Patient participation in clinical decision making in nursing
Patient participation in clinical decision making in nursing
– a collaborative effort between patients and nurses
ABSTRACT


The overall aim of the thesis was to study clinical decision making in nursing. This was performed by evaluation of the quality of nurses’ diagnostic statements and comparison of the concordance between nurses’ and patients’ perceptions of the patients’ nursing needs, as well as patient preferences for participation in clinical decision making. Further, predictors regarding patients’ active participation were investigated.

Quasi-experimental, comparative and cross-sectional descriptive study designs were used to collect data in acute care settings from randomly selected patient records (n = 140), nurse-patient dyads (n = 80), and patients discharged from hospital care (n = 428). Data were gathered using questionnaires and review of patient records.

The quality of nurses’ diagnostic statements improved by the means of education directed to nurses and implementation of new forms for recording supporting nursing care planning (I). Discrepancies were found concerning patients and nurses’ perceptions about what constitutes a problem for the patient as well as the severity and importance of acting on the problem (II). Further, nurses perceived that their patients preferred to be more active in clinical decision making compared with the patients’ own preferences for participation (III). Gender, education, living situation, and occupation were identified as predictors for preferring an active role in clinical decision making (IV).

The conclusions are that the accuracy of diagnostic statements needs to be addressed and validated further through systematic assessment of the patients’ perceptions and preferences concerning the health situation and preferences for participation in clinical decision making. Clinical implications are that nurses need to involve patients in identifying patient problems of relevance for nursing. Further, nurses also need to be aware of patients’ preferences for participation in clinical decision making in order that they can plan care in accordance with patient preferences and allow participation to the degree preferred by the patient.

Keywords: Clinical decision making, patient participation, nursing diagnosis, patient needs, nursing assessment, control preference scale.

Jan Florin, Department of Health and Social Sciences, Dalarna University, 791 88 Falun, Sweden. jfl@du.se
ORIGINAL PAPERS

This dissertation is based on the following papers, which are referred to in the text by their Roman numerals.


IV. Florin J., Ehnfors M. & Ehrenberg A. Predictors of patients’ participation in clinical decision making in nursing care. (Submitted)

Reprints of studies I, II, and III were made with kind permission from the publishers.
INTRODUCTION

In my previous experience as a nurse in an acute care ward and currently as a university lecturer in nursing, I have always been a spokesperson for systematic planning of nursing care and for the use of nursing diagnosis as basis for the selection of specific nursing interventions to reach desired nursing outcomes. The main idea with the nursing process model as a framework for problem solving is the focus on the individual’s unique health situation and the possibility to tailor interventions to suit the person’s needs. However, in order to make it work, nurses need to ‘know’ their patients. I sometimes had the impression that the nursing staff was not completely accurate in their descriptions of patients’ health care needs. I read statements in the patient record and listened to verbal inter-shift reports, sometimes revealing a lack of congruence with what I perceived when meeting with the patient. Information and understanding of patients’ perspective on health care needs did not always seem to be common knowledge by their caregivers. A key issue seemed to be the interaction between the patient and the nurse in which information was shared and communicated in both directions. From time to time, questions were nagging my mind and just waited to be answered: How well do nurses actually know their patients? In theory, individualised and patient centred nursing care is a cornerstone in clinical nursing practice, but do nurses know how the patients’ perceive their own situation and their preferred role in clinical decision making concerning their nursing care? This was the starting point of the research project reported in this thesis.
Registered nurses (RNs) identify patient needs and problems with the purpose of providing individualised nursing care. The clinical judgements and decisions about actions underpinning the care are essential for the outcome and quality of care. In many real life events knowledge and values are inherited in the same person, the person himself, but in health care decisions there is often an imbalance. Health professionals have a profound knowledge base on a general level about health and illnesses/diseases whilst the patient is the expert of his or her individual values and preferences regarding care. A short length of stay in hospital care, combined with demands for high quality care, increases the importance of identifying patient needs and problems in a systematic way and to individualise care accordingly. Therefore, RNs need to involve patients in identifying patient problems of relevance for nursing, as well as find ways of reaching a common understanding of the patient’s situation.

Patient’s role in health care
The importance of patients’ own activity in planning and implementing care has been stressed internationally over the years (WHO 1978, Institute of medicine 2003) and even in Sweden where patients, according to legislations, hold a strong position in the health care system (SFS 1982). Arguments have been raised that, in essence, patients have a “PhD” in their own uniqueness (Weed & Zimny 1989) and ought to be considered honorary members of the health care team (Edwards 2002). Patient participation in clinical decision making is seen as an indicator of quality in its own right (Wilde et al. 1994; Ruland 1999; IOM 2003) and inclusion of the patient’s perspective has been noted to improve nursing care and patient outcomes (Ruland 1999). The Institute of Medicine (IOM) in the U.S.A. identifies patient-centred care as one of five core competencies for health professionals. A central feature in patient-centred care is the patients’ participation, implying that professionals share decision making and management of care with patients (IOM
Further, IOM describes that the patient should be the source of control over decisions regarding health care needs and that customisation of care should be based on the patient’s needs and values rooted in shared knowledge and the free flow of information (IOM 2001). The Internet is suggested to be a catalyst serving to facilitate a balance of power among the key actors (Dickerson & Brennan 2002). To optimise care, identification and prioritisation of needs and problems have to be decided in negotiation between health professionals and the patients in a shared decision making encounter (Charles et al. 1997), with consideration of the time perspective and available resources.

Nursing care
The International Council of Nurses (ICN) identifies that nursing encompasses autonomous and collaborative care of individuals of all ages, families, groups, and communities, sick or well, and in all settings. Nursing includes the promotion of health, prevention of illness, and the care of ill, disabled, and dying people. Advocacy, promotion of a safe environment, research, participation in shaping health policy and in patient and health system management, and education are also key nursing roles (ICN). The concept of individualised nursing care has been discussed since the late 1970s in Sweden, where a prerequisite is to ‘know the patient’ (Radwin 1996; 1998), to have knowledge of the individual situation, and how the patients themselves perceive the situation. RNs are guided by their intentions to do good for the patients, described as benevolence (Lutzen & Nordin 1993) and beneficence (Woodward 1998). Communication skills are of the utmost importance in nursing, considering that nursing always is two-folded with both task-oriented and relational aspects (Peplau 1952; Jonsdottir et al. 2004). However, in the case of caring for patients that cannot participate in information exchange the burden of interpretation placed on the RN is considerable and needs to be performed with respect and sensibility for patient integrity and autonomy.
Nursing process model

The nursing process model has provided a structure for critical thinking and reasoning in nursing since the 1950s when it was first presented by Lydia Hall. The aim of the nursing process is to identify the needs of the individual patient and tailor interventions to meet those needs. Values underpinning the nursing process model identify the importance of the individual’s autonomy and free will to make decisions regarding his/her own care. The patient and the nurse are regarded as partners in a relationship where the nurse interacts with the patient in order to solve the bio-psychosocial needs by maximising the individual’s positive interaction with the environment, level of wellness, and degree of self-actualisation (Sundeen et al. 1994).

The nursing process model is a systematic general problem-solving model originating from general system theory using the assessment of the patient’s status as a point of departure. Initially, the process consisted of four subsequent phases: assessment, planning, intervention, and evaluation (Yura & Walsh 1988). The focus was mostly on nursing care needs connected to medical conditions, but the attempts to classify nursing care problems requiring nursing attention led to the development of nursing diagnoses. In 1973, The American Nurses Association (ANA) published the Standards of Nursing Practice in which the nursing process was described with five subsequent steps, adding diagnosis as the second step. Gordon (1982) and Carnevali and colleagues (1984) extended the discussion of the nursing process and the nurse’s management of information and making decisions. The second generation of the nursing process model described the process with five subsequent steps: assessment, diagnosis, planning, implementation, and evaluation. However, the nursing process model has been criticised for focusing too heavily on solving problems. Boychuk Duchscher (1999) points out the insufficiency of the model as a basis for nursing practice because of the traditional product orientation and lack of ingredients encompassing critical thinking (e.g., reflection, dialogue, and dialectical thinking). There are suggestions of a third generation of the nursing process model. Pesut and Herman (1999) proposed a model of reflective clinical reasoning in which a repeated reflected comparison between present state and
outcome determines the clinical judgement and decision to end the reasoning situation or reframing the situation, altering the decisions about the course of action (Figure 1.)

**Nursing documentation in patient records**

Nursing content in patient records is often categorised according to the nursing process model. Available audit instruments for reviewing nursing documentation initially only reflected a quantitative perspective (Nordström & Gardulf 1993), but extended to a review of the process (Ehnfors & Smedby 1993) and explicitly address both quantitative and qualitative dimensions (Björvell et al. 2000). Educational interventions to improve documentation practice have positive effects on quantity and quality of nursing documentation (Ehnfors 1993; Ehrenberg & Ehnfors 1999a; Rosendahl Darmer et al. 2006).

---

**Figure 1.** The outcome-present state-test (OPT) model of reflective clinical reasoning (Pesut & Herman 1999)

Altering the charting system or record forms do not seem to bring about better content in patient records (Moen et al. 1997). However, introduction of electronic health record systems with standardised information templates improved the structure and content in the nursing discharge notes (Hellesö et al. 2004). An initial positive effect of education on nurses’ ability to identify patient problems is often not sustained over time (Heaven & Maguire 1996). Interventions combining education and development of forms for recording seem to have positive effects on the documentation of the nursing process (Engvall 1994; Wallentin et al. 1996; Björvell et al. 2002). An intervention package with education in combination with organisational change, including trained change agents and support given to chief nurses, led to a sustained long-term increase of quantity as well as quality of nursing documentation (Björvell et al. 2002). Even so, the improvements were marginal and there is evidence of major deficiencies in nursing documentation in relation to systematic structure and comprehensiveness (Ehrenberg & Ehnfors 1999b; Ehrenberg & Ehnfors 2001; Ehrenberg et al. 2004).

Nursing diagnosis
A nursing diagnosis is defined by the North American Nursing Diagnosis Association (NANDA) as a “clinical judgment about individual, family, or community responses to actual or potential health problems/life processes. A nursing diagnosis provides the basis for selection of nursing interventions to achieve outcomes for which the nurse is accountable” (NANDA 2001, p. 245). A nursing diagnosis can be regarded as both a process and a product, where the process precedes the product and includes clinical reasoning and a judgement. The process involves activities such as collecting, interpreting, and clustering information about the patient and finally naming the cluster (Carnevali 1983). As a product, it is preferably stated as a short, clear statement expressed with concise terms that identifies the patient's problems or health status. Major approaches to express nursing diagnoses are either to select diagnoses from taxonomies of
standardised diagnostic statements (e.g., NANDA 2001) or to express diagnoses in free text (Carnevali 1983; 1996). When stating diagnoses, the PES format is widely used (Gordon 1994; Carnevali 1996; NANDA 2001). Three essential components are identified in the statement: the problem (P), its aetiologies (E), and signs and symptoms (S). NANDA and Carnevali interpret and use the PES format slightly different. The S-component is seen by NANDA (2001) as evidence for the presence of the problems, whereas Carnevali (1996) often use the S-component to state actual consequences of the problem.

Incentives for RNs to use nursing diagnoses are e.g. to be able see the patient as an individual and as a whole, and to facilitate nursing care (Axelsson et al. 2006). A literature review of nursing diagnoses impact on nursing practice concluded that nursing diagnoses seemed to improve the assessment documentation, quality of reported interventions, and outcomes attained (Muller-Staub et al. 2006). However, there is always a risk for low accuracy nursing diagnoses, as confirmed in several studies (Lunney 1990; 2003). The use of a framework borrowed from evidence-based medicine incorporating clinical expertise and experience and patient preferences and values in clinical decision making could improve the interpretation of patient data (Levin et al. 2004).

In Sweden, varied frequencies of nursing diagnoses in patient records have been reported, ranging from 10% in acute care settings (Ehnfors & Smedby 1993; Nordström & Gardulf 1996) to 71% of patient records from nursing homes where all the nurses had completed a university course in documentation of nursing care (Fagrell et al. 1998). A study of district nurses’ documentation practice reported that nursing diagnoses hardly existed in the records (Törnvall et al. 2004). Positive long-term effects on quantity and quality of nursing diagnoses, although not to very high levels, have been reported following a complex intervention with education as one part of the package (Björvell et al. 2002).
Needs and problems
Need is ‘a socially constructed concept that is closely bound up with identities, expectation, and context’ (Cowley et al. 2000, p. 127) in relation to health. Liss (1990) discussed varying perspectives on the concept in which one perspective was an ill health notion, where health care needs could be understood as deficiencies in health or social wellbeing that called for preventive, curative, or rehabilitative actions.

In this thesis, a need is defined as “a difference between an actual state and a goal” (Liss 1990, p. 89). According to Liss (1990, p. 117), two conditions are needed: “1) there is a difference between two states on the health dimension – between the actual state and the goal of need; 2) health care is necessary for the elimination of the difference – that is, for reaching the goal of need”. To a certain extent, the persons themselves can be the provider of personal health care activities to eliminate the difference. However, when a person’s own resources are not sufficient, there is a need for health care from professionals. This is in line with Carnevali’s (1993) description of health as a balance between resources and requirements in daily living. Health care is necessary in case of an imbalance between resources and requirements. Further, needs can be divided into needs and wants, where needs must be satisfied, but wants are expressions rooted in personal psychological states and thus can be deferred (Holmes & Warelow 1997). The concept of problem involves a perception and recognition of the discrepancy between what is and what ought to be (Liss 1990). In this thesis, a need that the persons can satisfy but with difficulties, or cannot satisfy by themselves, using internal or external resources, constitutes a problem. The concepts of need and problem are used interchangeably in the text.

