising the digitalized patient records and the introduction of LEAN to all staff members were an obstruction to the planned QI.

Integrating a theoretical concept like empowerment into everyday clinical work was a challenge. The healthcare professionals expressed the different qualifications to adopt research findings into everyday work. The difference between the healthcare professionals’ notions of empowerment and the difficulties in achieving empowerment for persons with CKD and their family members was described as a complex situation in chronic kidney care. There were difficulties in achieving the same effects in the three healthcare units owing to differences in resources and management. The QI was beyond the ordinary area of work of the healthcare professionals and its maintenance thus required considerable effort.

The healthcare professionals made references to difficulties in inter-professional work. The members of the project group were aware from the start of the problems involved in getting all the staff engaged in the improvement work. It was hard to involve the physicians in the project and additional meetings were organized to encourage their participation in the
ongoing work. In addition, though the healthcare professionals were respectful of the research process, they found that collaboration with the researcher inhibited their own plans and ideas for improvement.

The healthcare professionals described their negative experiences of QI—mostly through lack of follow-up or support—as a possible barrier. The duration of the project was long, and it was a challenge to maintain engagement within the group. In the course of the QI, some healthcare professionals became disappointed and underwent a change in their attitude from being active to becoming more passive. There were difficulties in engaging persons with CKD and their family members in the learning meetings (lärcafé). The healthcare professionals also described the lack of evaluation regarding some parts of the intervention.
Discussion

This thesis aims was to explore the meaning of empowerment from the perspective of persons with CKD and their family members (Studies I and II) and to evaluate the outcomes of an QI for the persons with CKD (Study III). The implementation of the QI for empowerment in the context of chronic kidney care was also explored from a professional perspective (Study IV). This discussion section will cover the main findings from the four studies within this thesis. First, the creation of trust and learning in chronic kidney care and family members’ having strength to assume responsibility for the person with CKD will be discussed in relation to empowerment as described in the literature and in relation to the healthcare organization. Second, the results of the evaluation of the QI will be addressed regarding the complexity of empowerment and in relation to quality of care. Third, the findings relating to facilitators (as moving spirit and encouragement) and barriers (as the limitations of the organization) will be discussed in terms of implementing an QI, drivers for change, the context and modalities of QI.

Experiences of empowerment in chronic kidney care

The findings in this thesis relate to persons with CKD and their family members regarding empowerment in chronic kidney care. In the relationship between the person with CKD and healthcare professionals (Study I), empowerment was described as an encounter that created trust and learning. The persons with CKD indicated that empowerment emerged from trust in the healthcare professionals’ competence and decisions. At the same time, empowerment was also based on the acquisition of knowledge (by the persons with CKD) requisite for self-management and decision making in chronic kidney care. There are thus two sides to the coin. Empowerment for
the persons with CKD and their family members was experienced through their ability to have access to healthcare professionals (Studies I and II), and that access consisted of knowledge and information about the disease and was a source of security. This is in line with previous findings about empowerment from the perspective of persons with other long-term diseases: empowerment was described as understanding the diagnosis and the ability to fit the disease into one’s own life (Aujoülat, Marcolongo, Bonadiman, & Deccache, 2008). Hence, for persons with long-term disease, barriers for empowerment can exist in encounters with environmental conditions, such as structural factors in the organization of care and the attitudes and approaches of healthcare professionals (Paterson, 2001; Rogers, 2008; The Swedish Agency for Health and Care Services Analysis, 2012). Thus, for the person with CKD, experience of trust and learning needs to be created in the environment of chronic kidney care.

The experience of empowerment for persons with CKD (Study I) was described as participation in decision making: there was a range from those who considered it essential to those who though that there was little need for such participation. Individuals in the latter category referred to placing the responsibility for decision making in the hands of healthcare professionals. Persons with CKD having knowledge related to their condition and the healthcare professionals’ attitudes to those persons’ participation in the decision making had a great impact on the professionals’ considerations regarding such participation. In concept analyses of empowerment, the concept has been defined as the individual’s control of aspects affecting their lives and the freedom to make their own choices (Gibson, 1991; Rodwell, 1996). Awareness of empowerment for persons with disease in a healthcare context may be part of changes in society as a whole, whereby individuals are generally more aware of their rights (Colombo, Moja, Gonzalez-Lorenzo, Liberati, & Mosconi, 2012). There are now increased social expectations for the individual to make their own choices in health care (Christensen & Hewitt-Taylor, 2007). This is underscored by healthcare professionals’ interest in supporting persons with long-term diseases toward being more active and informed such that they can participate effectively in decision making in such areas as diabetes care (Adolfsson, Smide, Gregeby,
Fernström, & Wikblad, 2004; Funnell & Anderson, 2003). However, it has also been argued that the literature on empowerment creates an illusion of such an individual as an independent person, free of choice who, provided with objective data, is capable and willing to making decisions regarding their care (Powers, 2003).

