

Department of Nursing, Karolinska Institutet, Stockholm,  
Sweden

**Patients with cancer -  
their preferences and experiences of  
participation in treatment and care decisions**

Ethel Ramfelt



Stockholm 2004

Published and printed by Repro Print  
Box 21085, 100 31 Stockholm, Sweden  
© Ethel Ramfelt, 2004  
ISBN: 91-7349-925-0

## ABSTRACT

### **Patients with cancer - their preferences and experiences of participation in treatment and care decisions**

The main aim of this thesis was to investigate preferences for participating in treatment decision-making among patients with colorectal cancer before treatment and at a one-year follow-up and to compare the relationship between these preferences and coping factors. An additional aim was to explore the patients' meaning of illness and their experiences of decision-making concerning treatment and care. The aim of study I was to examine preferences about the degree of participation in treatment decisions among a group of patients with colorectal cancer and to relate the results to the patients' sense of coherence and the meaning they attributed to the disease. The results show that 62 % of the patients preferred a collaborative role in treatment decisions. There were no statistically significant differences between the preferred roles with respect to the patients' sense of coherence and the meaning they attributed to the disease. The aim of study II was to compare preferences for participation in treatment decisions before and one-year after surgery with the patients' sense of coherence. The results show that before surgery 71 % of the patients and at the one-year follow-up 75 % of the patients' preferred collaborative roles in decision-making. Sixty-four percent maintained their preferred roles from before surgery to the one-year follow-up. There were no statistically significant differences between the preferred roles with respect to the patients' sense of coherence either before surgery or at follow-up. The aim of study III was to explore emotional and interactional perspectives of the meaning of illness, for a one-year illness period from the time of receiving the cancer diagnosis. The constant comparative method was used to analyse data. The meaning of the illness was expressed in the main theme, 'Attempting to find meaning in illness in order to achieve emotional coherence'. The theme consists of two dimensions; unified and dichotomised embodiment. The sub-themes of unified embodiment dimension were: gratefulness, confidence in oneself and others, looking forward, and creating a new future. The sub-themes of the dichotomised dimension embodiment were; altered self-worth, loss of temporality, infringement, and loss of integrity. The aim of study IV was to explore and conceptualise the experiences of participating in decisions. The constant comparative method was used. The concept of participation was formulated into the main theme as 'Compliant participation in serious decisions'. The theme comprised two variations, complying with participation and complying without participation. Complying with participating was characterised by a high level of self-confidence and self-competence and refers to open dialogues between the participant, physician and nurse. Complying without participating was characterised by the participants' uncertainty and being urged to submit to decisions with a minimum delay without having time to consider the information provided or influence the treatment and care process. Conclusion: A patient's preference in participation in treatment and care decision-making seems to be preconditioned by many factors, above all their understanding of the situation, information attained, the meaning they ascribe to the illness as well as interpersonal factors. To participate builds on open and affirming dialogues, information and knowledge about the illness. This helps the patient to experience a sense of coherence and self-control. The findings suggest that support of a patient's participation in treatment and care decision-making should aim to minimise or prevent distress and uncertainty. Increased patient participation in treatment and care decision making is interpreted as a health promoting way to cope with their illness.

*Keywords:* Patient participation, decision-making, preferences, compliant, sense of coherence, meaning of illness, interrelationship and dialogue.

## ORIGINAL PAPERS

This thesis is based on the following papers, which are referred to in the text by their Roman numerals (I-IV).

- I            Ramfelt E., Langius A., Björvell H., Nordström G. Treatment decision-making and its relation to the sense of coherence and the meaning of the disease in a group of patients with colorectal Cancer. *European Journal of Cancer Care* 2000; 9: 158-165.
  
- II            Ramfelt E., Lützén K., Nordström G. Treatment decision-making in a group of patients with colorectal cancer before surgery and a one-year follow-up. Submitted.
  
- III           Ramfelt E., Severinsson E., Lützén K. Attempting to find meaning in illness to achieve emotional coherence: The experiences of patients with colorectal cancer. *Cancer Nursing* 2002; 25 (2): 141-149.
  
- IV           Ramfelt E., Lützén K. Treatment plan decisions: colorectal cancer patients' approaches to participation. Submitted.

Reprints of the original papers were made with the publisher's permission.

# CONTENTS

<b>ABSTRACT .....</b>	<b>3</b>
<b>ORIGINAL PAPERS .....</b>	<b>4</b>
<b>CONTENTS .....</b>	<b>5</b>
<b>INTRODUCTION .....</b>	<b>7</b>
<b>BACKGROUND.....</b>	<b>8</b>
CONCEPTUALISATION OF DECISION-MAKING.....	8
DECISION-MAKING AND CANCER ILLNESS .....	9
DECISION-MAKING AND COPING IN ILLNESS .....	10
PARTICIPATION AND DECISION-MAKING.....	11
SUMMARY OF RESEARCH PROBLEM.....	12
<b>AIMS OF THE THESIS .....</b>	<b>13</b>
<b>METHODOLOGICAL ASPECTS.....</b>	<b>14</b>
COMBINED METHODS APPROACH.....	14
OVERVIEW OF STUDIES INCLUDED IN THESIS .....	15
PARTICIPANTS IN STUDIES I - IV .....	16
QUANTITATIVE DATA (I & II) .....	17
<i>Selection of Participants</i> .....	18
<i>Collection of Data</i> .....	18
The Control Preferences Scale .....	19
Lipowski's categories for meaning of illness.....	20
The Sense of Coherence scale .....	20
<i>Analysis of Data</i> .....	20
Analysis of the card order.....	20
Statistical analysis .....	21
QUALITATIVE DATA (III & IV) .....	21
<i>Validity and reliability</i> .....	22
<i>Analysis of Data</i> .....	23
<i>Study III</i> .....	23
<i>Study IV</i> .....	23
<b>ETHICAL CONSIDERATIONS .....</b>	<b>24</b>
<b>SUMMARY OF FINDINGS .....</b>	<b>25</b>
STUDY I.....	25
STUDY II.....	26
STUDY III .....	29
STUDY IV .....	30
<b>GENERAL DISCUSSION AND CONCLUSIONS .....</b>	<b>31</b>
DISCUSSION OF FINDINGS .....	31

METHODOLOGICAL REFLECTIONS .....	36
CONCLUSIONS .....	38
<b>IMPLICATIONS FOR FUTURE RESEARCH.....</b>	<b>38</b>
<b>ACKNOWLEDGEMENT .....</b>	<b>39</b>
<b>REFERENCES .....</b>	<b>41</b>
<b>SWEDISH SUMMARY .....</b>	<b>48</b>

## INTRODUCTION

It is well known that in many societies the word cancer evokes strong emotional reactions and, for the person with cancer, a life crisis. A person who receives a diagnosis of cancer does not only have to deal with the meaning of a serious illness, but also with difficult decisions that have to be made during the course of the treatment and care. Becoming a patient with a life-threatening illness entails relying on others to make the “right” decision in the hope that it will lead to a cure. A majority of those who receive a diagnosis of cancer do not have in advance knowledge of the course of the illness or the outcome of treatment and thus may trust the physician (s) and the nurse (s) to decide what is best for them. Other patients may expect to participate in the decision-making process in order to understand the consequences of different alternatives.

Overshadowing all decisions is the fear of death. The incentive for this thesis was my questions: What does it mean to those who have received a diagnosis of cancer? Do patients with cancer prefer to participate in decisions concerning their treatment and care, and how do their preferences vary? I was especially interested in persons who had just received the diagnosis of cancer, since in my clinical experience these patients know little about the course and outcome of their illness and are therefore extremely anxious and hesitate to make decisions.

An update of The Swedish Health and Medical Services (1982) legislation argues for a counselling and supportive role on the part of the healthcare professionals in order to promote patient involvement (Sahlin, 2000). This view of the patient may be seen as active promotion of the autonomous choices of the individual (Beauchamp & Childress, 2001). My interpretation is that this act assumes that most patients desire and have the competence to participate in their treatment and care decisions. For patients who recently have been diagnosed with cancer, participation in treatment and care decisions must be balanced against their previous health care experiences and their vulnerability.

The focus of this thesis is on how patients cope with their concerns about the illness, their fears and doubts and how these concerns influence the possibility of participating in treatment decisions.

This thesis is built on four studies (I - IV) with a descriptive statistical design (I & II), and an explorative design (III & IV). Meanings attributed to the illness and decision-making identified in study I and II served as a sensitising of the framework for the research in studies III and IV. Thus, the statistical findings concerning the degree of participation-roles in treatment decisions led to

questions concerning the meaning attributed by the patients to the illness and their experiences of participation in decision-making. In order to explore these questions, methods for collecting and analysing qualitative data were used.

## BACKGROUND

### Conceptualisation of Decision-Making

According to Ofstad (1961), the explanation of decision-making is that we react and take position on an issue, on the basis of which we make up our mind to perform a certain action. Further, the most common use of decision-making is to make a judgment regarding what we ought to do in a particular situation after having deliberated on various alternative courses of action. Another view of decision-making is suggested by, for example, Kelly (1955), Janis & Mann (1977), Antonovsky (1979) and Lazarus (1984, 1991), who see individuals' decision-making as formed by previous experiences, cognition, affect (emotions), and by interpersonal processes, thus, as a social process. Another aspect not included in Ofstad's (1961) definition is the asymmetry of knowledge power between patient and healthcare professional.

In order to make the world meaningful, we predict and control events in our world and construct hypotheses about those events (Kelly, 1955). Thus, the meaning one attributes to a situation and decision-making implies that an event is open to a variety of interpretations depending on the way in which it is understood (Lazarus, 1991).

Decision-making in health care situations, especially when the patient receives a diagnosis of cancer, the social environment, interaction and relationships between patient and healthcare professional may be of great importance. Furthermore, the aspect of asymmetry of knowledge and power between patient and healthcare professional and the effects on patient's capacity for decision making is an additional factor to consider (Pellegrino & Thomasma, 1988).

The concept of decision-making has a close association with the concepts of autonomy, informed consent and integrity. The main principle of autonomy is a view of people as equals, irrespective of one's particular conception of the good life, or of that which gives meaning to life (Dworkin, 1988). The concept of integrity used in this thesis refers to a change of self during illness (Morse, 1997; Charmaz, 2002).



## Decision-Making and Cancer Illness

Decision-making with specific focus on patients with cancer illness is a broad research field in nursing research. Some examples of this type of research are: developing theory based rating scales to measure preferences in the area of health-related problems (Degner & Aquino Russel, 1988; Degner et al., 1997b; Ehrenberger *et al.*, 2002), intervention studies designed to provide decisional support and aid for patients who want to participate in decisions about their treatment (Davison & Degner, 1997, 2002; Sainio *et al.*, 2001a; Sainio *et al.*, 2001b; Feldman-Stewart *et al.*, 2004). Preferences for participation in health care decisions are described as roles on a continuum ranging from a complete patient control, i.e. active participation, through collaboration or sharing, to passive participation where the physician and/or other healthcare professionals make decisions on behalf of the patient (Ende *et al.*, 1989; Beisecker & Beisecker, 1990; Degner & Sloan, 1992).

