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Patient Involvement
– A Service Perspective

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Abstract

For a long time, patients were seen as weak and passive recipients of care, whose only role was to provide information and comply with doctors' orders. This is beginning to change, and patients are more seen as autonomous, active, and involved collaborators in care, co-creating value with service providers and others. In parallel, the healthcare sector is changing due to an aging population, advances in technology, medical know-how, and the prevalence of chronic diseases, which all call for a more involved patient. During the last decade, patient involvement in healthcare has been recognized as important to provide more efficient, integrated, patient-focused healthcare. Despite this recent gain in attention, there is a gap between rhetoric's and practice, since the meaning and benefits of patient involvement are unclear both in theory and practice. This thesis takes an alternate perspective on patient involvement, departing from service theory on value creation and customer involvement. It aims to understand and explore patient involvement and how patients can be involved in both the use, and development, of healthcare services.

This thesis is based on three different studies using both qualitative and quantitative research methods. The first study is a systematic literature review of healthcare research, addressing the topic of patient involvement and related concepts. Based on a total of 125 reviewed empirical articles, this study serves as an introduction and orientation to the diverse field. It aims to contribute to the knowledge base in the growing research field of patient involvement. The second study addresses and explores lead-user theory as a method to identify highly innovative patients who can be suitable for involvement in healthcare development. The third study explores how patients, depending on disease, care process and context, can take different roles in healthcare development.

The results indicate that patient involvement is not an isolated activity but influences the whole healthcare system. This extends the view of patient involvement from just decision-making and isolated encounters to patients potentially being substantially involved in all aspects of healthcare. This is also important in involvement in use. The patient's individual experiences, context, and type of illness play an important role in development initiatives. Patients should be selected carefully, for involvement in healthcare development, depending on the goal of the initiative. The type of illness and the patient's context are key factors to the kind of contributions patients can make. Depending on the type of illness, and if it shows up mostly at home or at the care provider's, patients develop different contributions.

This thesis contributes to understanding patient involvement by taking a service perspective on co-creation and customer involvement. This approach to patient involvement extends the traditional view by proposing that patients should be involved in all stages of healthcare. Understanding how individuals create value and

manage their health is important for individuals, healthcare providers, and government. Much of a patient's value creation takes place outside the patient-provider sphere, and is therefore unknown to the healthcare provider. By actively involving patients in both use and development, healthcare providers can apply a whole-person perspective.

Sammanfattning

Förutsättningarna för vården har förändrats under de senaste decennierna. Anledningar till dessa förändringar utgörs av bland annat en åldrande befolkning, teknisk och medicinsk utveckling och en ökad förekomst av kroniska sjukdomar. Traditionellt har patienter setts som passiva mottagare av vård, vars roll endast varit att svara på frågor samt följa läkarens ordination av behandling. På senare tid har detta dock börjat förändras. Patienter börjar att i högre grad ses som självständiga, engagerade och deltagande i vården. Enligt detta nya betraktningssätt kan patienter bidra aktivt till värdeskapande, tillsammans med vårdpersonal och andra resurser. Under det senaste decenniet har patientinvolvering setts som en allt viktigare del för att kunna leverera en mer effektiv, integrerad och patientfokuserad vård.

Trots detta ökande intresse, finns det en skillnad mellan retorik och praktik. Patientinvolvering och fördelarna med patientinvolvering är oklara både i teori och praktik – bland forskare, sjukvårdspersonal och patienter. Denna licentiatsavhandling utgår från ett tjänsteperspektiv på patientinvolvering och syftar till att förstå och undersöka hur patienter kan vara involverade i användandet och utvecklingen av vården.

Avhandlingen bygger på tre olika studier med både kvalitativa och kvantitativa forskningsmetoder. Resultaten av studierna tyder på att patientinvolvering inte är en isolerad process utan istället kan ses som något som påverkar alla delar av sjukvården. Detta utökar synen på vad patientinvolvering kan vara. Istället för att se patientinvolvering som kopplat till att patienten ger information och är involverad i beslutsfattande, kan patienten vara involverad i alla aspekter av sjukvården, både i själva utförandet och utvecklingen. Men det är också viktigt att patientens individuella erfarenheter och preferenser, sammanhang och sjukdomsbild spelar en stor roll för hur mycket och vilken typ av involvering som är lämplig. Vid patientinvolvering i utvecklingen av vården, bör patienter väljas noggrant beroende på mål med utvecklingen och vilken typ av involvering det rör sig om. Även sammanhang och typ av sjukdom är viktiga faktorer för vilken typ av bidrag som kan förväntas av patienter. Beroende på typ av sjukdom och kontext, kan patienter förväntas bidra på olika sätt.

Denna avhandling bidrar till en ökad förståelse för patienters involvering i vården genom att ta utgångspunkt ur ett tjänsteperspektiv men fokus på värdeskapande och patienters engagemang. Detta förhållningsätt till patientinvolvering utökar den traditionella synen på involvering genom att föreslå att patienter ska vara involverade i alla steg och aktiviteter i vården. Mycket av patientens värdeskapande sker utanför vården, i den privata sfären, och är därför dolt för vårdgivaren. Att förstå hur patienter skapar värde och sköter sin hälsa är grundläggande för att kunna förbättra vården och stödja patientens egna ansträngningar. Genom att aktivt involvera patienter både i den egna vården men även i utvecklingen av vården i stort är det möjligt att gemensamt skapa en bättre vård.

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Linköping, April 2014

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List of appended papers

This thesis builds on the three papers listed below. The division of work between the authors of this thesis and co-authors are listed under each paper.

Paper A

Snyder, H., Engström, J. (2013). The antecedents and Consequences of patient involvement: A systematic review and thematic analysis.

Presented at the International HELIX Conference 2013. Submitted to journal.

The author of this thesis contributed to the research idea, research design, empirical work, analysis, and writing.

Paper B

Engström, J., Snyder, H. (2014). Patient involvement in healthcare service development: Who to involve and why.

A previous version was presented at the 13th International Research Symposium on Service Excellence in Management (QUIS), Karlstad, 2013. Submitted to journal.

The author of this thesis contributed to the research idea, research design, empirical work, analysis, and writing.

Paper C

Poksinska, B., Witell, L., Engström, J., et al. (2014). Patient participation in healthcare services development: The influence of illness and context on the patient role.

Submitted to edited book.

The author of this thesis primarily contributed to research idea, empirical work and analysis.

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1 Introduction

Healthcare has an extensive impact on the quality of day-to-day life (Berry and Bendapudi, 2007). Life expectancy in Sweden is high, and the country performs well on comparisons of disease-oriented indicators of health service outcomes and quality of care (Anell et al., 2012). All developed economies face problems with increasing pressure on health service budgets, due to an aging population, development of new treatments, technological advances that expand demand for treatment, and rising patient expectations (Saritas and Keenan, 2004). In parallel, the nature of medical problems in the Western world is starting to shift. The prevalence of infectious and acute diseases gave way in the last century to chronic diseases (Cottam and Leadbeater, 2004; Institute of Medicine, 2001). The need for systematic change and innovation in healthcare is well recognized in Western countries. However, traditional health services are ill-equipped to tackle these challenges, which has resulted in an endless debate (Porter and Teisberg, 2006). The need for high-quality services at reasonable cost levels has increased the emphasis on understanding how sustainable change can be created (IoM, 2001).

Healthcare is relevant to everyone. A challenge is to seek and influence individuals who are healthy and wish to remain so, as well as those who are sick (Crié and Chebat, 2012). This is becoming more important as a large part of diseases are caused or influenced by lifestyle activities such as diet and exercise (Cottam and Leadbeater, 2004). As mentioned above, we now face an increasing number of individuals living with chronic diseases. This transformation adds to the complexity of healthcare. The rise of chronic diseases calls for a change, not only in the service offered by practitioners, but also in organizational practices, competences, and conceptual outlook (Gallouj and Djellal, 2011). This change also demands a more active patient. For example, the average person with diabetes spends about three hours a year with their physician, which leaves them with thousands of hours to self-manage their condition (Cottam and Leadbeater, 2004). There is great potential for exploring, both on organizational and individual levels, how to support patients' self-management and how they create value in their day-to-day life. As the patient is the only one experiencing the whole care process from inside, they should also have a key role in planning, designing, and developing healthcare and implementing, testing and evaluating solutions (Cottam and Leadbeater, 2004).

There have been a variety of Swedish health reforms over the past decades, such as decentralization, concentrating hospital services, improving coordinated care, privatization, and responsiveness to patients' needs (Anell et al., 2012; Axelsson, 2000). This is manifested in increased freedom for patients to choose their doctor and care provider (Axelsson, 2000). These customer-driven changes in healthcare (Axelsson, 2000; Tritter and McCallum, 2006) reflect a shift from the traditional view of patients as passive care recipients to patients as autonomous, active, involved collaborators (Anderson and Funnell, 2005; Bodenheimer et al., 2002; Elg et al., 2012; Engström, 2012; Longtin et al., 2010; McColl-Kennedy et al., 2012). Healthcare

providers can deliver better services if they can recognize and use patients as collaborators (Elg et al., 2011; Engström, 2012; Longtin et al., 2010). In other research fields, such as service and marketing research, the customer is well-recognized as an active contributor who co-creates value (Alam, 2012; Grönroos, 2006; Gustafsson et al., 2012; Vargo and Lusch, 2004; Witell et al., 2011). This is also reflected in healthcare. However, even with changes to make healthcare more patient-centered, patients still feel that their needs are not understood, they are not getting enough information, are not invited to participate in decision-making and that healthcare providers lack respect and empathy (Institute of Medicine, 2001).

A number of related, relevant doctoral theses have recently been published on the subject of development and quality improvement in healthcare (e.g Andersson, 2013; Lifvergren, 2013; Engström, 2014). This thesis uses a service perspective on value creation and customer involvement to examine quality in healthcare. It contributes to understanding patient involvement and how patients can be involved in healthcare development and use. This includes a new conceptual outlook on patient involvement and how patients can be involved in all healthcare activities. Although patients in other research topics are referred to as users or healthcare customers, I refer to them as patients in this thesis. However, when I discuss theory from other domains, I use the terms *customer* or *user*, as in the original work.

1.1 Patient involvement

The concept of patient involvement builds on the rationale of patients' right to have a central position in the healthcare process (Eurobarometer, 2012). Trends of activating and involving patients are seen through new institutional and organizational arrangements (Elg et al., 2012). The idea of involving patients is not new, and is an important component in concepts such as patient-centered care (Laine and Davidoff, 1996; Robinson et al., 2008), shared decision-making (Elwyn et al., 1999; Légaré et al., 2008; Saba et al., 2006), empowerment (Anderson and Funnell, 2005; Fox et al., 2005a; Rodwell, 1996) and self-management (Bodenheimer et al., 2002; Lorig and Holman, 2003; Soto et al., 2007). In this thesis I broadly define patient involvement, in line with Longtin et al. (2010), as deliberate activation of the patient that relates to a multitude of aspects of healthcare, such as self-care, patient education, decision-making and development. This implies that patient involvement can be described, discussed or used in practice in relation to how patients are involved in different levels and stages of the design, development, planning, and use of healthcare.

During the last decade, involving patients in development and designing healthcare processes has gained increased attention (Bate et al., 2004). Patient involvement in healthcare can deliver more efficient, integrated, patient-focused healthcare (Greenhalgh et al., 2010). In the use of healthcare services, patients have a key role in helping to reach an accurate diagnosis, deciding on appropriate treatment, choosing an experienced and safe provider, ensuring that treatment is appropriately administered, monitored, and followed, and identifying adverse events and taking appropriate action (Vincent and Coulter, 2002).

Despite this recent gain in attention, there is a gap between rhetoric and practice. Although recent reforms are moving toward more patient-centered models for organizing healthcare, existing models, perspectives, and approaches cannot be relied on to deliver the required change (Bate et al., 2004). In addition, the meaning of patient involvement is still unclear. Its benefits are not well understood (Eurobarometer, 2012; Greenhalgh et al., 2010), and patient involvement is often seen as something done to the patient instead of with them (Eurobarometer, 2012). Research concerning patient involvement has been limited to certain types of patients in consulting with doctors focusing on treatment decisions, rather than a broader consideration of including patients in development and research (Thompson, 2007). Traditional methods for including the patient view in healthcare development and use are reactive, such as patient surveys or information given to providers during consultations (Groene, et al., 2009). This is also in line with Engström (2012), who concludes that the possibilities of involving patient in development is unknown. Therefore, it is necessary to search for alternative approaches for large-scale participative changes in healthcare.