Participation in care has been viewed as an active process of taking responsibility for decisions concerning one’s own health (Cahill, 1996, 1998). The persons with CKD varied in how they regarded their participation in chronic kidney care decisions: from very important to not important at all (Study I). Hence, when a person with CKD prefers not to participate, the multiple choices or healthcare professionals’ expectations of active participation in care may increase their stress (Lazarus & Folkman, 1984). There is evidence that the involvement of the person with disease in decisions as to choice of treatment improves their feelings of control and partnership in health care (Colombo, et al., 2012). In the context of persons with long-term disease, empowerment is referred to as a concept of self-management of the disease and self-efficacy (Aujoulat, d’Hoore, et al., 2007). It may be argued that the person with CKD has limited ability to accomplish empowerment in chronic kidney care owing to impaired cognitive function (Elias et al., 2009; Iles-Smith, 2005), though cognition is strongly related to self-efficacy (Bandura, 1977). Consequently, forcing empowerment—as it is defined in the literature—upon the person with CKD may not be the best approach. Instead, there is a need to ascertain how the person wants and needs to be treated in healthcare encounters (Christensen & Hewitt-Taylor, 2006).

To the best of the author’s knowledge, empowerment in outpatient care, as experienced by family members of persons with pre-dialysis CKD, has not previously been described. In this study, the family members’ empowerment in chronic kidney care was accomplished by their experience of having the strength to assume the responsibility, as required, for the person with CKD (Study II). The family members’ strength to assume this responsibility was
evident in their being involved in the sick person’s care (Study II). Previous research in the context of intensive care supports this finding, though experiences of powerlessness associated with the family members’ inability to help the sick person have been reported (Johansson, Fridlund, & Hildingh, 2005; Johansson, Hildingh, Wenneberg, Fridlund, & Ahlstrom, 2006). Furthermore, in the present study, it was found that being regarded as a respected partner in the sick person’s care was an essential element in the family members’ experience of empowerment (Study II). The family members’ involvement in decision making and in the partnership with healthcare professionals has previously been described as an important aspect of empowerment in palliative care (Funk, Allan, & Stajduhar, 2009) and in critical care (Wahlin, Ek, & Idvall, 2009). In addition, the literature illustrates how empowerment for the family members in healthcare increases when healthcare professionals listen to their experiences and acknowledge their competence (Bohn, Wright, & Moules, 2003; Ziegert, Fridlund, & Lidell, 2007). However, in the present study, the family members (Study II) described a feeling of being left out (Study II). This experience was related to their limited opportunity of being invited to attend the healthcare encounters of the person with CKD. The family members were uncertain about their role in the person’s care and described the healthcare structures and processes as a barrier. The family members’ inability to obtain the same information as the sick person (Study II) decrease their understanding of the disease (Benkel, Wijk & Molander, 2012) and signifies the absence of empowerment as defined in concept analysis (Ellis-Stoll & Popkess-Vawter, 1998; Gibson, 1991; Rodwell, 1996). Consequently, the findings of the present study (Study II) support the need to involve family members in chronic kidney care as a means of obtaining healthcare professionals’ support so that the family members can handle their own situation and support the person with CKD when required. Furthermore, empowerment for family members in chronic kidney care is significant for quality of care (Socialstyrelsen, 2009).
The family members should naturally play a part in the case of chronic kidney care (Socialstyrelsen, 2009). However, in the present study, empowerment for the family members was found to be related to partnership in the decision making with respect to the chronic kidney care of the person with CKD (Study II). This may be viewed as paternalism (Christensen & Hewitt-Taylor, 2006), though encounters with healthcare professionals that create trust and learning was seen to be essential for the experience of empowerment among persons with CKD (Study I). Hence, to avoid paternalism, healthcare professionals need to consider empowerment of both the person with CKD and their family members. Therefore, family members’ empowerment is a necessary component, but in and of itself it is insufficient for achieving quality of care (Patel, Peterson, & Kimmel, 2005).

Complexity of evaluating QI intervention based on empowerment

The impact of an QI is important in providing useful knowledge for future QI interventions (Batalden & Davidoff, 2007). In the present study, the QI for empowerment in chronic kidney care did not produce many significant changes (Study III). The Swe-DES assessments showed no significant differences between baseline and follow-up in the two groups; there were likewise no significant differences between or within the intervention and comparison groups. This is in line with the results of an previous study regarding empowerment in diabetes care: no significant between group differences were found of an intervention aimed to increase the self-efficacy of persons with diabetes involving education to both healthcare professionals and persons with diabetes (Piatt et al., 2006). One factor that may have an impact on the results of empowerment in an QI (Study III) is the ambiguity of the concept though empowerment takes different forms depending on the individual and the context (Rappaport, 1984). A further factor may be the attitude of healthcare professionals as it contributing to the process of empowerment (Aujoulat, d'Hoore, et al., 2007; Gibson, 1991). In person-centred care, the concept of empowerment is crucial in shifting from the perspective of healthcare professionals (Christensen & Hewitt-Taylor, 2006;
WHO, 2012) toward that of the person with long-term diseases (Edvardsson, Fetherstonhaugh, & Nay, 2010; Ekman et al., 2011). However, Keers et al. (2006) argued that since empowerment is a broad concept that involves different aspects, no consensus has been reached on how to measure it. In addition, every attempt to measure empowerment will add to our understanding of the concept (Rappaport, 1984).

