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Let me be part of the plan

Experiences of information and information needs after
colorectal cancer surgery

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Abstract

The overall aim of this thesis is to study the experiences of patients and next of kin with regard to information and information needs after being discharged after colorectal cancer surgery. The aim was also to study factors related to this.

Different methods were combined in this explorative study in order to obtain diverse types of data. Patients who had undergone surgery for colorectal cancer at three hospitals in southern Sweden were included consecutively. The sample consisted of one main sample of 100 patients participating in the questionnaire studies (Papers I and II), and 16 patients from this sample and their next of kin also participated in interviews (Papers III and IV). Data were collected during the first seven weeks after discharge from hospital in order to cover the first period after discharge, the first weeks of recovery at home and to include the prognostic information at the post-discharge visit at the surgical department. In Papers I and II patients responded to the questionnaires EORTC QLQ-C30, QLQ-CR38, QLQ-INFO25, ECOG-PS and SOC-13 within the first 2 weeks at home and again 5 to 7 weeks after discharge. Data concerning health status (ASA), occupation (ISCO-88) and tumour stage were obtained from the computerized records. In Papers III and IV, patients and their next of kin were interviewed separately two times. The main focus was on their experiences of information at discharge and their information needs during the first seven weeks at home. All transcribed texts were analysed using qualitative content analysis.

The results from Papers I and III demonstrated that patients wanted to receive more information about different areas, but they also went on to describe how they received information and what consequences this had during the first period at home. The main finding was that they wanted to participate more in the information process; to receive more information, to be part of the planning and having time to ask questions. Understanding the cancer disease and managing the worries it created was an area that patients kept coming back to, and information was vital managing both. The lack of important information caused both anxiety and insecurity, while receiving information could bring about some calm and peace. In Paper I and II, gender, preoperative health status and cohabitation explained some of the variations in the information questionnaire QLQ-INFO25, indicating that women, those who lived alone and patients with worse health status experienced less received

information. Those patients are more vulnerable with regard to information after colorectal cancer surgery and need more information and support in this area. In Paper IV the next of kin reflected about the complexity and the responsibility of their own new role. This included managing their own feelings and worries for the present and the future, sharing all parts of the patient's life and supporting both the patient and the rest of the family in different ways. In order to be able to fulfil the new role of support person, it was vital to participate in the patient's life and to have access to the same information as the patient. The next of kin needed to be included in the patient's cancer trajectory, receive verbal information with them and have the opportunity to ask their own questions. They wanted to know in advance the time of the discharge conversation and to be there with the patient. They emphasized the importance of being treated well and listened to during these meetings with the healthcare professionals.

The expressed need to participate more in the information was articulated by both patients and next of kin. They wanted to be invited to do so and to be acknowledged as individuals. The need to have a relationship with the healthcare professionals who provided information was closely linked to how patients and next of kin valued and experienced the information. The importance of creating a foundation for mutual communication by listening, giving responses and showing interest in the individual patient was clearly present. Participating in the information meetings would not only satisfy their own needs but also assist the patient's recall. Patients in our study needed a better planned discharge from hospital, but some were more vulnerable in this situation. Women, those with worse health status before surgery and those who lived alone expressed an increased need for information.

Original papers

This thesis is based on the following papers referred to in the text by their Roman numerals:

- I Lithner M, Johansson J, Andersson E, Jakobsson U, Palmquist I, Klevsgård R. Perceived information after surgery for colorectal cancer - an explorative study. *Colorectal Dis.* 2012 Nov;14(11):1340-50.
- II Lithner M, Jakobsson U, Andersson E, Klevsgård R, Palmquist I, Johansson J. Patients' perception of information and health-related quality of life 1 month after discharge for colorectal cancer surgery. *Accepted for publication in Journal of Cancer Education.*
- III Lithner M, Klevsgård R, Johansson J, Andersson E. The significance of information after discharge for colorectal cancer surgery - a qualitative study. *Submitted.*
- IV Lithner M, Klevsgård R, Johansson J, Andersson E. Accessing information in order to manage the strain of a new demanding role - a qualitative study of the next of kin of patients after colorectal cancer surgery. *Submitted.*

The papers have been reprinted with kind permission of each journal.

Abbreviations and definitions

ASA	American Association for Anesthesiologists' physical status classification system
CRC	Colorectal cancer
EBCD	Experience-based co-design
ECOG - PS	Eastern cooperative oncology group - Performance status in patients with cancer
EORTC	European organization for research and treatment of cancer
ERAS	Enhanced recovery after surgery
ERP	Enhanced recovery programme
HRQOL	Health-related quality of life
LOS	Length of hospital stay, from the day of surgery to discharge
Next of kin	The co-habiting person closest to the patient
PREM	Patient reported experience measures
PT	Physiotherapist
QLQ-C30	EORTC questionnaire that measure health-related quality of life in patients with cancer
QLQ-CR38	EORTC questionnaire that measure diagnosis specific health-related quality of life for patients with colorectal cancer
QLQ-INFO25	EORTC questionnaire that measure received information
QOL	Quality of life
RN	Registered nurse
Skill level	International standard classification of occupations, organizes different professions into skill levels
SOC	Sense of coherence
TNM	Tumour stage I-IV

Preface

My first experience of healthcare was as a seventeen-year-old trainee in the small hospital in Trelleborg. I was training to become an assistant nurse and participated in all aspects of the work in both a medical and a surgical ward. The seriousness of the work did not discourage me but instead inspired both my interest and development.

During my two years as a nursing assistant in the general hospital in Malmö I worked in a stroke and heart unit, a unit for serious skin diseases and in accident and emergency. My experiences from these years varied from how to care for patients with intractable leg ulcers, to end-of-life care for heart failure and helping intoxicated patients after suicide attempts. I will always value this period of work in clinical practice where my primary task was to provide physical and emotional patient care. My interest for identifying both patients' unspoken needs as well as the ones they expressed began during these early years.

I continued being interested in clinical practice during my two decades as a registered nurse in the hospital in Lund, but in addition to clinical work with patients came other assignments like the administrative parts of nursing care. My interest for patient information and further studies started during this period and has never wavered. After one year as a clinical nurse, I began my first course in specialized surgical care and studied at the same time as my clinical work. I worked as clinical nurse in a surgical ward, specialized in care for patients with cancer in the esophagus for seven years, then as a supervisor for two years in one of three nursing teams.

After one summer in palliative home care, I then worked in outpatient care: firstly providing chemotherapy for patients with colorectal cancer, with both curative and palliative aims. I met many patients during this period who talked about the first difficult weeks just after discharge from hospital and the information and support that they felt was lacking. This was the point of departure for my interest for this specific phase of the cancer process. After beginning my PhD studies, my clinical work changed to pre- and postoperative care for patients with melanoma and breast cancer. The clinical work alongside the research studies has kept me focused on the original motivation for my studies: to provide benefits for the patients and their families by improving the knowledge foundation for nursing care.

Introduction

When patients with colorectal cancer and their next of kin meet the registered nurse in outpatient care after surgery, they often present a need for sharing the stories of their experiences during hospitalization and the first weeks at home after discharge from hospital. They describe their difficulties in adapting to the situation at home and managing on their own after discharge (Blazeby *et al.*, 2010). When information is lacking and it is hard to access a personal contact in healthcare, the situation of patients at home become insecure.

Since patients spend an increasingly shorter period of time in hospital after surgery, the transition from hospital to home constitutes a weak point in the patient's cancer trajectory; during the time in hospital attention is most focused on handling physical symptoms (Jonsson *et al.*, 2011). The need for recovery continues at home but patients describe how they lack information on what to expect at home and feel alone when trying to manage the situation (Beaver *et al.*, 2010). Patients note that the information they received at discharge is inconsistent, often general, not tailored to their individual needs and not adjusted to their family situation at home (McMurray *et al.*, 2007). Most unmet needs come up during the treatment phase of the cancer trajectory, with a peak during the first week at home after surgery (Blazeby *et al.*, 2010, Harrison *et al.*, 2009, Harrison *et al.*, 2011).

Since both our clinical experiences and some research findings indicated a vulnerable time with clearly unmet needs during the first weeks after discharge, this specific time period between the day of discharge from hospital and the first postoperative visit attracted our interest (Harrison *et al.*, 2011). Patients present various symptoms, problems and needs during the early recovery period at home that clearly indicate that information and support often are lacking during this transition period. The changing environment: from around-the-clock hospital care to managing at home on your own is a major change, even when next of kin are present and supportive. We wanted to understand more about the meaning and importance of information during this phase of the cancer trajectory, but also to shed some light on the variation between individuals concerning their expressed needs for information. Therefore different variables like health-related quality of life and individual ability to manage difficulties were included in order to study any possible link to information needs.

Thus this study started from the desire to know more about the experiences of patients and next of kin during the first month at home, what information they need and whether their physical and emotional status or their personal characteristics had any bearing on the need for information.

Background

Early recovery at home after colorectal cancer surgery

During the first period time after discharge from hospital after colorectal surgery, patients have to face a variety of symptoms and problems such as severe fatigue, insomnia, nausea and bowel problems and these are most intense during the first week at home (Wennstrom *et al.*, 2010, Harrison *et al.*, 2011). Discharge takes place earlier if patients live with a spouse compared to patients living alone, and here more symptoms can be expected for the patient and the next of kin to manage (Kelly *et al.*, 2012). In addition to the stress of physical symptoms, patients also experience a loss of dignity and control, which increases their dependence and makes the situation even harder to manage (Worster and Holmes, 2009, Jakobsson *et al.*, 2014). The emotional status of the patients reflects their physical condition to a large extent during the first days and weeks at home. When patients have recovered some of their independence, the awareness of cancer comes back and reminds them of the threatening situation. During this early phase of the cancer trajectory, patients are trying to manage their reactions to the cancer diagnosis and need information to make sense of the situation (McCaughan and McKenna, 2007). The first two weeks at home are the most vulnerable time for patients with cancer and their emotional health is known to be more unstable during this period (Lin *et al.*, 2009). These findings emphasize the importance of letting patients voice their own perspective on their information needs during this critical period of their cancer trajectory.

The preparation for the transition from hospital care to home has a large impact during the first time period at home, and when information is lacking this makes patients feel more tired and insecure (Norlyk and Harder, 2011). Patients with cancer need support throughout the whole cancer trajectory and anxiety and depression can be lowered and health-related quality of life (HRQOL) improved when patients information needs are satisfied (Husson *et al.*, 2011, Harrison *et al.*, 2009). This research emphasizes the importance for nurses in engaging more actively in the discharge of the patients from hospital; in identifying the needs of the patient and their family and facilitating the discharge from hospital according to these needs.

Colorectal cancer

Colorectal cancer (CRC) is rare in developing countries, but is the third-most frequent malignancy in the European Union after breast and prostate cancer, and the second-most frequent cause of death after lung cancer (Van De Velde *et al.*, 2014). There were 342 100 new cases and 150 000 deaths in the European Union during 2012 (Ferlay *et al.*, 2013). The incidence is higher in men than in women and increases with age; median age is 70 at diagnosis (Brenner *et al.*, 2013). The survival rate has reached over 60% in high-income countries but has remained less than 50% in low-income countries. A difference in survival is also seen in patients with higher-level education compared to lower-level; higher-level education is associated with better survival in patients with colon and rectal cancer (Cavalli-Bjorkman *et al.*, 2011).

Some major risk factors for CRC have been identified in the literature like: old age, male gender, family history of CRC, low physical activity and inflammatory bowel diseases (Brenner *et al.*, 2013). A diet rich in fat, refined carbohydrates and animal protein constitutes a risk factor (WHO, 2010). By decreasing the consumption of processed meat and increasing the intake of vegetables and fruit, the risk of CRC can be reduced. Avoiding a sedentary lifestyle and obesity may also decrease the risk (Ferlay *et al.*, 2013). Environmental factors also play an important role in CRC incidence, since migrant populations quickly reach the same risk level as of the adopted country (WHO, 2010).

Colorectal cancer is a slow growing adenocarcinoma and often develops over more than 10 years, mostly from a dysplastic adenoma (Brenner *et al.*, 2013). Two forms of hereditary CRC non-polyposis colorectal cancer (HNCCP) are associated with an 70-80% increased risk of getting CRC and familial adenomatous polyposis (FAP), and represent 3-5% of all cases of CRC (Van De Velde *et al.*, 2014).

The diagnosis is usually established with endoscopy, as part of a screening programme or after the medical investigation of symptoms related to CRC (Labianca *et al.*, 2010). Faecal occult blood testing (FOBT) can also be used for early detection of CRC or in screening programmes (Van De Velde *et al.*, 2014). In Sweden no general screening is being carried out to date, but the Swedish Association of Local Authorities and Regions are initiating a national study evaluating the effect of screening with colonoscopy or FOBT on patient survival (SALAR, 2013).

Individuals experience discomfort in the earliest phase of the trajectory before the cancer has even been diagnosed (Epstein and Street, 2007). The screening situation can produce anxiety both about unpleasant investigations and the risk of having cancer. This in itself can become an obstacle to participation in the screening

programme (Javanparast *et al.*, 2012). Even in this early phase of the trajectory, the future patient demonstrates an obvious need for the commitment and knowledge of healthcare professionals in order to facilitate the situation.

Many different methods can be used to diagnose CRC and also to stage the tumour preoperatively; computed tomography (CT), X-ray investigation with barium enema, ultrasound, magnetic resonance imaging, CT-PET where CT is combined with positron emissions tomography (Labianca *et al.*, 2010). Staging before surgery focuses on how the tumour grows locoregionally, if there is more than one tumour and on distant metastasis (Van De Velde *et al.*, 2014). The most studied biological marker, Carcinoembryonic Antigen (CEA), can also be of some use in preoperative staging and in postoperative follow-up, but has low predictive value in diagnosing asymptomatic persons.

Surgical treatment

Surgery is the traditional approach to treat CRC (Brown, 2007). Part of the bowel is removed and the ends are sewn together. The tumour and adherent lymph nodes are sent for pathology staging. The surgery can be performed with open or laparoscopic surgery and no differences in eliminating the disease or overall survival have been noted between these two techniques (Van De Velde *et al.*, 2014). However patients experience several benefits from early recovery after laparoscopic surgery compared to open surgery: less pain, shorter postoperative bowel paralysis, improved lung function and better quality of life (QOL) (Schwenk *et al.*, 2005).

If the cancer is located in the upper part of rectum, sphincter-saving surgery is performed with low anterior resection. Patients are usually very pleased if they can avoid having a stoma, but with low anastomosis they can experience frequent gastrointestinal problems like; incomplete evacuation, excessive flatus, urgency, perianal soreness and bloating (Nikoletti *et al.*, 2008). In some cases a temporary stoma is needed, and this can often be removed after a couple of months.

Patients with low rectal cancer usually have an abdominoperineal resection including sphincter resection, which result in a permanent stoma (Bossemma *et al.*, 2011). Since patients with a stoma have access to additional information from an enterostomal therapist, patients without a stoma were chosen for this study (Beaver *et al.*, 2010).

Enhanced recovery after surgery (ERAS) appeared almost twenty years ago in a small Danish study with eight elderly, high-risk patients who received 'stress-free' surgery (Bardram *et al.*, 1995). Enhanced recovery programme (ERP) and fast-track rehabilitation are other names used to describe ERAS and these all comprise many

different factors in a comprehensive protocol (Donohoe *et al.*, 2011). The aim of the protocol is to reduce the physiological and psychological stress of surgery to enable rapid recovery, while reducing complications and the length of stay in hospital (Rawlinson *et al.*, 2011, Spanjersberg *et al.*, 2011, Van De Velde *et al.*, 2014). The protocol contains several preoperative factors, for example: assessment to reduce operative risk, information and counselling, carbohydrate loading, short fast before surgery, preanesthetic medication and no bowel preparation (Donohoe *et al.*, 2011). The preoperative information in ERAS is one of the factors associated with reduced length of hospital stay (Aarts *et al.*, 2012). The perioperative factors aim at reducing postoperative nausea and vomiting and reducing thromboembolism using minimally invasive techniques, restricted fluid regime, prevention of hypothermia, avoiding nasogastric intubation and reducing pain after surgery with perioperative and postoperative epidural analgesics remaining for 24-48 hours after surgery.

The presence of comorbidities is an important factor to consider before surgery and before discharge. Comorbidities increase both the risk of complications and mortality during the first year as well as 2-5 years after CRC surgery (Erichsen *et al.*, 2013). The ASA Physical status classification system is frequently used in Sweden and internationally when anaesthesiologists assess the risk of surgery for the individual patient (Owens *et al.*, 1978, ASA, 2014).

Medical treatment

Depending on the severity of the cancer some patients are recommended further treatment with chemotherapy. Patients with stage III CRC have a risk of recurrence between 15-50% and receive recommendations for adjuvant chemotherapy (Van Cutsem *et al.*, 2013). It is also recommended that patients in stage II with a high risk of relapse like perforated tumours, bowel obstruction or less than 12 lymph nodes removed during surgery, undergo adjuvant therapy (Brenner *et al.*, 2013). The combination of fluoropyrimidine (capecitabine or 5FU) and oxaliplatin as adjuvant therapy increases the overall chance of survival and the patient being disease-free and is mostly administered for 6 months (Brenner *et al.*, 2013, Des Guetz *et al.*, 2010). Patients experience many side effects after chemotherapy with oxaliplatin and/or capecitabine, and the most frequent are fatigue, diarrhoea and emotional distress (Borjeson *et al.*, 2012). They also report having nausea, loss of appetite, pain, neurological problems related to coldness and irritation in skin and mucous membrane. Some of these side-effects are more or less persistent among patients even 6-12 months after finishing the adjuvant therapy: fatigue, watery eyes and problems with bowel function (McCaughan *et al.*, 2012). This calls for a comprehensive

attitude towards assessing patients' needs during all phases of the cancer trajectory; after the treatment has finished there is still need for information and support.