Patients, as a holistic entity, can hold a variety of needs, often divided in physical, psychological, social and spiritual, and religious needs. There is a tendency to overemphasise the physical dimension, probably because it is easier to define and measure, but it could be pointed out that participation in decision making in itself
could be a need, as well as integrity, continuity, and communication (Hallström & Elander 2001a).

RNs and patients have been seen to differ in perceptions of patient health care needs or problems though the findings are inconclusive. Nurses and patients hold different opinions about the presence of nursing problems in somatic (Farrell 1991; Adamsen & Tewes 2000) and psychiatric settings (Hansen et al. 2002). In general, nurses overestimate their patients’ nursing problems, with emotional problems being overestimated more often than physical ones (Farrell 1991; Löfmark et al. 1999). Lauri and colleagues (1997) reported a contrasting result in which nurses underestimated almost all the patients’ nursing problems. In particular, it has been demonstrated that nurses underestimated patients’ perceived self-care ability (Richardson 1992), level of fatigue (Tiesinga et al. 2002), and pain intensity (Blomqvist & Hallberg 1999; Hall-Lord et al. 1999; Hovi & Lauri 1999; Sloman et al. 2005). Moreover, nurses overestimated patients’ anxiety and depression (Lampic et al. 1996) and worries (Biley 1989; Harrison et al. 1996). Finally, patients tended to report more unmet needs than health care professionals identified (Kersten et al. 2000), predominantly in the psychosocial realm (Kent et al. 1996; Soothill et al. 2001).

Decision making
Quite a few concepts are used to describe critical thinking in health care (e.g., clinical reasoning, diagnostic reasoning, decision making, judgement, and problem solving). Sometimes the concepts are used interchangeably (Hendry & Walker 2004) but they have slightly different features (Dowding & Thompson 2003). Critical thinking is described by Ennis (1996, p.xvii) as “a process, the goal of which is to make reasonable decisions about what to believe and what to do.” Clinical decision making is a process that involves both diagnostic reasoning and clinical judgement (Tanner 1987). Judgement and decision making are examples of reasoning as both a process and a product, the outcome of the process. It is important to realise the cyclical features of the process in which the resulting
actions are directed by reflection and reflection is in turn influenced by those actions (Conger & Mezza 1996).

Different thinking strategies, used in clinical reasoning that are aimed at decision-making, have been described, including the hypothetico-deductive method, decision analysis theory, pattern recognition, and intuition (Benner 1984; Brennan & Strombom 1998; Fonteyn 1998; Offredy 1998). Harbison (2001) argued that RNs might have adopted Benner’s work a bit uncritically. Being reassured that they are ‘experts’ using ‘intuition’ for high quality decision making, motivation to examine their decisions using other perspectives might be lacking. Even so, a more systematic ongoing process is often representing a rationale underlying the expert’s intuitive practice (Harbison 2001). Heuristics and experiential knowledge are important but not a sufficient basis for clinical decision making (Thompson 2003). André (2004) reported that general practitioners’ ‘Rules of thumb’, a form of tacit knowledge in some areas, were possible to verbalise, which makes the knowledge explicit. A unifying framework connecting the different theories is that of Buckingham and Adams (2000b), who interpret clinical decision making as classification behaviour. They argued that linking cues with diagnostic categories, usually regarded as pattern recognition, actually is the same process as connecting evidence with hypothesis in the sense that it is a form of classification activity. Their general model of classification could be used as a common frame of reference for understanding clinical decision making and contributing to multidisciplinary collaboration in which data provide cues to identify categories. However, a prioritisation of needs has to be done as a part of the classification thinking. Priority setting is an essential part of care planning in which patient needs are classified as having different priority. Hendry and Walker (2004, p. 427) defined priority setting as, “the ordering of nursing problems using notions of urgency and/or importance, in order to establish a preferential order for nursing actions”.

The social policy statement by ANA (1980) recognises the pivotal role of diagnostic reasoning in nursing and the ability to choose appropriate interventions
to achieve expected outcomes. In this thesis, Tanner’s definition of clinical judgement is used:

“a series of decisions made by the nurse, in interaction with the client regarding (a) the type of observations to be made in the client situation, (b) the evaluation of data observed and derivation of meaning (diagnosis), and (c) nursing actions that should be taken with or on behalf of the client” (Tanner 1987, p. 154).

The definition reflects the phases of the nursing process, explicitly stressing the importance of interaction with the patient. Judgement and decision making are closely related but have distinct differences since they generate different cognitive demands (Dowding & Thompson 2003). Judgement can be regarded as ‘an assessment between alternatives’ integrating different aspects of information about a person or a thing. Decision making has been described as ‘a choice between alternatives’ in which the process is focused on choosing a particular course of action (Dowie 1993). Dowding and Thompson (2003) stress the importance of distinguishing between the concepts. A nurse could make an accurate judgement (e.g., about a patient’s risk for pressure ulcer), but make a poor decision by choosing a poor action. However, the environment of care has implications on need identification and response. The RN needs to distinguish between ‘signal’ and ‘noise’ in order to be able to name the patients situation, combined with a stage of framing the situation, depending on philosophy of care and organisational issues and time (Carr 2004).

It is problematic to define judgements as good or bad since nurses operate in an environment characterised by uncertainty (Buckingham & Adams 2000a). Drawing on the discussion on self-assessed and others-assessed needs (Liss 1990), the subjective dimension in clinical judgement in nursing is profound. There is seldom a definite right or wrong and differences in opinions exist depending on perspective, values, beliefs, and hopes related to information and knowledge in the situation. Whose perspective is to be the prevailing one, the RN’s or the patient’s?
When uncertainty exists, there is reason to involve the patient as the primary decision maker (Weed & Weed 1999).

**Patient participation**
To expand the previous discussion on the patient’s role, there is growing consensus that patients ought to be more involved in their own care. This agreement stems from political ideas, ethical thinking, and research in health care. The patient's position is moving towards being a customer; evident in an increasing degree of personal choice and personal rights, care guarantee, and a right to self-determination (Nordgren 2004). Participation is linked to the concepts of power and empowerment. Power is seen as extrapersonal, indicating that an increase in one's power must be balanced with a decrease in someone else's power. Prerequisites to generate power are opportunities and sufficient information. Empowerment is an individual process in which the person is interacting with the environment pursuing impact on his/her life (Kuokkanen & Leino-Kilpi 2000). It is notable that a patient must be an active participant in his/her empowerment, indicating that RNs cannot empower patients: the role is to facilitate and support the empowerment (Laverack 2005). The major responsibility to invite patients as active partners in decision making in nursing is inevitably the nurses’ since the patient is in a subordinate position and cannot be expected to take the lead. Patients experiences in relation to health issues should be valued as evidence contributing to the decision-making process and that partnership with health care professionals is important (Rycroft-Malone et al. 2004a). Further, there is a need for a context receptive for change, addressing power and authority processes, and with appropriate and transparent decision-making processes (Rycroft-Malone et al. 2004b).

Patient participation involves several dimensions, including collaboration, partnership, and involvement, sometimes used interchangeably (Cahill 1998; Kirk & Glendinning 1998) though Ashworth and colleagues (1992) contend that those
dimensions do not necessarily indicate genuine participation. Most commonly, patient participation is described as a hierarchy with increasing degrees of participation, especially in relation to decision making. Cahill (1996) described a hierarchical relationship in which increased involvement or collaboration leads to participation, with partnership at the top of the hierarchy. However, patient participation in care and care giving can be seen as a process as well. Tutton (2005) described a dynamic process, enacted through the themes of emotional work, understanding the person, facilitation, and partnership, that takes place within a context that could affect the process (e.g., time constraints, ward environment, or degrees of teamwork). The concept of participation, as understood from the patients’ perspective, was reported by Eldh and colleagues (2004). Participation was experienced as being confident, comprehending, and seeking and maintaining a sense of control.

A distinction needs to be made between decisional autonomy (decision making) and executional autonomy (implementing decisions). Even though ability for executional autonomy is decreased, the patient possibly still can perform his decisional autonomy, but there is a risk of violation of the patient's right to participation in that respect (Matiasson et al. 1997). Provision of health care involves a mutual problem-solving process between health professionals and patients in which patients’ participation in decision making is facilitated or even needs to be requested (Balzer-Riley 1996; ICN 2003). D’Onofrio (1980, p.274) suggested that patient participation was “patient engagement in problem identification and prioritisation, establishment of change objectives and the process of making decisions about how change will be accomplished”.

Patient participation in health care decision making can be placed in an independency-dependency continuum that could range from non-participation through co-determination and delegation to self-determination (Sahlberg Blom 2001), sometimes expressed as passive to responsible (Latvala et al. 1999, Latvala 2002) or passive to active participation (Degner & Sloan 1992; Sainio et al. 2001;
Caress et al. 2002; Kraetschmer et al. 2004). An alternative way of describing participation was suggested by Andershed (1998) using the metaphors “involvement in the light”. This kind of participation is promoted by a trusting relationship between the patient and the staff and “involvement in the dark” as characterised by insufficient interplay and collaboration.

Charavel and colleagues (2001) described models placed on the continuum: (1) a paternalistic model in which the health professionals make the decisions, (2) an informative model in which health professionals provide the patients with information to enable them to select the desired treatment, (3) an interpretative model in which health professionals and patients interact to identify the patients wishes and values and support them to select treatment, and (4) a deliberative model that is very close to the interpretative model but adds a moral dimension to the interaction that emphasises the discussion between two partners. Charles and colleagues (1997) proposed the ‘shared model’: a two-way exchange of information with both the patient and the professional stating their treatment preferences and reach an agreement on the decision. The key characteristics are at least two participants sharing information acting to build consensus and eventually reaching an agreement.

Research findings suggest that patient preferences for participation in clinical decision making differ because of age, gender, socio-economic status, and severity of the medical problem (Degner & Sloan 1992, Degner et al. 1997, McKinstry 2000, Henderson & Shum 2003). These findings, however, are inconclusive. Cahill (1998) concluded that patients generally preferred to be active but that caregivers preferred to see the patient as a more passive recipient of care despite their acknowledgement of the positive value of active involvement. Patient participation was regarded by RNs as both a goal and a means in nursing care (Jewell 1994). However, if patients and RNs have a different understanding of the concept participation, then real patient participation might be difficult to achieve in the clinical encounter (Sainio et al. 2001; Eldh 2006)
Prerequisites for patient participation
The same factors have been identified to either facilitate or work against patient participation in decision making. The factors include access to information and knowledge, quality of professional-patient relationship, time, actual medical situation, and personal characteristics of nurses and patients. Possession of sufficient and adequate information facilitates participation, whereas lack of knowledge functions as a hindrance for more active participation (Caress et al. 2002). Nurses’ communication skill is a pivotal prerequisite for patient participation in decision making. Communication deficits have been identified as one of the principal barriers to partnership building between nurses and patients (Keatinge et al. 2002). Professionals need to be willing to listen and establish a good provider-patient relationship (Caress et al. 2002), and they need to encourage patients to ask questions (Timonen & Sihvonen 2000) and to probe questions themselves (Efraimsson et al. 2004). Casey (1995) proposed a framework for patient involvement in nursing practice. The degree of participation is indicated by the intersection of two axes: a communication – non-communication and a person-centred – nurse-centred continuum (Fig. 2). Nurses practicing “communicating/nurse-centred” care are authoritative and controlling but allow participation by giving patients permission to participate.

![Diagram of Nursing Approaches to Involvement in Care](Figure 2. Nursing approaches to involvement in care (Casey 1995))
Nurses who act according to “Non-communicating/nurse-centred” care behave in ways in which exclusion of patients from participation is common. A “non-communicating/person-centred” nurse makes assumptions about patients’ needs, wishes, and abilities mostly based on her/his own subjective opinion. Nurses applying a “communicating/person-centred” care approach share their knowledge and expertise with patients, with negotiation of care in focus using patient participation as an essential ingredient.

**Patient participation in clinical decision making**
Several studies of patients’ or relatives’ participation in a Swedish nursing context have been reported, including studies on children’s participation (Runeson 2002), where the need for information and participation was most prominent in non-threatening situations in comparison with threatening ones. Participation was not allowed to the extent judged to be optimal. Sahlberg Blom (2001) showed that the autonomy of cancer patients in the final phase of life could be categorised on a scale from self-determination to non-participation. Andershed (1998) described the involvement of relatives to patients in the final phase of life using the categories to know, to be, and to do. Hedberg (2005) discussed the gap between nurses’ decision making and communication in clinical practice with the expected performance related to work regulations and goals of conduct expressed in nursing education. Eldh (2006) explored the concept of participation from the patients’ perspective, adding several dimensions to the concept, such as being confident, comprehend, and seeking and maintaining a sense of control. Efraimsson (2005) investigated women’s participation in discharge planning conferences, revealing a professional dominance in the situation combined with feelings of being left outside and unheard.