The experience of empowerment for a person with CKD depends on their own attributes in terms of self-efficacy (Bandura, 1977; Gibson, 1991; Rotter, 1966). Self-efficacy, which is linked to the concept of empowerment (Zimmerman & Rappaport, 1988), is strongly related to an individual’s cognitive function. Cognition is prerequisite for the individual’s ability to change their behavior. Furthermore, the individual’s motivation in setting and accomplishing goals and evaluating the consequences of a particular behavior in the future is rooted in cognition (Bandura, 1977). This is in line with the findings of Feste and Anderson, who claimed that in diabetes care, empowerment is achieved mostly by the individual themselves even if the process of accomplishing empowerment needs to be facilitated by healthcare professionals (Feste & Anderson, 1995). In sum, the individual’s capacity and differences in cognition and personality need to be taken into account when organizing person-centred chronic kidney care. This is because individual differences appear in a broader construct of empowerment (Zimmerman & Rappaport, 1988).

In the present study, the intervention group WCQ-S scores were significantly higher with the index of escape/avoidance. This index is related to emotion-focused coping (Lazarus & Folkman, 1984). Coping with illness can be viewed as a facilitator for empowerment (Keers et al., 2006). The correlations between the scores for escape/avoidance and pain/discomfort may be related to the fact that some issues and concerns related to living with CKD may not fit into the problem-solving framework; hence, emotional coping is an appropriate coping strategy (Lazarus & Folkman, 1984). This
may also be the case in the correlation between escape/avoidance and usual activities.

Most improvements were found in the healthcare professionals’ support of individualized care (ICS-A and ICS-B). Significant differences between the intervention and comparison groups were evident in the ICS-A with the index of personal life situation. This means that the intervention group received significantly higher support from the healthcare professionals with regard to their personal life situation in chronic kidney care. Within-group differences were found only in the intervention group with the ICS-A for indexes of personal life situation and decisional control and with ICS-B for the index of personal life situation in chronic kidney care. Previously, having a sense of control over one’s life was found to be related to an individual’s mental and physical health (Woodall, et al., 2010). For persons with CKD, their view of individualized care was measured using ICS-A and their perception of individualized care was measured using ICS-B. These are two dimensions of the concept of individualized care. Clearly, it is not sufficient for healthcare professionals to take into account the individual characteristics of persons with disease, their personal life situation and decisional control over care. Healthcare professionals must also put this information into practice so that the person with disease can feel that their individuality is being recognized and considered in terms of their care (Suhonen et al., 2005). The intervention group gave higher scores to the healthcare professionals’ specific interventions in supporting individuality in care than they did of individuality in the care they received. This is in line with previous findings, which indicate that person-centred healthcare is easier to view than to actually receive by persons with disease (Suhonen, 2008). This may be related to the strong influence of the organization culture and system in which care is delivered (WHO, 2012). In Sweden, issues related to quality of care from the person’s with disease perspective have been stressed in the form of The Health and Medical Services Act (SFS 2010:659).
With the item “I have followed the instructions received in care” (ICS-B), the intervention group scores were significantly lower than those of the comparison group (Study III). Hence, in the context of chronic kidney care, this result may be related to impaired cognition, which is an early symptom in CKD (Elias, et al., 2009), though cognition plays a role in motivation and behavior changes (Bandura, 1977). The result may also be related to increased knowledge making persons with disease more comfortable and secure in making their own choices so as to fit the management of the disease into their lives. That would be in accordance with the notion of empowerment as the opportunity to define and achieve one’s own goals (Gibson, 1991; Rodwell, 1996) and encouraging persons with long-term disease to reflect on their own experiences and on what works for them (Ellis-Stoll & Popkess-Vawter, 1998; Feste & Anderson, 1995). This finding could be seen as being in conflict with healthcare professionals’ training, which is based on the medical model that holds them responsible for health problems and the traditional idea whereby healthcare professionals know best (Funnell & Anderson, 2004). However, a literature review of interventions for persons with diabetes found that empowerment interventions improved the individuals’ health and decreased their medical use (Deakin, McShane, Cade, & Williams, 2004).

Perhaps depending on the context, not all QI will lead to actual improvement (Scott, 2009; Øvretveit, et al., 2011b). The process of empowerment in healthcare includes a combination of attributes that relate to both the nurse and the person with disease (Gibson, 1991). This interdependence of attributes highlights the complex issues involved in persons with disease achieving empowerment in healthcare encounters. Furthermore, this complexity emphasizes the importance in respecting the needs, values, and preferences of the person with CKD in the process of care (Morgan & Yoder, 2012). One study describes the challenges of QI for individual empowerment in healthcare as being related to the healthcare professionals’ traditional paternalistic approach in the relationship with persons with disease (Colombo, et al., 2012). The dominance of an organization culture may affect the healthcare professionals’ ability to change their habits and routines to strengthen the empowerment of persons with disease (Chassin &
Loeb, 2011). In addition, nurses need to experience empowerment in the healthcare organization to facilitate empowerment for persons with disease (Christensen & Hewitt-Taylor, 2006). Focusing on the relationship between the experience of empowerment by a person with a long-term condition and the healthcare context will contribute to our understanding of empowerment (Shearer & Reed, 2004) and quality of care (McCarthy & Freeman, 2008). Moreover, the healthcare professionals’ skills and support of the individual’s needs are essential toward implementing strategies to provide empowerment in care (Begum & Por, 2010).