Biological agents are frequently used in patients with metastatic CRC, often in combination with chemotherapy. These agents use multiple mechanisms to slow the growth of new blood vessels (anti VEGF) and to inhibit the signalling pathways involved in regeneration of new cells (anti EGFR) (Nelson and Benson, 2013).

The cancer trajectory

The trajectory of the disease is unique for each diagnosis and formed by the process of the disease, treatment and care options (Fletcher *et al.*, 2012). The cancer trajectory is composed of phases with transitional periods where patients move between phases. A transition occupies a space between what has already happened and something else that is evolving. Transitions are more dynamic periods with increased uncertainty, vulnerability and information needs (Squiers *et al.*, 2005). Transitions theory is a complex and important area of nursing research, but here the concept is only used to describe how patients move from one phase to another in their cancer trajectory (Meleis, 2010). Moving from active treatment like surgery to early survivorship constitutes one transition between phases. The trajectory of the next of kin comprises the patient's phases but also include the adjustments that need to be made in response to the patient's needs at that time (Blum and Sherman, 2010). Much more focus has been on the patient's trajectory, while the needs of next of kin during the cancer trajectory need to receive more attention.

The term cancer trajectory differs somewhat in use and scope. The American National Cancer Institute call it cancer care continuum and uses five phases that apply to all patients with cancer: prevention, screening, diagnosis, treatment and survivorship (Epstein and Street, 2007). The end-of-life phase is not included since it only affects some of the patients. Five main phases of the cancer care pathway were identified in a study from UK, starting with: diagnosis and treatment, followed by rehabilitation, monitoring, progressive illness and an end-of-life phase (Maher and McConnell, 2011). The monitoring phase includes patients at risk of recurrence but without active treatment and who might have remaining symptoms of complications. Another classification of the cancer care continuum can be seen in an American study with four denominated terms: pre-treatment, in-treatment, post-treatment and recurrence (Squiers *et al.*, 2005). The patients from the in-treatment and recurrence phase expressed the greatest need for information.

The readiness of patients to receive and adapt to information varies along the cancer trajectory. In an interview study, the initial period after diagnosis was described as a state of shock by patients with cancer (McCaughan and McKenna, 2007), Their lives turned into a nightmare and they could not take in any information during this period. Over the following days and weeks, this state turned into a phase where patients tried to make sense of the situation for themselves and needed information in order to do so. The time needed to understand such major information differs between patients and where they find themselves in the trajectory. This increases the importance of finding ways for healthcare professionals to identify and adjust the information according to the individual needs and phases of patients and next of kin.

The patient and the next of kin

A person is always part of a context when they become ‘a person with cancer’, and the disease transforms not only their life but the lives of the people close to them. Placing the patient in the centre means changing the objectification of a patient as part of a group with a joint diagnosis to be a person with their own needs and their own family and context (Ekman, 2014). The participants in our study are named ‘patients’ in Paper I-IV according to the respective journal’s practice. However, the initial position in designing this study has always been to view the patient as a person with individual experiences and needs.

Becoming a person who has cancer changes the patient’s life but the cancer affect the next of kin too. Being next of kin to a patient with cancer has a great impact on a person’s daily life and means dealing with not only one’s own grief and uncertainty after the diagnosis and sharing the patient’s situation, but also being expected to provide support during a shorter or longer period, depending on the prognosis. This situation has a great influence on the lives of the next of kin and can result in physical, emotional and social problems (Stenberg *et al.*, 2010).

Next of kin to patients with CRC clearly express that they have their own information needs and that they feel marginalized by both the patient and the healthcare professionals when they are excluded from information and decisions after surgery, according to two Swedish studies (Ohlsson-Nevo *et al.*, 2012, Ohlsson-Nevo *et al.*, 2013). The relationship between the next of kin and the patient is affected by the patient’s physical condition and this also affects their shared private life. Some of the next of kin felt trapped in unwanted tasks and were disappointed about unsupportive healthcare. They did not have enough information about the

normal path of recovery, which increased stress and meant they had to search for information. Sometimes the patient was prepared for the postoperative recovery, while the next of kin was not and so the latter was not able to cope with the patient's needs during this period. Some of the next of kin felt overwhelmed by the combination of seeing how the patient suffered and providing extensive support at the same time. They washed sheets and bought incontinence pads, drove the patient to the hospital, took on responsibility for all household chores, while their own social life became non-existent. The emotional and practical support was often appreciated by the patient but was sometimes also taken for granted (Ohlsson-Nevo *et al.*, 2012). When information was lacking, next of kin sometimes felt lonely and left out by both the patient and healthcare professionals. The next of kin felt a duty to help the patient and share their burden, but the illness had influenced and narrowed their own life (Ohlsson-Nevo *et al.*, 2013).

In most studies the next of kin to a patient is a partner or spouse (Ohlsson-Nevo *et al.*, 2012), but the family structure can vary considerably and the next of kin is just as likely to be a parent, sibling, child or a close friend (Ohlsson-Nevo *et al.*, 2013). In research the next of kin are often called caregivers, but this term has been avoided in this thesis since the actual care that was given to patients differed between being extensive to no care at all. Being a next of kin and a caregiver is known to cause severe distress and correlates to the patient's distress, suggesting that the two react like one emotional system: a patient-caregiver dyad (Northouse *et al.*, 2012). Gender is an associated factor to distress among caregivers. Female caregivers spend more time providing care, perceive less support from others and experience more mental and physical morbidity compared to male caregivers (Northouse *et al.*, 2012, Li and Loke, 2013).

Recent research focus on the patient and the next of kin as an indivisible dyad and the importance of well-functioning communication between them. Some authors indicate that healthcare professionals should assist in facilitating this communication between family members (Li and Loke, 2014). However this could be complicated with regard to the self-determination of both patients and next of kin. The patient might choose not to involve their family in information and decisions and the next of kin may prefer to avoid engaging in caring for the patient at home. This draws attention to the importance of learning to know the family situation before providing person-centred cancer information to patients and their families.

Information

The concept of information is used in many different areas of research but mostly in information science where many different models and theories have been developed and used (Case, 2012). Most of these have evolved within workplace information requirements or in a broader perspective on how people use and look for information in society at large. As early as 1981, a British researcher in information science proposed a shift from using the term information need, and instead use information-seeking towards the satisfaction of needs (Wilson, 1981).

Information needs

Strikingly few studies define the concept of information needs, considering all the publications with the main focus of investigating patients' need for information (Nikoletti *et al.*, 2008, Adams *et al.*, 2009). The concept of information needs exist within many different fields beyond healthcare and is often used without being defined, as if its meaning were indisputable. Information needs are often used interchangeably with learning needs and educational needs without these terms being defined (Timmins, 2006). According to Case, a researcher in information science, the concept of information needs is difficult to use in research since it is not easily observable (Case, 2012). The concept is frequently described as the cause of and reason for seeking information and is usually adapted to the particular interest of the respective author. Case believes that it is problematic to assume that one internal need will be the sole reason for information-seeking actions. When trying to clarify how information needs arise, he summarizes several other researchers' work into three concepts: seeking answers, reduce uncertainty and making sense. All of which are easy to apply to a patient in the early phase of the cancer trajectory.

According to Timmins, attributes of the concept signify recurring characteristics of how it is used in the literature, and these attributes are used to help differentiate the concept from others (Timmins, 2006). She states that attributes to information needs are that they are *individual* and *expressed* by patients or next of kin, and that information needs often are used as the starting point for information provision in healthcare, even though it often relies on normative needs, decided by the healthcare professionals. In Timmins' study she describes information needs as individual and that they exist primarily to help the person to cope with the stressful event: 'true information needs are those expressed spontaneously by the client/family to staff' and 'the need for information is all about coping with events' p. 379 (Timmins, 2006).

The Oxford English Dictionary has a number of definitions for *information* (Oxford English Dictionary, 2014), one of which is ‘knowledge communicated concerning some particular fact, subject, or event; that of which one is apprised or told’. Another one is ‘the imparting of knowledge in general, communication of instructive knowledge, education and training’. *Need* is defined as; to require, demand, to question, to call upon any one for information or a thing desired (Oxford English Dictionary, 2014). These findings implicate that both *information* and *need* is part of a process with a direction and an object, not something that just happens in general communication with no purpose.

The two oldest articles in the literature describing information needs in healthcare are from 1976 and 1980; both were published in medical journals (McIntosh, 1976, Cassileth *et al.*, 1980). They do not use definitions of information needs per se, but rather use other phrases to describe the meaning and use of the concept (Table 1). These were followed a decade later by publications in nursing, medicine and psychology.

Table 1. Information needs - definitions and related terms

Authors	Definitions/related terms
(McIntosh, 1976) Medicine	Desire for information, wanted information, seek information (p. 300, 301, 302)
(Cassileth <i>et al.</i> , 1980) Medicine	Desire for information, seek information (p. 832, 835)
(Derdarian, 1987a) Nursing	Inherent in the definition of information as factual, theoretical, or experimental knowledge relevant to an object or situation, is the implication that a need for information derives from its lack. The degree of need for the information may be characterized by the degree of its lack (p. 109)
(Derdarian, 1987b) Nursing	Need for information: a lack of knowledge; incomplete or unclear knowledge (p. 157)
(Mesters <i>et al.</i> , 2001) Nursing and medicine	As an experience of shortness in information concerning a life domain which is of relevance to the patient (p. 254)
(Timmins, 2006) Nursing	True information needs are those expressed spontaneously by the client/family to staff (p. 379)
(Tsuchiya and Horn, 2009) Psychology and medicine	Information provision need is defined as cancer-related medical information and informational and social support provision after discharge (p. 150)
(Ormandy, 2011) Nursing	Recognition that their knowledge is inadequate to satisfy a goal, within the context/situation that they find themselves at a specific point in the time (p. 92)

Two related terms to *information needs* are *coping* and *decision-making*, both appearing in Derdarian's paper from 1987a and used frequently ever since (Eheman *et al.*, 2009). Information-seeking has also been used as a related term for information need, and was identified as one of the five forms of coping mechanisms by Cohen and Lazarus (1973) and has been a related term associated to information needs since then. Interestingly Cohen and Lazarus found that both patients seeking information and those avoiding it showed similar capacities for coping after surgery. The last definition in Table 1 originates from the field of nursing and comprises the importance of turning information to knowledge, that a need means a deficiency in a person's knowledge, that it is defined by the individual and that the need differs during a disease trajectory (Ormandy, 2011). According to Ormandy educational need and information needs both imply a lack of knowledge, but education need refers to an objectively measured need, often by someone else, and therefore implies a normative definition.

Information recall

Factors that facilitate recall of information are hard to establish, especially when it comes to recall of verbal information. In a review of 43 studies, the authors suggested that interventions tailored to the individual cancer patient had the best effect on recall: audiotapes of the patients' own consultations and the use of question prompt sheet (van der Meulen *et al.*, 2008). Lower-level education and higher age are factors that decrease the recall of health information (Ayotte *et al.*, 2009), and the importance of age is confirmed in another study, but only when the amount of information was considered (Jansen *et al.*, 2008). If more information was communicated, older persons remembered less than younger ones. Recall also varied with prognosis, where those with poorer prognosis recalled less information, and, in that study, prognosis was a better predictor of information recall than age (Jansen *et al.*, 2008). It is not possible to establish the exact content and method used to provide information to patients and next of kin after this has been done, or to control for sources of information other than healthcare professionals. This contributes towards the difficulties in achieving measurable effects with regard to information interventions.

Written information can help recall of information; however the quality and readability are often too low. In a Swedish study, education materials from 27 hospitals were analysed by language technology and then the results were complemented with focus-group interviews of 15 former patients with CRC. Of the education materials, 44% were not suitable for the purpose, and 29% of all the material was difficult to understand (Smith *et al.*, 2014). The interviews resulted in

different topics that needed to be improved in CRC patient education; general and personal care, personal implications, Internet, significant others, access to healthcare and patient support groups.

A person's health literacy is known to affect both the seeking for and the recall of information (Ayotte *et al.*, 2009, von Wagner *et al.*, 2009). It is also associated with requiring a longer reading time and lower self-efficacy. The term literacy is well known and widely used, while health literacy is more recent and the definition has been developed over the last two decades (Berkman *et al.*, 2010). Health literacy is a complex concept and cannot be defined by basic reading skills alone. It include a person's ability to obtain, process and understand health information and to communicate in different health contexts in order to make informed health decisions (Berkman *et al.*, 2010, Johnson and Case, 2012).

Johnson's Comprehensive Model of Information Seeking

Since a solid definition of information needs still is being developed, a model of information seeking is used as the theoretical framework for this thesis in order to interpret the findings and assist in clarifying the context of information (Johnson and Case, 2012). Johnson's Comprehensive Model for Information Seeking (CMIS) was chosen since it has been tested in different contexts and has been proven to be feasible for use in clinical trials as a theoretical framework for interventions and to evaluate findings (Han *et al.*, 2010, Kelly *et al.*, 2007). The main variables in the model have been identified, described and adjusted to patients with colorectal cancer, for use in this thesis (Figure 1). Several parts of the model could also be applied to next of kin but they are not discussed in depth in this paragraph in order to minimize repetition.

The *Antecedent* factors in Figure 1 reflect the underlying motivation for a person to seek information and include corresponding factors like *Demographics*, *Personal experience*, *Salience* and *Beliefs*. *Demographics* like age, gender, education, occupation and socioeconomic status can affect the way a person seeks information; and the classic high information seeker is a white, middle-aged woman with high socioeconomic status (Johnson and Case, 2012). However, the demographic factors only explain a small part of the variance in information seeking. *Personal experience* is an important factor when patients chose a channel or source of information. The patient can have his or her own experience of previous cancers or other diseases, or the next of kin or a close friend may have had an experience of cancer that affects the patient's current information seeking. *Salience* signifies the personal significance of the information to the individual patient and whether he or she perceive that the information is applicable to their present situation (Johnson and Case, 2012). The

relevance of the information is closely connected to the salience. How the patient perceives his or her control over the situation is part of the patients' *Beliefs* and can represent both a facilitator and a hindrance to the information-seeking process. To actually seek information involves admitting that one does not know this information and may signify a problem for persons with low self-esteem.

The antecedents provide the initial motivation to seek information, but the actual search itself is driven by the *Information-carrier factors, Characteristics* and *Utilities*. These factors concern the specific channels selected when seeking information and how much information is used and in what way (Johnson and Case, 2012). When patients select information channels they are influenced by the *Characteristics*, that is, how they perceive the quality of the channel; patients value the intentions of the channel, its trustworthiness, accuracy and its communication potential.

Most patients make use of more than one channel and the usage varies during the cancer trajectory. Johnson describes two types of channels; *Interpersonal* and *Mediated* (Johnson and Case, 2012). The *Interpersonal* channel involves healthcare professionals, family members and friends with whom you can talk. When communication is insufficient with healthcare professionals, this can lead to poorer recall for patients. Family members frequently act on patients' behalf and seek information, mostly on the Internet, outside the healthcare setting.

The *Mediated* channels consist of Internet including social networks, written material, newspapers, libraries and telephone services and assume an active seeker of information. When patients and their families seek information on the Internet they do it for different reasons: for reassurance, for second opinions, to understand received information and to avoid bothering healthcare professionals (Johnson and Case, 2012). In order to obtain reassurance, they can use social networks and connect with other users with experience of similar health concerns. The great advantage with the Internet is the easy accessibility of information. However, this coincides with deficiencies in the quality of the information, where personal experiences often tend to be the source of information.

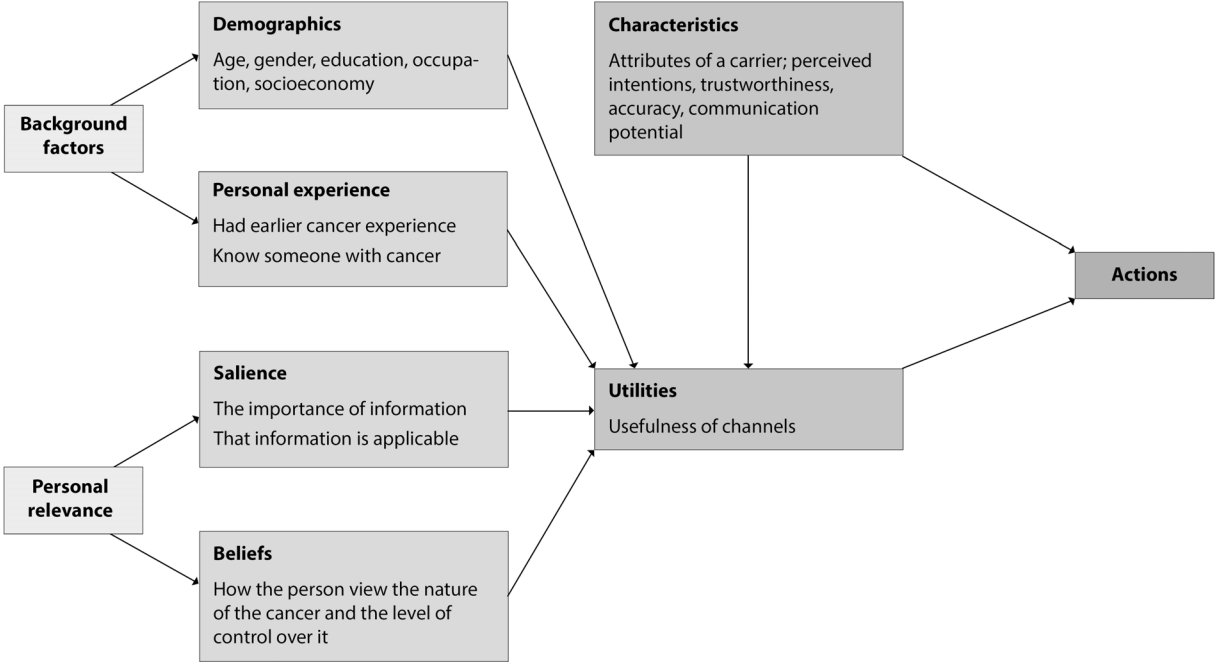


Figure 1. An interpretation of the Comprehensive Model for Information Seeking (CMIS). Approved by David Johnson (Johnson & Case 2012, page 40).

