

Patient participation – what it is and what it is not

*“– The most ordinary patient, yes even the very lowest,
is allowed some say in the matter of her own prescription.
That way she defines her humanity.”*

The character Virginia Woolf in the movie *The hours*, 2002

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Abstract

In general, patient participation is regarded as being informed and partaking in decision making regarding one's care and treatment. This interpretation is common in legislation throughout the Western world and corresponding documents guiding health care professionals, as well as in scientific studies. Even though this understanding of the word *participation* can be traced to a growing emphasis on individuals' autonomy in society and to certain dictionary definitions, there are other ways of understanding participation from a semantic point of view, and no trace of patients' descriptions of what it is to participate can be found in these definitions.

Hence, the aim of this dissertation was to understand patients' experience of the phenomenon of patient participation. An additional aim was to understand patients' experience of non-participation and to describe the conditions for patient participation and non-participation, in order to understand the prerequisites for patient participation.

The dissertation comprises four papers. The philosophical ideas of Ricoeur provided a basis for the studies: how communication can present ways to understand and explain experiences of phenomena through phenomenological hermeneutics. The first and second studies involved a group of patients living with chronic heart failure. For the first study, 10 patients were interviewed, with a narrative approach, about their experience of participation and non-participation, as defined by the participants. For the second study, 11 visits by three patients at a nurse-led outpatient clinic were observed, and consecutive interviews were performed with the patients and the nurses, investigating what they experience as patient participation and non-participation. A triangulation of data was performed to analyse the occurrence of the phenomena in the observed visits. For paper 3 and 4, a questionnaire was developed and distributed among a diverse group of people who had recent experience of being patients. The questionnaire comprised respondent's description of what patient participation is, using items based on findings in Study 1, along with open-ended questions for additional aspects and general issues regarding situations in which the respondent had experienced patient participation and/or non-participation.

The findings show additional aspects to patient participation: patient participation is being provided with information and knowledge in order for one to comprehend one's body, disease, and treatment and to be able to take self-care actions based on the context and one's values. Participation was also found to include providing the information and knowledge one has about the experience of illness and symptoms and of one's situation. Participation occurs when being listened to and being recognised as an individual and a partner in the health care team. Non-participation, on the other hand, occurs when one is regarded as a symptom, a problem to be solved. To avoid non-participation, the information provided needs to be based on the individual's need and with recognition of the patient's knowledge and context.

In conclusion, patient participation needs to be reconsidered in health care regulations and in clinical settings: patients' definitions of participation, found to be close to the dictionaries' description of sharing, should be recognised and opportunities provided for sharing knowledge and experience in two-way-communication.

Keywords: patient participation, non-participation, phenomenological hermeneutics, communication

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Original publications

The thesis comprises the following four papers, which will be referred to in the text by their Roman numerals.

- I. Eldh AC, Ehnfors M, Ekman I. The phenomena of participation and non-participation in health care – experiences of patients attending a nurse-led clinic for chronic heart failure. *Eur J Cardiovasc Nurs.* 2004;3:239-46.
 - II. Eldh AC, Ehnfors M, Ekman I. The meaning of patient participation for patients and nurses at a nurse-led outpatient clinic for chronic heart failure. *Eur J Cardiovasc Nurs.* 2006;5:45-53.
 - III. Eldh AC, Ekman I, Ehnfors M. Additional understanding of participation in health care – findings from a patient survey. (Manuscript).
 - IV. Eldh AC, Ekman I, Ehnfors M. Conditions for patient participation and non-participation in health care. *Nurs Ethics.* 2006;13(5):503-14.
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Introduction

I must admit that as a young nurse, I did not pay much attention to the regulations concerning the patient's right to participate in his or her health care. My clinical experience is primarily in the paediatric sector, where premature and newborn children in need of intensive care are given voice by their parents. Despite my lack of recognition of these rights, however, looking back, I remember situations in which parents took the role of partners in making decisions for their children; I recall, above all, a situation when a newborn child was discovered to be in serious heart failure and thus was in need of urgent transport for surgery. In the dialogue regarding the procedure, the parents asked the physician where the closest heart surgical clinic was, which clinic that had the best results, and where it was located. The clinic with the best results was not the closest one, but the parents told the physician that they preferred that their baby be transported there. This wish was respected, and the baby was transported for surgery, which was performed immediately and with success.

I recall other situations in which parents were involved, for instance when bringing their children clothes, blankets, or toys, which were placed in the incubators, giving each child some kind of self. It seemed that as long as we could guarantee safe medical practice, staff stretched the routines to support parents' right to speak for their child. Yet there were also situations that felt awkward, such as when we, as staff, convinced the family of a premature girl that they should take her home, even though the parents expressed worries and concern about the child's (low) weight. Perhaps my frustration was caused by a sense that the family was not involved or taking part in the dialogue regarding their child's situation and needs...

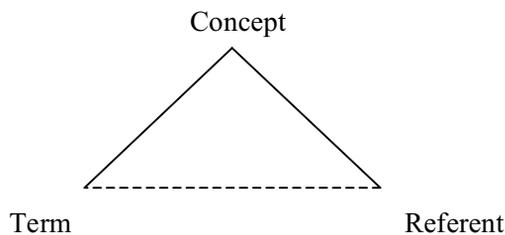
Later I was engaged in quality assurance and development work at a general hospital for adults with somatic disorders and learnt that even though the patients were often able to speak for themselves, there existed what I considered to be obstacles to their partaking as members of their health care team; traditional rounds were performed, there were visiting hours for next of kin, and care plans were completed and sent forward without the patients' being involved. As the legislative directive became clear to me, in that as a patient one has the right to participate, I became embarrassingly aware of the issue that we, as health care providers, were expected to provide for patient participation but seemed to have little knowledge of what patient participation in health care means. Thus, my initial concern was what patient participation represents.

Background

An integrative analysis of patient participation and non-participation

To understand health care, one must understand the phenomena that relate to it.¹ A phenomenon is an aspect of reality that can be consciously sensed or experienced.¹ The experience can be communicated to others in a dialogue that might be verbal or written (i.e. a text). The lived experience springs from the body: the body experiences, as the being experiences.² A phenomenon can be experienced only through one's own body, but it can be communicated to others in the discourse that takes place between two individuals. Communication opens the possibility not only of experiencing but of sharing the experience. To be able to communicate,³ however, we need a common understanding of the words.⁴ A word that we use, i.e. a term or symbol, refers to a concept, which is the idea or thought we have, and a referent, which is what we refer to, e.g. a phenomenon that we experience. The term, the concept, and the referent correspond to each other, as described, for example, in the Ogden and Richards' triangle (Figure 1). The relationship between term and referent is indirect, however, as we require the concept to outline the idea or thought, i.e. apply meaning to the referent.

Figure 1. Applied after Ogden and Richards' semiotic triangle (p. 11)⁴



Consequently, focusing on the phenomenon of patient participation, we need an agreed understanding with respect to the term (the word) and an agreed content of the concept (the idea), which should originate from the experience of the phenomenon (the referent). Accordingly, I performed an extensive literature review⁵ to reach an initial understanding of *participation* and create a background to the studies performed within this thesis. The review included an analysis of how participation is described and/or considered from five viewpoints: legislative and semantic views, views found in nursing

theoretical works and in databases and classifications, and a scientific view, as presented in Table 1. As a means of reaching an understanding of a concept, it has been suggested that an analysis of the opposite concept is valuable⁵; *non-participation* was, therefore, included in the literature review.

Thus, I embarked on this scientific project initially through the literature review, by tracing the origin of *patient participation* as a term and as a concept related to health care. Accordingly, I will present an overview of the five outlooks. Later, this became the basis for my studies, performed on the subject of the phenomena of participation and non-participation as experienced by patients.

Table 1 Literature review – performance

Scope/Source	Search process	Keywords	Analysis
Legislation/Internet	Electronic search for legislation in European and North American countries published in either a Scandinavian language or English	Government and patients' rights	Integrative review
Thesauri and dictionaries/ The Main City Library, the Royal library, and the University Library at the Karolinska Institute, all in Stockholm	Purposeful selection, manual search	Participation, patient participation, non-participation, involvement, autonomy, and empowerment	Semantic analysis
Nursing theorists/Textbooks	Purposeful selection, manual search	Manifest analysis: the term <i>participation</i> Latent analysis: interpretation of participation and related concepts	Analysis inspired by content analysis, ⁶ involving both latent and manifest content analysis
Health care classifications/ MeSH, ICF and previous ICDH, VIPS	Electronic and manual search	Patient participation, involvement, information, self-determination, compliance, preferences, autonomy, and empowerment Non-participation, non-compliance, and refusal	Integrative review
Scientific literature/ Databases: PubMed and CINAHL	Electronic search with limits set to human studies, regarding adults, articles with abstracts reported in English; no limits were initially set for publication date	Patient participation (in combination with parts of or whole words related to phenomena, hermeneutic, qualitative studies, quantitative studies, or perception) Empowerment, involvement, self-determination, and patient autonomy (with similar combinations) Patient non-participation	Integrative review including: How the authors labelled the concept, and/or which keywords were used Presence of explicit and/or implicit definition of the concept in the introduction/background If the concept was measured and, if so, how and with what instrument Presence of a definition of the concept in the discussion or conclusion Excluding: effectiveness of interventions not considered, as no meta-analysis was performed ⁷

Legal aspects of patient participation

In many Western countries, the past decades have shown a trend towards enhancement of patients' rights to influence and direct their care. This has been explained as a result of the social movements of the 1960s and 1970s, in which the existing social hierarchies were challenged for the benefit of individuals' autonomy.⁸ This trend has taken a range of expressions throughout Western society, for example the Dutch right to determine when to end one's life,⁹ Finnish and American regulations concerning the writing of living wills,^{10,11} and the Norwegian demand for the informed patient that can partake in planning for care.¹² The Swedish Health and Medical Service Act constitutes that care should be of good quality and should be based on respect for the individual's self-determination and integrity. In the most recent revision of the Act, the patient's right to participate is clearly expressed and outlined.¹³ The Act states that to be able to express one's will, to practise self-determination, and to participate in care, the patient has to be well informed about the illness, treatment options, and possibilities. The statements are based on assumptions related to people's will to participate and to influence their life, assumed to be natural in all citizens irrespective of age and gender. It is mandatory for caregivers to establish purposeful quality assurance systems,¹⁴ including routines that certify that the patients, and their next of kin, receive information and are made participants.

In a national Swedish report on patient participation,¹⁵ the patient's right to participate is stressed. Patient participation is defined as receiving individually adjusted information and having the possibility to choose treatments and to seek a second opinion. Patients' rights have also been described as the right to receive care and treatment.¹⁶ In that perspective, the jurisdiction for the patient's right to voice complaints is included.

Perspectives on participation and non-participation from the semantic analysis

The word *participation* is ancient, apparently used even in Old Swedish.¹⁷ A Swedish dictionary from 1925 shows that *participation*, at that time, was defined as having knowledge, to partake in, or to be involved in.¹⁸

Participation can be seen as being a part of an act; *participation* probably originates from the same root as partaking: to partake, to share.¹⁹ Partake is described as to 'take part', 'share', 'be involved', 'play a part', and 'contribute', whereas to participate is described as to 'share', 'take part', 'play a part', 'be a party', 'engage', be 'involved', 'contribute' or 'cooperate'. To participate is also described as to 'share' or 'communicate', whereas participation is 'the action of partaking', 'taking part', 'associating', or 'sharing' with others in some action or matter, more specifically described as 'the

specific involvement of members of a community or organization in decisions which affect their lives and work'.²⁰

A thesaurus shows that in English, participation is synonymous with 'part', 'involvement', 'sharing', 'taking part', 'partnership', 'cooperation', or 'contribution'.²¹ These synonyms are equivalent to the Swedish synonyms.²²

The word *empowerment* is described as the 'gaining of the capability to participate fully in decision-making processes in an equitable and fair fashion'. Empowerment can be achieved by individuals or groups. The term involvement, on the other hand, is described as the act of including or the state of being included.²³

Non-participation is not commonly included in thesauri^{20,21} but has been defined as 'not taking part'.²⁴

This legislative and semantic analysis shows that there are broad descriptions of the term *participation*, yet the concepts in legislations seems to be based on one specified definition, found in the well-known, standard *Oxford English Dictionary*: 'the specific involvement of members of a community or organization in decisions which affect their lives and work'.²⁰ This definition seems to have been transposed directly to the health care field. Thus, patient participation has been assumed to mean the involvement of patients in decisions that affect their care and treatment.

Terms related to participation and non-participation according to health care classifications

The National Library of Medicines database, MeSH,²⁵ is the controlled-vocabulary thesaurus used for indexing articles in the Medline database. MeSH descriptors are organized into 16 categories and then further divided into subcategories, creating a hierarchical tree starting with the most general descriptor and ending with the most specific. Patient participation is found in three branches of the N-category, Health Care, one under Patient Acceptance of Health Care and two under Consumer Participation. Consumer Involvement is equivalent to Consumer Participation, which is noted as 'Community or individual involvement in the decision-making progress', whereas Patient Participation is noted as patient involvement in the decision-making process in matters pertaining to health. The database text clarifies that patient participation should not be confused with patient compliance, which is, rather, defined as 'voluntary cooperation of the patient in following a prescribed regimen'.

The term autonomy is noted in MeSH as Professional Autonomy or Personal Autonomy, the latter defined as 'self-directing freedom and especially moral independence'; furthermore, 'an ethical principle holds that the autonomy of persons ought to be respected'. The term is found in various parts of

the MeSH tree structure, for example under Principle-Based Ethics, although before 2001 it was indexed as Freedom.²⁵

The entry term Patient Preference corresponds to Patient Satisfaction, noted as '*the degree to which the individual regards the health care service or product or the manner in which it is delivered by the provider as useful, effective, or beneficial*'. The term Self-Determination is found to be related to legislation and provides a reference to the Patient Self-Determination Act. This federal American act of 1990 presents that individuals receiving health care services will be given an opportunity to participate in and direct health care decisions affecting them.²⁵

Empowerment is not defined as a MeSH-term. Non-participation does not answer to any term in the MeSH-database, but Refusal to Participate and Treatment Refusal do. Refusal to participate is noted as '*refusal to take part in activities or procedures that are requested or expected of an individual*'. The description notes that refusal to participate could refer to health personnel's refusing to participate in specific medical procedures. The refusal of patients to participate is, on the other hand, described as '*refusal by patients or members of the public to take part in clinical trials or health promoting programs*'. Treatment refusal is described as '*patient or client refusal of or resistance to medical, psychological, or psychiatric treatment*'.²⁵

I conclude that in the MeSH-database, patient participation is regarded as connected to decision making and that compliance is regarded as acceptance of suggested treatment. The description of patient participation as related to decision making is supported in the Self-Determination note, which supports the idea that patient participation is generally regarded as equalling being involved in decisions. Even though autonomy is described as a basis for the development of patient rights,⁸ neither autonomy nor preferences are linked to the term *participation* in the database. In addition, *non-participation* seems not to be linked to these aspects but, rather, seems to focus on refusal. Furthermore, my analysis indicates that refusals by health personnel are regarded as related to an ethical line of reasoning, an aspect that seems to be lacking in definitions regarding patients' refusal.

In a widely implemented Swedish model for nursing documentation,²⁶ *participation* is used as one of the keywords for nursing interventions. Participation is described as either abstract, e.g. taking part in planning, or concrete, e.g. performing self-care tasks. It has been suggested that enhanced patient participation can be reached through the patient's being involved in care planning and decision making or in performing self-care. Furthermore, International Classification of Functioning, Disability and Health, ICF,²⁷ has a domain for activities and participation. Participation appeared in the earlier versions of the classification (ICIDH-2) separate from activity. Even though

they are now merged, they still carry their specific definitions, whereby participation is defined as ‘*being involved in a life situation*’.

