Subjective recovery following colorectal cancer treatment

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In memory of my beloved mother Gun-Britt

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LIST OF ABBREVIATIONS

AICR	American Institute for Cancer Research
CRC	Colorectal cancer
CRF	Cancer-related fatigue
EORTC	European Organization for Research and Treatment of Cancer
ERAS	Enhanced Recovery After Surgery
f-Hb	Feces hemoglobin
FOBTs	Fecal occult blood tests
GHS/QoL	Global health status/Quality of life scale
HADS	The Hospital Anxiety and Depression Scale
Hb	Hemoglobin
HNPCC	Hereditary nonpolyposis colorectal cancer
HRQoL	Health-related quality of life
IPQ-R	The Illness Perception Questionnaire - Revised
NCCN	National Comprehensive Cancer Network
NSAID	Non-steroidal Anti-Inflammatory Drugs
QLQ-C30	Cancer specific Quality of Life Questionnaire
RCC	Regional Cancer Center
SCRCR	Swedish Colorectal Cancer Registry
WGO	World Gastroenterology Organization

ABSTRACT

As a basis for nursing support for survivors and partners following CRC treatment, the overall aim of the present thesis was to explore the first year of subjective recovery following such treatment. First, the focus was on illness perceptions and self-reorientation in cancer care settings from the survivors' perspective as well as on cancer care settings and illness perceptions from the partners' perspective. Second, the focus was on investigating relations between fatigue, mental health, gastrointestinal health, illness perceptions and self-efficacy in relation to maintaining everyday activities, where health-related quality of life (HRQoL) was the outcome measure.

Persons treated for CRC at a county hospital in western Sweden and their partners were the participants. In Study I (n=17), III (n=46) and IV (n=39) the participants were survivors, and in Study II (n =18) the participants were survivors and partners. In Study I and II, data were collected through interviews and analyzed using Grounded Theory methodology. In Study III and IV, data were collected through questionnaires and statistically analyzed. The following questionnaires were used: European Organization for Research and Treatment of Cancer's (EORTC) cancer-specific Quality of Life Questionnaire (QLQ-C30); the Hospital Anxiety and Depression Scale (HADS); the Illness Perception Questionnaire-Revised (IPQ-R); and the Maintain Function Scale.

In Study I, the theoretical model explained self-reorientation as the individual trying to achieve congruence in self-perception. The core of self-reorientation was questions that did not have clear answers. Not knowing the cause of cancer, or not being able to understand bodily reactions, meant losing one's former sense of self. In Study II, the theoretical model illustrated illness perceptions of survivors and partners in relation to the experienced contemporary cancer care environment. Information and non-continuity was experienced as troublesome if there was no specific healthcare professional to contact if needed, and the time after discharge was characterized by loneliness. Survivors' and partners' illness perceptions were incompatible: Survivors tended to minimize the seriousness, while partners were more focused on seeing cancer as a life-changing event. In Study III, fatigue and diarrhea were identified as negative predictors of HRQoL, while self-efficacy in relation to maintaining everyday activities was identified as a positive predictor. The Maintain Function Scale was suitable for assessing self-efficacy in relation to maintaining everyday activities. Study IV showed a significant decrease in level of self-efficacy at 12 months. Emotional representations and fatigue, respectively, functioned as mediators between self-efficacy and HRQoL.

In conclusion, nurse-led follow up consultations after discharge need to be prioritized after treatment for CRC. Because illness perceptions not only influence self-reorientation but also function as a mediator between self-efficacy in relation to maintaining everyday activities and HRQoL, illness perceptions and self-efficacy need to be in focus when addressing symptoms. In addition to prioritizing nursing care after discharge, the informational burden, lack of continuity and strain on partners found in the results should be addressed during treatment.

Keywords: Cancer care, colorectal cancer, fatigue, grounded theory, health-related quality of life, illness perceptions, nursing, partners, path analysis, recovery, self-efficacy, self-reorientation.