The *Utilities* in Johnson's model refer to how the channels are used (Johnson and Case, 2012). They all constitute great potential for patients and next of kin to access information but they also have weaknesses. When one channel cannot fulfil their needs, patients and next of kin can use another to make up for the inadequacies. Not only channels differ but also patients' expectations differ between various channels and how to use them. People tend to select the channels that reduce uncertainty. When healthcare professionals act as an information channel, they need to work out what channels the patient would prefer to use, provide this information and also to prevent information overload.

Patients' information styles will affect their *Information-seeking actions* (Johnson and Case, 2012). It is frequently assumed that patients with cancer are active seekers of information, but irrespective of information style, many patients avoid information in the early phase of the trajectory. Some patients continue to avoid information throughout the trajectory and various interpretations have been used to explain this behaviour. Avoidance could be connected to low self-efficacy, a more elementary use of information channels or not believing that information would actually be helpful (Johnson and Case, 2012). It could also depend on being very afraid of receiving bad news about the prognosis, and not knowing thus seems preferable.

Information style can be grouped into: active, moderately active and passive information styles, and differs according to age, health status, cancer type, marital status, education and occupation (Eheman *et al.*, 2009). Older patients with worse health status, who are divorced or single and with lower-level education used a more passive information-seeking style in Eheman's study. Patients with breast cancer were more active seekers than other groups of patients with cancer. The information-seeking style also varied in regard to time in the cancer trajectory; before starting treatment with chemotherapy or radiotherapy, patients were more active in seeking information than in the post-treatment phase (Eheman *et al.*, 2009). During their experience of cancer, patients reach a turning-point when they can manage to acknowledge that they are living with cancer, and this enables them to be more active in the information process (van der Molen, 2000).

Health-related quality of life

After many decades of use there are still controversies in how to use and define the concepts of health, quality of life (QOL) and health-related quality of life (HRQOL). Some authors argue that the ongoing process in itself will result in continuous learning and development of the concepts (Barofsky, 2012).

The most commonly used definition of health is from the World Health Organization from 1948 (WHO, 2014). It has not been changed since that year:

Health is a state of complete physical, mental and social well-being and not merely the absence of disease or infirmity.

The WHO definition of health has been criticized as being utopian in the description of physical health and the concept of well-being as too vague to interpret (Larson, 1999). Other aspects of health have been identified as important parts of health like health promotion, progress towards higher functioning and integration of mind, body and soul. Ability to adapt to physical and social environment are also seen as health components (Larson, 1999, Ware, 1984).

A fundamental concept in QOL is the individual person's experience of their subjective well-being (Phillips, 2006). Subjective well-being comprises a person's satisfaction with life, happiness, meaning of life, spirituality and self-knowledge; how the person judge their own well-being to be. In contrast to this concept, the objective well-being is normative and relate to what a citizen could reasonably expect from society and from life (Phillips, 2006).

QOL and HRQOL are often used interchangeably and some authors claim that QOL comprises all aspects of HRQOL, and that an additional concept is thus not useful (Phillips, 2006). HRQOL is multi-dimensional and comprises subjective well-being, disease-related and treatment-related symptoms and physical, psychological and social functioning (Phillips, 2006, Velikova, 2012). HRQOL can be seen as a narrower concept than QOL and does not include the influence of the environment to the same degree.

The European Organisation for Research and Treatment of Cancer (EORTC) does not use an official definition of QOL or HRQOL when referring to their instruments, but describes QOL as a more general concept and HRQOL as being connected to a clinical context (Fayers and Machin, 2007). On the EORTC webpage, they use both concepts, but emphasize HRQOL when referring to the effect of the cancer on the individual person (EORTC, 2014).

HRQOL is a multi-dimensional construct covering at least several key dimensions such as disease and treatment-related symptoms as well as physical, psychological and social functioning.

In the first two publications concerning QLQ-C30, Aaronson uses the term QOL with the intention of incorporating physical, emotional and social health issues. (Aaronson *et al.*, 1993, Osoba, 1991). Aaronson based the EORTC's conceptual framework upon three researchers, but there is not much information describing how

the sources were used (Ware, 1984, Schipper *et al.*, 1984, Priestman and Baum, 1976). One of the authors separates the definitions of QOL and health status, where QOL embrace the individual state of health including other factors like family life, finances and accommodation, while health status is defined as absence of disease with completeness, proper function and well-being (Ware, 1984). No actual definition of the items in the different EORTC instruments exist, rather they are defined by their own wording in the instrument (Aronson *et al.*, 1993, Fayers *et al.*, 2001).

In the 1940s the first simple scales were used as endpoints in cancer trials. This was a reaction to the traditional measures used at that time: morbidity and mortality (Cox *et al.*, 1992). The European Organisation for Research and Treatment, was founded 1962 as an international organization without beneficial interest (Fayers *et al.*, 2001). Its purpose was to develop, coordinate and stimulate cancer research in Europe. In 1980 an EORTC group started focusing on the area of quality of life and made an integrated system with modules to evaluate quality of life in patients with cancer. The first version of QLQ-C36 was ready for use in 1987 and was designed to be: cancer specific, multi-dimensional, appropriate for self-administration and applicable for use in different cultural settings. The abbreviation signifies: Quality of Life Questionnaire – Cancer 36 items. The next version of the instrument, QLQ-C30, was tested for validity and reliability and published 1993 (Aronson *et al.*, 1993). The actual steps in creating the first versions of the instrument have been published but the description of the process is limited (Osoba, 1991). In a later article EORTC declare their overall policy on how to design new diagnose specific modules; literature search, interviews with healthcare staff and patients, comparison with existing modules and testing (Sprangers *et al.*, 1998). Translation of all instruments from EORTC is done according to the same standardized routines; forward-backward procedure by two independent translators who are native speakers, discrepancies arbitrated by a third person and a pilot test of the questionnaire (Koller *et al.*, 2007).

Sense of coherence

A patient's personal qualities are known to influence their need for information and their motivation to seek information (Johnson and Case, 2012). More than five decades ago, the importance of patients' individual traits were already under discussion, and the development of the research area has continued to grow (Janis, 1958).

Antonovsky's claim that the foundation for effective coping with stressors is based on the factors in his salutogenic model sense of coherence (SOC) (Antonovsky, 1993). It consists of three main components: comprehensibility, meaningfulness and manageability. Antonovsky describes how different life experiences as a whole form a person's SOC. Experience of predictability lays the foundation for the component comprehension, a good balance during difficult times forms the basis for manageability and participation in the results lay the foundation for meaningfulness (Antonovsky *et al.*, 2003). The individual's SOC develops during childhood and adolescence and stabilizes in young adults. Persons with lower SOC seem to have a less stable scoring when major traumatic life events occur, while those with higher SOC only drop in scoring for a shorter period and then regain their usual level (Antonovsky *et al.*, 2003). The SOC scale is correlated to QOL in patients where those with high SOC also score high in QOL (Eriksson and Lindstrom, 2007). Since patients clearly differ in their ability to manage their cancer there is a need to study potential associations between SOC and information needs among patients with CRC.

Discharge from hospital

The criteria for discharge after colorectal cancer vary between hospitals and between countries with different health systems. The majority of the studies in a review by Fiore *et al.* (2012) used more than one criteria to assess readiness for discharge. The most frequently used criteria were: tolerance of oral intake and returned bowel function. In only 8 of 156 studies adequate home arrangements were used as criteria, and patients' acceptance of discharge were used in 12 of the studies. This indicates that a more comprehensive view on patients' situation is needed in order to prepare for the situation at home during the first days and weeks after hospital discharge. Age is an important factor when it comes to information in conjunction with discharge planning. Increasing age adds to the risk of being a frail, elderly person with decreased physiological reserves and lowered resistance to stressors, and it is strongly associated with complications after surgery. This is connected to an increased need for additional care after discharge from hospital, and this need can be predicted before surgery (Lapar, 2011). Information needs are known to vary after discharge due to age, where younger patients want more information than older ones do (Suhonen *et al.*, 2005). But despite old age (80+) patients can still express a distinct wish to participate in the discharge process, but their ability to receive information can be negatively influenced by impaired hearing ability (Foss and Hofoss, 2011). Patients report having problems understanding the information they receive in

hospital, and require assistance from nurses and family members to interpret the information (Worster and Holmes, 2009).

The need for a structured, comprehensive discharge planning is clearly visible in the literature but the best clinical practice remains to be identified. Individual studies can show some effect of different interventions like nurse-led discharge planning to reduce readmissions in patients with heart failure. The authors demonstrated decreased readmissions but could not identify the most effective components in the discharge intervention (Lambrinou *et al.*, 2012). In another review with heart failure multi-disciplinary teams using program with in-person communication were most effective in reducing readmissions (Sochalski *et al.*, 2009). A Cochrane review suggests that discharge planning tailored to the individual patient probably reduces length of stay and readmissions in older patients with a medical condition (Shepperd *et al.*, 2013), indicating a need for further research on surgical cancer patients' needs post-discharge.

There are groups of patients that are more vulnerable at discharge from hospital to home because their own ability to participate in the discharge process and the information are limited due to intellectual disability or dementia (Heid-Grubman, 2013). Both groups have difficulties comprehending new or complex information or learning new skills, which often leads to healthcare professionals withholding information about diagnosis and prognosis (O'Regan and Drummond, 2008). The next of kin of patients with intellectual disability or dementia emphasize that they play an absolutely essential role and must be included in all information and discharge planning for these patients (Fitzgerald *et al.*, 2011, O'Regan and Drummond, 2008).

Since patients and next of kin receive and access information from different sources at different occasions, it is not possible to define exactly what information they received just before discharge. When defining information at discharge it therefore needs to include all information that patients and next of kin received during the cancer trajectory up to this point.

Scientific perspective

The clinical scientist works in a very concrete situation where the aim of the research is to evaluate a new intervention or to obtain new knowledge that could be used to form future interventions that benefit patients.

The philosopher Karl Popper argued that it is more difficult to verify a hypothesis than to falsify the null hypothesis. The researcher must therefore formulate a positive hypothesis about the expected outcome (H1), while at the same time formulating the opposite, that is, the falsification of the hypothesis. Popper asserted that even if the hypothesis is falsified during the research, this will result in increased knowledge and coming closer to the 'truth' (Chalmers, 2007). Although Popper's method had an enormous impact on the scientific community, it also had its critics. Philosophers like Thomas Kuhn argued against the falsification of H1 and stated that all research was not intended to verify or falsify theories but to gather knowledge and concepts within a certain field (Hacking, 2007). The theoretical position taken in this thesis are more in line with Kuhn, since the aim was to explore a field (information) during one specific part of patients' cancer trajectories, not to test a theory or hypothesis.

Paul Feyerabend, a philosopher, believed that there is no objective truth of reality: everything is an interpretation (Molander and Hartman, 2003). Different perceptions of what the researcher observes may be related to different experiences and theoretical backgrounds. This can easily be applied to the qualitative research in this thesis, but also concerns the results from the quantitative papers. In quantitative research, several choices are made by the researchers during the process of the study: which instruments to use, what statistical methods to perform and what results to report. During all phases of the research, an interpretation of what is relevant in that specific area is estimated and forms the basis for decisions made.

Rationale

The design for these four parts of the thesis was grounded in a deductive reasoning in the sense that we drew a logical conclusion from the clinical experience, which told us that patients and families need information (Chalmers, 2007). So an entry or 'theory' existed that information needs were present. Even though many people are diagnosed with colorectal cancer every year in Sweden and internationally, very little research had been published on the specific information needs of this group of patients and their next of kin when this study was designed. The shortage of nursing research in this area had implications for clinical practice and more knowledge was needed in order to bring about changes in clinical nursing care. This means that the design was somewhat inductive as we could not relate to any existing previous research in this specific area.

From the first discussions on which design and methods to use, the position has always been to keep the patient and the next of kin in the forefront. To have access to

information constitutes a prerequisite for the patient to be able to influence his or her own situation and to make informed decisions about care and treatment. During the whole research process, our goal has been to move away from an old-fashioned view of patients as passive recipients.

To identify the experiences of patients and next of kin with regard to information and information needs during the first seven weeks after discharge for colorectal cancer surgery was the basis for the design of the study. Varying perspectives to explore this specific time and phase of the cancer trajectory were chosen in order to gain a broad and deep understanding of different aspects of the needs of patients and next of kin. It was important to provide patients and their next of kin with their own 'voice' and to let their opinions be an evident part of the results. This position motivated the use of both qualitative and quantitative methods.

Data collection was performed in three hospitals. Two of the hospitals had already implemented the ERAS programme before the data collection of this study started and the third one did this some years later. The design was made primarily to explore and describe the situation for patients suffering from CRC in this region and not to look for differences between programmes and hospitals.

Aim

The overall aim of this thesis is to study the experiences of patients and next of kin with regard to information and information needs after being discharged after colorectal cancer surgery, as well as the factors related to this.

Specific aims were to:

- Explore how patients perceive information after surgery for colorectal cancer and what their information needs are according to EORTC QLQ-INFO25. The aim was also to determine factors affecting received information (I).
- Investigate how patients perceive information and their health-related quality of life one month after discharge after colorectal cancer surgery. The aim was also to compare these results with the first two weeks at home and to identify factors related to the perception of information (II).
- Explore the experiences of patients with regard to information and their information needs after discharge after colorectal cancer surgery (III).
- To explore the experiences of next of kin with regard to information and their information needs after the patients' discharge after colorectal cancer surgery (IV).

Methods

Design

This thesis is designed to address the information needs of patients and next of kin after colorectal cancer surgery in four prospective studies, Table 2. A broad research approach was used in order to investigate various aspects of this area. The overall design was explorative in order to study different dimensions of experiences of information and information needs.

Table 2. Overview of papers in the thesis

	Design	Participants	Measurements	Analysis
Paper I	Explorative, descriptive and qualitative	100 patients	QLQ-INFO25 QLQ-C30 QLQ-CR38 SOC-13 ISCO-88 ECOG-PS ASA Tumour stage Written comments	Ward's cluster analysis Chi-square test Mann-Whitney U-test Kruskal-Wallis Fisher's Exact Test Multiple linear regression analysis (backward) Kolmogorov-Smirnov test Nagelkerkes R ² Hosmer and Lemeshow test Qualitative content analysis
Paper II	Explorative, comparative	100 patients	QLQ-INFO25 QLQ-C30 QLQ-CR38 SOC-13 ASA Tumour stage	Wilcoxon's signed rank test Mann-Whitney U-test Spearman's correlation
Paper III	Qualitative	16 patients	Individual interviews	Qualitative content analysis
Paper IV	Qualitative	16 next of kin	Individual interviews	Qualitative content analysis

The objective of exploratory research is to gather preliminary information that will help define the issues. Both descriptive and qualitative methods are used in this study (LoBiondo-Wood and Haber, 2010) and in Paper II a comparative method is used. The explorative design of this research project was chosen in order to investigate the experience of patients and next of kin with regard to information and their information needs, but also to look for factors associated with the patients' scoring of received information. Since the overall aim was not to test a hypothesis, no power calculation was performed. The sample size is usually small in explorative studies (Burns and Grove, 2009), and 100 participants were chosen to generate results that are relevant from the clinical point of view.

Patients from three different hospitals were included to enhance variation in the experience of patients and next of kin. The time frame of seven weeks for data collection was designed to cover the first period after discharge, the first weeks of recovery at home and to include the prognostic information at the post-discharge visit at the surgical department. Figure 2 shows where in this process the data collection took place.

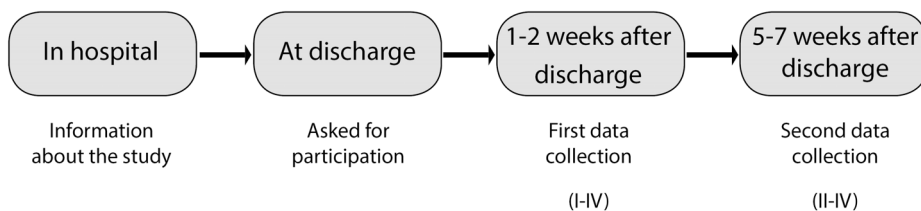


Figure 2. Timeline for data collection

Samples and context

The sample consisted of one main sample of 100 patients participating in the questionnaire studies (Paper I and II). From this group 16 patients and their next of kin were asked to take part in the interviews (Paper III and IV).

Participants and sampling procedures

Paper I and II

All patients who had undergone surgery for colorectal cancer at two university hospitals and one county hospital in southern Sweden were evaluated for inclusion in this prospective study. The patients were included in the study consecutively, if they were adults over eighteen-years-old, had undergone surgery for colorectal cancer, were able to read Swedish and had signed a written form for informed consent. Patients with a stoma received special information and support, and were not included. Patients' characteristics at the first data collection are shown in Table 3.

A registered nurse (RN) or a nurse manager from the ward identified eligible patients through a handwritten calendar where all patients were registered before surgery. The nurse estimated their ability to communicate and read Swedish. None of these nurses provided care for the patients.

The time period for inclusion of patients differed between hospitals. The data collection started in one hospital and, when no problems were identified, the other two hospitals followed. In hospital A the inclusion lasted between February 2007 and June 2009; in hospital B from March 2007 to February 2009 and in hospital C from October 2007 to April 2009.