Patient participation as expressed by nurse theorists

Because theory is a key factor for guiding research and practice (as well as education),²⁸ I have included the works of some nurse theorists^{1,29} in the integrative analysis. The works that I selected are considered influential in professional nursing in Sweden: the ideas and standards of Florence Nightingale influenced the first nursing colleges in Sweden,³⁰⁻³² Virginia Henderson influenced the World Health Organization’s (WHO) definition of nursing,³³ and Katie Eriksson is presented as an important contributor to the development of the nursing profession in Sweden,³⁴ which was apparent to me during my education in the mid-1980s. This is also the case for Dorothea Orem, who has influenced a number of clinical settings throughout Sweden (Nilsson U-B. 2002, Swedish Organisation for Nursing Theory, personal communication, Jan 18). The nurse theorists thus chosen are not to be considered the complete picture, i.e. they represent works described as philosophies (Nightingale and Eriksson) as well as grand theories (Orem) but not theories or mid-range theories,³⁵ yet together they mirror a hundred years of development in academic nursing.

In the development of the work done by nurse theorists, there has been an important shift since the earliest theories.²⁸ Where, for example, Henderson and Orem focused on descriptions of illness and health and what the nurse can do to assist the individual to gain or recover health, later theorists have tended to focus on the phenomenon of nursing rather than the actions of nurses.³⁵

In her work, Nightingale focused on descriptions of the nurse’s actions and interventions.³⁶ She described the relationship between the nurse and the patient in two ways: the nurse as a servant to the ill but also the nurse as the one who knows what is best for the patient. There is a balance in power between the people interacting in the relationship, yet the text shows signs of both participation and non-participation: Nightingale expressed that the patient’s desires should be respected but that the nurse is to decide for the patient, knowing what is best for him or her in both physical and social matters. Nightingale stressed that the patient’s needs and wishes might differ from time to time, and she assumed that the dialogue between the nurse and the patient would be focused on the illness and health of the patient, even though the patient also should be informed about societal facts. The patient’s right to get proper information is specified, so that he or she can make the correct decisions. The analysis showed no explicit occurrence of the term *patient participation*, yet in my analysis, I identified implicit aspects

that suggested a power shift between the nurse and the patient. I interpreted Nightingale's work to suggest that patients' needs and wishes might differ but are to be respected.

Henderson's work shows similarities with Nightingale's, even though Henderson developed nurses' functions³⁷: the nurse should know the patient's needs and desires, and should be open to shifts in the patient's situation. Henderson defined nursing in 14 statements, all beginning with the words '*To help the patient...*'. To gain independence, the patient should be encouraged to take part in self-care actions. If the nurse identifies obstacles hindering the patient from taking part in those actions, he or she is responsible for removing these impediments. The nursing actions are to be seen not as doing for but doing instead of (the patient) until his or her independence is gained or regained. In the analysis, I found no explicit sign that patient participation was considered but interpreted that Henderson proposed that the patient is to be respected.

The self-care deficit theory was initially developed during the 1950s by a group of co-workers led by Dorothea Orem.³⁸ Participation can be seen as fundamental in the work, as the relationship between the individual in need of care and the nurse builds on a balance between the individual's self-care and self-care needs. This relationship presupposes partnership, and the nurse's role is to act when and where the individual lacks the ability to do so. The primary goal is gaining or regaining independence for the individual, even though the need might be lifelong. In the latter case, the individual's choices are to be the aim of the nursing actions, and if these choices are not known, they should be sought after as what the individual would have chosen or done, if he or she had the will, knowledge, and power. Orem also declared the individual's right not to perform self-care actions or fulfil self-care needs. Because the nurse is a complement to the individual, their relationship requires agreement, communication, and cooperation. In addition to *participation*, Orem also used the word *engage* in a positive aspect, as in an individual's engaging in self-care-needs, and in a negative perspective, in that the engagement does not always correlate with the individual's self-care needs. Cooperation and power were also considered: power was seen as being capable of and capable to, where the latter is in focus with respect to the actions of nursing. The nurse is always to trust the decisions of the patient. The patient can take on five different roles, which vary from having no active role as an observer to playing an active role in understanding his or her own self-care needs and mastering the necessary circumstances to meet them. The analysis showed that Orem referred to patient participation explicitly as well as implicitly: the terms *participation* and *engage* are used, and my interpretation of Orem's work is that *participation* means being capable of

and capable to, and it also means not acting. The patient knows his or her needs, and the patient's decisions are always trustworthy.

In agreement with Orem, Eriksson has described a state of mind as well as the development of nursing.³⁹ Even though many references have been made, for example, to Nightingale's and Henderson's works, Eriksson has criticized the earlier theoretical work as focused on actions. Instead, she suggested seeking the inner sense of caring, which extends to the core of all care regardless of profession. Patient participation is covered both explicitly and implicitly in Eriksson's work, the basis of which is sharing. To share, however, there has to be an interaction, an interplay, which presupposes trust. Learning is another assumption for caring, an act that also needs interplay, whereby the individual adjusts the information to his or her present context. The explicit reasoning of participation is further developed in the sense of sharing, described as a unity formed by the carer and the patient. Furthermore, participation is an implicit issue in the work, and in my analysis, I concluded that Eriksson suggested that participation as sharing presupposes an interplay, which, in turn, presupposes mutual trust and forms unity. Furthermore, learning is an act whereby the individual adjusts information to his or her present context.

Patient participation and non-participation as regarded in scientific studies

Looking back in the database Medline (PubMed),⁴⁰ one finds that even though *participation* was present from the origin of the database in 1966, the first articles that indicate a direct association to *patient participation* are found only in 1973. In the same period, titles are found that indicate studies of patients' wishes to participate or the effects of patient participation. The numbers of articles on participation published in general were fewer than 10 per year up until 1972. Between 1972 and 1976, there was a minor increase to fewer than 100 articles on the subject each year. In the years between 1977 and 1987, another increase in articles on participation appeared, to approximately 100 to 200 articles per year. An exception is noted for 1980, when more than 500 articles on participation were registered in the database. Today, approximately 500 articles per year relate to patient participation.

Of the early articles that reported on patient (or client) participation, registered in 1966 to 1970 in the database, four out of nine concerned parents' participation within paediatric care. Later works focusing on paediatric health care, however, also included the child. A number of Swedish studies have been published regarding patient and parent participation in paediatric care, for example, Runesson,⁴¹ whose findings indicate that children are not always involved in the discussions and decisions regarding themselves

in the way that the international Convention on the Rights of the Child prescribes.

However, my analysis focuses on the adult individual, primarily in relation to somatic health care. According to the United Nations' (UN) Declaration of Human Rights, '*All human beings are born free and equal in dignity and rights. They are endowed with reason and conscience and should act towards one another in a spirit of brotherhood*'.⁴² In this analysis, this has been interpreted as having the right to participate on one's own terms. WHO stated in 1994 that there is a '*need to reinforce the values of solidarity, equity and human rights, while recognizing the rights of individuals to freedom of choice, participation and dignity*'.⁴³ These fundamental rights direct us to the importance of each individual, sick or well, having the right to participate on his or her terms, as WHO has stated: patients should receive information, and patient participation be encouraged. All members of the health care staff share the responsibility to fulfil these qualifications.⁴⁴

Most studies that deal with patient participation or closely related concepts are from the United States. However, the American studies seem to label the issue not *participation* but, rather, autonomy or decision making. In addition, a number of studies have been performed in the United Kingdom, and these are more often labelled patient participation, although some are labelled decision making or involvement. Canada, Australia, Finland, and the Netherlands are countries that also crop up in searches for studies regarding patient participation.⁴⁰

Quite a few Swedish doctoral studies have focused on different views of patient participation. In the late 1980s, for example, Sätterlund Larsson studied patients' involvement.⁴⁵ She reported that patients were more likely to state that they had been involved in the decision to undergo surgery if they were satisfied with the care and the surgical outcome. The theoretical basis for the study was communication and power. Integrity has also been studied. Results from Andersson⁴⁶ have indicated that to participate in one's own care, the patient's integrity has to be respected. The caregiver should explore what the patient experiences as problems, provide relevant information, and ensure that the patient understands the information. Client participation in the rehabilitation process has also been studied,⁴⁷ and the results indicated that a structured method improved clients' participation in goal formulation and that rehabilitation improved when clients were engaged in their health care.

The area of patient participation has been studied both with qualitative and with quantitative approaches, yet few studies have described the phenomena of patient participation. When this thesis was initiated, I could find only one phenomenological study with an explicit aim of defining the phenomenon

of patient participation.⁴⁸ In the study, patient participation was suggested to involve shared aims as well as shared desires between interactants. The authors suggested that the process of participation is twofold, in that the participating partners in the health care act, the health care giver and the health care receiver, must have a common understanding as well as respect for each other's contribution. Yet, the authors clarified that the suggested definition is not based primarily on patients' experiences (Ashworth P. and Ashworth A. 2003, personal communication, August 14). In a concept analysis by Cahill, published in 1996,⁴⁹ patient participation was compared with partnership, collaboration, and involvement, with the author presenting these in a hierarchical order, wherein involvement/collaboration is the lowest level, participation mid-level, and partnership the highest level. Nevertheless, in examining the references, one finds that Cahill's analysis seems to be based mainly on studies in which health care staff or professionals have given their view on patient participation.

A number of studies that have dealt with the issue of patient participation can be divided roughly in five groups:

1. perception of self-determination,
2. preferences for participation in decision making on treatment,
3. degree of participation,
4. aspects that influence the degree of participation in decision making, and
5. interventions to increase participation,

with a sixth group regarding patient non-participation, which is also presented.

1. Patients' perception of self-determination

Self-determination, regarded as a perspective of participation, has been expressed as trusting and accepting.⁵⁰ Patients want the right to self-determination, yet some patients do not necessarily wish to be involved in decisions. In one study,⁵¹ integrity was found to be created by the individuals as they believe in themselves, set boundaries, and have control over themselves and the situation. A theme found to be related to integrity was confidence, which included participating. Participating was, in turn, defined as occurring when the patient is active and is regarded as a collaborator and expert-partner.

2. Preferences for patient participation in decision making

Participation, meaning the preference to participate in making decisions on treatments, has been studied, for example by Degner *et al*⁵² and Ruland *et al*.⁵³ Making decisions includes decisions at the end of life,⁵⁴ although some people decline to make decisions over issues such as the withdrawal of treatment, whereas others want other people (either relatives or physicians) to decide. Similar findings have been found in other studies⁵⁵: decision-making authority is granted to physicians (for technical expertise) and to family members (for concern about individual interests) and is shifted according to the prognosis. As well, concern might be focused primarily on serious illness rather than on medical interventions, and discussions on advance directives should therefore focus on acceptable health status rather than on medical interventions. Moreover, preferences in decision making might differ between patients that are health care professionals and those that are not: one study⁵⁶ presented that both groups preferred that the principal role in decision making be handled by the provider. Physicians were, however, a little more interested in decision making than non-physician patients. In that perspective, Deber *et al*⁵⁷ found that few patients wished to hand over the decision-making control to their physician. Rather, they believed that physicians should assist patients in problem solving and support their decision making.

3. Degree of patient participation

Yet other studies have focused on the degree to which patients have experienced participation.^{58,59} In a questionnaire developed to measure patient satisfaction,⁶⁰ participation consisted of items regarding being involved in the planning of care, discussing aims for the treatment, and receiving and understanding information. The studies showed that people experience participation, i.e. experienced being involved in decision making. Bradley *et al*⁶¹ found difficulties in long-term care in enhancing residents' participation and autonomy regarding the residents' capacity to participate in discussions of advance directives. Patients in another study⁶² requested equal roles in decision making when asked about scenarios related to hypertension, prostate cancer, or depression: furthermore, they requested greater control regarding possible scenarios of hysterectomy or cholecystectomy. Meanwhile, the physicians in the study wanted to have more control in the former cases and a less-than-equal role in the latter.

4. Aspects that influence the degree of patient participation in decision making

Fletcher⁶³ has stated the necessity of being aware of the cultural context and health value for understanding the decisional processes that affect individual health behaviours. Previous knowledge and an individual's own resources are also important factors that need attention if the health care provider is to give the patient an opportunity to participate. Patients can be either passive or active with respect to receiving or avoiding information.⁶⁴ A study of women's experiences of recurrent ovarian cancer⁶⁵ concluded that once the patients had improved their understanding, the need for involvement and control over treatment decisions intensified.

Preferences for receiving information on treatment options and for making decisions vary between individuals. Factors that influence decision making might be the patient's sex, age, and the health condition, but physicians often do not investigate their patients' preferences for being involved in decision making. Patients, on the other hand, need better decision aids, and patient motivation needs to be better understood. Researchers have noted a discrepancy between the moral belief in patient autonomy and the traditional attitude that many patients do not want to exercise decision making.⁶⁶

5. Interventions to increase patient participation

Sharing information and building the relationship are linked components of a working relationship between the caregiver and the patient. The relationship should be patient centred, according to McWilliam *et al.*⁶⁷ In a group of patients with ulcerative colitis, patients' perception of involvement in disease management was improved by clarification of treatment decisions.⁶⁸ Wensing *et al.*⁶⁹ proposed that *patient-centred communication* embraces shared decision making and Sharkey⁷⁰ has argued for a '*collaborative relationship*' between patients and caregivers. Yet, a study of emergency dental treatment showed that dentists' communicative behaviour was not related to the information-seeking or participatory behaviours of the patients.⁷¹ The experience of using decisional support aids among a group of women with breast cancer proved that the women were, to some extent, too stressed and overwhelmed to make a decision. Among other things, they trusted the opinion and advice given by physicians about treatment decisions and stressed the importance of support from family and friends in decision making. The women found nurses unavailable or uninvolved in decision making and initially missed the benefits of a multidisciplinary approach.⁷²

Larson⁷³ claimed that patients usually recognized physicians as information providers and that they felt comfortable discussing emotions with nurses with respect to decisions regarding resuscitation. Furthermore,

patients emphasized their right to decision-making opportunities regarding these matters. Other researchers⁷⁴ have argued for a more complex and richer picture of the relationships between nurses and patients. User involvement is not optional, stated Oliviere,⁷⁵ as he explored user-centred care. He equated involvement with participation and stated that patient perspectives are essential for improved quality and training.

6. Patient non-participation

The search for studies regarding non-participation presented yet another perspective⁴⁰; non-participation matches articles reporting non-compliance primarily to scientific studies or pharmacological treatment.

Summary of the integrative analysis

What does this tell us about patient participation? To begin with, most studies related to patient participation are from North America and Western Europe, thus indicating that the issue of patient participation is primarily an issue of the Western world, even though the statements on individuals' rights are global.⁴² Furthermore, I have noticed that many researchers have dealt with the concept without clarifying their definition of participation. That is especially apparent in the quantitative studies, where there seems to be an assumption as to what patient participation is, primarily equivalent to the legal definitions, which creates the basis for investigating the degree to which patients experience participation.

Other concepts, such as autonomy, are more commonly clarified. Autonomy is regarded in a wide range of works; in the health care field, autonomy is considered, for example in works regarding professional autonomy^{76,77} and ethics committees,⁷⁸ as well as patient autonomy.⁷⁹ Autonomy has its background in philosophy and politics, deriving from the Greek words for *self* and *law*.⁸⁰ In a philosophical sense, a human can be seen as autonomous '*if she does what she chooses to do (because she chooses to do so) and chooses to do as she does because she wants*' (my translation).⁸¹ From a health care perspective, autonomy has been defined as '*the exercise of considered, independent judgement to effect a desirable outcome*'.⁸² Yet, Jones⁸³ stated that '*ill-health represents the most serious threat of all to autonomy and reduces resistance to paternalism*'.