CONTENTS

INTRODUCTION

The concept of recovery can be seen from a clinical and a subjective perspective, and each perspective brings its own meaning to this concept. Clinical recovery has a medical focus, and the main concern from this perspective is cure (Slade, Amering & Oades, 2008) and how to help patients return to a pretreatment level of functioning (Allvin, Berg, Idvall & Nilsson, 2007). Care regimens aiming to improve clinical recovery and shortening hospital time have been applied in colorectal cancer (CRC) surgery in recent years (Regional Cancer Center [RCC], 2016) and, consequently, at present more people are living longer after their CRC treatment (Swedish Colorectal Cancer Registry [SCRCR], 2016; RCC, 2016). In addition to the clinical perspective, the subjective perspective on recovery brings yet another profound meaning. Subjective recovery has a personal focus, and the main concern from this perspective is to experience satisfaction in life even with the limitations of illness and the life-changing process it entails (Slade et al., 2008; Leamy, Bird, Boutillier, Williams & Slade, 2011). In cancer recovery, this means the journey during which persons treated for cancer and those close to them learn to manage different illness consequences and to live with a history of malignancy (McCorkle et al., 2011). Subjective recovery involves an alteration from being a cancer patient or a partner to being a cancer survivor or a survivor's partner. The meaning of being a cancer survivor is being someone who has lived through cancer treatment; has been impacted in different ways by this experience; is in the follow-up phase of their cancer treatment; and whose experience is personal and contextual (Hebdon, 2015). Cancer disease and its treatments bring long-term effects and changes that require observation, care and rehabilitation interventions (McCorkle et al., 2011), and colorectal cancer is no exception. The major part of the recovery following modern CRC treatment takes place at home after discharge (Jakobsson, Idvall, & Wann-Hansson, 2014). Research shows that the first year following CRC treatment is marked by symptoms and other illness consequences, such as fatigue and mental and gastrointestinal health distress, known to negatively affect health-related quality of life (HRQoL) (Tsunoda, Nakao, Hiratsuka, Tsunoda & Kusano, 2007; Theodoropoulos, Karantanos, Stamopoulos, & Zografos, 2013), and CRC survivors are supposed to manage these consequences without direct support from healthcare. Personal beliefs and thoughts about illness, self and capability, i.e. illness perceptions (Leventhal, Idler, & Leventhal 1999), self-perception (Petrie & Weinman, 1997) and self-efficacy (Clarke & Dodge, 1999), play a role in how symptoms and other illness consequences are managed, but how CRC survivors beliefs and thoughts regarding their illness, self and capability are associated with symptoms and other illness consequences in recovery has not been sufficiently explored. Consequently, subjective recovery regarding illness perceptions, self-reorientation, self-efficacy and HRQoL (symptoms and subjective health following CRC treatment) constitute the main focus of this thesis and the basis for developing nursing support interventions.

BACKGROUND

Colorectal cancer

CRC is estimated as the third most common cancer disease in men and the second most common cancer in females worldwide (Ferlay et al., 2015). Recent figures from the Swedish colorectal cancer registry (2017) show that 6782 persons were diagnosed with CRC in Sweden in 2016. When divided into colon and rectal cancer, the data show that the incidence of colon cancer is steadily increasing, and has been doing so since the1970s. This increase is partly explained by the age structure in Sweden, which today consists of a large proportion of older individuals. However, the age-standardized incidence is also increasing, which is why the total increase in colon cancer cases cannot solely be explained by age (SCRCR, 2016). In 2016, as many as 4602 persons were diagnosed with colon cancer in Sweden, slightly more females than males (SCRCR, 2017). Unlike colon cancer, the incidence of rectal cancer has been stable since the beginning of the 21st century, and about 2000 persons per year are diagnosed with rectal cancer, slightly more males than females (SCRCR, 2016). In 2016, 2180 persons were diagnosed with rectal cancer (SCRCR, 2017).