Studies of patient participation in medical decision making report figures of patients preferred participatory role with quite wide ranges. To summarise, patients in specific medical decision-making situations preferred to have a passive
role in 27-78% of the time, whereas a collaborative role was preferred in 17-64%. Furthermore, 4-32% of the patients preferred being active in decision making (Sätterlund-Larsson et al. 1989; Beaver et al. 1996; Butow et al. 1997; Beaver et al. 1999; Ramfelt et al. 2000; Protière et al. 2000; Gattellari et al. 2001; Sainio et al. 2001; Davison & Degner 2002; Schou et al. 2002).

Cultural differences in opinions between RNs and patients in relation to involvement in decision making have been identified in five European countries, where differences between the northern and southern parts might be explained by different educational levels or the basic training systems of nurses (Scott et al. 2003a). Further, the model of autonomy, rooted in an individualistic view of human life, may not be suitable in countries where the role of the family in people’s lives is more pronounced. Studies reflecting the UK perspective reported that nurses in elderly care (Scott et al. 2003b) and midwives (Scott et al. 2003c) reported that patients were offered opportunities to participate in decision making to a higher extent compared with patients’ reports of being offered such an opportunity. In contrast, surgical patients generally reported a more positive view on frequency of involvement in decision making than what nurses reported (Scott et al. 2003d).

Interventions aiming to increase patient participation have been reported (e.g., feeding forward of patient data to clinicians, which prepares for mutual identification of patient needs and preferences, and shared decision making (Wensing & Grol 1998; Ruland 1999; Ruland & Moore 2001), as well as provision of information about health care providers performance, interactive patient education, and feedback to clinicians about patients' evaluation of care (Wensing & Grol 1998). Feeding forward of information increased clinicians’ recognition of patients’ health problems and needs for care (Wensing & Grol 1998), and the inclusion of patient preferences in decision support systems have been seen to have great acceptance and perceived usefulness by professionals (Ruland 2004). Patients’ daily intake of energy has been observed to increase (Pedersen 2005). Inclusion of the patient’s perspective in health care decision
making improves nursing care and patient outcomes (e.g., care priorities in attunement with patient preferences, greater preference achievement, and better physical functioning) (Ruland 1999).

Rationale for the thesis
Clinical decision making in nursing is a complex task often performed under a great deal of uncertainty (e.g., rooted in subjective values and preferences). In order to provide individualised care in accordance with patient preferences, RNs need to be aware of the patients’ perspective and preferences for care. The review reveals that techniques to elicit patient preferences for nursing care, and by that increasing participation in the decision-making process, have been tested with promising results. However, the knowledge of patients’ preferences and experiences of participation in clinical decision making in nursing and level of congruence with RNs’ perceptions is still rather limited. Acute somatic hospital care is a relatively unexplored setting regarding clinical decision making in nursing. There is a need to increase the knowledge in this context, especially because of the necessity for clinical decision making with high accuracy to optimise nursing care during a relatively short hospital stay. If the assessment and planning of nursing care is not optimal, or in line with patient preferences, the care processes during the given time frame will be negatively influenced and ultimately the quality of nursing care could be jeopardised.

Therefore, there is a need for increased knowledge on clinical decision making, including identification and formulation of needs of nursing care, and patient decision-making role preferences in general, and congruence in perceptions with RNs from a Swedish perspective.
The overall objective of this thesis was to study clinical decision making in nursing, with special focus on diagnostic statement quality, patient participation, and the coherence between patients’ and nurses’ perceptions of needs and preferred participatory role.

The specific aims of the studies were to:

1. Investigate the effect on the quality of nursing diagnoses documented in patient records of an intervention comprising education and implementation of new forms for recording (study I).
2. Determine the degree of consistency between RNs’ and patients’ perceptions of presence, severity, and importance of nursing problems in an acute care setting (study II).
3. Compare the degree of concordance between patients’ and RNs’ perceptions of patients’ preferences in participating in clinical decision making in nursing practice (study III).
4. Compare patients’ actual level of participation in clinical decision making in nursing with their preferred participatory role (study III).
5. Investigate predictors of patient preferences for active participation in nursing decision making (study IV).
MATERIAL AND METHODS

Three research projects (study I, study II and III together, and study IV) with separate data gathering procedures have been performed to complete this thesis. The studies were conducted between 1999 and 2006 in acute care settings. The wards were chosen because of their interest to participate in the study. The wards were typical for acute care settings in Sweden with an organisation of nursing care that best could be described as team care, i.e. a group of RNs shares responsibility for the care of a group of patients. Often, a division of labour is prevailing with a task-oriented rather than patient-centred organisation of care. In practice, the responsibility for planning nursing care is often placed on the group and not on an individual RN, even though documents might state otherwise. The RNs often worked both day and night shifts and were active in varying professional groups depending on staff mix resources, sometimes displaying daily variations.

Table 1. Overview of study designs and research methodologies.

<table>
<thead>
<tr>
<th>Study</th>
<th>Design</th>
<th>Sample</th>
<th>Data collection method</th>
<th>Data analyses</th>
</tr>
</thead>
<tbody>
<tr>
<td>I</td>
<td>Quasi-experimental pre-test post-test design</td>
<td>140 randomly selected patient records from experimental (n=70) and control wards (n=70) equally distributed before and after intervention</td>
<td>Record audit; CAT-CH-ING, QOD</td>
<td>Descriptive, inferential statistics (Students t-test, χ² – test)</td>
</tr>
<tr>
<td>II</td>
<td>Cross-sectional comparative survey</td>
<td>Convenience sample of 80 nurse-patient dyads</td>
<td>Questionnaire</td>
<td>Descriptive statistics, inferential statistics (Wilcoxon’s signed-rank test, McNemar, Svensson methodology for ordered data)</td>
</tr>
<tr>
<td>III</td>
<td>Cross-sectional comparative survey</td>
<td>Convenience sample of 80 nurse-patient dyads</td>
<td>Control Preference Scale, questionnaire</td>
<td>Descriptive statistics, inferential statistics (Sign test, Mann Whitney U-test)</td>
</tr>
<tr>
<td>IV</td>
<td>Cross-sectional comparative survey</td>
<td>Consecutive sample of 428 patients</td>
<td>Questionnaire, Control Preference Scale</td>
<td>Descriptive statistics, inferential statistics (Multiple logistic regression)</td>
</tr>
</tbody>
</table>
Consequently, both patients and RNs interact with many persons, sometimes shifting on a daily basis. An overview of study designs and research methodologies is given in Table 1. More detailed descriptions of material and methods for each separate research project are found below.

**Study I**
A quasi-experimental pre-test – post-test design was used. The study was conducted at a regional Swedish hospital at a ward for infectious diseases (experimental group) and three medical wards (control group).

**Sample and characteristics**
The sample comprised 140 randomly selected patient records from both the experimental ward and control wards, which meant a retrieval of 70 patient records from the archives for each group. Of these, 35 records reflected the documentation practice for patients treated during a three-month time span before and after the intervention respectively. The sample constituted approximately 10% of the total number of records during the study period at the experimental ward and 5% at the control wards. The records were mostly describing the care of patients acutely admitted to hospital care (98%), displaying equal median length of stay between groups, with a few outliers in the experimental group. The RNs in the experimental group had a mean age of 39 years (SD 10.1), whereas RNs in the control group were 41 years of age (SD 10.2). Apart from education in documentation practice incorporated in basic nursing education, two RNs in the experimental group and five RNs in the control group had a university course in documentation practice. The staff ratio was 0.57 RNs per patient bed at the experiment ward and 0.55 at the control wards, ranging from 0.46 to 0.72. RN’s worked in teams with assistant nurses depending on staff mix for the shift and sick leaves.
Record audit instruments

The instrument CAT-CH-ING (Björvell et al. 2000) was used to measure the quality of RNs diagnostic statements. CAT-CH-ING is an audit instrument that is reported to be both valid and reliable (Björvell et al. 2000). The instrument measures quantity and quality of documentation based on the nursing process and Swedish regulations. In paper I, analyses of the two variables measuring quantity and quality of nursing diagnoses, measured on a four-point ordinal scale, is reported. The instrument comprises 26 variables in total. Further, a scale to measure the quality of diagnostic statements was developed for this study based on instruments developed by Ziegler (1984) and Lunney (1990). Existing instruments were regarded relevant but not directly applicable because of differences between Swedish and American use of nursing diagnoses. The scale Quality of Nursing Diagnosis (QOD) (Table 2) reflects four components divided into 14 dichotomous characteristics of a diagnostic statement, which evaluates diagnostic structure (S) and relevance (R). The components Problem, Aetiology, and Signs/symptoms reflect the commonly used PES format when stating nursing diagnoses, adding an additional fourth general component to the scale. Each criterion was valued as absent (zero points) or present (one point), yielding a maximum score of 14. Higher scores reflect better quality in the diagnostic statement.

Intervention and procedure

The intervention consisted of an educational program for RNs in the use of the VIPS model (Ehnfors et al. 2002), acronym for the Swedish spelling of Wellbeing, Integrity, Prevention, and Safety. The purpose was to increase the understanding and use of the nursing process as a problem-solving method in clinical practice. Each nurse participated in five separate 3-hour sessions, meeting approximately every second week. During the sessions, real and fictitious patient cases were discussed with a focus on nurses’ care planning activities (e.g., stating nursing diagnoses, outcomes, and planned interventions). New forms for recording were discussed during the sessions and then developed by one of the researchers (JF).
Table 2. Criteria in the QOD instrument for measuring the quality of diagnostic statements.

<table>
<thead>
<tr>
<th>Component</th>
<th>Criteria</th>
</tr>
</thead>
<tbody>
<tr>
<td>Problem</td>
<td>(S) 1. Only one problem is identified in the diagnostic statement.</td>
</tr>
<tr>
<td></td>
<td>(R**) 2. The problem is potentially changeable with nursing care.</td>
</tr>
<tr>
<td></td>
<td>(S) 3. The problem is concrete enough to generate specific outcomes or actions for nursing care.</td>
</tr>
<tr>
<td>Aetiology</td>
<td>(S) 4 One or several aetiologies is/are identified in the diagnostic statement.</td>
</tr>
<tr>
<td></td>
<td>(R) 5. The aetiology is potentially changeable with nursing care.</td>
</tr>
<tr>
<td></td>
<td>(S) 6. The aetiology is concrete enough to generate specific outcomes or actions for nursing care.</td>
</tr>
<tr>
<td>Signs/ symptoms</td>
<td>(S) 7. One or several signs/symptoms is/are identified in the diagnostic statement.</td>
</tr>
<tr>
<td></td>
<td>(R) 8. Signs/symptoms are potentially changeable with nursing care.</td>
</tr>
<tr>
<td></td>
<td>(S) 9. Signs/symptoms are concrete enough to generate specific outcomes or actions for nursing care.</td>
</tr>
<tr>
<td>General</td>
<td>(S) 10. Both the problem and aetiology components are present in the diagnostic statement.</td>
</tr>
<tr>
<td></td>
<td>(S) 11. Problem and aetiology are interconnected by the phrase &quot;related to&quot; or similar.</td>
</tr>
<tr>
<td></td>
<td>(S) 12. Problem and aetiology are interconnected with signs/symptoms by the phrase &quot;leading to&quot; or similar.</td>
</tr>
<tr>
<td></td>
<td>(R) 13. The diagnostic statement is asymmetric (not circular) and logically structured. Logically, one should be able to see the problem as related to the aetiology and the signs/symptoms as a consequence or a validation of the problem.</td>
</tr>
<tr>
<td></td>
<td>(R) 14. The diagnostic statement is supported by relevant data to a satisfying degree.</td>
</tr>
</tbody>
</table>

* S = structure; ** R = relevance

The proposed forms added three pages to the existing documents used on the ward. Page one displayed a more structured assessment of patient history and status. Page two displayed four columns for documenting diagnosis, expected outcome, interventions, and evaluation along side the same rows to visualise the connection between the different parts. Additional interventions and discharge planning were documented on page three. Together, the documents intended to give an overview of the patient’s health care needs and the plans for dealing with
them, including discharge planning. The forms were subsequently presented and implemented in the experimental ward at the end of the educational intervention.

Patient records were retrieved from the archives and documents containing nursing notes were copied. A nursing diagnosis was defined as a statement identifying patient problems, causes, and consequences or just problem statements by which there was evidence in the patient record that nursing actions had been planned or implemented to deal with the problem. When notes on a nursing problem appeared several times, the most precise wording with most detailed aetiology or consequences was chosen for the analysis.

**Study II and III**
A cross-sectional comparative survey design was applied using a hospital ward for infectious diseases as the setting for collecting data from patient-nurse dyads.

**Sample and characteristics**
A convenience sample of 80 patients, out of an eligible group of 330 patients, and 30 RNs in charge of their care participated in the study. The study was conducted from November 2002 to January 2003. Inclusion criteria for patients were: (1) aged 18 years or older, (2) admitted to the ward less than 48 hours before data collection and expected to stay for at least three days, (3) able to communicate in Swedish, (4) participation did not jeopardise the current health condition of the patients as judged from the interviewer’s (JF) own experience as an acute care nurse, and (5) being cared for by a RN willing to participate in the study. Exclusion criteria were expected length of stay less than three days, suffering from cognitive impairments because of dementia or confusion, and too medically ill or in poor health condition. Eligible participants and reasons for dropouts are displayed in Figure 3. A final sample of 80 patients was recruited, of whom 59 patients also provided data for follow-up comparison.
Figure 3. Number of eligible patients in study II and III and reasons for losses.