Preferences for participation roles in decision-making have been the subject of extensive research within cancer populations, which revealed that the level of “decisional control” ranges from a role of making one’s own decision (Davison *et al.* 2002) via collaborative role (Hack *et al.*, 1994; Degner *et al.*, 1997a; Davison & Degner, 1997; Rothenbacher *et al.* 1997; Hack & Degner, 1999; Wallberg *et al.*, 2000; Sanders & Skevington, 2003), to passive role (Degner & Sloan, 1992; Davison *et al.*, 1995; Beaver *et al.*, 1996; Bilodeau & Degner, 1996). These differences in the degree of participation have generally been explained in relation to demographic characteristics. For example, age and education, have been found to be strongly correlated and that, younger patients (Blanchard *et al.*, 1988; Degner & Sloan, 1992; Beaver *et al.*, 1996; Bilodeau & Degner, 1996; Rothenbacher *et al.*, 1997; Wallberg *et al.*, 2000; Sainio & Lauri, 2003) and patients with a higher level of education prefer a more active participatory role in decision-making when compared to older patients and those with a lower level of education (Hack *et al.*, 1994; Beaver *et al.*, 1996; Degner *et al.*, 1997; Rothenbacher *et al.*, 1997). However, this research did not relate personal characteristics, such of appraisal, coping, relationships and satisfaction with decision-making, to decisional roles as suggested by other researchers (Hack & Degner, 1999; Sainio *et al.*, 2001b). In these studies, environmental factors and demands, as well as the illness experience and personality traits are considered to play an important role in the degree to which patients participate in making decisions (Sahlberg-Blom *et al.*, 2000; Sainio *et al.*, 2001a).

Due to the large number of studies using similar as well as different methods to explore preferences for participation in decision-making in different groups of patients with cancer, conclusive knowledge now exists.

## Decision-Making and Coping in Illness

As a concept, coping has a variety of conceptual meanings and is often interchangeable with related concepts such as mastery and self-esteem (Taylor, 1983). Factors such as general beliefs and goals and, individual variables comprising values, commitments as well as environment aspects are antecedent and prerequisite conditions that influence the decisional process (Lazarus & Folkman, 1984). Inherent coping is the meaning one ascribe to a situation (Lipowski, 1970; Antonovsky, 1979).

Park & Folkman (1997) consider that the meaning individuals assuming situations pertains order, e.g. beliefs about the world, beliefs about one's self and the world. They distinguish meaning as both global and situational in which the motivational dimension of meaning refers to the person-environmental transaction. Thus, how patients define themselves in relation to their illness plays an important role in their coping as does the clinical environment with which they are confronted.

Antonovsky (1987; 1987) describes coping as sense of coherence and equal to health, which he believes plays a major role in determining an individual's ability, not only to survive but also to benefit from exposure to stressful stimuli. The three components comprising the sense of coherence concept are 1) comprehensibility – implying that the stimuli are predictable and explicable, 2) manageability – meaning that resources are available to meet the demands, and 3) meaningfulness – indicating that the demands are challenges, worthy of investment and engagement. Furthermore, a high sense of coherence has emotionally supportive functions (Lipowski, 1970; Antonovsky, 1987; Lazarus, 1991). Lipowski (1970) describes the meaning of illness or disease by using eight categories (challenge, enemy, loss, punishment, relief, strategy, value and weakness) reflecting an individual's experiences, knowledge, cultural background and beliefs.

Studies in patients with cancer that have used Lipowski's (1970) categories show that the three most frequent categories used to describe the meaning these patients ascribe to their illness were challenge, value and enemy (Luker *et al.*, 1996) while according to a study by Wallberg *et al.* (2003), the top three categories were, challenge, enemy and irreparable loss. In addition, Barkwell (1991) reveal that those patients who regarded their disease as a challenge reported significantly lower pain scores, lower depression scores and higher coping scores, compared with patients who viewed their pain as an enemy or punishment. Thus, an optimistic view of the illness is health supportive. Antonovsky's (1979; 1987), Lazarus's (1991) Lipowski's (1970), and Kelly's (1955)

perspectives imply that coping is directed towards managing emotions, preserving self and interpersonal relationships. For coping to be efficient there must be agreement between personal beliefs, values, commitments and the environmental situation.

What are the adaptational factors that could facilitate interpersonal communication in order to ensure patients' active participation and co-operation with the aim of increasing personal control? Lazarus (1991), Damasio (1999; 2003) and Green (1992) consider that emotions play an important role in preserving life, as well as enhancing well-being and reducing suffering. First, emotions are feelings or affects as well as cognitions and desires (Damasio 1999, 2003). Second, emotions are the spontaneous affective responses which may be morally important as an ability to be affected by another person's distress (Damasio, 2003; Nortvedt, 2004). Thus, emotions also function in promoting another persons good.

From this discussion, it seems reasonable to assume that emotions influence patients' competence to participate in treatment and care decisions. In order to gain a deeper knowledge and understanding of patients' participation in decision-making situations related to treatment and care planning, factors, such as sense of coherence, meaning of the illness and interaction between the patient and healthcare professionals are important to explore.

## **Participation and Decision-Making**

Participation in decision-making can also be seen as an inherent part of the coping process (Lazarus & Folkman, 1984; Antonovsky, 1987). Included in patient participation is the core component of information and patient knowledge. Access to information about illness, treatment and care is crucial in helping patients to understand and cope with their illness.

All participation and relationships in health care decisions involves a power dimension, such as the power of knowledge. It dominates the communication between the patient and the professionals (Tourigny, 1994), which means that a hierarchy of values is formed in each encounter (Thomasma, 1994). This hierarchy of values must be taken into account when we try to explain and interpret patients' experiences of participation in decision-making (Pellegrino & Thomasma, 1988).

Strategies for obtaining information and knowledge as well as reflections about different decision situations are also an aspect of participation. However, the information and knowledge aspects on the participation in decision-making are related to coping.

## Summary of Research Problem

Receiving a cancer diagnosis thrusts patients into situations in which they are relatively powerless and inexperienced. In these situations, when the patients have to participate in treatment and care planning, especially when they recently have received the diagnosis of cancer, the environment, interaction and relationships between patient and healthcare professional can be of importance. What are the adaptational factors that could facilitate interpersonal communication in order to ensure patients' participation and co-operation with the aim of increasing personal control?

If we consider that emotions play an important role in preserving life, as well as enhancing well-being and reducing suffering it seems reasonable to assume that these influence patients' competence to participate in treatment and care decisions. Second, emotions are the spontaneous affective responses which can be morally important as an ability to be affected by another person's distress. Thus, emotions can also function in promoting another persons good.

The knowledge power asymmetry between the patients and the healthcare professional raise the question whether and to what degree and if patients deliberately can participate in decisional situations. On the one hand, participation in decision-making can be seen as an active health promotion in terms of the individual's preserving of self efforts. On the other, an increased patient participation in decision-making can imply that patients assume responsibility for the health outcome and in this case, there is little empirical research evidence to suggest that such an activity is appropriate or even beneficial for all individuals.

However, due to patients' illness, recently received a cancer diagnosis, it is reasonable to assume, that several factors determining their possibilities to deliberately participate in treatment and care decision-making.

In order to gain a deeper understanding and knowledge of patients' participation in decision-making situations related to treatment and care planning, factors, such as sense of coherence, meaning of the illness and interaction between the patient and healthcare professionals are important to explore.

## AIMS OF THE THESIS

The general aim of this thesis, consisting of four empirical studies, was to investigate the preferences for participating in treatment decision-making in patients with colorectal cancer before treatment and at a one-year follow-up and to compare the relationship between these preferences and coping factors. An additional general aim was to explore the patients' meaning of illness and their experiences of decision-making concerning treatment and care. The specific aims of each study are to:

- examine preferences about the degree of participation in treatment decision-making in a group of patients with colorectal cancer and to relate the results to the patients' socio-demographic data, self-evaluated sense of coherence and the meaning they attribute to the disease. (I)
- compare preferences about the degree of participation in treatment decision-making in a group of patients with colorectal cancer before and one year after surgery, and to compare these preferences to the patients' actual participatory role before surgery and their sense of coherence. (II)
- explore emotional and interactional perspectives in the meaning of illness in patients with colorectal cancer, from the time of receiving the cancer diagnosis and during a one-year illness period. (III)
- explore and conceptualise the experiences of participation in treatment planning decisions and their meaning from the perspective of patients recently treated for colorectal cancer. (IV)

## METHODOLOGICAL ASPECTS

### **Combined Methods Approach**

The thesis consists of four empirical studies (I - IV) using a descriptive statistical design (I & II) and an explorative design (III & IV). The categorisation of research into descriptive statistical and explorative designs is based on Brink & Wood (1998). In this thesis the combined methods approach is aimed at supplement each other. The combining of methods developed during the research process.

Since the aim of studies I and II, was to explore whether the preferences for participation in decision-making could be related to sense of coherence and the meaning of the disease and socio-demographic data, a quantitative design was necessary. A second aim of study II was guided by the questions whether participation preferences change over time, from before surgery to one year later, whether the patients' preferences for participation accord with their actual participatory role, and whether participation in decision-making after one year could be related to sense of coherence.

The central idea of descriptive statistical design is that the reality is ordered and can be studied by means of validated instruments (Polit & Hungler, 1999). The risk inherent in this method is, however, that the central meaning of complex human situations, when measured by thoroughly validated questionnaires, is not considered. Criticism has also been levelled at the use of this design for phenomena that are not predictable or predefined. The results of studies I and II led to the need to further explore the patients' accounts of the meaning of illness and treatment and care decision-making and how they acted and reacted in these situations, questions that could best be studied by using a qualitative explorative approach.

The qualitative exploratory design used in studies III and IV departs from the assumption that reality is mentally constructed and emerges from the interactive processes between individuals (Kelly, 1955; Schutz, 1999). Since study III indicated a connection between the patients' emotions and decision-making, it raised the question of if and how patients in a life threatening situation have the competence to deliberately participate in decision-making when they are dependent on the help and knowledge provided by the health care professionals.

The experiences related by the participants and the examples of patient participation in decision-making used in this thesis are for the most part within

the environment of hospital care although some are taken from the area of primary health care (III & IV).