In summary, challenges facing patient involvement are practical (where, when, and how to involve patients) and conceptual (how to understand and conceptualize patient involvement).

1.2 A service perspective on healthcare

Bower (2003) argues that there are three forces driving innovation in healthcare: Technological opportunities, growth in demand for better healthcare, and growth in cost. Future challenges for healthcare are needing innovations that include the individual patient (Bitner and Brown, 2008) and restructuring care systems toward patient-centered models (IoM, 2001). The importance of innovation is widely recognized in both the service and manufacturing industry (Drejer, 2004; Gallouj and Weinstein, 1997; Sundbo, 1997) and is a main driver for economic growth (Drejer, 2004; Toivonen and Tuominen, 2009). Innovation in the public sector, such as healthcare, has been downplayed in favor of studies of innovation in the private sector, particularly in manufacturing (Drejer, 2004; Windrum and García-Goñi, 2008). In healthcare, innovation research has been concentrated around medical innovations, such as new tools, drugs and technologies, and analyzed from the perspective of medical professionals (Djellal and Gallouj, 2008).

However, innovations are not the only focus of medicine today. As the service sector is growing, service innovations are receiving increased interest (Drejer, 2004). In service innovation, the provider-user interface is important (Gallouj and Savona, 2008; Toivonen and Tuominen, 2009). Alam and Perry (2002), conclude that one of the differences between product and service innovation is the need for a different degree of, and means for, user involvement and participation. In service and marketing research, customer involvement in new service development is an important area of investigation (Alam and Perry, 2002; Carbonell et al., 2009), and

customers are seen as active contributors in developing new products and services (Witell et al., 2011).

Traditionally, service and healthcare have been two separate research fields, but recently, service researchers have become interested in healthcare (e.g., Berry and Bendapudi, 2007; Berry et al., 2006; Elg et al., 2012; Ferguson et al., 2010; Gruber and Frugone, 2011; McColl-Kennedy et al., 2012; Moliner, 2009). The service perspective stretches beyond identifying customer needs to actively collaborate with, and learn from, customers to adapt to their individual needs (Vargo and Lusch, 2004). Instead of passively receiving goods and services, customers actively contribute, co-creating value with the service provider and others. This idea differs from the conventional view of value in healthcare as far from a monetary point of view (Porter and Teisberg, 2006; Porter, 2010).

Traditionally, patients are seen as passive recipients, upon who care providers act and deliver value. From a service perspective on healthcare, patients are collaborators who actively contribute to their own care, co-creating value with care providers and others. Despite the growing number of articles investigating healthcare from a service perspective, there have been limited attempts to understand how it should be translated and interpreted in relation to patient involvement and how service perspective and healthcare approaches to patient involvement can be combined. Service theory offers a number of analytical tools for understanding how patients create value. Therefore, this perspective, even if it should be applied with caution for the healthcare context, can provide valuable insights on how to understand patient involvement. This extends the view of patient involvement from decision-making and isolated encounters to patients being substantially involved in all aspects of healthcare.

1.3 Purpose and research questions

Patient involvement as a theoretical concept has not been extensively discussed (Thompson, 2007). By exploring an alternative approach to patient involvement, there may be a better understanding of broadly involving patients and other healthcare users in all stages and activities of healthcare. Based on this discussion, the overall purpose of the thesis is:

To contribute to increased knowledge and understanding of patient involvement from a service perspective

The purpose rests on the assumption that healthcare providers could benefit from understanding patient involvement from a service perspective in all stages and activities of healthcare. For this reason, this thesis has the following research questions:

RQ1: How are patients involved in the use of healthcare services and development?

Research relating to patient involvement stretches over various research fields and is difficult to summarize. Therefore, this research question aims to summarize the various ways patients are involved in executing and developing care and identifying potentials and shortcomings. This research question is mainly discussed in Chapter 2 and paper A, but is also empirically investigated in paper B and C.

RQ2: What are the implications of applying a service perspective on patient involvement?

As we acknowledge a more active and involved patient role, there is an alternate perspective for understanding and conceptualizing patient involvement. This research question aims to discuss the theoretical implications, including pros and cons, of applying a service perspective on patient involvement in all stages and activities of healthcare. Applying this perspective can provide valuable insights on how to understand patient involvement. The theoretical foundation for this is presented in Chapter 2 and continues in Chapter 6 by discussing similarities, differences, and the implications of cross-fertilization between service research and healthcare research on patient involvement.

1.4 Outline of this thesis

This thesis consists of one framework and three appended research papers. The framework's purpose is to deepen the discussion of the aim and purpose of patient involvement, present theoretical and empirical contributions from healthcare and service research, and identify research gaps in both fields. The framework consists of seven chapters that are summarized in Figure 1.

The initial chapter consists of a description of the research area and main subjects, presenting the purpose and research questions. Chapter 2 presents and discusses the research field of patient involvement from a healthcare perspective. This includes the concept of quality from a healthcare perspective, various research concepts related to patient involvement, and challenges in involving patient in healthcare use and development. It then summarizes the research gaps. Chapter 3 presents the theoretical foundation of this thesis with theory from service and marketing literature. This includes the service perspective, the concepts of value and value creation, and theories of customer involvement. It also explains the main differences between regular customers and patients, and considerations when transferring service theory to a healthcare context. Chapter 4 presents the chosen research strategy, process, method, and methodological considerations. It then discusses these topics in relationship to quality criteria. Chapter 5 summarizes the three appended papers in this thesis. They are presented with background, main objectives, findings, and contributions. Chapter 6 discusses the implications of applying a service perspective to patient involvement and healthcare and presents a theoretical framework for understanding patient involvement. It also presents the main conclusions and directions for further research

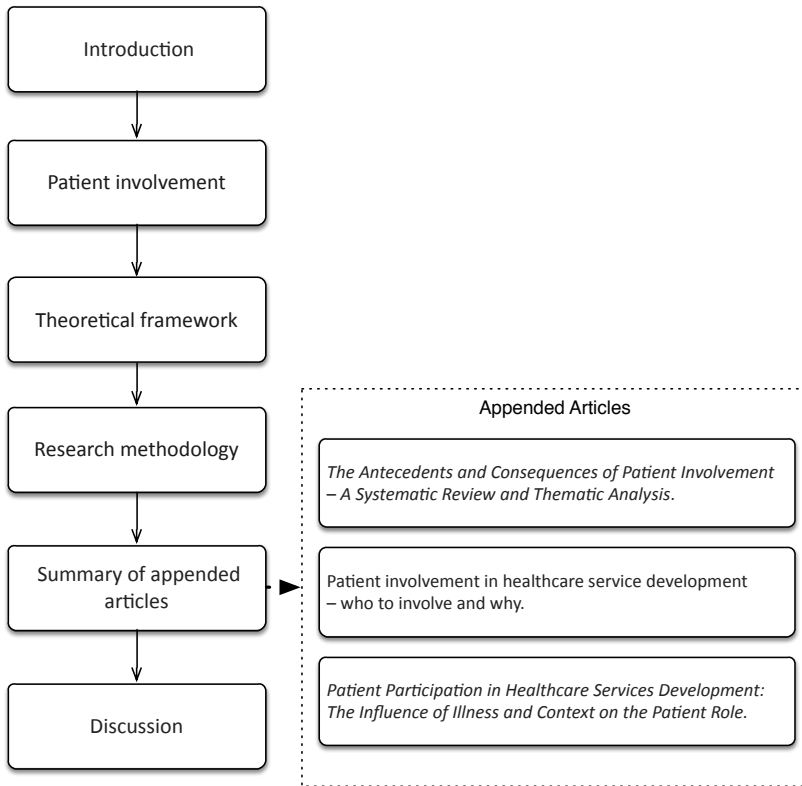


Figure 1 The structure of this thesis

2 Patient involvement

To understand how patients are involved in healthcare, this chapter presents and discusses research on quality, patient involvement, and related concepts from a healthcare research perspective. While parts of this chapter are based on findings in Paper A, this is a more detailed exploration of the interrelated concepts of patient involvement, including non-empirical articles and books excluded from the paper. First, the concepts of quality and value are discussed from a healthcare perspective, and then the different types of concepts used in the literature relating to patient involvement are presented and explained. Finally, challenges facing patient involvement and gaps in research are discussed.

2.1 Patient involvement as a key concept in quality improvement

The quality movement and ideas have spread widely during the last decades from manufacturing to service, healthcare, nonprofit organizations, and educational institutions (Cole and Scott, 2000). The concept of quality in healthcare is not new, and has become an increasingly important factor both for patients' well-being and economical survival (IoM, 2001). In the last decade, quality of care has become an important healthcare issue among authorities, policymakers, managers, physicians, and patients (Grol, 2001). This has manifested in a number of approaches, such as evidence-based medicine (EBM), total quality management (TQM), improvement science, professional development, and patient empowerment. Raven et al., (2012) argue that understanding good quality of care and how it can be measured is critical to improving health services.

Defining health and quality within healthcare are complex because of individual differences and the difficult relationship between health services and health outcomes (IoM, 1990). Quality in healthcare can also be seen as limiting the gap between actual or received care and expected care as stated by the Institute of Medicine (IoM) (1990, p.21), which defines quality in healthcare as *"the degree to which health services for individuals and populations increase the likelihood of desired health outcomes and are consistent with current professional practice."* Building on this definition, the IoM presented six characteristics of high-quality care (2001). These have been widely adopted by other organizations active in improving the quality of healthcare. High-quality care must be:

1. *Safe*: Avoiding injuries to patients from the care that is intended to help them
2. *Effective*: Providing services based on scientific knowledge to all who could benefit and refraining from providing services to those not likely to benefit (avoiding underuse and overuse)
3. *Patient-centered*: Providing care that is respectful of, and responsive to, individual patient preferences, needs, and values and ensuring that patient values guide all clinical decisions

4. *Timely*: Reducing waits and sometimes harmful delays for both those who receive and those who give care
5. *Efficient*: Avoiding waste, in particular waste of equipment, supplies, ideas, and energy.
6. *Equitable*: providing care that does not vary in quality because of personal characteristics such as gender, ethnicity, geographic location, and socioeconomic status.

Achieving major gains in these six dimensions would significantly improve healthcare, making it better at meeting patient needs, as they would experience care that was safer and more reliable, responsive, integrated and available (IoM, 2001). The traditional measuring of productivity, efficiency and quality in healthcare and the service sector is misleading, as it ignores customer contributions (Nordgren, 2009). However, the contribution and involvement of patients to provide high quality care is not ignored in healthcare as several researchers see the involvement of patients as essential to providing high quality care (e.g., Davies, 2005; Grol, 2001; Longtin et al., 2010). In the following, some of the concepts and aspects of patient involvement research are presented and discussed.

2.2 Patient involvement research

Patient involvement describes if and how patients (both as individuals and groups) are involved at different levels, stages, and activities of designing, developing, planning, and using healthcare. The importance of involving patients in planning and executing healthcare is gaining attention in research (Anderson and Funnell, 2005; Bodenheimer et al., 2002; Elg et al., 2012; Grol et al., 2002; Haigh, 2008; Longtin et al., 2010; Lorig et al., 2008; Thornton et al., 2003; Vincent and Coulter, 2002). Patient involvement is not a unified concept. Instead, research concerning patients is gaining attention in a range of interrelated concepts and activities, such as such patient-centered care, patient empowerment, self-management, shared decision-making, and patient participation. These concepts all rest on arguments that patient involvement results in better, safer and more efficient care (Greenhalgh et al., 2010; Grol et al., 2002; Vincent and Coulter, 2002). These concepts are closely related, and I will briefly present them in the following sections.

2.2.1 Patient-centered care

The concept of patient-centered care is widely used in healthcare (Mead and Bower, 2000; Stewart, 2001; Stewart et al., 2000) and is a cornerstone for many practitioners (Stewart et al., 2000). It is also one of the six characteristics of high-quality care, according to the IoM (2001). Broadly, patient-centered care encompasses compassion, empathy and openness to patients' needs, values and individual preferences. In contrast to a biomedical model that is technology-, doctor-, or disease-centered, patient-centered medicine encourages considerably greater patient involvement (Mead and Bower, 2000). However, similar to patient involvement, the definition and understanding of patient-centered care differs, depending on who is using it (Mead

and Bower, 2000; Stewart, 2001). Rather than being a specific method, patient-centered care is an approach or a perspective on healthcare.