All RNs ($n = 35$) working at least part time on the ward during daytime shift were invited to participate. The final sample of nurses was 30 RNs since four RNs declined participation and one RN was never assigned to any of the patients participating in the study. RNs were allowed to participate in a maximum of five patient-nurse dyads, and did so in a median of two dyads (IQR 1.0 to 4.25; range 1 to 5). RNs in four dyads did not respond to the questionnaire within the given time frame, resulting in a final sample of 76 patient-nurse dyads amenable for analyses.

The patients displayed a variety of medical conditions, which were classified according to ICD-10 (WHO 2006). Infectious diseases, such as gastroenteritis or pneumonia, were the most common medical conditions. The median co-morbidity index for patients was 1 (IQR, 0 to 3), indicating rather low values of Co-morbidity as measured with the Co-morbidity Index (Charlson et al. 1987). Patient characteristics are displayed in detail in Table 3 and characteristics of RNs are displayed in Table 4.
Table 3. The patients’ characteristics in study II, III and IV.

<table>
<thead>
<tr>
<th>Demographic variables</th>
<th>Studies II and III (n = 80)</th>
<th>Study IV (n = 428)</th>
</tr>
</thead>
<tbody>
<tr>
<td>Gender</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Female</td>
<td>37 (46%)</td>
<td>172 (40%)</td>
</tr>
<tr>
<td>Male</td>
<td>43 (54%)</td>
<td>256 (60%)</td>
</tr>
<tr>
<td>Age, mean age (SD&lt;sup&gt;a&lt;/sup&gt;)</td>
<td>59 (16.5)</td>
<td>64 (14.3)</td>
</tr>
<tr>
<td>Median (IQR&lt;sup&gt;b&lt;/sup&gt;)</td>
<td>61 (45 to 73)</td>
<td>65 (57 to 74)</td>
</tr>
<tr>
<td>Range</td>
<td>23 - 84</td>
<td>18 - 94</td>
</tr>
<tr>
<td>Length of stay&lt;sup&gt;c&lt;/sup&gt;</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Mean (SD&lt;sup&gt;a&lt;/sup&gt;)</td>
<td>6 (4.0)</td>
<td>5 (3.5)</td>
</tr>
<tr>
<td>Median (IQR&lt;sup&gt;b&lt;/sup&gt;)</td>
<td>5 (3.75 to 7)</td>
<td>4 (3 to 6)</td>
</tr>
<tr>
<td>Range</td>
<td>3 - 26</td>
<td>1 – 26</td>
</tr>
<tr>
<td>Living situation</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Living alone</td>
<td>27 (34%)</td>
<td>110 (26%)</td>
</tr>
<tr>
<td>Living together with adult/child</td>
<td>53 (66%)</td>
<td>314 (73%)</td>
</tr>
<tr>
<td>Missing data</td>
<td>4</td>
<td>1</td>
</tr>
<tr>
<td>Education</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Basic education</td>
<td>32 (40%)</td>
<td>244 (57%)</td>
</tr>
<tr>
<td>High school</td>
<td>35 (44%)</td>
<td>92 (22%)</td>
</tr>
<tr>
<td>University</td>
<td>11 (14%)</td>
<td>90 (21%)</td>
</tr>
<tr>
<td>Missing data</td>
<td>2</td>
<td>2</td>
</tr>
<tr>
<td>Employment status</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Employed</td>
<td>135 (32%)</td>
<td></td>
</tr>
<tr>
<td>Student/unemployed</td>
<td>17 (4%)</td>
<td></td>
</tr>
<tr>
<td>Senior citizen</td>
<td>275 (64%)</td>
<td></td>
</tr>
<tr>
<td>Missing data</td>
<td>1</td>
<td>1</td>
</tr>
</tbody>
</table>

<sup>a</sup> Standard deviation, <sup>b</sup> Interquartile range<sup>c</sup> Data missing for 69 patients in study IV

**Questionnaires**

In study II, a 43-item questionnaire organised in nine subscales comprising physical, psychosocial, and spiritual needs in nursing was developed to elicit perceptions of needs and problems in nursing. The items were identified in the literature on patient problems with relevance for nursing including concepts from the International Classification of Functioning, Disability, and Health (ICF) (WHO 2003), nursing diagnosis classification developed by the North American Nursing Diagnosis Association (NANDA 2001), and descriptions of essential nursing needs from the VIPS model (Ehnfors et al. 2002).
Table 4. Characteristics of nurses in study II and III.

<table>
<thead>
<tr>
<th>Demographic variables</th>
<th>Study II and III (n = 30)</th>
</tr>
</thead>
<tbody>
<tr>
<td>Gender</td>
<td></td>
</tr>
<tr>
<td>Female</td>
<td>29 (97%)</td>
</tr>
<tr>
<td>Male</td>
<td>1 (3%)</td>
</tr>
<tr>
<td>Age</td>
<td></td>
</tr>
<tr>
<td>Mean age (SD(^a))</td>
<td>34 (8.7)</td>
</tr>
<tr>
<td>Median (IQR(^b))</td>
<td>31 (28 to 40)</td>
</tr>
<tr>
<td>Range</td>
<td>23 - 59</td>
</tr>
<tr>
<td>Time since registration as a nurse</td>
<td></td>
</tr>
<tr>
<td>Mean years (SD(^a))</td>
<td>4.6 (8.1)</td>
</tr>
<tr>
<td>Median years (IQR(^b))</td>
<td>1.5 (1 to 4)</td>
</tr>
<tr>
<td>Range</td>
<td>0.1 - 36</td>
</tr>
<tr>
<td>Employment as a nurse at the ward</td>
<td></td>
</tr>
<tr>
<td>Mean years (SD(^a))</td>
<td>3.2 (6.4)</td>
</tr>
<tr>
<td>Median years (IQR(^b))</td>
<td>1 (1 to 3)</td>
</tr>
<tr>
<td>Range</td>
<td>0.1 - 35</td>
</tr>
</tbody>
</table>

\(^a\) Standard deviation, \(^b\) Interquartile range

Responses to each item are made in three subsequent steps: (1) to identify the presence of a problem by indicating “yes” or “no”, (2) to describe the severity of the problem on a four-point ordinal scale ranging from a ‘mild problem’ to a ‘very severe problem’, and (3) rate the importance of the problem using a four-point ordinal scale ranging from ‘not important’ to ‘very important’. If no problem was identified in step 1, the respondent ticked the box ‘no problem’ and continued responding to the next item. The questionnaire eliciting RNs perceptions was identical to that of the patients but the statements reflected a professional perspective on a specific patient.

Card sort technique
The Control Preference Scale (CPS) developed by Degner and Sloan (1992) was used in study III and IV in a slightly modified way. CPS is a card sort technique displaying five decision-making roles in the interaction between patient and
physician. The cards should be ordered from the most preferred option to the least preferred, which would create an ordinal scale ranging from ABCDE to EDCBA, representing different degrees of patient control. There are 120 possible permutations of the cards. The CPS has previously been used to elicit patients’ preferred roles in decision making in medical care (Degner & Sloan 1992; Beaver et al. 1996, Beaver et al. 1999, Ramfelt et al. 2000). In this research project, the wording of the cards was modified to focus on the nurse-patient relationship and decision making in nursing; further, the scale order was reversed in order to describe increasing degree of patient control from A to E. The cards now ranged from a passive role (cards A and B), through a collaborative role (card C) to an active role (cards D and E) as displayed in Figure 4.

In study III, patients used the CPS to state their preferred clinical decision-making role in the following dimensions: (1) needs of nursing care in general, (2) physiological needs and (3) psychological/spiritual needs. The cards were presented

![Figure 4. The card options in the modified Control Preference Scale](image-url)
in the fixed order A, B, C, D, and E before each response. The wording of the cards was also used as categorical descriptions described in questionnaires in both study III and IV. In study III, RNs stated how they perceived their patients’ preferences for participation in clinical decision making by ordering the role descriptions A, B, C, D, and E. The wording of the descriptions was rephrased to reflect an outside perspective: ‘The patient prefers to...’ instead of ‘I prefer to...’.

A follow-up self-reporting questionnaire to elicit patients experienced participation in clinical decision making was based on the same categorical descriptions. The questionnaire covered both physical and psychological/spiritual needs, divided into nine broad areas labelled according to some of the key words for current health status in the VIPS model (Ehnfors et al. 2002). The nine categories were communication, breathing and circulation, nutrition, elimination, skin care, activity, sleep, pain, and psychosocial needs and problems. Patients stated their preferences by selecting one card for each of the nine areas, if applicable, that best described their decision-making role during the recent hospitalisation.

Procedure
The patients responded to the questionnaire (paper II) through structured interviews, taking approximately 15 minutes. The interviews were conducted in each patient’s room. Patients’ median time on the ward before completing the questionnaire was 26 hours (IQR 20 to 39 hours). The patients then continued responding by ordering the options in the CPS (paper III). The RN assigned to the patients’ care received a corresponding questionnaire and was asked to complete it during the current work shift. This questionnaire, however, included the additional questions about patient preferences for participation. All questionnaires were coded so that the answers from the patient-nurse dyads could be identified. Patients received the follow-up questionnaire before leaving the hospital and could either respond directly by handing in the questionnaire in a sealed envelope or take it home and return it by mail in a pre-stamped envelope. Agreements were made with
five patients having severely impaired vision to respond to the follow-up questionnaire by a telephone interview conducted within a week from discharge.

Study IV
A cross-sectional comparative survey design was applied collecting data from patients recently being cared for in acute somatic hospital care. In all, 15 wards participated, which included internal medical wards, orthopaedic, surgical, and cardiology wards at a university hospital and a regional hospital in Sweden.

Sample and characteristics
Respondents were recruited from the group of approximately 2000 patients who had been discharged in April to June 2006 at the participating wards. Further, participants should be 18 years or older for inclusion. Exclusion criteria were lack of ability to communicate in Swedish and cognitive deficits hampering the ability to participate, as judged by the RNs before discharge. Totally, 876 persons gav

The patients displayed a broad disease spectrum, reflecting the specialities of participating wards. Totally, 127 patients were treated for circulatory system disorders (e.g., myocardial infarction, angina pectoris, and arrhythmias), 64 for various surgical diseases (e.g., diseases from the abdomen and urinary tract), 40 for various cancer diseases, 37 for disorders in the skeletal system (e.g., fractures, arthritis, and lumbago), 20 for respiratory diseases (e.g., acute breathing problems, chronic obstructive lung diseases, and pneumonia), and 62 were categorised as others, classified with the International Classification of Diseases (WHO 2006), hereby including a variety of disorders not being placed in the before mentioned
categories. A total of 78 values were missing because of lack of 69 patients’ consent to extract the information from the record and because 9 patient records were not found at the time. Median co-morbidity index was 1 (IQR, 0 to 2), indicating rather low values of co-morbidity as measured with the Co-morbidity Index (Charlson et al. 1987).

**Questionnaire**
The categorical descriptions derived from the CPS were used, with respondents selecting the one description that best described: (1) their preferences for participation, and if applicable, (2) experienced degree of participation during their recent hospitalisation. The questionnaire consisted of a global question about participation in the area of nursing needs in general. Further, questions were posed on a more detailed level for physical and psychological/spiritual needs. The category labels, derived from the key words for current health status in the VIPS model (Ehnfors et al. 2002), were communication, breathing and circulation, nutrition, elimination, skin care, activity, sleep, pain, psychosocial, and spiritual/cultural needs and problems. However, only the global question concerning nursing needs in general is reported in paper IV. The questionnaire also elicited patient characteristics such as age, gender, education, living conditions, and employment status. Moreover, a measurement of personal disposition was used based on the following three questions proposed by Lundberg & Nyström Peck (1995): [1] Do you usually see solutions to problems and difficulties that other people find hopeless? [2] Do you usually feel that your daily life is a source for personal satisfaction? [3] Do you usually feel that things happening to you in your daily life are hard to understand? Responses were given on a 3-point ordinal scale with the categories: ‘no’, ‘yes, sometimes’, and ‘yes, always’. Additionally, nine questions related to clinical decision making were identified and elicited from the Empowerment scale (Faulkner 2001). The response set for these items was a 3-point scale with the categories: ‘no’, ‘yes, sometimes’, and ‘yes, often’, with a possibility to state ‘not applicable’.
Patients weighted sum of co-morbidity conditions was described using Charlson’s Co-morbidity Index, where the patients’ medical diagnoses received a weight ranging from 0 to 4 points depending on the seriousness of the condition (Charlson et al. 1987).

**Procedure**
After permission obtained by written informed consent, names and addresses of discharged patients were communicated once a week from the wards to the research team. Information about the study and invitation to participate was sent by mail to all persons on the lists within eight days from discharge, including a form for informed consent to participate and a questionnaire. The informed consent also included permission to abstract some information from the patient’s record. A pre-paid return envelope was included for the responses and non-respondents received a reminder letter within three weeks.