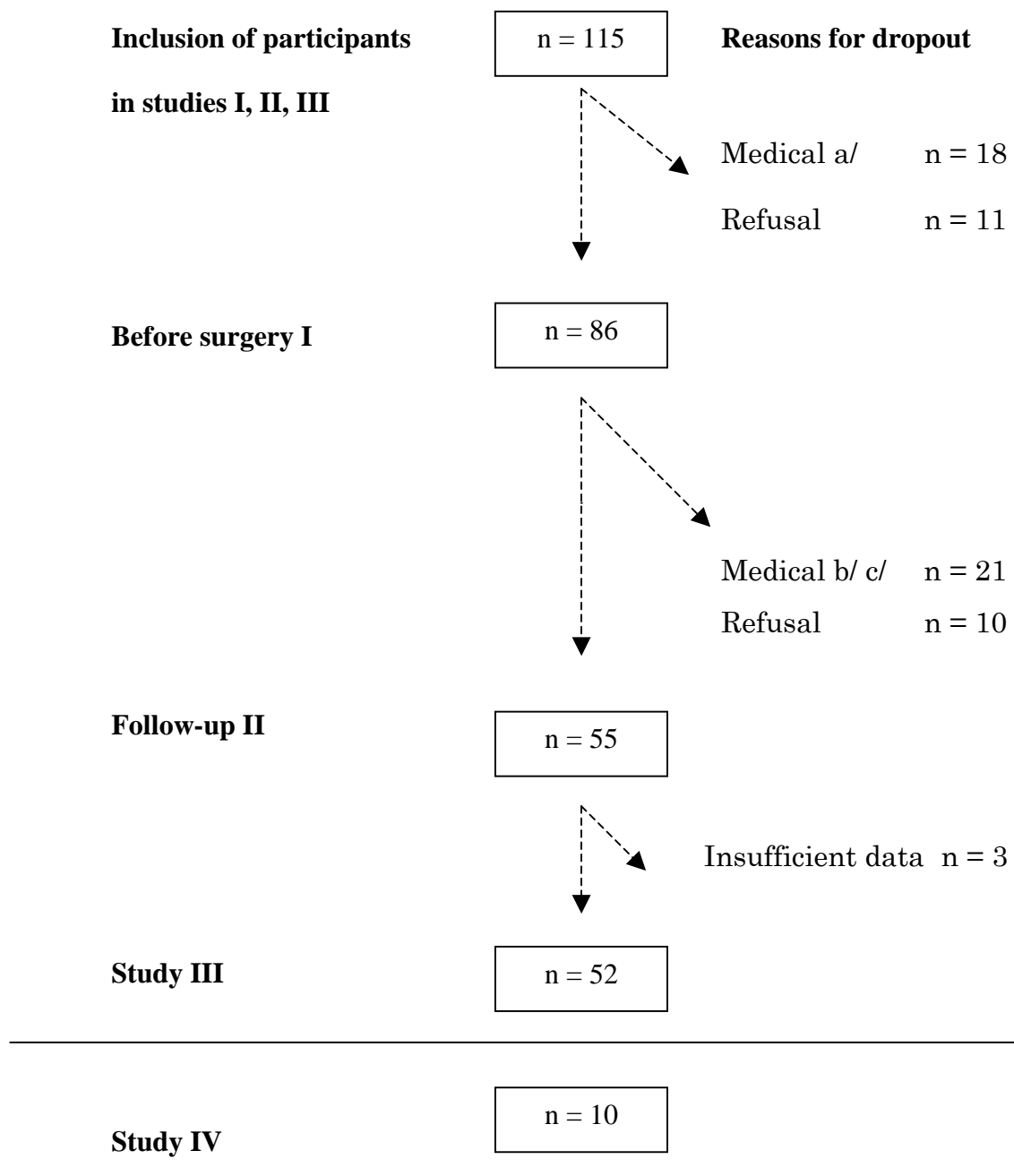
## METHODS AND PARTICIPANTS

### Overview of Studies Included in Thesis

**Table 1.** Design, participants, data collection methods and analysis used in the four studies.

<b>Study</b>	<b>I</b>	<b>II</b>	<b>III</b>	<b>IV</b>
<b>Participants (numbers)</b>	86	55	52	10
<b>Design</b>	Descriptive Statistical analysis	Descriptive Statistical analysis	Explorative Qualitative descriptive	Explorative Qualitative descriptive
<b>Data collection instruments</b>	Control Preferences Scale (CPS) Sense of Coherence scale (SOC) Lipowski's Categories	Control Preferences Scale (CPS) Sense of Coherence scale (SOC)	Lipowski's Categories and Interview	Interview
<b>Methods for data analysis and interpretation</b>	Descriptive statistical analysis	Descriptive statistical analysis	The Constant Comparative Analysis	The Constant Comparative Analysis

## Participants in Studies I - IV



**Figure 1.** The number of eligible participants in studies I, II and III and reasons for dropouts at the different points in time:

a/ deteriorating physical and mental condition prevented participation;

b/ physical condition (n = 8), and death (n = 10);

c/ non-cancer (n = 3).



**Table 1.** Descriptive characteristic of the participants in studies I – III.

<b>Variables</b>	<b>Study I</b> (n = 86)	<b>Study II</b> (n = 55)	<b>Study III</b> (n = 52)
<b>Age</b> (mean and SD) years	70 (10)	69 (11)	68 (12)
Range (years)	34–83	34–83	34–83
	n (%)	n (%)	n (%)
<b>Sex</b>			
Male	41 (48)	26 (47)	25 (48)
Female	45 (52)	29 (53)	27 (52)
<b>Marital status</b>			
Married/Cohabiting	55 (64)	33 (60)	33 (63)
Living alone	31 (36)	22 (40)	19 (37)
<b>Cancer sites</b>			
Colon	58 (67)	35 (64)	36 (69)
Rectum	28 (33)	20 (36)	16 (31)
<b>Metastasis</b>	41 (48)	24 (44)	24 (46)

## Quantitative Data (I & II)

This thesis began with two small-scale descriptive statistical studies (I & II) aimed at describing the degree of preferred participation role in treatment decision-making in a group of patients with colorectal cancer. Another aim was to relate the patients' preferred participation role to sociodemographic data, the sense of coherence, and the meaning of their disease (I), and to compare the degree of preferred participation in treatment decision-making before and one year after surgery (II). An additional aim was to compare these preferences to the patients' actual participatory role before surgery and their sense of coherence.

Because the same measures were applied in both studies (I & II), they are presented together (Method section, Collection of data). Study I included 86, and study II 55 patients (Figure 1). The concept of participation and preferences for decision-making used in study I and II is the Control Preferences Scale (Degner *et al.*, 1997b), which includes active, collaborative and passive participation roles (I & II).

### **Selection of Participants**

The inclusion criteria were: patients who were planned for elective and adjuvant therapy within a three-week period, no other cancer diagnosis, ability to speak and read Swedish, and the physical, mental, and cognitive capacity to answer questionnaires. The patients were consecutively recruited to the studies (I - III). Only those patients who were too ill to participate or who exhibited signs of mental deterioration in their interaction with the research nurse were excluded. The number of eligible patients with a clear diagnosis of or suspected colorectal cancer and the reasons for dropout at different points in time are shown in Figure 1. The patients' sociodemographic and disease characteristic are shown in Table 2.

Patients with colorectal cancer were selected based on the fact that colorectal cancer is one of the most common types of cancer in Sweden (Cancer Incidence in Sweden 2002). This type of disease is closely associated with age, with an increased incidence after the age of 60 years. The older person who develops cancer is in a different life situation to a younger person in that they also experience other burdens commonly associated with ageing. Compared to younger persons, elderly persons are more at risk, because, among other things, their needs are associated with decreased social support. In the year 2002, the incidence in Sweden was 5,468 cases comprising about 12 % of all cancer cases (Cancer Incidence in Sweden 2002).

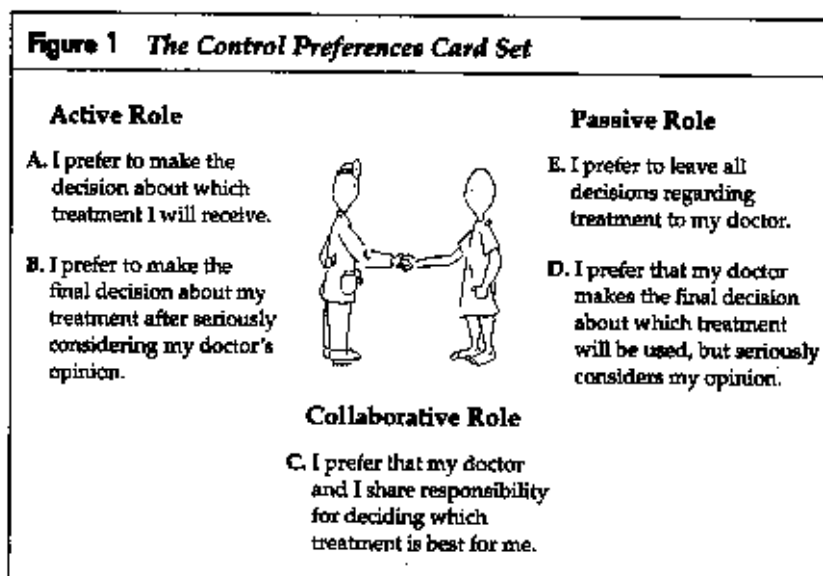
### **Collection of Data**

The patients were invited to answer the questionnaires and to take part in interviews in the ward or its vicinity the day before surgery (I). At the follow-up investigation (II) the participants were invited to choose the place for the interview, and most of them chose their homes or a private area at their place of work. Socio-demographic data (sex, age, formal education, and marital status) were collected by a questionnaire prepared for studies I - III. Medical data, such as cancer sites and metastases, were obtained from the participants' medical records (Table 1).

## The Control Preferences Scale

Studies I and II employed the Control Preferences Scale (CPS), developed by Degner *et al.* (1997b), which consist of a card-sorting technique that focuses on the preferred level of participation in treatment decision-making, was used (Figure 2).

---



**Figure 2.** The Control Preference Card Set shown as Figure 1. From Degner *et al.*, (1997b) *Canadian Journal of Nursing Research*, 29(3), 21-43. (Reproduced by permission of CJNR).

---

The order of preference A, B, C, D, E represents the most active role preferred, whereas the reverse order preference E, D, C, B, A represents the most passive role. To decrease measurement error, the cards were presented to the respondents in a fixed order B, D, C, E, A, as suggested by Degner *et al.*, (1997b). Every card was compared with every other card in sets of two until the preference order of the five cards was unfolded. One hundred and twenty combinations are possible. The reliability of the method has been demonstrated (Degner *et al.*, 1997b).

When the patients' order of preference was obtained, they were asked to reconsider and describe which participatory role they had actually assumed

---

about their planned surgical treatment (I & II). After that the participants picked the one card that was closest to the degree of their actual participatory role.

### **Lipowski's categories for meaning of illness**

The meaning of disease (I) or illness (III) consisting of eight categories (challenge, enemy, loss, punishment, relief, strategy, value, and weakness), as outlined by Lipowski (1970), was used in the studies. These categories reflect an individual's experiences and beliefs and aim to describe the perceived meaning of an illness. Cards, each of which contained one category, were presented randomly to the patients. The patients were told to choose the one card that was closest to the meaning they ascribe to cancer illness. This measure has been used in women with breast cancer (Luker *et al.*, 1996; Wallberg *et al.*, 2003) and patients with pain (Barkwell, 1991).

In the analysis of study I, the eight categories were divided into two groups, the optimistic group (challenge, relief, strategy, and value) and the pessimistic group (enemy, loss, punishment and weakness).

### **The Sense of Coherence scale**

Antonovsky's sense of coherence (SOC) scale (Antonovsky, 1987) comprising 29 items, which measure the three components comprehensibility, manageability and meaningfulness; the concept of SOC were used in studies I and II. The scale is self-administered and has a semantically differentiated format, with each item ranging from 1 to 7 and with two anchoring responses. The items are aggregated to one unitary scale ranging between 29 - 203 points and the higher the score the stronger the SOC. The SOC scale has shown reliability and validity, for example, (Langius & Björvell, 1993; Persson *et al.*, 2001).

## **Analysis of Data**

### **Analysis of the card order**

According to the Degner *et al.* (1997b) model based on Coomb's (1976) unfolding theory, only the consistent orders of the preferences should be included in the analysis. This theory maintains that preference orders that do not fulfil this criterion should be excluded from the analysis, which usually involves on average 30% of the combinations (Degner *et al.*, 1997b). However, in studies I, and II, all the combinations of the CPS chosen by the patients were included in the data analysis. Four groups were formed, based on the patients' two most preferred cards. Contrary to Degner *et al.*, (1997b), the combinations AB and AC were considered as Active Participation, CB and CD were deemed Collaborative Participation, and EC and ED were considered as Passive Participation. The remaining combinations not falling within these three groups formed a fourth

group entitled “Others”. However, in study II, when considering subsequent research (Wallberg *et al.*, 2000), we decided to modify the four groups, based on the participants’ two most preferred cards. The combination AB formed the Active Participation group, BC, BD, CB, CD, DB and DC formed the Collaborative Participation group, while DE, EC and ED formed the Passive Participation group.

In the analysis of the agreement (I & II) between the preferred and the actual participatory role, only one card was used, either the Active role, i.e. card A or B, the collaborative role, card C, and the Passive role, card D or E, in accordance with the classification of Degner *et al.*, (1997b).