Implementing an improvement intervention

The drivers for change in this study may be examined in terms of the healthcare professionals’ moving spirit, which they describe as a facilitator for the QI (Study IV). The healthcare professionals invited the assistance of the research group in supporting the improvements to the quality of care (Study IV). The healthcare professionals were aware that they could work in a more person-centred manner and wanted to know more about the individual with CKD and their family members’ experiences of empowerment in chronic kidney care. The healthcare professionals in this study described a positive attitude to improving the individualization of care. They started the QI with a common value system, based on the interview findings of empowerment and reading the anthology. Hence, defining a common value system based on the philosophy of empowerment is a first step toward providing person-centred care. This is consistent with Feste and Anderson (1995) who describe healthcare professionals’ behavior as being guided by a philosophy, i.e., the values of how things should be done. In the present study, the healthcare professionals described the common value system as a valuable reminder of the bottom-up perspective of quality of care. For professional development, it is essential to reflect on current values in health care (Funnell & Anderson, 2003). The application of research results to a practical context has been viewed as an individual issue; however, this is a complex area that requires both organizational and educational input (Kajermo, Nordstrom, Krusebrant, & Lutzen, 2001).
addition, evidence related to the specific context was described as facilitating QI by the healthcare professionals in the present study (Study IV). This finding is in contrast to implementing evidence-based guidelines. Implementing guidelines has been criticized as having a top-down perspective in improving healthcare (Cochrane et al., 2007). However, it is necessary to take both perspectives into account with regard to the quality of care (Grol, Baker, & Moss, 2002).

A further facilitator for the QI intervention was the healthcare professionals’ experiences of *encouragement* (Study IV). This is in line with previous literature describing the lack of encouragement as a barrier to change (Grol & Wensing, 2004). In the present study, the encouragement was described in terms of reinforcement from the persons involved, the energy from the group, and the different personas involved in the QI. The healthcare professionals referred to reinforcement received from the managers involved as supportive to the resource endorsement. Furthermore, the healthcare professionals described the positive, confirming atmosphere in the group, and all of them undertook different roles in the QI intervention. Previous literature has shown that the most efficient teamwork in the healthcare setting was when the team members perceived a supportive atmosphere, when the activities were distributed among all team members, and when there was encouragement in good individual performances (Thylefors, Persson, & Hellström, 2005).

The healthcare professionals described the perspectives on empowerment of persons with CKD and their family members as assisting their own professional development. Marshall found that healthcare professionals’ ongoing learning was grounded in their opportunity to reflect on clinical issues (Marshall, 2011). In the present study, the healthcare professionals’ learning from each other in the QI was facilitated by sharing perspectives with the researchers and the other professionals (Study IV). This is in line with the findings of Mitki et al. (1997), who argued that QI is rooted in experiential learning theory. Furthermore, an organization can continuously
improve if the mechanism of learning, i.e., learning style and processes, is taken into account.

The QI (Study IV) was supported by an interactive research approach through introducing the findings of empowerment from the perspective of the persons with CKD and their family members. Interactive research (Aagaard Nielsen & Svensson, 2006) is a strategy for improving research utilization aimed at improving health care (Jagosh et al., 2012; Munten, van den Bogaard, Cox, Garretsen, & Bongers, 2010; Schmittdiel, Grumbach, & Selby, 2010). The outcome feedback in real time has been an important facilitator for improvement in long-term care settings (Doran et al., 2007). However, the interactive research approach in Study IV may not have been the main reason for the implemented intervention: the strength of the healthcare professionals incentive to improve chronic kidney care through the empowerment of the person with CKD may have been the most important impact factor. The QI (Study IV) was perceived by the healthcare professionals as important and meaningful because the interventions were based on the experience of empowerment by the persons with CKD and their family members. The positive results in taking into account the perspectives of persons with disease in successfully introducing QI in health care have been described elsewhere (Glasson et al., 2006; Rogers, 2003). The willingness to reach a common goal and the healthcare professionals’ satisfaction with what was accomplished are linked to a good team environment (Thylefors, et al., 2005). The QI involved all the staff, but it was initiated by the project group and five other healthcare professionals. This may have facilitated the execution of tailored interventions that influences successful implementation (Grol & Wensing, 2004). In addition, including healthcare professionals at all levels of the healthcare organization at an early stage of the intervention increased the chances of sustainable implementation (Greenhalgh et al., 2004).

However, some findings in the present study related to barriers in the implementation process and indicated limitations of the organization (Study
IV). This is in line with the results of previous studies, which identified the organization as a prominent barrier to change (Grol & Grimshaw, 2003) and the use of research findings (Kajermo et al., 2010; Rycroft-Malone, 2008). The members of the project group described a lack of cooperation with the different organizational levels (Study IV). The project manager had authority only over their own unit. Moreover, changes in the organization hindered the QI throughout the implementation phases. Illuminating which circumstances that are more or less important at different phases of an QI is valuable knowledge in QI (Øvretveit, 2011a). A lack of interplay within the organization was the factor that most impeded the process. Previous literature describe in addition to barriers within the organization, barriers for change can also be found at other levels of the healthcare system in terms of individual healthcare professional, the person with CKD, the, the team, and society as a whole (Grol & Grimshaw, 2003).