Based on the above outline, autonomy can be regarded as associated with self-determination, yet in the literature studied for this work, the connection between participation and self-determination, decision making, and autonomy is complex. From a semantic point of view, autonomy relates to self-determination and to decision making but not to participation. Legislation seem to be based on the assumption that patient participation equals

being provided with information and opportunities for partaking in decision making. Yet, various aspects found in the definitions of participation provide different and broader interpretations, as well as relations to terms that are close in meaning, such as involvement. The definitions used in the MeSH database share the view found in legislation. In the scientific literature, I have recognized two attitudes in general: agreement with the definitions in legislation and the MeSH database (and thus the narrow definition in one, yet standard, dictionary²⁰) and, on the other hand, a question as to whether patient participation is related to autonomy and thus is a more complex concept. In the context of care, *participation* seems to be used as equivalent to involvement, whereas autonomy is stated as a moral perspective that can be demonstrated in people's actions. Integrity is a phenomenon related to autonomy, and many similarities in the descriptions of participation and integrity can be seen. Self-determination and preferences seem to be parts, or aspects, of participation. Self-determination can possibly be regarded as the act of participating, for example in a dialogue or in a decision. A preference, on the other hand, seems to be the will behind the act: the individual's desires and needs formulated as a choice.

The definition of *participation* as the active involvement of members of a community or organization in decisions that affect their lives or work²⁰ has come to be regarded as directly applicable to health care: that taking part in decisions regarding issues that affect one's life is applicable to matters in health care. However, by narrowing the concept solely to that aspect means leaving out major aspects, such as sharing, taking part, contributing, or cooperating, which are also definitions of participation. In the literature review, I found no reflection on the basis for choosing this aspect. Narrowing the definition of participation mainly to decision making indicates that there is no differences between individuals' information and knowledge in matters concerning their social situation and environment and the individuals' information and knowledge regarding their body, symptoms, health, and health care. I have found no trace of reflection on whether this alteration is accepted by patients, or has even been discussed. It seems that researchers have resolved the issue by including the understanding that the patient should be provided with individually adjusted information.

Non-participation seems not to have had much attention in scientific studies, apart from as in a lack of compliance to treatment or studies, even though MeSH suggests that participation should not be confused with compliance. The view of a non-participating patient as one who does not comply with a prescribed treatment or does not conform to a study indicates that the collaborating team of health care staff and patients is yet to come, despite the

expressions of patient autonomy that exist in the health care literature and the ideas of patient autonomy that seem to be the aim of legislation.

Rationale

From this analysis, I conclude that there is a lack of knowledge concerning what patient participation means when being a patient. Furthermore, participation seems to be looked on as something that is granted patients: patients should be provided with information and opportunities for partaking in decision making,

However, this approach does not relate to those suggested in the selected works of nursing theorists, where I found implicit aspects of patient participation which appealed to an additional aspect of patient participation: the patient as a trustworthy partner. Although these works have influenced nursing education and clinical practice, at least in Sweden, it seems that they have had little or no impact on the scientific studies in the area. Rather, the scientific studies seem to have used the perspective that patients should have the right to participate, i.e. be invited to share some of the decisions with the health care staff. What generally appears is that patient participation requires that the health care staff offer some of their power, information, or tasks to the patient. This attitude also occur in clinical settings, as a Swedish study among registered nurses rendered categories related to patient participation which focused, for example, on resources and opportunities for influence. The category of focusing resources contained the perspective that nurses provided information and followed up on how this influenced patients' understanding and ability to cooperate.⁸⁴

So far, the general assertion of patients' right to participate in health care is unmistakable. Yet, the picture of patient participation lacks a component, as the definitions of participation in health care seem not to have considered the experiences and expectations of the people for whom health care exists, i.e. the patients. Furthermore, the analysis indicate a lack of knowledge not only what the concepts of participation and non-participation represents and whether general definitions relates to patients experiences, but also what it takes to prevent patients' experiences of non-participation and what it takes for patient participation to occur in health care, from the patients' point of view.

Aim

There is a lack of agreement related to the general definitions of *patient participation* and *non-participation*, and the definitions lack a reflection of patients' experience of the phenomena, even though patients' rights to participate are stated in legislation and health care directives in Sweden and other countries throughout the world. An overall aim of this thesis was to understand what patient participation and non-participation represent to patients, and so to illuminate what is required for patient participation to occur.

The specific aims were to study

1. patient participation and non-participation as experienced by a group of patients with prolonged experience of contact with health care (I, II);
2. patient participation and non-participation as shown in patients' visits at a nurse-led outpatient clinic and as experienced by the patients and described by the nurses (II);
3. patient participation as described by patients in a larger, general population, in comparison to the first study (III); and
4. situations experienced by patients as patient participation and non-participation and the conditions for the experiences (IV).

Method

Theoretical considerations related to data collection and analysis

The phenomenological hermeneutics described by Ricoeur provided a basis to approach the phenomena of patient participation and non-participation from the perspective of being in the patient role: One of Ricoeur's fundamental statement is that of '*I am*',⁸⁵ which is considered a hallmark of his argument that all humans are beings in the world, each and every one with an individual experience. Ricoeur said further that the being does not solely exist but also communicates.⁸⁶ The lived experience springs from the body: the body experiences, as the being experiences. Communication opens the possibility not only to experience but to share the experience.² The phenomenological hermeneutic dimension is not just a method but also provides an ontological base for caring science, implying that language, texts, and words are central to knowledge.²⁹ To understand the other, we have to combine the interpretation with the being. Thus the methodology is important, but it does not stand alone from the ontology.⁸⁵ Interpreting the experience of others creates a base for a human being's understanding of him- or herself.²

Communication is a central idea of Ricoeur's philosophy, and dialogue is an interaction in which words are enriched with symbols and metaphors.⁸⁷ The interaction takes place between a person's experience, and his or her narrative, and the narrative in the form of the text, which opens up its world to the reader.⁸⁵ In this thesis, the aim was to understand and explain the lived experience of the phenomena of participation and non-participation as experienced by people who are in contact with health care in the role of patients. However, the experience of others cannot be fully reached but should be understood as how I, as a researcher using systematic methods, understand and explain their communicated experience.⁸⁸

Nursing and caring as used in data collection and analysis

To authorize the participants to define the boundaries of patient participation and non-participation, I generally use the word *care*^a in the studies, i.e. in interviews, questionnaires, and interactions with the participants. Consequently, the words *care* and *caring*, respectively, are used in the articles derived from the studies. Caring is a common word, and it is widely used in lay language for general descriptions of health care, nursing, and medical care. Thus, the word *nursing* is not used in the interactions, even though

nursing corresponds to caring.¹ Caring can be seen, e.g. a relationship, an attitude, or an intervention. From my point of view, caring is not connected to a specific profession but is multi-professional and thus encompasses reciprocity and interactions between the patient and all health care professionals.⁸⁹ As a result, the findings, discussion, and conclusions are expected to be appropriate to all health care professions and I will clarify when making specific associations to nurses or nursing.

Characteristics of the studies

Data collection for the studies was initiated in late 2002 and completed in the summer of 2004, whereas analysis of the data was performed from the early 2003 until early 2006. An overall presentation of the studies is set in Table 2.

Table 2 Framework, participants, setting, data collection, and analysis: general description

Paper	I	II	III	IV
Frame-work	Inductive	Inductive	Inductive and deductive	Inductive
Inclusion criteria	Prolonged experience of heart failure (HF) and contact with health care Ability to provide informed consent and communicate in Swedish	Planned for series of visits to nurse-led outpatient clinic for HF Ability to provide informed consent and communicate in Swedish	Patient who had visited an outpatient clinic or were admitted to home from ward Ability to provide informed consent and communicate in Swedish	
Parti-cipants	10 patients (6 men, 4 women) with HF	<ul style="list-style-type: none"> • 3 men with HF • 2 nurse specialists in HF (women) 	362 persons who had visited the hospital or had been admitted as patients: <ul style="list-style-type: none"> • 209 women, • 147 men, • and 6 participants whose sex was unknown 	
Setting/Recruit-ment setting	Nurse-led outpatient clinic for HF	Nurse-led outpatient clinic for HF	Hospital for acute somatic care	
Data collection	Interviews with narrative questions	Field notes from observations Interviews with narrative questions with <ul style="list-style-type: none"> • patients and • nurses 	Questionnaire including a question regarding what patient participation is with <ul style="list-style-type: none"> • suggested items and • open-ended 	Questionnaire including open-ended questions regarding situations and conditions for experiences of patient participation and non-participation
Data collection period	Late 2002 and early 2003	Observations initiated late 2003. Observations and interviews completed spring 2004.	Development of the questionnaire completed early spring 2004, including pilot Survey performed in late spring and early summer 2004	
Data analysis	Phenomenological hermeneutics	Phenomenological hermeneutics	Descriptive statistics and qualitative descriptive analysis	Qualitative content analysis
Data analysis period	2003, final analysis completed spring 2004	Initiated in spring 2004, completed early 2005	Initiated winter 2004/2005, completed winter 2005/2006	Initiated in fall 2004, completed fall 2005

Participants and setting

Throughout the studies, I focused on recruiting participants with personal experience of being a patient and thus, presumably, with personal experience of the phenomena of patient participation and non-participation, rather than as, e.g., a relative of a patient or a health care professional.

Paper I

In the planning for the first study, we assumed that living with a chronic illness meant that one has experience of being a patient and can provide key information.⁹⁰ A number of people are living with chronic illness in our society, and the choice was people diagnosed with chronic heart failure (CHF). CHF is an escalating health problem in the industrialized world, partly because of a growing elderly population.⁹¹ CHF can be caused by, e.g., myocardial dysfunction, valve abnormalities, or pericardial disease, or can be induced by rhythm disturbances. The treatment is complex, including both pharmacological and non-pharmacological interventions, with an aim to improve quality and length of life and prevent progression of symptoms. Treatment of CHF should be compatible with a team approach in health care, with a focus on education and counselling along with optimal pharmacological treatment.

Participants were recruited for the first study as they visited a nurse-led outpatient clinic for heart failure (HF) at a local hospital in Sweden. The initial number of participants was set to 10, as a likely number of participants to provide enough data that could be analysed thoroughly. Yet, the option was left open to include more people if needed to explore the phenomena comprehensively. During recruitment, three patients declined to participate in an interview, as they felt too tired or ill to participate, and thus another three were recruited. The final number of participants was ten patients, six men and four women. The participants met the criteria of being able to give informed consent and to communicate in Swedish. All participants had extensive experience of being a patient: their contact with the hospital due to their heart failure diagnosis had been for at least 2 months, and six had had a contact that had lasted for more than 12 months. The participants' HFs were classified as New York Heart Association (NYHA) class II or III, meaning that they had a slight-to-marked limitation in physical activity, as ordinary or less-than-ordinary activity results in symptoms such as fatigue, palpitations, or dyspnoea.⁹¹ Five patients had experiences of other illnesses that had also caused prolonged contact with the health care system. As key informants,⁹² the participants provided extensive narratives with rich content regarding the phenomena of patient participation and non-participation, and no further recruitment of participants was regarded as necessary.

Paper II

The second study was performed at a nurse-led outpatient clinic for HF at a local hospital in Sweden. This type of setting is common in Sweden; in 2001, two-thirds of hospitals had nurse-led outpatient clinics for HF,⁹³ and the interventions in these clinics, such as education and counselling, have been found to improve self-care behaviours such as daily weight control, fluid restriction, and taking actions when gaining weight among people with heart failure.⁹⁴

The participants in the second study were patients scheduled consecutively after a chosen date for their first visit to the nurse-led outpatient clinic and their assigned nurse specialists. Information was given to four patients and two nurses, who all individually gave informed consent to participate in the study. All participants met the criteria of being able to give informed consent and to communicate in Swedish. For one patient, only the first visit at the outpatient clinic was observed, as her subsequent visit was set at the same time as another participant's, and as a result she was not included in the study, whereas all visits (3–4 visits each) of the other participants were observed (a total of 11 visits). The final participants, consequently, consisted of three male patients (ages 53, 77, and 79 years) diagnosed with HF, initial NYHA class II or III, and the two nurse specialists, both women, who were assigned to these patients and carried out the patients' visits at the outpatient clinic. The nurses had long experience as nurse specialists within the field of cardiovascular nursing and had been in charge of the nurse-led clinic for more than five years. As the field notes from the 11 visits provided rich observational data that were appropriate for a thorough hermeneutic analysis and provided an identifiable pattern to the visits, no further participants were included.

Papers III and IV

After the initial studies among key informants, the following study (Papers III and IV) was performed with a larger population to gain an extended understanding of the phenomena. The questionnaires were distributed at an acute somatic hospital with approximately 250 beds. The setting was used as a means of reaching people with experience of being a patient. Along with the other hospitals in the region, this health care provider carries out annual surveys regarding patient satisfaction. So as not to interfere with their survey, the questionnaire was distributed through six of the clinics at the hospital during a quarter of the year when their annual enquiry regarding patient satisfaction did not take place. Questionnaires were distributed at each of the three clinics that had inpatient wards, i.e. the clinics for internal medicine, surgery, and orthopaedics, 100 questionnaires per clinic. An additional 100

were distributed at each clinic that provided outpatient services (the clinics for internal medicine, surgery, arthroscopy, orthopaedic surgery, day surgery, and acute and emergency). Altogether 900 questionnaires were distributed.

By returning a completed questionnaire by post, 362 patients participated in the studies. The distribution between women and men who responded were similar to the population of patients visiting the hospital during the distribution period: about 58% of the respondents were women, whereas 54% of the visitors to the hospital were women, and about 41% of the respondents were men (46% men visiting the hospital). Less than 2% of the respondents did not respond to the question regarding sex. The questionnaires distributed to patients that had been admitted to an inpatient setting yielded a higher response rate than those distributed to patients visiting outpatients settings: 134 out of 300 possible responses belonged to the group that had been admitted at wards (equalling roughly 45%), whereas 226 out of 600 possible respondents in the outpatients settings (about 38%) completed and returned the questionnaire.

Data collection

Papers I and II

For the first study, data were gathered using individual, thematic interviews with narrative questions,⁹⁵ which I (as the primary investigator) conducted. When visiting the clinic, the patients had been offered, and had accepted, a letter of information about the study, which was given out by their nurse specialist at the nurse-led clinic. These patients were subsequently contacted by telephone. All patients had read the information before giving individual consent to participate in the study.⁹² The interviews were set for a date, time, and place convenient to the participants and were thus, by the participants' preferences, held either at the hospital in a private office separate from the clinic for HF or in the patients' home. An interview guide with pre-formulated questions was used to conduct the interviews. The questions concerned both situations when the participant had experienced participation and circumstances when he or she had experienced not participating, what participation was to him or her, and what he or she thought that non-participation was. The interviews were audio-taped and transcribed verbatim to Microsoft Word files for subsequent analysis.

For the second study (Paper II), data were gathered from three perspectives, providing for data triangulation.^{92,96} Initially, field notes from observations were taken, and when all observations were completed, individual interviews with narrative questions were performed with the patients and with their assigned nurses. The field notes were taken during the total of 11 visits of the three patients to the nurse-led outpatient clinic for heart failure.

The visits observed were all the visits the patients made to the nurse-led clinic for the purpose of up-titration of prescribed medication to goal doses and for counselling and education about HF and the effects and side effects of the treatment. In addition to these 11 visits, the first visit of a fourth patient was also observed, as previously noted, but as the following visit took place at the same time as that of another participant, the patient was not included in the study. However, the data were used as a reference for analysing the structure and content of visit procedures. Participants' consent was obtained before the study and again before each observation and interview.