Gerteis et al. (1993) highlights several important dimensions of patient-centered care, including respecting patients' values, needs, and preferences, the importance of coordinating care, informing and educating patients, showing emotional support, and involving family and friends. Involving family and friends refers to involving them in decision-making, supporting them as caregivers, and recognizing their needs and contributions. Stewart (2003) highlights six slightly different, interrelating components for patient-centered care: Exploring both the disease and the illness experience; understanding the whole person; finding common ground for partnership; incorporating prevention and health promotion; enhancing the doctor-patient relationship; and being realistic about personal limitations and issues such as availability of time and resources.

2.2.2 Patient empowerment

Patient empowerment has been defined as *“a social process of recognizing, promoting, and enhancing people’s abilities to meet their own needs, solve their own problems and mobilize the necessary resources in order to control their lives”* (Gibson 1991, p. 359). However, it can be described and analyzed at individual, organizational, or community levels (Tveiten and Knutsen, 2011). Patient empowerment is often discussed in relation to chronic or long-term diseases, such as diabetes (Anderson et al., 1995; Funnell et al., 1991) or cancer (Bulsara et al., 2004; Davison, 1997; Turton and Cooke, 2000). It is also described in relation to other areas, such as weight loss (Fox et al., 2005b; Leske et al., 2012). In chronic and long-term diseases, the responsibility for the day-to-day care falls heavily on patients and their families. By strengthening collaborative relationships, healthcare providers can help patients better handle decision-making and self-care (Von Korff et al., 1997).

The concept of patient empowerment builds on the notion that internal motivation is more effective than external motivation for changing lifestyle (Anderson and Funnell, 2005; Bodenheimer et al., 2002). Funnell et al., (1991) state that the goals for empowering patients are promoting autonomous behavior and maximizing individual potential. Patient empowerment is both a outcome and a process (Anderson and Funnell, 2010). The process is the discovery of the individual’s inherent capacity to be responsible and take control of their own life (Funnell et al., 1991). Patients should be encouraged to solve their own problems with information from professionals (Bodenheimer et al., 2002). Patient empowerment is associated with outcomes such as self-efficacy, sense of control, growth, improved health, and well-being (Gibson, 1991). An empowered patient takes greater care of their own health, which results in less pressure on the health system (Windrum and García-Goñi, 2008). Relating to medical consultations, Ouschan et al. (2000) propose three dimensions of patient empowerment regarding different domains:

1. Patient control over illness management (patient domain)
2. Patient participation during the patient-physician encounter (interaction

domain)

3. Patient education/support received from the physician (physician domain)

Patient empowerment not only requires patients' perceptions and behaviors but also requires providers to educate and activate patients (Ouschan et al., 2006).

2.2.3 Self-management

Self-management is a common term in health education (Lorig and Holman, 2003), often used in regard to chronic diseases (Bodenheimer et al., 2002; Lorig and Holman, 2003; Northern, 2001). Lorig and Holman (2003) argue that it is impossible for patients not to self manage diseases. Even if patients do not engage, this decision reflects a management style. Whether a patient is engaging in preventive health activities such as exercise or diets, or living with chronic diseases such as asthma, the individual is responsible for every-day management. Furthermore, the issue of self-management is especially important to patients with chronic diseases where self-management is a lifetime task.

Barlow et al. (2002) discuss that self-management may be one way to bridge the gap between patients' needs and the capacity of healthcare services to meet those needs. They define self-management as: *"The individual's ability to manage the symptoms, treatment, physical and psychosocial consequences and life style changes inherent in living with a chronic condition. Efficacious self-management encompasses ability to monitor one's condition and to affect the cognitive, behavioral and emotional responses necessary to maintain a satisfactory quality of life. Thus, a dynamic and continuous process of self-regulation is established."*

Core patient self-management skills include problem-solving, decision-making, resource utilization, forming patient/healthcare provider partnerships, and taking action (Lorig and Holman, 2003).

2.2.4 Shared decision-making

Shared decision-making (SDM) is promoted as an ideal model for treatment decision-making (Charles et al., 1997; Saba et al., 2006). Even if not well-defined, the key principle of SDM is a process that involves at least two participants (the patient and the physician), and often more (including family or professional colleagues) (Charles et al., 1997). Research suggests that most patients want to be involved in medical decision-making and know about treatment alternatives (Guadagnoli and Ward, 1998). However, individual vary in the extent to which they want to participate (Murray et al., 2007a; Schneider et al., 2006). Therefore, patients should exercise the degree of control they wish. In some cases, patients want a large role, yet in other cases, they may delegate most decisions to a clinician. However, patients' rights to be informed and participate in decision-making is well accepted, but not always well implemented (Murray et al., 2007b; Stevenson, 2003).

Towle and Godolphin (1999) developed a set of competencies for physicians and patients to engage in SDM, stating that professionals should:

1. Develop a partnership with the patient
2. Establish or review the patient's preferences for information (such as amount or format)
3. Establish or review the patient's preferences for role in decision-making (such as risk-taking and degree of involvement for self and others)
4. Ascertain and respond to patient's ideas, concerns, and expectations (such as about disease-management options)
5. Identify choices (including ideas and information the patient might have) and evaluate the research evidence in relation to the individual patient
6. Present (or direct patients to) evidence, taking into account competencies 2 and 3, and framing effects (how presentation of the information may influence decision-making). Help patients reflect on, and assess the effect of decisions with regard to values and lifestyle
7. Make or negotiate a decision in partnership with the patient and resolve conflict
8. Agree on an action plan and complete arrangements for follow-up.

Additional steps can involve other health professionals and form a team around the patients, and including family members and others. However, this can differ depending on culture, social status, and age groups. Towle and Godolphin (1999) acknowledge that the patient also must be competent to engage in SDM, such as defining a preferred role in decision-making, engaging in partnership with physicians, articulating health problems and expectations, communicating, accessing and evaluating information, and negotiating and agreeing on action plan. Therefore, SDM is a mutual process, in which both patients and professionals must be active and involved.

2.3 Challenges with patient involvement

There are an extensive number of concerns and challenges to overcome in the area of patient-involvement research. In the following, I discuss some of these challenges.

2.3.1 Attitudes towards patient involvement

One challenge facing patient involvement is the sometimes conflicting needs and preferences for involvement between patients and professionals. Healthcare professionals' attitudes and feelings toward involving patients are important factors to patient involvement, as they influence patient behavior and facilitate involvement (Carlsen and Aakvik, 2006; Singh et al., 2010). Greenhalgh et al. (2010) state that one of the major obstacles to involving patients lies in hierarchical power structures and professional barriers in institutional practices in healthcare. Tveiten and Knutsen (2011) show that even though professionals acknowledge the potential value of participation, they still prefer to see patients as passive recipients of care. This is also a problem in relation to decision-making, in which several studies show that even if practitioners agreed to patient involvement in decision-making, they did not

implement this in practice (Carlsen and Aakvik, 2006; Stevenson, 2003; Watson et al., 2008).

A number of articles address the question of patients' and healthcare professionals' attitudes and preferences toward patient involvement (Braddock III CH, 1999; Hawley et al., 2007; Jahng et al., 2005; Keating et al., 2002; Thornton et al., 2003), especially in relation to decision making. Individual preferences for involvement in healthcare services varies among patients and professionals (Benbassat et al., 1998; Jahng et al., 2005; Kiesler and Auerbach, 2006; Little et al., 2001; Morecroft et al., 2006). For development, patients' wishes to be involved can depend on availability, interest in the topic, time commitment, and skills patients' feel they can contribute (Greenhalgh et al., 2010). In healthcare use, patient preferences and attitudes about involvement relate to personal factors, such as age and socioeconomic status (McKinstry, 2000; Murray et al., 2007a), as well as attitudes and behaviors from healthcare professionals (Timmermans et al., 2006) and knowledge about their own illness (Ramfelt and Lützén, 2005). Therefore, the degree of involvement must be customized to fit the individual patient. Individualized care does not need to be synonymous with active patient involvement as not all patients wish to be active (Waterworth and Luker, 1990).

2.3.2 Preparation for involvement

Preparing and enabling patients for involvement is important (Greenhalgh et al., 2010). In research, this is discussed as concepts such as patient education and patient empowerment. Even if these concepts are closely related, they are divided into different research streams. The goal of patient empowerment is to make patients more active and able to manage their illness. Patient education regarding disease and treatment is an important part of this, as it plays a key role in enabling involvement in decision-making and participating in care (Gallefoss and Bakke, 2000; Street Jr. et al., 2009).

Healthcare professionals must also learn to involve patients, as lack of training and education can be a barrier for implementation (Körner et al., 2012; Légaré et al., 2008). Through training in specific techniques for patient involvement and improving communication skills, healthcare professionals can enable patients and support them in use and development of healthcare (Timmermans et al., 2006). In addition, it is important to build organizational systems that support the process of involvement. This can be in the form of IT systems, education programs, and alternative ways of organizing care that allow for patient involvement at different levels (Cottam and Leadbeater, 2004). On a higher level, another challenge is how to organize and fit patient involvement activities in the existing healthcare system.

2.4 Gaps in healthcare research of patient involvement

The subject of patient involvement is gaining increased attention in a large number of publications in several fields of healthcare research. Analyzing the research, a large variety of forms of patient involvement are discussed and empirically tested in

relation to different areas of healthcare. This includes involvement in decision-making, medical consultations, and self-care activities. An important stream of research covers subjects that prepare patients and professionals for involvement, such as empowering, educating, and preparing patients and professionals.

Although the research is promising, few articles treat patient involvement across illnesses, and authors rarely discuss generalizability. There is also a lack of articles focused on patient involvement in developing, planning, and designing care. A large portion of research focuses on specific areas or situations in healthcare (such as consultations or decision-making) and relates to chronic diseases, especially cancer and diabetes. There is a lack of studies that examine patient involvement on both theoretical and applied levels as to how and when to involve patients, and the outcomes of involvement on the health-care system.

3 Theoretical framework

The following chapter aims to present and discuss the theoretical foundation and assumptions that underlie this thesis. The theoretical framework consists of theory originating foremost from service marketing and innovation research. Other theoretical starting points, such as quality management or organizational theory might also be relevant. However, service marketing research offers substantial theoretical groundwork for the customers' potential in creating value and developing service, which is central to the aim of this thesis. In this chapter I present and discuss the underlying logic of service research and service management, moving on to different aspects of value creation. I then discuss the rationale for involving customers, specific methods for involvement, and related issues such as degree of involvement and which customers to involve. Finally I consider the potential and limitations of using these theories as a starting point for research on patient involvement.

In this thesis I refer to service as a mindset, rather than a category or activity. It is defined as the *“application of specialized competences (knowledge and skills) through deeds, processes, and performances for the benefit of another entity or the entity itself”* (Vargo and Lusch, 2004 p.2). Service science is the study of service systems and the co-creation of value within constellations of integrated resources (Spohrer et al., 2007).

3.1 A service perspective

Service can be seen as a category of market offerings, but also as a perspective on value creation, rather than a specific activity (Edvardsson et al., 2005). Traditionally, mainstream-marketing research considered service as an addition to products. Development of service-oriented concepts and models began in the 1970s (Grönroos, 2006). In goods or manufacturing business logic, resources are provided to the customer for a defined purpose to support that specific process (Grönroos, 2006; Ng and Smith, 2012; Raval and Grönroos, 1996). The provider adds value to an offering and the customer's value is equivalent to the monetary exchange value, or value-in-exchange (Grönroos, 2006; Vargo and Lusch, 2004). In goods-logic marketing models, the customer has the responsibility to effectively use resources and consume value, but does not provide any means to enter the consumption process in an interactive way (Grönroos, 2006; Prahalad and Ramaswamy, 2004). This tradition is also present in healthcare, which has a history of applying goods-logic models, where value is something that is delivered by the healthcare supplier in production to the patient (Elg et al., 2012; Nordgren, 2011, 2009).