### **Statistical analysis**

The variables were considered to be normally distributed (I & II) and parametric methods were used (Polit & Hungler, 1999). A statistical significance of  $p < 0.05$  was considered acceptable (I). In study II the actual p-value is presented. Continuous data, age and the SOC scores were tested by means of Student’s *t* test for independent groups, while ANOVA was employed for the three dependent groups. Nominal data, sex, education, marital status, and the CPS groups were tested by means of the chi-square test and where appropriate, the Fisher’s exact test. Internal consistency for the SOC scale was measured by the Cronbach’s alpha coefficient (Siegel & Castellan, 1988).

The agreement between the patient’s actual and preferred role in treatment decision-making was analysed by Cohen’s kappa-coefficient (Armitage & Berry, 1996). The value 0 represents a no agreement, while 1 represents a total agreement (Fleiss, 1981). Due to the small number of individuals in the CPS groups, Active Participation ( $n = 1$ ) before surgery (I) and ( $n = 1$ ) at follow-up (II), and “Others” ( $n = 3$ ) before surgery (I), and ( $n = 1$ ) at follow-up (II), these groups were excluded from the statistical calculations.

### **Qualitative Data (III & IV)**

Results from studies I and II guided the qualitative exploratory design of study III, the meaning of illness and the inquiries for study IV about participants’ experiences of participation in decision-making.

A qualitative design with interviews has two main goals (Brink & Wood, 1998). The first is problem discovery, while the second is goal- and problem definition – exploring a concept in depth and in a way that makes it possible to describe an experience or its meaning (p. 309).

The data collection method with interviews aimed at gaining knowledge of the experiential meaning of the illness (III) and the experiences of participation in treatment and care planning decisions (IV). In both studies, constant comparative analysis, developed in grounded theory methodology (Glaser & Strauss, 1967) was used. The intention of grounded theory methodology, as introduced by Glaser & Strauss (1967), is to explore social processes and to identify human characteristics for responding to and dealing with various life circumstances (a recent historical summary, Lomborg & Kirkevold (2003).

Although the aims in study III and IV were not to formulate a theory about a social process, the method of constant comparative analysis used for theory development was considered appropriate. The interviews were broad and allowed change during collection of data, as recommended in method of grounded theory (Glaser & Strauss, 1967). Data collection and analysis was an alternating process, which means that analysis started as soon as empirical data were available. Systematic data collection, analysis and literature reviews allowed for flexibility in the conceptualisation of participation in decisions about treatment, which would reflect the experiences of patients with cancer (Schreiber, 2001).

In study IV, according to the constant comparison method, the selection of participants (Schreiber, 2001 pp. 63-67), the exact number of participants was not determined before the study, since the subjects are not units of analysis. The units identified in the data may be incidents or situations.

All potential participants with a history of being recently treated for colorectal cancer were informed about the study prior to planning for surgery and adjuvant therapy. Later, about one to two weeks after discharge from the hospital, they were contacted by the research nurse about their willingness to communicate their experiences of treatment planning decisions. Selection of participants continued until saturation was reached, i.e., no new information about the core category (or main theme) is forthcoming from the data collection process.

### **Validity and reliability**

In qualitative research, validity and reliability generally refer to how well the empirical data analysis reflects the experiences or perceptions (Morse *et al.*, 2002). The epistemology of the research approach determines specific validity and reliability criteria, thus ensuring rigor in the qualitative research process. These strategies include investigator responsiveness, methodological coherence, theoretical sampling, sampling adequacy and saturation. In this study, the entire constant comparative analysis process addressed these issues. If the conceptualisation “fits”, the participants will be able to validate the analysis by recognising it as a description of their own experiences (Schreiber, 2001).

However, due to the participants' illness, it was considered unethical to ask them to validate the research findings. In spite of the stringency of the method of constant comparative analysis method, not being able to present the analysis to the participants can be regarded as a methodological limitation.

As a nurse and extensive experience in the neurosurgical care with seriously ill patients, some methodological implications may be present. On the one hand, this experience can contribute to an understanding of the phenomena and environment under study and may serve as a facilitating 'bridge' between interviewer and interviewee (Thorne *et al.*, 1997). On the other hand, however, the experience or preunderstanding may influence the researcher in the analysis process. To counteract this possible influence, discussions of potential interpretations of the data were continuously held in research seminars.

## **Analysis of Data**

### **Study III**

The basis of this study was Lipowski's (1970) eight categories previously described in study I (Method section, Quantitative data). Statements from 52 participants (25 men and 27 women) were included in study III (Table 1). The participants were requested to choose one of these eight categories, which were randomly presented on eight cards. When they had chosen the one card that was closest to the meaning they ascribed to their illness they were asked to describe, in their own words, how they thought, understood and dealt with their illness. Their responses were transcribed verbatim. A total of 150 statements were identified and analysed.

Emotions, seen as experiential (LeDoux, 1998; Damasio, 1999) and social products (Charon, 2004; Damasio, 2003) sensitised the coding of the data. By means of open coding, theoretical coding and conceptualisation, the theoretical codes were subsumed into conceptual categories that seemed to relate to the participants' meanings (Glaser, 1992; Schreiber, 2001). At a further level of abstraction (III) the main theme was developed and formulated.

### **Study IV**

Ten (n = 10) participants, eight men and two women, aged between 61 and 76 years, participated in the study. All interviews were conducted in out-patient settings chosen by the participant. The interviews were audio taped and transcribed verbatim.

The constant comparison data analysis process (Glaser, 1992) use inductive-deductive method approach. As in grounded theory, in this analysis literature review was used. Although previous studies (I & II) were theory based, however,

this literature aimed at filling gaps in existing knowledge rather than providing a framework for the analysis. Each interview began with an open question: Could you please tell me about a situation in which a decision was made about your treatment and care? The interview continued with focus on the discussions regarding the treatment and care. The interviews lasted between 30 minutes and 1 hour. During the analysis it was possible to follow-up two participants with a second interview.

The constant comparison data analysis (Glaser, 1992) used in this study consisted of the following: open coding, theoretical coding, and conceptualisation of the relationship between substantive codes. By comparing aspects of decision-making experiences, theoretical codes were identified and guided subsequent data collection, i.e., theoretical sampling (Glaser, 1992; Schreiber, 2001).

The theoretical codes were assigned to conceptual categories that seemed to relate to the meaning of the experiences: preserving self, making sense of the illness, ambivalence of one's own desires, and compliant decisions by others. These categories were further developed and organised into a main theme.

## ETHICAL CONSIDERATIONS

Every step in this type of research includes ethical considerations. The first step concerns the recruitment of subjects. In studies I - IV the patients received written information about the study before being admitted to the ward. In addition, a verbal explanation about the study was provided in the ward on the day before surgery. The patients were given sufficient time to ask questions. From an ethical point of view it is important to justify interviewing patients with a life-threatening illness. Therefore, throughout the data collection process, I actively listened for cues concerning the willingness of these emotionally vulnerable subjects. However, research involving interviews with patients in vulnerable situations may also be beneficial and therapeutic. Throughout the studies the patients were informed about their right to decline participation or to withdraw at any time. Confidentiality was guaranteed throughout the study. The Ethic Committee at Huddinge University Hospital, reg. nos. 112/1995 (I - III) and 323/2001 (IV) granted formal approval.



## SUMMARY OF FINDINGS

### Study I

The findings of study I describe the participants' preferred level of participation in decision-making before surgery, in relation to the meaning they attributed to the disease and their sense of coherence. The most common order of preference, chosen by 28% of the participants, was C, D, B, E, A, the second E, C, D, B, A, chosen by 21% of the participants, and the third C, D, E, B, A chosen by 17%. One participant chose the most active preference card order A, B, C, D, E and 6% of the participants chose the most passive card order, E, D, C, B, A.

When considering the participants' two most preferred cards the Collaborative Participation (cards CB or CD), was chosen by 62% of the patients. Passive Participation (cards EC or ED) was chosen by 28%. One patient chose Active Participation (AB or AC) and 9% chose an inconsistent card order, referred to in this study as the "Others" group. There were no significant differences between the groups with regard to age, sex, education and marital status.

A comparison of the actual participatory role with the preferred level of participation showed that, in 44% of cases, the actual and preferred level of participation were the same, while 48% indicated that their actual role was more passive than they would have liked. The remaining 8% of the participants had achieved a more active role, compared with their preferred roles. Cohen's kappa-coefficient for agreement between the preferred role and the actual participatory role was 0.13, indicating poor agreement.

The distribution of Lipowski's categories shows that 71% ascribed an optimistic meaning to their disease. There were no significant differences between the optimistic and the pessimistic groups with regard to age, sex, education, marital status and metastatic disease or between the CPS groups with regard to the Lipowski's optimistic and pessimistic categories.

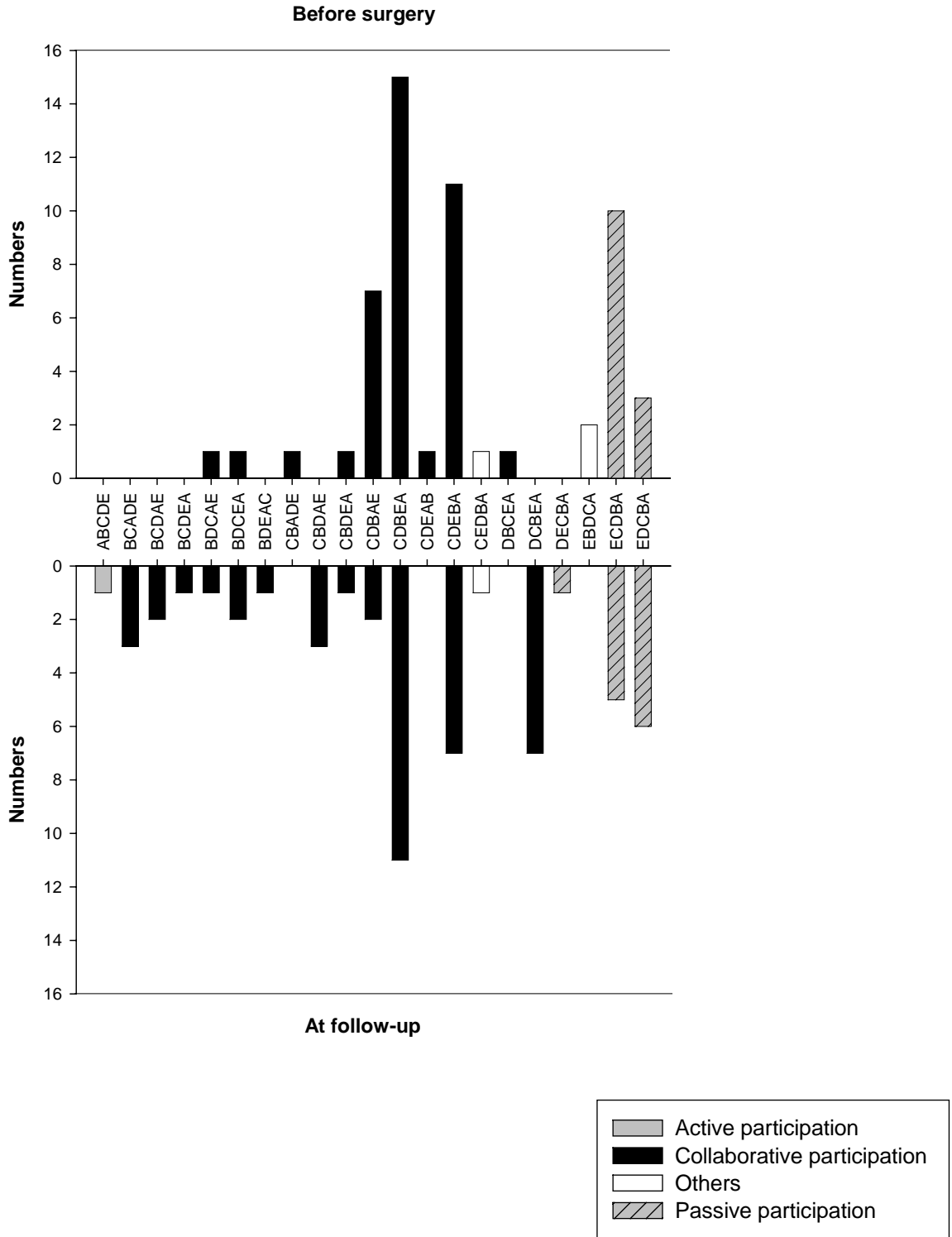
The mean SOC score in the total sample was 150. There were no significant differences with regard to sex, education, marital status and metastatic disease. Furthermore, no relation was found between the SOC score and age. When we compared the SOC score with the CPS groups, i.e. Collaborative Participation, Passive Participation, Others, and Active Participation, no significant differences were found. Furthermore, no significant differences were found between the patients whose preferred and actual participatory roles agreed and those without such agreement with regard to the SOC score.

