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# The Patient–Health-professional Interaction in a Hospital Setting

EVA JANGLAND



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### **Abstract**

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The overall aim of the thesis was to describe patient–health-professional interactions in a hospital setting, with a specific focus on the surgical care unit. The thesis consists of four studies and includes both qualitative and quantitative studies. Content analysis and phenomenography were used in the qualitative studies; the quantitative study was an intervention study with a three-phase quasi-experimental design.

The findings of study I showed that patient complaints to a local Patients' Advisory Committee about negative interactions with health professionals most often concerned the perceived insufficiencies of information, respect, and empathy. The findings of study II showed that experiences of negative interactions with health professionals caused long-term consequences for individual patients and reduced patients' confidence in upcoming consultations. The findings of the phenomenographic study (III) showed that surgical nurses understand an important part of their work in qualitatively different ways, which can be presented as a hierarchy of increasing complexity and comprehensiveness. In the most restricted understanding, surgical nurses focus on the work task, whereas in the others surgical nurses demonstrate increasing degrees of patient-centeredness. Finally, the results of study IV showed that an uncomplicated intervention that invited patients to express their daily questions and concerns in writing (using the 'Tell-us card') improved the patients' perceptions of participation in their care in a surgical care unit. For further implementation of the Tell-us card to succeed, it needs to be prioritized and supported by leaders in ongoing quality improvement work.

The value of a patient-focused interaction needs to be the subject of ongoing discussions in surgical care units. Patients' stories of negative interactions could be used as a starting point for discussions in professional reflection sessions. It is important to discuss and become aware of different ways of understanding professional interactions and relationships with patients; these discussions could open up new areas of professional development. Providing patients an opportunity to ask their questions and express their concerns in writing, and using this information in the patient–health-professional interaction, could be an important step towards improved patient participation.

**Keywords:** The patient–health-professional interaction, relationship, complaints, patient participation, hospital setting, quality of care, content analysis, phenomenography, intervention

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To Lasse, Linus & Sanna

*Cover drawing Carina Lindgren, 2011*

*Back cover photography Charlotte Haglund, 2010*

A journey of a thousand miles must begin with a single step  
Lao-Tse (604 BC)



# List of Papers

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

- I Jangland, E., Gunningberg, L. & Carlsson, M (2009). Patients' and relatives' complaints about encounters and communication in health care: evidence for quality improvement. *Patient Education and Counseling* 75 (2), 199-204.
- II Jangland, E., Larsson, J., Carlsson, M. & Gunningberg, L. Patients' complaints about negative interactions with health professionals in a surgical setting (*Submitted*).
- III Jangland, E., Larsson, J. & Gunningberg, L (2011). Surgical nurses' different understandings of their interactions with patients: a phenomenographic study. *Scandinavian Journal of Caring Sciences* 25(1)
- IV Jangland, E., Carlsson, M., Lundgren, E. & Gunningberg, L. The impact of an intervention to improve patient participation in a surgical care unit: a quasi-experimental study (*Submitted*).

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# Abbreviations

AN	Assistant nurse
PAC	Patients' Advisory Committee
RN	Registered nurse

## **Termed used in this thesis**

Assistant Nurse	Non-licensed nurse with upper secondary school
Clinical nurse specialist	Registered nurse with a postgraduate course in nursing
Health professionals	Physicians, registered nurses, and assistant nurses
Surgical nurse	Registered nurse working in a surgical care unit



# Preface

One day a local Patients' Advisory Committee<sup>1</sup> in Sweden receives a letter from an old woman, in which she describes her struggle with the health care system. She has recently been informed that she has a cancer diagnosis and that she is on a waiting list for abdominal surgery. In the letter she describes having had several X-ray examinations as well as radiation therapy. She was shocked by the information that she had cancer, but she thinks it was delivered the best way possible. But she describes the psychological support available from health care after the information as 'non-existent'. She also describes her struggle to receive information from the health care organisation about self-care for the side-effects of her treatment. In a long series of frustrating phone calls she is transferred from one unit to another, to outpatient clinics, and back again. It seems that no one is responsible for her care, and she is left with unanswered questions and no support. She describes her loneliness and comments that no one should be left so alone in this situation. Her main reason in contacting the committee is to share her negative experience in the hope it will improve care for others.

Every year about 26 000 patients<sup>2</sup> in Sweden report negative events in health care to Patients Advisory Committees, and about 15% of their reports recount uncaring relations with health professionals. The letter described above gives voice to just one patient in a surgical context, but her hope was to speak for many. A patient who is scheduled for a surgical procedure is in a vulnerable situation and may have many concerns and worries related to a serious diagnosis and to undergoing surgery. During my research project I worked with a local Patients' Advisory Committee. Some health professionals I met were unwilling to take the complaints seriously and argued that these complaints represent only a small proportion of all admissions and visits to health care. I believe, however, that these patients have something important to tell us. Listening to their stories could be a good start towards bringing a new understanding of the patient's perspective to health care, and their experiences could be used in the improvement of quality of care.

<sup>1</sup> (Svenska) Patientnämndens kansli

<sup>2</sup> Unpublished data at the Patients' Advisory Committee, 2010

## Outline of the thesis

I will start with a brief overview of the Swedish organisation that handles patients' complaints about health care, followed by a description of the organisation of the surgical care unit, including the perspectives of registered nurses on their work in this context. The introduction section also gives an overview of the main concepts and theoretical frameworks used in the thesis, which comprises three qualitative studies and one quantitative study. The methods section describes the content analysis and phenomenography used in the qualitative studies and the quasi-experimental design and approach used in the quantitative study. This is followed by the results section and discussion of the findings. There is also a discussion of the trustworthiness and rigour of the studies. The thesis will end with conclusions from the studies and their clinical implications for the surgical care unit and competence development in health professionals.

# Introduction

## The value of a caring relationship in a professional context

A caring relationship is an important factor in health care, both in nursing care and medical treatment. The ‘soft’ qualities (kindness, sensitivity, respect, etc.) of the interaction in a professional context are important not only for their obvious emotional attractiveness, but also for their positive effect on patients’ health and well-being, patient safety, and patients’ satisfaction with quality of care [1-5]. Their value to health care is that patients who feel cared for and who have access to information will use health care less often, but will not hesitate to seek medical attention when it is necessary [6-7]. This in turn should positively influence health professionals’ efficiency at work.

Patients admitted to hospital for an operation expect to receive high quality medical treatment and nursing care, including access to information, the opportunity to participate in care, and a trustful, caring relationship with the health professionals [8-9]. A patient with an acute illness or serious diagnosis is in a vulnerable situation and dependent on professionals for care. To help the patient to cope with this distressing situation, health professionals need to show respect, empathy, and a personal approach in the patient interaction [10-12].

Although many health professionals do good work with a heavy workload every day, patients’ expectations and needs are not always fulfilled in health care [8, 13]. Some patients make a conscious decision to report their dissatisfaction with hospital care to the appropriate authority in their country [14-16]. Studies report the need to consider patients’ complaints as a valuable resource, or a ‘trigger’, for improving the quality of care [15-16]. Each year about 26 000 patients in Sweden report their dissatisfaction with hospital care to the local Patients’ Advisory Committee (PAC), but to date these patients and their complaints have remained mostly unstudied. Only one interview study including six such patients was identified [17]. A starting point for this thesis was: What are these patients’ experiences?

To improve quality of care in patient interactions in the fast-paced culture of surgical care, it is important to further study the patient–health–professional interaction and patients’ opportunities to participate in their care in the specific surgical context. How health professionals behave in the interaction with the patient will influence the patient’s experience of the interaction. Therefore it is important to study how health professionals understand their role in this part of their work. The thesis presents the perspectives of patients and registered nurses (RNs) towards their experiences of the patient–health–professional interaction.

This thesis is based on the principal that health care should be guided by humanistic principles and respect for human rights [18-20]. This principle should guide all health professionals and is outlined in the Health and Medical Services Act [21], which legislates that patients should be treated with respect and their integrity protected. Patient should also have access to information and be involved in their care [5, 22]. This requires that health professionals see the patient from a holistic perspective as a person first and consider the persons’ individual experience during the interaction. Health professionals should also make an effort to identify the individual patient’s preferences and abilities for participation.

## Reports to the Patients’ Advisory Committee

In Sweden, the nationwide organisation where patients or their relatives may report dissatisfaction with health care or ask questions, the Patient’s Advisory Committee (PAC), has an office in every county council [23]. If a complaint needs to be investigated further, patients may also file an application to the National Board of Health and Welfare or to the national Patient Insurance Company. The focus of the Swedish patient safety law is to identify needed improvements in the health care system, not to identify and blame individual health professionals [24].

The local PACs act on behalf of the patients or the relatives. It has been reported that the complaints to PACs about uncaring relations with health professionals are increasing. It has also been reported that there is probably a considerable number of complaints of uncaring approaches unidentified as such in the official statistics. This may be because a complaint that includes aspects about medical treatment, as well as complaints about uncaring relations or lack of communication, will be filed as a ‘care and treatment report’ and other included complaints will be lost to tracking [13].

The reports at the local PAC are filed in an electronic system, used throughout the country. Each complaint is investigated by the committee and feed-



back is given to each health professional involved, as well as to the head of the department, who are given the opportunity to respond.

During 2008 a total of 1114 reports<sup>3</sup> were registered in the electronic system at the local PAC in the county council of Uppsala under the following categories: 'care and treatment' (n=568); 'encounters and communication' (i.e. reports about uncaring relations) (n=148); organisation and regulation (n=382); and 'other' (n=16). A total of 663 reports (60%) were related to care at the university hospital. In the electronic system the patients' name and address are registered, but age, nationality, family situation, education, and diagnosis are not registered automatically. We know from the unpublished data from 2008 at the PAC that the majority of reports related to 'encounters and communication' are made by women (n=102, 69%), other demographic characteristics of patients who report to the PAC are unknown.

Therefore, to complete the best possible demographic picture of patients who have complained to the PAC in Uppsala, the author conducted a detailed review of the available data. A random selection of 10 percent (n=72) of the reports registered in Uppsala under the categories of 'care and treatment' (n=57) and 'encounters and communication' (n=15) during 2008 were included in the review. The majority of those who filed the reviewed reports were women (n=49, 68%). The reports filed under 'care and treatment' (n=57) also included complaints about uncaring relations or dissatisfaction with information (n=14, 25%). A total of 10 reports (14%) were made by patients with a cancer diagnosis, while 48 reports (67%) were made by patients with other diagnoses. In 14 reports (19%) the diagnosis was not reported. Many reports contained no information about the patients' age (n=36, 50%) or family situation (n=53, 74%). No file in the review contained information about education or nationality. In sum, the review confirmed that demographic characteristics of patients reporting to the PAC, other than gender, are not filed often enough in the electronic system to draw any conclusions about the reporting patient population.

<sup>3</sup>Statistics published in a local report at The Patients' Advisory Committee in the county council of Uppsala 2008.

## The surgical care unit – the registered nurse’s perspective

A surgical care unit in Sweden is a multi-professional work place that employs staff in various positions, including registered nurses (RNs), assistant nurses (ANs), and surgeons. The care of the patient requires a close collaboration between various departments and many professionals. Patients are admitted from a waiting list, the emergency department, or other units. The professional relationship and communications with the patient are fundamental to high quality in both nursing care and medical treatment. However, in this thesis the professional focus is on the attitudes and experiences of the RNs and how they understand their roles, relationships, and interactions with patients.

Today the RNs in a surgical care unit have to deal with a very complex health care system. Patients are operated on with surgery techniques that have advanced considerably since 20 years ago, and the patients come to the ward earlier in the postoperative phase, needing more advanced nursing care and monitoring. Meanwhile, length of stay is becoming shorter, while patients are older and need more assistance. Organisational changes in the pre-operative phase also mean that many patients come for a polyclinic visit before admission and are then admitted to the unit on the day of surgery. Altogether, patients’ responsibility for their own self-care before and after hospital stay has increased, but time for providing information and support has grown shorter.

In Sweden, many newly graduated RNs work in surgical care units, which demand different qualities of the surgical nurse to meet different patient groups in a fast-paced culture. A problem related to competence in nursing care in the surgical unit is that many RNs work only a few years in the surgical care unit before they leave for other units or education as a clinical nurse specialist in other areas, but clinical nurse specialists in surgical care units in Sweden are few. Research shows that the surgical nurse values caring in practice, but struggle daily to maintain quality nursing care [25]. Other studies point out that RNs describe the relationship with patients as an important part of work, but report that they do not have the time or the energy to communicate with patients [26-28]. Research has also reported how vulnerable and anxious patients feel prior to a surgical procedure and how important it is for RNs to adopt an individual approach to the patient [29-31]. However, because of the many technical procedures and administrative demands of the work, it can be a challenge for the surgical nurse to establish a trustful relationship with the patient in the short time available.

Competence development for RNs in the surgical care unit often focuses on medical knowledge and technical aspects of the work. Although the relationship with the patient and communication skills is included in competence documents [32], professional growth and development in these areas is not always prioritised in clinical practice. Just as there is little time available for relating and communicating with the patient, there is also very little time for surgical nurses to reflect upon their professional roles. How surgical nurses interact with patients will be influenced by how they understand this aspect of their work [33], and how the surgical nurses act and behave in their interactions with the patients will influence the patients' experience of the interaction. There seems to be a lack of studies that address the surgical nurses' way of understanding their role in the patient interaction. A deeper understanding about this aspect of the work could be useful in learning and developing competence in the profession [34-35].

## Fundamental concepts related to the patient–health-professional interaction

During the work of this project it was evident that a number of concepts in this research area are interrelated and overlap each other, e.g. interaction, relationship, and care relation. These concepts could also be understood in different ways by different health professionals, as well as used differently by researchers. Other concepts such as communication, professional manner, trust, and patient participation are also fundamental in the patient–health-professional interaction. As described by Meleis [36], concepts may be seen as the building blocks of theories and the cornerstones of every discipline and therefore important to define and clarify. Supported by a literature review a clarification of the fundamental concepts in this thesis follows (Figure 1).