The risk of developing CRC is influenced by different factors, such as lifestyle, some other diseases, genetics and age. When it comes to lifestyle factors, a diet high in red meat and processed meat, obesity, inactivity, smoking, and (for men) alcohol consumption are known risk factors (American Institute for Cancer Research [AICR], 2007). These lifestyle factors are more common in the West, which is reflected by the high incidence figures for CRC in these regions of the world (American Cancer Society, 2015). Other known risk factors are inflammatory bowel diseases such as ulcerative colitis and Crohn’s disease (Ullman & Itzkowitz, 2011) as well as diabetes (Berster & Goke, 2008). Colorectal cancer among parents, siblings or children is another risk factor, and a reason to investigate whether or not a genetic cause is present (Valle, 2014). One genetic cause is mutations in the DNA mismatch repair genes MLH1, MSH2, MSH6 or PMS2, referred to as hereditary nonpolyposis colorectal cancer (HNPCC) (Aarnio, Mecklin, Aaltonen, Nystrom-Lahti & Jarvinen, 1995). In addition, age is the single most prominent risk factor (American Cancer Society, 2015). The risk of developing CRC is at its peak at the age of 75 years (Hamilton et al., 2009).

Some factors most likely exhibit protective properties against CRC, for instance physical activity and a diet high in fiber-rich fruits and vegetables (AICR, 2007). In addition to diet and exercise, evidence suggests that NSAIDs protect against adenomatous polyposis (Baron et al., 2003) and reduce the risk of developing CRC (Nan et al., 2015). Other evidence suggests that replacement therapy with estrogens seems to offer protection against CRC among postmenopausal women (Morch, Lidegaard, Keiding, Lokkegaard & Kjaer, 2016).

Diagnosis

Symptoms and signs of CRC are often unclear and vague. Symptoms that lead to suspicion are among others: changed bowel habits, such as constipation or difficulties emptying the bowel completely. Other signs and symptoms are rectal bleeding, and/or visible blood or mucus in stool, changed shape of feces, cramping in lower abdomen, loss of appetite, or weight loss. Sometimes blood loss from the cancer leads to anemia, thus causing weakness and fatigue. The signs and symptoms mentioned above often lead to contact with the health service. However, early-stage colorectal cancer usually causes diffuse symptoms (American Cancer Society, 2015) and therefore CRC in the early stage is more often found in connection with health or other illness controls. Fecal occult blood tests (FOBTs) discover hemoglobin (Hb) in feces. Screening for blood in feces (f-Hb) offers a possibility for early detection, and evidence shows that early detection by screening can reduce the mortality due to CRC by 15% (Hewitson, Glasziou, Watson, Towler & Irwig, 2008). Fecal occult blood testing every year or two, starting at the age of 50, is now an international recommendation (World Gastroenterology organization [WGO], 2007). In Sweden, the National Board of Health and Welfare (2015) recommends population-based screening of men and women aged 60-74 every two years. However, in 2016, screening was only implemented in the Stockholm healthcare region, consisting of Stockholm and Gotland counties (Törnberg, Olsson, Nilbert, 2016). The advantage of using colonoscopy as a screening method is under investigation in a large randomized trial (Kaminski et al., 2012). A first analysis of the study shows that colonoscopy screening entails high rates of detection, and the final results of this study are expected in 2020 (Bretthauer et al., 2016).

In 2016, investigation of suspected colorectal cancer became standardized in Sweden. And a stringent diagnostic procedure is now performed whenever there is a well-grounded suspicion of CRC. The diagnostic procedure, which can be expanded according to individual needs, includes anamnesis and physical examination, followed by endoscopy, biopsy and radiological examination (Åhlström Riklund, Blomqvist, Torkzad & Hellström, 2016). Date of diagnosis is primarily based on the clinical diagnosis, i.e., when the tumor can be identified through endoscopic or radiological examinations (SCRCR, 2016). The clinical diagnosis is followed by a pathological-anatomical diagnosis (PAD); this diagnosis includes tumor identification and classification according to grade of dysplasia, tumor location and a so-called TNM classification, where T stands for the expansion of tumor tissue, N stands for the spread to nearby lymph nodes, and M stands for metastasis to other organs or to distant lymph nodes. The pathological-anatomical diagnosis contributes to the assessment of disease severity and treatment options (Glimelius, Tiret, Cervantes, Arnold, & Group, 2013; Labianca et al., 2013; Åhlström Riklund, Blomqvist, Torkzad & Hellström, 2016).

Contemporary cancer care

The Swedish national care program from 2016 is synchronized with the 2014 recommendations from the National Board of Health and Welfare and includes evidence ranking as well as a national standard for nursing care (RCC, 2016). Before 2016, when the latest national care program for CRC was released, both medical and nursing care regimens could vary between regions in Sweden. Today the regimen is equivalent in that a multidisciplinary conference for clinical management of treatment options should be held before treatment begins, and in that one contact nurse has to be assigned to each patient under treatment (The National Board of Health and Welfare, 2014).