Table 3. Patients' characteristics in Paper I-II (n=100)

Women, %	45
Living alone, %	31
Age, Mean (SD)	69.9 (10.5)
Length of Stay, Mean (SD)	9.0 (5.6)
Hospital A – non-ERAS, %	55
Hospital B – ERAS, %	26
Hospital C – ERAS, %	19
ASA – Preop. health status* %	
1 - Healthy normal patient	13
2 - Mild systemic disease	66
3 - Severe, but stable systemic disease	18
4 - Severe systemic disease	2
Types of surgery, %	
Right hemi colectomy	39
Right hemi colectomy + transv res.	2
Transverse resection	2
Left hemi colectomy	11
Sigmoid resection	29
Anterior resection	16
Subtotal colectomy	1
Postoperative complications, %	
Surgical	14
General/medical	5
Tumour stages, %	
I	15
II	41
III	36
IV	8

* n = 99

During the time of inclusion, 161 patients were assessed as being eligible for inclusion in the study. Thirty-one wanted to participate but were excluded for various reasons and 30 chose not to participate (Figure 3). One hundred patients participated in study I and II. An analysis was performed to investigate if there were any statistically significant differences between the study group (n=100) and non-respondents (n=61) regarding age, gender, length of stay (LOS) or preoperative health status (ASA) (Owens *et al.*, 1978). The results showed no significant differences regarding age, gender, LOS or ASA between the groups. The mean age was 69.9 in the study group and 72.8 in the non-respondents group ($p=0.08$). The respective proportions of

women were 45% and 59% ($p=0.08$) and the mean LOS was 8.99 and 8.91 days ($p=0.18$). The mean ASA scores were 2.09 and 2.13 ($p=0.69$).

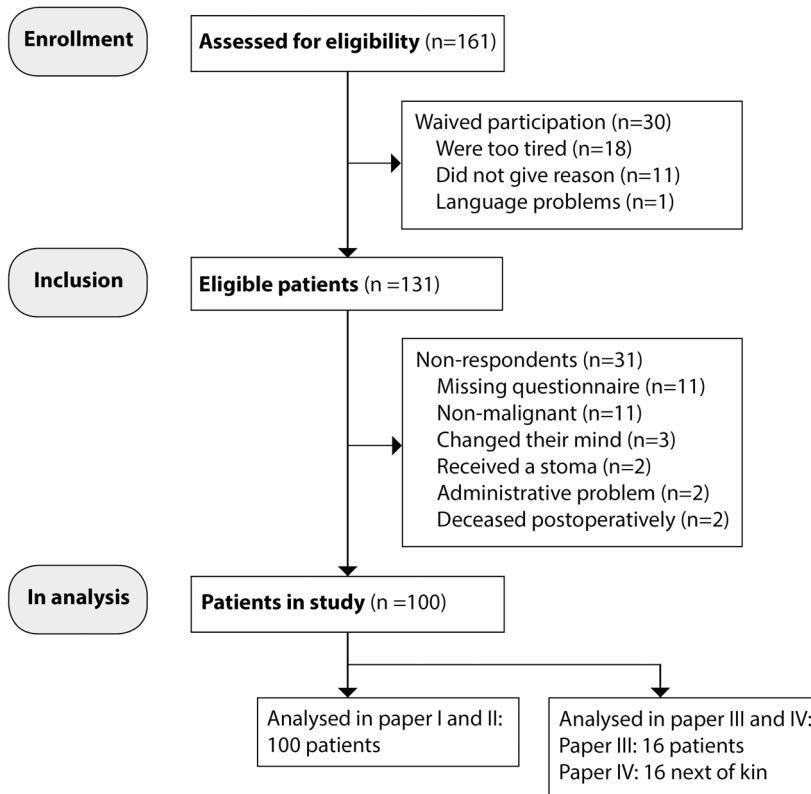


Figure 3. Patients' flow

Paper III and IV

From the sample in Paper I and II ($n=100$), 16 patients were included in an additional part of the study with interviews (paper III). The inclusion criteria for these patients were that they lived with someone who was their next of kin and that both wanted to participate in interviews (Paper IV). Next of kin was defined as a person living with the patient. The first eleven patients in Paper III were included consecutively, with no age limit. Eight of these patients were older than 65 years of age. In order to increase the variation in the interviews only patients of working age – less than 65 – were included from that time on.

In Paper III ten men and six women were interviewed; 15 lived with a spouse/partner and one with an adult child. There were children living at home in three of the sixteen families. Ten of the next of kin in study IV were women and six were men. Patients and next of kin had white-collar or blue-collar professions, among patients there were eight of each. Eight of the patients had co-morbidities like heart or lung disease, diabetes or movement disorders and had earlier experiences of healthcare (Table 4). Half of the patients came from hospitals using enhanced recovery after surgery (ERAS) (Kehlet, 2009). Eight of the patients received recommendations for further treatment with chemotherapy.

Table 4. Patient characteristics in Paper III and age of next of kin in Paper IV

Sex	Age Mean 66.6	Chemo- therapy	Co-morbidity	Age next of kin Mean 62.4
M	50	-	-	45
M	51	Yes	Heart disease	46
F	56	-	Movement disorder	18
M	57	Yes	-	57
F	60	Yes	-	65
M	63	Yes	Prostatic disease	55
M	64	Yes	Heart disease, diabetes	59
F	64	*	-	59
F	67	-	-	72
M	72	Yes	Heart disease and movement disorder	71
M	72	-	Heart disease, diabetes	69
F	73	-	Lung disease	76
M	77	-	Heart disease	73
F	78	Yes	Heart disease, stroke	75
M	79	Yes	Heart disease, lung disease	76
M	82	-	-	83

* This patient had not received information about the pathology report at the time of the second interview.

Context of information provision

Two of three hospitals used an enhanced recovery after surgery (ERAS) during the time of this study (Kehlet, 2009). The *preoperative information* was given during the outpatient visit before surgery. The surgeon (resident or specialist) and the registered nurse (RN) met all patients before admission and provided verbal and written information. The contents of the preoperative information were similar in the two ERAS hospitals (B and C) but differed slightly in comparison to the non-ERAS

hospital (A), written information was provided to patients from ERAS hospitals (Figure 4 and Appendix I).

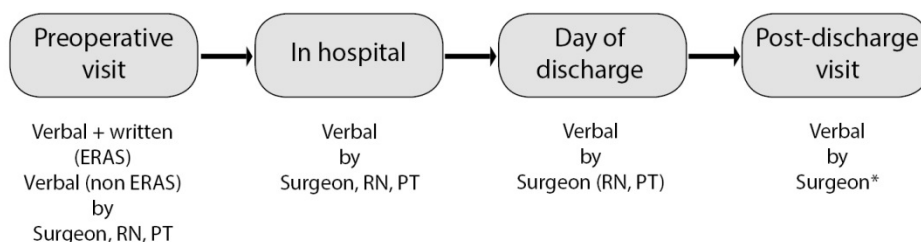
During hospitalization patients met one of the surgeons during the rounds every weekday. They met the nurses and the physiotherapist (PT) more frequently during daily care. Questions were asked and information was passed on during these encounters.

The routines for *discharge* were similar in all three hospitals; unsystematic verbal information from the surgeon, physiotherapist and nurse about the surgery, physical activity, wound care and a prescription of pain medication.

The *post-discharge* visit at the surgical department was similar in all the hospitals with verbal information by a surgeon about one month after discharge. In one of the hospitals patients also met a nurse. Some patients then received recommendations to undergo further chemotherapy treatment and these patients received an appointment with an oncologist and a nurse at the oncology department before the therapy started.

Knowledge about how much the next of kin actually followed the patient's cancer trajectory and accompanied him or her to different visits was not known before the data collection. There were no procedures for providing next of kin with structured information or for ensuring involvement.

Patients and next of kin may have used different sources of information like friends, newspapers and Internet, but this was not controlled in this study.



* In hospital C patients also met an RN.

Figure 4. Patients' access to information from healthcare professionals during the first part of the cancer trajectory (all verbal information was unsystematic).

Data collection

Data was collected from the self-reported questionnaire, computerized medical records and interviews and was conducted at two different times, 1-2 weeks and 5-7 weeks after discharge, Figure 2.

Patients received verbal and written information about the study while on the hospital ward and were asked just before discharge or by telephone during their first days at home if they wanted to participate in the study. Written informed consent was signed by all participants. Self-reported questionnaires were sent to the patients' homes and a return envelope was included. One reminder was sent if no response was received.

Before data collection started, a hospital counsellor in each of the three hospitals was informed about the study. Participants in the study were offered to talk to the counsellor when they needed.

Self-reported questionnaires

In Paper I and II patients were asked to complete the same questionnaires twice: first during the first 2 weeks at home and the second time 5-7 weeks after discharge. In study I the participants had the opportunity to write supplementary comments on information perceived as important but not mentioned in the questionnaire. If the questionnaire was not returned, one reminder was sent by post.

HRQOL and received information

The European Organization for Research and Treatment of Cancer – EORTC created three of the instruments used in Paper I and II: QLQ-C30, QLQ-INFO25 and QLQ-CR38. They had been translated to Swedish and published in other studies (Michelson *et al.*, 2000, Arraras *et al.*, 2010). The main part of all three questionnaires uses a 4-point Likert scale ranging from 1 (Not at all) to 4 (Very much) (Fayers *et al.*, 2001). In the two overall QOL questions in QLQ-C30 the answers have a 1-7 range and in QLQ-INFO25 4 questions have a yes/no response (Arraras *et al.*, 2010). Irrespective of which response alternative used the scores are linearly transformed to 0-100 in all of the instruments according to the EORTC manual (Fayers *et al.*, 2001). An outline of these three instruments' distribution of items and their respective alpha values is shown in Table 5.

Table 5. Self-reported questionnaires (Paper I and II)

Instrument	Measure	Item	Range	Direction	Alpha†	Reference
QLQ-C30	Global Health/QOL	2	1-7	↑ better QOL	0.54-0.86	Aaronson <i>et al.</i> , 1993 Kaasa <i>et al.</i> , 1995
	Symptom	13	1-4	↓ fewer symptoms	0.62-0.89	
	Function	15	1-4	↑ better function		
QLQ-INFO25	Amount of received information	19	1-4	↑ more info	0.70-0.91	Arraras <i>et al.</i> , 2010
	Quality of info	2	1-4	↑ better info		
	Wish more/less info	2	Yes/No			
QLQ-CR38	Symptom	23 §	1-4	↓ fewer symptoms	0.38-0.83	Sprangers <i>et al.</i> , 1999 Thaysen <i>et al.</i> , 2012
	Function	7	1-4	↑ better function	0.35-0.85	
SOC-13	Sense of coherence	13	1-7	↑ better sense of coherence	0.74-0.91	Antonovsky, 1993
ECOG-PS	Performance status	1	0-5	↓ better performance	Single item	Conill <i>et al.</i> , 1990

† Lowest and highest alpha value from subscales. § Eight items related to stoma were not used in this thesis.

QLQ-C30 is an instrument developed to assess QOL in patients with cancer (Aronson *et al.*, 1993). It contains five functional scales, nine symptom scales/item and two items assessing Global Health and overall QOL (Table 5). High scores on the Functional scales and the Global Health/QOL indicate high/good QOL. High scores on the Symptom scales mean more symptoms/problems (Fayers *et al.*, 2001).

In combination with *QLQ-C30*, different modules are used to cover specific diagnoses and areas connected to cancer treatment. The module *QLQ-INFO25* has been developed to measure information received by patients with cancer at different stages of their disease and treatment (Arraras *et al.*, 2004, Arraras *et al.*, 2007, Adler *et al.*, 2009, Arraras *et al.*, 2010). The 25 items are organised in 4 multi-item scales and single items; 4 items have a dichotomous response with yes/no instead of the 4-point Likert scale (Appendix II, Table 5). High scores indicate a high level of information received. The psychometric testing of *QLQ-INFO25* was done by Arraras *et al.* 2010 and showed an internal consistency for the entire scale of $\alpha=0.91$ and for each subscale $\alpha>0.70$. The test-retest reliability (intraclass correlation) was >0.70 (Arraras *et al.*, 2010).

QLQ-CR38 was the most recent colorectal module in use when our data collection started (Sprangers *et al.*, 1999) and it consists of four functional scales/items and seven symptom scales, Table 5. High scores on the Functional scales mean high/good QOL, while high scores on the symptom scales mean more symptoms/problems (Sprangers, 1994). The reliability of the scale vary and a later version *QLQ-CR29* shows higher alpha values between 0.69-0.83 (Whistance *et al.*, 2009).

SOC-13 and ECOG-PS

SOC-13 is a 13-item instrument to measure Sense Of Coherence (Antonovsky, 1993). SOC includes three dimensions; comprehensibility, manageability and meaningfulness which are the basis for successful coping with stressors, according to Antonovsky. Patients answer statements on a 7-point Likert scale, rendering a total score from 13-91, where higher scores indicate a stronger sense of coherence. Several studies have demonstrated high reliability with alpha values between 0.74-0.91 (Antonovsky, 1993, Antonovsky *et al.*, 2003).

ECOG-PS (Eastern Cooperative Oncology Group) is a one-item instrument measuring physical performance status in patients with cancer, scoring from 0 (fully active) to 5 (dead) (Oken *et al.*, 1982). The association between ECOG-PS scoring when reported by patients compared to the physician, correlates moderately according to Kendall's correlation 0.58-0.61 (Conill *et al.*, 1990). Therefore patients in our study scored the ECOG-PS themselves, using the scale steps 0-4, where 4 signifies a

person who is completely disabled and cannot carry out any self-care and is totally confined to bed or chair (Oken *et al.*, 1982).

Written comments

The last page of the questionnaires contained an empty page where patients had the option to write comments regarding the information they had received during the hospital stay and about information they wanted to receive. The data consisted of 14 pages of comments altogether (Paper I).

Data from medical records

The *ASA*-physical classification system was used to classify patients into levels of preoperative health status (Owens *et al.*, 1978). The system was developed by the American Society of Anaesthesiologists to grade patients' risk of complications during surgery (ASA, 2014). According to the instructions on the webpage, there is no additional information to help to define these categories further, apart from the classification system itself in Table 6. In our study the classification was made by the anaesthesiologist as a part of the preoperative assessment before surgery and was registered in a computerized system used in the surgery department. Only ASA 1-4 occurred in our study.

Table 6. ASA Physical Status Classification System

ASA 1	A normal healthy patient
ASA 2	A patient with mild systemic disease
ASA 3	A patient with severe systemic disease
ASA 4	A patient with severe systemic disease that is a constant threat to life
ASA 5	A moribund patient who is not expected to survive without the operation
ASA 6	A declared brain-dead patient whose organs are being removed for donor purposes

(ASA, 2014)

A simplified version of the *TNM* Tumour stage was used in this study to divide the prognostic stage into I-IV. T refers to tumour and how deeply it has penetrated the colon wall, N stands for lymph node involvement, and M stands for metastases if the cancer has spread to other body parts. In stages I and II the cancer is confined to the intestinal wall; in stage III it has spread to regional lymph nodes and in stage IV it

denotes distant metastasis (Sobin *et al.*, 2002). TNM was registered in the pathology report in the computerized medical record.

ISCO-88 is the International Standard Classification of Occupations, a classification that organizes different professions into skill levels (ILO, 2014). The skill levels 1-4 represent a value set for the variable occupation, classified through different tasks and duties of jobs (Paper I, Table 1). Higher level means that more skills and education are required to manage the occupation. Patients' occupations were registered in the medical record and classified into ISCO level by the study researcher.

Data from interviews

Patients provided verbal and written information for their next of kin, and both signed the written informed consent form before the data collection started. Patients participating in the interviews also filled in questionnaires, and this was done after each interview in order to minimize the influence of the questions in the questionnaire.

The participants were interviewed individually in their homes in separate rooms on two occasions, 1-2 weeks after discharge and a second time, 5-7 weeks after discharge. The interviews were semi-structured and performed between April 2007 and January 2009. All interviews were recorded and transcribed verbatim by two medical secretaries and one university student. All texts were closely cross-checked against the original verbal interview by the first author of the papers, and all disparities were rectified.

At the time of the second interview, one patient had received information that the diagnosis was a benign tumour. Therefore, the second interview and the next of kin's were excluded from the analysis.

The interview questions were the same with patients and next of kin and on both occasions. They started with a question like: *Can you tell me about the information you received before discharge and what you consider to be important information?* An interview guide was used and embraced the following areas:

- Experiences related to receiving information before discharge.
- What information do you need now after surgery and discharge?
- What information is of the most importance?
- How you want to receive this information?

The data from the interviews constituted 431 pages of text for Paper III and 312 pages for Paper IV (A4 format, single-spaced).

Analysis

The analyses in this thesis are both quantitative and qualitative.

Statistics

Since data from the EORTC instruments were transformed to interval data, parametric testing was used when the criteria had been fulfilled. When the data were not normally distributed, non-parametric tests were used. Both descriptive and analytical methods were used to analyse the scoring from the questionnaires. The computer programs SPSS 17 and PASW 18 and 22 were used to analyse the data for Paper I and II. A p-value of <0.05 was considered statistically significant.

Imputation of missing data

EORTC recommend the use of imputation (mean substitution) when a respondent has missing values in some items. In this thesis a stricter variant than that in the EORTC instructions was used for imputation (Fayers *et al.*, 2001, Fayers and Machin, 2007). When there were three or fewer items missing in QLQ-INFO25, QLQ-C30 or QLQ-CR38 respectively; the mean value for the whole group on that subscale was then used (in study I two items or fewer were used in QLQ-C30 and QLQ-CR38). Due to too many missing values in three subscales concerning sexual enjoyment (Paper I and II) and sexual problems (Paper II) in QLQ-CR38, the results from these subscales were not included in the analysis.