**Reliability and validity**
Face validity of the QOD scale (study I) was judged to be good through minor pilot testing of the understandability and usage of the scale. Content validity was established by identifying characteristics in existing instruments and the ongoing professional discussions in the literature on requirements for nursing diagnoses statements. The facet of the construct is restricted to the structural quality of the diagnostic statement to a high extent and is not intended to reflect the accuracy of the diagnosis in the clinical arena. Estimates of internal consistency for the QOD scale showed a Cronbach’s alpha coefficient value of 0.863. Concurrent validity of the QOD scale was estimated by the use of items in CAT-CH-ING (Björvell et al. 2002), showing a correlation of 0.31 between measures, which was judged as reasonably good considering that the two measures do not reflect exactly the same dimensions in the concept nursing diagnosis. Interrater reliability was calculated for 10% of the sample, showing a Kappa value of 0.93 for the whole QOD scale. A kappa value > 0.75 was interpreted as excellent agreement (Fleiss 1981).
Cronbach’s alpha for the 43-item questionnaire developed in study II was 0.875, which was obtained after removal of the item dental hygiene from the scale because of zero variance. Alpha values exceeded the suggested minimal value of 0.75 for a scale to be considered reliable (Nunally 1978).

The reconstruction and rephrasing of the items in the CPS scale (study II and III) was tested on a small group of patients and nurse specialists, indicating that it measured the same concept and showed good face validity. The use of the scale as response categories in a questionnaire is a modification that has previously been used (e.g. Ford et al. 2003; Doherty & Doherty 2005).

A pilot test in study IV of the questionnaire’s comprehensibility and understandability was conducted to test face validity. This test led to minor revisions of the wording and layout of the questionnaire.

**Ethical considerations**
Patients and RNs in study I-IV were invited to participate in the studies after receiving written and/or verbal information. Participants were informed about the voluntary nature of participation, the right to withdraw at any time, and confidential handling of the data. In particular, patients were informed that their decision to participate or not in the study was a separate issue without any connection to their care or relation with the staff. Informed consent to participate was elicited verbally from patients and RNs in study II and III and in writing by the respondents in study IV. The researcher and not the staff performed data gathering in study II and III. The patients in study IV were approached after discharge, thereby reducing a possible ‘white coat’-effect. Written permission to conduct the studies was obtained from chief executives at the clinics. No ethics review was performed in study I since it did not directly involve patients or intervene with the care given and was regarded as ethically correct according to prevailing national research ethics praxis. Data were collected through a retrospective review of patient records stripped from personal identification to
preserve anonymity. The research ethics committee at Uppsala University gave approval to study II and III (No. 275/02) and study IV (No. 355/2005).

Data analyses
For descriptive purposes in study I – IV, raw numbers, percentage proportions, means, standard deviation, median, interquartile range, and range were used depending on the properties of the data (Altman 1991). SPSS version 11.0, 13.0 and 14.0 were used for analyses. The level of statistical significance was set to 0.05.

In study I, data were treated as interval data and a subsequent paired student’s t-test was used in analyses of differences between pre- and post-test performance. After categorisation of the diagnoses, the Chi-square test was used to make analysis of differences between groups.

In study II, data were derived from paired observations in which the patients’ perceptions were seen as the gold standard. Wilcoxon’s signed-rank test analysed differences between groups for continuous variables. Sensitivity, specificity, and predictive values on the RNs’ perceptions in relation to patient perceptions were calculated. McNemar’s test was employed to analyse agreement/disagreement between groups for categorical data. Finally, the pattern of agreement/disagreement between the pairs of ordered categorical values was also analysed using the methodology developed by Svensson (Svensson 1998; Svensson & Starmark 2002).

In study III, the Sign test was used for analysing differences between patients and RNs’ perception of the patients’ most preferred role in clinical decision making. Differences between subgroups, identified by gender, social situation, and age, were analysed using the Mann-Whitney U test. A discrepancy score was also calculated by subtracting the preferred role score from the experienced role score.

In study IV, univariate logistic regression analyses were performed to examine relationships between independent and dependent variables. The five categories of
the variable preferred decision-making role (dependent variable) was dichotomised into ‘passive’ versus ‘active’ for purposes of multiple regression analyses, where the mid alternative (I prefer that my nurses and I share responsibility for deciding which treatment is best for me) on the scale was referred to as passive. Multiple logistic regression analyses were employed with variables showing a significant relationship with the dependent variable as explanatory variables. The variable occupation was also included in the analysis since the p-value was in the realm of significance. Odds ratios and probability values for adopting an active role in clinical decision making were calculated. Cohen’s kappa and percentage agreement were used for analyses of interrater reliability. Spearman’s rho and Cronbach’s alpha coefficient were used as validity measures.
RESULTS

Quality of nursing diagnoses (Paper I)
The quality of RNs formulation of nursing diagnoses improved at the experimental ward after education and implementation of new forms for recording, whereas no improvement was found at the control wards. However, control wards could not act as true controls because of significant differences between wards on the outcome variable at pre-test. Thus, the control wards could serve merely as a comparison in general terms (Figure 5). The frequency of specific diagnoses stated at the experimental ward after the intervention was doubled, whereas mere problem statements decreased with 50%. The average diagnostic quality score at the experimental ward increased from 6.5 to 8.8 points. No quality improvement of the diagnostic statements was observed for the problem component in which average scores were high at both measurement times. However, the quality values improved concerning the etiologic component, the sign/symptom component, and the general component as well. Five diagnoses obtained the maximum score of 14 points and 10 points or more were identified at post-test in 49% of the diagnoses (n = 28) as compared with 29% (n = 16) at pre-test.

No quality improvement of the diagnostic statements was observed at the control wards over time for any of the four components. The average diagnostic quality scores obtained before and after the intervention period were 4.3 and 4.4, respectively. In general, serious flaws in the use of the aetiology component were found. The etiologic component was not identified in 37% of the diagnoses, and when present, the descriptions lacked precision and were largely not potentially changeable with nursing care. Notably, the patients’ needs or problems often focused on medical conditions and were not documented at all in 33% of the patient records in the control wards and 13% in the experimental ward.
* improvement in the experimental ward at post-test, $X^2 (2) = 12.69; p < .01$

Figure 5. Diagnostic levels at pre- and post-test for experimental and control wards.

**Congruence in perception of needs (paper II)**
A rather large discrepancy in identification was revealed between patients and RNs’ perceptions of patient needs. RNs, in general, identified more needs than the patients did, while 38% of the RNs identified fewer needs. However, the needs perceived by patients were identified by the RNs with a sensitivity of 0.53 and a predictive value of 0.50 (Table 5).

Lowest mean sensitivity values were found for needs related to the areas *Nutrition* (0.22) and *Emotions/spirituality* (0.24). Furthermore, low positive predictive values for the subscales indicate that RNs and patients often identified different problems.
Table 5. RNs’ sensitivity, specificity, and predictive values of problems perceived by patients (n= 614), displayed for subscales.

<table>
<thead>
<tr>
<th>Subscale</th>
<th>Number of problems n</th>
<th>Sensitivity m (SD)</th>
<th>Specificity m (SD)</th>
<th>Positive predictive value in %</th>
</tr>
</thead>
<tbody>
<tr>
<td>Communication</td>
<td>16</td>
<td>0.31 (0.27)</td>
<td>0.94 (0.05)</td>
<td>31</td>
</tr>
<tr>
<td>Breathing/circulation</td>
<td>59</td>
<td>0.57 (0.09)</td>
<td>0.84 (0.11)</td>
<td>59</td>
</tr>
<tr>
<td>Nutrition</td>
<td>104</td>
<td>0.22 (0.26)</td>
<td>0.90 (0.11)</td>
<td>25</td>
</tr>
<tr>
<td>Elimination</td>
<td>47</td>
<td>0.42 (0.35)</td>
<td>0.91 (0.06)</td>
<td>38</td>
</tr>
<tr>
<td>Skin</td>
<td>35</td>
<td>0.49 (0.54)</td>
<td>0.89 (0.13)</td>
<td>60</td>
</tr>
<tr>
<td>Activity</td>
<td>51</td>
<td>0.80 (0.22)</td>
<td>0.82 (0.03)</td>
<td>35</td>
</tr>
<tr>
<td>Sleep/tiredness</td>
<td>124</td>
<td>0.55 (0.14)</td>
<td>0.60 (0.19)</td>
<td>51</td>
</tr>
<tr>
<td>Pain/sensory perception</td>
<td>86</td>
<td>0.34 (0.29)</td>
<td>0.78 (0.12)</td>
<td>44</td>
</tr>
<tr>
<td>Emotions/spirituality</td>
<td>92</td>
<td>0.24 (0.21)</td>
<td>0.81 (0.15)</td>
<td>20</td>
</tr>
<tr>
<td>Total</td>
<td>614</td>
<td>0.53 (0.29)</td>
<td>0.85 (0.11)</td>
<td>50</td>
</tr>
</tbody>
</table>

Patients identified 309 needs that were not identified by their RNs, including several severe needs (33%), particularly in the areas of *Nutrition, Sleep, Pain, and Emotions/spirituality* (Figure 6). RNs underestimated the severity in 47% of the 305 mutually identified problems. The RNs perceived the same degree of severity as reported by the patients in 27% of the needs, whereas a higher degree of severity was perceived in 27%. Estimated values for Relative Position (RP) indicated systematic disagreement in position on the scale, whereas values for Relative Concentration (RC) indicated minor overall systematic disagreement in concentration. A rather large individual variation in pairs of responses, unexplained by the systematic disagreement, was revealed by relative Rank-Variance (RV) estimates. An overall agreement of the importance of patient problems was found in 44% of the needs.
The RNs underestimated the importance of 273 of the 305 mutually identified needs. The RNs underestimated the importance of 32% of the needs and overestimated the importance in 24%. Low values on RP and RC indicated minor systematic differences, whereas the RV value indicated a moderate individual variance between nurse and patient perceptions.

**Participation in clinical decision making (paper III)**

Patients most frequent choice of preference order for nursing needs in general was ABCDE, going from passive to active, (20%, n = 16) and for RNs it was CDEBA (14%, n = 11). Patients never chose the option E as their first choice of preference, whereas the RNs did so in 12 of the 76 dyads. Patients preferred to be more active in clinical decision making concerning psychosocial needs and physical problems as compared with needs for nursing in general. In comparison with RNs perceptions, patients preferred a more passive role in clinical decision making for nursing needs in general. More specifically, 61% of the patients preferred a passive role, whereas the RNs perceived that only 24% of the patients preferred such a role. An active role was preferred by 9% of the patients, whereas the RNs perceived that 45% of the patients preferred to be active participants (Table 6).
Table 6. Distribution of patients’ (n = 76) and RNs’ (n = 76) first choice concerning patients’ role of participation in clinical decision making for general, physical, and psychosocial nursing needs.

<table>
<thead>
<tr>
<th>Type Of needs</th>
<th>Participatory role</th>
<th>Passive role (cards A and B)</th>
<th>%</th>
<th>n</th>
<th>%</th>
<th>n</th>
<th>%</th>
<th>n</th>
<th>%</th>
<th>n</th>
<th>Total</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td></td>
<td>Active role (cards D and E)</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td></td>
<td></td>
<td>Missing data</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Needs in general</td>
<td>Patients</td>
<td>61</td>
<td>46</td>
<td></td>
<td>30</td>
<td>23</td>
<td>9</td>
<td>7</td>
<td>0</td>
<td>100</td>
<td>76</td>
</tr>
<tr>
<td></td>
<td>RNs</td>
<td>24</td>
<td>18</td>
<td></td>
<td>32</td>
<td>24</td>
<td>45</td>
<td>34</td>
<td>0</td>
<td>100</td>
<td>76</td>
</tr>
<tr>
<td>Physical needs</td>
<td>Patients</td>
<td>41</td>
<td>31</td>
<td></td>
<td>24</td>
<td>18</td>
<td>34</td>
<td>26</td>
<td>1</td>
<td>100</td>
<td>76</td>
</tr>
<tr>
<td></td>
<td>RNs</td>
<td>7</td>
<td>5</td>
<td></td>
<td>12</td>
<td>9</td>
<td>82</td>
<td>62</td>
<td>0</td>
<td>100</td>
<td>76</td>
</tr>
<tr>
<td>Psychosocial needs</td>
<td>Patients</td>
<td>37</td>
<td>28</td>
<td></td>
<td>37</td>
<td>28</td>
<td>25</td>
<td>19</td>
<td>1</td>
<td>100</td>
<td>76</td>
</tr>
<tr>
<td></td>
<td>RNs</td>
<td>4</td>
<td>3</td>
<td></td>
<td>24</td>
<td>18</td>
<td>72</td>
<td>54</td>
<td>1</td>
<td>100</td>
<td>76</td>
</tr>
</tbody>
</table>

The RNs in 64% (n = 49) of the dyads perceived that their patients preferred a more active participatory role than the patients’ own perceptions. The RNs perceived that their patients preferred a more passive role in 20% (n = 15) of the dyads, whereas there was agreement about the preferred role in 16% (n = 12). In general, 29% of the patients (n = 80) perceived that the actual decision-making role cohered with the preferred role, whereas 37% had been more passive and 34% more active than they had preferred to be. The patients made 228 judgements about the experienced participatory role across the nine specific categories of needs. The patients had been more active than preferred in 88 (39%) of those judgements and more passive in 94 (41%). An actual role matching the preferred role was found in 46 (20%) of the judgements (Figure 7).