The field notes, which were handwritten in a notebook, were taken continuously during the observations. After each observation I went to a quiet office to recall the incidents and actions of the visits. I also clarified the field notes, as the continuous notes were often made in a type of shorthand. In some cases, an initial analysis was written, but on separate pages in the notebook from the field notes. The field notes included records of the actions and interactions that took place during the visits, issues raised, who spoke, and who did what in the dialogue (e.g. who phrased a question and who answered, who talked, and episodes of silence on the part of the participants).⁹⁷ No voluntary interactions were initiated during the visits, but I responded if the patient or nurse turned to me directly for communication. The visiting rooms were small, and thus I sat quite close to the participants during the visits but out of the way of actions and interactions. Additional notes were made about the physical atmosphere of the room.⁹⁸ After all observations had been performed, all notes were typed verbatim in Microsoft Word files for analysis.

The interviews for Paper II were performed after the observations were completed but before the analysis was initiated. As the principal investigator, I conducted all interviews, which were tape-recorded and later transcribed verbatim to text. The interviews were set for a date, time, and place convenient to the participants. The interviews with the patients were, thus, according to their preferences, held either in the patient's home or office. Two of the interviews with patients were held within a month of the participant's last visit at the clinic, but as one patient became critically ill, the third interview was postponed for four months until he recovered and wanted to complete the interview. The same interview guide used in Paper I was used in the interviews with the participants in Paper II, thus including questions concerning experiences of participation and of non-participation.

The interviews with the nurses took place in each nurse's office after all observed visits had been accomplished; they were held one directly after the other, so that the nurses would not influence each other's ideas of the phenomena. The interviews with the nurses followed the same guide as those

with the patients (in Papers I and II), but the questions were rephrased to what ‘patient participation’ was, e.g. ‘What is patient non-participation to you?’ and ‘Can you tell me about a situation when you experienced that a patient participated?’

All interviews (I and II) contained a probing question referring to how participation has been described in the literature, which was asked when the participant seemed to have exhausted his or her experience of participation and non-participation: the statement ‘Participation has (also) been described as receiving information, partaking in setting goals, and being listened to’ was followed by a question as to what the patient/nurse thought about these descriptions of participation. This probing question in some cases rendered a response associated to one or more of the descriptions and in some the response did not relate to the descriptions, but in all interviews it brought additional information from the participant to the narrative, indicating that it promoted a new line of thought.

Papers III and IV

For Papers III and IV, a questionnaire was developed, as existing questionnaires used for surveying patient participation were found to appraise the extent to which patients have experienced participating^{58,99,100} or preferences for participation⁵² using predefined definitions rather than the respondents’ experience of participation. In addition, there were no questionnaires that encompassed experiences of patient non-participation.

The questionnaire consisted of nine questions: key questions regarding what respondents described as participating as a patient and questions regarding situations and conditions when the respondent had experienced participation or non-participation, respectively. Five additional questions were asked about respondents’ background (sex, age group, setting visited, duration of symptoms, and presence of other disease/disability causing contact with the health care sector). Only the background question regarding setting held a reference to the hospital where the questionnaire was distributed: the respondent was asked to mark which setting he or she had visited/been treated at/was cared for at present to provide data on the number of responses from different types of settings. All other questions were general. As the focus of the study was the phenomena of participation and non-participation, the questions were phrased based on the idea that an experience can ‘be’ as well as ‘be sensed’. All questions were phrased in ordinary language to support the idea that we wanted the respondents’ experience as patients, i.e. their experience of everyday living. The questionnaire (in Swedish) is found in Appendix 1.

The question regarding what it is to participate (Paper III) was accompanied by suggested items, as the probing question during the interviews (I, II) seemed to have provided input to patients' thoughts on participation and non-participation. The suggested items were also means for investigating whether the themes found in Paper I would correspond to findings in a larger population. The question of what it is to participate was followed by 11 items, then a query for the respondent to present additional descriptions if he or she desired. The questionnaire contained instructions for the respondent to mark the item or items that conveyed his or her experience. To define and phrase 10 of the 11 suggested items, the three themes related to participation found in Paper I were used: participation as being confident, comprehending, and seeking and maintaining a sense of control. All themes were expressed in their active form in the questionnaire, and the suggested three or four items per theme were phrased based on patient interviews in the first study (I). One additional item regarding patient participation was phrased from the nursing documentation model commonly used throughout Sweden and other Scandinavian countries.¹⁰¹ Legislation was also examined, as well as questionnaires used for surveying the extent to which patients have experienced participation,^{58,99,100} to find out how other researchers have phrased patient participation.

The questions also asked the respondent to describe a situation in which he or she had experienced participating or, respectively, not participating (IV), including a request for reasons as to why the respondent perceived that he or she had experienced this, in order for the respondents to describe the conditions for the experience. These questions were all open-ended.

A pilot study was performed at a clinic not partaking in the principal study: 20 questionnaires were distributed to outpatients visiting the clinic for acute and chronic pain. The 14 responses sent back by post indicated that the questions were regarded as we intended: to arrive at descriptions of what it is to participate when being a patient, and situations in which the respondents had experienced that they participated or not participated, as well as the conditions for these respective experiences. Furthermore the respondents had no enquiries to us about the questionnaire, and only a minor revision of the questionnaire to clarify the background question regarding the type of setting the patient had visited was needed and made.

Three hundred questionnaires were distributed to inpatients and 600 to outpatients. Each questionnaire was accompanied by a letter of information and an envelope with prepaid postage for response. The questionnaire package contained information that the study aimed to explore how people experience participation in the role as a patient, that partaking in the study was voluntary, and that the participants could later decline responding by

not returning the questionnaire, even if they had initially given consent to participate. The questionnaires were distributed consecutively after a set date, until each unit had distributed its share of 100 questionnaires. All questionnaires were distributed within six weeks of the start of the study. Patients leaving the hospital during this period after visiting an outpatient clinic or being discharged to their home, and who meet the inclusion criteria, were informed about the study and asked if they wanted to respond to the questionnaire, i.e. partake in the survey. Inclusion criteria were that participants should be able to understand and communicate in Swedish and to provide consent to participate. Verbal information, corresponding to the written information, was provided individually by me (as the principal researcher) or an assigned contact person among the regular staff in each unit. Consent was obtained through the patients' acceptance of the questionnaire, after they were informed about the survey and what it meant to participate in the study. There was no registration as to the patients' consent or refusal. If a patient replied that he or she had already been asked to participate when visiting another setting during the survey, that patient was not asked to respond again.

Data analysis

The analysis of the texts for Papers I and II, consisting of the verbatim transcribed interviews in Paper I and transcribed field notes and interviews for Paper II, was accomplished according to a movement through the hermeneutic circle, whereby all stages are repeated until no further information can be retrieved from the texts.⁸⁸ The analysis was inspired by the phenomenological hermeneutic approach described by Ricoeur^{85,88} and followed the interpreting structure that consisted of naïve reading, structural analysis, and comprehensive understanding. Thus, the analysis included the following stages:

- 1) Each text was read and reread to find and formulate its sense. When the texts were read thorough, the formulated senses of the texts were compared to find similarities and differences. The texts were also read to get a sense of the whole material.
- 2) Sub-themes were formed from numerous rereading of each text and the whole material.
- 3) All researchers, i.e. IE, ME, and me, performed various rereading of the texts and critical analysis of the sub-themes.
- 4) Sub-themes were analysed for associations, and themes were formed. The texts were read again, as individual texts and as a whole, focusing on aspects of each theme. Analysis and dialogue continued until agreement on common themes had been reached.

In Paper II, interviews and observations were used to achieve a comprehensive approach¹⁰² to the research area. Apart from the phenomenological hermeneutic analysis¹⁰³ of the field notes from observations and transcribed texts from the narrative interviews, the data were interpreted in triangulation^{92,96} to obtain an understanding of the phenomena of patient participation and non-participation, as experienced by the patients and described by the nurses, and as interpreted as shown in the patients' visits at the clinic.

For Paper III, all data were recorded in SPSS (version 13.0) before analysis. Both a quantitative and a qualitative analysis were performed,¹⁰⁴ as the methods apply to different data but can be combined to illuminate the phenomenon from different angles. The suggested items and the background data were subjected to a deductive method, whereas the open-ended responses, relating additional descriptions of patient participation, were analysed using an inductive method,¹⁰⁵ and the results of these analyses were subsequently combined in abduction,⁹⁶ as follows:

1. The open descriptions regarding what participation was to the patients were analysed first, using qualitative descriptive analysis.¹⁰⁵ Analysis began with a repeated reading of all responses to the open-ended question. Then, meaning units were identified. Longer meaning units were condensed, but shorter responses were kept in their original form. Sub-themes were then formed. Throughout the analysis, an interpretative approach was used.⁸⁸
2. For the nominal data, i.e. the responses to background questions and the choice of describing participation using the suggested items, descriptive statistics were generated. All 11 suggested items were tested for significant relationships to the background variables (sex, age group, symptom duration, setting, and presence of other disease or disability causing contact with the health care sector) using chi-square tests. Results with p values < 0.05 were considered statistically significant.
3. Subsequently, the inductive and deductive analysis approaches were combined in abduction,⁹⁶ as follows:
 - a) the quantitative findings were compared with the themes from which we had drawn the suggested items and
 - b) the sub-themes (along with original open responses and the analysis of these) were analysed in relation to the suggested items and their corresponding themes, so that we could determine whether they contributed to present items and themes or formed additional sub-themes and themes related to patient participation.

In Paper IV, an interpretive approach was maintained, and the data (i.e. the descriptions regarding situations and conditions wherein respondents had experienced participation or non-participation as a patient) were subjected to qualitative content analysis.¹⁰⁶ The analysis began with repeated reading of all responses to the open-ended question. Subsequently, meaning units consisting of the full response or parts of a response, from a few words to a full sentence, were identified. Longer meaning units were then condensed, but shorter responses were kept in their original form. Finally, sub-themes and, later, themes were formed.

Throughout the analysis, counting was performed when it was applicable to the data, in order to investigate how often a theme was interpreted in the interviews (I), and how often an interpreted theme occurred (III, IV).¹⁰⁷

Ethical implications

The studies adhere to the principles outlined in the Helsinki Declaration¹⁰⁸ and were approved by the ethical committee of the Karolinska Institute, Stockholm, Sweden. Particular attention was paid to the fact that partaking should be voluntary and that the participants should not be identified. Thus, the verbal and written information illuminated that the research was not tied to the caregiver where the patients were enlisted and no feedback was given by the researchers to the health care staff regarding patients' willingness or unwillingness to participate. This approach also aimed at preventing identification of participants. In the presentation of the findings, whether in this dissertation or in the articles, specific remarks that might lead to the identification of individuals have been excluded, to provide anonymity for the participants. During the second study, participant's identification of each other was unavoidable, but identification by others was prevented by excluding specific remarks that could lead to identification. Furthermore, in the second study, the effort to follow ethical research principles related to illuminating whether the observations interfered with the visits; all observations were performed by me but were analysed separately by all researchers involved in the study. The supervising researcher, IE, has extensive experience in the area of nurse-led outpatient clinics for HF, and her individual analysis of the field notes confirmed that the observations had not interfered with but, rather, mirrored the common practice and procedures, as well as information generally provided, by nurse specialists in this area.

Papers III and IV were based on an anonymous questionnaire in which no registrations regarding the decision of whether to participate were made, to provide people visiting the hospital as patients with the conditions to participate voluntarily in the study, and with no collection of data that could be connected to an individual, such as name, dates, or reason for being treated

at or visiting the hospital. Thus no feedback could be or was given by the researchers to the hospital staff as to who among the patients that had visited or been treated at the hospital participated and who did not.

Findings

Experiences of patient participation and non-participation of patients with chronic heart failure (I)

The patients' experiences of participation were interpreted as 'Being confident', 'Comprehending', and 'Seeking and maintaining a sense of control', whereas non-participation was experienced as 'Not understanding', 'Not being in control', 'Lacking a relationship', and 'Not being accountable'.

The interpretation indicated that the most common theme relating to participation in the narratives was participation as 'Being confident'. The sub-themes were being confident in oneself and being confident in the caregiver. The aspect of participation as being confident in oneself held multiple characteristics, such as being confident in one's ability, in the body's ability, in the signs and symptoms that one's body communicates, and in one's own goals. Being confident in the caregiver revealed aspects of collaboration and the necessity of having one assigned contact as well as being listened to.

The theme 'Comprehending' comprised sub-themes of comprehending information and comprehending one's own body, the disease, and the treatment. Comprehending information was expressed as using the information as a reason to act differently. Comprehend one's own body was illustrated as knowing the body's reactions, recognizing symptoms and why they occur, and knowing the degree of seriousness of the symptoms. Comprehending also related to the disease and treatment, in that participation meant comprehending the disease's effects on one's body and the aim and consequences of the treatment as well as its estimated effects.

The third theme on participation was 'Seeking and maintaining a sense of control'. This theme contained aspects such as demanding proper care but also the need to stand up for oneself, which comprised cross-checking, e.g. checking that a current caregiver knew what other caregivers had prescribed and recommended. Participation also held aspects such as seeking and maintaining a sense of control over the planning and follow-up.

Of the four themes related to non-participation, three also held several sub-themes: 'Not understanding', 'Not being in control', and 'Not being accountable':

- 'Not understanding' held aspects such as not understanding the health care structure, the expectations of others, the reasons for treatment, or the signs and symptoms of one's body.

- ‘Not being in control’ comprised three sub-themes: a lack of control over the disease, a lack of control over the treatment, and a lack of control over access to the care one believed was needed. ‘Not being in control’ indicated an absence of goals or plans for treatment. Non-participation included not knowing what to expect, and having no idea as to when and how symptoms of the disease could manifest themselves. In addition, non-participation meant not knowing when the next step in the treatment would take place or what the treatment would involve or be like.
- ‘Not being accountable’ was a theme relating to non-participation that held four sub-themes: not being respected, lacking value as an individual human, being physically or emotionally exposed, and being regarded as a bearer of disease rather than as an individual.

In addition, non-participation as ‘Lacking a relationship’ related to the experience of having to deal with a variety of caregivers.

Participation and non-participation were also interpreted as a changing process. A variation in the experiences of participation occurred in the narratives, and it appeared that different phases of the disease and treatment, as well as contacts with different parts of the health care sector, influenced the experience of patient participation. For example, participation seemed to be experienced in certain ways when the patient was acutely ill but contained other aspects once the individual had lived with the disease for some time and had had a regular contact with the health care sector.

Patient participation and non-participation as experienced by patients and nurses, and as shown in visits at a nurse-led outpatient clinic for heart failure (II)

The interpretation of the observed visits displayed that the nurses took the initiatives during visits, yet the patients contributed with information, cooperation, and questions. A dialogue occurred until the exchange of certain kinds of information was completed. The structural analysis of the observations from the patient visits resulted in two themes: ‘Uniform procedures’ and ‘Exchange of certain information’. The uniform procedure theme consisted of physical check-ups and checks that patients recalled previously given information. Certain information exchange consisted of the information nurses provided, which seemed to be information planned in advance. Furthermore, patients provided information and asked questions, either voluntarily or when prompted. Questions and comments from patients were regarded, yet the structure reverted to the standard once the issue was handled.

The analysis illustrated situations in the patient visits that showed correspondence between the interpreted experiences of patient participation and non-participation by patients and nurses.

Participation, as in 'Being responsible and accepting responsibility according to an individual's situation' appeared, and thus the patients' experience of participation was interpreted as apparent in the visits. The theme was formed from the interpretation of the interviews, in which the patients' experiences of participation were reflected in their feelings of being in tune with the staff and of being paid attention to and having their wishes, needs, and decisions respected. Participation included the information the patient required and the need for sharing the information one has as a patient, and of acting to maintain or regain health.

The interpretation of patients' experience of non-participation included not having the information or knowledge needed, not being regarded as an individual, and being told what to do or how to act without any notice taken of their situation or opinion. Patients' experience of non-participation was formulated as a main theme: 'Lacking an equal relationship while being controlled without further information or with a lack of respect for the patient and his situation'. This theme was interpreted as apparent in the observed visits at the clinic.