Statistical analyses

The Kruskal-Wallis test was used to investigate differences between the three hospitals concerning: age, LOS and QLQ-INFO25 Global score. The Chi square test and Fisher's Exact Test were used to analyse differences between the two ERAS hospitals and the non-ERAS hospital concerning information needs (one item from QLQ-INFO25 *Do you wish to receive more information?*).

To explore the perceived information and to identify factors affecting received information a hierarchical cluster analysis was performed using Ward's method on all subscales of QLQ-INFO25. A two-cluster solution was chosen. Cluster 1 included

patients that scored more received information and cluster 2 those who scored less received information. Differences in nominal data (gender, living alone) between the clusters were analysed with Chi-square test, and differences in ordinal and interval/ratio data (ASA, age) were analysed using Mann-Whitney U-test.

The results of the QLQ-INFO25 questionnaires were used as the main dependent variable. A multiple linear regression analysis with backward elimination was performed in order to identify determinants of the variation in the QLQ-INFO25 Global Score. The independent variables gender, ASA, LOS, age, cohabitation, Skill level, ECOG-PS, SOC-13 and surgical complications were included in the final regression analysis. To test the validity of the model the residuals (test for normality) were analysed using a histogram and the Kolmogorov-Smirnov test. The Nagelkerkes R^2 and the Hosmer and Lemeshow test were used to test the model's goodness-of-fit, that is, how well the model can predict future outcomes.

The factors used for analysis in Paper II were chosen for reasons of clinical relevance (tumour stage, HRQOL, SOC) and from the literature, including Paper I (ASA, gender, age, living alone) (Mazor *et al.*, 2013).

Wilcoxon's signed rank test was used to compare variables between the first two weeks and one month later. The Mann-Whitney U test was used to study variations between patients with low and high scores in ASA physical classification, cohabitation, low or high tumour stage, gender and differences between hospitals. Spearman's correlation was used to study association between QLQ-INFO25 and SOC.

Clinical significance

Measures of clinical significance were used to convert data from the QOL measurements to the clinical situation. A commonly applied method is the definition of a change in QOL as more than 10 points (after linear transformation) (Osoba *et al.*, 1998). In a review article with 82 articles reporting QLQ-C30 data, the mean value was the most common way to report the findings and was used in 94% of the studies, while clinical significance was used in 38% of the studies (Cocks *et al.*, 2008). Changes between 5-10 points are considered to be a small change, 10-20 as moderate and >20 as large (Osoba *et al.*, 1998). Clinical significance is relevant in this thesis with regard to the cluster analysis in Paper I and the comparative analyses in Paper II.

Qualitative content analysis

Qualitative content analysis was used to analyse the transcribed text from the interviews in Paper III and IV and from the written comments in Paper I. An inductive method was used where the researcher let the codes and categories emerge directly from the interviews and the texts (Patton, 2002). Qualitative research is usually inductive in the early phase of data collection and analysis, but in the later phase existing literature is used to assure the authenticity and adequacy of the inductive findings.

The inductive analysis of the transcribed text can be done in many different ways and steps but the description of these steps shows similarities even though the terminology varies between different authors (Burnard *et al.*, 2008, Catanzaro, 1988, Graneheim and Lundman, 2004, Elo and Kyngas, 2008). The steps of the analysis process used in this study were inspired by Berg and Hsieh & Shannon (Berg, 2004, Hsieh and Shannon, 2005).

A conventional approach was used including both manifest and latent analysis (Hsieh and Shannon, 2005). The conventional approach is used when the study design is aimed at describing a phenomenon when the existing literature is limited. The advantage is that direct information can be obtained from study participants without applying preconceived categories or theories. Content analysis can also be divided into manifest and latent analysis, where *manifest* refers to those elements that are physically present in the text and the *latent* content is extended to an interpretive reading of the symbolism underlying the physical data (Berg, 2004, Hsieh and Shannon, 2005).

The main steps of the analysis

The transcribed texts from the first interviews were analysed as one text before reading and analysing the second interviews. This was done in order to get a general understanding of the participants' experiences from their first two weeks at home, before focusing on the next interviews. No comparison was carried out between first and second interviews or between participants from hospitals using ERAS or not. The main purpose of the second interview was to increase variation and not to make comparisons between the first weeks at home and one month later.

- The main study question was kept in mind at all times during the first general reading of the texts from the first interviews, while keeping an open mind to any unanticipated results from the data. The whole text was read again many times during the analysis process.
- Ideas were written down continuously during the reading process.

- Meaning units related to the research question were selected and coded. Four interviews were coded by two of the authors and then compared.
- All of the interviews, the meaning units and the codes were discussed at several meetings and led to different areas with various content developing into categories and subcategories.
- The whole text was read again to check the relevance of the categories and subcategories and to find if there were any additional areas of interest.
- Then the text from the second interviews was read and analysed in the same way. The categories and all subcategories from the first interviews were confirmed, while the content and meaning became richer and deeper. In Paper III one new subcategory about chemotherapy was added after the reading of the second interviews. In Paper IV a similar case occurred: a subcategory concerning further treatment with chemotherapy had come up in the first interviews but was quite tentative, becoming more comprehensive and evident after the second interviews.
- In the last step, all four authors reflected upon the findings and came to an agreement on one overall theme embracing the categories and subcategories in Papers III and IV respectively.

In Paper I the texts from the comments were analysed by a more simplified version by three of the authors. The entire text was read several times. Meaning units related to the aim of the study were identified in the text and grouped into categories, and then the text was read again to see if these categories corresponded to the original meaning of the text.

Pre-understanding

The interviewer had more than fifteen years of surgical and oncological cancer care experience in both the in-hospital and outpatient environments. She provided adjuvant and palliative chemotherapy treatment for patients with colorectal cancer for seven years, but finished this clinical work before the data collection of this study started. All the authors in Papers III and IV had several years' experience in surgical cancer care. At least two of the authors read all interviews several times during the analysis process, and the others read some of the interviews.

Software

The software NVIVO version 9 and 10 for computerized qualitative data analysis was used to sort and manage the interview data (Bazeley, 2007). Meaning units from the

transcribed texts were sorted into subcategories. The text with meaning units/citations from all participants in each subcategory became a new text and part of the analysis process.

Ethical considerations

The ethical considerations of this thesis followed the Helsinki declaration (WMA, 2013). It is the duty of the researcher to promote and safeguard the health of patients and those who are involved in medical research and to be guided by the ethical principles for autonomy, non-maleficence, beneficence and justice (Beauchamp and Childress, 2001). Every precaution was taken to protect the privacy of the participants and the confidentiality of their personal information. The participants could also withdraw from the study at any time. All research in this thesis was evaluated in the regional ethics review board in Lund 2006 (Dnr 558/2006).

Autonomy referred to self-governance in the old Greek independent city-states (Beauchamp and Childress, 2001). Its meaning has since then been extended to many other fields. In healthcare autonomy now involves individual choices, privacy and being one's own person. Most theories of autonomy agree that *liberty* (independence from controlling influences), *agency* (capacity for intentional action) and *understanding* (to a substantial degree) are the three principal conditions required for a patient to perform an autonomous action. A patient can experience diminished autonomy when being cared for by healthcare professionals and their authority can render it more difficult for the patient to exercise autonomy. This entire thesis focuses on the importance of information during the cancer trajectory for both patients and next of kin, and highlights the deficient autonomy they experience when there is a lack of information and understanding.

During inclusion of patients and next of kin in the study, a nurse manager or an RN on each ward invited patients to participate in the study. None of these had any previous relation to the patient or next of kin and were rarely involved in direct patient care. Patients were given verbal and written information in order to perform an autonomous choice whether to participate in the study or not.

Non-maleficence refers to not inflicting additional harm to an already vulnerable patient (WMA, 2013). It can be seen as the first basic step in guarding the patients' rights in medical and nursing research. In the following steps the focus changes from not inflicting harm to preventing and removing harm and to promoting good and contributing to patients' welfare, also referred to as beneficence (Beauchamp and Childress, 2001).

Doing harm can also imply injustice, violation or wrongdoing. In clinical research it can involve being promised a cure that is not achieved or finishing an ongoing treatment due to study protocol, which can lead to major disappointment and a feeling of emotional injury for patients and the next of kin. It could also involve asking for answers during interviews that cause emotional difficulties too early in the cancer process for the patient or next of kin to handle. In this study great care was taken both before and during the data collection to minimize the impact of the study on the participants physical, mental and social integrity (WMA, 2013). Before all interviews began, a period of time was spent listening to the patients' description of their current situation. After finishing the interview, patients could ask questions concerning nursing care and further treatment. If the interview situation highlighted a need for emotional support, contact with a counsellor was offered. One participant chose to meet a counsellor several times. Participants filling in questionnaires had access to the same support.

Positive beneficence and utility are two principles included in *beneficence*. Positive beneficence requires that participants are provided with benefits from the study; while utility involves balancing benefits and disadvantages for the patients. Several patients and next of kin clearly demonstrated how much they appreciated having the opportunity to talk to the interviewer after finishing the interviews, to discuss treatments and to ask questions concerning information that they had not understood or things that they wanted to know more about. This meant providing the participants with benefits in order to balance the possible disadvantages to some extent.

The principle of *justice* in healthcare can be applied to having the same access to healthcare. If the patient loses benefits or has increased burdens due to the particular situation as a patient, he or she would suffer from injustice (Beauchamp and Childress, 2001). This could involve a wrongful act or an omission of care, where patients have a right to a fair distribution of healthcare. Aristotle's quotation: 'Equal must be treated equally, and unequals must be treated unequally', constitutes the minimal requirement in all theories of justice. This appears to be non-controversial, but equality could be hard to accomplish, and how does this differ between an individual patient and a group of patients? To be offered participation in research can be viewed as having fair access to the advantages of research, both for the patient with cancer and the next of kin. They both constitute vulnerable groups to include in research, but if the participation could provide benefits to them in some way it would be unjust not to offer them participation in the study. By attaining access to more information patients (Paper III) and their next of kin (Paper IV) received more support in order to deal with their situation more effectively.

Results

The results from the four studies in this thesis are presented under the following headings: *Patients' experiences of information, information needs, HRQOL and related factors*; *Patients' experiences of information and their information needs* and *Next of kin experiences of information and their information needs*.

Patients' experiences of information, information needs, HRQOL and related factors

The findings in this paragraph comprise evaluations of patients' received information, information need, HRQOL, SOC-13 and ECOG-PS from Paper I-II.

Received information

The results in Papers I and II show the highest mean scores in received information in two subscales (in brackets first and second measurements); *Medical tests* (60.2/59.6) and *Disease* (42.0/47.3), Figure 5. Patients reported lower scores in several subscales such as: *Things to help yourself* (32.3/30.0), *Treatment* (30.8/35.2), *Different places of care* (14.4/12.5) and *Other services* (14.2/15.2).

Patients scored low in *Received written information* (32.6/42.7) and high in *Want more information* (52.1/44.7), both indicating low quality and amount of received information. In *Satisfaction with information*, patients scored (57.5/60.1) and in *Has the information been helpful?* (60.8/60.7).

Patients' scoring in QLQ-INFO25 did not differ between the first measurement 1-2 weeks after discharge and at 5-7 weeks, only in the subscale *Disease*, patients indicated more received information at 5-7 weeks.

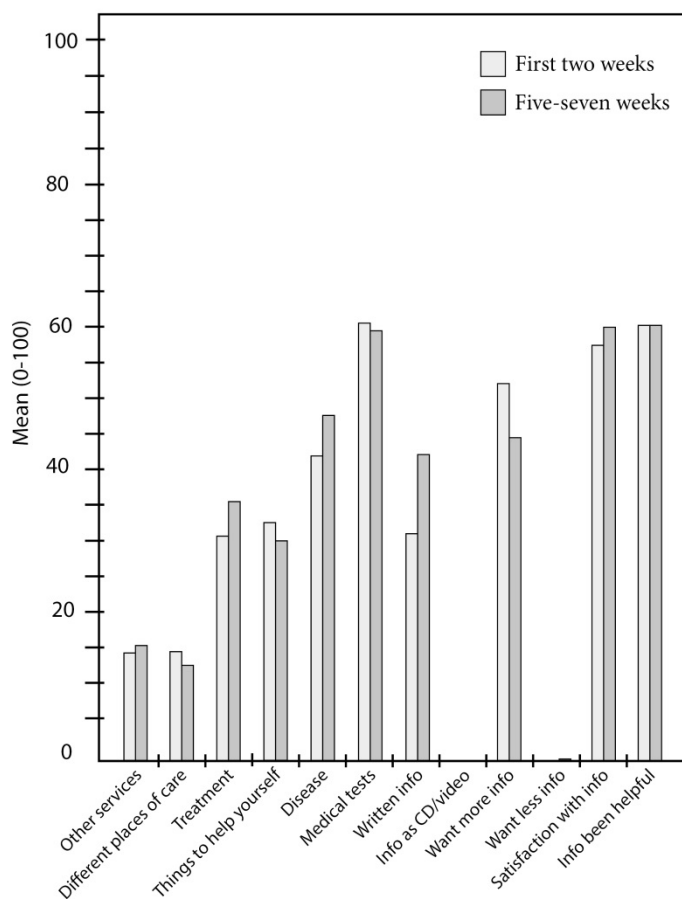


Figure 5. Perception of received information QLQ-INFO25 (high scores mean more received information or better quality)

The cluster analysis in Paper I revealed two groups of patients, indicating that they obtained more or less information before discharge for colorectal cancer surgery. There was a large and significant difference in information needs between the clusters. Among patients who had received more information, fewer wished to receive additional information (mean 24.2) compared to the other cluster (mean 87.9) ($p < 0.001$) (Paper I). In regard to receiving written information, the clusters also differed; the scoring were mean 2.4 in the cluster with less received information and mean 56.2 in the one with more received information ($p < 0.001$).

Functions, emotions and physical condition (HRQOL)

The results showed that patients' HRQOL was clearly affected by the surgery during the first two weeks at home (Figure 6). The most severe symptoms were; *Fatigue* (47.6), *Weight loss* (37.0), *Pain* (32.8), *Insomnia* (31.3), *Appetite loss* (29.7) and problems with *Micturition* (29.5). Ten symptoms improved significantly to one month later but four did not; *Nausea* $p=0.05$, *Dyspnoea* $p=0.44$, *Insomnia* $p=0.08$ and *Financial difficulties* $p=0.53$.

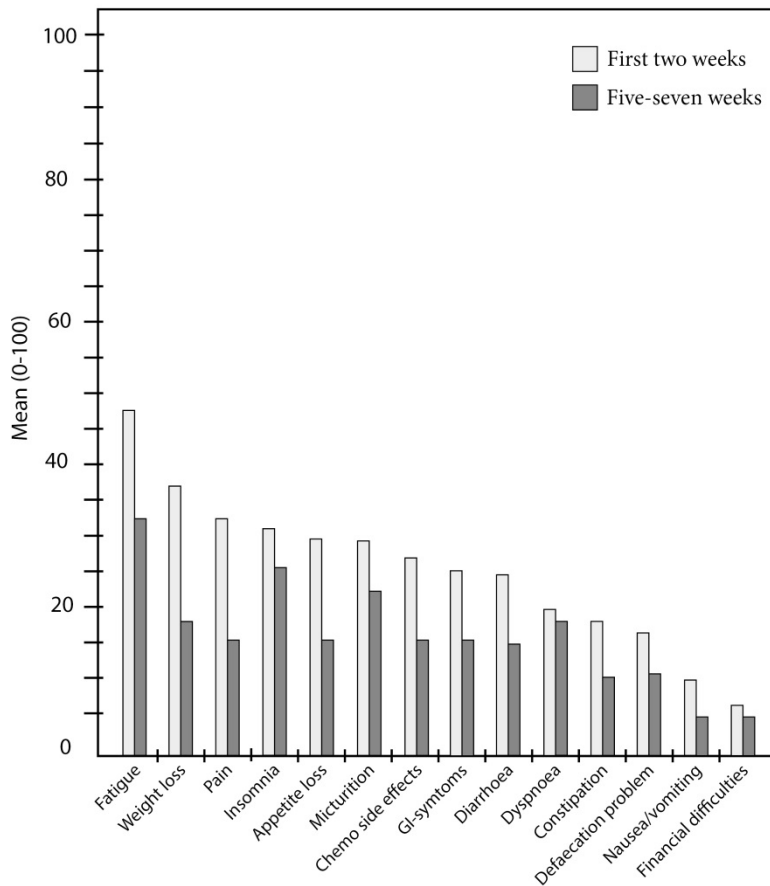


Figure 6. HRQOL Symptoms measured by QLQ-C30 and QLQ-CR38 (high scores mean worse symptoms).

Patients themselves graded their physical performance status with the ECOG-PS. During the first two weeks at home 11% of the patients were fully active, 42% were unable to carry out physically strenuous activity, 36% were able to manage all self-care, 4% managed some self-care and 1% was completely disabled.

The three functions in Figure 7 where patients indicated that they were most affected at 1-2 weeks were *Sexual function* (10.9), *Body image* (19.8) and *Role function* (45.6). These functions had improved significantly one month later.

The scoring of patients' *Emotional function* showed (78.3/79.9) in Figure 7, with no significant improvement the first month at home. Neither did the sense of coherence mean value change significantly during this period (70.1/69.5).