In the present study, the healthcare professionals also described the difficulties in collaborating with the different professionals involved in the care of persons with CKD. This is in line with previous research findings about the difficulties in inter-professional teamwork in accomplishing collective performance in healthcare (Kvarnström, 2008). Tylefors and colleagues (2005) argued that teamwork involving various professional contributions should be considered in person-centred care. The healthcare professionals in the present study (Study IV) were aware that to increase empowerment, there was a need for inter-professional and organizational collaboration and cooperation for the QI to be experienced by the persons with CKD and their family members. Hence, the barriers to collaboration and cooperation were something that the healthcare professionals wanted to bridge with the QI. The healthcare professionals’ early awareness of these barriers was not described as having promoted their feelings of increased collaboration and cooperation (Study IV). However, the healthcare professionals from the units involved in the QI felt that they were united in providing care. Awareness of barriers early in the process of implementation is described as being useful for successful QI if the QI is tailored to overcome the barriers (Bosch, Van Der Weijden, Wensing, & Grol, 2007).
The healthcare professionals stated that the lack of physicians in the QI intervention (Study IV) decreased the impact of the intervention. This decreased impact was related to the physicians’ authority in determining what was important in care. The insufficient authority of healthcare professionals has been recognized elsewhere as a barrier for implementing QI (Cochrane, et al., 2007; Francke, Smit, De Veer, & Mistiaen, 2008). The empowerment of persons with CKD and their family members in chronic kidney care requires a paradigm shift (Anderson & Funnell, 2010). Hence, QI toward empowerment demand organizational collaboration and management leadership, which directly influence healthcare culture (Kaplan, Provost, Froehle, & Margolis, 2012).

Even though in the present study, the healthcare professionals described strong encouragement as a facilitator in the QI intervention, the training and performing of PDSA cycles (Langley, 2009) for all staff was difficult to implement (Study IV). This was mainly because of a lack of resources and lack of cooperation among organizational levels. Improving care demands that healthcare professionals have knowledge of how to achieve quality of care. These findings may emphasize the importance of improvement knowledge being integrated into the healthcare professionals’ education. Within the healthcare professionals’ performance, one valuable competence is knowledge of ongoing QI toward improving quality and safety in care (Socialstyrelsen, 2005; The Swedish Society of Nursing, 2013). Furthermore, improvements in healthcare are regarded as part of everyday work and relate to essential professional knowledge (Batalden & Stoltz, 1993).

Some of the healthcare professionals in the present study stated that the QI needed to be in accordance with current routines (Study IV). Habits and routines are critical in interventions aimed at changing healthcare professionals’ and persons’ with disease behavior, such as in empowering encounters in care; this is because it is difficult to change repeated individual
behavior in a constant context. Furthermore, the healthcare professionals’ behavior is a response to contextual features that trigger their actions (Nilsen, Roback, Brostrom, & Ellstrom, 2012). This is in line with the definition of norms described in the theory of diffusion of innovation as being established, tolerable behavior in a social system (Rogers, 2003). It is clear that context has an impact on the results of QI interventions. It is also evident that the healthcare professionals’ motivation is central to the success of a QI intervention (Kaplan, et al., 2012). In addition, innovations that fit into existing values and ways of work are more likely to be implemented (Greenhalgh, et al., 2004). Therefore, there is a need to understand what drives the healthcare professionals toward improving quality of care. Furthermore, accomplishing QI need not be in accordance with current structures and behaviors; it may require different processes and values in health care (Adolfsson, et al., 2004; ).
Methodological considerations

In this thesis, both qualitative and quantitative methods have been used to answer the research questions. In qualitative research, trustworthiness of the research findings has to be established by using the criteria of credibility, transferability, dependability, and confirmability (Lincoln & Guba, 1985). In quantitative research, the internal and external validity and reliability need to be taken into consideration to increase the quality of the findings (Kazdin, 2003; Shadish, et al., 2002).

Establishing trustworthiness

The definition of qualitative research is to make sense of phenomena in terms of the meanings people apply to them (Denzin & Lincoln, 2005). To increase the credibility of the findings in the present study, an effort was made to provide sufficient description of the phenomena under investigation through the participants’ narrations: all experiences were included and described. The interviews took place according to the different participants’ own terms: they had the opportunity to share their experiences of empowerment in chronic kidney care (Studies I and II) and the QI (Study IV) in an open manner, without leading questions. However, with sensitive questions, the participants were allowed to choose whether they wanted to respond to the researcher. This may not have been a problem since none of the researchers was involved in the organization of care or had any relationship with the participants.

Throughout the analytical process, the interviews in their entirety served as a point of reference when deeper understanding was needed of the meaning units, codes, and subthemes. All the research group examined the analysis, i.e., whether the findings were supported by the raw data. The quotations in
the studies were used to make the results more credible. To preserve the original intended meaning, the quotations were translated directly from Swedish to English by an Englishman who spoke fluent Swedish. In the case study (Study IV), the case was well defined, i.e., the implementation process had a beginning and an end as well as a frame that included three care units to uphold the credibility of the findings. In addition, the analysis was based on data from multiple data collection to identify different realities (Yin, 2009) of the implementation process.

The interactive research approach offered the opportunity to understand the context. The researcher participated in ward meetings and at each step of the QI so as build trust and learn the culture. Choosing participants with diverse experiences (Studies I and II) also enhanced the credibility of the studies. Member checking was applied to increase confidence and credibility in interpreting the data (Studies I and II). The interviewer made a summary of the researchers’ interpretations of what was said to create an opportunity for the participants to clarify any misunderstandings. A discussion of the preliminary findings of the subthemes took place with the project group and healthcare professionals; this was in line with the interactive research approach (Study IV).