The interpretation of nurses' description of patient participation, formulated as the main theme 'Getting information and security to act', also appeared in the observed visits. This theme was related to patients' receiving information and knowledge about the disease, medication, and possible side effects, and about how to manage and ease symptoms. Patient participation was also reported as productive contact between patient and nurse. The main theme 'Getting information and security to act' was based on three themes: getting information, getting security, and getting the requirements to act (for oneself).

How the nurses described patient non-participation related to patients' not recognizing information or not recognizing the security of the contact and that nurses have an obligation, in some cases, to make decisions for a patient because of the nurse's professional knowledge and expertise. In the structural analysis, the interpretation provided that the nurses described patient non-participation as two themes: 'Not accepting' and 'Deciding for patient'. Patient non-participation as described by the nurses was articulated as the main theme 'Not accepting'. This theme also occurred in the interpretation of observed visits.

There was a difference between what patients experienced and nurses described as participation and non-participation, especially non-participation. Patients' experience of participation was interpreted as concerning

responsibility: a responsibility one has and recognizes from one's situation. For the nurses, on the other hand, participation was about patients' getting information. Patients thus experienced participation as something that they have and adopt, whereas nurses described participation as something that they give to the patient. There were no similarities between the interpreted experiences of patients and nurses' descriptions regarding patient non-participation.

Even though the phenomena of participation and non-participation appeared in the interpretation of the patient visits, the patients' experience of participation and non-participation had no visible influence on the visits: there was no dialogue in the visits between patients and nurses on what the patients expected or the way in which they wanted to participate on their own terms. The set structure and content influenced the encounter between the patient and the nurse; the nurses directed the structure and content, and thus how information and education were provided and attained. Disagreement occurred between patients and nurses during the visits, possibly as a result of the absence of dialogue about the patients' preferences and values.

Patients' common descriptions of participation (III)

Of the 900 patients that consented to the study, 362 returned the questionnaire: 361 described participation by marking suggested items, 97 also described participation in their own words, and 1 respondent described participation only in his own words.

The analysis of suggested items showed that the most common description of participation was that the staff listens to me, with 316 respondents marking this suggested item as participation. Other items that a majority of the respondents marked for describing participation were getting explanations of symptoms (299), to tell about symptoms/problems (294), having staff explain procedures (287), knowing plans (276), knowing whom I can/shall contact (272), knowing what to do to feel well (236), and taking part in planning (199). When comparing the marked items and the themes used for phrasing them, based on the findings in Paper I, the analysis showed that the top four marked items corresponded to the two themes of 'Being confident' and 'Comprehending'. All findings regarding frequency of descriptions based on suggested items are presented in Table 3.

Table 3 Participation as described with suggested items: frequencies and percentages (n = 362)

Suggested item	Number of times response chosen: by frequency and (%)
Being listened to by the staff	316 (87)
Getting explanations to my symptom/problem	299 (83)
Telling about my symptoms/problem	294 (81)
Having the staff explain procedures	287 (79)
Knowing what's planned	276 (76)
Knowing whom I can or shall contact	272 (75)
Knowing what to do to feel well	236 (65)
Taking part in planning of care/treatment	199 (55)
Performing care myself (for example take medication or change dressing)	175 (48)
Performing self-care (for example adjust diet)	153 (42)
Setting own goals	137 (38)

More than 80% of the respondents marked the items that the staff listens to me, getting explanations to my symptom/problem, and to tell about my symptoms/problem when responding to what patient participation meant to them. One of the most frequently chosen items was found to be related to a background variable: to tell about symptoms/problems had a statistically significant correlation ($p = 0.023$) to the duration of present symptom/disease. Another statistically significant relationship was found between the item knowing whom I can or shall contact and the background variable sex ($p = 0.002$); this item was chosen by more women than men when describing patient participation. Additionally, to perform care myself and perform self-care were found to have statistically significant relations to the background variables age group ($p = 0.002$ and $p = 0.004$, respectively) and other disease/disability causing current contact with the health care sector ($p = 0.002$ and $p = 0.044$, respectively): performing care myself was more often marked as an item related to participation by those who reported an additional disease/disability causing contact with the health care sector than by those who did not. Performing self-care was marked as participation more often by the older than by the younger respondents. Both of these items were, however, chosen by less than 50% of the respondents as means of describing patient participation.

In the open answers to the question ‘To participate or experience that I participate, is also to...’, descriptions included actions and attitudes of the patient, as well as actions and attitudes of the health care staff. The actions described indicate that participation meant to take self-care actions, to act in relation to health care staff, and to act in relation to the health care system. Similarly, the attitudes described illustrated that participation could include

attitudes either towards one's own health or disease or towards the health care staff and system. The descriptions of participation as the actions and attitudes of the health care staff showed that participation requires equality and respect for what the patient knows, senses, and thinks of the symptoms and situation and the plans for the treatment. In the 106 meaning units that emerged from the open-ended question, 16 sub-themes were interpreted as matching the suggested items and corresponding themes from Paper I. Another 6 sub-themes were interpreted as additional. The additional sub-themes formed a theme named 'Having productive communication based on respect'. This theme contained the aspects of patient participation as being respected as a human being, being regarded as an individual rather than as a disease or symptom, and being regarded as an equal to the other parties of the health care team—i.e. the professionals—as one who has knowledge and values that need to be recognized. This is regarded as related to the findings of Paper II, in which the patients experienced participation as being responsible and taking on responsibility.

Conditions for experiences of patient participation and non-participation (IV)

To the questions regarding conditions for patients' experiences of patient participation, 181 patients gave a response, of which 153 were considered relevant. Additionally, 124 patients responded to the questions regarding situations and conditions for patient non-participation, 102 of which were considered relevant.

The findings revealed seven themes that could be interpreted as conditions for situations in which the respondents had experienced patient participation. The themes were clustered, with their corresponding sub-themes, into two overarching themes: 'Knowledge' and 'Respect'.

The themes related to 'Knowledge' were being informed based on one's needs, having knowledge, making decisions based on one's knowledge and needs, receiving the care one regards as necessary, and performing self-care. The responses illustrated experiences both of obtaining knowledge and of having knowledge and sharing it with the health care staff. Knowledge was found to be more appropriate than information, as the respondents' experiences indicated that the information provided needed to be based on the person's needs and that patient participation occurred when the information had been given in such a manner that the patient could grasp it.

In the overarching theme 'Respect', the themes being regarded as an individual and playing a part in the planning interconnected. The texts that were interpreted as related to the sub-themes and themes showed that to experience patient participation, health care staff needed to be willing to

regard the patient as an individual, to focus on the person rather than the disease, to consider the person's situation, and to listen to and consider the problems or symptoms that the person described to the staff. Allowing the patient to decide dates for visits and surgical procedures was also an illustration of patient participation, regarded as respect for the individual's other engagements and everyday life.

Additionally, six themes in the responses describing situations and conditions for experiences of patient non-participation were found: three themes (and their corresponding sub-themes) that were clustered into a domain, or overarching theme, named 'Lack of knowledge', two themes with sub-themes corresponding to 'Lack of respect', and one theme, 'Passiveness', with its related sub-theme.

The descriptions interpreted as 'Lack of knowledge' assembled the themes not getting sufficient information, not getting the care one regards as necessary, and getting information but no explanation. The experience of non-participation appeared as a lack of personalized information, which occurred when the patient received standard information rather than the information the individual needed and when he or she did not get full information. Non-participation also occurred when an individual was told what to do or what would be done but not the reason. In addition, experiences of non-participation were described as being hindered in getting the care needed, indicating that the individuals' knowledge about the signs of illness or request for checkups were not taken into account and that when they asked for a contact or an appointment, that knowledge was ignored.

'Lack of respect' clustered the themes not having one's knowledge recognized and not being regarded as an individual. The interpretation revealed that respondents experienced non-participation when not being listened to or when the knowledge they have about their body, the signs of illness, or how to handle symptoms was not considered. The responses interpreted in these themes also showed that non-participation occurs when one is regarded as an object, rather than a subject, by the health care staff.

The theme not acting and its corresponding sub-themes were interpreted as related to a domain named 'Passiveness'. This theme illustrated that non-participation can also occur when patients regard themselves as responsible for acting yet do not perform any action.

Summary of the findings

The studies have provided the insight that patient participation carries a meaning of having knowledge about one's body, illness, and symptoms; of providing information to the health care staff; of being listened to, trusted, and recognized for one's knowledge and experience; and of being conside-

red a resourceful individual. All themes and sub-themes related to patients' experiences and descriptions of patient participation and non-participation are presented in Table 4.

Having information that can be used in one's daily life is central to patients' experience of patient participation. Thus, comprehension is vital, as participation is not just being able to recall information but also includes understanding information, having knowledge, and being able to exercise one's knowledge. Performing self-care and standing up for oneself have also arisen as aspects of patient participation. Providing information is an aspect of patient participation, and the studies have shown that patients provide information to health care professionals, i.e. participate. However, the nurses did not recognize this aspect as patient participation but focused on participation as being provided with information.

To patients, various aspects of sharing correspond to participation: sharing information, as in telling about one's experiences and knowledge, being listened to and receiving relevant information, and sharing respect between the parties in the health care interaction—the health care staff and the patient. It appears that being recognized and respected are vital conditions that need to take place for patient participation to occur.

Patient non-participation, on the other hand, occurs when the patient is not being listened to or is not receiving information, as well as when he or she is not being respected as a human being and/or individual. Furthermore, patient non-participation carries a meaning of not understanding one's situation and the circumstances, not receiving proper information, and being treated not as a person but, rather, as a symptom or a disease, a problem to solve, in interactions with health care staff.

Altogether, patient participation from a patient perspective relates to having knowledge, based either on one's own experience of one's body, symptoms, and context or on information provided by health care staff according to one's needs and in such a manner that it can be comprehended. Patients' knowledge generates confidence, yet for participation to occur, the knowledge one has as a patient must be recognized by the health care staff. Furthermore, patients recognise knowledge as participation, as it provides for being in control of handling one's disease and treatment in daily life, and knowing what will happen in contacts with the health care sector and where to turn for help among health care providers.

On the other hand, patient non-participation relates to lacking knowledge and lacking respect, which, in turn, relate to not having control over one's disease and of lacking productive contact with health care staff but, rather, experiencing being regarded as an object or being told what to do without explanations as to why.

Table 4 Overall presentation of themes and sub-themes related to patients' experiences and descriptions of patient participation and non-participation

Paper	Patient participation	Patient non-participation
I	<ul style="list-style-type: none"> ○ Being confident - in oneself (one's ability, the body's ability, the signals and signs that one's body communicates, and one's own goals) - in the caregiver (collaboration, the necessity of one assigned contact and of being listened to) ○ Comprehending - information - one's own body - the disease - the treatment ○ Seeking and maintaining a sense of control 	<ul style="list-style-type: none"> ○ Not understanding - the health care structure - the expectations of others - the reasons for treatment - the signs and symptoms of one's body ○ Not being in control - over the disease - over the treatment - over access to the care the patients believed they needed ○ Lacking a relationship ○ Not being accountable - not being respected - lacking value as an individual human - being physically or emotionally exposed - being regarded as a bearer of disease rather than an individual
II	<ul style="list-style-type: none"> ○ Being responsible and accepting responsibility according to the individual's situation - being an equal partner in the relationship - accepting responsibility - being responsible - being seen in one's context 	<ul style="list-style-type: none"> ○ Lacking an equal relationship while being controlled without further information or with a lack of respect for the patient and his situation - being controlled - lacking respect - lacking information
III	<ul style="list-style-type: none"> ○ Being confident^b - <i>that the staff listens to me</i> - <i>to tell about my symptoms/problem</i> - <i>to set my own goals</i> - being cared for in individualized manner - being confident with the health care staff - being confident with the situation - setting own goals - being cared for properly 	

^b Suggested items (phrased from Paper I) in italics, additional sub-themes in standard text.

	<ul style="list-style-type: none"> - being listened to o Having productive communication based on respect - getting requirements for a dialogue - being respected - being regarded as a person - being respected as an individual - having a suitable team - being invited to share in dialogue o Comprehending^b - <i>getting explanations of my symptom/problem</i> - <i>having the staff explain procedures</i> - <i>knowing what to do to feel well</i> - receiving information - having knowledge - taking actions based on knowing oneself - receiving information based on one's needs - taking actions based on knowledge o Being in control^b - <i>knowing what's planned</i> - <i>knowing whom I can or shall contact</i> - <i>taking part in planning of care/treatment</i> - <i>performing care myself</i> - having control over contact - having a regular contact - having conditions for making own plan/s - taking part in planning - having control over disease o To perform self-care^b - <i>to perform self-care</i> 	
IV	<p>Knowledge</p> <ul style="list-style-type: none"> o Being informed based on one's needs - when first being listened to, then being informed - when getting knowledge based on my questions and needs - when getting graspable explanations - when being told what's found and what's going on 	<p>Lack of knowledge</p> <ul style="list-style-type: none"> o Getting insufficient information - when I don't get enough information - when I don't know what will happen - when I don't know what has happened - when I'm not informed so I can take part in a decision

	<ul style="list-style-type: none"> ○ Having knowledge - when getting explanations rather than information - when getting information so I know how to act - when I handle my disease because of my knowledge - when I'm told what I can expect - when I learn how to react to symptoms ○ Making decisions based on one's knowledge and needs - when I decide based on what I know - when I receive information and then I can decide which treatment I prefer - when I decide together with my physician - when we find solutions together - when I decide based on the effect on my situation - when I set dates for visits and procedures according to my plans ○ Receiving the care one regard as necessary - when I get the treatment that I need - when I get the tests that I need - when I get the contact that I need ○ Performing self-care - when I can manage self-care - when I take part in activities 	<ul style="list-style-type: none"> - when I'm not informed on time - when not told where to turn ○ Not getting the care one regard as necessary - when I'm referred without dialogue - when I can't get in touch with the staff - when the treatment I need is postponed - when I can't get the care I believe I need ○ Getting information but no explanation - when I'm given results but no explanation - when treatment is given according to a set protocol - when information is given according to a set checklist - when I can't get rationales for procedures <p>Lack of respect</p> <ul style="list-style-type: none"> ○ Not having one's knowledge recognized - when my knowledge is not considered - when my description of symptoms are not taken seriously - when what I tell is not as important as test results - when diagnosis/treatment is established in advance, irrespective of my story ○ Not being regarded as an individual - when feeling that I'm stupid - when I'm blamed for my problems - when being regarded as an object - when I'm not seen for who I am - when I'm not listened to - when my opinion is not regarded - when my remarks are ignored and staff do as they prefer <p>Passiveness</p> <ul style="list-style-type: none"> ○ Not acting - when I lack energy to ask or tell - when I don't tell or do
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Discussion

In 1994, WHO stated the need to promote patients' rights in a document that, among other things, aimed to strengthen '*beneficial relationships between patients and health care providers, and in particular to promote a more active form of patient participation*'.⁴⁴ In February 2006, WHO presented another document, on empowering individuals as a means of improving health.¹⁰⁹ The document suggested that being involved in decisions in society is a vital factor in being empowered and indicates that participation—that is, being involved in decision making regarding factors that influences one's working or living environment—can be adapted to patient participation as being involved in decisions regarding one's health.

As I stated in the background analysis, patient participation has previously, with few exceptions, been regarded as related to partaking in decision making, both in legal documents and in research. However, according to the findings (I–IV), patient participation does not correspond only to being provided with information and taking part in decision making. Although patients' might experience participation as being a part of the team in planning, it was not the most common element in their narratives and descriptions of patient participation, and it seems not to be the most important aspect of their experiences of participation in health care. When we pay attention to the people primarily concerned, i.e. those who have personal experience of the phenomena of patient participation and non-participation, aspects of patient participation in addition to those previously assumed are found. Thus, I will suggest a broader view of patient participation and non-participation, and will discuss how patients' experiences can be used for patient participation to come about.