However, the goods-logic perspective has been criticized (see e.g. Grönroos, 2006; Ng and Smith, 2012; Vargo and Lusch, 2004). Vargo and Lusch (2004) argue that marketing theories for goods and services should not be separated. Instead, the whole economy should be seen as a service economy. They introduce and refined 10

foundational premises of S-D logic (Table 1), which intensified ongoing debates of goods-based logic versus service-based logic (Vargo and Lusch, 2008, 2004). Service logic (e.g., Grönroos, 2008, 2006), or service-dominant (S-D) logic (Vargo and Lusch, 2008, 2004) emphasizes the relativistic, context-dependent value that customers create as value-in-use (Grönroos, 2006; Lusch and Vargo, 2006; Vargo and Lusch, 2004). One way to illustrate and operationalize the difference between goods logic and service logic is the concept of operand and operant resources. Constantin and Lusch (1994) separate operand resources, which are resources upon which an operation or act is performed (mostly physical), from operant resources, which act on operand resources. Applying goods logic to healthcare, a patient would be an operand resource, to which the service provider does things.

Table 1 Foundational premises of S-D logic (Vargo and Lusch, 2008)

Premise number	Foundational premise
FP1	Service is the fundamental basis of exchange
FP2	Indirect exchange masks the fundamental basis of exchange
FP3	Goods are a distribution mechanism for service provision Operant resources are the fundamental source of competitive advantage
FP4	
FP5	All economies are service economies
FP6	The customer is always a co-creator of value The enterprise cannot deliver value, but only offer value propositions
FP7	A service-centered view is inherently customer oriented and relational
FP8	
FP9	All social and economic actors are resource integrators. Value is always uniquely and phenomenological determined by the beneficiary
FP10	

The concept of value has been debated for the last 2,000 years and has been given a variety of meanings. Holbrook (2002, p. 5) defines value as “*interactive, relativistic preference experience*,” In this sense, value is not a possession, object, or product, but instead is an interactive experience. Traditionally, creating customer value focused on satisfying customer needs, often through manufacturing products (Smith et al., 2014). In contrast, the service view of value is customer-centric and market-driven (Grönroos, 2006; Vargo and Lusch, 2004). This stretches beyond being customer-oriented and identifying customer needs to actively collaborating with, and learning from, customers to adapt to their individual needs (Vargo and Lusch, 2004). According to the service perspective of value in use, value emerges in the customer context during usage (Grönroos, 2011; Normann and Ramirez, 1993; Vargo and Lusch, 2004). Vargo and Lusch (2004 p. 6) argue that a “*service-centered dominant logic implies that value is defined by and co-created with the consumer rather than embedded in output* ” Therefore, the term *value-in-use* is more relevant than the

traditional *value-in-exchange* (Edvardsson et al., 2005; Vargo and Lusch, 2004).

Following a S-D logic, a firm cannot satisfy its customers, but can only offer value propositions and collaboratively support value co-creation (Smith et al., 2014). Translating this into healthcare, the patient is an operant resource, that is, an active contributor who not just consumes, but co-creates value. This means that value is not created or realized until patient uses or benefits from the provided service (Nordgren, 2009). The following section discusses the concept of value creation more in detail.

3.1.1 Value creation

The customer as an active contributor who co-creates value with providers and others is a well-known concept (Grönroos, 2006; Gustafsson et al., 2012; Lusch and Vargo, 2006; Ravald and Grönroos, 1996; Vargo and Lusch, 2004; Witell et al., 2011). There are some differences in how the concept of value-creation is interpreted and used, and it is possible to view value from a number of perspectives (Payne et al., 2008). These perspectives are somewhat contradictory, but also complement and highlight different aspects of value creation. Vargo and Lusch (2004) separate the concepts of co-production and value co-creation. The former refers to customer involvement in the development and creation of the company's offerings (patients helping healthcare providers design cancer treatment). Value co-creation is the realization of the offering (patients using healthcare services) (Ng and Smith, 2012). While customers always co-create value, they do not always co-produce the firm's offerings. However, co-production is as an important component of co-creation (Lusch and Vargo, 2006). In this thesis value co-creation is defined in line with McColl-Kennedy et al. (2012 p. 6) as "*a multiparty all-encompassing process with the focal firm and potentially other market-facing and public sources and private sources as well as customer activities.*"

Value creation as a process

Grönroos (2011 p. 282) defines value creation as "*a process through which the user becomes better of in some aspect.*" Grönroos and Ravald (2011) suggest the process should be divided into different parts. For the customer, the process consists of one open and one closed part. In the open part, the provider can create value with the customer. In the closed part, the customer is a sole creator of value. Similarly the provider's value-creation process has an open part, where providers and customers can interact, and a closed part, where the provider facilitates value for the customer. Grönroos (2011 p. 282) states: "*The total company process that leads to value-in-use for customers is needed to enable value creation, but all parts of it are not part of value creation for the customer.*"

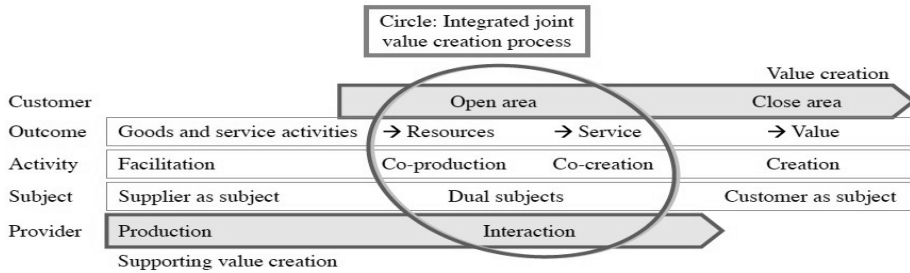


Figure 2 A model for understanding the value-creation process (Grönroos and Ravald, 2011)
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This model can be useful to understand the process of value creation, but it does not include and acknowledge recourses outside the provider and customer spheres.

Value constellations

Normann and Ramirez (1993) discuss the idea of value constellations, arguing that value should be analyzed as a value-creating system. Customers can engage in value-creation activities and interactions, integrating recourses from not only the local firm or a specific organization, but also other service providers or firms (Grönroos, 2008; Lusch and Vargo, 2006; McColl-Kennedy et al., 2012). The customer can also create value with private resources such as family, friends or other customers, or use customers-specific skills and personal knowledge that affect the value-creation process (McColl-Kennedy et al., 2012).

McColl-Kennedy et al. (2012) argue that customers may co-create value by integrating resources from the service provider and others, without traditional healthcare settings. Examples of this include complementary therapies and private sources such as family and self-activities. The benefits of receiving treatment and using healthcare services represent value in use, but the total value depends on integrating other recourses, such as family support, and motivation to comply with treatment and engage in activities that positively influence health. This can be described as value in context, which implies that value depends on integrating other resources, so must be defined as assessed in accordance to context (Vargo et al., 2008). Payne and Holt (2001) suggest that value is not an individual transaction but is instead created over time and influenced by changes and external influence.

Value creation as an experience

Value creation can also be a individual phenomenological experience for the customer (Helkkula, 2010; Helkkula et al., 2012; Holbrook, 2002; Prahalad and Ramaswamy, 2004). Prahalad and Ramaswamy (2004) suggest that that a service experience is individual, personalized, and social. A customer will experience interaction with a provider in an individual way, but at the same time, the customer is part of a social network that influences that experience (Helkkula et al., 2012). Ford and Dickson (2012) suggest that customers vary in their capability to co-create service experiences, depending on knowledge, skills, and abilities. S-D logic adopts and develops this view (Vargo and Lusch, 2004,2008) in the foundations of the concept of value. However,

not all co-creation experiences are positive for the customer, and interaction with providers may be perceived negatively (Prahalad and Ramaswamy, 2004).

Co-creation practice styles

McColl-Kennedy et al. (2012) highlight the activities and interactions of co-creation, suggesting that different healthcare customers have different co-creation styles. Their typology is based on the different perceptions of the customer’s role in relationship to levels of activities (low to high) and the number of interactions with different individuals in the firm, other market-facing and public sources, private sources, and self-generated activities in the service network (low to high) (Figure 3). Based on a qualitative study of cancer patients involving four focus groups and 20 in-depth interviews, the authors identify five value co-creation practice styles for healthcare customers: Passive compliance, pragmatic adapting, partnering, insular controlling, and team management (McColl-Kennedy et al., 2012).

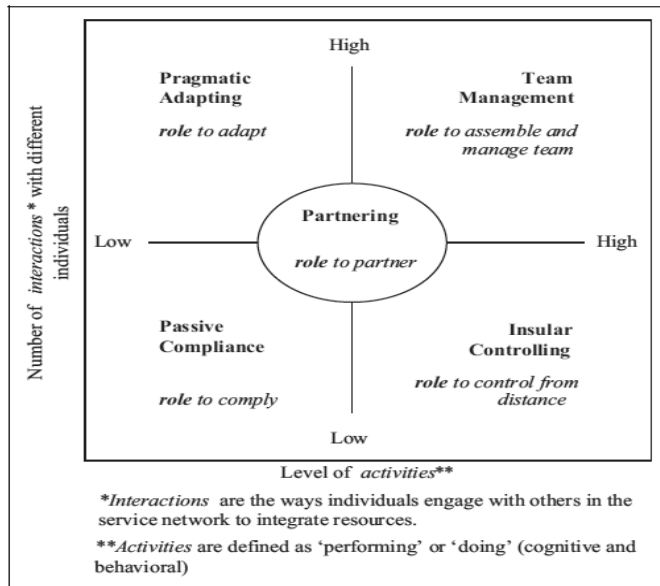


Figure 3 Customer value co-creation practice styles (McColl-Kennedy et al., 2012). Reprinted with permission of SAGE Publications © 2012

Linked to each style, eight broad themes of activities are identified. These are connected to behavioral activities, such as cooperating; collating information; combining complementary therapies; co-learning; connecting with family, friends, doctors, other health professionals, and support groups; changing ways of doing things; co-production; and positive thinking. This theory suggests that different patient types have different co-creation practice styles and should be supported in different ways, depending on how they create value.

Limitations of interactive approaches to value creation

There are some limitations to these interactive views of value creation. Echeverri and Skålen (2011) mention two in particular. First, value-creation frameworks built on

interaction are not usually based on systematic empirical research but conceptualize or draw on empirical illustrations. Therefore, there is a knowledge gap in how these value formations take place in practice. The second limitation is the lack of research discussing negative aspects of interactive value formation. Echeverri and Skålen (2011) introduce the concept of co-destruction of value, which refers to the collaborative destruction of value between providers and customers. This includes interaction that customers perceive negatively.

The following section discusses the rationale of customer involvement is discussed, as well as approaches and methods for involvement and different issues such as degree of involvement and which customers to involve.

3.2 Customer involvement

Customer involvement in service and innovation literature broadly refers to the *“processes, deeds and interactions where a service provider collaborates with current (or potential) customers to learn about the market and alter organizational behavior”* (Matthing et al., 2004, p. 487). The concept of involvement in the development and innovation process gained attention in the context of new service-development research (Alam and Perry, 2002; Alam, 2006; Carbonell et al., 2009; Papastathopoulou and Hultink, 2012; Witell et al., 2011). Customer involvement in development activities relies on a number of closely related concepts, such as co-development (Chesbrough and Schwartz, 2007; Deck and Strom, 2002; Edvardsson et al., 2010), user involvement (Alam, 2002; Barki and Hartwick, 1989; Ives and Olson, 1984; Magnusson et al., 2003), customer interaction (Alam, 2006; Gruner and Homburg, 2000), customer participation (Bendapudi and Leone, 2003; Kelley et al., 1990), lead-user methodology (Oliveira and von Hippel, 2011; von Hippel, 1986), and user innovation (Morrison et al., 2000; von Hippel, 2005).

Customers can be involved in the development or innovation of the providers' offerings, but they also use the service. Witell et al. (2011) introduce the concept of co-creation for others as *“activities in which customers actively participate in the early phases of the development process by contributing information about their own needs and/or suggesting ideas for future services that they would value being able to use.”* (Witell et al., 2011, p. 143). They extend co-creation to include activities during the innovation and consumption processes. Co-creation for others entails that customers create ideas and detect value in context. In parallel, customers engage in behaviors that were previously viewed as provider activities, creating value for themselves by for instance booking holiday trips online or scheduling doctors appointments online (Moeller et al., 2013). In healthcare, health information sites and forums allow users to perform self-diagnosis, develop treatment plans, find information, and get advice online. Rather than depending on the service provider, customers can access information and perform the service themselves.

3.2.1 A rationale for customer involvement

Following S-D logic (Vargo and Lusch, 2004), user involvement is essential for service development. Organizations may not always know or understand which products or services satisfy customers wants and needs, leading to high-quality services (Parasuraman et al., 1985). Misunderstandings can waste resources such as time, effort and money. Incentives for involving customers in development are promising. In innovation research, an important research stream concerns innovation that comes from customers rather than development departments (Edvardsson et al., 2012).