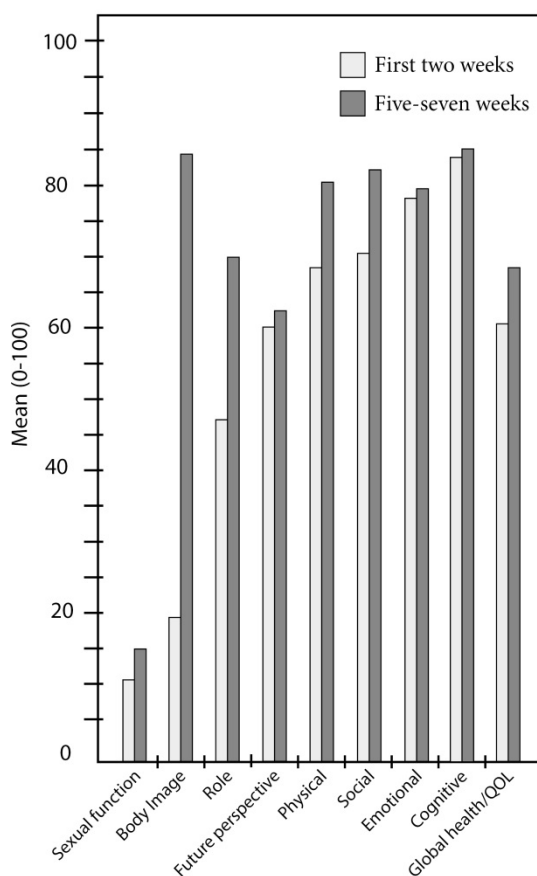


Figure 7. HRQOL Functions and Global Health/QOL measured by QLQ-C30 and QLQ-CR38 (low scores mean worse symptoms or low QOL).

Factors related to received information

The variation in QLQ-INFO25 Global Score was explained up to 7% by the gender and ASA score, indicating that women and patients with worse preoperative health status obtained less received information. These results from Paper I were confirmed in Paper II, where patients with ASA 3-4 reported significantly less received information in subscales concerning the Disease, Treatment and Medical tests 5-7 weeks after discharge. This group of patients also scored worse HRQOL and had a lower sense of coherence compared to those with ASA 1-2.

The scoring of QLQ-INFO25 in Paper II was associated with cohabitation, where patients living alone scored lower on all subscales/items of received information except one. Two of these were significant: information concerning Medical tests (diff 14.5, $p=0.02$) and whether the information had been Helpful (diff 13.3, $p=0.02$).

In Paper II receiving written information was significantly associated with being a patient from an ERAS hospital compared to a non-ERAS hospital ($p=0.04$). However, no difference were observed regarding information needs between ERAS and non-ERAS hospitals according to the item 'Wish more information' ($p=0.39$).

Patients' experience of information and information needs

These qualitative results derive mainly from the interviews in Paper III.

The overall theme in Paper III showed that patients tried to regain control in life by using information. The main categories concerned *Using information to make daily life work*, *Wanting to partake in the information* and *Needing information to manage the worries and make the disease comprehensible*.

Patients wanted to receive more information on certain areas of information but also elaborated on how they received information and what consequences this had for the first time spent at home. They wanted to participate in the information process; to be able to participate in both the planning of the discharge process and what information they would have access to, as well as having time to ask questions. The information needed to be honest and straightforward, and they needed the information to be provided in a mutual meeting in a separate room.

One area of information concerned being prepared to handle daily life when returning home from hospital. Knowing what to expect during the first weeks at home and how to improve recovery was described as important information and was often missing. Patients often commented on how the waiting for the next set of

information worried them and made it hard to resume their normal life. They both wanted and dreaded more information. Receiving information about the need for continuous treatment with chemotherapy was a new obstacle to be overcome. New information was needed to manage this phase of the cancer trajectory, such as information on practical planning of treatment appointments, what side effects to expect and more existential questions as to how the chemotherapy would affect their chances of survival.

To understand the cancer disease and to manage the worries it created was an area that patients kept coming back to again and again with different words and expressions. Information was vital to manage both. They had a need to understand the cancer, what it had brought into their life and how to manage it in the best way. In order to accomplish this, the patients needed both time and access to information. They feared the recurrence of the cancer and needed to know how serious the cancer was and what to expect in the future. They moved between hope and despair depending on which information they had last received. The lack of important information increased both anxiety and insecurity, while receiving information helped to bring about calm and peace-of-mind.

Next of kin experience of information and information needs

The next of kin presented their view on both their information needs and their experience of trying to access information from healthcare professionals and the patient in Paper IV.

The analysis of the interviews revealed an overall theme where next of kin needed more information and preparation in order to manage the strain of a new demanding role of being the closest person to a patient with colorectal cancer. The main categories concerned *Participating in the patient's life*, *Being a support* and *Being in a condition of waiting*.

Next of kin reflected over the complexity and the responsibility of the role. It included managing their own feelings and worries for the present and the future, sharing all parts of the patients' life and supporting both the patient and the rest of the family in different ways.

In order to fulfil the new role of being a support, it was vital to participate in the patient's life and to have access to the same information as the patient. The next of kin needed to be included in the patients' cancer trajectory, to receive verbal

information along with them and to have the opportunity to ask their own questions. Next of kin wanted to know in advance when the discharge conversation would take place and to be there with the patient. They emphasized the importance of being treated well and listened to during these meetings with the healthcare professionals. They voiced many concerns about the disease and asked for information on: how malignant the cancer was, how fast it was growing, how many lymph nodes contained cancer and what that really meant. The most urgent question was if the cancer was gone and the risk of recurrence. Being next of kin to a patient who needed chemotherapy created further difficulties in an already demanding situation. Next of kin expressed the need for information about: the significance of chemotherapy, why it was needed when all the cancer was removed and how much the therapy would improve the chances for survival. They also needed practical information about treatment times and what side-effects to expect.

Being a support meant helping the patient and the family to meet their needs both practically and emotionally. To be able to give that kind of support, next of kin first needed to receive some support themselves. They needed to be prepared for what to expect during the first weeks at home, what physical and emotional needs the patient could have and how to support them in the best way. They reflected about how much the healthcare professionals really knew about the patient's situation at home, seeing that the information the patient and they themselves had received was lacking in important areas. Since the next of kin coordinated the patient's and the family's life and dealt with relations to friends and persons outside the family, they became a very important person in the patient's cancer trajectory. In order to manage this role, the next of kin needed information about the disease and treatment, but also on how to meet the special needs of their children and the best way to help the patient process emotional distress with regard to the cancer diagnosis.

Waiting times for information were considered to be too long by the next of kin and seriously affected family life. Other plans had to be put on hold until information had been received or until the next appointment had been booked. Waiting for information on different investigations and not knowing when these would be ready and when they would receive the information became a hurdle for the next of kin and the family. The waiting in itself increased the anxiety and uncertainty next of kin experienced in this situation and they described it as severe and difficult. Next of kin had many thoughts about the future and how things would turn out if the patient did not survive cancer. When asking about chances for survival and what the future might be, next of kin did not get any answers from the healthcare professionals, which increased their anxiety.

Discussion

Methodological considerations

In all research, the methods used to obtain findings need to be questioned before the utility of findings can be assessed and conclusions proposed.

Validity

The concept of validity can be defined as the relevance of the data collected for the selected problem being examined and the ability of the instruments to measure what is to be measured. Even though all instruments had frequently been used in clinical research before, the results and conclusions need to be questioned. To establish the validity of a questionnaire is part of a process of determining which conclusions that can be made about a group of participants, based on the scores from this instrument (Streiner and Norman, 2003). The most the researcher can conclude from a study is that the instrument is valid in this group of participants at this specific time.

Internal validity refers to how much an investigation can eliminate alternative explanations for the results (Kazdin, 2003). One threat to internal validity could be an unplanned event that occurs and affects the results which Kazdin refers to as a *history*. Data collection over a long period of time could present such a threat. There could be changes during this period as to how patients and their next of kin are informed. However according to the nurses, who selected patients for screening at each hospital, there were no changes in the organization of information given to patients or next of kin during this period. The introduction of enhanced recovery after surgery, ERAS, could also be assumed to affect the scoring of QLQ-INFO25. In hospitals B and C this had already been done before the data collection started, and in hospital A, ERAS was introduced after our data collection was finished.

No check was performed in order to determine whether the participant in the study actually filled out the questionnaire at home himself or herself (Papers I and II). Individuals suffering from fatigue or other symptoms during the first weeks at home might have received help from next of kin, which, in turn, could have affected the

scoring and the internal validity to a certain extent. Even if next of kin have influenced the answers slightly, these could still be close to the patient's own answers. When the next of kin acts as a proxy and grades the experiences of the patient, the difference in scoring between patients and the proxy tends to be small, with a tendency for next of kin to score slightly lower in functions and higher in symptoms (Fayers and Machin, 2007).

The results from QLQ-INFO25 during the first two weeks at home concerning the need for more information, remained at the second data collection one month later and demonstrate that the need still exists. Similar results with apparent needs for additional information are also evident in both interviews in Paper III, which support the validity of the findings from the questionnaires.

One weakness of the study design in this thesis was that it was not possible to establish retrospectively what information that had actually been transferred. Observations could have improved this part of the design and illuminated the content and quality of the information exchange between both patients and their next of kin and the healthcare professionals.

Construct validity refers to the interpreting of the causal relationship presented in a study. Here, it is applied to the degree to which the instrument measure the intended construct (Kazdin, 2003, Streiner and Norman, 2003). When measuring variables that are not directly observed and instead using underlying factors, constructs are used to explain the relationship between behaviours and attitudes. In the design of this thesis, the intention was initially to find an instrument for measuring patients' information needs during the first period after discharge for cancer surgery. In one of the earliest publications of QLQ-INFO25, the instrument construct was defined as evaluating the cancer patients' information needs. In the further development of the instrument, the main construct of the instrument was changed to evaluate cancer patients' received information and this could therefore constitute a threat to the validity of the construct (Arraras *et al.*, 2007). At the time of the next publication of the instrument, our data collection had already started and the main focus of the thesis was broadened from investigating information needs to also comprising the evaluation of received information. Nineteen of the 25 items in QLQ-INFO25 address the amount of received information and six items address the quality aspects. One item specifically asks the patient if he or she wishes to receive more information. Low scores on received information can be interpreted as being in need for more information in these subscales or items.

In QLQ-INFO25 all items are linearly transformed from the original response alternatives on a Likert scale to 0-100 according to the EORTC manual (Fayers *et al.*, 2001). Since the one item that asks patients if they wish to receive more information

is a yes/no question, this raises questions about the meaning and clinical significance of a mean value of 52.1 from 100 patients during the first two weeks at home after discharge for CRC, Paper I. The significance of HRQOL measures in clinical practice varies with regard to the phase of the patient's trajectory and the purpose of the measurement. HRQOL is often used to compare the effect of different interventions and treatments between groups where changes in 10 scores is considered a relevant clinical change, but this usefulness can be extended considerably (Osoba, 2007). Measuring HRQOL can be a natural part of the patient's trajectory. In the diagnosis phase, the scoring can be used to identify problems and symptoms that are relevant in order to obtain a correct diagnosis. The patient's HRQOL can be used in combination with blood and imaging tests to evaluate the effects and side-effects during the treatment phase. It can also be used to identify remaining problems and symptoms concerning the cancer and the treatment during the early and late follow-up phases. In one publication, the scoring of HRQOL was used to identify support needs of the patients (Snyder *et al.*, 2010).

When it comes to *statistical conclusion validity*, this comprises the classification of threats related to data evaluation. Here statistical power, how to choose statistical methods and which interpretations of findings are emphasized is noted (Kazdin, 2003). Low statistical power can be a threat to validity. Due to the exploratory design, no hypothesis was tested and no power calculation was performed. When using a quantitative explorative design, the number of participants is usually lower than in a confirmative study design (Burns and Grove, 2009). The number of participants in our study could of course be discussed, but it was estimated that 100 participants would lead to clinically interesting findings. Some difference in scoring of QLQ-INFO25 was expected between the first two weeks at home and after the post-discharge visit when important prognostic information was conveyed, but this difference was not evident in the findings (Paper II). This could be explained by having too few participants but could also be explained by the different perspectives on the importance of information displayed by the healthcare professionals designing the project and by the patients. Patients and next of kin might see the information more as a process than as one moment of extremely vital information.

The choice of statistical methods was guided by the overall intention of looking for variations during these seven weeks of the cancer trajectory. Further analysis also aimed at identifying factors associated with changes in perceptions of received information, and groups of patients that were expected to be more vulnerable. The findings reported were chosen for these same reasons and a balance in reporting both significant and non-significant findings was aimed for.

The *external validity* refers to the extent to which the findings can be generalized (Kazdin, 2003). One threat to external validity is the level of homogeneity of the

sample characteristics. Since there are few younger people or people who are not proficient in Swedish in this study, the results might not reflect all groups of patients. All results are based on patients with colorectal cancer, but parts of the findings concerning this specific phase of the trajectory could also be used in other groups of cancer patients. However, this proposal would need to be confirmed in future studies.

Selection bias could also be another threat to validity with regard to the selection of patients for this thesis. This could mean unconsciously avoiding specific groups of patients, for example, very sick persons. Since different nurses checked patients for eligibility in the three hospitals, this risk was reduced to some extent. In all three hospitals, all elective patients were registered in handwritten calendars; these were used to identify which patients could be screened for inclusion. This meant that each patient was given the same opportunity for participation and increased the probability of the sample being representative for the population.

Another risk for selection bias is that patients with reading and writing difficulties might have chosen to not participate in the study. This group constitutes about 5-8% of all people and can be expected to be a vulnerable group when it comes to receiving information during the cancer trajectory (Dyslexiföreningen, 2007). The group of patients who do not speak Swedish as a first language was not fully represented and could also be assumed to constitute a group with extensive information needs. Also the drop-out rate of patients could have been affected by literacy problems. Even though all participants could call up the researcher who collected their data, some patients who did not fill in the questionnaires might have been helped by a phone call offering support in dealing with the questionnaires.

Reliability

In psychometric testing, reliability refers to the extent that the measures assess the characteristics of interest in a consistent matter (Kazdin, 2003). A measure cannot be regarded as valid without reliability, even though reliability does not assure validity. Measuring internal consistency with Cronbach's alpha coefficient is one of the most widely used measures for the reliability of a questionnaire (Streiner and Norman, 2003). Cronbach's alpha refers to the degree to which the subparts of an instrument are measuring the same attribute or dimension. If there are many items in one instrument, the size of the alpha value increases. If alpha value is too high, then this may suggest a high level of item redundancy: when a number of items ask the same question in slightly different ways. Cronbach's alpha should therefore be above 0.7, but not much higher than 0.9, according to Streiner and Norman (2003). QLQ-INFO25 is the main instrument in Papers I and II and the alpha value for the

raw data was 0.895 (paper I). This is similar to the published validation studies for the instrument with alpha 0.91 (Arraras *et al.*, 2010) and 0.90 (Arraras *et al.*, 2011). This indicates a high internal consistency, even though the number of items is 25 and could contribute to the high value. QLQ-CR38, on the other hand, have had difficulties in reaching the lower threshold of 0.70 for an alpha value (Streiner and Norman, 2003). A later version of the questionnaire QLQ-CR29 demonstrates improved alpha values (Whistance *et al.*, 2009).

Trustworthiness

There is an ongoing discussion in qualitative research about the importance of having unified criteria for assessing and grading qualitative research (Cohen and Crabtree, 2008). However there are disparities about which concepts should be used. Some argue that qualitative research needs its own concepts, via the overarching concept of trustworthiness, while others emphasize the importance of using the same concept for all research and then referring to validity and reliability (Morse, 2002). Tenable arguments can be found for both approaches, but in this section trustworthiness has been chosen for the discussion of the qualitative methods with regard to credibility, dependability, confirmability and transferability (Lincoln and Guba, 1985) .

Credibility can be compared to internal validity when looking at the selected method and selection of participants. Credibility means viewing the quality of the data collection and to what extent the data and the analysis process are consistent with the purpose. The inferences made in the results need to be well-founded, ensuring that the results emanate from the participants' data and not from the researchers' pre-understanding and perspectives (Marshall and Rossman, 2006). The mode for selecting participants for the interview studies started with consecutive inclusion in three different hospitals. When the researcher listened to the audio files from the first eleven patients to check the transcribed material, it was noted that there were fewer younger participants and that they contributed more data related to the aim of the study. To enhance the credibility of the study, the criteria were changed and patients of working age were selected from then on. A total of sixteen participants was proposed and estimated to be feasible when performing two interviews with each participant. Another method would have been to include about ten patients and then transcribe and read through the texts to see if the last interviews conveyed any new data material. This process could continue until the researcher could see that data was being replicated. Many authors describe in detail how to select participants for interview studies, focusing on the importance of the setting the criteria and how the interviewer's qualities will affect data quality. However, very few discuss the actual

numbers of patients that must be included in order to attain credible findings (Berg, 2004).

The same questions were used during both interviews in Papers III and IV. In order to enhance the credibility, the interviewer could have listened to the first interview before doing the second one and used the opportunity to take further the questions that had been discussed the first time.

To cover the information needs during the first seven weeks at home, two interviews with each patient and next of kin were performed. This was done to enhance the variation in the material and increase the quality of the data, since repeated interviews are known to improve data quality (Burns and Grove, 2009).

The part of credibility concerning how well the data and the analysis process are in line with the aim of the research needs to include some comments on the latent analysis of the interview texts. As can be seen in the interview guide, the questions did not aim at a particularly deep level of contemplation concerning the participants' desire for information. However, both patients and next of kin illustrated a clear desire to talk, not only about the content of information, but also about their experiences and feelings connected to receiving or not receiving information. This added more data and depth to the analysis and made the latent part apparent while also improving credibility. The enlarged scope for the interviews followed the same path as the development of the QLQ-INFO25: in both cases the aim became broader in order to also comprise the experiences of receiving information.