To facilitate transferability of the findings, the methods used and participants involved in the different studies were carefully described. Furthermore, the cases described in the present study may be compared with other cases so as to add to previous knowledge about QI interventions. Furthermore, the process in the case study (Study IV) included a thick description of the context, allowing the reader to determine the transferability of the findings (Lincoln & Guba, 1985; Yin, 2009).

To establish dependability, the analysis was divided into several stages of development by way of facilitating a systematic inspection of the analysis. “Empowerment” is not a word commonly used in society at large, but in
Sweden it is usually described in such terms as (literally translated) “giving or delegating power to,” “self-determination,” or simply “power.” The researcher needs to have a pre-understanding of the concept; therefore, a literature review on empowerment was performed before the data collection took place, and this guided the follow-up questions in the interview and should increase the dependability of the findings (Lincoln & Guba, 1985).

Confirmability (Lincoln & Guba, 1985) is defined in terms of the critical, objective standpoint of the researcher. There is a risk in interactive research that the researcher comes too close to the subject of study to be fully critical. In addition, the interactive research approach stresses that participants be involved in the whole research process. In this interactive research project, the researcher provided a baseline and follow-up for the QI and followed the implementation of the QI. The researcher was also available for discussions related to the QI. What is perceived and how it is interpreted are determined by the individual; it may thus be difficult to obtain a true unbiased view. However, in this study, the researcher was aware of this problem and went over the findings with the participants (Study I, II, and IV), and a member check was made to retain confirmability. Confirmability was also maintained when the research group reached agreement about the findings. However, agreements on findings as an attempt to establish confirmability can also pose a threat to confirmability owing to the researchers’ different experiences and power issues among them. The data analysis was, though, performed independently in the research group, and the discussions about the findings took place in the form of an open dialogue. Furthermore, all the studies were scrutinized by other investigators outside the research group in seminars and conferences.
Establishing validity and reliability

In quantitative studies, validity can be established through the relationship between the cause and effect of an intervention. This relationship should be described as accurately as possible. Internal validity refers to the extent to which the intervention can be considered having made a significant difference in a specific case (Shadish et al., 2002). Randomization is the most effective method for managing confounders that can bias the results. However, a quasi-experimental design is appropriate when studying an intervention under typical conditions where it is not possible to conduct an RCT. Hence, to evaluate the QI intervention in the present study, a quasi-experimental design was used (Study III) with one intervention group and one comparison group. With this design, the threats to internal validity were taken into consideration. For the two groups used in this study, the events that occurred outside the intervention, the changes over time with the participants and interpretations of their responses to the interview questions, and the data collection were as similar as possible. To decrease diffusion of the intervention, baseline and follow-up measurements were performed at the same time in both groups. Furthermore, the geographic separation of the three hospitals may have decreased the diffusion of the intervention. In addition, using a comparison group, in which non-significant differences were found in most of the background variables relative to the intervention group, may have strengthened the inference that the results were related to the QI. Moreover, the statistical conclusion validity was increased by using appropriate statistics for non-parametric data. The results of the statistical methods employed were reported as mean values and standard deviations to facilitate comparison with the results of other published studies.

Long-term follow-up data are difficult to acquire because of the loss of participants through attrition (Shadish, et al., 2002). Since the participants in Study III were selected from the region in the national register of persons with CKD and their participation was voluntary, it was not possible to increase the sample size once the study had started. Low statistical power may have contributed to false conclusions about the improvement in quality
of care regarding empowerment and its impact on the outcomes of persons with CKD (such as Type II error) (Brace, et al., 2009). To increase the statistical power, the comparison cluster was constructed by aggregating two similar but distant hospitals into one group for comparison with the intervention group. It was difficult to assess the influence of low power on the results because there were no significant differences among non-responders, dropouts, and the two study groups in the available individual variables (Polit & Beck, 2012).

Though empowerment takes different forms in different individuals and contexts, a more tailored measurement to assess the outcomes of empowerment in this group of individuals may have been required (Bick & Graham, 2010; Rappaport, 1984). However, the instrumentation of the intervention was based on the complex, multidimensional concept of empowerment (Gibson, 1991) as an attempt to increase the construct validity of the study. The instruments used to measure empowerment (Swe-DES), coping (WCQ-S), and individualized care (ICS-A and ICS-B) were selected based on their psychometric properties. To the best of the author’s knowledge, this is the first time the Swedish version of the instruments has been used in intervention studies in chronic kidney care. When testing the reliability of the instrument (Study III) with reference to the consistency of the instrument (Kazdin, 2003), Cronbach’s alpha showed satisfactory internal consistency (Brace et al., 2009). When evaluating the QI, a maximum of five points in the Likert scales in the questionnaires may have made them less sensitive (for example, ceiling or floor effects) in identifying group differences. A broader range of scores is necessary to achieve high sensitivity in measuring changes (Kazdin, 2003). However, in this study, it was difficult to determine the impact of a five-point Likert scale relative to the identified group differences owing to low statistical power. In addition, few questionnaires are available for measuring empowerment in persons with CKD, which makes it difficult to determine how sensitive measures are to limited longitudinal psychometric tests.
External validity refers to the possibility of generalization of the findings (Kazdin, 2003; Shadish, et al., 2002). All persons with CKD in the national register who were treated in one of the three hospitals in the study were invited to participate (Study III). Although attrition was high, no significant differences were found in the background variables of sex and age in the non-responders and in the baseline data of the dropouts compared with the participants who remained in the study. Participants who remained in the study were representative for the population in terms of sex, age, and duration of disease. This may have increased the external validity of the study (Study III). In addition, the period between the pre- and posttest was 2 years. That may also have increased the external validity of the findings since that 2-year period was necessary for the healthcare professionals to carry out the QI in the real-world healthcare circumstances.