Ives and Olson (1984) find that involving customers improves system quality by providing more accurate lists of user requirement. In more recent literature, Alam and Perry (2002) identify several gains for involving customers in new service development, including improved customer relationships and better matching and understanding of customer's wants and needs. Carbonell et al. (2009) also find that customer involvement has a positive direct effect on technical quality and innovation speed. Furthermore, including customers in the development process may produce more innovative ideas than traditional market techniques (Magnusson et al., 2003; Witell et al., 2011).

Involving customers in the creation process increases the likelihood of new product success (von Hippel, 2001). A number of studies in industrial settings have shown that a high percentage of successful innovations was invented by users (Churchill et al., 2009). Von Hippel (2005) argues that user-centered innovation processes offer advantages over manufacturing-centric innovation development processes. Users can develop exactly what they want, rather than relying on manufacturers as their agents. Von Hippel (1994) introduces the concept of sticky information. Basic information and problem-solving capabilities must be brought together at a single locus to solve a problem. For a firm to innovate, identifying with customers needs is crucial, but this kind of information is expensive to acquire, and hard to transfer and use in a new location. Likewise, professional developers can be strongly blocked and limited by expertise and previous experience (Kristensson et al., 2003; von Hippel, 1986). Customers may be more open to novel solutions and usages (Kristensson et al., 2003). However, the concept still needs to be more grounded and defined in theory (Kristensson et al., 2008).

3.2.2 Methods for customer involvement

User-centered innovation processes differ from traditional manufacturing-centric models, in which users' only role is to have needs that the firm tries to identify and fill by developing new products or services (von Hippel, 2005). The concept of customer involvement stretches beyond traditional marketing techniques, such as just simply asking customers what they want. A practical involvement strategy is proposed to extract nonverbal latent needs (Magnusson et al., 2003; Matthing et al., 2004). Customers can be involved in all stages of development processes (Alam, 2002; Coviello and Joseph, 2012). This can include strategic planning, idea generation, idea

screening, business analysis, personnel training, testing, and commercialization (Alam, 2002).

Based on empirical findings Sandström et al. (2008) make seven research propositions as key strategies for user-involvement projects:

1. Users identifying needs in their own setting of use
2. Users identifying needs in their various roles
3. Providing users with analytical tools
4. Motivating users via the apparent benefit to be gained from their involvement
5. Non-reliance on brainstorming when generating ideas
6. Users not having too much knowledge of technology
7. Involving a heterogeneous group of users to ensure that a diversity of ideas is provided for future services

3.2.3 Degree of involvement

Customers can take several different roles in both use and development depending on the degree of their involvement (e.g., Alam, 2002; Bendapudi and Leone, 2003; Bettencourt, 1997; Bitner et al., 1997; Blazevic et al., 2003; Witell et al., 2011).

Sharing information between provider and customer happens in multiple encounters (Payne et al., 2008). The customer's role can be measured through interaction with the supplier. Hipp and Grupp (2005) suggest that the greatest amount of interaction with customers occurs when supervised by the provider and customers are physically present in service use. Bitner et al. (1997) describes different degrees of participation, from minimal where consumers are only present and the service provider does all the production work (low level of participation) to cases where consumer input, in the form of information, effort, or physical possessions, is required for the provider to create the service (moderate level of participation). In some cases, consumers have high levels of interaction where they have essential production roles that will affect the nature of the service outcome if they are not fulfilled.

Blazevic and Lievens (2008) make a distinction between passive users, active informers, and bi-directional creators in development, in which active informers give feedback for the supplier. Bi-directional creators take actively part in the development. Alam (2002) suggests a customer involvement continuum for development: Passive acquisition of input, where the customer provide input through ideas or solutions, information and feedback on a specific issue; developers approach the customer to gain information on a specific issue; extensive consultations with customers through focus groups or interviews with specific and predetermined objectives; and representation, where customers join the development team. Ives and Olson's (1984) descriptive model for user involvement separates involvement roles (participants, role set) from user involvement (type and degree of involvement). They also present a typology for understanding involvement:

1. No involvement: Customers are not invited to participate
2. Symbolic involvement: Customers' input is requested but ignored

3. Involvement by advice: Passive involvement in the form of interviews or surveys
4. Involvement by weak control
5. Involvement by doing: A customer can join the development team
6. Involvement by strong control: Customers can pay directly for new development output

Sandén (2007) develops this further by linking the degree of involvement to the view of the customer, ranging from passive buyer to active developer.

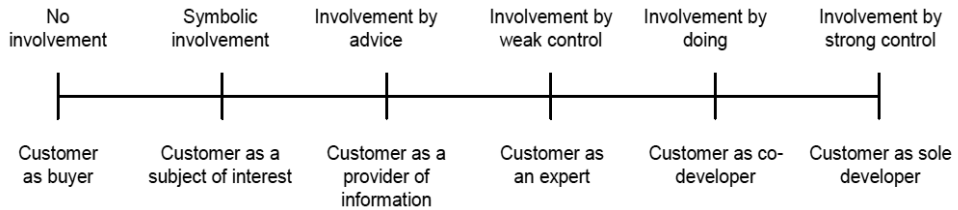


Figure 4 The customer involvement continuum by Sandén (2007) building on Ives and Ohlson (1984)

Different degrees of customer involvement depend on the aims and type of development project.

3.2.4 What customers to involve?

Different kind of users can be valuable in a development or innovation project, depending on the goal. Greenhalgh et al. (2004) argue that all users seek advances and are not simply passive recipients of innovation. They seek, modify, evaluate, and experiment and, find meaning with innovations to fit a particular task. They also try to improve or redesign innovations, often in dialogue with other users. All users can contribute to improvement and innovation, but some do so to a greater extent.

Von Hippel (1986) introduced the lead-user method. This is a proactive marketing method that aims to understand future customer needs by investigating users who have current needs that will exist in the future for most customers (von Hippel, 1986). Two characteristics identify a lead user (von Hippel, 1986). First, lead users face current needs that will be general in the marketplace in the future. Second, lead users significantly benefit from obtaining a solution to those needs. These users will typically attempt to address their needs and come up with solutions and innovations to solve these problems (von Hippel, 1986).

3.3 Applying a service perspective on patient involvement

The customer role has changed over the years. This is an on-going process in healthcare, where patients and other healthcare users actively involve in care, seek information, make informed choices, and co-create value (McColl-Kennedy et al., 2012; Nordgren, 2009). Examples from healthcare include approaches to self

management (Cradock, 2004; Lorig et al., 2001), patient education (Barlow and Barefoot, 1996), and patient-physician partnerships (Saba et al., 2006; Soto et al., 2007).

Berry and Bendapudi (2007) conclude that healthcare is a promising area for service research. Using service theory and customer involvement theory offers a conceptual framework for understanding patient involvement and practical tools and approaches that can be applied in practice. However, translating management concepts and theories to other contexts should be done with caution. The challenges and prerequisites in healthcare are different from those in manufacturing and other services industries. There are a number of context-specific conditions that must be carefully investigated and taken into account.

Due to a unique combination of high risks and high costs, healthcare is highly politicized and subject to extensive government regulation (Bower, 2003). Institutional practices, hierarchical power structures, and professional barriers also play a significant role in how patients can be involved (Greenhalgh et al., 2010). There are other differences from traditional services. Healthcare is a complex service sector, as it includes healthcare service providers, funders (public and private), and consumers, and is also closely related to other sectors, such as pharmaceutical and medical equipment suppliers (Saritas and Keenan, 2004).

Berry and Bendapudi (2007) state that healthcare services are one of the most important personal services that people consume. Despite commonalities with other services, departing from service theory when designing healthcare and facilitating patient involvement requires considering some context-specific requirements. The healthcare sector consists of both private and public actors. Alford (2002) states that in the private sector, customers can provide money in the amount of the purchase price in return for the goods or service provided by the firm. This exchange is direct. The customer has a range of competitive providers of the good or service from which to choose, and they wish to consume the good or service. As long as the provider makes a profit from each transaction, it seeks to maximize sales, either by increasing the number of customers or making more business with the same customer. In the public sector, such as most healthcare services, a customer focus based on economic exchange is not useful, as the individual customer pays (depending on country) a symbolic price for the service (Alford, 2002). Moreover, the customers cannot choose which healthcare treatments they want.

Traditionally patients have been viewed as weak, exposed, and dependent (Berry and Bendapudi, 2007), and bringing nothing to the table despite their illness (Bodenheimer et al., 2002). Berry and Bendapudi (2007) conclude that patients, unlike regular customers, are usually ill and under stress. Such circumstances can cause patients to be more emotional, demanding, and dependent than regular customers. Patients also perceive themselves to be at a disadvantage in knowledge and expertise (Berry and Bendapudi, 2007; Bodenheimer et al., 2002). Furthermore, they are not in control and cannot come and go as they like. They may be required to discuss personal issues to

receive care, which they are not likely to discuss with other service providers (Berry and Bendapudi, 2007; Crié and Chebat, 2013). Health systems can also be unsafe, and patients are at certain risk of being harmed when receiving care (Grol et al., 2002). Therefore, becoming an active collaborator can be problematic for the patient. Moreover, there are other customers than the patient who must be taken into consideration, such as family members, policy-makers, and citizens. This provides a unique challenge for healthcare service providers, as well as researchers seeking to involve patients. Therefore, it is important to explore and investigate if the theoretical propositions in service research can be translated into the healthcare context, and the implication of doing so.

4 Research approach

This chapter describes the research approach used in this thesis. First, I describe the background to the research and overall methodological considerations. I then move on to explain the research process and discuss quality criteria and methodological considerations related to both the literature review and empirical articles.

4.1 Background

During my time as a doctoral candidate, I was part of a Vinnova-funded research project called Service Innovations in Healthcare and HELIX Vinn Excellence Center. This is a joint collaboration between Helix, Linköping University, and Jönköping Academy. The project's aim is to contribute to increased knowledge of the prerequisites for successfully involving patients in development of healthcare services, how healthcare activities can be organized to facilitate and support such development, and development and dissemination of models of healthcare service innovations.

As the overall focus of my study was patient involvement, I read and studied theories of quality related to customer focus and customer involvement. Theories of value creation and customer involvement are closely related to quality, but unexplored in the field of healthcare. I found it promising to explore these theories as a starting point for developing research design and research questions.

4.2 Methodological considerations

Malterud (2001a) stresses that a broad base of medical and scientific knowledge is needed if medicine is to remain a research field founded on scientific knowledge. Traditionally, healthcare as a research field was a scientific discipline based on biomedical methods that were controlled, measured, counted, and analyzed by statistical methods (Malterud, 2001b). However, this is beginning to change, and other types of methods are gaining acceptance.

Alvesson and Sandberg (2012) explain that research in the social science takes different forms and has different objectives. For example, a researcher can aim to explain, predict, understand, describe, or investigate. Despite the different objectives and research styles, there is a broad consensus of the importance of generating interesting, original, significant theoretical contributions (Alvesson and Sandberg, 2012). My choice of theoretical framework is somewhat challenging, as it departs from traditional assumptions on patient involvement and healthcare in general at several points.

Epistemological issues in social science concern accepted knowledge in a discipline (Bryman and Bell, 2007). Bryman (2001) makes a division between qualitative and

quantitative research strategies. The quantitative approach relies on an objective view of science, in which research should be free from values. Research should be based on observations to capture reality, and the role of science is to test theories and provide material for the development of laws. The quantitative strategy usually relies on a deductive approach, in which the purpose of theory is to generate hypotheses that can be tested to allow for explanations and knowledge (Bryman and Bell, 2007). It is a strategy for collecting numerical data and emphasizes quantification of both data collection and analysis. The qualitative approach involves words rather than numbers. It typically has an inductive approach, in which the research process starts with the study subject or phenomena to generate theory (Alvesson and Sköldböck, 2009). A qualitative approach emphasizes how individuals interpret their social worlds and acknowledges that the social reality is constantly shifting.

Although these approaches are competing views on generating knowledge, the differences often can be just tendencies, rather than distinct divisions (Bryman and Bell, 2007) and can be seen as complementary (Malterud, 2001a). Both qualitative and quantitative research strategies and methods for data collection and analysis are suitable, depending on which kind of knowledge needs to be generated.