Dependability deals with how the researcher attempts to account for changed conditions in the studied phenomenon or in the design. Steps to establish dependability should be included in the research process in order to repeat and confirm the researcher's observations. This differs to the positivistic concept of reliability that assumes an unchanging world where studies can be replicated in an identical manner (Marshall and Rossman, 2006). In this study, the interview guide was discussed several times before the data collection started. To enhance dependability one of the researchers listened to the first two interviews and made small adjustments to the questions together with the interviewer.

Confirmability refers to the traditional concept objectivity and whether other researchers arrive at the same interpretations and conclusions (Marshall and Rossman, 2006). In order to enhance credibility for the interview studies, at least two analysers read the entire text once and the first author read the entire text several times. The coding done by the first author was cross-checked and discussed with the most experienced analyser. The final results of categories and themes were discussed during meetings with all authors. The original data was checked and rechecked several times during the analysis process. One way to establish confirmability is to attest that the

interview texts and findings actually emerged from the interviews. Using an external reviewer who checks the audio files, the transcribed interviews and findings is one way of increasing confirmability (Lincoln and Guba, 1985). This audit would take one person between one week to ten days to perform, and this was not done for this thesis. The use of citation from the interviews would be another way for the reader to see links between the original data and the findings. At least one citation was used to illustrate all subcategories in Papers III and IV.

Transferability means generalizing results to other settings and populations, and it requires that the context is made clear and is well understood. According to Lincoln & Guba (1985), proving transferability lies less in the original researcher procuring the results than on the person wanting to apply the results in a new context and population. The researcher's responsibility is, on the other hand, to clearly describe the studied group and the context. Similarities in information needs can be found when compared to other cancer diagnoses. In a study comparing information needs between patients with gynaecological, colorectal and breast cancer, there were similarities between patients in the first two groups when it came to information needs and how they achieved their preferred role in decision-making (Beaver and Booth, 2007). This suggests that some needs exist in several different cancer diagnoses.

Measurements contra interviews

The quantitative studies provide no knowledge of *why* certain factors are strongly linked to received information or information needs. There might be important factors that better explain the need for information, that were not included in the survey. The qualitative studies, on the other hand, produce a different kind of knowledge about the articulated need for information among patients and next of kin, but could not establish if this is the same as an *actual* need for information. Therefore a combined approach with questionnaires and interviews in order to explore patients' experiences and needs was chosen. In this explorative study both methods were useful and emphasized important areas where improvement were needed. However, in order to further increase the knowledge in this area, more studies are needed and this raises the issue of which methods to use in order to enhance knowledge and evaluate interventions.

Patient Reported Experience Measures (PREM) and questionnaires like the EORTCs are widely used in cancer care but are rarely questioned (de Silva, 2013, Fayers and Machin, 2007). Neither the items, subscales or the concept HRQOL are clearly defined. One strength with EORTC's questionnaires is that the content of the

instruments is developed in close collaboration with the patients (Arraras *et al.*, 2004, Arraras *et al.*, 2007) where interviews are used to establish important items and to evaluate the first versions of the questionnaires.

In one study the measurement of patients' HRQOL was the main intervention (Velikova *et al.*, 2010). Patients filled in the HRQOL questionnaire before the visit to the oncologist, who received a graphic printout of the results before the consultation. Patients in the intervention group rated their communication with the oncologist as significantly better.

When making choices about methods, the construction and purpose of the instrument are essential as is the aim of the research. If the aim is to evaluate an intervention or to know more about how patients value the information, qualitative interviews could be used in both cases. The advantage is that fewer patients are needed and the risk of missing important areas for the patient is decreased. On the other hand, if questionnaires are selected, a clear definition of the concepts and the main focus is needed to ensure that it comprises the desired outcome that is to be studied.

General discussion of Results

In the findings, both patients and next of kin express a need for more participation in the information process. This covers different aspects: access to various information content, needing to know beforehand what will happen during the cancer trajectory, the relationship between patient, next of kin and the healthcare professionals and the consequences of waiting times. The inadequacy of the received information is visible in the findings from both questionnaires and interviews and this lack of information made it hard for both the patient and the next of kin to manage daily life at home after discharge. Both groups defined which areas where they perceived deficiencies and the consequences that this entailed. They did not know what to expect from a normal recovery and this created problems when it came to managing symptoms and understanding the timeline. Both patients and next of kin needed to know in advance what kind of information they could expect to receive and when and why they needed to wait a certain time period before receiving it. They also made a connection between the quality of the information and the relationship with the healthcare professional. When they felt they were not being listened to, or did not understand how to manage the recovery at home and did not know what to expect during the weeks to come, this increased the anxiety and created a feeling of being left out.

Participation through information

The need for patients and next of kin to be more involved was perceived as important as the content of the information. This association between participation and access to information is also evident in other studies. In a Swedish study with patients in both in- and outpatient care, the majority of the patients linked the access to information and the relationship with healthcare professionals to participation (Eldh et al., 2010). The most common description of participation was that the staff listened to them, that they received explanations about symptoms and problems, that the staff explained procedures and that they knew who to contact. In a concept analysis on patient participation, the relationship with the nurse is emphasized as a defining attribute of participation (Sahlsten et al., 2008). When the nurse surrenders some power and control to the patient and they share information and knowledge with each other, this enhances participation. However, if patients and families are really to benefit from information exchange, this needs to be integrated not only into clinical nursing care but into the entire surgical team working with the patient. Each patient and their family have certain characteristics, experiences and beliefs when they begin the cancer trajectory and these affect how they experience their need for information and the information-seeking behaviour (Johnson and Case, 2012). Healthcare professionals constitute an important channel for mediating information and can provide something that neither friends nor the Internet can: individualized and evidence-based information communicated in a mutual relationship. The findings suggest that the goal of communication would be to identify their experience of cancer, how they value the importance of information and which information channels they prefer to use. This analysis needs to be performed early in the cancer trajectory and be well-documented in nursing and medical records.

The findings in this thesis demonstrate that the surgical nurses were not visible to the patients and next of kin, even though they spend more time with patients than most other healthcare professionals. When patients and next of kin describe how they experienced the information, they mostly talked about the surgeons' verbal information. At the same time, there are clearly gaps in the information content that need to be filled, as well as a need for easier access and more time to discuss the implications of the cancer for both patients and next of kin. This indicates a need for nurses to take a more active part in the surgical team when it comes to providing information and emotional support. All the healthcare professionals involved need to collaborate closely and clarify how responsibilities differ between professions and to make sure that all important areas of the family's information needs are covered.

There were deficiencies in the way information was provided and the participation made available to patients and next of kin was insufficient. They needed to feel more recognized and listened to, and to be more involved in information and planning of discharge. They also needed more information in order to be able to process the feelings that arose due to the cancer and the treatment. They had difficulties in finding and using the best channels for accessing information, and wanted to be more active in seeking information but needed an invitation from the healthcare professionals and some guidance in order to do this. During the analyses of the interviews with patients and next of kin, the significance of information widened to comprise the communication between them and the healthcare professionals. Patient-centred communication means more than the provision of information. It entails a process of mutual influence where healthcare professionals and patients need to have common goals for the meeting; and the determining factor is the healthcare professional's individual ability to consciously adjust the communication to meet the patient's needs (Epstein and Street, 2007, Mazor et al., 2013). Patients and their families value characteristics of healthcare professional like trust, feeling recognized and acknowledged, experiencing caring and continuity. These factors are related to self-awareness in the healthcare professional who needs to distinguish patient's needs and perspective while keeping these separate from their own. Communication skills training for nurses and physicians can improve their confidence in handling difficult meetings with patients and make them more positive about meeting patients' psychosocial needs (Moore et al., 2013). They used more open questions and showed more empathy towards patients after finishing communication training. The negative effect of waiting for information was clearly present in both the patients and next of kin in this thesis. The waiting made it harder to control fearful thoughts and increased the feeling of being left out of the process. When patients with cancer feel that their healthcare professionals could have provided information but did not, they experience this as a serious and even harmful omission (Mazor et al., 2013). The opposite was also seen in the Mazor study, when healthcare professionals helped patients prepare and foresee difficulties, the patients' appreciation was very evident and they felt supported. In our study, when information was delayed this increased patients' fear and anxiety and contributed to the distress of the entire family. Since the capacity of the healthcare professionals to handle interpersonal relations is a crucial part of patient-centred cancer care, it is essential to create the necessary external conditions for these kinds of encounters. Providing a calm environment, ensuring sufficient time for listening and answering questions and a clear agenda for all persons involved are prerequisites for creating the conditions for good communication.

Going home after surgery

The variation in received information and information needs was small during the first seven weeks at home. Some changes in information needs were observed concerning chemotherapy: one month after discharge, interest had increased among both patients and next of kin. At the same time it was hard to distinguish whether the participants were only referring to the short period just before discharge or whether they viewed their information needs as a continuum. Irrespective of this, the preparation for discharge was often seen as unplanned, confusing and the information about the actual time they would go home came far too late. Most next of kin were not able to meet the patient in hospital or participate in the short talk with the surgeon or nurse, which mean they were excluded from the discharge process. The same scenario was observed in a study with older patients where only 22% of those who wanted a next of kin to be present at discharge actually experienced this (Foss and Hofoss, 2011). These findings confirm that the transition from hospital to home is one of the more vulnerable parts of the cancer trajectory.

The structured planning before surgery was contrasted with the unexpected and often confusing discharge. The preoperative information and preparations helped patients to feel calm and confident and able to trust the healthcare professionals. But coordination of what would happen at discharge was lacking and the allocation of responsibilities for the healthcare professionals and the patient was unclear. The day of discharge was often stressful and patients found it hard to understand the process and feel part of it. This inadequate discharge planning among patients with cancer has also been observed in other countries. In an interview study from Australia, patients declared that they found the planning for discharge insufficient and that some did not have any planning at all (Drury and Inma, 2010). In a study of readmissions among older patients (65+) in general medicine, the failure to develop a care plan was the most frequent cause for being readmitted within 30 days of discharge (Scott et al., 2014). These findings emphasize the importance of providing discharge planning that is adjusted to the individual patient's needs in order to improve both quality aspects and economic conditions in cancer care. A systematic meta-review showed some evidence to support educational discharge interventions, which improved knowledge, emotional status and medication adherence (Mistiaen et al., 2007). To combine discharge planning with some support after discharge showed a positive effect in reducing readmissions, but the authors of this meta-review did not discuss who should be responsible for implementing these changes. In order to meet the needs of the individual patient and their family, all members of the surgical cancer care team obviously need to be involved and contribute with their particular expertise. When patients and next of kin described

the day of discharge, they hardly ever mentioned the nurse, suggesting that this role was quite indistinct for the patients in our study. The same issue is observed in a review of best practice in discharge planning where the authors conclude that some staff nurses experience the responsibilities regarding discharge planning as being unclear (Carroll and Dowling, 2007). When it comes to planning the discharge with patients after cancer surgery, someone clearly needs to take the overall lead and responsibility for carrying out the planning. This will be a suitable challenge for the nurses, to embrace this area of expertise in surgical cancer care.

ERAS and discharge information

When patients were asked if they wanted more information or not, there were no significant differences between patients from hospitals using ERAS or those not using it. Nor were there any significant differences between the mean values of the Global score in QLQ-INFO25 or LOS. However, significantly more patients from ERAS hospital had received written information. Preoperative counselling is an evident and important part of the ERAS protocol since a well-informed patient requires less analgesia and has enhanced recovery; however the need for additional postoperative counselling is not yet officially part of the protocol (Donohoe et al., 2011). Noticeably few articles address the importance of preparing patients for discharge, but we managed to identify two publications investigating patients' experiences after CRC surgery with ERAS. The authors confirmed our findings by reporting that the main concern for the patients was better access to information during the early days after discharge, and that more than half of the patients have only slightly recovered or not recovered at all at the time of discharge (Blazeby et al., 2010, Jakobsson et al., 2014). In this thesis the low number of participants in each group (ERAS 45, non-ERAS 55) could be an explanation for not finding differences between groups, but the lack of adherence to the protocol could be another reason. In a Swedish study the adherence to the ERAS protocol was followed from the start and continued for five years (Gustafsson et al., 2011). When ERAS was introduced the adherence to the protocol was 43.3%; at the end of the five years it had increased to 70.6%, indicating that several years are required in order to learn and implement ERAS.

ERAS is a structured programme but the last part, which involves preparing patients for leaving the hospital, seems to vary in quality. Even though some information concerning the first period of time at home is provided during preoperative counselling, this needs to be repeated and reinforced just before discharge. New questions have probably arisen during hospitalization that patients and next of kin need answered before discharge. When evaluating ERAS with interviews, patients

with complications experienced the enhanced recovery programme as less satisfactory (Blazeby et al., 2010). This could indicate that more vulnerable patients might end up outside the system, and not receive the support they need.

Transitions during the cancer trajectory

The transition from hospital care to home clearly resulted in increased vulnerability and greater information needs among both patients and their next of kin. The vulnerability in transitions always involves some change, acute or gradual (Blum and Sherman, 2010), and this change in responsibility from receiving attention and care from healthcare professionals during hospitalization to being on their own at home made both the patient and the next of kin feel uncertain. They became aware of their need for assistance to facilitate this transition in a smoother and better way.

Another transition was receiving information about the need for additional treatment with chemotherapy. This was as difficult emotionally as being diagnosed with cancer. In a study with newly diagnosed patients, the initial response to this kind of threat was to block out the information until they were able to process it. For some patients this could take hours or even weeks until they could open up to seeking and receiving information again, while others wanted immediate answers about the next step (Mazor et al., 2013, McCaughan and McKenna, 2007). Withholding information is another known protective mechanism patients use in order to shelter the next of kin from fear and stress (Li and Loke, 2014). This kind of protection was not appreciated by the next of kin in our study: it led to reverse effects and caused frustration and feelings of being left out. These complex reactions increase the need for healthcare professionals to employ careful listening before providing information that might be too much at a specific point in time.

Communication with patients and next of kin during the cancer trajectory involves much more than an exchange of information. It is clear from our results that both patients and next of kin value the relationship with healthcare professionals very highly. If the relationship does not function as desired, patients and next of kin might not take in the actual content of information and not see it as particularly important. The relationship comes first and allows patients and next of kin to open up to receiving and assimilating the information. Before providing information it is important to create suitable conditions for communication by responding to emotions, managing uncertainty, enabling self-management and forming a basis for decision-making (Epstein and Street, 2007). Among the most difficult experiences reported by patients is when the information concerning diagnosis and prognosis is insufficient in quality or quantity (Thorne et al., 2014), but receiving too much

information at the wrong time was also seen as disrespectful. When patients with CRC and their information needs are studied, as many as 62% of the studies do not address the stage of the cancer trajectory, (van Mossel et al., 2012). The findings in this thesis indicate that the dynamics of transitions in the cancer trajectory are an important factor to be considered and that must be more prominent in both clinical care as well as in future research.

Vulnerable groups

The results showed that having worse health status before surgery also had implications for the following phases of the cancer trajectory. These patients noted that they had received less information and were less satisfied with the information than healthier patients. It is hard to establish the exact process and reasons for these findings, to know whether the major obstacle is assimilating or accessing the information. The fact that gender is associated with information-seeking and satisfaction with information is well-known from earlier studies, with women expressing greater information needs (Johnson and Case, 2012). This could be connected with differences in how men and women view the importance and usefulness of information; men tend to put a lower priority on healthcare compared to other demands upon their attention, while women often act as caregivers for their families and pass on information to others (Johnson and Case, 2012). In this thesis, cohabitation was another demographic factor associated with both stating less received information and finding it less helpful. When testing the CMIS model in a health-related context, the antecedent factors like demographics, personal experience, salience and beliefs had only a small impact on information-seeking. This could suggest that the hospital context where much of the communication takes place is a more significant information-carrier. When patients singled out the most important aspect of information, they stated that receiving answers to questions was the most central and vital concern (Johnson and Case, 2012).

These results emphasize the need to identify risk factors before surgery and to adjust the discharge planning and information according to health status, gender and cohabitation status. It is also important to establish the family's involvement early in the discharge planning and include them in the communication insofar as this is possible (Bauer et al., 2009). The support for more vulnerable patients must continue after discharge and, when needed, be coordinated with municipal home care.

Patients with other kind of cancers

Receiving a cancer diagnosis always signifies a need for information, and this need demonstrates several similarities among patients with different kinds of cancer, regardless of diagnosis (Nagler et al., 2010). The most important information needs among different kinds of cancer was quite similar: prognosis/cure, disease stage and treatment options are the three most reported areas of information needs. This was seen in patients with breast, prostate, colorectal, lung, esophagus and gynaecologic cancer (Tariman et al., 2014). These cancers are all mostly treated with surgery and often with the addition of chemotherapy, but the impact of the surgical treatment differ to some extent between breast and esophageal surgery, for instance. Being operated for CRC without a stoma is one of the most common abdominal cancer surgeries in Sweden and can be seen as a surgical standard procedure if the healthcare perspective is used (Socialstyrelsen, 2013). However each patient and their next of kin experience the situation as highly specific and our findings indicate that information needs are often more concerned with the impact of having cancer than the consequences of surgical treatment. The surgery forces the patient to face the seriousness of the disease and creates a physical and emotional strain, which in turn accentuates the importance of accessing information in order to manage the situation. Some of the findings in this thesis are specific for patients with CRC: like how to manage gastrointestinal symptoms and self-care at home. However, the major part of the findings are most likely also applicable for other cancers. The need to receive more information, to participate to a greater extent in the information, to put up with waiting times and to experience the lack of information as extremely difficult are all generally applicable and could be applied to patients with other cancer diagnoses as well.