The mean SOC scores differed significantly between the patients included in the optimistic group and those in the pessimistic group. Thus, those with an optimistic view of their disease had a higher SOC. This, however, could be explained by meaningfulness, one of the concepts within the SOC.

## **Study II**

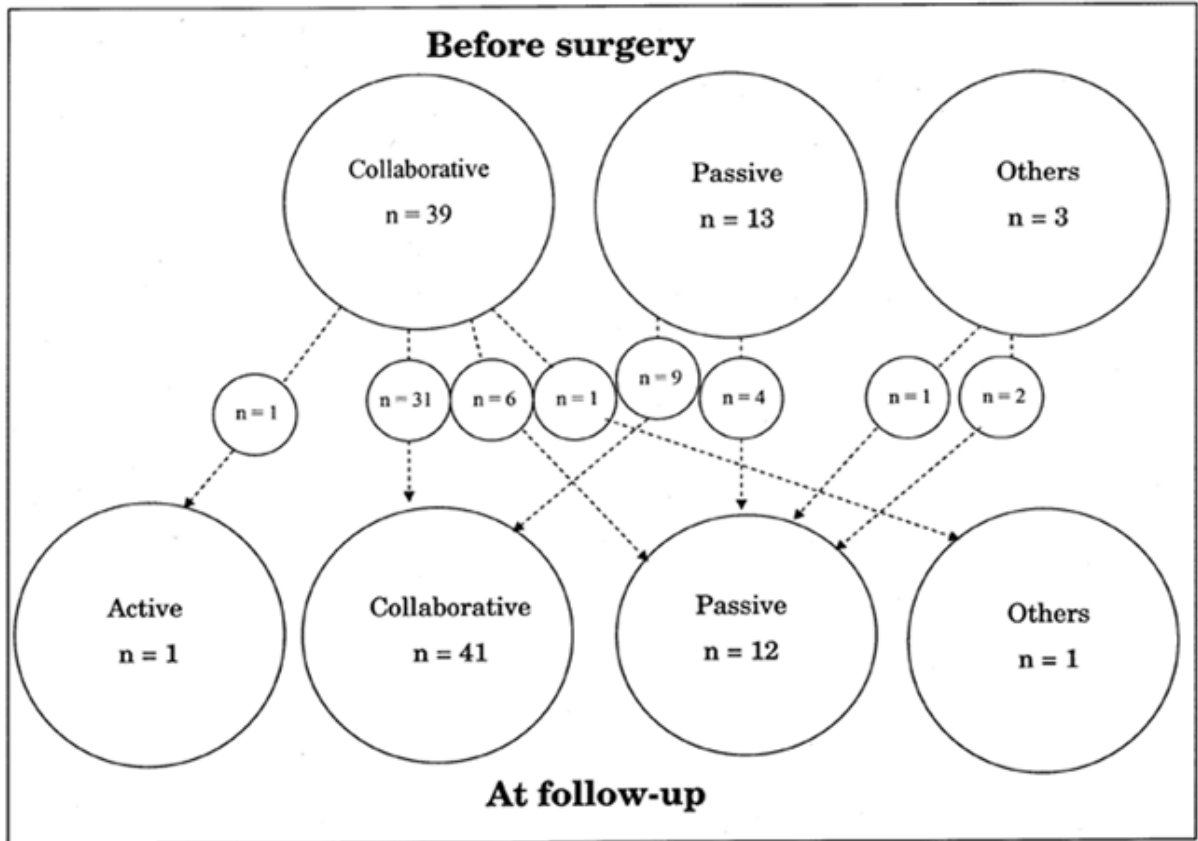
The findings of study II describe the participants' degree of participation in decision-making before surgery and at the one-year follow-up, their preferred level of participation before treatment and at the one-year follow-up, actual level of participation role, and the relation to the participants' sense of coherence.

Before surgery the 55 participants chose 13 of the 120 possible card combinations. The corresponding figure at follow-up was 17 combinations (Fig. 3). Before surgery the most common order of preference order C, D, B, E, A was chosen by 27% and at follow-up this order of preference was chosen by 20 % of the participants. At follow-up, one participant chose the most active card order, A, B, C, D, and E. Before surgery and at follow-up 5 % respectively 11% of participants chose the most passive card order, E, D, C, B, A.



**Figure 3.** The participants' order of preference before surgery and at follow-up, grouped into Active Participation, Collaborative Participation, Passive Participation and Others (n = 55).

With regard to the participants' preferred roles (two most preferred cards) before surgery and at follow-up, it was found that 64 % maintained their former preferences. The remaining 36 % changed their preferences (Fig 4).



**Figure 4.** Distribution of the change between the CPS groups, the Active Participation, Collaborative Participation, Passive Participation, and Others groups, before surgery and at the one-year follow-up (n=55).

Furthermore, when comparing the group whose preferences had changed (n = 20) with the group that showed no change (n = 35) with regard to socio-demographic variables, it was found that the former group, i.e. those who had changed, was older (mean 74 years) than the latter (mean 67 years) (p = .025).

In this study we compared the actual participatory role before surgery and the preferred role at follow-up. Almost one third (31 %) of the participants showed agreement was found between their preferred and actual participatory role while 54 % had a more passive role and 15 % a more active role compared with their preferred role.

The mean SOC score among the 55 participants before surgery was 148, and the corresponding figure at follow-up was 145. No statistically significant differences were found between the CPS groups and SOC. When comparing the SOC scores between the group that changed and that which showed no change at follow-up, no statistically significant differences were found.

The findings of studies I and II indicated that coping factors other than the sense of coherence can be involved in the participants' attitude towards participation in decision-making. This led to an investigation of the participants' meaning of illness, and their experiences of treatment and care decision situations, and how they acted in these; questions that best could be answered by using an explorative approach (III & IV).

### **Study III**

In study III the overall meaning of illness expressed by the participants was found in the main theme, 'Attempting to find meaning in illness in order to achieve emotional coherence'. The theme consists of two dimensions: unified embodiment and dichotomised embodiment. The meaning of unified embodiment included the following emotional sub-themes: gratefulness, having confidence in oneself and others, looking forward, and creating a new future. The themes encapsulated the desire to live and belief in survival.

This unified embodiment dimension was built on presence and together with memories and past experiences formed the basis for the orientation towards the future. The emotions were characterised by a unified self-body-in-control and expressed as, for example "important to deal with", "a firm decision to master this" and "important to recover and lead a normal life". The self-body-in-control or conscious decision to assume control was very obvious, especially in respondents who viewed the illness as a 'challenge' and a 'relief'.

The meaning of dichotomised embodiment included the following emotional sub-themes: altered self-worth, loss of temporality, and infringement of body integrity. These refer to the participants' struggle to come to terms with the violated of their body. They assumed a defensive attitude in their attempt to regain health and to prevent a recurrence of the cancer. The state of uncertainty, the absence of hope and goals, and the failure to look to the future were prominent within the dimension of dichotomised embodiment dimension. Their strong attempts to regain self-worth and the deep sense of infringement seemed to hinder the possibility of constructing a new reality.

Studies I and II specifically focused on the patients' decision making preferences, while study III, focused on their perception of meaning of their illness and identified qualitative aspects associated with the challenge presented by their condition. Patient participation, the decision to challenge the disease through self-control, was found to be connected with an overall optimism, which included hope, a belief in survival and the perceived possibility of avoiding a recurrence of the cancer (III).

## **Study IV**

The participants' experiences and meanings pertaining to participation in treatment and care decision-making were conceptualised in the main theme as 'Compliant participation in serious decisions'. The meanings concerned the preserving of self, making sense of the illness, ambivalence about one's own desires, and compliant decisions. The main theme included two variations: complying *with* participation and complying *without* participation.

Complying with participation was characterised by participants' descriptions of open dialogues, trust, self-confidence and self-competence. The variation consists of two dimensions: the open dialogue and the affirming dialogue. In both of these, the interpreted feelings were grounded on trust, and the dominant feelings were confidence, affirmation, and gratitude. One indicator of these feelings was that the participants expressed that they achieved self-control over the treatment and care. Clarity and transparency in the open dialogues encouraged the participants to become involved in both treatment planning and the caring process. The involvement allowed the patients to carefully and thoroughly consider whether to take decisions themselves or leave them to others. Thus, complying with participation, characterised by intimate dialogues, contributed to mutual respect in order to encounter each other. The close connection between patient and the caregiver and the fact that they were there for each other appear to be of significance in the decision-making process.

The variation complying *without* participation was characterised by and built on the participants' efforts to understand the severity of the illness and to be in self-control of the treatment and care by means of, for example, "speeding up" the process and searching for information, which implies that they were active in the process. The variation consists of two dimensions: the concealed dialogue and the absent dialogue. The lack of open dialogues had effects on the participants' perceptions and resulted in negative

feelings. In these the interpreted emotions were distrust, powerlessness, embarrassment, and uncertainty.

The meanings expressed by the participants on the subject of participation in treatment and care planning decisions were generally built on several discussions and actions during the caring period together with different physicians and nurses. The participants' descriptions of own actions in the discussions could be interpreted as both active and passive in an ongoing process.

The findings of study IV illuminate the need of commitment in building a trusting relationship between the patient and healthcare professional. It also points to highlights the importance of interaction and open dialogues as a means of supporting the patient and compensating for the knowledge gap, necessary to enable the patient to play a participatory role in decision-making.

## GENERAL DISCUSSION AND CONCLUSIONS

### **Discussion of Findings**

The four studies, focusing on cancer patients' attitudes and experiences of participation in decision-making, included in this thesis were undertaken because existing research inadequately describes participation in treatment and care plan decisions by patients recently diagnosed with and treated for cancer. The findings were expected to generate knowledge and understanding that could support healthcare professionals and contribute to a higher quality of care for these patients. The aims of this thesis were to examine preferences for participation in treatment and care decisions in patients with cancer and to explore patients' experiences of treatment planning decisions and the meaning of illness.

The main feature of participation preferences and experiences of participation were participatory roles in decision-making (I, II, IV). A significant feature in study III was the two approaches to the meaning of illness, aimed at controlling the illness. Study IV highlighted the participants' concerns and interaction, and the importance of relationship and dialogue between patient and healthcare professional to enable the patient to become a 'participant'.

The principles of caring as a human science (Benner & Wrubel, 1989; Watson, 1999) with emotional attunement, moral perception (Nortvedt, 2004) and adaptational aspects of coping in relation to participation on in

serious illness (Antonovsky, 1979, 1987; Lazarus, 1991) are at focus in the discussion. These principles underscore the participants' meaning of illness (III), participation in treatment and care decisions and emphasises the importance of a trusting relationship between patient and healthcare professional (Rodney *et al.*, 2004) (IV).