### Interaction, relationship, and care relation

In a professional context the interaction between the patient and the health professional takes place in a care relation. A care relation has been defined as 'a relation between a human being in the capacity of patient and a human being in the capacity of professional carer'. The concept can then be combined with relevant attributes, such 'caring' or 'uncaring', or it can remain neutral [37-38]. The relationship between the health professional and the patient could be described as a complex of attitudes, expectations, and behaviours attached to roles and expressed through interactions [39-40]. A caring relationship includes kindness, helpfulness, respect, sensitivity, tone of voice, shielding the patients' integrity and autonomy, and seeing the

patient as an individual [12, 41]. In the international scientific literature a combination of ‘patient–health-professional relationship’ and ‘interaction’ is used to describe different aspects of a caring relationship [42].

## Communication

According to several theorists and researchers communication is the key tool in the interaction, and the communication process is the vehicle through which the relationship with the patient is established [36 , 43]. Different theories and models have been used in health care to improve patient–health-professional interactions [39, 41, 44]. In the framework described by Feldman-Stewart *et al.* [39] four main components occur in the interaction between the patient and the health professional. These are as follows: first, the focus of the *interaction* including each participant’s communication goals; second, the *participants* themselves – the patient’s and professional’s needs, skills, values, beliefs, and emotions that affect the communication; third, the communication *process* including how messages are verbally and non-verbally conveyed and received; and fourth, the *environment* in which the communication occurs. The last component also includes external factors such as education, expectations, cultural influences, family and friends, personal experiences, and socioeconomic background.

As described, it is important to address the patient’s goal in the patient–health-professional interaction. The goal could be seen as an expression of one or more of the patient’s needs, and could prompt dialogue during the day and be one more step towards patient involvement in the care. In this thesis the communication framework of Feldman-Stewart *et al.* [39] was used in the design of study IV as well as in the analytic process to understand the outcomes of the patient–health-professional interactions.

## Professional manner and trust

In a professional context the interaction between the patient and the health professional also requires a professional manner of the professionals. A professional manner includes the health professionals’ knowledge, understanding, and awareness of the patient’s reactions as well as their own reaction in the relation with the patient. Professional manner comprises a continuous attempt to ensure that one’s professional conduct is guided by activity that benefits the person seeking help in both the short and the long term, not one’s own needs, feelings, and impulses. This requires showing respect, interest, warmth, humanity, empathy, and a personal approach in the patient interaction. Professional manner also requires the health professional to be aware of the asymmetry in the patient–health-professional interaction and the persons’ dependency as a patient [10]. Trust is the fundamental, yet si-

lent, aspect of the interaction that helps the patient to cope with a distressing situation. Trust in turn refers to different aspects, including interpersonal competence, technical competence, and trust in the organisation itself [45].

## Patient participation

The literature reveals ‘patient participation’ as a complex phenomenon [2, 46-47]. Researchers have defined critical attributes of patient participation as: an established relationship, respect for the individual, recognition of the individual’s knowledge and circumstances, as well as and shared information [46-47]. In this study the definition of patient participation is inspired by the work of Eldh [46], who recommends that the patient have knowledge and, where possible, control of the disease and treatment, to enable the patient to experience trust during the hospital stay and at discharge. A prerequisite for patient participation is a patient–health-professional interaction that includes dialogue characterized by respect, empathy, and recognition of the patient as both an individual and a partner in the health care team (Figure 1).

The literature shows that patients’ preferences for involvement are influenced by many different factors [2, 48-49]. Several studies point out that women prefer a more active role in decision making than men [2, 49-50]. Other factors influencing patients’ preferences include previous experiences of illness and medical care, the kind of decision that needs to be taken, earlier relationships with health professionals [2].

It is not possible to describe patient participation without also mentioning ‘patient-centred care’. Patient-centred care is a phrase used often both in research and in policy documents, but it is difficult to find one definition [51]. Patient-centred care is generally associated with patient participation, respect for the patient’s values and expressed needs, and other aspects of care such as the right of patients to choose where they receive care [22, 51-53]. However, patient-centred care has been described as reflecting the perspective of the health care system, not the patients. In recent years the concept of ‘person-centred care’ has been introduced and presented as focusing on patients as individuals and their unique experience of the disease, not the disease itself [54-55].

**What is a care relation?**

A relation between a human being in the capacity of patient and a human being in the capacity of professional carer [38].

**What is a caring relationship about?**

Kindness, helpfulness, respect, sensitivity, tone of voice, shielding integrity and autonomy, view of patients as individual people [12, 41].

**What is patient participation?**

The patient has knowledge and, where possible, control of the disease and treatment, is able to experience trust during the hospital stay and at discharge. A prerequisite for patient participation is a patient–health-professional interaction that includes dialogue characterized by respect, empathy, and recognition of the patient as both an individual and a partner in the health care team [46].

Figure 1. *A brief summary of fundamental concepts.*

## Patient perception of quality of care, with a specific focus on patient participation

Patient perception of quality of care has been used as a quality indicator for many years [43, 56-58]. A caring relationship is fundamental to high quality interactions with patients, and measuring patients' perceptions of quality of care is one approach to evaluate the interaction. Often items about the relationship with health professionals, provision of information, and opportunities for participation are included in patient questionnaires about the quality of care [8, 43, 56]. In Sweden a patient-centred theoretical model of quality of care was developed through a grounded theory approach [58], and that theoretical model was used as a framework for the last study of this thesis.

In Sweden patient perception of the quality of care has been measured in many quality improvement projects and hospital surveys [8-9, 59]. In the study by Fröjd *et al.* [9], including patients' admitted to both surgical and

medical units, the items about information, patient participation, and physicians' commitment, empathy, and respectful treatment of patients were identified as areas in need of improvement. In 2010 a national survey, initiated by the Swedish Association of Local Authorities and Regions, investigated patients' perceptions of the quality of care in Swedish hospitals. The findings show that many patients were dissatisfied with information and participation during their hospital stay [8]. The need to improve patient participation has also been highlighted in a national report by the National Board of Health and Welfare [13].

Although several reports address improving patient involvement in consultations, fewer seem to consider the hospital setting. Clinical interventions including patient-targeted checklists and patient-held records, and provider-targeted interventions such as education and training in communication skills, have been introduced to enhance patient participation in consultations [60]. In a hospital setting different interventions such as bedside reporting [61] and routinely asking patients to establish daily goals have been reported to improve patient involvement in care [62-63]. In a patient safety project in the US, patient involvement was considered vital to patient safety, and patients' goals were to be identified to all members of the health care team. In their project, the patients' perceptions of the quality of the communication and the teamwork were improved<sup>4</sup>.

While many studies report the need to recognize the patient as a resourceful partner in the health care team in different hospital settings [46, 64], others report that for a variety of reasons patients may be displaced, forgotten, or hindered from being an equal partner [7, 65-66]. It is also reported that strategies to improve patient participation are most often focused on physicians, while in a time of multi-professional care, interventions should include the whole health-care team [67]. There seem to be very few studies set in a surgical care unit that investigate how to improve patient participation by including the patient in the intervention.

<sup>4</sup> Local report - TOPS Project. Triad for Optimal Patient Safety (2007). University of California, San Francisco, US.

# Rationale for the studies

This research project was inspired during clinical practice in the high-pressure environment of the surgical care unit through direct observation of the need to deepen professional understanding of patients' experiences of interactions with health professionals. Although many health professionals do good work every day, hospital surveys and reports to local PACs show that patients' expectations and needs are not always met [8, 13]. Patients who report negative interactions with health professionals to their local PACs have made a conscious decision to report their experiences and this patient group has not been much studied before. Their experiences are valuable sources of insight and information for the health care organisation interested in advancing quality improvement.

Another area identified as in need of improvement in the clinical practice – closely linked to the issue above – was the need to prioritise professional competence in patient relations. Health professionals' behaviour in the interaction with the patient will influence the patient's experience of the interaction [33]. The relationship with the patient is fundamental to high quality care in both nursing care and medical treatment; this thesis focuses on RNs working in surgical care units. This aspect of the surgical nurse's work has not been well studied and could be useful in learning and developing competence in the nurse profession.

The intention of the research project was also to broaden the picture and investigate whether an intervention could improve patient participation, including the relationship in the patient–health-professional interaction. Although the regulations require a caring relationship and patient participation in health care [5, 22] barriers to patient participation have been reported in acute care hospital settings [25, 46, 65]. There remains a lack of intervention studies related to patient participation in surgical care units that include the whole health-care team, including the patient, in the intervention.



# Overall and specific aims

The overall aim of the thesis was to describe patient–health-professional interactions in a hospital setting, with a specific focus on the surgical care unit.

## Study I

The aim was to describe patients’ and relatives’ complaints to the local Patients’ Advisory Committee about their encounters and communication in health care.

## Study II

The aim was to describe the experiences of patients’ who complain about negative interactions with health professionals in a surgical care setting.

## Study III

The aim was to identify and describe different ways surgical nurses understand their roles and interactions with patients and their families in a surgical care setting.

## Study IV

The aim was to investigate the impact of patient self-written cards – ‘Tell-us cards’ – on the patients’ perception of quality of care, with a specific focus on patient participation. Another aim was to investigate the use of the Tell-us card from a patient perspective.

# Methods

## Design

This thesis consists of four studies (I-IV). Studies I and II had a qualitative approach and a content analysis was used. Study III also had a qualitative approach and phenomenography was used in the analysis. Study IV was an intervention study with a quasi-experimental design in three phases (A1, B, A2). Phases A1 and A2 were periods without intervention and phase B a period with intervention [68]. Phases A1 and A2 are presented as the control group in the results section and phase B as the intervention group. An overall presentation of the studies is shown in Table 1.

Table 1. *Overview of studies I-IV*

<b>Study</b>	<b>Design</b>	<b>Sample</b>	<b>Data collection</b>	<b>Data analysis</b>
I	Descriptive	Reports to the PAC (n=105)	Written reports and letters	Content analysis
II	Descriptive	Patients (n=15) who contacted the PAC	Interviews	Content analysis
III	Descriptive	RNs (n=17) in surgical care units	Interviews	Phenomenography
IV	Quasi-experimental	Patients (n=310) in surgical care units	Questionnaire	Non-parametric statistics

## Setting

### Studies I and II

Studies I and II took place at a local PAC. Study I included reports about 'encounters and communication' reported to the PAC. Study II was based on interviews with patients who had contacted the PAC to report a negative interaction with health professionals in surgical care. The interviews were performed between 2007 and 2009. Both studies I and II included patients who had been cared for at a university hospital in Sweden.

### Study III

The interviews in study III were performed during the spring of 2008 with RNs from seven different surgical care units at a university hospital and a general hospital in Sweden. The surgical care units admitted adult patients undergoing abdominal surgery, vascular-surgery/intervention, endocrine and breast surgery, and urology surgery. The patients were admitted from the waiting list and the emergency department.

### Study IV

Study IV was performed from October 2009 to May 2010 in two surgical care units at a university hospital in Sweden. The surgical care units admitted mainly adult patients undergoing colorectal, endocrine, or breast surgery, and also acute patients with abdominal pain or trauma. In the units an RN and an AN work in a team responsible for 6–17 patients depending on the time of the day. The team also includes a resident who performs ward rounds twice a day on weekdays and a surgeon on call once a day on weekends. Both report to a senior consultant. During hospital stay patients meet the surgeon responsible for the operation, the resident, or both. In each unit there is a nurse manager responsible for nursing care and a senior consultant for medical care. About 50 staff in various positions works in each unit.

## Subjects

### Study I

From 2002 to 2004, 1784 complaints about the quality of care at the university hospital were reported to the local PAC. A total of 194 complaints registered in the electronic system concerned 'encounters and communication'. Of these, 105 complaints were retrospectively included in the study. The complaints included were filed by patients (n=54), relatives

(n=47), and others (n=4). The reports consisted of data gathered from telephone calls (n=72), letters (n=28), electronic mail (n=3), or personal visits to the committee (n=2). The text in the included complaints varied from a few sentences from telephone calls to long letters that carefully described experiences of interactions with health professionals.

## Study II

The patients included in study II had either gone through a surgical procedure or were awaiting a planned surgery. Before or after surgery several of the patients were also planned to undergo other types of medical treatment or diagnostic procedures such as X-ray examination, chemotherapy, or radiation therapy. The participants were 13 women and 2 men between 30 and 74 years old (median 55 years). The characteristics of included patients are further described in Table 2.

Table 2. *Characteristics of patients (Study II)*

---

<b>Gender</b>	
Female	13
Male	2
<b>Family situation</b>	
Single/living alone	3
Married/cohabiting	12
<b>Occupation</b>	
Student	1
Employed	7
Retired	4
Unemployed	1
On sick leave	2
<b>Education level</b>	
Elementary school	1
Upper secondary school	10
University	4
<b>Nationality</b>	
Swedish (Non-Swedish) origin	15 (1)
<b>Diagnosis</b>	
Cancer diagnosis	8
Other diagnosis	6
Awaiting diagnosis	1
<b>Surgery</b>	
Yes	12
No	1
Awaiting surgery	2

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### Study III

In Study III, a strategic sample of RNs (n=17) from seven surgical care units in two hospitals, one university hospital and one county hospital, were invited to participate. The RNs were between 23 and 60 years of age (median 34) and had worked in direct nursing care from 1 to 32 years (mean 9, median 6). The RNs included were working day/evening shift (n=12), night shift (n=3), or rotation (n=2). Three of the RNs had a postgraduate course in surgical nursing. The RNs cared for 6–8 patients during a day shift; 8–11 patients during an evening shift; and 14–17 during a night shift. Each RN worked as a team with an AN. One of the units had reorganised according to the concept of ‘patient-focused care’, which meant that the nurse’s work station was moved closer to the patients’ rooms.

### Study IV

In study IV a consecutive sample of patients admitted from the surgical waiting list or from the emergency department was included. The inclusion criteria were patients with a surgical diagnosis with an expected hospital stay of at least one day. Patients were excluded if they were younger than 18 years, not able to speak or write in Swedish, or not willing or able to give informed consent. A number of ineligible patients with medical diagnoses were temporarily in the surgical care units because hospital was short of beds. These patients were not included.