Information – knowledge – comprehension

Previously, knowledge has not commonly been referred to in the literature, but I found information to be a common issue in the articles that related to patient participation, even though knowledge is an aspect of participation found in its early definitions.¹⁸ Knowledge can be described as knowing what and knowing how,¹⁷ and the word originates in part from the word for 'familiarity' and in part from 'play' or 'game'. The difference between information and knowledge lies mainly in the notion that information points primarily to the communication of facts, whereas knowledge is a body of facts learnt.¹¹⁰ Information is required for someone to gain knowledge, but having information does not necessarily mean that the individual has know-

ledge.³ Information also carries a different meaning from knowledge, in that providing or giving information does not necessarily mean that the partner in the dialogue understands the information provided.¹¹¹

In 2003, the Swedish National Board of Health and Welfare published a report on patient participation.¹⁵ The report stressed patients' right to participate, with participation defined as receiving individually tailored information, and having the possibility of choosing the treatment and of seeking a second opinion. Rather than participation's simply being the provision of information so that patients can partake in decisions, which appears in the legal definitions,¹¹² these findings show that having knowledge is itself an aspect of patient participation. Being informed is a prerequisite for having knowledge and comprehending, and patients experienced participation not only as receiving information but also as comprehending the information and comprehending the disease, their body, and the treatment (I, II). Study III later confirmed that receiving information and knowing facts were aspects of patient participation to a larger group of people with experience of being in the patient role. Furthermore, patient participation was described as occurring in situations when the patient had knowledge (IV). Hence, comprehending information and having knowledge are essential aspects of the experience of patient participation. As a result, the general focus on patient participation as being provided with information should be considered in relation to knowledge and comprehension, which carries the aspect of grasping information and being able to understand it.¹¹³ The findings support that being provided with individually adjusted information promotes patient participation, yet the information provided needs to be accompanied by opportunities for the individual to evaluate the content in relation to his or her situation and context.

The nurses, on the other hand, described patient participation as receiving information as a patient (II). In a review regarding patients' learning, the researchers investigated what patients prioritise as important to learn.¹¹⁴ They found that although the studies in the area were quite vague, there were indications that symptoms, signs, and medication are considered important areas. Nurses in nurse-led specialist clinics, and, presumably, nurses providing health care for patients with long-term symptoms in general, have the important task of providing patients with information and education.¹¹⁵ This should be based on what the individual needs and wants to know,³⁶ and the patient's experience should be a source for the communication. Often, however, the focus has rested on information content and how information is provided, with little respect accorded to how patients learn.¹¹⁴ To support patient participation, evidently patient learning is important, indicating a need to focus on how information is shared and the need for explanations to

supplement information in the patient-caregiver dialogue. The nurses carefully checked that patients could recall the information (II) but not whether they had comprehended the information the nurses had provided. Self-care behaviors, which have been found to be essential in optimizing health outcomes, specifically in heart failure, are dependant on adequate knowledge.¹¹⁶ Thus, nurses should recognize that patient comprehension is vital, i.e. they should support patients with relevant information and education, and, when needed, support interpretation of the information, so that patients can comprehend the information and acquire knowledge.

Inadequate and fragmented information and distrust were found to be factors that can isolate patients.¹¹⁷ Furthermore, non-participation is experienced when standard information is provided without further explanations, i.e. when information is provided without being connected to one's previous knowledge or related to the individual's circumstances, so that he or she, as a patient, can internalize the information (IV). In addition, lack of relevant information and knowledge can cause experiences of non-participation (II, IV) despite the rules and regulations that require health care staff to encourage patient participation.

In the International Classification of Functioning, Disability, and Health (ICF) participation is suggested to mean '*involvement in a life situation*'.²⁷ Involvement is pointed out as incorporating such things as partaking and being accepted or being engaged in an area of life. The findings suggest that participation also includes comprehending, which is a prerequisite for ICF's *applying knowledge*.

Patient participation can encompass providing information as a patient (II, III, IV). This aspect of patient participation has previously not been considered either in research or in health care legislations or similar documents. Patient participation contains the aspect of providing the staff with the knowledge and experience that one has (III, IV), and not only one's views on different treatments.¹¹⁸ Studies have shown that patient participation can be used to communicate feelings and symptoms to health care professionals¹¹⁸ and that participation can be defined in terms of asking questions and/or obtaining information. However, patient participation was also described as having and being able to use knowledge about one's situation, symptoms, and disease. Participation as sharing one's information and knowledge should be regarded along with the descriptions of participation as not only sharing but also being listened to: for positive patient-physician consultations to take place, there has to be, among other things, active listening from both parties,¹¹⁹ and the partaker's behaviour in the interaction might constrain or facilitate the other's response.¹²⁰ Nurses have also been found to interpret communication as a prerequisite for patient participation, along with, e.g., the aspect of sharing

information.⁸⁴ Being provided with information and providing information are thus two aspects of patient participation, supporting the assertion that the broader description of participation as sharing,²⁰ as in sharing information and knowledge, is more appropriate than the more restricted specification of patient participation as being provided with information as a prerequisite for partaking in decision making. Furthermore, communication is required for patient participation to occur.

Patient participation vs. non-participation

If patient participation meant solely being provided with information and partaking in decision making, as suggested in most literature, one could assume that non-participation equals not being provided with individual information and not partaking in decision making. However, I found little in the literature regarding how patient non-participation has previously been defined: only one dictionary provided a definition, suggesting that non-participation is not taking part.²⁴ As a way of expanding the understanding of the phenomenon of patient participation, non-participation was included in this investigation and analysis. The experiences and descriptions of patient non-participation mirrored patient participation to some extent: there were similarities regarding being respected and lacking respect, and regarding being in control and not being in control. However, the aspects of non-participation also provided for a separate understanding. Differences were noted as patient participation comprised aspects of understanding information, having knowledge, and comprehending the information, i.e. being able to use it whereas patient non-participation, on the other hand, mainly comprised aspects of not knowing, as in not having enough information. A comparison between '*comprehend*' and the corresponding theme of non-participation (i.e. to not understand) showed that to comprehend meant not only to obtain information but to grasp its contents and to be able to integrate it into one's life (I), suggesting that education provided for patients should be appropriate for the individual and related to previous knowledge.^{121,122}

Furthermore, the aspect of non-participation as being regarded as an illness or a problem to solve, rather than as a person, did not have an exact opposite among the themes related to patient participation. Mirroring this aspect of non-participation were themes that described patient participation as being listened to and respected, and having one's social context recognised. In addition, being able to decide for oneself based on one's own context was considered patient participation. Consequently, I suggest that patient participation and non-participation are not two ends of a continuum but, rather, separate yet related concepts. However, the phenomenon of patient

non-participation needs further investigation, and the concept should be defined for future clinical and research purposes.

Patient participation – a process taking place

Participation was experienced in similar ways by the patients in the studies, by means of having and providing knowledge, being respected, and having control over one's body and plans. Statistical tests with respect to subgroups could be done in only one part of this thesis (III), and the descriptions of participation were then compared to the reported demographic data: sex, age group, type of setting visited, duration of symptoms, and whether the patient had had other contacts with the health care sector (due to other disease or disability). Two variables probably related to how the patients choose to describe participation. First, 'to tell about symptoms/problems' showed a statistically significant correlation to 'duration of present symptom/disease', and even though the relations could not be illuminated fully, other researchers have suggested that living with a chronic disease requires an active patient role.¹²³ Second, more women than men chose to describe participation as 'to know whom I can contact', which corresponds to findings from other studies that women preferred a more active role than men when it came to decision making.¹²⁴

Setting goals has been suggested as an aspect of participation,⁴⁷ yet this item was not chosen to describe participation as often as, e.g., the aspects of being listened to and getting information (III). Rather, being confident in the goals one set was interpreted as patient participation (I). Hence, health care staff should enquire about and recognise the goals of the individual in the dialogue, and patients should put forward their preferences and goals. In the studies, there were examples of missed opportunities for a mutual understanding due to the lack of dialogue about the patient's goal and views (II), and experiences of non-participation occurred due to the lack of recognition of the individuals' experience (IV).

Participation has mainly carried a limitation to being involved in decision making (see, e.g., refs ^{52,57,124-126}). This comes as no surprise, as the MeSH database comprises patient participation since 1978, defining it as '*patient involvement in the decision-making process in matters pertaining to health*'.²⁵ Furthermore there seems to be an assumption that the health care staff should provide for conditions for participation, mainly through providing information,¹²⁷ and a number of studies have focused on interventions to increase partaking in decision making.^{128,129} Nevertheless, the studies indicate that the patients are already participating (I, II and IV), which is slightly different from the assumptions that patients need to be made participants. Ruland *et al*⁵³ have shown that patients want care to be based on their needs

rather than on nurses' perceptions, thus indicating the importance of being listened to and respected. Patient participation can apparently be viewed as having and sharing information and knowledge, being listened to and respected, and taking actions to maintain a sense of health and wellbeing (I–IV). With this latter understanding of patient participation, participation might be taking place in ways other than those considered for example in legislation and surveys regarding being involved in decision making. The patients in these studies shared experiences of situations in which they had experienced participation, e.g. had shared information and taken actions (I, II and IV). Furthermore, patient participation was influenced by external as well as internal conditions, as patient participation was considered both being responsible and accepting responsibility in relation to one's context (II).

However, although the patients regarded participation as an active, internal attitude held by the individual, the nurses experienced that they make patient participation happen (II). Nurses have perceived that patient participation might be hindered by nurses' lack of, or failure to use, knowledge regarding factors that facilitate patient participation,¹³⁰ e.g. lack of reflection on their need to be in control and on patients' needs. To experience participation, as in partaking in decision making and care, patients with cancer¹¹⁸ thought that an active attitude was required, among other things, such as reasonably good health. Access to information and good interactive relationships with nurses and physicians were found to promote participation. Additionally, conditions for participation occurred when the patient was listened to and the information he or she shared was recognised (IV). Thus, the efforts of health care professionals to support patient participation should be broadened from primarily providing information to sharing information, along with recognising patients' information, knowledge, and context, and incorporating both parties' active listening.

Some narratives indicated that patient participation can develop through a process (I). Processes in relations (between consultant and consultee)¹³¹ have been described as turning to a consultee-centred process through the presence of three major categories, namely approach, attention, and autonomy. All three categories interact as turning points, and the turn is influenced by the understanding of the other (approach); a shift of focus to the other, i.e. to the consultee rather than to the consultant (attention); and a sensible detachment, so that one's own feelings can be set aside and responsibility can be given with trust in the other's ability (autonomy). Likewise, the movement from an experience of non-participation to participation, through knowledge and relationships, might be conveyed by initial experiences of monologues, in which the patient experiences being provided with information and being

told what to do, but later, when a relationship has been established, having information shared by both parties in a dialogue, with both contributing knowledge (I). Patients' expectations of their role, as well as their past experiences,^{59,64,132} are important in the establishment of cooperation between the actors in health care. The expectations of the patients, as well as those of the nurses, influenced each one's behaviour and attitudes towards the other (II). Others have also described the importance of establishing relationships between the patient and the caregiver to achieve a health-promoting environment (e.g. ref.¹³³). Nurse-led clinics, with their well-defined and relatively long contact between the nurse specialist and the patient,⁹⁴ might promote this but must focus on the patient's needs.¹³⁴ Moreover, further studies regarding the experiences of and expectations for participation in varying illness situations and contacts with the health care sector are needed.

Participation as a question of respect rather than power

In some cases, the patients felt a responsibility to be active in their contact with health care staff, and they described non-participation as not taking actions (I, IV). The responses might be influenced by the fact that patients are expected to be active, in the sense of partaking in decision making. This indicates a need for further studies regarding whether patients consider themselves as participating, based on their own definition of participation. Other researchers have suggested that initially, the trend towards patients partaking in decision making meant that patients were allowed to make decisions; later it came to mean that patients were encouraged, and nowadays patients are forced to make decisions for themselves.¹³⁵ There were examples in these studies of patients blaming themselves for their experiences of non-participation when they were not being active (II, IV). However, non-participation might be experienced differently, primarily as a lack of control, a lack of knowledge, and a lack of respect for the individual, i.e. for his or her experience and knowledge, context, and/or value as a human (I, II and IV).

The personal self, i.e., the personal life, values, beliefs, and relationships, is in focus when patients make decisions concerning treatment,¹³⁶ and so to understand decisional processes, the cultural context and health values have to be considered.⁶³ I recognise that values also influence patient participation in a broader sense than solely partaking in decision making; being able to choose for oneself and being able to influence and direct one's own care according to one's needs and one's social situation also represent personal life, values, and relationships. The example of choosing when and where to schedule surgery (IV) might be regarded as partaking in a decision but also reflects that participation means considering one's context and social situation, i.e. being able to consider and value the health care need in one's social con-

text. When that context is recognised by the health care staff, participation can take place, as the individual and his or her values are recognised.

The conditions described in situations that were experienced as patient participation (IV) showed a focus on respect for the individual and the knowledge the individual carries. Patients' knowledge was related to the symptoms they experience as well as to their situation, i.e. the context in which they live with the disorder or symptoms. Thus, respect for the individual and the knowledge he or she carries is a necessary condition for patients' experience of participation. Respect for the person has been suggested to be a wider notion than autonomy, which is commonly regarded merely as the right to partake in decision making.¹³⁵ Respect for patient autonomy has been ranked higher in importance than professional expertise in physicians, which is possibly a reaction to the growing awareness of patients' rights.¹³⁷ Respect for a patient's integrity is a basis for achieving patient participation in planning and performing care,⁴⁶ and encompasses communication, whereby information is provided not only as a basis for decision making but also because it is an important factor in trust between health care professionals and patients. Lack of trust might indicate a deeper problem than a quest for patient autonomy, as Tauber has suggested.¹³⁸ Confidence and trust have, additionally, shown a positive correlation with satisfaction,¹³⁹ indicating that patients value respect and trust highly.

Interaction based on respect for the patient as an individual is an aspect of patient participation: the patients' experiences of participation incorporated confidence both towards the staff and towards themselves and their experiences, opinions, and goals (I), and recognition of each patient's unique knowledge and respect for the individual's description of his or her situation were found to be conditions for participation (IV). Furthermore, being respected and being regarded as an individual were considered patient participation (III). Studies have shown that nurses need to improve their skills in asking for the patient's experience.¹⁴⁰ Patient empowerment has been suggested to be a key to health care, yet there is a risk that staff will control the information they provide and consider patients empowered only if they make the decisions that the staff member defines as correct.¹⁴¹ Patients need to be recognised as having the power to determine nurse-patient interactions and communication.¹⁴² Furthermore, health care staff can recognize patient power by recognizing the individual's knowledge and confidence, and thus support patient participation.

In light of a 2003 report from the National Board of Health and Welfare, it seems that patient participation should be provided by the health care system.¹⁵ After the first study, an additional view was suggested: rather than participation being provided, indicating a lack of patient power, the focus

should be on sharing (I). The ideas around information as shared have further developed (II–IV), indicating a more equal power distribution than previously suggested. Presumably there are two parties, the patient and the health care professional, who interact to create conditions for participation: the caregiver provides general knowledge on anatomy and physiology, the disease, and the treatment, whereas the patient provides knowledge about the experience of symptoms, his or her body, and his or her situation and values. Each partaker in the dialogue thus carries valuable information that is useful for the other party:

- the health care provider, for developing knowledge and understanding about the illness and the illness experience of the individual, which can add to the understanding of patients' illness; and
- the patient, for developing knowledge and understanding about the body, the disease, and ways of living and coping with symptoms.

To support working relationships,⁶⁷ information should be regarded as shared, not given, to promote a relationship in which both parties' contributions are recognised.