The research in this study contains both qualitative and quantitative elements in design and methods for data collection and analysis. The analysis and synthesis of Paper A used a thematic analysis method, which is a qualitative method used to identify patterns from the literature and describe the various facets of the studied subject (Braun and Clarke, 2006). In Paper B and C, a qualitative approach was applied using a diary-based method for collecting data. In paper B, the analysis was done using quantitative coding and rating processes. In Paper C, data analysis was done using statistical regression. This will be further discussed in accordance to each paper.

4.3 Research process

I entered the project a few years after it began and started with an extensive literature review of the field of patient involvement and was simultaneously involved in a research project involving patient diaries. Figure 5 illustrated the main process and activities preceding my research. The literature review was based on nursing and medical research on different subjects relating to patient involvement, which gave me a useful introduction to the field.

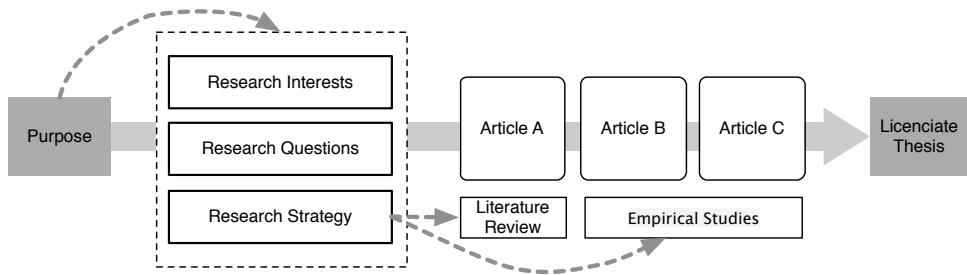


Figure 5 Illustration of the research process

My participation in the project, discussions, literature review, and theoretical knowledge yielded insights for formulating research aims and questions. After defining a broad framework for my research, I figured out a proper research approach. Since my first aim was to grasp the phenomenon of patient involvement, I chose a quantitative thematic analysis method to analyze the articles in the literature review. This gave me an overview and a detailed understanding for the field of research and connected subfields and subject areas. The empirical data for this study (patient diaries) was collected before I started this project, so I had no influence over the considerations regarding subjects, selection, and diary design. I compiled and coded the empirical data and decided on methods for analysis. In the empirical studies, I use a quantitative analysis to systematically investigate certain ideas and dimensions of patient involvement formulated from the review and previous knowledge. This included statistical and quantitative content analysis.

4.4 Reflections on the research process

This thesis is based on studies by different constellations and according to different research traditions (for overview, see table 2). A research design represents a logical set of statements so the study can be judged according to certain quality criteria (Yin, 2009). This section contains some reflections concerning the quality of the research. Reliability, internal and external validity, and secondary data are first presented and then discussed in relation to each article. Validity and reliability are interconnected such that that if measures and constructs are not reliable, the method is not valid.

4.4.1 Reliability

Reliability refers to the consistency of the measure of a concept (Bryman and Bell, 2007). The role of reliability is to reduce errors and bias (Yin, 2009). Reliability can be divided into external and internal categories. Reliability is the means by which a study can be replicated. If a study is repeated following the exact same procedure, the results should be the same (Yin, 2009). This is more difficult to assess for qualitative studies, since the same conditions almost never can be fully duplicated, so results can turn out differently (Bryman and Bell, 2007). Internal reliability refers to the means by which observers (if there is more than one) agree on the observation (Bryman and Bell, 2007).

4.4.2 Validity

Internal validity refers to the degree to which the results of the study match reality. In other words, it examines if the researcher studied what was intended (Bryman and Bell, 2007). This quality criteria applies when the researcher seeks to establish casual relationships and some conditions are believed to lead to other conditions (Yin, 2009). Lack of internal validity proposes that there are alternative explanations for relationships between two variables (Bryman and Bell, 2007). External validity concerns the degree to which the results of a study can be generalized beyond the context in which the research was conducted (Bryman and Bell, 2007). Can the findings be transferred across time and to other populations? The next sections discuss the appended articles in relation to these quality criteria.

4.4.3 Methodological considerations: Paper A

A systematic literature review explored and described patient involvement and how patients are involved in healthcare. Literature reviews are suitable when creating and building bodies of knowledge and synthesizing research (Tranfield et al., 2003).

We used a systematic review methodology to identify relevant articles and ensure reliability (Tranfield et al., 2003) It allowed for a transparent, documented research process with criteria for inclusion and exclusion of selected studies. We took the following steps, according to Tranfield et al. (2003), for a systematic review: Develop research questions; develop a strategy for collecting literature (including inclusion and exclusion criteria); develop a search plan to find literature (selecting suitable databases and search terms); and code and synthesize the literature. The search terms and databases were selected in collaboration with a search expert, to ensure validity (search terms captured relevant articles for the subject). All steps of the process were described in detail, including search strings in different databases and inclusion and exclusion criteria. This allows for the review to be replicated.

While systematic reviews are typically analyzed through a meta-analysis of empirical findings, the subject of patient involvement consists of a wide range of research methodologies, subjects and topics, which prevented us from applying this in our review. Since our objective was to explore the field, an inductive analysis without coding frameworks and preconceptions was preferred (Fingfeld-Connett, 2013). The analysis starts by coding raw data. We used a thematic analysis following Braun and Clarke's method (2006) to identify patterns from the literature and describe the various facets of patient involvement. When using both qualitative and quantitative content analysis, it is important to pay attention to the reliability of the coding, such that different coders code the data in the same way (Silverman, 2006). With our qualitative approach, we made no formal score on inter-rater reliability. Instead we continuously discussed and solved disagreement when forming themes throughout the analysis.

4.4.4 Methodological considerations: Paper B and C

The data for Articles B and C was collected using a qualitative, solicited, diary-based approach described in Elg et al. (2012a, 2011). This was collected before I started my

PhD studies. The data for these papers was collected from patient diaries, which were designed in collaboration between researchers and practitioners. The diaries were designed to involve patients in providing ideas for improvement and capture the patient perspective. Patients from orthopedics, gastroenterology, rehabilitation, and oncology were randomly selected to maximize variations of types of care and capture different types of ideas and experiences. The final sample consisted of 68 patient diaries for Paper B and 53 diaries for Paper C.

The purpose of Paper B was to explore the lead-user methodology in a healthcare context. We searched for diaries that stood out in terms of creativity and richness in description and reflections to ensure that such patients exist. This method was used in accordance with the lead-user method and the criteria were selected in accordance with theory innovativeness. To confirm that the best diaries were selected according to these criteria, two raters independently rated all diaries on a Likert scale from 1-7. A rating plan was developed using formal criteria, and definitions were agreed upon before rating diaries. To ensure reliability, we assessed inter-rater reliability, which was well above recommendations.

The purpose of Paper C was to explore the roles patients might have in healthcare service development. Patients who participated in our study were categorized either as having an episodic (patients in for orthopedic surgery) or a chronic disease (patients requiring rehabilitation or gastroenterology care). As a first step of analysis, all diaries were transcribed into plain text and independently read in full by at least two researchers to identify ideas for improvement, either explicitly stated or embedded in descriptions. This ensured the validity of ideas and reliability in the analysis process. The research team then jointly categorized ideas into different subject categories. We used logical regression to analyze differences between patient groups to detect potential patient roles.

I was not involved in the data collection or the design of the diaries for Studies B and C. This is a limitation of my thesis, as I had no influence over decisions leading to the collected data (diary design, participant selection), and I do not possess all the knowledge and insight in methodological choices and research process.

4.4.5 Ethical considerations

Papers B and C were approved by the Regional Ethical Review Board in Linköping (Ref. nos. 20029-09). All participants provided written informed consent. All participants were over the age of 18. Patients' autonomy was acknowledged in text, a cover letter, and the diary, stating that participation was voluntary and participants could withdraw from the study at any stage. Participants were also informed that confidentiality would be maintained when presenting the results.

Table 2 Summary of research design

Paper	Research approach	Data	Data collection	Subjects	Analysis
A	Qualitative	Peer-reviewed empirical articles	Systematic literature review	Empirical articles (n=125)	Thematic analysis
B	Qualitative and quantitative	68 patient diaries	Solicited diaries	Patients from oncology, orthopedics, rehabilitation and gastro (n=68)	Quantitative content analysis, panel method
C	Qualitative and quantitative	53 patient diaries	Solicited diaries	Patients from rehabilitation, orthopedics and gastro (n=53)	Statistical regression

5 Overview of appended papers

This chapter includes summaries of the appended papers of this thesis. The summaries start with explanations on how each paper relates to my overall purpose and research questions. They are then presented with the main purpose and objectives, empirical and data material, main findings, conclusions, and contributions of each paper.

5.1 Paper A: The antecedents and consequences of patient involvement: A systematic review and thematic analysis.

Snyder, H., Engström J.

5.1.1 Background

Paper A is a systematic review of healthcare research, which addresses the topic of patient involvement and related concepts. This introduces the diverse field, contributes to the knowledge base in the growing research field of patient involvement, and presents the various ways that patients can be involved in the development and use of healthcare services. It also highlights some of the potential limitations and gaps in patient involvement research. This relates to the overall purpose of understanding patient involvement and especially addresses RQ1.

The review addresses the following research questions: How does the literature describe patient involvement in healthcare, in terms of how patients are involved directly and how organizations promote and manage involvement; and what are the reported consequences of patient involvement? We used a systematic review strategy followed by a thematic analysis to address this. We conducted an electronic database search to identify empirical articles in English published between 1990 and 2012 in Pub Med, CINAHL and EBSCO (Academic Search Premier, Condit, and PsycINFO). The searches were conducted using three categories of MeSH terms and keywords: Category A, patient involvement, patient participation, patient compliance, empowerment, and patient power; Category B, cooperative behavior, collaboration, co-creation, co-designing, and cooperation; and Category C, self-care, attitude of health personnel, cost savings, self-help groups, and professional-patient relations. We choose to exclude articles concerning mental healthcare, and children and adolescents. This was to limit our sample.

After removing overlaps and irrelevant articles, 125 unique articles were included in the review. The results showed a steady increase in articles published on the subject in a large number of journals from different fields. A majority of the studies related to chronic diseases, especially cancer and diabetes.

5.1.2 Result and contributions

Using a thematic analysis, we identified nine themes in the patient involvement literature in healthcare research, divided into three main themes; enabler for patient involvement, types of patient involvement, and consequences of patient involvement, which Figure 6 presents.

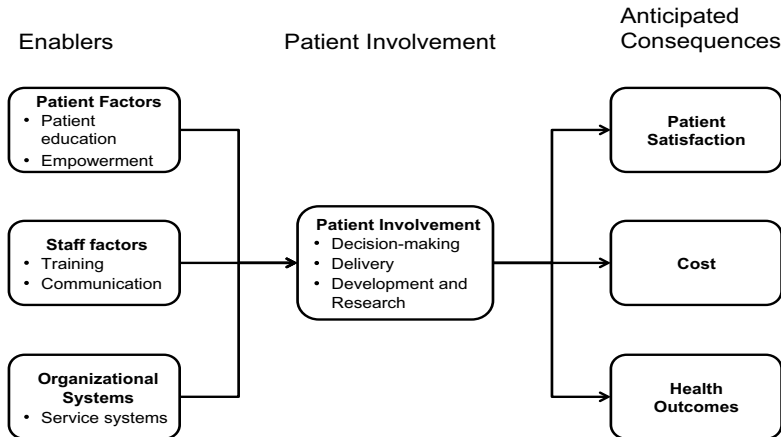


Figure 6 Model for patient involvement in healthcare

Three themes related to different forms of patient involvement. *Patient involvement in decision-making* relates to engaging the patient in decisions about treatment. Questions addressed preferences and attitudes among staff and patients, as well as supportive techniques and methods. *Patient involvement in healthcare execution* includes different ways to actively engage patients in executing care, such as self-care and medication. *Patient involvement in development and research* concerns methods and attitudes to include the patients' perspective in development and research.

Five themes concerned how to enable patient involvement, which was related to patient, staff, and organizational factors. *Patient empowerment* entails studies that focus on psychological aspects of helping patients gain control over their situations and become more capable for involvement. *Patient education* includes studies that examine how patient education and training can support patient involvement. *Staff training* includes studies that emphasize the need to train staff to support patient involvement. *Communication* concerns how medical professionals' communication skills can alter patient behavior and promote proactivity and involvement. *Service systems* concerns how technical and organizational systems can support patient involvement.