Accessing current, reliable information is a challenge for healthcare professionals (MacIntosh-Murray & Choo, 2005). In QI, the use of generalizable evidence is emphasized (Batalden & Davidoff, 2007). Even though RCTs are useful in providing evidence-based knowledge, the results are often difficult to adapt to an individual’s specific healthcare needs (Rycroft-Malone, 2008). Hence, a broader definition of evidence was used in this thesis (Socialstyrelsen, 2012; Rycroft-Malone et al., 2004; Willman, Stoltz, & Bahtsevani, 2011). Moreover, in person-centred care, the treatment should be tailored to meet the needs of each individual; therefore, basing clinical treatment only on RCT studies may be problematic in person-centred care (Rolfe, 2001).
Conclusions

As evident in the literature, the experiences of empowerment in chronic kidney care were largely similar to those in the care of other long-term diseases. However, empowerment for persons with CKD involves the creation of trust and learning in chronic kidney care; hence, there are two sides to the coin. The most interesting finding was the variable descriptions regarding the need to participate in healthcare decisions: the expression among persons with CKD ranged from such participation being thought unnecessary to it being thought essential. The family members experienced empowerment when they felt they could assume responsibility for their relative with CKD. This experience was facilitated by being an involved, respected partner in chronic kidney care. The QI had a significant impact on the view of individualized care among persons with CKD. They perceived support by the healthcare professionals regarding their personal life situation in care. The follow-up measurement of WCQ-S showed significantly higher scores in escape/avoidance in the intervention group. No significant difference was found in the Swe-DES measurements. These findings may reflect the ambiguous concept of empowerment.

In the implementation process of the QI in chronic kidney care, the facilitators described by the healthcare professionals were moving spirit and encouragement. The moving spirit was mostly supported by the healthcare professionals’ willingness to individualize the care. The creation of a common value system based on a bottom-up perspective was also facilitating. The healthcare professionals also stated that learning from one another and the opportunity for professional development facilitated the QI. Encouragement was described in terms of support from external and internal individuals involved in the QI. The energy in the group and the different personas involved in the implementation of the QI were also facilitating. The healthcare professionals referred to barriers in implementing the QI; these were related to the limitations of the organization. The lack of cooperation among the different healthcare units and levels of organization was described as a barrier. The
healthcare professionals also described difficulties in interprofessional work and in getting all staff members engaged with the QI.
Implications for practice and further research

Implications for healthcare practice

The findings relating to empowerment presented in this thesis show similarities with those in the literature. However, when taking the perspective of persons with disease into account in empowerment, it is important to note that empowerment can adopt different forms in different individuals and contexts. It is essential to be aware of this point when establishing quality of care. It is important to promote the healthcare professionals’ need to reflect on their attitudes and behavior regarding empowerment for each person with disease. The findings in this study reveal differing needs for participation in healthcare decisions. Participation is included in the construct of empowerment; healthcare professionals therefore need to identify the reasons for persons with disease not wishing to participate. Including the family members in the care of persons with CKD will increase the experience of empowerment. To facilitate empowerment in chronic kidney care, there is a need for a different structure and way of working. Healthcare professionals may take a bottom-up perspective into account when facilitating the implementation of quality of care. Furthermore, encouragement from persons at different levels and units and from professionals in the healthcare organization is needed to facilitate QI for empowerment.

Implications for education

Quality of care from the individual’s perspective needs to be emphasized in the education of healthcare professionals. In addition, understanding the family members’ perspective of living with a sick relative is important in the
education of healthcare professionals. This may facilitate the creation of a supportive environment for the persons with CKD and their family members toward increasing their empowerment. Training in improvement knowledge is difficult to achieve in clinical settings when everyday work has to be carried out. Therefore, this knowledge has to be integrated as a natural part of the professional training to facilitate healthcare improvements. Furthermore, inter-professional education is needed to bridge the barriers to high-quality care.

Implications for further research

QI based on empowerment from the individual’s perspective may be difficult to evaluate using non-specific measurements. Therefore, further research is needed to develop an instrument for measuring empowerment in chronic kidney care. Future studies should also provide valid, reliable instruments for longitudinal intervention studies. In the context of chronic kidney care, further research is required to examine the impact of cognitive impairment in relation to empowerment for persons with CKD. Additional study is necessary to investigate the impact of a common value system based on a bottom-up perspective in QI as well as that of an interactive research approach in facilitating the function of QI.
Ett kvalitetsförbättringsprojekt avseende empowerment inom njursjukvård
– en interaktiv forskningsansats

Utgångspunkten för projektet var att vården oftast planeras utifrån de professionellas perspektiv och att vårdkvalité bör definieras av personerna med långvarig sjukdom och deras närstående. När vårdkvalitet efterfrågas blir personer med långvarig sjukdom och deras närståendes upplevelser av självbestämmande, kontroll och delaktighet avgörande dvs. individens upplevelse av empowerment. Syftet med detta avhandlingsprojekt var att undersöka betydelsen av empowerment ur personers med långvarig njursjukdom i predialys fas (CKD) och deras närståendes perspektiv (Studie I och II). Dessutom att utvärdera resultatet av ett förbättringsarbete genom att jämföra empowerment hos 25 personer med CKD som deltog i förbättringsarbete med empowerment hos 21 personer som inte hade tillgång till förbättringsarbete (Studie III). För att få kunskap om vad som sker när vårdspecialist arbetar med förbättringsarbete följes arbetsprocessen utifrån ett personalperspektiv (Studie IV).