A consequence of the embedded inequality and that patients often are unexperienced (Nordgren & Fridlund, 2001) in the patient-health care relationship can be found in the variation Complying without participation (IV) where the distress dominate the searching for adequate knowledge about for example, the oncological therapy. If we consider caring as a face-to-face situation encounter (Benner & Wrubel, 1989; Watson, 1999), the findings could be interpreted in relation to the historical tradition of both medicine and nursing, i.e. compassionate behaviour (Nortvedt, 2001). From this perspective, participation in treatment and care decisions can be considered as an essential part of the commitment required to build a trusting relationship.

Insufficient and fragmented information caused distress and distrust and influenced the meanings attributed to decisions and seems to isolate the patients in their attempts to understand the illness, treatment and caring process. Fragmentised information is more complex and the message can be a great potential for distress rather than support with the consequence of difficulty to integrate the information and reach a sense of coherence (Antonovsky, 1993; Festinger, 1964). Here, access to new medical communication technology provides an opportunity for patients to learn about their illness; although this cannot replace face-to-face encounters and dialogues between patient and healthcare professionals. Accordingly, the feelings involved in compliant participation (IV) whether emotionally positive or negative could serve to inform and guide the preserving of self (Pörn, 1995; Morse & Beverly, 1995; Morse, 1998; Damasio, 1999). Their distress and frustration as well as self-confidence and gratitude may be seen as a way to maintain the self-concept intact or confirm the self picture (Rosenberg, 1979). For example was distrust given as an important reason for a patient to indicate that he wanted to make his own decisions.

When it comes to caring for dependent vulnerable patients, the moral priority is to provide support in order to encourage patients to communicate their concerns about health and illness rather than deciding on their behalf. In line with findings in study IV, it was found in a recent study (van Kleffens *et al.*, 2004), that four values have significance in the process of patients' decision-making: freedom, independence, trust and responsibility.



This can be compared to what Bergum, 2004 says, through open dialogues “emotions give body to words and brought back words to the body” and formed a sense of the situation (p. 500).

The patients’ experiences of participation in decision-making encounters were found to be an inter-subjective process. If the participant and healthcare professionals rely on their “taken-for-granted” assumptions and ideas about what patient participation means, they contribute to a process where the patient takes a waiting role (Schutz, 1999; Ashworth *et al.* (1992). Ashworth *et al.* (1992) assert that ‘participation’ should only be used when the healthcare professional is aware of the patients’ attitude of participation and when the patients see themselves as having the right to speak and be heard.

To help patients with a strong degree of self-confidence to cope is dependent on ‘the other’ confirming their identity. It also depends on the healthcare professionals’ use of the power conferred by their superior knowledge. Thus, patient participation rests on assumption that they are partners entrusted with knowledge and with a relatively unthreatened autonomy in the relationship. From this point of view the patients’ participatory role and involvement in treatment and care discussions should be considered as an essential part of the trusting relationship. The question is how strongly the healthcare authorities believe in allowing patients to actively participate.

Patient participation (IV) can also be interpreted in terms of interpersonal communication skills and abilities. The comprehensive dialogues, found in the Complying with participation variation, helped the patients to find answers not only about the treatment and illness but also to express their uncertainties, as well as to express their own desires. In accordance with a dynamic inter-subjective dialogue process, it is a question if patients’ use of information and decision preference profiles generated by a computer to develop roles in decision-making before consultation with healthcare professionals (Davison & Degner) always is supportive. Patient participation in terms of active, collaborative and passive roles can be seen as a ongoing mutual process in dialogue, rather than dichotomised entities (Feldman-Stewart *et al.*, 2004).

The findings from study I and II are in agreement with other studies based on the constructs of preferences roles (Degner *et al.*, 1997b), for example (Hack *et al.*, 1994; Degner *et al.*, 1997a; Stewart *et al.*, 2000; Wallberg *et al.*, 2000; Davison *et al.*, 2002; Sekimoto *et al.*, 2004), i.e. the majority of patients with cancer prefer collaborative roles.

In preferences for collaborative participation (I & II), the Compliant participation in serious illness (IV), and the participants' preserving of self in challenging the illness (III) their concerns about the illness and to influence the treatment plan were integrated. The open and affirming dialogues were interpreted as promoting and supporting their will, desires and competence to participate in decision-making. It also provided patients the opportunity to communicate their own values and beliefs, thus enhancing the relationship and supported their creating of sense of coherence, thus, promoting health (Antonovsky, 1979; Frankl, 1986), and enhanced the quality of treatment decision making (Maly *et al.*, 2004).

The interpretation of how individuals cope with their illness, whether they challenge the disease build relationships or fight against an enemy as found in study III may be compared to what Festinger (1964) and Antonovsky's (1979, 1987) consider the essence of trust, aimed at reducing the complexity of a situation in order to reach a sense of coherence. The different "generalized resistant resources" (Antonovsky 1979) approaches are perhaps a pattern of negentropic factors, that reduce chaos and actively promote health (Antonovsky, 1996). From this point of view it is important to be attentive to the individual patient's pattern of coping and to support consistency and coherence. The experiential meanings of illness shed light on health and illness as a complexity of emotions aimed at create consistence and coherence in order to facilitate recovery. However, the finding that the sense of coherence, measured by SOC (Antonovsky, 1987) was not related to decision-making preferences or to the actual participatory role (I & II) is worthy further investigation. The question is if the conceptualisation of the Sense of Coherence construct, built on the three concepts (manageability, comprehensibility and meaningfulness) is appropriate for investigating specific health and illness decision situations. Thus, having a perception in advance about a hypothetical preference role pertaining to participation in decisions and how to influence decisions would appear to be unreasonable. The interpretation is that the combination of personal values, beliefs, emotional state, illness, and the social encounter forms the process of an actual decisional participatory role characterised by presence (Ashworth *et al.*, 1992; Charon, 2004). This interpretation is supported by a recent study focusing on important aspects on decision process (Bus *et al.*, 2004). With regard to participation preferences and actual participation, it may well be that related factors, for example age and education, cause the patients to perceive and behave in a specific way. Furthermore, maybe patients behave in a particular way because it conforms and is congruent with expectations of healthcare professionals.

Possible, the patients' abeyance and hesitant responses is also a consequence of the relatives' attitude and possibilities to be involved in treatment and care decision-making. In a study of patients with cancer, Andershed *et al.* (2000), found that trusting relationship between the relative and staff improved the relatives chances of being involved and supportive in the patient's situation. Compliant participation can also be explained by considered the question of accountability for the care and treatment outcome. Thus, based on this discussion, the various complying participation approaches of seem reasonable and appropriate for each individual in their attempts to achieve a sense of coherence (Antonovsky, 1979, 1987). The participants' need for support and advice from the healthcare professionals is strong enough to ensure that they actually obtain support and advice while at the same time they opt for emotional balance due to their strong sense of duty and thus avoiding confusion (Antonovsky, 1996).

The main findings in the study III, attempting to find meaning in illness in order to achieve emotional coherence, and in study IV, Compliant participation in serious illness (IV) seem to be associated with the ability to maintain hope and to create a future supported by others (Taylor, 1983; Morse & Penrod, 1999). The meanings formulated served as a framework for consistency, comprising the body, the self, goals and future orientation. The different emotional experiences contributed to protecting the self against the threat of a recurrence of cancer and the possibility of death (LeDoux, 1998; Damasio, 1999). In studies of chronic illness (Charmaz, 1987) and of patients who survived serious injuries (Morse & Beverly, 1995), different strategies of redefining the self were found, which were aimed at protecting the self. In other words, the participants' emotional state controlled their thinking. The optimistic view can be described as consisting of appropriate self-enhancing motives in the face of the threat of a recurrence of the cancer as well as a normative response, i.e. the positive aspects derived are salutogenic (Antonovsky, 1987; 1996).

These types of self-enhancing strategies are what Younger (1991) regards as mastery, which is a prerequisite of acceptance and growth. Moving between different emotions (III), within this dimension, in order to find a balance points to the inconsistencies in emotions that characterise a threat. It may be understood as an exercise in total control over the responses (Mead, 1934) or the situation (Charon, 2004) i.e. control over reactions and in the interaction with the healthcare professionals and significant others. This discussion appears to reveal that the self-generated emotions aimed at

control the illness in different ways all have beneficial effects on the adaptation process associated with health and suffering (Eriksson, 1997).

The generalised hope found in study I, and within the unified embodiment dimension in study III, is interpreted as the defence against despair (Lazarus, 1991; Green, 1992; Damasio, 1999) or “innate capacity”, what Morse and Penrod (1999) call ‘enduring’ in a present - oriented state of being, when energy is devoted to suppressing emotions, ‘to holding on’ aimed at remaining in control (p.147). The participants’ need of help both supports and restricts the possibility of moving their perspectives towards the future. Particularly, in study III, the dimension classified as dichotomised embodiment, refers to the struggle to come to terms with the violated body, loss of integrity, and loss of temporality, while the ‘diseased body’ was no longer experienced as viable for future desires and beliefs. In agreement (IV), the scientific perspective restricted the participants’ possibilities to participate in decisions regarding alternative treatments even where such opportunities were explicitly offered.

The participants’ descriptions of their meaning of the illness (I & III) and Compliant participation (IV) do not only reflect their private views on those matters but also the way the stance of the healthcare authorities to these issues and the relationship between the patient and healthcare professionals (Radley & Billing, 1996), i.e. common-sense theorising about how patients should behave within the health care environment. What is the difference between successful participation and non-participation (I, II, IV)? In Schutz’ (1999) view, it can be interpreted as a mutual understanding of health care conventions.

Based on these studies (I - IV), my interpretation of the concepts ‘decision-making’ and ‘participation’ is that they can be seen as mutual process built on commitments and trust rather than normative constructions. Finally, the issues raised highlight the need for further research to investigate in what way individual and interpersonal circumstances support patients’ participation in decision making situations overshadowed by a life threatening illness.

## **Methodological Reflections**

According to Kuhn (1964), the self shifts with each new indication one makes to himself”, which raises a methodological issue concerning decision-making preferences. When the participants are required to rank their preferences and describe their experiences, they are influenced by the ‘public’ view, i.e. they reflect a morally acceptable view of the healthcare

authorities (Radley & Billing, 1996), while at the same time they are influenced by 'private' aspects related to the interviewer-interviewee relationship and interaction. These 'public' and 'private' perspectives can move back and forth during the course of an interview, by which process the participants can legitimise themselves. Retrospective accounts also address complex problems as they not only describe what the person is doing now to cope with what happened previously, but also what the person did then to cope with what happened at that time. Perhaps the concepts 'decision-making' and 'participation' are too abstract and complex to be measured.

Although the card sorting method and the CPS constructs (Degner et al., 1997b) in studies I and II have been used in several similar studies (see the Introduction section), the results may not be entirely comparable. First, all studies were assessed at different points in time in relation to the treatment or consultation and, second, there are differences in the methods of analysis.

The constant comparative analysis is primarily used to study processes and interactions in order to develop a theory (Glaser & Strauss, 1967). From this point of view it may be a limitation that data did not allow for this type of analysis. A research process with constant comparative analysis starts without preconceived theories or hypotheses. However, this research, started with the two descriptive statistical analyses based on a specific conceptualisation of decision making, the CPS constructs (Degner *et al.*, 1997) which may have influenced and limited the analysis. Nevertheless, constant comparative analysis was considered appropriate, as it allowed for flexibility in the interviews and for "new" data to emerge.

Another weakness of this thesis is the short statements from the open-ended question the patients ascribed the meaning of illness in study III. The weakness, although it was a significant question, is that limited time restricts the possibility to deepen the question because of concern for the patients' situation.

The order of interpretation of the data can be seen as both a weakness and a strength. The weakness regards that knowledge from the quantitative studies influenced the analysis of study IV. The strength is the opportunity to enlarge and deepen the scope of patients participation by asking unbiased questions.