A power calculation, based on previous results from surveys in the hospital, was made to decide the number of patients needed in the different study phases. It was estimated that for an effect-size of 0.35 in the primary endpoint ‘participation’ a sample size of 65 (A1), 130 (B), and 65 (A2) patients would be needed to find a significant difference between groups. With an estimated withdrawal rate of 25% and the lower power of a non-parametric analysis set at 10%, the number of patients included in the three phases was set to 95 (A1), 190 (B), and 95 (A2) (alpha <0.05 and power 0.80 with an estimated standard deviation of 1.0 in each item)

A total of 451 patients meeting the inclusion criteria were approached, 387 agreed to participate, and 310 completed the questionnaire in the different phases. Seventy-seven patients did not complete the postal questionnaire. The response rate in the groups varied from 78% to 81%. The mean age was 58 years (range 21–86; SD = 16) in the intervention group and 58.5 years (range 22–92; SD = 14.5) for controls. The background information of the included patients is described in Table 3.

Table 3. *Background information of patients (Study IV)*

	Control group n=153		Intervention group n=157	
	n	%	n	%
<b>Gender</b>				
Men	65	42	58	37
Women	88	58	99	63
<b>Admission</b>				
Waiting list	80	52	106	68
Acute	73	48	51	32
<b>Surgery</b>				
Yes	88	58	130	83
No	65	42	27	17
<b>Days of admission</b>				
0–1 day	21	14	16	10
2–3 days	74	48	60	38
4–6 days	34	22	42	27
2–9 days	13	8	14	9
10 or more days	11	7	25	16

Percentages in category ‘Days of admission’ in the control group do not add up to 100% due to rounding

## Data collection

### Study I

In study I all electronic reports about ‘encounters and communication’ during the study period were reviewed in detail by the author of the thesis. The reports were copied without including any personal information. This part of the study took place at the local PAC with the head of the committee.

### Study II

In study II data was collected through interviews with patients. Some interviews were conducted in person ( $n = 12$ ) and others, when the patient lived too far away to travel to the hospital ( $n = 2$ ) or felt too tired to travel ( $n = 1$ ), were conducted by telephone. The interviews were recorded and based on four main questions:

- Could you please tell me about the event(s) during the hospital stay that prompted you to contact the PAC?

- Could you please tell me how this event(s) and interactions with health-care professionals affected you?
- What ideas do you have about how the relationship could be improved?
- What was your reason(s) for contacting the PAC?

Probing questions were used during the interviews. The interviews lasted between 40 min and 1 h 30 min. The interviews were later transcribed verbatim by the author of the thesis.

### Study III

In study III data was collected through interviews with surgical nurses. The interviews were mainly conducted in a room outside the surgical nurses' work place and performed by the author of the thesis. A warm-up question was about how it was to work as a surgical nurse. Then the interview was guiding by the following questions:

- Could you please tell me about an interaction with a patient or relative when you felt satisfied in your profession as a nurse?
- Could you please tell me about an interaction with a patient or relative when you felt dissatisfied in your profession as a nurse?
- Could you please tell me about an interaction with a patient or relative that you think was difficult in your profession as a nurse?
- What is your role as a surgical nurse in relation to the patient or relative?

Probing questions were used during the interviews that lasted from 45 min to 1 h 40 min. The interviews were recorded and later transcribed verbatim by a secretary and the author of the thesis.

### Study IV

#### **Intervention**

In study IV the patient self-written cards, 'Tell-us cards', were introduced as the intervention. The Tell-us card had previously been used in the United States in the Triad for Optimal Patient Safety project<sup>4</sup> as a way to assess patients' goals for the day. Permission to translate and adapt the American version of the Tell-us card was obtained from the original researcher at the

<sup>4</sup> TOPS Project (2007) Triad for Optimal Patient Safety. University of California, San Francisco, US.



School of Nursing, University of California, San Francisco.

The Tell-us card was designed as a tent card with two sides, where the patients could write down their specific questions and concerns for the day or before discharge. One side of the card was printed with brief instructions and information about patient participation as follows:

Tell us what is important for you today or before discharge. It is important that you have the knowledge you need and that you are involved in your care. Please use the space on the opposite side of this card and write down your questions and concerns.

On the oppsite side of the card, with space for responses, was printed:

a) This is important for me today \_\_\_\_\_.

b) This is important for me before discharge \_\_\_\_\_.

The patients in the intervention group were asked to use the cards each day, and every morning the RN responsible for their care provided new cards. The card was placed in a fully visible spot on the table in the patients' room. What the patient wrote on the Tell-us card was regarded as a tool in the dialogue between the patient and health professionals, e.g. during ward rounds and discharge information sessions.

### **Standard procedure**

The control group in study IV received the units' standard level of information and communication during hospital stay and at discharge. The standard could vary depending upon the attending physician's or nurse's knowledge and capacity to perceive the patient's need for conversation, information, and support. In certain cases, patients received written information at discharge.

### **The questionnaire**

The data collection in study IV was performed using the questionnaire 'Quality from the Patient's Perspective'. The questionnaire is based on a patient-centred theoretical model of quality of care developed through a grounded theory approach [58]. According to the theoretical model, quality of care can be understood in light of two conditions: the resource structure of the organisation and the patients' preferences. In the theoretical framework the patients' perception of quality of care may be considered along four dimensions: medical-technical competence, physical-technical conditions, the degree of identity-orientation in the attitudes and actions of the caregiver, and the socio-cultural atmosphere [58, 69]. A short version of the questionnaire was used, but items from the long version in the dimension of

identity-orientation were added [70]. The questionnaire has been tested for validity and reliability [58, 70-71].

The questionnaire consisted of 54 items for patients in the control group (periods A1 and A2) and 62 for the intervention group (period B), measured the patient's perception of the quality of care ('This is what I experienced') and the subjective importance of each item ('This is how important it was to me'), and took about 15–20 minutes to complete. Items related to perceived quality of care were rated on a scale of 1 ('do not agree at all') to 4 ('completely agree'), and the subjective importance of the various items was also rated from 1 ('little or no importance') to 4 ('of the very highest importance 4'). Each item also had a 'not applicable' response alternative. In addition the questionnaire contained items about the patient's background, state of health, and counselling.

The patients in the intervention group were also given study-specific, mainly yes/no, questions concerning the Tell-us card asking:

- a) Whether the patient had used the card,
- b) Reason (if applicable) for not using the card,
- c) Whether the card was useful in the dialogue with health care professionals during hospital stay and/or before discharge, and
- d) Whether the card had allowed them to raise anything for discussion that they would not have mentioned had they not had the opportunity of writing it down on the card.

## Procedures

### Study I

A close collaboration with the local head of the PAC was established. She instructed the author of the thesis in how to find the reports in the electronic system and to locate the patients' letters stored in file folders.

### Study II

The patients in study II were informed about the study when they contacted their PAC and invited to participate in a letter from the head of the PAC. Informed written consent was collected from each participant. The name and telephone number of each consenting participant was provided to the first author, who made arrangements for the interviews, which were recorded.

## Study III

The RNs were invited to participate in the interview by a letter from the author of the thesis and co-researcher. Most interviews were performed during the RNs' workday.

## Study IV

At the start of the first period (A1), only limited information about the study was provided to the health professionals in order to avoid affecting the result. This information was given by the nurse managers. Before the start of the intervention both verbal and written information was given to all health professionals in the two units by the first author. Information about the study and how to use the Tell-us card was also repeated during the intervention several times during daily practice.

Patients in all periods were approached to take part in the study by the first author or one of four RNs who acted as co-ordinators for the study during data collection. Patients meeting the inclusion criteria were invited to participate at admission or, at the latest, within the first day of their hospital stay. The patients were given verbal and written information about the study and informed consent was collected. Within a week after discharge all patients were sent the questionnaire by post and were asked to send it back in a prepaid envelope. The questionnaires were coded, and up to two reminders were sent. All administration of the questionnaires was handled by the author of the thesis.

## Data analyses

### Studies I and II

Content analysis was used in studies I and II. According to Krippendorff [72] content analysis is a technique for drawing replicable and valid inferences from texts to elicit their subtexts. Different techniques and approaches may be used in content analysis [73], and the method makes it possible to describe both the overt content of a text as well as its underlying meaning.

Content analysis has been used as a quantitative research method for many years [74]. In recent years, the potential of content analysis as a method of qualitative analysis has been developed, and the method has come into wide use in health research [75], because it is well-suited for analysing data on multifaceted and sensitive phenomena [76]. In this thesis qualitative content

analysis has been used, however, in study I a count of subcategories was added as a final quantitative step in the otherwise qualitative analysis [77].

Qualitative content analysis is conducted by considering the descriptive (manifest) content the text describing it in terms of sub-categories and categories. In its more interpretative approach the underlying meaning of the text (latent content) is considered. In latent content analysis the aim is to answer the question of the meaning of the text, which and is then described in terms of sub-themes and themes [75].

In study I the manifest content was used. In study II the manifest content was used for the patients' reasons for contacting the PAC as well as for their suggestions for improvement. The underlying meaning of the text was considered to answer the question of how the negative interaction had affected the patient.

A summary of the analysis process used in studies I and II is described below. Because the analysis is a reflective process, it is necessary to go back and forth between the different steps.

- The analysis started with a reading of the entire text to grasp a sense of the whole. The text was read several times to understand the experience from the patient's perspective as expressed either in the reports or in the interviews.
- Meaningful passages were identified and divided into 'meaning units'.
- The text was further abstracted, and the meaning units were condensed (study II) and codified. A code could be seen as a word 'to think with' and transformed into the language of the researcher.
- The condensations were compared to the text and abstracted to create sub-categories and categories (study I) or sub-themes and themes (study II).

The analyses of studies I and II were carried out both independently by the author of the thesis, and together with co-authors. In study I, independent analyses of the reports were also performed by the co-authors. In study II the coding and the labelling of the sub-themes and themes were thoroughly discussed among all authors until negotiated consensus about the categorisation was reached [75, 78].

### Study III

In study III a phenomenographic method was used. Phenomenography was developed in educational research in the 1970s by a research group in Goth-

enburg, Sweden [79]. The ultimate goal of phenomenographic research is to describe the different ways a group of people make sense of, experience, and understand phenomena in the world around them [80]. The word 'phenomenon', from the Greek *phainomenon* ('thing appearing to view') is defined in philosophy as 'the object of a person's perception'. Any phenomenon can be studied by different research approaches. Phenomenography deals with how people understand or experience a phenomenon [79, 81]. The investigation is not directed at the phenomenon itself, but at the variation in people's ways of understanding it [79]. In any group of people there is always a limited number of qualitatively different ways of understanding a phenomenon. In study III the phenomenon is the interaction with the patient as understood by surgical nurses.

Phenomenography has been described as a useful method in learning and developing professional competence in health care [35, 81-82]. In study III the part of the surgical nurses' work that dealt with the interaction with the patient was studied. It is thought that people's behaviour is governed by their understanding [33]. Therefore, how surgical nurses interact with patients will be influenced by how they understand this aspect of their work. By exploring the different ways in which surgical nurses experience and understand the patient interaction, we can study what underlies the variation in how they behave towards patients. The surgical nurses' understanding will affect their attitudes and behaviours towards the patients, which will in turn influence patients' experiences of the interactions.

The recorded interviews were transcribed verbatim by a secretary and the author of the thesis. The author then listened through all of the interviews to verify the transcriptions. The analysis of the interviews was performed by the author of the thesis in close collaboration with two co-researchers using the methods outlined by Larsson & Holmström [81]. The text parts where the interview questions were answered were marked. In these passages the researcher looked for *what* was the surgical nurse's focus in the interaction and *how* it was described. A preliminary description of each nurses' predominant way of understanding the interaction was made. The descriptions were grouped into categories based on similarities and differences and a description of each category was formulated. The categories show the different ways of understanding the phenomenon on a collective level.

In phenomenographic research, the main result of a study is the categories of understanding and the internal relations between them, called the *outcome space*. As a last step in the present analysis the researchers investigated the internal relations between the categories and found the outcome space was structured hierarchically, as is often the case.

## Study IV

The data were registered in the KUPPIT computer programme [83] and imported to SPSS version 19.0 for analysis. Means, standard deviations, ranges, and percentages were used for descriptions of the data. For comparisons between groups (i.e. A1 versus A2, and intervention group versus control group) Chi-square test was used for dichotomous variables (eg. gender, nationality, family situation, surgery or not, type of admission) and Mann-Whitney U-test was used for ordinal variables (eg. length of hospital stay, education, and items about perceived quality of care). Student *t*-test was used for the continuous variable age. Statistical significance was set at  $p < 0.05$ .

## Ethical considerations of the studies

In studies I and III formal approval from the regional Ethical Review Board was not required according to national and local directives [84]. Study I was supported and approved by the head of the local PAC. Study III was approved by the heads of the departments in the two hospitals. Studies II and IV were approved by the regional Ethical Review Board in Uppsala (Dnr 2007/07 and Dnr 2009/170) and the head of the department of the university hospital (study IV).

Throughout all phases of the research, including all of the studies and analyses and the preparation of the manuscript, ethical standards for scientific work were followed, and ethical issues were considered carefully [85-86]. The participants in studies II, III, and IV received both written and oral information about the study and their participation, stating that participation was voluntary and that their responses would be treated confidentially. In studies II and IV, an informed consent was collected. The participants had the right to refuse participation without giving any reason and could withdraw from the studies at any time. In study I all personal information was omitted during the data collection. The interviews in studies II and III were transcribed with no personal data. In study IV a protocol was coded with the numbers used on the questionnaires to allow us to send reminders; protocols and returned questionnaires were stored separately in a locked place.

# Results

## Study I

Three categories were identified in which the patients or the relatives described dissatisfaction with the interaction during their visit or stay at the hospital: ‘Not receiving information or being given the option to participate’, ‘Not being met in a professional manner’ and ‘Not receiving nursing or practical support’. Complaints occurred throughout all parts of the visit or stay and included different departments as well as different health professionals. An overview of the categories and sub-categories is presented in table 4.

Table 4. *Overview of categories and sub-categories (Study I)*

<b>Category</b>	<b>Sub-category</b>
I. Not receiving information or being given the option to participate	Insufficient information Insufficient exchange of information between health professionals Insufficient participation Difficulty speaking or understanding the language Inappropriate conversation environment
II. Not being met in a professional manner	Insufficient respect Insufficient empathy Insufficient acknowledgement Poor conversation skills Professional’s abuse of position Insufficient emotional support Discrimination
III. Not receiving nursing or practical support	Insufficient nursing Insufficient practical support

Many patients and relatives described their experience of insufficient information during the hospital stay or visit at the hospital. Patients described that

they received insufficient information during the examination or when the diagnosis was given, or they felt the information was misleading. Also lack of physician continuity was reported either concerning information on the diagnosis or when treatment and care were planned. Patients felt insecure when they received different information from several physicians. Patients also described not receiving the results of tests and treatment within a reasonable time frame.