Predictors of preferences for participation (paper IV)
Respondents in general preferred adopting a passive role in clinical decision making in nursing, most commonly preferring option B, indicating that “my nurses make the final decision about which treatment will be used, but seriously considers my opinion”. No significant relationships were found between the dependent variable and the age of the patients, length of stay, medical speciality, occupational
status, previous working experience in the health care system, or experience from hospital care as such or from the actual ward. Nor was any relationships identified in relation to the measured internal disposition factors: perceived ability to find solutions on problems/difficulties that others find hopeless, perspective on daily life as a source of personal satisfaction, and perceived difficulties understanding things happening in daily life. However, multiple regression analyses showed that gender, education, living conditions, and occupational status were related to active role preferences (Table 7). Females were 1.8 times more likely to prefer an active decision making role as compared with male respondents, whereas respondents living alone were 1.8 times more likely to prefer an active role compared with respondents living together with someone else, be it another adult or a child. Higher educated respondents more likely preferred an active role (odds ratio 2.2) compared with those with lower level education. At the same time, senior citizens were more likely to prefer an active participation (odds ratio 2.0) compared with respondents who were working, unemployed, or students.
Table 7. Odds ratio for patient (n = 428) preference for active participation

<table>
<thead>
<tr>
<th>Variable</th>
<th>Univariate analyses</th>
<th></th>
<th>Multivariate analyses</th>
<th></th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>OR</td>
<td>CI</td>
<td>p-value</td>
<td>OR</td>
</tr>
<tr>
<td>Gender</td>
<td>1.922</td>
<td>1.213 – 3.045</td>
<td>.005</td>
<td>1.762</td>
</tr>
<tr>
<td>Living conditions</td>
<td>2.147</td>
<td>1.316 – 3.504</td>
<td>.002</td>
<td>1.818</td>
</tr>
<tr>
<td>Occupation</td>
<td>1.623</td>
<td>.0982 – 2.683</td>
<td>.059</td>
<td>1.982</td>
</tr>
</tbody>
</table>

* OR, odds ratio  
* CI, confidence interval

A probability value of 53% was estimated that female senior citizens with high education and living alone would prefer an active role in decision making. A probability value for men in the same situation was estimated to 39%. At the same time, working females with low education living together with someone had a probability value of 13% for preferring active participation in decision making. The corresponding figure for working men living with someone was 8% (Table 8).

Table 8. Probability values for active participation preferences depending on patient (n = 428) characteristics.

<table>
<thead>
<tr>
<th></th>
<th>Men %</th>
<th>Women %</th>
</tr>
</thead>
<tbody>
<tr>
<td>Gender</td>
<td>18</td>
<td>29</td>
</tr>
<tr>
<td>living alone</td>
<td>26</td>
<td>38</td>
</tr>
<tr>
<td>living together</td>
<td>15</td>
<td>24</td>
</tr>
<tr>
<td>living alone, low education</td>
<td>22</td>
<td>33</td>
</tr>
<tr>
<td>living alone, high education</td>
<td>33</td>
<td>46</td>
</tr>
<tr>
<td>living together, low education</td>
<td>12</td>
<td>19</td>
</tr>
<tr>
<td>living together, high education</td>
<td>20</td>
<td>30</td>
</tr>
<tr>
<td>living alone, low education, working</td>
<td>13</td>
<td>21</td>
</tr>
<tr>
<td>living alone, high education, working</td>
<td>25</td>
<td>37</td>
</tr>
<tr>
<td>living together, low education, working</td>
<td>8</td>
<td>13</td>
</tr>
<tr>
<td>living together, high education, working</td>
<td>15</td>
<td>24</td>
</tr>
<tr>
<td>living alone, low education, senior citizen</td>
<td>23</td>
<td>34</td>
</tr>
<tr>
<td>living alone, high education, senior citizen</td>
<td>39</td>
<td>53</td>
</tr>
<tr>
<td>living together, low education, senior citizen</td>
<td>14</td>
<td>22</td>
</tr>
<tr>
<td>living together, high education, senior citizen</td>
<td>26</td>
<td>39</td>
</tr>
</tbody>
</table>
DISCUSSION

The overarching questions of this thesis concern clinical decision making in nursing care planning and patient participation in this process. To fulfil the intentions and utilise the potential of patient-centred or individualised nursing care there needs to be a mutual understanding between RN’s and patients - an understanding of what constitutes the patient’s need for nursing care, and what are the relevant actions to reach the goal of care, as well as the roles in the interaction between patients and RNs. However, the present findings indicate that the diagnostic statements of RNs need to improve and can be improved in a short time frame through education. Furthermore, there was a discrepancy between the RN and the patient in the perception of the patient’s needs, which might hamper the quality of the decision making as a foundation for care decisions. At the same time, patients preferred adopting a passive role in clinical decision making, where gender, education, living conditions and occupational status were identified as predictors of active participation.

The identified discrepancies between patients and RNs’ perceptions of needs and role preferences form the basis for a model of clinical decision making (Fig. 8), modified from Brunswik’s lens model (Brunswik 1956) as reported in Dowding and Thompson (2003). Both the patients and the RNs’ subjective perspectives need to be considered in clinical decision making, as this would allow participation in accordance with the patients’ preferences. The aim of the process is a common understanding through a shared decision-making process with mutual information exchange. Extensions could be made to involve the family as a third actor, which would create a decisional triad (Dalton 2003; Ishikawa & Yamazaki 2005). In this thesis, a modification of Brunswik’s lens model is proposed involving both the patient and the RN in the decision-making process. The modified model also depicts that patients and RNs possibly utilise different cues with different weighting of the cues resulting in their respective subjective judgements of the situation at hand, where ultimately these are united and form a common understanding.
Figure 8. Model of clinical decision making to reach a common understanding (modified from Brunswik 1956)

The findings of differences in perceptions of needs and patients’ preferred participatory role is useful in discussions about patient-centred care, and the need for personal interaction between two subjects- the patient and the RN. The findings are discussed in further details in the following section.

**Quality of nursing diagnoses**
A combination of education and new forms for recording (study I) seemed to be a way to improve the RNs’ documentation skills (e.g., the quality of nursing diagnoses). However, because of pre-test differences between groups, the initial study design could not be utilised and the degree of improvement was not possible to determine. The improvement of documentation practice in a short time frame in the experimental ward supports previous findings (Fagrell et al. 1998; Björvell et al. 2002), although the sustainability over longer time remains unanswered in this study. No similar improvement was identified in the control wards, implying that...
change of professional practice requires external triggering and facilitation (Rycroft-Malone et al. 2004b). This finding is in contrast to reports that improved documentation practice occurs over time in the control group as well (Björvell et al. 2002). A longer time span for follow-up and threats to internal validity (such as effects of history and maturation) could explain such improvements.

Identification of the aetiology component in the diagnosis seemed to be the most crucial step, with remaining difficulties to achieve focus and precision in the statement. This flaw in diagnostic statements is in line with previous findings (Minton & Creason 1991, Dobrszyn 1995).

**Congruence in perception of needs**

Despite how well RNs manage to express their perceptions of the patients’ health care needs in diagnostic statements, the diagnoses can be questioned if the RNs have made inaccurate assessments of the patients’ needs. However, it must be pointed out that accuracy is not absolute; it is depending on one’s perspective and purpose (Fiske 1993). Further, there is not an absolute demand that the patients should agree: RNs sometimes need to state diagnoses and plan care without having a mutual understanding with the patient about the situation, i.e. lack of knowledge in handling daily life as a diabetic. Furthermore, the patients cannot always participate and give their perspective (e.g., because of cognitive deficits) in which case an RN or a significant other needs to function as a proxy. Here, the interpreter burden is extremely high and RNs advocacy task needs to be done with high sensitivity and respect for the person’s values and integrity.

RNs had considerable difficulties in identifying the needs perceived by their patients, at least during the initial phase of the hospital period (II). The RNs inability to identify needs on an individual basis in this study is consistent with previous findings (Farrell 1991; Lauri et al. 1997; Löfmark et al. 1999; Adamsen & Tewes 2000). Several needs were perceived by either the patient or the RN, but not by both at the same time. The RNs identified about half of the patients’ perceived needs, of which one out of four was described with the same degree of
severity as the patients described them. A mutual perception of the importance of attending to the needs was reached in less than half of the cases. Other studies have reported RNs’ recognition of patient-perceived needs with 70% agreement or better (Adamsen & Tewes 2000; Hansen et al 2002). However, comparisons between studies are difficult because of different study designs and varying populations and settings. The present study used nurse-patient dyads as the basis for comparison, whereas other studies have used a group of RNs’ perceptions of the patients’ situation, elicited from focus group interviews (Adamsen & Tewes 2000), perceptions of a general patient population and not in relation to specific patients (Hallström & Elander 2001b), and from dyads in which the RNs chose an appropriate patient whom they thought they knew well (Löfmark et al. 1999). The lower levels of agreement in our study might reflect the different samples and time frames used. It is noteworthy that many of the needs perceived by either the patient or the RN were found within the same areas: nutrition, pain, sleep/tiredness, and emotions/spirituality. Standardised tools are available for assessment of nutrition (e.g., Vellas et al. 1999) and pain (e.g., Gaston-Johansson 1996), but are not widely used in clinical practice, whereas tools for assessing psychosocial features are not available to the same extent. The use of more structured assessment methods is anticipated to support high quality decision making. In a study by Abayomi and Hackett (2004) RNs subjective risk assessment overlooked one third of patients identified with standardised risk score assessment. The correct categorisation of patients was 57%, just above a random categorisation, which supports the findings in this study with low sensitivity values based on subjective assessment. The RNs omitted many patient-perceived problems of pain and underestimated the severity of about one third of the mutually identified problems, which supports findings that RNs underestimated the patients pain (Blomqvist & Hallberg 1999; Hall-Lord et al. 1999; Hovi & Lauri 1999; Sloman et al. 2005), indicating a risk for undetected and untreated pain. The patients in study II expressed several needs in the psychosocial realm (e.g., anxiety, loneliness) that the RNs were not aware of, which supports findings showing that 23% of patients
with cancer reported unmet psychological needs (Kent et al. 1996; Soothill et al. 2001).

In Sweden, it is customary that the assigned RN assesses the patient at admission and then makes a clinical judgement of the patient’s care needs, but it is not common to use standardised assessment tools. After a thorough assessment, the RN should “know” the patient’s perspective and be able to combine that with knowledge that is of a more professional nature when planning care. The use of standardised assessment tools could increase the accuracy in patient assessment, especially if the patient contributes with data as well. Promising results have been reported, i.e. decision support aids for patient preference based care planning (Ruland 1998; 1999; Ruland & Moore 2001), and challenges for nursing informatics to meet patients needs and facilitate information exchange have been depicted (Gassert 1998). There is however, a backside with the use of standardised tools, namely the risk that the RNs critical reflective thinking will be hampered. The format chosen and the pre-formulated statements available might narrow the thinking about the patient and the situation at hand.

The patients and RNs’ merging perspectives of the health situation are vital parts in creating individualised nursing care. An essential subjective component needs to be taken into account when identifying needs of nursing care, goals, and actions, i.e. the patient’s preferences. Low-level agreements on what constitutes the patient’s health care needs will hamper the possibility to plan individualised care in accordance with the preferences and values of the patient. The identified lack of congruence in perceptions imply the existence of a “non-communicating/nurse-centred” care (Casey 1995) by which the nurse makes assumptions about patients’ needs, wishes, and abilities based on her/his subjective opinion. RNs ‘naming’ and ‘framing’ of patients’ needs in the encounter - negotiation of need and role perceptions - do not seem to have taken place as outlined by Carr (2004). It can be assumed that over time the RNs would have identified more of the needs perceived by the patients, but considering the limited length of stay in hospital care there is not much time to correct an initial lack of congruence in perceptions.
Participation in clinical decision making

The present findings indicate that RNs failed to assess the patients' preferences accurately, and possibly articulated perceptions rooted in a general view of a standardised patient population instead. The patients preferred a rather passive role in clinical decision making in nursing care, whereas RNs perceived the patients to prefer to be more active (study III and IV). Preferences for adopting a passive role, in this analysis including a shared role, have previously been reported such as in samples of cancer patients (Beaver et al. 1996, Beaver et al. 1999, Ramfelt et al 2000). The fact that the decision-making task in this study was quite vague, focusing on nursing needs in general might have affected the patients’ preferences for a passive role. The finding that patients in study III preferred to be more active in decision making concerning physical or psychosocial needs compared with needs in general supports this interpretation. There is a tendency in Western societies to draw the conclusion that active participation is the preferred behaviour of patients. However, several studies have shown that not all patients want to be active in decisions about their care (Waterworth & Luker 1990; Biley 1992; Cahill 1998). Furthermore, the patient's choice of a passive role in clinical decision making can be a deliberate action, which indicates a not totally passive role but more of an active decision to adopt a passive role.