We examined all articles for reported effects of patient involvement, but found that the paucity of convincing data and limitations in methodology made it difficult to estimate consequences. However, some studies reported a positive relationship

between patient involvement and adherence, satisfaction, healthcare cost, under certain conditions.

In summary, results indicate that involving patients in healthcare is promising under the right circumstances, as it can improve patient satisfaction and outcomes, as well as decrease costs. However, research is limited to specific areas of healthcare and diseases with unclear generalizability. The review contributes to both research and practice. First, it extends previous reviews conducted in the field, as it provides an overview of the field to researchers and professionals. Second, we present a tentative model synthesizing our findings, which other scholars can use as a starting point to verify, use, and expand these findings. This model can be helpful to care providers in their strategic work on patient involvement.

5.2 Paper B: Patient involvement in healthcare service development: Who to involve and why.

Engström J., Snyder, H.

5.2.1 Background

Paper B explores the lead-user methodology in a healthcare context. There is a lack of established methods, and knowledge about which patients to involve in service development (Grol, 2001). This second paper addresses this question and explores a method to identify highly innovative patients who are suitable for involvement in healthcare development. This relates to both the overall purpose of understanding patient involvement and **RQ1**.

This study is inspired by lead-user methodology, which stresses the need to identify the most innovative users for collaboration in development. The methodology posits that a small subset of users experiences needs ahead of the general market, will benefit more from a solution to a problem than most other users, and are especially suited for collaboration in development efforts (von Hippel, 1986). The study objectives describe what signifies the most innovative patients and how these patients can be identified and involved in healthcare development. The empirical data for this study was collected from an innovation initiative involving a diary-based method (Elg et al., 2012) that captures a patient's experiences and ideas in the patient's own context. Sixty-eight patients from oncology, rehabilitation, gastroenterology and orthopedic units used diaries designed to capture reflections and ideas for innovation. We rated all diaries according to creativity and richness in descriptions and reflections to identify the most innovative patients.

5.2.2 Results and contributions

Four high-performing patients were selected and portrayed, including brief backgrounds of their situation and needs, ideas they offered, and if and how they implemented their solutions. The selected patients displayed strong abilities to draw

from the experiences of being patients with skills and knowledge to find solutions to their needs and problems and needs. All selected patients were innovative in relation to a certain domain. Henry is a very innovative patient with regard to daily living aids. Simon provides ideas and reflections regarding social interactions among patients and staff. Agnes finds strategies to cope with her severe pain. David is a cancer patient who uses his life experience to analyze processes and managerial situations in healthcare.

The identified patients display abilities to extrapolate from their experiences to find solutions to perceived problems and needs. While the results show that there are important differences between lead users in other domains and the identified lead patients (Table 3), this methodology offers a model for how the most innovative users can be identified and involved in healthcare development with the goal of understanding and supporting patients' value co-creation and providing a patient perspective on healthcare development.

Table 3 Special conditions for innovative patients in service development

	Market	User situation	Drivers of users	Requires
Lead users	Unmet needs exist and are emerging due to underlying trends	Has strong needs and tries to find solutions Enthusiastic user.	Direct benefit from use	Innovative competencies
Most innovative patients	Unmet needs exist due to negligence to individual needs and needs in personal sphere	Has or sees strong needs and reflects on solutions, but often lacks ability to implement. Involuntary user.	Affinity with provider Empathy with co-patients	Relational competencies

We make several contributions and suggestions on how to identify patients for collaboration, and learn from patients, and describe a four-step process for involving patients in development:

1. Form an interdisciplinary team, including different actors such as nurses, physicians, healthcare management, and patient organizations.
2. Identify problematic areas and unmet needs within the selected care process or area.
3. Identify suitable participants for involvement.
4. Involve and work with patients to improve or generate new solutions within the service system.

5.3 Paper C: The influence of disease and context on patient participation in healthcare service development.

Poksinska, B., Witell, L., Engström, J., Elg M., Snyder, H

5.3.1 Background

While service developers in other domains frequently involve users (Kristensson et al., 2008), this practice remains unexplored in healthcare development (Engström, 2012). A problem is the knowledge gap of which patients to involve and how to do so. By getting access to the various contexts in which patients experience problems, develop ideas for solving these problems, and sometimes realize these ideas into solutions, a healthcare provider can gain valuable ideas about how to design and improve healthcare services. Paper C, in line with Paper B, continues to explore which patients to involve, but with a different aim. Paper C investigates the various roles a patient may have in healthcare service development and examines how the type of disease, care process (episodic/chronic), and context (home/care provider) influences what forms of patient participation in healthcare service development are suitable. This contributes to the overall purpose of understanding patient involvement and RQ1.

The empirical data for this study was collected in the same way as for Paper B (Elg et al., 2012). Fifty-three patient diaries were collected from rehabilitation, gastroenterology and orthopedic units. From the diaries, 360 ideas for improvement were identified and coded according to their types, characteristics and sources (home/care provider). Logistic regression was used to investigate the influence that the independent variables (type of disease and context) and their interaction effect had on the dependent variables and how these related to characteristics and sources of ideas.

5.3.2 Results and contributions

Patients contributed a range of different types of ideas, including administrative matters, healthcare staff attitudes, informational subjects, medical care, medication, daily living aids, practical issues, and psychological and social aspects. There were four types of patient groups: Episodic diseases at home, chronic diseases at home, episodic diseases at hospitals, and chronic diseases at hospitals. Overall, patient ideas concerned a variety of subjects and depended on context and disease.

The groups had differences in types of ideas that were delivered. Episodic patients at home primarily provided ideas concerning daily living aids, practical issues, and medical care, primarily regarding how to cope with everyday life after hip surgery. Patients in the hospital provided ideas focused on administrative matters, informational subjects, and attitudes of healthcare staff. In the case of chronic patients, the difference between the home and hospital context was not so distinct. In general, patients were better at identifying solutions in their home context than in the hospital.

Patients' roles in executing or implementing ideas differed, depending on context and type of disease. Chronic patients' ideas often stemmed from negative incidents and sources. For episodic patients at home, ideas stemmed from positive events. There were also differences for type of disease. For chronic patients, ideas emerged from continuous problems. For episodic patients, ideas came from new situations. The results of this paper can help care providers and researchers select appropriate methods for involving patients in healthcare development. Based on the type of disease (episodic/chronic) and context (home/hospital), we suggested four types of roles for patient involvement in development (Figure 7): Feedback provider, problem solver, co-developer, and expert. Depending on role, we suggested different methods for involvement.

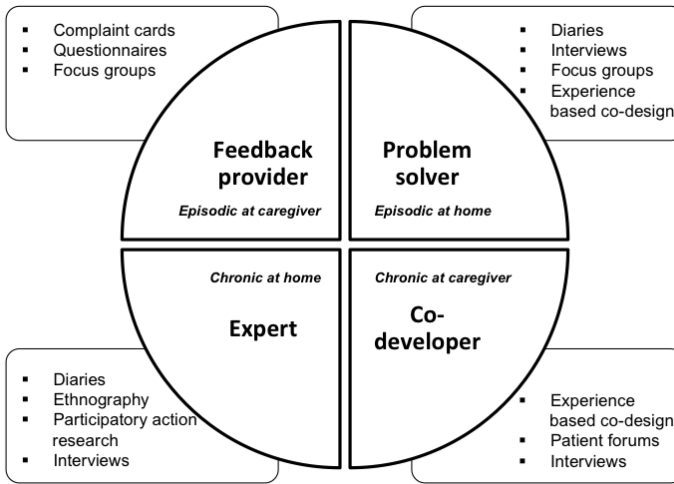


Figure 7 Different roles of patients in healthcare development

6 Discussion and conclusions

This chapter contains the final discussion of this research. This thesis rests on the theoretical propositions and assumptions that patients can be active collaborators in all stages and activities of healthcare and co-create value. The purpose of this thesis is to understand and explore patient involvement from a service perspective. To fulfill this purpose, an extensive and systematic literature review of healthcare research was conducted and compared to service literature of customer involvement and value creation. Exploration of patient involvement in development was empirically investigated in Paper B and C. In Paper B by using theory about lead users to show how certain patients can be especially valuable in contributing to innovation and in Paper C by exploring how patients, depending on disease, care process and context, can take different roles in the development of healthcare.

This discussion addresses the overall purpose of understanding patient involvement from a service-research perspective and implications this might have. It also discusses how patient currently are involved and the potential of widening the approach of patient involvement.

6.1 Patient involvement in healthcare

The first aim of this thesis was to explore and understand how patients currently are involved in healthcare, with regard to the use and development of healthcare services. As the role of patients has started to change during the last decade from being passive recipients to active collaborators, the importance of patient involvement has gained attention in both research and practice (Greenhalgh et al., 2010). The importance of involving patients builds on the rationale that patients have the right to be equal partners regarding their own care and play a key role in reaching accurate diagnoses, treatment decision-making, self-care, and disease monitoring (Vincent and Coulter, 2002). Patients have information and experiences to which care providers do not have access. There are strong arguments for involving patients in all stages of healthcare development (Elg et al., 2012). Therefore, healthcare services should be developed not only from the inside-out, but also from the outside-in, by interacting with patients and other healthcare users.

From a service perspective, customer involvement is essential for service development. Customers hold experience and knowledge about their own value co-creation (Vargo and Lusch, 2008, 2004). Understanding how patients create value and manage their health is important, both for them and for healthcare providers and government (McColl-Kennedy et al., 2012). Much of a patient's value creation takes place outside the patient-provider sphere, and is unknown to the healthcare provider (Grönroos and Ravald, 2011). By actively involving patients, healthcare providers can apply a whole-person perspective.

The topic of patient involvement is studied in a number of contexts. Patients are studied by interviews, surveys, and observing consultations in interrelated research streams such as patient empowerment, self-management, shared decision-making, and patient-centered care. In Paper A, different subject themes provided an overview of empirical studies relating to patient involvement. Broadly, eight themes were identified in the form of enablers for involvement, such as patient empowerment and education, staff training and communication, and development of supportive service systems. Other themes examined types of patient involvement activities, such as decision-making, self-care, and development and research. Even if these studies are promising, this does not mean that patients are actively involved in developing or using healthcare services. Instead, they are often used as information providers and treated as operand resources or objects on which healthcare professionals act. Patient involvement is described as something done to patients or a method to increase the chances of them complying with treatment.

This perspective on patient involvement works rather well in isolated encounters when there is a simple cure, such as treating an infection or performing a standard surgical procedure. However, as healthcare is changing from not only cure infectious or acute diseases but also to prevent and manage chronic diseases, it becomes more important to acknowledge the patients and other users as operand resources who co-create care with the service provider and other resources in using and developing healthcare services. This shift, together with other healthcare sector challenges, such as an aging population, rapidly increasing costs and poor quality, calls for changes in the conceptual and fundamental outlook of healthcare and the meaning of patient involvement.

Moreover, a careful examination of the literature showed that, despite the large amount of articles published on patient involvement, there was an overwhelming focus on specific questions about certain diseases. There was a lack of studies developing overall definitions, frameworks, and theories by which to understand patient involvement and its implementation and effects in healthcare organizations on a general level. There were also few robust studies of patient involvement in development and research.

6.2 Implications of applying a service perspective on patient involvement

Creating value is the main purpose of economic exchange (Vargo and Lusch, 2004). In service research, the customer is essential to both value creation and co-production (Grönroos, 2006; Prahalad and Ramaswamy, 2004; Vargo and Lusch, 2004). Traditional models of value in healthcare focus on health outcomes versus cost (Porter, 2010). Patient involvement is often limited to isolated encounters and treatment decision-making (Thompson, 2007).

This thesis does not recommend a specific organizational approach or methods for patient involvement. Instead, it contributes to understanding patient involvement in a

wider perception, moving beyond shared decision-making and compliance with treatment. In this discussion, I suggest an alternate view on patient involvement, applying a service perspective, summarized in Table 4. This approach is not entirely new, nor is it a complete solution to all challenges facing patient involvement. However, by presenting a distinction between two approaches, the purpose of this conceptual outlook is to contribute to a broader understanding of patient involvement.