Projektet initierades av vårdspecialist då de önskade vetenskapligt stöd med att stärka personers med CKD och deras närståendes empowerment i vården. Vårdspecialisten ville förbättra vården genom att utgå ifrån deras erfarenheter av att bli bemyndiga av personalen dvs. empowerment. En interaktiv forskningsansats användes för att nå målet med förbättringsarbete. Forskningsansatsen innebar ett nära samarbete mellan vårdspecialist och forskare i syftet att lära av varandra. Forskaren genomförde intervjuer med personer med CKD och deras närstående där de beskrev sina upplevelser av
empowerment i vården. Resultaten av dessa intervjuer presenterades för vårdpersonalen i s.k. lärande seminarier i syfte att vårdpersonalen skulle få ett relevant underlag för sitt förbättringsarbete. Dessutom fungerade forskaren som ett stöd när det gällde diskussioner av begreppet empowerment i vårdpersonalens kliniska vardag.

Deltagare som bidrog till intervju resultaten omfattade totalt 20 personer med CKD (Studie I) och 12 närstående (Studie II). Utöver intervjuer med personerna med CKD och deras anhöriga intervjuades 12 vårdpersonal i syftet att studera deras erfarenheter av förbättringsarbetet (Studie IV). Samtliga intervjuer och de inspelade projektgruppsmötena under förbättringsarbetet analyserades med kvalitativ tolkande innehållsanalys. Den quasi-experimentella studien analyserades med icke parametrisk statistik (Studie III).

Resultatet av intervjuerna blev grunden för förbättringsarbetet och visade att empowerment för personer med CKD upplevs som ett förtroendeskapande och lärande möte i sjukvården. Detta underlättades vid tillgång till hälso- och sjukvård när personerna behövde det och genom vårdpersonalens positiva inställning till att ta tillvara personernas kunskap och förmedla professionell kunskap. För personer med CKD var det viktigt att förstå informationen som ges av vårdpersonalen. Lite överraskande var det att inte alla uttryckte att delaktighet i vården var viktigt för att uppleva empowerment. Personerna med CKD uttryckte även frånvaro av empowerment i vården. Detta berodde främst på bristen på att kunna ha inflytande över vad som sker i vården (Studie I).

I intervjuerna med de 12 närstående till personerna med CKD beskrevs empowerment som att ha styrkan att ta ansvar. Det underlättades av deras möjlighet att bli bekräftade och respekterade som en naturlig partner i den sjukes vård. De närstående uttryckte även brist på empowerment, de menade att deras behov av kunskap och delaktighet inte passade in i vårdens rutiner.
och traditionella sätt att arbeta. Gemensamt för personerna med CKD och deras närståendes upplevelser av empowerment var att de hyste förtroende och tillit till vårdpersonalen att de gav bästa möjliga vård (Studie II).

Vårdpersonalens förbättringsarbete innebar att forskaren genomförde lärande seminarier kring intervjuresultaten, workshops kring begreppet empowerment, reflektionsträffar kring empowerment och gav stöd till personalen att utforma en gemensam värdegrund kring bemötande. Personen startade lärkafé där information från vårdpersonalen utgick från personer med CKD och deras närståendes behov. Dessutom utvecklades informationsmaterial för den närstående som också uttryckligen blev inbjuden att vara delaktig i den sjukes vården. Utvärderingen av förbättringsarbete visade en signifikant skillnad mellan interventionsgruppen (25 individer) och jämförelsegruppen (21 individer) avseende att interventionsgruppen skattade högre poäng i individuell vård (ICS) när det gäller att i vården bli tillfrågad om den personliga livssituationen. Vid jämförelse av poäng mellan utgångsläget och efter 2 år inom grupperna upvisade endast interventionsgruppen signifikant förbättrad empowerment i vården (Studie III).

Intervjuerna med vårdpersonalen före och efter förbättringsarbete och de upprepade projektgruppsmötena under arbetet (2 år) visade att det som vårdpersonalen beskrev som underlättande i implementeringsprocessen av förbättringsarbete kunde sammanfattas i två teman: Drivkraft och Uppmuntran. Drivkraften representeras av vårdpersonalens vilja att förbättra vården för personerna med CKD och deras närstående och viljan att utvecklas professionellt. Uppmuntran fick vårdpersonalen av både externa och interna källor. Samarbetet med forskare och stöd från det lokala centrum för förbättringskunskap (Qulturum) tillsammans med uppbakning av klinikchefen och projektledaren var nödvändigt för förbättringsarbete, liksom energin i gruppen och mixen av olika personligheter. Ur intervjuerna växte också fram ett tema Begränsningar i organisationen, som belyste en barriär i implementeringsprocessen av förbättringsarbete. Detta beskrevs
som bristen på samarbete mellan organisationsnivåer, svårigheter i det interprofessionella arbetet och vårdpersonalens tidigare negativa erfarenheter av förbättringsarbete (Studie IV).

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