Personal characteristics, such as gender, education, living conditions, and occupational status, were all associated with patients’ preferences for adopting an active role in clinical decision making (IV). Female senior citizens with high education and living alone were more likely to prefer an active role, whereas male respondents with low education, working, and living together with someone displayed the lowest probabilities for adopting an active role. High education as a predictor of active participation has previously been identified (Beaver et al. 1996; O’Connor et al. 2003; Sanders & Skevington 2003) though the findings that active participation was preferred by senior citizens (study IV) and persons living alone (study III and IV) are in contrast with several reports (Hämäläinen et al. 2003; Lemonidou et al. 2003; Sainio & Lauri 2003). In study IV, women preferred adopting an active role, which supports some findings (Kristensson-Hallström
1999; Sainio & Lauri 2003), but are in contrast to other findings of low preferences for active participation among women (Hämäläinen et al. 2003) or no differences related to gender (Butow et al. 1997, Caress et al. 2002). The focus in this study on needs of nursing, instead of medical decision making, might explain why persons living alone preferred to be more active participants than persons co-habiting, contrasting reports where persons living together adopted a more active role in medical decision making (Sainio & Lauri 2003). Single people may have to take on the responsibility for their daily life, whereas persons who are co-habiting can rely on their next of kin being interested in their wellbeing as well. Women’s preferences for more active participatory roles might be explained by social role expectations, historically and culturally fostered and expected to be interested in taking care of themselves, as well as attending to others. Taking responsibility for care is more intertwined in the female social role than in the male role. A diffusion of roles in this aspect has happened over time, but a diversion is still thought to be common in older age groups. However, it should be noted that a majority of the respondents preferred adopting a passive role.

In this study age was not a predictor for participation, which is in contrast with an extensive amount of previous findings (mostly in medical decision making) in which younger patients tended to prefer more active roles (Beaver et al. 1996; Frosch & Kaplan 1999; Runesson 2002; Henderson & Shum 2003; Hämäläinen et al. 2003; Sainio & Lauri 2003; Kidd et al. 2004). However, age is implicitly related to being retired or working, so age must be taken into account when interpreting the findings. Explanations to why older persons are more reluctant to participate in decisions about their care are suggested to be found in the social exchange theory of ageing (Kenny 1990), or that passive dependent behaviour might be related to learned helplessness and not so much to a desire not to be in control (Barber et al. 1994). The learned helplessness concept could be understood in the idea of being a patient, but still, senior citizens were represented more often in the small group of patients preferring to adopt an active role in this study. Older patients’ higher preferences for privacy, as compared with younger patients (Bauer 1994), could possibly be a factor explaining senior citizens’ higher preferences for
participation in clinical decision making found in study IV. Older patients also regarded control and choice as characteristics of dignity (Walsh & Kowanko 2002), which might be a factor that should be taken under consideration.

**Congruence in perceptions of participation**

In comparison with RNs’ perceptions, patients preferred a more passive role in clinical decision making about nursing needs in general (study III). One out of ten patients preferred an active role whereas the RNs perceived that almost half of the patients preferred to be active. An agreement about role preferences was found in 16% of the dyads, whereas almost two thirds of the RNs overestimated their patients’ willingness to adopt an active role. An interpretation of these findings is that the RNs held a generalised position based on social desirability, emphasising the value of active patient participation based on ethical and legal points of view as well as therapeutic values (Guadagnoli & Ward 1998, Hickey & Kipping 1998). Thus, the RNs failed to grasp the individual’s perspective.

About one third of the patients in study III perceived that their experienced participatory role in decision making equalled their preferences: approximately one third perceived being more active and one third being more passive than preferred. RNs seemed to adopt the rhetoric of patient participation but were not successful in involving patients in decision making according to their own stated perceptions of the patients’ preferences, not even to the level preferred by the patients themselves, which was even more moderate. Agreement between patients’ preferred and experienced participation in decision making, irrespective of preferred degree of participation, is assumed to increase patients’ satisfaction with care (Lam et al. 2003) and will perhaps affect compliance with prescribed care as well.

The findings in this thesis describe a rather large discrepancy between patients and RNs’ perspectives on role preferences as well as identification of needs for nursing. Several factors need to be considered when interpreting the findings, of which, some aspects are outlined below. There needs to be more transparency in clinical
decision making on various levels, both from an individual standpoint as well as on an organisational level. The use of heuristics or disease schemata, which are knowledge structures formed from previous experience, might be underpinning wrongly stated initial hypotheses, leading to errors in selection of diagnosis and treatment. Initially stated hypotheses have been seen to be maintained by professionals even if subsequent data contradicts the hypotheses (Patel & Currie 2005).

Clinical decision making is also a question of power and who is supposed to hold and exercise that power. There is a risk that patients' inability to be independent in the performance of activities in daily life is equalled with an equal lack of ability to execute decisional autonomy. True participation might be difficult to achieve as long as the concept of 'patient' is used, implying a subordinate role relative to health professionals. At the same time, professionals seem unable to feel comfortable and succeed in sharing power and knowledge with the patients in practice, even though they acknowledge the idea in theory (Poulton 1999; Thorne et al. 2000; Henderson 2003). Further, health professionals’ blocking behaviours, lack of facilitating behaviours, retaining information, and reduction of time for the encounter (Paterson 2001; Sainio et al. 2001; Runesson 2002; Martin et al. 2003; Millard et al. 2006) could all hinder active participation of patients. Institutional constraints and the environment where nursing care takes place need to be considered as well. Exchange of information between a patient and a RN is a matter of mutual trust, and the organisation of care and actual ward environment need to support an open and honest relation. Exchange of information of a more private nature in a shared patient room at the ward might be hampered because of lack of privacy and confidentiality. The RNs might adopt a ‘careful conversation’ style, which would leave out more sensitive subjects and questions (Torjuul & Sørlie 2006). The significance of time, continuity, and the RN being present in a close relationship with the patient has been reported as prerequisites for reaching a shared understanding in community nursing (Öhman & Söderberg 2004). There is reason to believe that it is relevant for nursing in an acute care environment as well. An authentic encounter characterised by an “I-
The relationship between patient and RN (Snellman 2001) is thought to be beneficial for the congruence in perceptions and the quality of nursing care. These aspects of the patient–nurse interaction have not been explicitly investigated in this thesis. However, the conditions for the encounter and formats for eliciting patient needs and preferences is of vital importance for the equality in the encounter as well as the quality of the information gathered, and as a consequence to that, of the RNs’ understanding of the patient’s perspective.

**Nursing process**

There are several advocates for the benefits of using a structured approach for assessment and planning of nursing care (Clark & Lang 1992; Hansebo *et al.* 1999; Lockwood & Marshall 1999), but standardised assessment needs to be utilised with the aim of identifying the patient’s unique health situation as an existential human being. The use of systematic data collection/assessment tools that is, e.g., based on the nursing process model or the VIPS model (Ehnfors *et al.* 2002), always holds a risk for professional use of a check-list approach instead of a patient-led approach, and by that a risk of overlooking the patient’s perspective. The nursing process in itself is focused on the individual patient’s unique situation and needs but the use of the model does not assure that the individual’s perspective is identified. In a way, it is problematic and possibly contradictory to use a model derived from system theory to describe and grasp health situations that, perhaps more correctly, could be described in an existentialistic perspective. The explicit use of a nursing philosophy or nursing theory underpinning care could be useful in this respect. However, despite the long tradition of using the nursing process model as a framework for problem solving, the revealed discrepancies in perceptions between the patient and the RN indicate that patient assessment might not be systematic and comprehensive enough to elicit the patient’s perspective. This finding indicates that the idea, or the focus, of the nursing process model has not been fully understood or reached. The RNs did not know their patients well enough to grasp the patients’ perspective of their health care needs. Reasons for the
lack of agreement might be found in the still prevailing common perception of the professionals as the expert and the patient as the help-seeker and task-oriented organisation of nursing care. What possibilities do RNs in the Swedish health care systems of today have to get to know the patient? RNs are often assigned to ward duty schemes that comprise both day and night shifts, with an input on the resource planning allowing for more personal solutions of ward duty schemes. Furthermore, wards in Sweden are often organised according to a group allocation system in which RNs might shift groups depending on staff mix needs. Because of this relocation, both patients and RNs interact with several persons, sometimes shifting on a daily basis. The organisation has thus in a way declined from the responsibility to assure continuity in patient-nurse interaction, placing the responsibility for continuity on the individual RN. At the same time, a division in labour is often prevailing, with a task-oriented rather than patient-centred organisation of care. RNs take on the responsibility for medical and administrative activities while nurse assistants perform the nursing activities. In Sweden, discussions about primary nursing as an ideology and way to organise nursing care is largely absent, even though some debate has recently taken place dealing with the concept of patient-focused care (Myers 1998) (“patientnärmre vård” in Swedish, Inde 2006). It is also necessary to consider the environment as an important part of caring and use the environment’s therapeutic potential in nursing care (Edvardsson et al. 2006). RNs need to regain access to nursing tasks in acute care settings in order to be able to identify the needs and wants of their patients. The RNs need to be more active at bedside in all aspects of nursing care. If RNs should provide care according to their own perceptions of patient needs, it is likely that in some respects they would offer care that is not wanted and therefore fail to attend to needs that are important to the patient.

**Methodological considerations**
Considering relatively small sample sizes, non-randomised sampling procedures, and data collection methods in need of further validation, generalisation of the
findings in study I-IV must be done with caution. Further, a general objection that could be raised is my own involvement at the ward for infectious diseases. I was previously employed at the ward and was involved as leader for the educational intervention in study I. To evaluate one's own practice is not optimal, but was in this study the only feasible way to perform data collection. Here, the evaluation of diagnostic statements was performed in randomly selected patient records where I, as a nurse, had participated with documented problem statements for two patients at pre-test and post-test, which was considered to have minor effects on the outcome. The choice to use the patient’s perception as the gold standard can be discussed since the comparison was performed based on two subjective perceptions.

Sample selection
A common way to evaluate effects of educational interventions on documentation practice is to compare the content in patient records before and after an intervention (e.g., Björvell et al. 2002). This was also done in study I. Confounding factors could be that RNs were given time to sit down and talk about documentation practice, the researchers role as facilitator, or that the RNs were already in a development process of their documentation practice. Staff ratios were similar but cultural differences on the wards could play a role, primarily explaining the initial differences in diagnostic quality between experimental and control wards. However, the selection of patient records as the unit of analysis is somewhat troublesome since the intervention was supposed to lead to a hypothesised improvement in the RNs’ thinking, knowledge, and ability to document clinical judgements. This ability is of course reflected in the recorded content, but there is a risk that comparisons will be performed on content derived from two partly different groups of RNs. Staff exchange happens over time so the groups of participating RNs might vary. Further, the result could be biased if individual RNs provide more content that is documented to the analyses than others do, which lets individual characteristics influence the findings to a higher
extent. An alternative design would have been to compare the performance of identified RNs before and after the intervention.

Possible threats to external validity in study II, III and IV are the sample selection and personal characteristics of both patients and RNs, implying that generalisation of the findings needs to be done with caution. Here, an intended consecutive approach could not be fully accomplished and convenience samples of patients were included in the studies (II, III, and IV). Reasons for the flaws in sampling were difficulties on the wards with providing names of all patients that matched the inclusion criteria because of time constraints or because of problems in the continuity in eliciting informed consent before discharge. No systematic bias is anticipated though generalisation of the findings should be done with great care considering the response rate in study IV. It must be pointed out that the patients participating in the studies were those that could talk and interact verbally with the RNs. The group of patients thought to be most vulnerable has not been included in the studies, and their perceptions of nursing needs and preferences of participation could not be inferred from the reported findings. Randomised sampling procedures would have been preferable but were not seen as feasible in the clinical settings.

**Instruments**

The QOD scale for measuring the quality of diagnostic statements (study I) was regarded as easy to use and showed satisfactory reliability and validity, but further psychometric testing is warranted. The relatively narrow range of the scale might hamper discriminative ability. However, a variety of responses were identified, even if there was a tendency that summed scores were positioned at certain points because of internal correlations between variables. For example, the existence of an aetiology component was positively associated with the aetiology being *specific enough*, and *possible to affect*. A positive association was established with the item *existence of both problem and aetiology*, which is more or less implicit, leading to a lower discriminative ability of the scale.

Needs of nursing care may vary depending on the patients’ medical condition. There is, however, no reason to believe that the findings in study II would have
been different with patients displaying other nursing care needs since the level of agreement in the dyads on each subscale was moderate. The 43 separate variables in study II were identified in the literature and were not intended to lead to a summed severity score for nursing needs. Further refinement of the questions can be done using factor analysis, but calculation of Cronbach’s alpha measurements was not considered necessary. The robustness and reliability of the response alternatives over time need further testing.