There was a discrepancy between the experience of patient non-participation by patients and by nurses (II). From the patients' perspective, health care professionals could overrule them, but for the nurses, non-participation reflected the fact that patients did not accept what was offered them. Patient participation and non-participation occurred in the patient visits, as described by both patients and the nurses, yet these visits included no noticeable discussion regarding patients' experiences and expectations of participation (II). The set structure and content influenced the encounter between patient and nurse; the nurses directed the structure and content, and thus how information and education were provided and attained. In some places, lack of consensus between patients and nurses was interpreted, possibly as a result of the absence of dialogue about the patients' preferences and values. Kettunen *et al* have suggested that patients need to be recognised as influencing their interactions and communications with nurses.¹⁴² The lack of dialogue seemed to have a negative influence on the conditions for providing information and education. Moreover, non-participation was described as not being respected and the absence of dialogue in which one's knowledge and views are recognized, and experiences of non-participation occurred when the patient was not regarded as a human being but, rather, was seen as a disease or disorder, a problem that needed to be solved (IV).

Theoretical impact on caring

There seem to be an assumption that good care presumes patient participation, as expressed in health care legislation. On the other hand, the definitions of patient participation in health care cannot be traced to patients' descriptions, thus lacking the patient and user perspective. Nerheim⁴³ has suggested that caring should focus on experience and that interpretation is brought into the dialogue between patients and health care professionals; the patient's voice as well as the health professional's should be heard in the communication. Kuhse⁴⁴ argued that each patient has to be regarded as an individual, and nurses can acknowledge ethical norms by recognizing each individual's autonomy. People with the experience of being in the patient role should be included in the dialogue regarding the expectations of good care. What legislation and regulating standards have focused on, i.e. patient participation primarily regarded as partaking in decision making, seems to be based mainly on a semantic derivation by administrative authorities, which might stem from a tradition in which conditions for good care are set by formal authorities. There is a lack of critical commentary on the fact that the assumption lacks a connection to how the phenomenon is experienced by patients, i.e. the people it primarily concerns. Rather than critical analysis of how patient participation is defined, there is discussion in the literature regarding patient autonomy: the idea that patient participation can be translated as partaking in decision making seems to spring from the idea of autonomous citizens or employees partaking in decisions that have an impact on their lives and social environment. Previously no researchers seem to have asked patients whether this is a correct assumption. The studies that make up this dissertation have shown that in some respects it is, although the patients provided additional aspects of patient participation, which correspond to a broader definition.

Some of the additional findings also parallel the works of nursing theorists discussed early: in the background analysis, the works of Nightingale, Henderson, Orem, and Eriksson were all found to deal implicitly with the issue of patient participation. Furthermore patient participation was found to be covered explicitly in the works of Orem and Eriksson. Orem³⁸ seems to regard participation as fundamental in nursing: the relationship between the individual in need of care and the nurse presupposes participation in the sense of the patient's partaking in self-care actions. Orem has written about the individual engaging in self-care needs in its positive sense.

Participation is affected by, among other factors, interest and concern, which Orem has outlined as expressions of interest in and knowledge of health and health care. The nurse can teach the patient only if he or she knows what the patient needs to know. These aspects of Orem's ideas are

in accord with my findings, yet patient participation was also found to include providing one's knowledge to the health care staff. Furthermore, the aspects brought forward by the patients include not only knowledge but the experience of their illness, their symptoms, and their situation, including their context, of which the illness experience is a part. Orem³⁸ further wrote that nurses and patients relate to each other in human interactions, and she pointed out the necessity of both parties' regarding each other as subjects in the relation.

A work widely known among Swedish nurses is that of Kati Eriksson,³⁹ which, as presented, also covers patient participation explicitly and implicitly. Her work seems to outline sharing as a basis for caring; to share, there has to be an interaction, an interplay, which presupposes trust. Sharing is described as unity between the carer and the patient. Learning is a second prerequisite for caring, an act that also needs interplay, whereby the individual adjusts information to his or her present context. Eriksson's inclusion of sharing in participation aligns with how participation is defined in a broad sense in dictionaries,^{19,20} and corresponds to the sharing that patients experience when the focus is turned to them.

The findings indicate that the reasoning related to patient participation by nursing theorists such as Orem and Eriksson has implications for the view of patient participation as a caring issue. The general idea of patient participation in legislation seems not to be influenced by the ideas raised by nursing theorists, and I assume that these works have had little impact on the definitions of good care. As a paradigm,¹⁴⁵ caring includes ethical norms; for nurses, the prerequisites are described as, e.g., respect for human rights and for individuals' right to choice.¹⁴⁶ Even though the idea of caring as a paradigm is not undisputable, and caring might instead be recognised as a development of a discipline,¹ in both scientific and clinical areas we need to embrace and expand the knowledge of the concepts related to caring, including patient participation. Furthermore the ethical foundations should apply to how we use the knowledge regarding patient participation. As a result, we should consider patients' experiences of participation when applying definitions to the term, and our ethics-based understanding of individuals as autonomous speaks to the voice of the patient being considered, along with the voice of the health care professional. Ricoeur's philosophical works on hermeneutics apply to this attitude, as he developed the idea that each human being has experiences to share with others in communication.^{2,85-87} The fact that patients regard sharing their information and knowledge regarding their experience of symptoms, illness, and treatment as participation makes a difference to their interactions with health care staff: the parties partaking in the communication need to share and interpret each other's experience.

Methodological considerations

General considerations of methods

Investigating phenomena can involve various analytic methods in the phenomenological field. To me, it was important that the ontological base corresponded to my values, which I found Ricoeur's philosophy to do, with its focus on communication as a way of explaining and understanding the meaning of a phenomenon as experienced by others.⁸⁸ It is important that the findings mirror the method used in a study,¹⁴⁷ and the interpretative approach should thus influence the findings. However, a critical questioning of one's interpretation is crucial, as the interpretation seeks the best interpretation of the common meaning, not the experience itself, which opens up in the text.⁸⁸ The validation of interpretations in this thesis consisted mainly of parallel interpretations and critical dialogue with my supervisors and co-authors. Furthermore, data collection was performed using multiple methods. One way of reaching the human experience of a phenomenon was narrative,¹⁴⁸ which we considered appropriate for studying people's experience of patient participation and non-participation. In one study (II), this was combined with observations to triangulate data. Furthermore, the questionnaire used for the study presented in Papers III and IV provided access to more people and thus a way to validate the findings in a larger population. However the questionnaire did not provide the opportunities for narratives that the interviews did. The participants in all studies had personal experience of being in the patient role and were, as such, considered appropriate to solicit for their experiences of the phenomena. Further critical considerations identified in each paper are outlined below.

Paper I

The findings were validated by parallel interpretation and critical dialogue, but others might have found other aspects or themes if they had been involved in the interpretation.¹⁴⁹ The task of explaining and understanding the phenomena, through the interpretation of experiences of others and one's preunderstanding, is challenging, and some studies have stayed too close to the manifest content of participants' own words.¹⁴⁷ Interpretation can be considered both a strength and a weakness in analysis using the hermeneutic tradition: the interpretation process is guided by our preunderstanding (i.e. our preconceived ideas and understandings that we bring to the text), which leads to a constant questioning of the analysis that, in turn, connects it to a deep understanding of how human beings experience a phenomenon.⁸⁸

All participants had what was considered extensive experience of contact with the health care sector. Certain aspects were found during the analysis that indicated that the experience of participation might be influenced by

acute illness. As this was not the key issue for the study, possible relations between what patients experience as patient participation in relation to the length of illness was investigated further in Paper III.

Paper II

The initial plan was to observe visits at the nurse-led outpatient clinic of the participants of the first study, to which they all had given consent. However, before data collection was completed, some of the participants were no longer patients at the clinic (because of severe illness, death, or referral). Thus, other participants were recruited for the second study, which also provided us the opportunity to follow full series of visits^c to the clinic rather than single visits. As a result, all visits had similar circumstances and were not influenced by previous relations between the patient and the nurse specialist. The fact that the patient participants in the study were all men (and that both nurses were women) might be a limitation. Studies have shown that women prefer a more active role in medical decision making than men do,¹²⁴ but I found no studies that supported the idea that men and women experience participation differently.

As principal investigator, I took field notes during observations. Even though I was not participating in the interactions and dialogue during the visits, one cannot consider me an entirely non-participating observer,¹⁵⁰ as I was sitting visibly in the room, quite close to the participants (seated on a stool in a corner where none of the activities were taking place, so there would be no need to change the routine during the visit). As one person has a limited chance of capturing all actions, there might have been incidents that were not noted in the field notes. It has been suggested that video cameras might be more reliable than field notes, as all researchers involved in the study can see what took place. However that presupposes that the camera can capture everything.¹⁵¹ In this particular case, the visiting rooms were not big enough to set up a video camera that could capture all actions and interactions of the participants. Furthermore, the presence of a video camera would have altered the possibilities of carrying out the visits in an ordinary manner and so would have interfered with the visits. The fact that reality is never the same as a film was also considered, and that research is always dependant on the questions that the researcher brings to the text, no matter how the text comes to be.¹⁵¹

Papers III and IV

The overall response rate of 40% to the survey was considered acceptable, as there were no opportunities for reminders.¹⁵² Yet, 362 responses were returned, and the descriptions and experiences of more people than we could

have reached with interviews, given the current resource limitations, were obtained. A mail survey would have given us opportunities for reminders, as would lists of the patients who had accepted the questionnaire. Reminders would probably have yielded a higher response rate, yet at that time, these approaches were considered inappropriate: a mail survey would have required the use of the hospital's records to sample the population for the study, which was, considered a negative impact on the personal integrity of the people who had visited the specific health care provider. Furthermore we wanted to reinforce that the survey applied to the participants' experiences of patient participation and non-participation in general. Thus, personal delivery of the questionnaires with verbal information, along with the written, was chosen. We considered compiling a list of patients who had accepted the questionnaire but found that it was too time consuming for the contact persons among the staff. Furthermore, keeping lists of previous and present patients at wards and clinics was considered a risk to patient anonymity and, as mentioned, as having a negative impact on integrity. Instead, with the chosen method for data collection, the respondents were provided with the possibility of remaining anonymous to us as researchers both at inclusion and when responding, and we also had the opportunity to provide the respondents with verbal information that the survey focused on their views on patient participation in general, not how they had perceived participation and non-participation in the setting where the questionnaire was distributed.

Although validity was tested in a pilot study, we received a number of non-relevant responses to the question regarding situations and conditions in which the respondent had experienced patient participation and, later, non-participation (IV). A number of respondents replied, "This has never happened," or gave similar responses. These might be responses to whether participation had taken place or not, instead of what we had intended: to reach a description of situations and conditions for an experience of participation. The non-relevant responses might indicate vague phrasing or might possibly be related to whether the respondent had previously responded to the annual patient satisfaction questionnaire distributed at all major hospitals in the area. As the annual questionnaire includes issues regarding whether the patient has participated, our question might have been understood as whether participation or non-participation had taken place. However, most responses viewed as non-relevant were very short, suggesting that the respondents had experiences of participation or non-participation, but the responses did not outline the conditions for the experience, and as a result, we could not analyse them further. In future surveys regarding experiences of patients, whether related to participation or to other phenomena, opportunities for follow-up and analysis of internal or external refusals could also provide

for sorting out misunderstandings and allow for supplementary information from respondents.

A further disadvantage identified with the questionnaire was that the space provided for the open-ended responses might have limited the responses. This supports the notion that open-ended questions in questionnaires supplement but cannot replace interviews in studies regarding phenomena: in combining these methods, we found the questionnaires useful for obtaining descriptions from larger populations¹⁵³ and the interviews appropriate for in-depth experiences of a limited group of people regarding patient participation and non-participation.

Conclusion

Based on the findings, I ascribe the broader meaning to patient participation: the way patients experienced participation and non-participation showed aspects in addition to those that had been found previously in the literature review regarding scientific studies and legislation. Similarities were found between the thesaurus broader definition of participation, as in sharing, and the patients' experiences of participation. Rather than using the narrowing descriptions of participation as being involved in decisions that concerns one's health care, the broader description of sharing should be a basis for dialogue on patient participation. That would provide for patient participation as previously known, i.e. as being provided with individually adjusted information and invited to partake in decisions related to one's care and treatment (in Sweden, also the possibility of seeking a second opinion). However, sharing would also allow for the additional perspectives found in this work to be considered:

- Participation as comprehending, as in comprehending how one's body works, what happens in one's body when symptoms occur, and how the treatment works. Participation includes comprehending the treatment plans that are set up, how and why procedures are performed, and what procedures and actions will take place. Furthermore, participation from a patient's perspective includes taking action based on knowledge about one's body, the disease, and treatment, and one's own situation, and also providing the health care staff with the knowledge and experience one has about one's body, symptoms, and social context.
- Participation as having productive communication in which one receives appropriate information that makes sense in one's situation, and that information is provided so that one can capture it and transform it into knowledge that is useful in one's daily life.

- Participation as being confident, containing aspects of being confident in one's knowledge about one's body and symptoms, in one's ability to handle one's symptoms and treatment, in the goals one has for oneself and in relation to the health care staff.
- Participation as having control over one's body, the symptoms, and the treatment, as well as being in control of the contact with the health care sector.

Furthermore, as patients experienced participation when they were shown respect and when knowledge was shared, as well as when health care professionals listened to and recognised their knowledge about their body and situation, these aspects should be recognised, as in sharing respect.

On the other hand, the findings indicate that patient non-participation is not a clear opposite of patient participation but, rather, is a separate concept. A general definition of patient non-participation for research and clinical purposes is needed, and it should consider

- patient non-participation as not understanding, not being in control, lacking a relationship, and being told what to do without further explanations, indicating that one is regarded as not being accountable to choose adequate actions appropriate to one's situation; and
- patient non-participation as not receiving information according to one's needs, as a lack of respect for the individual as a human being, and as being regarded as a disease rather than as an individual.

The findings support that patients should be recognised as resourceful individuals who have unique knowledge that can contribute to their health care, both by adding knowledge that might affect their health care plans and actions and by providing information *to* the health care staff regarding their experiences and knowledge. Patient participation requires respect for the individual, recognition of the individual's knowledge and circumstances, and communication by all parties, as well as active listening to the information and knowledge the patient provides.

Implications for practice

Many have called for a change from a paternalistic attitude among health care professionals to team-oriented work, in which the patient is included as a partner.¹⁵⁴ As individuals, we advocate for ourselves, and in a caring relationship, it is important to establish what needs to be cared for. Opportunities for people in the patient role to speak for themselves are needed in health care, regarding not only the decisions that health care professionals anticipate but also the factors and knowledge that the individual, as a patient, regards as relevant and important. The patient's lived experience needs to be given space by health care staff in interactions with patients¹⁵⁵ along with the issue of patient participation, in order to arrive at a consensus and to facilitate patient participation from the individual's perspective. Among other aspects, these findings show that when patient participation was not a subject of dialogue in patient visits at a nurse-led outpatient clinic, conflicting values concerning participation and non-participation were revealed. Lack of consensus between patients and health professionals on assessments of the severity of symptoms have previously been reported,¹⁵⁶ and these findings underscore the need for nurses to listen to and interpret patient's subjective experiences (i.e. symptoms) in addition to making clinical observations of signs.¹³⁴

Generally, a daily task for health care staff is to provide information to patients, a task that derives from both a legislative and a professional responsibility to provide information. The fact that many patients tell about being provided with standard information suggests that the information content might generally be based on what the health care professional considers important. However, being provided with standard information has been shown to result in experiences of non-participation. Rather, information should be provided based on the individual's previous knowledge and identified needs for information and should be followed by a dialogue confirming that the information has been understood and that patient comprehension has been attained. Furthermore, health care professionals have to listen to and recognize the knowledge that the patient has and can provide as a way of supporting patient participation and providing conditions for the creation of a team with opportunities for dialogue, and for sharing of information and knowledge.