Some patients experienced that they had not been given the option to participate in decision about whether they wanted to participate in a teaching situation with students or not. Other patients experienced that they were not allowed to discuss the treatment with the physician and to participate in the conversation or the medical decision.

Many complaints related to the fact that patients and relatives perceived that health professionals did not approach the patient or their family member in a professional manner. Reports about insufficient respect and insufficient empathy were reported by many of the patients.

Some patients described situations in which they felt that health professionals had abused their position and this caused the patient anxiety and offence. Aggressive attitudes, displays of irritation and even threats were reported. Patients said that they felt frightened, did not ask for more information and felt that they were an annoyance.

## Study II

The majority of the patients in study II contacted their PAC to share their negative experience of interactions with health professionals in the hope to improve care of other patients. Many wanted to point out to their PAC the importance of a caring relation in improving patient education. The quotation from a woman give the reader an impression what many patients pointed out in the interviews.

‘But I felt that you can’t treat people this way. It doesn’t help me. I can’t do much about my own situation, but I can just hope that others won’t have to go through it, that was the thought.’

In study II, patients’ experiences of negative interactions are described under three main themes: ‘having lost confidence’, ‘feeling like a nuisance’ and ‘feeling abandoned and lonely’. Negative interactions with health professionals caused long-term consequences for many patients, including suffering, feeling of insecurity, and worry. It also reduced their confidence in up-



coming consultations. The complaints included were mainly directed towards physicians and RNs. Table 5 provides an overview of the themes and the sub-themes. A summary of the content in the sub-themes is described below.

Table 5. *Overview of themes and sub-themes (Study II)*

Theme/sub-theme
<b>I. Having lost confidence</b> Feeling insecure about the disease or treatment Doubting one's own symptoms Feeling responsible for coordinating care
<b>II. Feeling like a nuisance</b> Not wanting to disturb caregivers Fighting for one's right
<b>III. Feeling abandoned and lonely</b> Suffering needlessly Feeling dehumanized

**I. Having lost confidence**

Patients described that they felt insecure when meeting health professionals and that they had no one to trust. Some patients felt that they were insufficiently informed about the disease or treatment and they felt that they did not know all they needed. They also believed that their needs for information could not be fulfilled in the hospital. As a result of uncaring relations some patients also began to doubt their own somatic symptoms and wondered whether they had just made them up. Some patients experienced confused and disjointed contact with the hospital and felt that the responsibility for the coordination of their care and difficult decisions were thrust upon them. The patients described having to call the hospital to remind staff to book examinations or blood tests or to check whether they were needed, because it was unclear to them.

**II. Feeling like a nuisance**

Because of uncaring relations some patients were reluctant to disturb the physician or the RN in their work. Patients who needed to ask questions or to tell health professionals about their needs, felt that it was futile to ask and

was worried to be a ‘troublesome’ patient. When information was provided arrogantly or insensitively, patients ended up feeling voiceless and sad. Some patients described that they tried at all costs to maintain good relations with health professionals to avoid bad medical treatment or nursing care in the future. Although many patients described their own doubt, sadness, and disappointment after a negative interaction, some also described how they learned to fight for their rights, i.e. to argue for the right to be taken seriously and to be respected.

### **III. Feeling abandoned and lonely**

Patients diagnosed with cancer described unnecessary suffering because of insufficient emotional support. They described a feeling of existential loneliness – a void – where they tried to cope with information about the diagnosis and plans for treatment. Insufficient acknowledgment and missing information added unnecessarily to patients’ stress. Some patients felt either not respected as human beings or neglected during treatment, especially when treatment seemed to be performed as if on an assembly line, or when the patient felt treated more as a diagnosis or a case than as an individual.

### **Patients’ suggestions for improving patient –health-professional interactions**

The patients made a number of different suggestions about how the patient–health-professional interaction could be improved such as improved emotional support, improved information, better administration and coordination and to receive an apology when a mistake has been done.

## Study III

Four different ways of understanding the surgical nurse's role in interactions with the patient were identified:

- A. Focusing on medical treatment, following prescribed instructions, and maintaining routines;
- B. Providing information, giving service, and coordinating care and treatment
- C. Seeing patients as vulnerable people and helping and supporting them as individuals
- D. Inviting patients to participate in the caring process and encouraging them to take responsibility in their own care. Seeing each patient as a person with individual needs and personal resources.

The categories, representing surgical nurses' different ways of understanding the interaction with the patient, are interconnected and built on one another. Understanding A represents a restricted and task-oriented approach, the surgical nurse has the work task in focus in the interaction with the patient. The others are more patient-focused, but also more complex. In category B-D, the surgical nurse has the person in focus, but differs in the increasingly complex way they see the patient as a person, with each higher level including the abilities of the level below. Understanding D is presented as the most comprehensive one, since a surgical nurse with this understanding has the capacity to focus on several aspects of the nurse-patient relationship depending on the demands of the situation at hand.

The findings show that some surgical nurses with short work experience described how they base their work on a patient-focused understanding of the nurse-patient relationship (C), whereas some surgical nurses with long experience of surgical care understood the interactions through understanding A or B. The result indicates that the professional competence in this area does not necessarily develop over time.

## Study IV

The use of the Tell-us card resulted in significant improvements in patients' abilities to participate in decisions in their nursing and medical care. The patients' opportunity to participate in decisions about their nursing care revealed a significant difference ( $p=0.02$ ) between the groups: a mean score of

3.2 (SD = 1.0) was reported in the intervention group compared to 2.9 (SD = 1.0) in the control group. Also a significant difference ( $p=0.004$ ) in the patients' opportunity to participate in the decisions about their medical care was seen between the groups. The patients in the intervention group had a mean score of 3.5 (SD = 1.0) on the item, while the control group scored a mean of 2.7 (SD = 1.1) Figure 2.

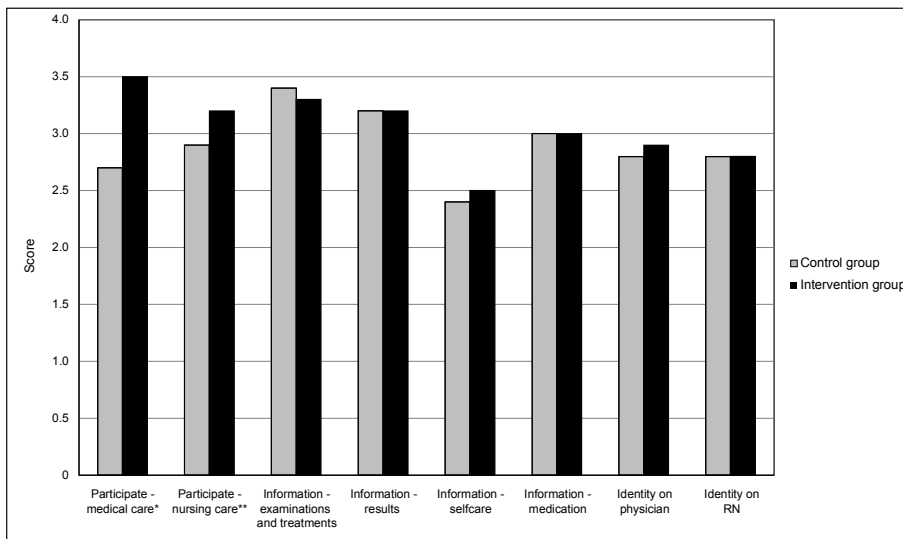


Figure 2. Patients' perception of the quality of care in the dimension of 'Identity-oriented approach' presented with mean values.

(Score 1 = Do not agree at all. Score 4 = Completely agree)

\*  $p=0.004$ , \*\*  $p=0.02$

As shown in figure 3 the patients in the intervention group also reported significantly higher quality of care regarding RNs' and ANs' commitment ( $p=0.008$ ), empathy ( $p=0.004$ ), and respectful treatment ( $p=0.011$ ) of patients compared to the patients in the control group. There was no significant difference in the patients' perception of physicians' commitment, empathy, or respectful treatment between the groups.

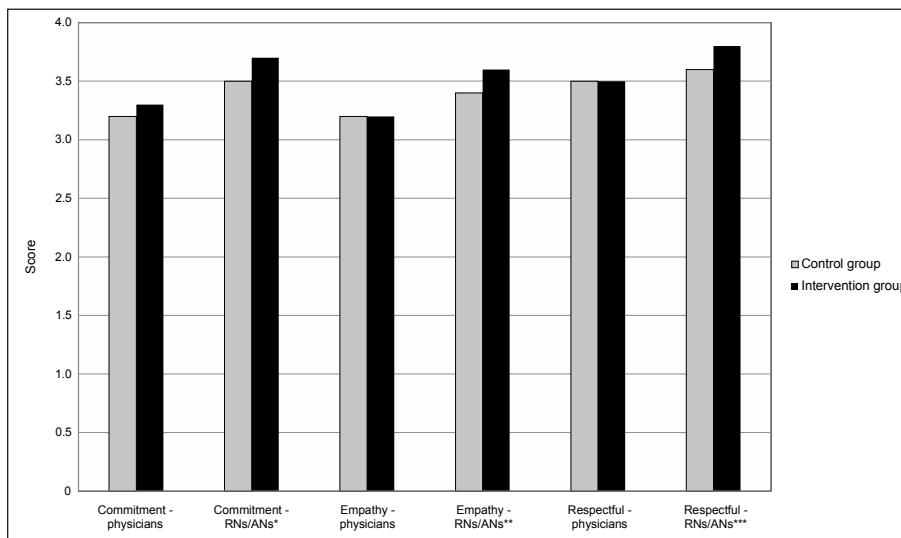


Figure 3. *Patients' perception of the quality of care in the dimension of 'Identity-oriented approach' presented with mean values*

(Score 1= Do not agree at all, Score 4=Completely agree)

\*  $p=0.008$ , \*\* $p=0.004$ , \*\*\* $p=0.011$

There were no significant differences in any of the six items related to information. The findings show that many patients did not feel they received useful information about self-care or about the identity of the physician or RN in charge. The item regarding useful information about self-care had the lowest mean score throughout the study phases. To summarize both intervention and control groups, 141 patients (51%) reported that they did not receive useful information about self-care (scores 1 and 2), 120 patients (40%) reported that they did not receive information about which physician was responsible for their medical care, and 109 patients (36%) did not receive information about which RN was responsible for their nursing care. Figure 4.

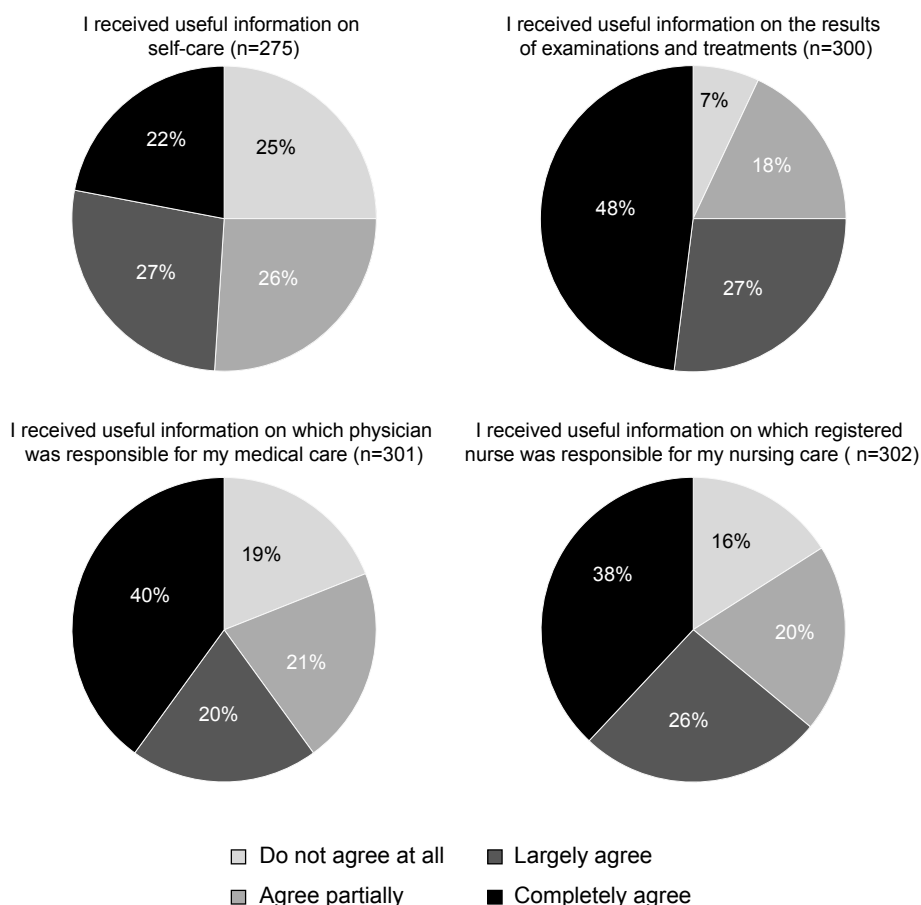


Figure 4. The distribution how patients in all study phases answered on the four pointed scale in items about information.  
(Score 1= Do not agree at all, Score 2=Agree partially, Score 3= Largely agree, Score 4=Completely agree)

There were significant differences in how useful patients' think the Tell-us card was in the dialogue with RNs and ANs ( $p < 0.001$ ) compared with physicians. The patients found the Tell-us card more useful in their interaction with RNs and ANs than with physicians. In the intervention group, 126 out of 157 patients (80%) used the card every day or at least once during the hospital stay. The sub-group analyses show that the Tell-us card was most valuable for patients admitted from the waiting list for a surgical procedure, with a hospital stay less than a week.

Patients most often wrote short comments on the Tell-us cards, but some long descriptions were also seen. In summary, many patients wrote about their need for information, as well as support with nursing needs. Some patients, in worry before the operation, expressed their need for emotional support on the cards.