Information and HRQOL

Patients' HRQOL was severely affected during the first two weeks at home, especially concerning some of the physical symptoms and functions. This was also seen in a study with CRC patients where they indicated most unmet supportive care needs during the first week at home (Harrison et al., 2011). In this thesis no association was found between increased physical needs and information needs: even when the physical status improved the scoring of information did not change. However, the patients' physical condition highlights the importance of receiving information in order to manage the symptoms experienced during the first weeks at home. The combination of physical symptoms and emotional strain contribute to making this

period extremely difficult, and that in turn could make it harder to remember and assimilate information during this phase.

The next of kin in our study support the patient in many ways during this phase of the cancer trajectory; for some this is limited to a shorter period and for others this continues until the end of the patient's life (Fletcher et al., 2012). Lack of information was one of the most reported social problems and caused social isolation, according to a study with caregivers (Stenberg et al., 2010). The stressors next of kin experience affect their health outcomes and including them early in the trajectory might prevent some of the physical, social and emotional problems.

Channels for information

The importance of receiving information and of preparation before leaving hospital is evident in the findings. But the need to provide access to information after discharge is also seen as important. The motivation to implement these results is further emphasized by a new Patients' Act that was adopted by the Swedish Parliament and will come into force on January 1, 2015 (SALAR, 2014). The aim is to strengthen the position of the patient and to promote self-determination and participation. One important part of the Act is an increased demand on reformed patient information including treatment-related content but also on the expected trajectory of the disease and the care. One improvement in the Act is that the caregiver needs to ensure that the patient has been informed. This is of course extremely important for the patients and their families, yet at the same time it demonstrates the issues of implementing this in the daily encounters between the healthcare professional and the patient with CRC.

As mentioned earlier, the surgical nurse needs to become a more significant channel of information for the patient and the next of kin when planning and organizing the discharge. This also requires continuous consultation with the rest of the surgical team: surgeon, physiotherapist and assistant nurse. The surgical nurse also needs to introduce the function of the specialist nurse in open care to minimize unnecessary interruptions in the care and information process. The specialist nurse knows how to provide information and facilitate vulnerable transitions for patients with CRC while supporting their next of kin. In an RCT, patients' experiences during cancer care were improved by the care of a specialist nurse when it came to information, psychosocial care and reduced vulnerability (Wagner et al., 2014). However, the effect of introducing specialist nurses varies and the role, job description and qualifications differ and needs to be made more consistent (Hendren and Fiscella, 2014).

The need to meet healthcare professionals who listened, responded to questions and showed interest in the individual patient and next of kin were all issues that were noted frequently in the findings. This is unfortunately confirmed by many other studies. The increasing amount of research during the last decade has led to a growing interest in using patients' opinions in order to improve care (de Silva, 2013). The use of patient reported experience measures (PREM) is becoming increasingly common, not only in Sweden. PREM usually consists of questionnaires with primarily closed questions which focus on patients' perception of and satisfaction with care. PREM could also include other methods like interviews with individuals or focus groups (de Silva, 2013). Another way of approaching PREM is using experience-based co-design (EBCD) (Bate and Robert, 2006). It is a user-focused design process that strives to take the patient involvement one step further than patient-centred care. EBCD place the experiences of patients and users at the centre of the design process together with clinical and process goals. The understanding of the subjective experience of care is used to try to design a healthcare experience that will be more successful and fulfilling than previously. The traditional view of the patient as a more or less passive recipient is exchanged for the new role of a user who designs the care together with healthcare professionals on an equal footing. Experience is defined as knowledge acquired from close and direct personal observation or contact (Bate and Robert, 2006). Stories and storytelling are methods used in experience design, and the goal is to ensure that the healthcare truly reflect the needs of patients, next of kin and healthcare professionals (Pickles et al., 2008, Gustavsson, 2014). All their combined experiences are used when co-designing changes in healthcare.

A future common ground

When synthesizing the findings from this thesis, the focus directs towards the meeting between the healthcare professional (here the surgical nurse) and the patient with their next of kin. In this meeting, the family's entire experience of the cancer trajectory starts to evolve and will affect their information needs. The significance of the meeting will affect the patient and the family, not only during the active phases of the cancer trajectory, but for many years to come. The need for the individual nurse to make use of their self-awareness in order to distinguish the other person's information needs and perspective requires more attention. It takes both personal maturity and motivation in order to manage this.

However, this need for a mutual information meeting is universal for all kinds of cancer and the fulfilment of this need should not depend only on the maturity and characteristics of the individual healthcare professional. The tremendous challenge is

how everyone involved in healthcare could apply this approach in meetings with patients and their families. This position needs to be taken by the management and leadership in healthcare and then it needs to permeate throughout the entire organization. In all undergraduate degree programmes in healthcare, group exercises in communication skills for students from all personnel groups are to be recommended. After graduation, these exercises should recur at regular intervals during all clinical duty and, like training in cardiac resuscitation, be compulsory. Evaluation of patients and relatives experiences of care should be made annually using diverse PREM methods and be linked to both an implementation plan and to the quality register. If this approach become the hallmark of success in healthcare, then the individual patient with cancer and their family could be more active participants in improving the cancer trajectory together with healthcare professionals.

Conclusions and clinical implications

The expressed need to participate more in the exchange of information was articulated by both patients and next of kin. They wanted to be involved and to be acknowledged as individuals. Including patients and their family in information exchange and communication would also contribute to more direct feedback on the relevance of the information, what is most important to them and when in the cancer trajectory they need it. The information would be more individualized and more likely to meet their needs. The need to have a relationship with the healthcare professionals who provided information was closely linked to how patients and next of kin valued and experienced the information. The importance of creating a foundation for mutual communication by listening, responding and showing interest in the individual patient was clearly present. Encouraging communication skills training for healthcare professionals is one way of improving the information and the relationship with patients and next of kin.

The necessity of identifying information needs early in the cancer trajectory became apparent in the findings. Before the first appointment in the surgical department, the family can give an outline about how they would like to receive communications about cancer information. They could use a web-based form, or arrive earlier for appointments and receive guidance from a receptionist in filling in an eReader or on paper. This form would contain a few short questions with tick boxes about earlier experiences of cancer, preferences for information channels, areas considered most important and information-seeking behavior (*seeking/avoiding*). The form would end with an open question regarding other information requirements. This would provide a basis for a patient- and family-focused meeting and enhance conditions for a satisfactory encounter.

The next of kin had their own needs for information and articulated these. Participating in information meetings would satisfy their needs but would also assist the patient's recall. Many patients experience fatigue, pain and insomnia during the early recovery as well as a stressful hospital environment. This has a negative effect on concentration and memory. By inviting the next of kin to participate would probably help to clarify the entire family's information needs and, at the same time, improve the experience and recall.

Patients in our study wanted the discharge from hospital to be better planned, but some patients were more vulnerable and had greater needs in this situation. Women, those with worse health status before surgery and those who lived alone expressed a need for more information and more preparation before leaving hospital. It is important to identify these patients early in the trajectory in order to have enough time to make individualized plans before discharge. Therefore, the presence of risk factors should be assessed during the first visit to the surgical department. Finding out if next of kin are involved and the extension of their commitment should also be done early on. Planning discharge with the patient and next of kin could start before admission for surgery.

The patients in our study focused on the information from the physicians. However a specialized nurse with a solid education and experience could probably complete some of the information and make up for the time patients did not receive from their physicians. This nurse could, for example, repeat prognostic information and provide more time for questions and for discussing fears concerning the future. A specialized nurse in open care could work more closely with the surgical nurse on the ward and collaborate when planning the discharge with more vulnerable patients and their next of kin. More structured collaboration is needed in the surgical team in order to enhance quality and effectiveness. Practical aspects like finding rooms for meetings and times for pre-planned appointments also need to be given priority.

The current information situation differs somewhat from the time when this study was designed. Today patients and next of kin need guidance on where to find updated and evidence-based information on the Internet. Our findings show that it is also important to provide access to a personal contact at the surgical and oncological department and easy access to telephone support.

Since the use of PREM is becoming more common in evaluating and improving patient care, the usability of different measures needs to be continuously discussed and appraised with focus on the methods that best reflect the needs of patients and families.

Future studies

Some groups of patients participating in this study were more vulnerable and more knowledge is needed in order to also facilitate discharge planning for other vulnerable groups: patients with complications, frail older patients, those with low literacy or cognitive impairments and those who do not have Swedish as their first language. The aim would be to investigate what interventions more vulnerable patients need in order to access and assimilate information and to facilitate these needs accordingly, while evaluating both quality aspects and cost-effectiveness.

Information for patients with CRC concerns the entire team of healthcare professionals and therefore it is also important to use a multi-disciplinary team when designing all interventions and research.

In order to understand more about how patients and next of kin select and use information channels, it would be useful to design a longitudinal study, where they choose between the available channels of information with their choices being registered during different phases of the cancer trajectory.

The quantitative studies in this thesis provided no knowledge of why certain factors are linked to the amount of received information and information needs. It may be that there are important factors that better explain the need for information, but are not included in the survey. The EBCD method could be used in order to determine these factors, identify areas in need of improvement and to enhance satisfaction with information.

Since the ERAS protocol has demonstrated good results in decreasing LOS and postoperative morbidity, it would be relevant to study the last part of the care process in hospital and how the discharge information works in combination with the preoperative counselling.

Svensk sammanfattning

När patienten lämnar sjukhuset och återvänder hem efter en operation för kolorektal cancer (tjocktarm och ändtarm) innebär det en stor omställning. De är inte återställda efter den stora bukoperationen och upplever olika symtom som smärta, tarmbesvär och stor trötthet. Eftersom vårdtiderna blir allt kortare har deras återhämtning bara påbörjats på sjukhuset och de kommer hem med fler symtom. De närstående påverkas av detta i hög grad och behövs som praktiskt och känslomässigt stöd under de första veckorna i hemmet. Våra tidigare möten med patienter och närstående har visat att denna övergång från sjukhusvård till hemmet är sårbar och att det saknas information och stöd. Detta bekräftas också av litteraturen.

Kolorektal cancer är den tredje vanligaste cancersjukdomen hos både män och kvinnor i Sverige och drygt 4 000 personer och deras familjer drabbas varje år. Operation är den traditionella behandlingen. Numera används ofta ett accelererat vårdförlopp, vilket är ett multidisciplinärt behandlingsprogram avsett att minska den kirurgiska stressen för kroppen under operation och där vårdtiden blir sammanlagt ca 2-4 dagar. Förutom operationen kan tilläggsbehandling i form av cytostatika behövas.

Att ha tillgång till information under cancersjukdomens förlopp är oerhört viktigt för både patienter och närstående. Trots att detta varit känt under åtskilliga årtionden så fortsätter patienter och deras familjer att visa sin otillfredsställelse med den information som erbjuds från sjukvården. Informationen upplevs sakna viktiga delar och inte förbereda patienten på det som väntar, vilket skapar ännu mer oro och otrygghet. Därför valde vi att fokusera på vilka erfarenheter av information patienter och närstående haft i samband med hemgång från sjukhuset och vilket behov av information de har den första tiden hemma.

Avhandlingen består av fyra delarbeten med det övergripande syftet att undersöka patienters och närståendes erfarenheter av information och deras behov av information efter hemgång. Syftet var också att identifiera faktorer som kan påverka detta. Datainsamlingsperioden omfattade de första sju veckorna efter hemgång. Den skulle inbegripa både de första påfrestande dagarna och veckorna i hemmet, samt det uppföljande besöket på sjukhuset där information om operationsresultat och prognos för framtiden förmedlades.

Patienter, vilka hade opererats för kolorektal cancer vid tre olika sjukhus i södra Sverige, tillfrågades om att delta i studien. Ett hundra personer deltog varav 45 kvinnor och medelåldern var 69,9 år för hela gruppen.

De första två delstudierna var kvantitativa och undersökte hur patienter uppfattade informationen inför hemgång, vilka behov av information de hade och faktorer som kunde relateras till detta. Data bestod av frågeformulär och uppgifter från den datoriserade journalen. Hälsostatus före operation, yrke och tumörstadium var data från journalen. Erhållen information, behov av mer information, livskvalitet, fysisk förmåga och känsla av sammanhang var olika områden som undersöktes via frågeformulär vid två tillfällen; 1-2 veckor efter hemgång och en månad senare.

Patienterna svarade generellt att de inte fått tillräckligt med information vilket tyder på att de saknade den informationen eller inte kom ihåg den. Hälften av patienterna önskade mer information än de fått. De områden där de erhållit mest information var; undersökningsresultat, information om cancersjukdomen och behandling av cancer. Det var små och inte signifikanta skillnader i uppfattningarna om informationen mellan 1-2 veckor efter hemgång jämfört med en månad senare. Detta kan tolkas som att informationen som erhölls vid återbesöket efter operation inte påverkade patienternas upplevelse av informationen i någon stor utsträckning. När det gäller livskvaliteten däremot hade patienterna mer fysiska symptom och sämre funktioner precis när de kommit hem jämfört med en månad senare, men ingen koppling till informationen kunde urskiljas. De faktorer som kunde kopplas till information var; sämre hälsostatus, att vara kvinna och att bo ensam. Dessa grupper uppfattade att de hade fått mindre information. Detta tyder på en ökad sårbarhet hos dessa patienter när det gäller information vid hemgång.

I den tredje delstudien blev 16 av patienterna intervjuade två gånger, 1-2 veckor efter hemgång och en månad senare. De utskrivna texterna analyserades med hjälp av metoden innehållsanalys, där både de mer påtagliga delarna av texten lyfts fram men också den mer underliggande innebörden av det patienterna berättat i samband med intervjuerna. Frågorna inriktades mot hur de upplevt informationen inför hemgången och vad de hade behövt för att klara den första tiden hemma.

Det övergripande resultatet visade att patienterna upplevde att de förlorade en stor del av sin kontroll i samband med cancersjukdomen och att de behövde information för att kunna återfå den. De ville delta mer i informationen och planeringen inför hemgången. För att förstå vad cancersjukdomen egentligen innebar för just dem som individer behövde de få veta mer om den och även om varför de fick just den behandlingen. Alla deltagarna i studien hade blivit opererade men vissa fick tilläggshandling med cytostatika, vilket i sig skapade behov av ytterligare information. Deltagarna i studien ville veta mer om vad som skulle hända hemgångsdagen och när utskrivningssamtalen skulle ske och med vem. De behövde mer kännedom om praktiska saker den första tiden hemma, som vilken fysisk träning som var bäst i början, vad man skulle äta och dricka, vad normal tarmfunktion var och hur operationssåret skulle skötas. Intervjuerna visade också hur viktigt det var med själva informationsmötet de hade med olika personer bland vårdpersonalen, att mötena blev ömsesidiga och stödjande för patienten. Kvaliteten på det mötet påverkade i stor

utsträckning vilket uppfattning de hade av vården de erhållit. Vid dessa möten önskade de hjälp att hantera oron inför framtiden.

Även de 16 närstående som levde tillsammans med de intervjuade patienterna fick genomgå individuella intervjuer vid två tillfällen. Intervjufrågorna fokuserade på hur de som närstående uppfattat informationen och vad de hade behövt veta för att kunna ta hand om patienten på ett bra sätt hemma.

Resultatet från intervjuerna med de närstående visade att de behövde ha tillgång till mer information för att kunna klara av de påfrestningar som deras nya funktion som stöd åt patienten innebar. De ville delta mer i patientens liv under cancerförloppet och att få tillgång till information gjorde det möjligt. Liksom patienten behövde de mer kunskap om själva cancersjukdomen och dess behandling. De ville ha rak och ärlig information från vårdpersonalen och värderade också själva informationsmötet som oerhört viktigt. Det var påfrestande för de närstående att se patienten vänta på olika slags information och våndas under väntetiden. När det saknades information om vad nästa steg i processen innebar eller när olika saker skulle ske, så ökade oron och osäkerheten, samtidigt som det egna hemlivet och sociala aktiviteter fick skjutas på framtiden.

Sammanfattningsvis visade resultaten att både patienter och närstående behövde bli betydligt mer delaktiga i informationen och planeringen inför hemgången. De behövde mer information än de hade fått för att förstå sjukdomen men också för att hantera symptom och den första tiden av återhämtning i hemmet. De beskrev inte bara behovet av information utan också hur viktigt det var att bli lyssnad på och respekterad, att få känslomässigt stöd och bekräftelse under samtalen. Vikten av att identifiera patientens och familjens informationsbehov tidigt i cancerförloppet framkom i intervjuerna. Vårdpersonalen behöver också veta mer om varje familjs tidigare erfarenheter av cancer och på vilket sätt de helst söker och önskar få information.

De närstående artikulerade tydligt i intervjuerna att de hade egna behov av information och att de ville vara med vid de tillfällen då patienten fick information. Genom att låta de närstående delta i informationen i större utsträckning skulle deras tillfredsställelse öka, men det skulle också vara ett stöd för patienten att komma ihåg vad som sagts. Den närstående kan också hjälpa till att tydliggöra vilket informationsbehov familjen har.

Samtalen och förberedelserna inför hemgång upplevdes ofta som oplanerade och stressiga, och både patienter och närstående ville få delta i samtalen och ställa sina frågor. Vissa grupper av patienter visade sig vara mer sårbara när det gäller informationen inför hemgång. De som hade sämre hälsotillstånd, de som bodde ensamma och de som var kvinnor angav att de fått mindre och sämre information. Det är viktigt att identifiera de mest sårbara patienterna tidigt i vårdförloppet, före operationen, så att planeringen och informationen under sjukhusvistelsen kan underlätta den första tiden hemma.

Tillgången till information förändras ständigt i vårt samhälle och patienter och närstående kan använda olika informationskällor som kompletterar varandra. De behöver råd om vilka websidor som har aktuella och relevanta forskningsresultat anpassat till just deras sjukdom. De behöver samtidigt ha tillgång till en personlig kontakt på den ansvariga kliniken dit de kan ringa och få råd och stöd. En del får support från olika grupper inom sociala medier där man kan dela känslor och upplevelser med andra i liknande situation.

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