The strength of these studies (I – IV) is that all data is from the perspective and experiences of patients. This perspective is of importance in finding ways to include patients who holds less knowledge about the body, illness, medicine and the health care organisation in the decision-making process.

The findings from the quantitative statistical studies (I & II) and explorative studies III and IV point to the multifaceted and highly individual appraisal of meaning of illness and participation in decision-making situations, which indicate that combined methods supplemented the understanding of patients participation.

The findings from the quantitative statistical studies (I & II) and explorative studies III and IV point to the multifaceted and individual appraisal of meaning of illness and participation in decision-making situations, which indicate that the combined methods supplemented each other.

## **Conclusions**

A patient's preference in participation in treatment and care decision-making seems to be preconditioned by many factors, above all their understanding of the situation, information attained, the meaning they ascribe to the illness as well as interpersonal factors. To participate (or choosing not to participate) builds on open and affirming dialogues, information and knowledge about the illness. This helps the patient to experience a sense of coherence and self-control.

The findings suggest that support of a patient's participation in treatment and care decision-making should aim to minimise or prevent distress and uncertainty. Increased patient participation in treatment and care decision making is interpreted as a health promoting way to cope with their illness.

## **IMPLICATIONS FOR FUTURE RESEARCH**

These findings (I - IV) illuminate the need for further research within the area of patient participation in decision-making with specific focus on interpersonal commitment and trusting relationship, and environmental conditions.

These studies suggest that patient participation could be further investigated by:

- Exploring patients communication and understanding of information in relation to decision-making competence for participation;
- Exploring patient and healthcare professionals' strategies for patients' participation with focus on the process for supportive participation in decision-making;

- Exploring the relationship and interaction between the patients and healthcare professionals and the environmental conditions that promote patient participation.

## ACKNOWLEDGEMENT

During the years when I have carried out the studies resulting in this thesis I have been supported and guided by many significant persons. First of all, I want thank all the participants for giving their time and sharing their experiences, and who guided me to this knowledge.

I especially express my gratitude to the following persons:

My main supervisor, Professor *Kim Lützén*, who with great generosity, excellence and wisdom guided with creative inspiration.

My first supervisor Professor *Gun Nordström*, who introduced me into the field of research, guided, and criticized my work with perseverance.

Professor Emeritus *Hjördis Björvell*, who showed me enthusiasm and interests in my early steps in the world of research.

My supervisor, Associate Professor *Staffan Törngren*, at South Hospital, for interest and supporting me.

Professor *Elisabeth Severinsson*, for your generosity, in-depth knowledge and outstanding support.

Ph.D. *Inger Magnusson*, and MD. and *Sven Goldman* who gave me opportunity to provide these studies in patients with colorectal cancer.

All doctoral colleagues at Ersta Sköndal University College for creative and stimulating seminar discussions.

Associate Professor *Britt-Marie Ternstedt*, who supported me in the last phase of this work.

My colleagues and very best friends *Gunilla Stolt* and *Gunilla Petersson* for always listen, sharing my concerns, and gave me enjoying intellectual didactic talks during this process.

All my friends and research colleagues at Department of Nursing, Karolinska Institutet, for during the years sharing the pleasures and obstacles in this research.

My beloved family, *Lauri, Göran* and *Helen, Annita* and *Patrik, Jenny* and *Jonathan*, and my sister *Gunilla*, who was aimed to, but prevented to make this journey.

*Gullvi Nilsson*, for excellent language revising the manuscripts.

*Stefan Eriksson*, Department of Nursing, for generously provided good research conditions.

The studies were supported by grants from the Karolinska Institutet, the Board of Research for Health and Caring Sciences, and the Center for Health Care Sciences, Karolinska Institutet Stockholm.



## REFERENCES

- Andershed B. & Ternestedt B-M. (2000) Being a close relative of a dying person: development of the concepts "involvement in the light and in the dark". *Cancer Nurs* 23, 151-159.
- Antonovsky A. (1979) *Health stress and coping*. Jossey-Bass Publishers, San Fransisco, California.
- Antonovsky A. (1987) *Unravelling the mystery of health*. Jossey-Bass Publishers, San Fransisco, California.
- Antonovsky A. (1993) Complexity, conflict, chaos, coherence, coercion and civility. *Social Sci Med* 37, 969-981.
- Antonovsky A. (1996) The salutogenic model as a theory to guide health promotion. *Health Promotion International* 11, 11-18.
- Armitage P. & Berry G. (1996) *Statistical methods in medical research*. 3<sup>rd</sup> ed. Blackwell Science, Wien.
- Ashworth P.D., Longmate M.A. & Morrison P. (1992) Patient participating: its meaning and significans in the context of caring. *J Adv Nurs* 17, 1430-1439.
- Barkwell D. (1991) Ascribed meaning: A critical factor in coping and pain attenuation in patients with cancer-related pain. *J Palliat Care* 7, 5-14.
- Beauchamp T.L. & Childress J.F. (2001) *Principles of biomedical ethics*. 5<sup>th</sup> ed. Oxford University Press, Inc., New York.
- Beaver K., Luker K.A., Owens R.G., Leinster S.J., Degner L.F. & Sloan J.A. (1996) Treatment decision-making in women newly diagnosed with breast cancer. *Cancer Nurs* 19, 8-19.
- Beisecker A. & Beisecker T. (1990) Patient information-seeking behaviours when communicating with doctors. *Med Care* 28, 19-28.
- Benner P. & Wrubel J. (1989) *The primacy of caring: stress and coping in health and illness*. Addison-Wesley, Menlo Park, California.
- Bergum V. (2004) *Relational ethics in nursing*. Eds. Storch, J.L. Rodney, P. Starzomski, R. pp. 485-502. Pearson Prentice Hall, Toronto, Ontario.
- Bilodeau B.A. & Degner L.F. (1996) Information needs, sources of information, and decisional roles in women with breast cancer. *Oncol Nurs Forum* 23, 691-696.

- Blanchard C.G., Labrecque M.S., Ruckdeschel J.C. & Blanchard E.B. (1988) Information and decision-making preferences of hospitalized adult cancer patients. *Soc Sci Med* 27, 1139-1145.
- Brink P.J. & Wood M.J. (1998) *Advanced design in nursing research*. 2<sup>nd</sup> ed. SAGE Publications, Thousand Oaks, California.
- Bus G S., Solomon, M., Short, L. & Butow P. (2004) A matter of trust – patient’s views on decision making in colorectal cancer. *Health Expectations* 7, 104-114.
- Charmaz K. (1987) Struggling for a self: identity levels of the chronically ill. *Research in the Sociology of Health Care* 6, 283-321.
- Charmaz K. (2002) The self as habit: the reconstruction of self in chronic illness. *Occup Ther J Res* 22, 31S-41S.
- Charon J.M. (2004) *Symbolic interactionism, an introduction, an interpretation, an integration*. 8<sup>th</sup> ed. Pearson Prentice Hall, New Jersey.
- Coombs C.H. (1976) A theory of data. MI:Mathesis Press, Ann Arbor.
- Damasio A. (1999) *The feeling of what happens. Body and emotion in the making of consciousness*. William Heinemann, London.
- Damasio A. (2003) Looking for Spinoza. Joy, sorrow, and the feeling brain. Harcourt, Inc. Orlando, Florida
- Davison B.J. & Degner L.F. (1997) Empowerment of men newly diagnosed with prostate cancer. *Cancer Nurs* 20, 187-196.
- Davison B.J. & Degner L.F. (2002) Feasibility of using a computer-assisted intervention to enhance the way women with breast cancer communicate with their physician. *Cancer Nurs* 25, 417-424.
- Davison B.J., Degner L.F. & Morgon T.R. (1995) Information and decision-making preferences of men with prostate cancer. *Oncol Nurs Forum* 22, 1401-1408.
- Davison B.J., Gleave M.E., Goldenberg S.L., Degner L.F., Hoffart D. & Berkowitz J. (2002) Assessing information and decision preferences of men with prostata cancer and their partners. *Cancer Nurs* 25, 42-49.
- Degner L.F. & Aquino Russel C. (1988) Preferences for treatment control among adults with cancer. *Res Nurs Health* 11, 367-374.
- Degner L.F., Kristjanson L.J., Bowman D., Sloan J.A., Carriere K.C., O’Neil J., Bilodeau B., Watson P. & Mueller B. (1997a) Information needs and decisional preferences in women with breast cancer. *JAMA* 277, 1485-1492.

- Degner L.F. & Sloan J. (1992) Decision making during serious illness: what role do patients really want to play? *J Clin Epidemiol* 45, 941-950.
- Degner L.F., Sloan J.A. & Venkatesh P. (1997b) The Control Preferences Scale. *Can J Nurs Res* 29, 21-43.
- Dworkin G. (1988) *The theory and practice of autonomy*. Cambridge University Press, New York.
- Ehrenberger H.E., Alligood M.R., Thomas S.P., Wallace D.C. & Licavoli C.M. (2002) Testing a theory of decision-making derived from King's systems framework in women eligible for a cancer clinical trial. *Nurs Sci Q* 15, 156-163.
- Ende J., Kazis L., Ash A. & Moskowitz M.A. (1989) Measuring patients' desire for autonomy: Decision making and information-seeking preferences among medical patients. *J Gen Intern Med* 4, 24-30.
- Eriksson K. (1997) Caring, spirituality and suffering. In *Caring from the heart: The convergence of caring and spirituality*. Ed. Roach M.S. pp 68-84. Paulist Press.
- Feldman-Stewart D., Brundage, M D. & Van Manen, L. (2004) Patient-focussed decision-making in early-stage prostate cancer: insights from a cognitively based decision aid. *Health Expectations* 7, 126-141.
- Festinger L. (1964) *Conflict, decision, and dissonance*. Stanford University Press, Stanford, California.
- Fleiss J.L. (1981) *Statistical methods for rates and proportions*. John Wiley & Sons, New York.
- Frankl V. (1986) *The doctor and the soul*. Vintage Books, New York: NW.
- Glaser B.G. (1992) *Basics of grounded theory analysis*. Sociology Press, Mill Valley.
- Glaser B.G. & Strauss A.L. (1967) *The discovery of grounded theory*. Aldine, Chicago.
- Green O.H. (1992) *The emotions*. Kluwer Academic Publishers, Dordrecht.
- Hack T., Degner L.F. & Dyck D.G. (1994) Relationship between preferences for decisional control and illness information among women with breast cancer: a quantitative and qualitative analysis. *Soc Sci Med* 39, 279-289.
- Hack T.F. & Degner L.F. (1999) Coping with breast cancer: a cluster analytic approach. *Breast Cancer Res Treat* 54, 185-194.