The focus of the questions in study III and IV were deliberately broad: e.g., the respondents were asked to state their preferences for participation in clinical decision making about their nursing care as such, and not for a narrowly defined decision. Arguments have been posed that it is illogical to ask about patients’ preferred role without assuring that they have adequate information to make decisions (Elwyn et al. 1999). The research question posed here was intended to describe an attitude about participation in clinical decision making, well aware that respondents presumably used slightly different foundations for their responses. The CPS scale was rephrased and a reversed order of response categories was used, still thought to measure the concept of patient preferences for participation in clinical decision making. However, the alteration made, which is a departure from the recommended use of CPS, might have influenced the result of the analyses (e.g., the choice to present the alternatives in a fixed order from A to E and not pair-wise and the transfer of the response categories into a questionnaire format). Further, it is recommended to use Coombs unfolding theory in the analyses. According to the theory, only 11 response alternatives fall on the main hypothesised dimension and only these should be analysed (Coombs 1964; Degner & Sloan 2002). However, in this thesis all combinations of the response alternatives were included in the analyses.

**Implications for practice**
RNs need to identify their interaction and communication with the patients as important prerequisites for care as well as an important part of the nursing care.
RNs need to reflect on their communication skills in the assessment of patients. There is a need for thorough and structured methods and tools for eliciting patient preferences with regards to needs of nursing and participation in decision making in the clinical setting. The specific methods and tools might vary depending on the clinical area, but the need for comprehensible and structured methods is common. Nursing informatics can provide interesting possibilities with decision support systems to enhance such an endeavour. Further, RNs need to address the issue of shared decision making, not just in theory but also in their clinical practice, and realise the professionals’ initial responsibility to invite to a dialogue with the patient. More deliberate facilitation of patient participation in clinical decision making needs to be applied in clinical practice. It is important to point out that patient typologies of participation preferences, as described in this thesis, cannot function as a justification of a paternalistic decision-making approach over time for patients preferring a passive role. Autonomy is still a valid principle fostering self-determination and patients ought to be in a position to determine how they want to exercise their autonomy, even if that is by deliberately adopting a passive role. The RNs have a professional responsibility to act in such a way that patients can participate and make decisions according to their own values from an informed position.

**Future research**

It would be of further interest to study the variability of practice of individual RNs in relation to agreement with their patients’ perception of needs and preferences for participation in nursing care. Does the individual RN maintain the same degree of agreement regardless of type of care needs or over time? What factors seem to influence the RNs’ accuracy in identifying patient needs?

Further studies are needed of the effects on care processes of feeding information forward to RNs about the patients’ perspective regarding their health care needs and participation preferences in clinical decision making. Patients’ self-reporting using information technology applications as an information vehicle...
(e.g., CHOICE) (Ruland 1999) could be applied and tested in new patient groups covering new areas of information interchange, i.e. various chronic disease groups and senior citizens in community dwellings where the encounters take place over longer periods of time. Studies of patient self-reporting of information in the patient record could be conducted from aspects such as effects on care processes, care activities attuned to patient perceived needs, goal attainment, and satisfaction with care. The demands on information technology applications used to support clinical decision-making processes need further validation. There is also a need to develop standardised terms for the concepts of participation and autonomy to be integrated with, information about diagnosis, interventions, and outcomes in a patient-centred multi-professional electronic health care record. Some work has been reported of the use of semantic structures to represent preference elicitations (Ruland & Bakken 2001) and some research has started in the area (Caldwell et al. 2003) but more research is needed.
CONCLUSIONS

The major conclusions drawn from the studies in this thesis are:

- The quality of RNs’ stated nursing diagnoses could be improved by education and development of forms for recording.
- The aetiology component in the diagnosis was a weak link in nurses’ diagnostic statements.
- Patients and RNs in acute care settings did not agree to a rather large extent on the patients’ needs for nursing care.
- The RNs often underestimated the severity and importance of patients’ perceived needs.
- Patients on admission to hospital care mostly preferred adopting a passive role in clinical decision making concerning their nursing care.
- Patients’ gender, education, social living conditions, and occupational status were predictors of active participation in clinical decision making regarding nursing care.
- There was considerable disagreement in patients’ and RNs’ perceptions concerning the patients’ preferences for participation in clinical decision making in nursing in acute care settings.
- The coherence between patients’ preferences for participation and their experienced participation in clinical decision making in nursing varied considerably. Many patients were more active or more passive than preferred.

To summarize, the best way to know patients’ preferences is through assessment of the individual patient by thorough identification of needs for nursing care and preferred participatory role in clinical decision making. The establishment of a trusting relationship between the patient and the RN is the key in getting to know the patient, and as a consequence, being able to give individualised nursing care.
Patientens delaktighet i kliniskt beslutsfattande i omvårdnad – ett gemensamt ansvar för patienter och sjuksköterskor

Bakgrund

Syfte
Avhandlingens övergripande syfte var att undersöka kliniskt beslutsfattande inom omvårdnad med speciellt fokus på omvårdnadsdiagnosers kvalitet, patientens delaktighet i beslutsprocessen och överensstämmelsen mellan patienters och sjuksköterskors uppfattningar om behov och problem inom omvårdnad.

Specifika syften för respektive delarbeten var att I) undersöka effekten av utbildning i omvårdnadsdiagnostik riktad till sjuksköterskor och utveckling av
journaldokument på omvårdnadsdiagnosers kvalitet, II) beskriva överensstämmelse i patienters och sjuksköterskors bedömningar av förekomst, svårighetsgrad och betydelse av problem inom omvårdnaden, III) beskriva samstämmighet mellan patienters och sjuksköterskors uppfattning om patientens preferenser för delaktighet i kliniskt beslutsfattande i omvårdnaden, jämför samstämmighet mellan patienters preferenser och faktiska erfarenhet av delaktighet samt IV) identifiera prediktorer för patienters preferenser att delta i kliniskt beslutsfattande om den egna omvårdnaden.

Material och metod
Studier har genomförts med beskrivande, jämförande och kvasi-experimentell design på avdelningar inom somatisk sjukhusvård. Urvalet består av 140 patientjournaler (studie I), 80 patient-sjuksköterskepar (studie II och III) samt 428 patienter som nyligen blivit utskrivna från somatisk sjukhusvård (studie IV). Data har insamlats genom granskning av innehåll i patientjournaler samt genom enkäter till patienter och sjuksköterskor. Instrumenten CAT-CH-ING och Control Preference Scale har använts tillsammans med frågeformulär som utvecklats specifikt för studien.

Resultat
Delarbete I

Delarbete II
Sjuksköterskorna identifierade de omvårdnadsbehov och problem som patienterna uppfattade sig ha med en sensitivitet på 0.53 och ett prediktivt värde på 0.50. Det
innebär att patienterna delvis identifierade andra problem än sjuksköterskorna; framför allt var det vanligt inom områdena nutrition, sömn, smärta och känslor/andlighet. Sjuksköterskorna underskattade problemens svårighetsgrad för 47 % av de behov och problem som hade identifierats gemensamt av patienter och sjuksköterskor. En gemensam uppfattning om betydelsen av att få stöd och hjälp med att lösa omvårdnadsproblemet fanns i knappt hälften av fallen.

**Delarbete III**

En majoritet av sjuksköterskorna uppfattade att patienterna föredrog att vara mer aktiva i det kliniska beslutsfattandet om omvårdnad än vad patienterna själva uppgav. Sammanlagt 61 % av patienterna föredrog en passiv roll i beslutsfattandet, medan sjuksköterskorna angav att 24 % ville vara passiva. Preferenser om en aktiv roll i beslutsfattande angavs av 9 % av patienterna, medan sjuksköterskorna hade uppfattat att 45 % av patienterna föredrog en aktiv roll. Totalt 71 % av patienterna upplevde att de inte hade varit delaktiga i den utsträckning de själva hade föredragit; 37 % hade varit mer passiva och 34 % mer aktiva. Patienterna uppgav att de intagit en mer passiv roll än vad de hade önskat i samband med behov och problem inom områdena kommunikation, andning och smärta, medan en mer aktiv roll än önskat förekom i samband med behov och problem inom områdena aktivitet och känslor/roller.

**Delarbete IV**

En majoritet av patienterna i sluten somatisk vård föredrog att inledningsvis under vårperioden inta en passiv roll i kliniskt beslutsfattande om omvårdnad. Sammanlagt 22 % av patienterna föredrog en aktiv roll. Faktorer som predicerade preferenser för att inta en aktiv roll var kön (Odds ratio [OR] = 1.8), utbildning (OR = 2.2), levnadsförhållanden (OR = 1.8) och sysselsättning, d.v.s. om personen var yrkesarbetande eller pensionär (OR = 2.0). Sannolikheten var 53 % att en pensionerad högutbildad kvinna som levde ensam föredrog att vara aktiv i beslutsfattandet om sin egen omvårdnad. Sannolikheten för att en yrkesarbetande
lägutbildad man som levde tillsammans med någon annan föredrog att vara aktiv var 8 %.

**Slutsatser**

Kvaliteten på de omvårdnadsdiagnoser som sjuksköterskan ställer kan förbättras genom utbildning, men orsakerna till omvårdnadsproblemen behöver identifieras på ett tydligare sätt. Det fanns en skillnad i hur patienter och sjuksköterskor uppfattade vad som utgjorde ett omvårdnadsbehov eller problem samt problemets svårighetsgrad och betydelse. Sjuksköterskan identifierade 53 % av de omvårdnadsproblem som patienten själv identifierade, samtidigt som sjuksköterskan identifierade andra omvårdnadsproblem som inte patienten uppfattade. Uppfattningarna skiljde sig också åt om vilken roll patienten föredrog att ha i det kliniska beslutsfattande om omvårdnad. Faktorer som kunde predikera patientens preferenser att ha en aktiv roll i kliniskt beslutsfattande var kön, utbildningsnivå, boendesituation och om personen yrkesarbetade eller var pensionär.

En slutsats av den påvisade diskrepansen i uppfattningar är att sjuksköterskor i högre grad behöver involvera patienterna i en diskussion om hälsotillståndet, behovet av omvårdnad och patientens önskan att delta i beslut om sin omvårdnad. Det är nödvändigt för att så länge det är möjligt kunna uppnå en samsyn som grund för planering och genomförande av omvårdnaden. Om sjuksköterskan validerar sina egna bedömningar om behovet av omvårdnad med patienten kan kvaliteten på bedömningarna förbättras. Patientens perspektiv blir en explicit del av beslutsunderlaget vid planering av omvårdnad, vilket sannolikt också påverkar omvårdnadens innehåll och därmed även omvårdnadens kvalitet. Det bästa sättet att identifiera det individuella perspektivet är genom en systematisk bedömning i dialog mellan sjuksköterskan och den enskilde patienten. Mötet och dialogen mellan patienten och sjuksköterskan är en förutsättning för en god omvårdnad men är också en central del av själva omvårdnaden.
ACKNOWLEDGEMENTS

I have met several persons during this endeavour. People who have positively contributed to the project by letting me take part of their skills and knowledge, sharing experiences, and good friendship. In particular, I would like to express my sincere gratitude to my supervisors:

- associate professor Anna Ehrenberg, my primary supervisor, for your constructive criticism combined with excellent guidance and support on the knobbled path, spiced with a great dose of friendship and memories from our travels around the world of research.

- professor Margareta Ehnfors, my co-supervisor, for your excellent guidance and positive encouragement and constructive criticism, as well as for your friendship and our shared experiences and memories from around the globe.

I would like to give special thanks to:

- All the patients and nurses who have participated in the studies.

- The department of Health and Social Sciences at Dalarna University, and especially director Eva Bäck for providing generous working conditions and support for the completion of this thesis.

- The department of Health Sciences at Örebro University, and director Eva Sahlberg Blom, for providing me with a working environment, including financial support that made this work possible.

- The whole group of doctoral students at the department of Health Sciences, Örebro University, for many intriguing and interesting discussions at our seminars.

- All my colleagues at the institution of Health and Social Sciences at Högskolan Dalarna for your interest in my work and providing an inspiring counterbalance by sharing every day concerns, in education as well as in life.

- Leslie Shaps for your skilled and rapidly performed language revisions.
• Birgitte Kolsung, research administrator at the Department of Health Sciences at Örebro University, for your help with organising, facilitating my life as a doctoral student, and getting things together at the end of the project.

• Ingrid Hellegren Fix, head nurse during my previous employment as a nurse, for believing in me and supporting me over the years.

Last but not least, I would like to thank:

• Marie, Martin and Alice, my three beloved children, for just being the ones you are, and for the things we do that enrich life far beyond any thesis project.

The studies have been financially supported by The Dalarna Research Council (Dalarnas Forskningsråd) and Högskolan Dalarna.


Bauer I. (1994) *Patients' privacy: exploratory study of patients' perceptions of their privacy in a German Acute Care Hospital*. Avebury Ashgate, Aldershot.


Efraimsson E. (2005) Vårdplaneringsmötet. En studie av det institutionella samtalet mellan äldre kvinnor, närstående och vårdare. (Discharge planning conference. A study of the institutionalized conversation between elderly women, next of kin and staff). Umeå University Medical Dissertations 967. The Department of Nursing, Umeå University, Umeå. (In Swedish)


Runeson I. (2002) *Children's participation in decision-making in health care.* Department of Medical Ethics, Faculty of Medicine, Lund University, Lund.


Sahlberg Blom E. (2001) *Autonomi, beroende, livskvalitet. Livets sista månad för 56 cancerpatienter.* (Autonomy, dependence, and quality of life. The last month in the lives of 56 patients with cancer.) Uppsala Dissertations from the Faculty of Medicine 997, Uppsala University, Uppsala. (In Swedish)