Table 4 Two perspectives on patient involvement

	Traditional perspective on patient involvement	Service perspective on patient involvement
Creator of value	Healthcare service provider delivers value to the patient	Patients, networks and healthcare service provider co-creates value
Process of patient involvement	Healthcare providers involve patients in medical consultations and decision making regarding treatment	Patients can be involved in all stages and activities of healthcare
Role of service provider	Produce and perform treatment on patients	Facilitate and co-create value together with patients and other actors and resources
Role of patients	To comply with treatment “follow doctors orders”	Co-create value through the integration of healthcare-provided resources with other private and public resources
Methods for patient involvement	Passive information or feedback providers	Active collaborators both in use and development of care

6.2.1 Creator of value

Value in healthcare has traditionally been driven by factors such as volume of service delivered or monetary output versus health outcomes, or as “*health outcomes achieved per dollar spent*” (Porter, 2010, p. 2477). Lack of value from this perspective is expensive, with poor quality and health outcomes. Maximum efficiency is achieved by standardizing care processes. This driver or measurement of value is relevant, as output in relation to cost encompasses some aspects of quality. However, even if medical health outcomes from a healthcare provider’s perspective are important, they neglect the active contribution and perceived value for the patient. The driver of value derives from actual use of healthcare service with a service perspective on value in healthcare (McColl-Kennedy et al., 2012; Vargo and Lusch, 2004), and quality is assessed by the value the patient perceives. Therefore, the view of value in healthcare changes from something that is produced and delivered to the patient to something that is co-created. This implies that patients and other users should play an active role in developing, using, and evaluating their service. For the most part, the aims of health outcomes, efficiency, and patient involvement are complementary. However, there will sometimes be tension among these factors. Therefore, it is

important for healthcare providers, professionals, and patients to work together to balance competing objectives.

Physicians generally determine patients' needs, while patients are largely passive (Windrum and García-Goñi, 2008). This reflects the traditional view of patients as weak, dependent, passive recipients of care (Berry and Bendapudi, 2007; Elg et al., 2012). A service perspective on patient involvement implies that all actors, including patients, healthcare service providers and surrounding networks, co-create value (Elg et al., 2012; Engström, 2012; McColl-Kennedy et al., 2012; Payne et al., 2008). Therefore, patients should not be viewed as isolated units, but instead be understood in the context of their own networks.

6.2.2 Process of patient involvement

In healthcare research, studies regarding patient involvement mostly focus on involvement in decision-making regarding treatment. Some studies examined involvement in use of healthcare services, but only a few studies addressed patient involvement in development of healthcare. More often, the process of involving patients concentrated on isolated encounters such as medical consultations or a specific decision regarding treatment (Thompson, 2007).

In contrast, applying a service perspective goes beyond patient involvement as simply listening to the patient during consultations and giving them the option of different treatments. Instead, value creation and patient involvement take place over time and are adjusted to the specific situation (Payne and Holt, 2001). Engagement from individuals is necessary for creating value (Prahalad and Ramaswamy, 2004). This view implies that the healthcare provider would benefit from including patients and other users in all parts of healthcare and cannot autonomously design and deliver healthcare services. Also, as the individual patient's value creation takes place outside the sphere of the healthcare provider, patient involvement should be supported both inside and outside the healthcare setting. For example, many patients living with chronic or long-term diseases manage their disease themselves. Therefore, other resources must be taken into consideration and can be of value for the patient. These resources can include family and friends, other healthcare providers, patient's networks, and Internet health forums and information sites.

It is important to define what is and is not co-creation (Prahalad and Ramaswamy, 2004). The point with this is not just to provide distributed versions of traditional services, apply models of self-service (having patients to do more of the work themselves within the traditional healthcare system), or delegate responsibility away from the service provider. Instead, patient involvement should be interactive and a process in which patients, other users, and professionals play a key part in defining needs and finding solutions, then testing and implementing them on a individual level and in larger development and innovation initiatives. However, there is still a lack of research of what, and how much, patient can do on their own, and which parts of care should be concentrated in hospitals or other care facilities, for safety and quality reasons.

6.2.3 Roles of providers and patients

Greenhalgh et al. (2010) state that specific hierarchical power structures and professional barriers play significant roles in how patients are, and can be, involved. The service view implies changes in the roles of all actors involved in creating healthcare and instead of targets of treatment, professionals should see patients as collaborators.

Prahalad and Ramaswamy (2004) argue that consumers want to interact and co-create value not just with one service provider but also with communities of professionals, service providers, and other consumers. In healthcare, this would imply a change from a distinct separation between providers and patients, where the healthcare provider sets the rules, delivers the treatment and the patients comply with orders, to patients who actively contribute and co-create value with the service provider and other actors in the network. When patient involvement is no longer just a transaction between the physician and the individual patient, but collaboration between actors (such as family, friends, health information sites, and online health communities), the roles, traditional tasks, and responsibilities of patients and physicians becomes blurry.

Patient involvement should not be a threat to the medical profession and its expertise. Instead, the healthcare system collaborates and facilitates value (Grönroos and Ravald, 2011), supporting patients and other users. Commitment to involve patients also does not imply that professionals must provide patients with unnecessary care, just because they request it. In contrast to other services, healthcare is highly regulated, and patients (or, in some cases, professionals) cannot fully choose which services, treatments, or medications they want (Bower, 2003). Therefore, a significant responsibility still lies with the healthcare provider to propose the right treatment to the individual patient, but also to support patient to actively engage in decision-making and self-care.

The importance of educating and empowering patients is widely discussed in healthcare research. A number of studies address efforts to strengthen the role of patients to prepare and enable them for a more active role in care (Brennan, 1999; Ouschan et al., 2006). An empowered patient takes greater care of their own health (Windrum and García-Goñi, 2008). Since specific hierarchical power structures and professional barriers may hinder professionals, research also shows the importance of educating health professionals on how to involve patients (Légaré et al., 2008; Timmermans et al., 2006). Individuals have unique features, abilities, and skills that influence the co-creation process (Ford and Dickson, 2012; Helkkula et al., 2012; Prahalad and Ramaswamy, 2004). In the context of healthcare, research shows that individual patients may have different preferences, abilities, and roles in involvement (Hill et al., 2009; McColl-Kennedy et al., 2012; McKinstry, 2000). McColl-Kennedy et al. (2012) suggest that different customers have different activity patterns and integrate resources differently within their personal network. Also, not all patients wish to be actively involved. Therefore, patient involvement initiatives must be customized to the individual patient. Collaboration and involvement methods should be adjusted in accordance.

6.2.4 Methods for patient involvement

According to a service view on healthcare, involving patients in service development is essential to obtaining their perspectives and understandings of their own value creation. Where, when, and how patients should be involved in healthcare is still somewhat unanswered. Traditional methods for including the patient view in healthcare development and use are reactive, such as patient feedback in the form of surveys, or information provided during consultations. Such methods are typically performed after care is completed, with limited value for development (Groene, et al., 2009). In Paper A, a review of healthcare research on patient involvement found three main forms of patient involvement: Decision-making, execution, or use of healthcare in development and research. There were also studies investigating enabling patient involvement, such as patient education and empowerment, and educating professionals on how to involve patients and organize for patient involvement. There are numerous models and investigations of patient involvement during consultations (Ouschan et al., 2006) and decision-making (Morecroft et al., 2006). Attitudes toward patient involvement are also being examined (e.g., Légaré et al., 2008; Murray et al., 2007a, 2007b; Schneider et al., 2006). However, these models are only used in practice. There is a lack of models on a more aggregated level that move beyond specific diseases and situations. By only modifying traditional top-down execution models for healthcare, the degree and effect of patient involvement is limited.

Current service development and innovation research suggest the use of proactive methods based on user co-creation (Witell et al., 2011). Involving customers improves system quality and understanding of customer needs, and may result in more innovative ideas (e.g., Alam, 2002; Ives and Olson, 1984; Witell et al., 2011). Involving users also provides opportunities to obtain “sticky” information that is otherwise hard to grasp (Hippel, 1994). Taking a patient perspective of development in Studies B and C, we used a diary-based approach to capture patients’ experiences and ideas for improvement.

All patients must be involved to some extent in their own care, such as keeping their medical appointments and taking their medicine. Although all patients have the potential to contribute to improvement and innovation, some users innovate to a greater extent (Greenhalgh et al., 2010; von Hippel, 1986), so are especially valuable to involve in development. Depending on the development initiative’s objectives, different kinds of users are suitable. Paper B was inspired by the lead-user method. This proactive method aims to understand future customer needs by investigating lead users, who have current needs that will exist in the future for most other users. The results indicate important differences between lead users in other domains and lead patients in this study. The patients in Paper B, are not trend leaders, but display abilities to extrapolate from their experiences to find solutions to their problems and needs. They utilize very sticky information, and are willing and able to share and provide thick descriptions. This is important to gain access to patients’ perspectives on healthcare, and support patients’ value co-creation (McColl-Kennedy et al., 2012). Unlike other lead users, these patients are not always in the position to implement their ideas and solutions. This can be due to a number of factors such as ability and

illness, but also because of the healthcare context over which patients have little control. The strategy of involving a subset of patients should not be seen as an elitist way of developing healthcare, but rather a way to identify users who are willing and able to share experiences and solutions that can benefit not only themselves, but also other patients.

In service research, customers can take several different roles in both use and development, depending on the degree of their involvement (e.g., Alam, 2002; Bendapudi and Leone, 2003; Bettencourt, 1997; Bitner et al., 1997; Blazevic et al., 2003; Witell et al., 2011). Depending on the aims and type of development project, different degrees and forms of involvement can be suitable. The results of Paper C indicate that type of disease and patient context affects the kind of contribution patients can provide in the development of healthcare services. Based on this, patients can take roles in development ranging from feedback providers, to problem-solvers, to co-developers of care, to patient experts. Depending on the aim and patient group, different methods for involvement in development might be suitable.

6.3 Conclusions

This thesis contributes to understanding patient involvement by taking a service perspective on co-creation and customer involvement as a starting point. This approach extends the traditional view of patient involvement by proposing that patients should be involved in all stages of healthcare.

In line with both healthcare and service researchers (e.g., Bodenheimer T et al., 2002; Elg et al., 2012; Engström, 2012; Lorig and Holman, 2003; McColl-Kennedy et al., 2012; Nordgren, 2009), I suggest a broader view of patient involvement. At the core of this approach to patient involvement is the new role of patients and other users who are no longer just passively receiving healthcare services. Even if healthcare systems adhere to this view in theory, moving to greater patient involvement will imply changes. This thesis does not recommend specific organizational approaches or methods for patient involvement. Rather than being an organizational construct, a service perspective on patient involvement is a new perspective on involving patients in both the use and development of healthcare. Patient involvement is likely to involve a wide variety of conceptual, theoretical models and practical approaches, depending on type of care and individual preferences.

Paper A shows that there are a number of ways in which patients could be involved in the use and development of healthcare services. This was synthesized in a tentative model. In the review, the examined articles often focused on specific illnesses and testing a certain method, but did not provide overall definitions, frameworks and theories by which to understand patient involvement on a more general, aggregated level. Applying a service perspective on patient involvement is promising in theory, but needs to be adjusted to fit the specific context and the challenges of healthcare services. How we should define the concept of patient involvement, what it means to involve patients, and who is a patient are questions that researchers and caregivers must think about when developing and innovating healthcare.

The new role of the patient as an active co-creator of value differs from the traditional view and requires changes in the organizational system (McColl-Kennedy et al., 2012). Healthcare providers adopting this approach must be more open and reduce the control and strict boundaries between patients and care providers. This includes preparing both patients and healthcare professionals for involvement and building up the healthcare system to support this. The results of Study A indicate that even if there is a lack of studies taking a general view of patient involvement, patient involvement is not an isolated activity but should be viewed as something that influences the whole healthcare system. Patients' individual experiences, context, and type of illness also play an important role in development initiatives. When planning patient involvement in development, patients should be selected carefully, depending on the goal of the initiative. As the results of Paper C indicate, the type of illness and patient context are key factors to the expected types of contributions. Depending on the type of illness, and if it is treated at home or at a care-provider facility, patients develop different ideas.

6.4 Direction for further research

As with all research processes, this one resulted in a number of questions relating to patient involvement in innovation and co-creation of healthcare.

One question concerns the patient experience of value creation. The question of what patients actually do when they create value and how they integrate resources within and outside the service provider is still somewhat unknown. By exploring the patient's experience and co-creation styles, healthcare providers can better understand and support the value creation of patients.

The second question concerns the contribution of healthcare users to public-service innovation. While the literature of patient involvement provides some examples of how to involve patients, there is a potential in developing novel methods for patients and other healthcare users to be involved and contribute to service innovation in healthcare.

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