# Discussion

This thesis presents the patient–health-professional interaction in a hospital setting. The findings show that experiences of negative interactions with health professionals caused long-term consequences for individual patients. The findings also provide the insight that surgical nurses understand an important part of their work in qualitative different ways. Finally, the results show that patient participation in a surgical care unit could be improved with an uncomplicated tool that includes the patient in the intervention.

## Patients' experiences of interactions with health professionals

The findings in studies I and II revealed that patients' experiences of negative interactions with health professionals caused long-term insecurity, worry, and suffering. The stories told by the patients reveal a gap between the patient–health-professional interactions as described in policy documents and as it is experienced in clinical practice. Although the findings in studies I and II present a dark picture of health care, through patients' descriptions of uncaring relations and a lost confidence in health professionals, the starting point and continuing aim of this thesis is 'improvement'. First we need to achieve a deeper understanding of patients' experiences of negative interactions with professionals. Second it is important to use the patients' negative experiences as a resource for quality improvement. As reported [15-16, 87-88], patients' experiences are an important source of evidence in quality improvement work, as well as a valuable contribution towards humanizing the caring practice [89-90].

The results from study II show us that patients' experiences of suffering and loneliness in a surgical context were related to health professionals' lack of recognition of the patients needs for emotional or informative support. Although earlier studies report similar findings about patients' suffering related to health professional interactions in different settings [91-93], this patient group – people cared for in a surgical care context who subsequently complained to their local PAC about uncaring patient-professional relations –has not been much studied before. The findings reveal how vulnerable and anx-



ious a patient can be in the surgical context and how important it is for patients to have a trustful relationship with health professionals to be able to cope with this distressing situation. This is shown clearly in the example from study II, where one patient described her fearfulness before the surgical procedure. She did not know the identity of the surgeon, and she felt that she had no one to trust in the preoperative phase. Studies show trust as the fundamental silent aspect of the patient–health-professional interaction that helps the patient to cope with a distressing situation [44-45]. As reported, a caring relationship also has an impact on patients' health and well-being, as well as on quality of care [1, 94]. However, to improve patient relations it is important for health professionals to identify the patient's individual need for support. This is important to discuss, because patients in the interviews said that they sometimes were offered support, but not the kind of support they needed. That individuals need various amounts of various types of social support (information, emotional, appraisal, and practical) has been described by House [11], and in a professional context each individual's particular combination of needs should be identified clearly.

In studies I and II we wanted to achieve a deeper understanding of the complaints about uncaring relations the PAC dealt with. Besides experiences of uncaring relations, many reports also included interactions when patients did not have access to the information they needed, as well as situations when they experienced non-participation. Similar findings are reported in the international literature about the content of patients' complaints [14-16]. Furthermore, in a review of reports about 'care and treatment' it was shown that many of these reports also included aspects of uncaring relations and dissatisfaction with both the information and the communications. Similar findings have been reported in unpublished data from PAC, indicating a number of unknown cases about uncaring relations in the official statistics in Sweden.

We know from the data at the PAC that the majority of reports related to uncaring relations are made by women, which was confirmed in the review of reports in this thesis. Similar findings are reported in a survey from The Netherlands that reports the majority of complaints to their committees came from women [95]. In contrast, in a study from the UK, complaints from men and women were almost equal in number [14]. However, several studies do not report the demographic characteristics of the participants [15-16]. One explanation for the gender imbalance in Sweden has been suggested to be that women are likely to use more health care than men [13]. The findings from study II suggest no clear reason for the gender imbalance in complaints, but the majority of the patients were women and their main reason for contacting the PAC was to share their negative experience in the hope of improving care for others.

Several patients in study II described unnecessary suffering because of insufficient support after receiving a cancer diagnosis, during the waiting time for a surgical procedure, or while waiting for test results. The patients experienced being uncared for, and their reports indicate a lack of continuity in the 'care chain'. These findings are in agreement with another Swedish study that reported uncaring relations in a hospital, but in different settings [17]. It is noteworthy, however, that the majority of the patients in study II had no complaints about their medical treatment. However, from a patients' perspective, it was evident that a caring relationship, psychological support, and appropriate information must all be present for a high quality of care. These findings are confirmed by a Swedish government report on the national strategy for improved cancer care [96] that reports that although quality indicators related to medical care are mostly met, information and psychological support during waits for operations and other stressful times are inadequate. To improve the quality and continuity of care, six regional cancer centres have been established in Sweden. Patient participation and the continuity of health professionals in each patient's care are highlighted as key tools in the improvement of care for this patient group. It is also suggested that all patients should be offered a permanent contact with a clinical nurse specialist [96].

Some patients in studies I and II described situations in which health professionals abused their positions. Several patients reported that although they experienced an uncaring relation they tried to maintain good relations with health professionals. Because of their dependency for care they did not complain, because they were afraid they might receive an even worse consultation the next time, or not receive the best medical or nursing care, if they complained. We do not know what is behind these situations from the health professionals' perspective. Many health professionals deal daily with difficult patient relations and reactions in clinical practice. A number of studies report that time for communication with patients is not always valued in the organisation [97] and that a lack of time is a barrier to holistic care [98]. Other reports show that a 'task-centred' approach is still more valued in the organisation than a 'patient-centred' one, leading to a lack of communication with the patient [99-100]. However, patients should not bear the burden of these organisational issues. Although the patient's position has been strengthened in Swedish health care over the last decade [5, 22], the findings in this thesis suggest that the issue should be emphasised in clinical practice, in competence development, and in quality improvement work.

## Patient participation and quality improvement in the surgical care unit

The intervention study (IV) shows that the use of the Tell-us card resulted in significant improvements in patients' opportunities to participate in decisions in the nursing care and in the medical care. Allowing the patients to ask their daily questions and express their concerns in writing also improved RNs' and ANs' commitment, empathy, and respect towards the patients compared with the control group. The patients thought that the Tell-us card was more useful in the interaction with the RNs and ANs than with the physicians. However, the findings also show that many patients did not receive useful information, about such things as self-care or the identity on the physician and the RN in charge.

The findings of the intervention study show us that an inexpensive, uncomplicated tool could effectively improve patient participation in a surgical care unit. Time for education and quality improvement work may be limited in a busy organisation, but it is evident also that small changes could improve patients' perception of quality of care. Since much research is performed to improve patient participation in consultations [51, 67], the design that includes the whole health-care team in an acute hospital setting, including the patient, is valuable [67]. However, this is a result of one single study. The implementation of the Tell-us card should be followed by studies that include different patient groups and units to confirm the findings. Furthermore, the implementation of a new routine is a complex process that should be evaluated. In the implementation some complications were observed, e.g. some patients had difficulty handling the Tell-us card and sometimes patients' written concerns were not considered by the health professionals.

Although the patients in study IV reported improved participation in decision making, some patients found it difficult to handle the Tell-us card or simply did not use it. Similar findings were reported in the patient safety project in the United States where patients also used self-written cards during the hospital stay [62]. Being asked to take a more active role was perhaps a new idea to many patients, and it is evident that there was a need to present the card several times to the patient. Patients' preferences for involvement in their care are complex [2], and it is important for health professionals to identify the individual patient's preferences and capabilities for participation [2, 49]. In a surgical care unit it is also important to remember that the individual patients' preferences for involvement could be changed daily with their health status, and the decision to adopt a passive role is also an expression of preference, and hence also form of participation. According to the framework presented by Feldman-Stewart *et al.* [39] it is important in the patient-health-professional interaction to address the patient's goal. For ex-

ample, one patient in study II, with a long postoperative phase and complications, described her negative experience of the rushed pace of the ward rounds. Her experience was of health professionals passing quickly by, telling her 'what they were going to do with her', without taking time to listen to her questions. Use of the 'Tell-us card' could be a valuable way to capture patients' questions and expectations regularly, and thereby to improve patient involvement. However, this requires that the health professionals go beyond collecting the cards and actually make time to listen to the patient and respond.

Some areas could easily improve the quality of the patient–health-professional interaction. It would be easy to provide patients with the identity of their responsible physician and RN by entering this information on the Tell-us card. Other areas require a more comprehensive approach, especially how the card is understood, prioritised, and used by health professionals. For example, some patients in the intervention study reported that they used the Tell-us cards, but that no one on the health care team paid any attention to their questions and concerns. We do not know the reasons for this, but findings of study III may provide a potential explanation. In study III surgical nurses with the most restricted understanding of their role in the patient-professional relationship focused on the work task. A surgical nurse with this understanding will probably find it difficult to identify and prioritise patients' needs and expectations about participation. The findings also raise questions about how health professionals understand the concept of 'patient participation'. Recent research reports that both staff and patients tend to understand patient participation in terms of merely giving or receiving information [101]. So, although a patient-centred approach is stressed as an important issue in health-care, it may be difficult for health professionals to act in a patient-centred way. It has been argued that to develop a new competence at work, person's way of understanding must be interrupted and challenged [102]. One way to accomplish this could be to use patients' experiences of negative interactions as a reflective tool in sessions for all professionals in the unit. By reflecting on the patients' experiences and their own roles in the interactions, health professionals could learn about their own ways of acting in the interaction with the patient.

As described earlier, many reports about negative interactions to the local PAC (studies I and II) included complaints about lack of information. In the interviews (II) several patients said they did not receive information about their surgery or self-care after the surgical procedure. In the intervention study (IV) the information items had the lowest scores in all study phases. Many of the questions that the patients addressed on the Tell-us cards, as well as the suggestions the patients in study II reported as important for improvement, were about things that from a health professional perspective

could be regarded as 'routine', but as seen by the patient are, as one patient said, 'a big thing'. The need to improve patient information has been highlighted throughout the years in a number of studies and reports [8-9, 13], as well as in the legislation [5]. Nevertheless, it is obvious that the adequate provision of information should be prioritised in the quality improvement work in the surgical care unit. Health professionals should first be aware of the value of 'routine' information. Second, how information is given should be evaluated at the organisational level. In many other countries clinical nurse specialists, with an advanced degree in nursing care, have an important role in providing patients with information [3, 103]. In surgical care units in Sweden RNs with advanced degree in nursing are rare. To establish high quality nursing care in Sweden there is a need to increase the number of clinical nurse specialists in surgical care units. Information provision could also be improved by considering the use of different technologies, e.g. interactive computer programs, as adjuncts to written and oral information [104-105]. The different possibilities for technology, probably yet just beginning to develop, open up another large research area.

As described in the introduction, patient perception of the quality of care has been used as a quality indicator in hospitals for many years [43], but should now be prioritised in an ongoing process. This was also evident in the intervention study. After withdrawal of the intervention, no continuing improvement was observed in the last phase of the study. The implementation of the Tell-us card could be seen as a new routine, and in a clinical setting this implementation is a process that takes time, and should be emphasised and supported further. However, any evaluation of quality of care also should engage staff so that they feel ownership of, and the ability to influence, the outcomes. This could be achieved through ordinary quality improvement methods, such as setting unit level goals and initiating small tests of change [106]. Nurse managers have an important position in promoting the prerequisites for quality improvement work. Hence, patient acquisition of information and interaction with health professionals should be regarded as routine quality indicators in the surgical care unit, just as wait-time for surgery, hospital-acquired infection, and pressure ulcers are already.

A most valuable approach to improving quality of care may be to continuously invite patients to individually and focus group interviews about their perception of the quality of care. For example, it would be valuable to ask patients how to outline patient information in the surgical care context in different ways and with different technology. This qualitative approach could be added as a supplement to hospital surveys to deepen understanding of patients' experiences and needs. In this way the patients' experiences and suggestions will be a resource for identifying areas for quality improvement in the units.

## Surgical nurses' different understandings of their interactions with patients

In study III the focus was on exploring how RNs in surgical care units experience their role and interactions with patients and their families. Four qualitatively different ways of understanding the nurse-patient relationship were identified. The understandings represent a hierarchy of increasing complexity and comprehensiveness. In the most restricted understanding, surgical nurses focus on the work task, whereas in the others surgical nurses demonstrate increasing degrees of patient-centeredness. The findings have implications for competence development in clinical practice as well as in education in the profession to reach a more patient-focused care.

The findings provide the valuable insight that surgical nurses understand an important part of their work in qualitative different ways. Some surgical nurses explained that they did not have time to prioritise the communication aspect of work. The technical parts of the work and administrative tasks were instead prioritised. A number of studies report that surgical nurses struggle daily to maintain quality nursing care, but the fast-paced culture and demands of the surgical unit means the relationship with the patients is not prioritised [25-27]. This 'task-oriented' approach is not only an obstacle to excellence in nursing care in the surgical care unit, it is also a barrier to overall effectiveness at work [99, 107]. It has been reported that providing professionals with clinical supervision or supportive group discussions benefits both their competence development and their quality of care [99, 108-111]. However, because of the urgency of tasks associated with surgical care, reflection about the professional role is often neglected because there seems to be no available time for it. Since the surgical nurses' understandings affect their attitudes and behaviours towards the patient, which in turn influence the patient's experience of the interaction, competence development in patient relations will produce benefits for quality of care in the long term. Thus, the findings support the need of surgical nurses for time at ward meetings or with supervisors to discuss and become aware of different ways of understanding their interactions and relationships with patients. It is also important that leaders are aware of the different ways of seeing the interaction with the patient and that competence development within this area is prioritised.

The findings indicate that some surgical nurses with short working experience already base their work on a more patient-focused understanding, indicating that professional competence in this area does not necessarily develop over time. Similar findings were reported in a phenomenographic study among anaesthetists [82]. Many newly graduated RNs work in surgical care units, which demand different qualities of the RN to meet many different

patient groups in a fast-paced culture. Today many RNs work only a few years in the surgical care unit. Reasons for this are interrelated and complex. Therefore it is important to remember that RNs with short working experience are vulnerable and need to be supported; otherwise, the organisational culture at the ward may force them to act in a task-oriented way or to leave the field.

To realise patient-centred care in surgical care, RNs should incorporate all four understandings of their interactions with the patient and their role in the nurse-patient relationship. That includes the most comprehensive one, where the patient is seen as a person, with weaknesses and strengths, individual needs and personal resources. Through this understanding of the nursing role in the patient interaction, nursing care in the surgical unit could attain excellence.

## Methodological considerations

The strength of this thesis is that it covers both qualitative and quantitative studies. The qualitative studies deepen the understanding of the phenomenon, and the quantitative approach broadens the picture. The trustworthiness and the rigour of the studies follow, but first a reflection about a linguistic complication in the research project.