The findings might imply that health care professionals should reconsider their attitudes towards and expectations of people who are in contact with the health care sector as patients. Far too many patients in these studies shared experiences of not being respected. Health care professionals should recognize patients' right to life and choice,¹⁴⁶ in the sense that people make choices that are appropriate for them based on their knowledge, their situation, and their values. What might be considered patients' non-compliance

can be caused by the absence of dialogue between the patient and the professionals regarding a patient's expectations, a lack of support that would help a patient to comprehend provided information, and a lack of recognition of the patient's situation. In fact, health care professionals should recognize that a choice made by a patient might well be an action of patient participation. For health care professionals, the way to achieve the understanding necessary to support the individual's experience of participation is to engage in dialogues that encompass patients' knowledge and context. Listening to the individual is a basis for ethics in care,¹⁵⁷ and recognizing the individual's experience and choice is a tribute to human rights.^{42,43}

For many years health care professionals have been instructed to encourage patients to participate in their care. The findings of these studies add new perspectives to the dialogues regarding patients' experiences of and expectations for partaking in health care. Primarily, health care professionals should take the opportunity to support patient participation by recognizing the patient as a person, a resourceful partner in the health care team, who has information and knowledge that needs attention.

Sammanfattning på svenska (Summary in Swedish)

Att vara delaktig som patient – vad det är och inte är

Bakgrund

Samhället har utvecklats mot ett individcentrerat ansvar för bl a ekonomi och hälsa. *Delaktighet* är det ord som vanligen används när dessa frågor diskuteras. *Delaktighet* har visserligen definierats till att som medlem i ett samhälle eller organisation vara involverad i de beslut som berör ens liv eller arbete, men *delaktighet* har också vidare betydelser, som att dela eller att kommunicera.

De finns många studier av patientdelaktighet som huvudsakligen beaktat delaktighet i den snävare betydelsen: att som patient få information och vara delaktig i beslut om vård och behandling. I de studier som berör att inte vara delaktig framkommer ytterligare en aspekt: att det motsvarar att inte följa föreskriven behandling eller inte medverka i vetenskapliga studier. Det finns inget bestämt svenskt ord för motsatsen till delaktighet, *d v s* att inte vara delaktig, och det är sparsamt beskrivet i ordböcker och lexikon, men en definition av att det engelska ordet *non-participation* är att inte ta del.

Trots omfattande dokumentation inom området saknades det studier av patienters beskrivning av att vara delaktig respektive att inte vara delaktig i vården och vilka förutsättningar som leder till att man, som patient, upplever delaktighet och dess motsats, vilket i detta arbete benämnts *odelaktighet*.

Syfte

Det övergripande syftet med avhandlingsarbetet var att förstå och beskriva vad patienter upplever att det är att vara respektive inte vara delaktig i vården. Därutöver syftade arbetet till att beskriva när och varför patienter känt sig delaktiga eller odelaktiga, för att förstå vilka förutsättningar som behövs för att patienter ska uppleva delaktighet i vården.

Metod

Studierna har haft en fenomenologisk-hermeneutisk ansats, i vilken kommunikation är essentiell för att förklara och förstå hur människor upplever fenomenen: att vara delaktig eller inte delaktig i rollen som patient. Avhandlingen baseras på fyra artiklar av vad personer med erfarenhet av patientrollen kommunicerat att delaktighet och odelaktighet är, när och varför delaktighet

och odelaktighet uppstår, och de centrala teman som tolkats i patienternas utsagor:

- I den första studien intervjuades tio patienter vid en sjuksköterskeledd hjärtsviktsmottagning. I intervjuerna, som genomfördes enskilt och individuellt, beskrev patienterna vad delaktighet och odelaktighet betydde för dem och återgav berättelser om situationer då de varit respektive inte varit delaktiga i vården. Intervjuerna, som vägledades av en frågeguide, spelades in på band och överfördes senare ordagrant till text, som tolkades utifrån Ricoeurs texttolkningsteori.
- I studie 2 bestod data av fältanteckningar från observationer av patientbesök vid en sjuksköterskeledd hjärtsviktsmottagning och intervjuer med de patienter som besökte mottagningen liksom med de sjuksköterskor som ansvarade för patienternas besök. Tre patienters samtliga besök på mottagningen observerades, totalt elva besök. Efter att besöksserierna avslutats genomfördes individuella intervjuer med de tre patienterna och de två sjuksköterskorna. Dessa intervjuer följde samma frågeguide och struktur som delstudie 1, med motsvarande frågor om vad patientdelaktighet och patientodelaktighet betydde för sjuksköterskorna. De tre textmängderna (fältanteckningar, intervjuer med patienter och intervjuer med sjuksköterskor) tolkades utifrån Ricoeurs texttolkningsteori och därefter tolkades texterna i relation till varandra: de teman som patienterna respektive sjuksköterskorna beskrev som delaktighet och odelaktighet ställdes i relation till vad som framkom i fältanteckningarna från de möten mellan parterna som observerats på mottagningen.
- Följande delstudie (vilken presenteras i avhandlingens tredje och fjärde artikel) baserades på en enkätundersökning bland personer som nyligen varit inskrivna vid eller gjort ett mottagningsbesök vid ett akutsjukhus för somatisk vård. Enkäten utformades specifikt för studien och patienterna ombads att beskriva vad det är att vara delaktig som patient. Svaren kunde anges med föreslagna alternativ, vilka formulerats utifrån utsagor i delstudie 1 och den litteraturgenomgång som föregick datainsamlingen, och/eller med egna ord. Därtill ombads patienterna att beskriva ett tillfälle då de varit delaktiga och vad det var i den situationen som gjorde att de känt sig delaktiga i vården. Motsvarande fråga för odelaktighet ställdes också. I artikel 3 presenteras analysen av svaren på frågan om vad det är att vara delaktig som patient. Eftersom svaren bestod av både fasta och öppna svar genomfördes såväl statistisk analys som kvalitativ deskriptiv analys. Den fjärde artikeln behandlar svaren på frågorna om situationer då delaktighet respektive odelaktighet förekommit, vilka analyserats med kvalitativ innehållsanalys. De två första

artiklarna samt den fjärde baserades på ett induktivt tillvägagångssätt, medan den tredje var delvis induktiv och delvis deduktiv, då resultaten jämfördes med de teman som framkommit i den första delstudien.

Resultat

För patienter innebär delaktighet att ha tilltro, att förstå och att ha kontroll. Att vara delaktig som patient innebär att ha kunskap om sin kropp, sin sjukdom och sina symtom, och att känna tillit till den kunskapen, så att man kan hantera sin sjukdom och sina symtom i vardagen. Att inte vara delaktig innebär att inte förstå och att inte ha kontroll över vare sig sin sjukdom och dess behandling eller sina symtom. En aspekt som framkommit, nämligen att upplevelsen av delaktighet kan vara beroende av vilken sjukdomssituation man är i, liksom vilken vårdkontakt man har, behöver ytterligare belysas i framtida studier.

Vidare har studierna visat att patienterna upplevde delaktighet som ett ansvar som utövas utifrån egna värderingar och den situation man befinner sig i, medan sjuksköterskor betraktade patientdelaktighet som att bli informerad så att man, som patient, kan agera. Vad patienterna upplevde som odelaktighet, att bli anmodad till åtgärder utan hänsyn till ens situation, skiljde sig från sjuksköterskornas upplevelse av patientodelaktighet, vilken innebar att en patient inte följde direktiv. De upplevelser av delaktighet och odelaktighet som framkom i intervjuer med patienter och sjuksköterskor återfanns i observationerna från mottagningsbesöken. Observationerna visade också att bristen på dialog om delaktighet kan leda till missförstånd och bristande förutsättningar för patienten att tillägna sig information och undervisning.

Den förståelse av patientdelaktighet, som att förstå och känna tillit, som identifierades i den första studien kunde relateras till en större population: de beskrivningar som flest använde för att beskriva delaktighet speglade vikten av dialog, i bemärkelsen att få berätta om sina symtom, att bli lyssnad till och att få förklaringar till ens symtom och de undersökningar som behövs. De aspekter som därutöver framkom var att delaktighet är att ha en relevant kommunikation där dialogen kännetecknas av respekt.

De situationer där delaktighet uppstått kännetecknades av att patienten hade respekterats som individ och varit en aktiv partner i planering av vården. En förutsättning var att patientens kunskap och situation hade beaktats av hälso- och sjukvårdspersonalen. Upplevelser av odelaktighet speglade att den information som givits inte hade varit anpassad efter patientens behov, att patienten blivit anmodad vad han eller hon skulle göra utan att det gavs någon förklaring till varför, liksom att patienten upplevt att hälso- och sjukvårdspersonalen såg honom eller henne som ett symtom, en sjukdom eller ett

problem snarare än en individ med ett symtom, en sjukdom eller ett problem. Likaså uppstod upplevelser av odelaktighet när patienten inte givits möjlighet att få den vård som han eller hon bedömde som nödvändig, vilket tolkades som att patientens kunskap och bedömning inte beaktats.

Diskussion

Resultaten bör läsas utifrån följande begränsningar: i den första studien intervjuades tio personer, i den andra följdes elva besök för tre patienter hos två specialistsjuksköterskor och i enkätundersökningen deltog 362 patienter. Dock gjordes datainsamling i den första studien tills det inte framkom några nya aspekter i intervjuerna och i den andra utifrån att den gav ett tillräckligt rikt material som var möjligt att tolka utifrån delarna till en sammanhängande helhet. Vidare var enkätundersökningen helt anonym, vilket medförde att bortfallsanalys inte kunde genomföras. Analyserna har kontinuerligt utsatts för kritisk granskning inom och utanför forskargruppen, men utgör dock tolkningar av de utsagor som lämnats i intervjuer och enkäter liksom av de fältanteckningar som gjorts vid de deltagande observationerna. Resultaten kan likväl ge insikt i vad delaktighet och odelaktighet kan betyda då man är i kontakt med hälso- och sjukvård i rollen som patient.

Patienternas upplevelser och beskrivningar av delaktighet kännetecknades av att förmedla information till hälso- och sjukvårdspersonalen, vilket kan relateras till den vidare betydelsen av delaktighet, som att dela. Vidare beskrevs delaktighet som att bli lyssnad till och trodd och att den kunskap och erfarenhet som man har som patient tillvaratas och att man upplever sig som en resurs i dialogen med vårdpersonalen. Detta tyder på ett behov av ökad respekt för patienten som individ och som en resurs i hälso- och sjukvårdsteamet.

Resultaten visar också att patienter förmedlar information och erfarenheter, vilket tyder på att delaktighet, såsom patienter kan uppleva det, kan äga rum även då det inte är fråga om att vara delaktig i beslut. Debatten om *patient empowerment* bör därför omfatta inte bara att vara med i planering utan också att få dela information med personalen, d v s både få och förmedla kunskap. Därtill har studierna visat på en brist på överensstämmelse mellan hur patienter upplever delaktighet och hur patientdelaktighet vanligen betraktas, av hälso- och sjukvårdspersonal, i andra studier och i lagtexter.

En förutsättning för delaktighet är att den information som ges förmedlas utifrån den kunskap patienten har och på ett sådant sätt att den motsvarar hans eller hennes behov. Resultaten visar på en skillnad mellan att kunna återge information och att ha omsatt information i kunskap, där det senare är en förutsättning för upplevelsen av delaktighet, i det att kunskap kan omsättas i praktisk handling, för att t ex utöva egenvård. Upplevelser av

odelaktighet uppstår när vårdpersonalen inte lyssnar till patienten, när informationen är otillräcklig liksom när man som patient inte blir sedd eller respekterad som den individ man är, vilket tyder på att kommunikation mellan patient och vårdpersonal behöver uppmärksammas för att skapa förutsättningar för delaktighet.

Slutsats

Resultaten visar att patientdelaktighet har en vidare betydelse för patienter än den snäva definition som vanligen används: att förse med information och ges förutsättningar att medverka i beslut som rör ens vård och behandling. Detta bör beaktas i formuleringen av rådgivande och styrande dokument för hälso- och sjukvård liksom i kliniska möten mellan patient och sjukvårdspersonal. De aspekter som framkommit ligger nära beskrivningen av delaktighet som att dela, särskilt i fråga om att dela information och kunskap.

En traditionell tolkning av patientodelaktighet, som att inte följa föreskriven behandling eller medverka i studier, visar få likheter med innebörden av odelaktighet från patienternas synvinkel. Att inte vara delaktig bör definieras, med beaktande av patientperspektivet, för att möjliggöra en framtida dialog om vad som kan förhindra upplevelse av odelaktighet i hälso- och sjukvård.

Eftersom ytterligare aspekter framkommit på vad som kan ge förutsättningar för patientdelaktighet i vården bör hälso- och sjukvårdspersonal ta initiativ till dialog med patienter om förväntningar på delaktighet i vården, och beakta att patienten har en unik kunskap om sin situation, sina symptom och upplevelsen av en sjukdom. För att delaktighet ska uppstå behöver patienten bli en partner i dialogen, vilket kan ge förutsättningar för ett ömsesidigt informationsutbyte.

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Notes

- ^a In Swedish: vård.
- ^b Suggested items (phrased from Paper I) in italics, additional sub-themes in standard text.
- ^c Patients are assigned to a number of visits to the nurse-led outpatient clinic for up-titration to goal doses and for education and counselling. The numbers of visits is individual, but visits usually end when goal doses have been reached.

Appendix 1. Questionnaire (In Swedish)

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1. Jag är: kvinna man

2. Jag är: 29 år eller yngre 30 – 59 år
 60 – 79 år 80 år eller äldre

3. Vid aktuell vårdkontakt har jag besökt eller vårdats/behandlats vid:

- kirurgavdelning kirurgmottagning
- ortopedavdelning ortopedmottagning
- medicinavdelning medicinmottagning
- ArthroClinic akutmottagning
- dagoperation smärtmottagning/APS
- annat:.....

4. De besvär eller den sjukdom som var orsak till besöket/behandlingen/vårdperioden har jag haft:

- kortare tid än 1 månad
- mellan 1 och 6 månader
- längre tid än 6 månader men kortare än 1 år
- längre tid än 1 år

5. Jag har annan sjukdom eller handikapp som medför att jag har kontakt med hälso- och sjukvård: (Annan kontakt kan vara t ex primärvård/vårdcentral, läkarmottagning, företagshälsövård, sjukhus, hemsjukvård, rehabilitering eller motsvarande.)

Ja Nej

6. Att, som patient, vara eller känna mig **delaktig** är för mig att:
 (Sätt kryss för det eller de alternativ som överensstämmer med din uppfattning.)

- berätta om mina symtom/besvär
- vårdpersonal lyssnar på mig
- vårdpersonal förklarar undersökningar
- få förklaring till mina symtom/besvär
- sätta upp egna mål
- veta vad som planeras
- vara med i planering av vård/behandling
- sköta vissa saker själv (t ex ta mediciner eller byta bandage)
- utföra egenvård (t ex anpassa kost)
- veta vem jag ska eller kan kontakta
- veta hur jag ska göra för att må bra

Att vara, eller känna mig, **delaktig** är också att:

7. Ett tillfälle jag var, eller kände mig, **delaktig** i vården var när:

Jag var/kände mig **delaktig** för att:

Att **inte** vara, eller inte känna mig, **delaktig** är också att:

9. Ett tillfälle jag **inte** var, eller inte kände mig, **delaktig** i vården var när:

Jag var/kände mig **inte delaktig** för att:

8. Att som patient **inte** vara, eller inte känna mig, **delaktig** är för mig att:

(Sätt kryss för det eller de alternativ som överensstämmer med din uppfattning.)

- få direktiv eller ordination utan förklaring
- få information som jag inte förstår
- inte ges tillfälle att berätta hur jag mår
- inte vara med i att fatta beslut om min vård/behandling
- inte vara med i planering
- inte bli respekterad som individ