- Janis I.L. & Mann L. (1977) *A conflict model of decision making. Decision making. A psychological analysis of the conflict, choice, and commitment.* pp 45-80. The Free Press, London.
- Kelly G. (1955) *The psychology of personal construct.* Norton, New York.
- Van Kleffens T. van Baarsen B. van Leeuwen E. (2004) The medical practice of patient autonomy and cancer treatment refusals: a patients' and physicians' perspective. *Soc. Sci. Med.* 58, 2325-2336.
- Kuhn M H. (1964) Major trends in symbolic interaction theory in the past twenty-five years. *The Sociological Quarterly*, 5, 62-84.
- Langius A. & Björvell H. (1993) Coping ability and functional status in a swedish population sample. *Scand J Caring Sci* 7, 3-10.
- Lazarus R.S. (1991) *Emotion and adaptation.* Oxford University Press, New York.
- Lazarus R.S. & Folkman S. (1984) *Stress, appraisal, and coping.* Springer, New York.
- LeDoux J. (1998) *The emotional brain The mysterious underpinnings of emotional life.* Phoenix, London.
- Lipowski Z.J. (1970) Physical illness, the individual and the coping process. *Psychiatr Med* 1, 91-102.
- Lomborg K. & Kirkevold M. (2003) Truth and validity in grounded theory - a reconsidered realist interpretation of the criteria: fit, work, relevance and modifiability. *Nursing Philosophy* 4, 189-200.
- Luker K.A., Beaver K., Leinster S.J. & Owens R.G. (1996) Meaning of illness for women with breast cancer. *J Adv Nurs* 23, 1194-1201.
- Maly R C., Umezawa Y., Leake B. & Silliman R. (2004) Determinants of participation in treatment decision-making by old breast cancer patients. *Breast Cancer Res. Treat.* 85, 201-209.
- Mead G.H. (1934) *Mind, self, and society. From the standpoint of a social behaviorist.* The University of Chicago Press, Chicago.
- Morse J.M. (1997) Responding to threats to integrity of self. *Adv Nurs Sci* 19, 21-36.
- Morse J.M., Barrett M., Mayan M., Olson K. & Spiers J. (2002) Verification strategies for establishing reliability and validity in qualitative research. *International Journal of Qualitative Methods Retrieved from <http://www.ualberta.ca/~ijqm/>* 1, 1-19.

- Morse J.M. & Beverly O. (1995) Preserving self: from victim, to patient to disabled person. *J Adv Nurs* 21, 886-896.
- Morse, J.M. & Mitcham, C. (1998) The experience of agonizing pain and signals of disembodiment. *J Psychosom Res* 14 6, 667-680.
- Morse J.M. & Penrod J. (1999) Linking concepts of enduring, uncertainty, suffering, and hope. *Image J Nurs Sch* 31, 145-150.
- Nordgren S. & Fridlund B. (2001) Patients' perceptions of self-determination as expressed in the context of care. *J Adv Nurs* 35, 117-125.
- Nortvedt P. (2001) Clinical sensitivity: the inseparability of ethical perspectiveness and clinical knowledge. *Sch Inq Nurs Pract* 15, 25-43.
- Nortvedt P. (2004) *Emotions and Ethics*. In *Toward a moral horizon. Nursing ethics for leadership and practice*. Eds. Storch, J.L. Rodney, P. Starzomski, R. pp. 447-464. Pearson Prentice Hall, Toronto Ontario.
- Ofstad H. (1961) *An inquiry into the freedom of decision*. Norwegian Universities Press, Norway.
- Park C.L. & Folkman S. (1997) Meaning in the context of stress and coping. *Review of General Psychology* 1, 115-144.
- Pellegrino E.D. & Thomasma D.C. (1988) *For the patient's good: The restoration of beneficence in health care*. Oxford University Press, New York.
- Persson L., Larsson G., Ohlsson O. & Hallberg I.R. (2001) Acute leukaemia or highly malignant lymphoma patients' quality of life over two years: a pilot study. *Eur J Cancer Care (Engl)* 10, 36-47.
- Polit D.F. & Hungler B.P. (1999) *Nursing research principles and methods*. 6<sup>th</sup> ed. Lippincott, Philadelphia.
- Pörn, I. (1995) Till frågan om livets mening. In: *Hälsosamma tankar (Healthy thoughts)*. Eds. Liss, P-E. & Petersson, B. pp. 126-135. Nya Doxa, Falun
- Radley A. & Billing M. (1996) Accounts of health and illness: dilemmas and representations. *Sociol Health Illn* 18, 220-240.
- Rodney P., Brown, H. Liaschenko, L. *Moral agency: Relational connections and trust*. Eds. Storch, J.L. Rodney, P. Starzomski, R. pp. 154-177. Pearson Prentice Hall, Toronto Ontario.
- Rosenberg M. (1979) *Conceiving the self*. Basic Books, Inc., Publishers, New York.
- Rothenbacher D., Lutz M.P. & Porzsolt F. (1997) Treatment decisions in palliative cancer care: patients' preferences for involvement and doctors' knowledge about it. *Eur J Cancer* 33, 1184-1189.

- Sahlberg-Blom E., Ternestedt B. & Johansson J. (2000) Patient participation in decision making at the end of life as seen by a close relative. *Nurs Ethics* 7, 296-311.
- Sahlin J. (2000) *Hälso- och sjukvårdslagen. Med kommentarer* (The Health and Medical Services Act. With comments) 6<sup>th</sup> ed. Norstedts Juridik, Stockholm.
- Sainio C., Eriksson E. & Lauri S. (2001a) Patient participation in decision-making about care. The cancer patient's point of view. *Cancer Nurs* 24, 172-179.
- Sainio C. & Lauri S. (2003) Cancer patients' decision-making regarding treatment and nursing care. *J Adv Nurs* 41, 250-260.
- Sainio C., Lauri S. & Eriksson E. (2001b) Cancer patients' views and experiences of participation in care and decision making. *Nurs Ethics* 8, 97-113.
- Sanders T. & Skevington S. (2003) Do bowel cancer patients participate in treatment decision-making? Findings from a qualitative study. *Eur J Cancer Care* 12, 166-175.
- Schreiber R.S. (2001) *The "how to" of grounded theory: avoiding the pitfalls*. In Using grounded theory in nursing. Ed. Schreiber R.S. & Stern P.N. pp 55-95. Springer Publishing Company, New York.
- Schutz A. (1999) *Den sociala världens fenomenologi*. Daidalos, Uddevalla.
- Sekimoto M., Asai A., Ohnishi M., Nishigaki E., Fukui T., Shimbo T., Imanaka Y. (2004) Patients' preferences for involvement in treatment decision making in Japan. *BMC Fam. Pract.* 5, 1-10.
- Siegel S. & Castellan N.J. (1988) *Nonparametric statistics for the behavioral sciences*. McGraw-Hill, Inc., Toronto.
- Stewart D.E., Wong F., Cheung A.M., Dancey J., Meana M., Cameron J.I., McAndrews M.P., Bunston T., Murphy J. & Rosen B. (2000) Information needs and decisional preferences among women with ovarian cancer. *Gynecol Oncol* 77, 357-361.
- Taylor S.E. (1983) Adjustment to threatening events A theory of cognitive adaptation. *Am Psychol* 38, 1161-1173.
- Thomasma D.C. (1994) *Toward a new medical ethics*. In Interpretive phenomenology, embodiment, caring, and ethics in health and illness illness. Ed. Benner P. pp 85-98. SAGE, Thousand Oaks, California.
- Thorne S., Reimer Kirkham S. & MacDonald-Emes J. (1997) Interpretive description: a noncategorical qualitative alternative for developing nursing knowledge. *Res Nurs Health* 20, 169-177.

- Tourigny S.C. (1994) Integrating ethics with symbolic interactionism: the case of oncology. *Qualitative Health Research* 4, 163-185.
- Wallberg B., Michelson H., Nystedt M., Bolund C., Degner L. & Wilking N. (2003) The meaning of breast cancer. *Acta Oncol* 42, 30-35.
- Wallberg B., Michelson H., Nystedt M., Bolund C., Degner L.F. & Wilking N. (2000) Information needs and preferences for participation in treatment decisions among Swedish breast cancer patients. *Acta Oncol* 39, 467-476.
- Watson J. (1999) *Nursing: Human science and human care. A theory of nursing.* National League for Nursing, New York.
- Younger J.B. (1991) A theory of mastery. *Advances in Nursing Science* 14, 76-89.

## SWEDISH SUMMARY

Denna avhandling bygger på fyra empiriska studier utförda med beskrivande statistisk analys och explorativ kvalitativ metod. Det övergripande syftet med avhandlingen var att undersöka i vilken grad patienter med kolorektal önskar medverka i sin vård och behandling samt hur patienter hanterar diagnosbeskedet och överväger medverkan i beslutsfattande.

**Delstudie I.** Syftet med studie I var att beskriva i vilken omfattning patienter med kolorektal cancer vill medverka i beslut kring sin vård och behandling samt relatera dessa beslut till känsla av sammanhang samt innebörden av sjukdomen. Data från 86 patienter analyserades med beskrivande statistisk analys.

Resultatet visade att 62 % av patienterna önskar en samarbetsroll och 28 % en passiv roll i beslutsfattandet kring sin vård och behandling. En jämförelse mellan önskad roll och den beslutsroll patienterna verkligen medverkade i visade överensstämmelse på 44 %. Sjuttien procent av patienterna hade en optimistisk syn på sin sjukdom. Det fanns ingen signifikant statistisk skillnad mellan olika beslutsroller, känsla av sammanhang och innebörden (meaning) av sjukdomen.

**Delstudie II** Syftet med studie II var att jämföra i vilken omfattning patienter med kolorektal cancer ville medverka i beslut kring sin vård och behandling, före och ett år efter operation, samt att jämföra dessa önskemål med känslan av sammanhang och patienternas verkliga beslutsroll. Data från 55 patienter analyserades med beskrivande statistisk analys. Resultatet visade att vid de två undersökningarna, före och ett år efter operation, ville 71 % respektive 75 % av patienterna ha en samarbetsroll i beslutsfattande. En majoritet av patienterna, 64 %, behöll den önskade beslutsrollen från före operation till ett år efter operation. Överensstämmelse mellan den önskade beslutsrollen och den roll patienterna verkligen medverkade i var 31 %. Det fanns ingen signifikant statistisk skillnad mellan önskad beslutsroll och känslan av sammanhang varken före operation eller vid uppföljningen ett år senare.

**Delstudie III** Syftet med studie III var undersöka det emotionella och interaktionella perspektivet på innebörden (meaning) av sjukdomen, före operation, efter tre månader och ett år. Data från 52 patienter med kolorektal cancer analyserades med konstant komparativ metod tillsammans med en tolkande analys. Resultatet formulerades i ett huvudtema "Försök att finna innebörden av sjukdomen för att uppnå känslomässig balans" och två dimensioner: den sammanhållna (unified) förkroppsligade (embodiment) och den tudelade (dicotomised) förkroppsligade. Kännetecken för den sammanhållna dimensionen var hopp och stark tilltro till sig själv, uppskattning av relationer



och tro på framtiden. Kännetecknen för den tudelade dimensionen var kamp mot en fiende, förlust av tidsperspektiv samt brist på hopp och tilltro.

**Delstudie IV** Syftet med studie IV var att undersöka patienters upplevelser av diskussioner kring beslut om behandling och vård i nära anslutning till den kirurgiska och onkologiska behandlingen. I studien intervjuades 10 patienter. Data analyserades med konstant komparativ metod för att generera deskriptiva kategorier om patienternas upplevelser. Resultatet formulerades i ett huvudtema "Undfallande deltagande vid allvarliga beslut" och två variationer: tillmötesgående genom samverkan i beslutsfattande och tillmötesgående utan samverkan i beslutsfattande. Tillmötesgående genom samverkan kännetecknades av öppna diskussioner, tilltro, samarbete och överlämnade av besluten, medan tillmötesgående utan samverkan kännetecknades av misstro, otillräcklig och diffus information samt deltagarnas fokus på kroppsliga problem.

**Slutsatser.** De fyra studierna visade att patienter med kolorektal cancer i olika grad önskade av samarbetsroller i beslut kring sin vård och behandling såväl före som ett år efter operation. Den interpersonella relationen och interaktionen mellan patienten och läkare eller sjuksköterska tycks ha betydelse för dennes medverkan i beslutsfattandet. För att patienter med en allvarlig och livshotande cancersjukdom ska kunna medverka i beslut kring sin vård och behandling krävs en relation och interaktion med dialog. Ytterligare forskning kring sociala interpersonella förtroenden mellan patienter och vårdgivare krävs för att förstå förutsättningarna för patients medverkan i sin vård och behandling.