One linguistic complication when performing research in this field in Sweden and comparing the findings with international studies, is the Swedish word '*bemötande*'. The word is commonly used in daily language by patients and health professionals as well as in policy documents in Sweden. However, the word has not an obvious translation into English. In the international literature a combination of 'patient-health professional relationship' and 'interaction' is used to describe these aspects of the patient-health professional interaction [42], and these terms are used within this thesis. However, in paper I the word 'encounter' is sometimes used where today I would use a combination of the words mentioned above.

To achieve trustworthiness several aspects were considered during the research process in studies I-III [112-113]. To enhance dependability in the interview studies (II and III) the first author interviewed all the participants using an interview guide with open-ended questions. The participants were encouraged to speak freely and to give concrete examples of their own experiences. Probing questions were used to increase the richness and depth of the interviews [114]. All interviews were transcribed as soon as possible after they were conducted by the author (II) of the thesis and a secretary (III). All transcriptions were verified by the author to reduce the risk of misunderstanding

and to ensure a high level of accuracy in the transcriptions. One limitation was the author's own limited experience of performing qualitative research. However, the credibility of the findings are supported by the fact that the analysis was carried out in close collaboration with the co-authors, who are experienced qualitative researcher. In study I independent analyses of all reports were performed by the co-authors. In all studies the coding and the labelling of the categories and subcategories was discussed among the authors until a negotiated consensus about the categorisation was reached [75, 78]. The categories and themes within the papers were confirmed and verified with quotations from the interviews [113].

## Study I

The strength of study I is that it provides an overview of hospital conditions underlying reports about negative interactions with health professionals. The findings are valuable to understanding how dissatisfaction and communication breakdowns occur in health care. One limitation is the fact that the complaints had already been categorized at the PAC. Another limitation was the high number of reports excluded because descriptions of their complaints in telephone reports were too short to be used in content analysis. On the other hand, most of the reports included in the study had detailed descriptions that were appropriate for the analysis. Another limitation is the lack of background characteristics of the patients and relatives in the reports. Due to the retrospective design of the study and the lack of this information in the electronic system at the PAC, this information could not be collected. Therefore, a detailed review was performed to complete the demographic picture of all patients who have reported to a local PAC. The review confirmed the unpublished data at the PAC that the majority of patients who report to the PAC are women. However, the review also showed that there is a deficit of background information in the electronic system.

## Study II

The strength of study II is that the interviews provide valuable insights into the patients' experiences. However, a number of limitations need to be considered. One limitation is the fact that patients were selected from one hospital. It could have been valuable to sample a group of patients from other regions as well, but this was not possible for economic reasons. One limitation is the number of participants included. The 15 patients included comprised a smaller number of participants than was originally intended. A total of 23 patients were invited to participate, but 8 women declined, 2 of whom were reluctant to relive the experience and fearful of possible consequences, and 6 for reasons unknown. Another limitation is the lack of gender balance.



Only two men were included. We know, however, that the majority of reports related to uncaring relations in Sweden are made by women [13].

### Study III.

The strength of study III is its ability to provide insight into the views of a selected group of RNs in Sweden about important aspects of their role in caring for patients in the surgical care unit. A strategic sample was used to capture as many understandings of the phenomenon as possible. An adequate sample size for phenomenographic research has been described as comprising enough people to ensure variation, but not so many that it is difficult to manage the data [80]. In study III no new understandings was discovered during the analysis of the last 5 or 6 interviews, the sample was considered sufficient.

How do we know that interviewees describe their actual experience, rather than what they believe are the right answers or what is described in policy documents? In the interviews the RNs were encouraged to speak freely about their own experiences and to give concrete examples to avoid descriptions based on how things should be. This way of asking questions gives a much deeper insight into how the interviewees actually see the concept in practice and provides the interviewer a better opportunity to explore and probe in a comfortable and non-threatening way. It also elicits more information about the persons' actual experiences than narrow 'What is – ?' questions [80]. During the last phase of the interview the interviewer returned to all the main open questions to give the RNs time for more reflection and the opportunity to provide additional examples.

A strength of the study is that participants from two different hospitals, with different cultures and hospital sizes, were included. A limitation is that only one male nurse was included, but at the time of the interviews there were mainly female nurses employed in the actual units. The information provided by the male nurse did not differ from that of the female nurses. My own clinical experience as a RN in the surgical setting raised considerations about my risk of taking things for granted and having blind spots during the interviews. However, I paid attention to this during the interviews by asking the nurses for clarifications and examples about their own experiences and was conscious of my own interpretations and opinions during the interviews.

### Study IV

The main strength of study IV is that the patient is included in the intervention. More intervention studies are needed in this field, and the whole health-care team – including the patient –should be included in the

intervention. Another strength is that it is an intervention study, although a quasi-experimental design is admittedly a weaker design than a randomized controlled trial. However, it was not possible in the clinical practice to randomize the patients to different groups. For clarity in the reporting of the study design the 'Transparent Reporting of Evaluations with Non-randomized Designs' (TREND) was followed [115].

One limitation is the fact that the postal questionnaire as well as the Tell-us card was in Swedish, which excluded a number of non-Swedish speakers. The intervention also seemed to exclude patients who had difficulty writing on the Tell-us card or answering a postal questionnaire because of a vision impairment, dyslexia, or a tremor related to medical diagnosis. In future research, these patient groups need to be included. Also, acute patients with an expected short hospital stay seemed more likely to decline participation in the intervention group. It is possible that the recruitment of patients sometime within the first day by only a limited number of RNs, rather than all at once at admission by the RN in charge, resulted in a higher number of exclusions of patients admitted from the emergency department. However, we considered it important to limit the number of staff responsible in the inclusion process to avoid undue staff drop-out related to shortage of time in the clinical practice.

The questionnaire is a validated instrument, tested for reliability, and it seems to be easy for the patients to use. Drop-out rates of 19% to 22% were seen in the different phases. Reasons for most people not answering the questionnaire are unknown, but some reasons for the drop-out were unknown address, hospital stay over two months, and death of the patient. However, the rate of response could be considered fairly good. One limitation in the questionnaire is that RNs and ANs are grouped together in the different items. However, it would not be reasonable to ask patients completing the questionnaire to differentiate RNs from ANs in clinical practice in a surgical care unit they both work close to the patient and many patients are not fully aware of the differences between them.

# Conclusions

This thesis investigated the patient–health-professional interaction in a hospital setting. The conclusions are:

- Patient complaints about negative interactions most often concerned the perceived lack of sufficient information, respect, and empathy from health professionals (Study I).
- Experiences of negative interactions with health professionals caused long-term consequences for patients in a surgical care context, including suffering, insecurity, and worry. It also reduced their confidence in upcoming consultations (Study II).
- Four qualitatively different ways of understanding the nurse-patient relationship were identified among surgical nurses. The understandings represent a hierarchy of increasing complexity and comprehensiveness. In the most restricted understanding, surgical nurses focus on the work task, whereas in the others surgical nurses demonstrate increasing degrees of patient-centeredness (Study III).
- The use of the Tell-us card improved the patients' participation in some areas of nursing and medical care in the surgical care units. The implementation of the Tell-us card could be an important step towards improved patient participation in the surgical care unit (Study IV).
- The value of a patient-focused interaction should be the subject of ongoing discussions in all surgical care units (Study I-IV).

## Clinical implications and future research

The main reason the woman in the preface shared her negative experience in the hospital was her hope of influencing care for others. This woman, like many other patients, had to struggle to receive basic information. In contrast, at the same hospital where she received her cancer diagnosis, all women diagnosed with breast cancer are supported by a clinical nurse specialist. Thus, the findings reveal that all patient groups with serious diagnoses are not provided with the same support. This lack of professional support causes unacceptable suffering for individual patients. Further research should emphasize the identification of patient groups that are in need of support in the preoperative phase, during admission, and after discharge. Further research should also shed more light on patient participation in the surgical care unit and improvements the delivery of information.

During this research project I have learned about, and to some extent come to understand, the complexity of the patient–health-professional interaction, and some of my questions have been answered. But this research project also marks the beginning of further research in the field. Because of the complexity of both the phenomenon and health care organisations, it is a challenge to design studies related to quality of care, but it is very important to continue to study and evaluate it to be able to improve it.

These findings point out the need for patients to have access to information and to be involved in their care. However, many patients in the surgical care units reported that they did not have such basic information as the identity of their responsible physician and RN, or what they should do for self-care. It would be easy to improve information about the physician and the RN in charge by simply adding their names to the Tell-us card.

This thesis has also examined how surgical nurses' understand their role in interaction with patients. Many newly graduated RNs work in surgical care units, which demands different qualities of the RN nurse to meet many different patient groups in a fast-paced, high-pressure culture. To realise a patient-centred approach in surgical nursing, RNs should incorporate all four understandings of their interactions with the patient and their role in the nurse-patient relationship. Surgical nurses need to have time at ward meetings or with supervisors to discuss and become aware of different ways of

understanding their interactions and relationships with patients. In this way new areas of professional development may be opened up. The finding indicates that some surgical nurses with short working experience already base their work on a more patient-focused understanding. These surgical nurses are vulnerable and need to be supported. Otherwise, the organisational culture at the ward may force them to act in a task-oriented way. In further research it should be valuable to further study newly graduated RNs and the ways they understand their role in the interaction with patients.

The findings reveal that negative interactions with health professionals caused feeling of insecurity, worry, and suffering that continued for the individual patient long after the actual experience. To improve patient interactions in the surgical care unit, patients' stories of negative interactions could provide the impetus towards reflection sessions including all medical and nursing staff in the surgical care unit and new education for all health professionals to develop competence in patient relations. In the fast-paced culture of the surgical care unit, time for reflection is often neglected. However, it is not only RNs, but all health professionals who need to reflect upon how patients cared for on the unit. Thus, it is important that leaders are aware of the different ways of seeing the interaction with the patient, that discussion and learning is encouraged, and that competence development in this area is prioritised.

The use of the Tell-us card improved the patients' participation in some areas in nursing and medical care in the surgical care units. Allowing patients to express their questions and concerns in writing and using this information in the patient–health-professional interaction is inexpensive, uncomplicated, and effective. The Tell-us card was most valuable for patients admitted from the waiting list for a surgical procedure, with a hospital stay under a week. In future research the implementation of the Tell-us card should include different patient groups in different hospital units to confirm these findings and further improve the use of the Tell-us card.

Finally, the findings of the intervention study show that after withdrawal of the intervention, no continuing improvement in patient-professional relations was observed, showing that it had no lasting effect on professional attitudes or practices. Implementation of a new routine in a clinical setting is a complicated process that takes time to be assimilated. Interventions such as the Tell-us card and professional development opportunities to improve patient relations should be prioritised and supported by leadership to further work in quality improvement.

## Svensk sammanfattning (Swedish summary)

Tidigare forskning, såväl internationellt som nationellt, betonar vikten av att patienten är delaktig i sin vård och en partner i vårdteamet. Detta är viktigt för att uppnå en god vårdkvalitet och det är också en förutsättning för att vården skall vara säker. Forskningsresultat och nationella kvalitetsutvärderingar visar även att patienter upplever situationer i vården då hälso- och sjukvårdspersonal inte lyssnar till patienten, då information är otillräcklig och patienten inte respekteras. Varje år kontaktar cirka 26 000 personer i Sverige patientnämndens kansli med klagomål på händelser i sjukvården. Av dessa klagomål är cirka 15 % så kallade 'bemötandeärenden'. Det finns få studier som analyserat vad dessa ärenden innehåller.

Kirurgisk vård har de senaste åren genomgått organisatoriska förändringar. Tiden som patienten är inskriven på sjukhuset har förkortats jämfört med tidigare. Samtalen inför operation sker ofta vid ett öppenvårdsbesök och patienten skrivs ofta in på sjukhuset samma dag som operationen genomförs. Detta innebär att patienterna själva förväntas sköta en större del av egenvård både före och efter operationen i hemmet. En förutsättning för att detta skall fungera är att patienten blir mer delaktig i sin vård. Ett bra bemötande och välutvecklad kommunikation är viktigt för att uppnå en sådan delaktighet.

Studier inom kirurgisk vård visar att sjuksköterskan värdesätter bemötande och kommunikation med patienten, men att denna del av arbetet inte prioriteras beroende på ett högt arbetstempo där mer medicintekniska arbetsuppgifterna dominerar. Kirurgsjuksköterskans arbete ställer stora krav på hennes/hans förmåga att vårda och möta många olika patientgrupper med olika behov. Även om bemötande, kommunikation och undervisning är ett viktigt kompetensområde i sjuksköterskans profession avsätts förvånansvärt lite tid för reflektion och kompetensutveckling för detta. Hur kirurgsjuksköterskan förstår sin roll i mötet med patienten påverkar hur sjuksköterskan agerar i mötet med patienten. Detta antas i sin tur påverka hur patienten upplever mötet med sjuksköterskan. Att få fördjupad kunskap om sjuksköterskans förståelse om sin roll i mötet med patienten är en viktig utgångspunkt i lärande och i kompetensutveckling i yrkesrollen.

Det övergripande syftet i avhandlingen var att beskriva möten i vården mellan patienten och hälso- och sjukvårdspersonal. Avhandlingen består av fyra

delarbeten där både kvalitativa och kvantitativa metoder används. Delarbete I och II har en beskrivande design och innehållsanalys har används. Även delarbete III har en beskrivande design och fenomenografisk metod har används. Slutligen genomfördes i delarbete IV en interventionsstudie.

I delarbete I var syftet att beskriva innehållet i 'bemötandeärenden' (n=105) vid patientnämndens kansli beträffande vården vid ett universitetssjukhus. Resultatet visar att bristande information, respekt och empati var de vanligaste orsakerna till att patienter och anhöriga kontaktat kansliet. För att få en fördjupad kunskap om vilka konsekvenser negativa möten i vården orsakat patienten genomfördes i delarbete II intervjuer med patienter (n=15) som vårdats vid kirurgisk vårdavdelning eller besökt kirurgisk mottagning och som därefter kontaktat patientnämndens kansli. Resultatet visar att negativa möten i vården fått till följd att patienter tappar förtroende för läkaren och/eller sjuksköterskan och att dessa erfarenheter skapat osäkerhet, onödig oro och lidande dels under vårdtiden, men även lång tid efter utskrivning. Flertalet patienter beskriver att de är nöjda med den medicinska vården, men att det brustit i det psykologiska stödet eller den information de fått i samband med ett besked om en cancerdiagnos.

I den fenomenografiska studien i delarbete III presenteras hur kirurgsjuksköterskor förstår sin roll i mötet med patienten. Resultatet visar att kirurgsjuksköterskor uppfattar sin roll i mötet med patienten på olika sätt. Vissa sjuksköterskor har ett uppgiftsorienterat fokus i mötet med patienten, medan andra sjuksköterskor har en bredare förståelse om sin roll och fokuserar på patienten men i olika hög grad. Resultatet kan vara ett redskap för reflektion och användas i utbildning för att stimulera sjuksköterskor att fördjupa sin yrkesroll.

Avslutningsvis har en interventionsstudie (IV) genomförts på två kirurgavdelningar för att utvärdera om patientens delaktighet i vården kunde förbättras. I studien utvärderades om vårdkvalitet kunde förbättras genom enkel intervention vad gäller delaktighet, kvalitet på information, engagemang, respekt och empati. Studien genomfördes på två kirurgavdelningar där patienter med framförallt tarmkirurgiska- och endokrinkirurgiska sjukdomar samt traumapatienter vårdades. Patienterna skrevs in på avdelningarna dels akut via akutmottagningen och dels planerat direkt från hemmet inför en planerad operation. Patienterna i interventionsgruppen erbjöds att varje dag skriva ned frågor och funderingar på ett för studien utarbetat '*Patientkort*', vad som var viktig för patienten under dagen på avdelningen och/eller inför utskrivning. Patientkortet skulle vara ett verktyg i dialogen med patienten vid exempelvis ronder och utskrivningssamtal. Patientkortet placerades på patientens sängbord så det skulle vara synligt för alla yrkeskategorier som vårdade patienten. Patienten fick dagligen ett nytt patientkort. Utvärdering

genomfördes genom att patienterna (n=310) efter utskrivning fick besvara en enkät. Enkäten som användes i studien var 'KUPP' - Kvalitet Ur Patientens Perspektiv. Resultaten visar på signifikanta förbättringar i interventionsgruppen vad gäller delaktighet och bemötande. Patienterna som använde patientkortet under vårdtiden i rapporterade i högre grad att de haft möjlighet att delta i beslut vad gäller både omvårdnaden och den medicinska vården jämfört med patienterna i kontrollgruppen som inte fått del av patientkortet. Patienterna som använt patientkortet rapporterar också att de upplevde att sjuksköterskorna och undersköterskorna visade mer engagemang, mer empati och bemötte dem med större respekt jämfört med patienterna i kontrollgruppen. Resultatet visar dock också att många patienter upplevde informationen under vårdtiden som bristfällig och detta förbättrades inte genom införandet av patientkortet. Vidare visar resultatet att förbättringen vad gäller patientens möjlighet till delaktighet och förbättrat bemötande inte kvarstod när patientkortet togs bort.

Sammanfattningsvis visar avhandlingsarbetet att betydelsen av ett gott bemötande och att patienten görs delaktig i sin vård kontinuerligt måste prioriteras och diskuteras inom kirurgisk vård. Patientens berättelser om negativa möten i vården kan användas som utgångspunkt för reflektion i utbildning och i handledning för alla yrkeskategorier. Att på detta sätt få reflektera över patientens erfarenheter i vården kan vara ett viktigt verktyg i att utveckla hälso- och sjukvårdspersonalens yrkesroll. Avhandlingen visar att patientens delaktighet i vården kunde förbättras genom en enkel och resurssnål åtgärd. Införandet av en ny rutin som denna bör stödjas av chefer i ett fortsatt förbättringsarbete på avdelningarna. För att förbättra patientens delaktighet i vården är det viktigt att göra fler studier där patienten på samma sätt som i denna avhandling involveras i interventionen.



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# References

1. Griffin, SJ., Kinmonth, A-L., Veltman, MWM., Gillard, S., Grant, J., Stewart, M., 2004. Effect on Health-Related Outcomes of Interventions to Alter the Interaction Between Patients and Practitioners: A Systematic Review of Trials. *Annals of Family Medicine* 2 (6), 595-608.
2. Say, R., Murtagh, M., Thomson, R., 2006. Patients' preferences for involvement in medical decision making: a narrative review. *Patient Education and Counseling* 60 (2), 102-14.
3. Charlton, C., Dearing, K., Berry, J., Johnson, MJ., 2008. Nurse practitioners' communication styles and their impact on patient outcomes: An integrated literature review. *Journal of the American Academy of Nurse Practitioners* 20 (7), 382-388.
4. The Joint Commission., 2010. National Patient Safety Goals (NPSGs). Accessed on: November 17, 2010, available at: <http://www.jointcommission.org/PatientSafety/NationalPatientSafetyGoals/>
5. SOSFS., 2010 [National Board of Health and Welfare]. Din skyldighet att informera och göra patienten delaktig - handbok för vårdgivare, verksamhetschefer och personal [Your obligation to inform and involve the patient - handbook for caregivers, heads of departments and staff]. Accessed on: January 17, 2011, available at: <http://www.socialstyrelsen.se/publikationer2011/2011-2-7> [In Swedish].
6. Henderson, A., Zernike, W., 2001. A study of the impact of discharge information for surgical patients. *Journal of Advanced Nursing*. 35 (3), 435-441.
7. Simi, S., Patoia, L., 2010. The importance of being patient. *Journal of Ambulatory Care Management* 33 (3), 257-264.
8. SALAR., 2010. Sveriges kommuner och landsting. [Swedish Association of Local Authorities and Regions]. Nationell patientenkät [National patient survey]. Accessed on: November 17, 2010, available at: [http://www.indikator.org/publik/pdf/1\\_379.pdf](http://www.indikator.org/publik/pdf/1_379.pdf) [in Swedish].
9. Fröjd, C., Leo Swenne, C., Rubertsson, C., Gunningberg, L., Wadensten, B., 2011. Patient information and participation still in need of improvement. Evaluation of patients' perception of quality of care. *Journal of Nurse Management*. online DOI: 10.1111/j.1365-2834.2010.01197.x

10. Holm, U., 1987. Empati- att förstå andra människor känslor.[Empathy – to understand other peoples feelings] Natur och Kultur. Stockholm. [in Swedish].
11. House, JS., 1981. Work stress and social support. Philippines: Addison-Wesley.
12. Croona, G., 2003. Etik & Utmaning. Om lärande av bemötande i professionsutbildning. [Etics and Challenge. Learning and teaching human encounters in professional education] Växjö university press. Doctoral thesis. [Written in Swedish with a summary in English].
13. National Board of Health and Welfare., 2009. Hälso- och sjukvårdsrapport [Health-care report]. Accessed on: January 20, 2011. available at: [http://www.socialstyrelsen.se/Lists/Artikelkatalog/Attachments/8496/20009-126-72\\_2000912672\\_rev2.pdf](http://www.socialstyrelsen.se/Lists/Artikelkatalog/Attachments/8496/20009-126-72_2000912672_rev2.pdf) [in Swedish].
14. Siyambalapitiya, S., Caunt, J., Harrison, N., White, L., Weremczuk, D., Fernando, D., 2007. A 22 month study of patient complaints at a National Health Service hospital. *International Journal of Nursing Practice* 13 (2), 107-110.
15. Parry, J., Hewage, U., 2009. Investigating complaints to improve practice and develop policy. *International Journal of Health Care Quality Assurance* 22 (7), 663-669.
16. Hsieh, SY., 2010. The use of patient complaints to drive quality improvement: an exploratory study in Taiwan. *Health Services Management Research* 23(1), 5-11.
17. Eriksson, U., Svedlund, M., 2007. Struggling for confirmation – patients' experiences of dissatisfaction with hospital care. *Journal of Clinical Nursing* 16 (3), 438-446.
18. United Nation., The Universal Declaration of Human Rights. Accessed on: January 17, 2011, available at: <http://www.un.org/en/documents/udhr/>
19. ICN., [International Council of Nurses]. 2006. The ICN code of ethics for nurses. Accessed on: January 17, 2011, available at: [http://www.icn.ch/images/stories/documents/about/icncode\\_english.pdf](http://www.icn.ch/images/stories/documents/about/icncode_english.pdf)
20. SSF., Svensk sjuksköterskeförening. [The Swedish Society of Nursing] 2010. Värdegrund för sjuksköterskor [Basic principles for registered nurses]. Accessed on: January 17, 2011, available at: [http://www.swenurse.se/PageFiles/8810/Nr55\\_13okt\\_NYWEB.pdf](http://www.swenurse.se/PageFiles/8810/Nr55_13okt_NYWEB.pdf)
21. SOSFS., [National Board of Health and Welfare] (1982:763) Hälso och sjukvårdslagen [The Health and Medical Services Act]. Swedish State Book 2005. Liber AB Stockholm [In Swedish].

22. SOSFS., [National Board of Health and Welfare]. 2005. God Vård. Om ledningssystem för kvalitet och patient säker vård i hälso- och sjukvården. [Good care. System for quality and patient safety in health care] Stockholm. Accessed on: March, 29, 2011, available at: [http://www.socialstyrelsen.se/Lists/Artikelkatalog/Attachments/9406/2006-101-2\\_20061012.pdf](http://www.socialstyrelsen.se/Lists/Artikelkatalog/Attachments/9406/2006-101-2_20061012.pdf) [In Swedish].
23. SOSFS., [National Board of Health and Welfare]. Lag (1998:1656) om patientnämndsverksamhet [Law (1998:1656) on patient committee activity]. Swedish State Book 2005, Liber AB, Stockholm [In Swedish].
24. SOSFS., [National Board of Health and Welfare]. Patientsäkerhetslagen (2010:659). [The Patient safety law (2010:659)]. Accessed on: January 13, 2011, available at: <http://www.riksdagen.se/webbnav/index.aspx?nid=3911&bet=2010:659>. [In Swedish]
25. Enns, C., Gregory, D., 2007. Lamentation and loss: expressions of caring by contemporary surgical nurses. *Journal of Advanced Nursing* 58 (4), 339-347.
26. Billeter-Koponen, S., Fredén, L., 2005. Long-term stress, burnout and patient-nurse relations: qualitative interview study about nurses' experiences. *Scandinavian Journal of Caring Sciences* 19 (1), 20-27.
27. Furåker, F., 2008. Registered nurses' views on their professional role. *Journal of Nursing Management* 16 (8), 933-941.
28. Fulton, JA., 2008. Strategies used by nurses when managing the emotional needs of patients. *Learning in Health and Social Care* 7 (4), 157-167.
29. Moene, M., Bergbom, I., Skott, C., 2005. Patients' existential situation prior to colorectal surgery. *Journal of Advanced Nursing* 54 (2), 199-207.
30. Gilmartin, J., Wright, K., 2008. Day surgery: patients' felt abandoned during the preoperative wait. *Journal of Clinical Nursing* 17 (18), 2418-2425.
31. Mitchell, M., 2003. Patient anxiety and modern elective surgery: a literature review. *Journal of Clinical Nursing* 12 (6), 806-815.
32. SOSFS., [National Board of Health and Welfare] Kompetensbeskrivning för sjuksköterskor [Competence description for registered nurses]. 2005. Stockholm. Accessed on: January 17, 2011, available at: <http://www.socialstyrelsen.se/Publicerat/2005/8673/2005-105-1.htm> [In Swedish].
33. Giorgi, A., 1989. An example of harmony between descriptive reports and behavior. *Journal of Phenomenological Psychology* 20, 60-88.
34. Dall'Alba, G., Sandberg, J., 1996. Educating for competence in professional practice. *Instructional Science* 24, 411-37.
35. Sjöström, B., Dahlgren, LO., 2002. Applying phenomenography in nursing research. *Journal of Advanced Nursing* 40 (3) 339-345.

36. Meleis, AI., 2007. Chapter 13: On Interactions. In: Theoretical Nursing. Development & Progress. Lippincott Williams & Wilkins. Philadelphia.
37. Kasén, A., 2002. Den vårdande relationen. [The caring relationship]. [In Swedish with an English summary]. Doctoral thesis. Department of Caring Science, Åbo Akademi University. Turku, Finland: Åbo Akademi University Press.
38. Björck, M., Sandman, L., 2007. Vårdrelation. Ett försök att tydliggöra begreppsanvändningen.[ *The care relation. Trying to clarify the use of the concept*]. Vård i Norden 86 (27),14-19 [In Swedish with a summary in English]
39. Feldman-Stewart, D., Brundage, M.D., Tishelman, C., 2005. A conceptual framework for patient-professional communication: an application to the cancer context. *Psycho-Oncology* 14 (10), 801-809.
40. Carlsson, L., Feldman-Stewart, D., Tishelman, C., Brundage, M. 2005. Patient-professional communication research in cancer: An integrative review of research methods in the context of a conceptual framework. *Psycho-Oncology* 14 (10), 812-828.
41. Gustafsson, B., 2004. Bekräftande omvårdnad. SAUK-modellen för vård och omsorg.[ Confirming nursing. The SAUC-model for health and community care]. Lund: Studentlitteratur. Andra upplagan [in Swedish].
42. Shattell, M., 2004. Nurse-patient interaction: a review of the literature. *Journal of Clinical Nursing* 13 (6), 714-722.
43. Donabedian, A., 1988. The quality of care. How can it be assessed? *Journal of the American Medical Association* 260 (12), 1743-1748.
44. Frankel, RM., Stein, T., 1999. Getting the most out of the Clinical Encounter: The Four Habit Model. *The Permanente Journal*.
45. Thom, DH., Hall, M., Pawlson, G., 2004. Measuring patients' trust in physicians when assessing quality of care. *Health Affairs* 23 (4), 124-132.
46. Eldh, AC., 2006. Patient participation—what it is and what it is not. Doctoral thesis. Örebro Studies in Caring Sciences, Örebro University, Department of Health Sciences, Örebro, Sweden.
47. Larsson, IE., 2008. Patienten som medaktör. Studier av patientdelaktighet och hur sådan stimuleras och hindras. [Patient and co-actor. Studies of Patient Participation and How This is Stimulated and Hindered] Doctoral thesis. The Sahlgrenska Academy at Göteborg University, Göteborg [in Swedish with summary in English].
48. Doherty, C., Doherty, W., 2005. Patients' preferences for involvement in clinical decision-making within secondary care and the factors that influence their preferences. *Journal of Nursing Management*. 13 (2), 119-127.

49. Florin, J., 2006. Patient participation in clinical decision making in nursing—a collaborative effort between patients and nurses. Doctoral thesis. Örebro Studies in Caring Sciences, Örebro University, Department of Health Sciences, Örebro, Sweden.
50. Beaver, K., Campbell Craven, O., Jones, D., Luker, K., Susnerwala, S., 2009. Colorectal cancer patient' attitudes towards involvement in decision making. *Health Expectations* 12 (1), 27-37.
51. Lewin, S., Skea, Z., Entwistle, V.A., Zwarensteine, M., Dick, J., 2009. Interventions for providers to promote a patient-centred approach in clinical consultations. *Cochrane Database of Systematic Reviews*. 2001, Issue 4. Art. No.: CD003267. DOI: 10.1002/14651858.CD003267. (Edited [no change to conclusions], published in Issue 1, 2009).
52. Kvåle, K., Bondevik, M., 2008. What is important for patient centred care? A qualitative study about the perception of patients with cancer. *Scandinavian Journal of Caring Sciences* 22 (4), 582-589.
53. Holmström, I., Röing, M., 2010. The relation between patient-centeredness and patient empowerment: a discussion on concepts. *Patient Education and Counseling* 79 (2), 167-172.
54. SSF., 2010. [The Swedish Society of Nursing] Svensk sjuksköterskeförening om personcentrerad vård. [ The Swedish Society of Nursing about person centered care] Accessed on: March, 29, 2011, available at: [http://www.swenurse.se/PageFiles/5957/Nr80\\_26nov\\_OM%20Personcetrerad.pdf](http://www.swenurse.se/PageFiles/5957/Nr80_26nov_OM%20Personcetrerad.pdf) [In Swedish].
55. GPCC., 2010. Centrum för personcentrerad vård [Centrum for person-centered care]. University of Gothenburg. Accessed on: March, 29, 2011, available at: <http://www.gpcc.gu.se/personcentrerad-var/> [In Swedish].
56. Wilde, B., Larsson, G., Larsson, M., Starrin, B., 1994. Quality of care. Development of a patient-centered questionnaire based on a grounded theory model. *Scandinavian Journal of Caring Sciences* 8, 39-48.
57. Sitzia, J., 1999. How valid and reliable are patient satisfaction data? An analysis of 195 studies. *International Journal of Quality in Health Care* 11 (4), 319-328.
58. Wilde, B., 1994. Quality of care: models, instruments and empirical results among elderly. Doctor thesis Department of Geriatric Medicine, Vasa Hospital, University of Gothenburg, Gothenburg, Sweden.
59. Wilde Larsson, B., Larsson, G., Wickman Chantereau, M., Stael von Holstein, K., 2005. International comparisons of patients' views on quality of care. *International Journal of Health Care Quality Assurance* 18 (1), 62-73.



60. Kinnarsley, P., Edwards, AGK., Hood, K., Cadbury, N., Ryan, R., Prout, H., Owen, D., MacBeth, F., Butow, P., Butler, C., 2007. Interventions before consultations for helping patients address their information needs. *Cochrane Database of Systematic Reviews* 2007, Issue 3. Art. No.: CD004565. DOI: 10.1002/14651858.CD004565.pub2.
61. Timonen, L., Sihvonen, M., 2000. Patient participation in bedside reporting on surgical wards. *Journal of Clinical Nursing* 9 (4), 542-548.
62. Sehgal, N., Green, A., Vidyarthi, A., Blegan, M., Wachter, R., 2010. Patients whiteboards as a communication tool in the hospital setting: A survey of practices and recommendations. *Journal of Hospital Medicine* 5 (4), 234-239.
63. Scott-Smith, J., Greenhouse, PK., 2007. Transforming Care at the Bedside: Patient-Controlled Liberalized Diet. *Journal of Interprofessional Care* 21(2), 179–188.
64. Edwards, C., 2002. A proposal that patients be considered honorary members of the healthcare team. *Journal of Clinical Nursing* 11 (3), 340-348.
65. Sahlsten, M., Larsson, I., Plos, K., Lindecrona, C., 2005. Hindrance for patient participation in nursing care. *Scandinavian Journal of Caring Sciences* 19 (3), 223-229.
66. Larsson, I., Sahlsten, M., Segesten, K., Plos, K., 2011. Patients' perceptions of barriers for participation in nursing care. *Scandinavian Journal of Caring Sciences*. Online publication doi: 10.1111/j.1471-6712.2010.00866.x
67. Haywood, K., Marshall, S., Fitzpatrick, R., 2006. Patient participation in the consultation process: A structured review of intervention strategies. *Patient Education and Counseling* 63 (1-2), 12-23.
68. Kazdin, AE., 2003. *Research Design in Clinical Psychology*. 4<sup>th</sup> edition. Allyn & Bacon, Boston.
69. Wilde-Larsson, B., Larsson, G., Larsson, M., 2001. KUPP-boken. Vägledning till frågeformuläret KUPP. Kvalitet Ur Patientens Perspektiv. Fjärde upplagan. [The QPP Book: Quality from the patient's perspective, 4th edn] Grafiska gruppen, Stockholm . [In Swedish].
70. Wilde Larsson, B., Larsson, G., 2002. Development of a short form of the Quality from the Patient's Perspective (QPP) questionnaire. *Journal of Clinical Nursing* 11 (5), 681-687.
71. Wilde Larsson, B., 2000. Does the method of data collection affect patients' evaluation of quality of care? *International Journal of Nursing Practice* 6 (6), 284-291.
72. Krippendorff, K., 2004. *Content Analysis. An Introduction to its Methodology*, 2<sup>nd</sup> edition. London.

73. Hsieh, H-F., Shannon, SE., 2005. Three approaches to qualitative content analysis. *Qualitative Health Research* 15 (9), 1277-1288.
74. Morgan, DL., 1993. Qualitative content analysis: a guide to paths not taken. *Qualitative Health Research* 3, 112-121.
75. Graneheim, U.H., Lundman, L., 2004. Qualitative content analysis in nursing research: concepts, procedures and measures to achieve trustworthiness. *Nurse Education Today* 24 (2), 105–112.
76. Elo, S., Kyngäs, H., 2008. The qualitative content analysis process. *Journal of Advanced Nursing* 62 (1), 107-115.
77. Berg, BL., 2004. *Qualitative Research Methods for the Social Sciences*. Fifth Edition. Pearson Education.
78. Wahlström, R., Dahlgren, L-O., Tomson, G., Diwan, V.K., Beermann B., 1997. Changing primary doctors' conceptions – a qualitative approach to evaluating an intervention. *Advances in Health Sciences Education* 2 (3), 221-236.
79. Marton, F., Booth, S., 1997. Chapter 6: The idea of phenomenography. In: *Learning and Awareness*. Lawrence Erlbaum Associates, Publishers, Mahwah NJ, pp 110-136.
80. Barnard, A., McCoscher, H., Gerber, R., 1999. Phenomenography: a qualitative research approach for exploring understanding in health care. *Qualitative Health Research* 9, 212-226.
81. Larsson, J., Holmström, I., 2007. Phenomenographic or phenomenological analysis: does it matter? Examples from a study on anaesthesiologists' work. *International Journal of Qualitative Studies in Health and Well-being* 2 (2), 55-64.
82. Larsson, J., Holmström, I., Rosenqvist, U., 2003. Professional artist, good Samaritan, servant and co-ordinator: four ways of understanding the anaesthetist's work. *Acta Anaesthesiologica Scandinavica* 47 (7), 787-793.
83. KUPPIT, Version 2007. Administration and support by ImproveIT, Halmstad, Sweden. <http://www.improveit.se> [in Swedish].
84. Codex., Regler och riktlinjer för forskning. [Rules and guidelines for research]. Accessed June 10, 2010, available at: <http://www.codex.uu.se> [In Swedish].
85. World Medical Association Declaration of Helsinki. Ethical Principles for Medical Research Involving Human Subjects. Accessed June 10, 2010, available at: <http://www.wma.net/en/30publications/10policies/b3/index.html>.

86. SFS (Swedish Code of Statutes), 2003:460. Lag om etikprövning av forskning som avser människor. [The act concerning the ethical review of research involving human beings]. Accessed June 10, 2010, available at: <http://www.riksdagen.se/webbnav/index.aspx?nid=3911&bet=2003:460> [In Swedish].
87. Rycroft-Malone, J., Seers, K., Titchen, A., Harvey, G., Kitson, A., McCormack, B., 2004. What counts as evidence in evidence-based practice? *Journal of Advanced Nursing* 47 (1), 81-90.
88. Kitson, A., Rycroft-Malone, J., Harvey, G., McCormack, B., Seers, K., Titchen, A., 2008. Evaluating the successful implementation of evidence into practice using the PARISH framework: theoretical and practical challenges. *Implementation Science* 3,1
89. Todres, L., Galvin, K., Dahlberg, K., 2007. Lifeworld-led healthcare: revisiting a humanising philosophy that integrates emerging trends. *Medicine, Health Care and Philosophy* 10 (1), 53-56.
90. Todres, L., Galvin, K., Holloway, I., 2009. The humanization of healthcare: a value framework for qualitative research. *International Journal of Qualitative Studies on Health and Well-Being* 4 (2), 68-77.
91. Attre, M., 2000. Patients' and relatives' experiences and perspectives of 'good' and 'not so good' quality care. *Journal of Advanced Nursing* 33 (4), 456-466.
92. Arman, M., Rehnsfeldt, A., Lindholm, L., Hamrin, E., Eriksson, K., 2004. Suffering related to health care: a study of breast cancer patients' experiences. *International Journal of Nursing Practice* 10 (6), 248-256.
93. Dahlberg, K., 2007. The enigmatic phenomenon of loneliness. *International Journal of Qualitative Studies on Health and Well-Being* 2 (4), 195-207.
94. Verheul, W., Sanders, A., Bensing, J., 2010. The effect of physicians' affect-oriented communication style and raising expectations on analogue patients' anxiety, affect and expectancies. *Patient Education Counseling* 80 (3), 300-306.
95. Friele, R., Sluijs, E., 2006. Patient expectations of fair complaint handling in hospitals: empirical data. *BMC Health Services Research* 6, 106-114.
96. Socialdepartementets PM om kriterier för RCC., 2011. [Swedish government report on the national strategy for improved cancer care]. Accessed March 10, 2011, available at: [http://www.skl.se/vi\\_arbetar\\_med/halsaochvard/cancervard/regionala\\_cancercentrum](http://www.skl.se/vi_arbetar_med/halsaochvard/cancervard/regionala_cancercentrum). [in Swedish].
97. Torjuul, K., Sorlie, V., 2006. Nursing is different than medicine: ethical difficulties in the process of care in surgical units. *Journal of Advanced Nursing* 56 (4), 404-413.

98. Davis, L., 2005. A phenomenological study of patients' expectations concerning nursing care. *Holistic Nursing Practice* 19 (3), 126-133.
99. McCabe, C., 2004. Nurse-patient communication: an exploration of patients' experiences. *Journal of Clinical Nursing* 13 (1), 41-49.
100. Scott-Findlay, S., Golden-Biddle, K., 2005. Understanding how organizational culture shapes research use. *The Journal of Nursing Administration* 35 (7/8), 359-365.
101. Höglund, A., Winblad, U., Arnetz, A., Arnets, J., 2010. Patient participation during hospitalization for myocardial infarction: perceptions among patients and personal. *Scandinavian Journal of Caring Sciences* 24 (3), 482-489.
102. Sandberg, J., 2000. Understanding human competence at work. An interpretative approach. *The Academy of Management Journal* 43 (1), 9-17.
103. Mills, M., Davidson, R., 2002. Cancer patients' sources of information: use and quality issues. *Psycho-Oncology* 11(5), 371-378.
104. Kessler, T.M., Nachburb, B.H., Wolfgang, W., 2005. Patients' perception of preoperative information by interactive computer program-exemplified by cholecystectomy. *Patient Education and Counseling* 59 (2), 135-140.
105. Keulers, B., Welters, C., Spauwen, P., Houpt, P., 2007. Can face-to-face patient education be replaced by computer-based patient education? A randomised trial *Patient Education and Counseling* 67 (1-2), 176-182.
106. Batalden, P.B., Davidoff, F., 2007. What is 'quality improvement' and how can it transform health care? *Quality and Safety in Health Care* 16 (1), 2-3.
107. Kuokkanen, L., Leino-Kilpi, H., 2000. Power and empowerment in nursing: three theoretical approaches. *Journal of Advanced Nursing* 31 (1), 235-241.
108. Bégat, I., Ellefsen, B., Severinsson, E., 2005. Nurses' satisfaction with their work environment and the outcomes of clinical nursing supervision on nurses' experiences of well-being: a Norwegian study. *Journal of Nursing Management* 13 (3), 221-230.
109. Boström Lindberg, E., 2007. Increased job satisfaction after small group reflection on an intensive care unit. *Dimensions of critical care nursing* 26 (4), 163-167.
110. Lindh, I.-B., Severinsson, E., Berg, A., 2008. Exploring student nurses' reflection on moral responsibility in practice. *Reflective Practice* 9 (4), 437-448.
111. Branch, W.T., 2010. The road to professionalism: reflective practice and reflective learning. *Patient Education and Counseling* 80 (3), 327-332.
112. Lincoln, Y.S., Guba, E.G., 1985. *Naturalistic inquiry*. Sage, Beverly Hills CA.

113. Patton, MQ., 2002. Qualitative Research & Evaluation Methods. 3 edition. Sage, Thousands Oaks, CA.
114. Kvale, S. 1977. Den kvalitativa forskningsintervjun [The qualitative research interview] Studentlitteratur. Narayana Press [In Swedish].
115. Des Jarlais, D., Lyles, C., Crepaz, N., and the TREND group., 2004. Improving the reporting quality of nonrandomized evaluations of behavioural and public health interventions: The TREND statement. American Journal of Public Health 94 (3), 361-366.
116. McCall Smith, A., 2005. The No.1 Ladies' Detective Agency. Abacus. London.

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