CRC is first and foremost surgically treated. Curative treatment for colorectal cancer usually means that the part of the bowel where the tumor is located is surgically removed. Surgical technique is determined by tumor location and the ability to maintain good bowel function. Surgery can be performed both open or by laparoscopic procedure, and the latter is considered gentler and to promote faster clinical recovery for the patient. The National Board of Health and Welfare (2014) recommends that laparoscopic surgery be offered as a treatment option to patients, and this surgical technique is now used more extensively than before. In recent years, traditional perioperative care has been found to be associated with prolonged postoperative recovery (Varadhan et al., 2010). As part of shortening the clinical recovery period, a fast-track surgery program, also called the Enhanced Recovery After Surgery (ERAS) care regimen, was introduced as an alternative approach to traditional perioperative care in Sweden (Lassen et al., 2011), and since 2016 the ERAS regimen is recommended in elective colorectal cancer surgery in Sweden (RCC, 2016). This program is intended to optimize the patient's ability to regain bowel function more quickly after surgery, as well as to improve clinical recovery and reduce hospital time by optimizing all preoperative and perioperative interventions (Basse et al., 2002; Varadhan et al., 2010). The hospital time after surgery for uncomplicated CRC, when the ERAS concept is applied, is between 3 to 10 days (Varadhan et al., 2010). In curative treatment radiation and /or chemotherapy, are additional treatment options that may improve the prognosis. In more severe cases of rectal cancer, neoadjuvant radiation therapy is recommended to reduce the risk of recurrence. In colon cancer, there is not enough evidence to support the benefit of neoadjuvant radiation, however, in some cases of locally advanced colon cancer a combination of radiation and chemotherapy may be considered. In colon cancer, there is strong evidence for adjuvant chemotherapy two months after surgery as part of reducing the risk of recurrence. If cure is out of reach, different palliative treatments intended to offer symptom relief and improve quality of life are considered (RCC, 2016).

The numbers of survivors in modern cancer care are growing. The overall survival after CRC has improved over the past two decades. The overall 5-year survival after CRC is today around 65%, somewhat better for women than for men. In rectal cancer, the survival is continuously improving, whereas in colon cancer the improvement has leveled out. Owing to the increased incidence of and survival after CRC, the number of persons living with this cancer disease has increased, which is why CRC today may be considered a chronic disease. In 2010, as many as 44,000 persons were living with CRC in Sweden (SCRCR, 2016; RCC, 2016). Cancer is often initially regarded as an acute disease, i.e. it has a sudden onset and requires prompt treatment. Acute diseases, however, ends in a short time with recovery or death (Bell & Ristovski-Slijepcevic, 2013). Because a person successfully treated, free from cancer and in remission nonetheless lives with the risk of relapse within five years or later (Baade, Youlden, Chambers, 2011), cancer disease instead involves long-term surveillance and sometimes treatment (McCorkle et al., 2011).

Clinical recovery

The concept of recovery includes clinical recovery (Slade et al., 2008), also referred to as medical recovery (collier 2010). This definition represents the voice of medicine, implying a focus on cure or remission as an outcome. This recovery is the recovery seen with the eyes of the healthcare provider. Clinical recovery can be described by the defining attributes of recovery after surgery; the defining attributes are as follows:

> an energy-requiring process, a return to a state of normality and wholeness defined by comparative standards, regaining control over physical, psychological, social and habitual functions, returning to preoperative levels of independency/dependency in activities of daily living and, regaining one's optimum level of well-being (Allvin et al., 2007, p554).

Rehabilitation refers to the environment and the actions that healthcare professionals create to enable recovery (Deegan, 1988). In 2014, the first national care program concerning cancer rehabilitation of adult persons was released in Sweden. The care program focuses on cancer rehabilitation during the period in which the patient receives oncology treatment; the last update of the program was in April 2017 (RCC, 2017). The basics included in the rehabilitation efforts, and also specified in the CRC care program, state that the patient and family members should be informed about the support interventions that are available. The patient should also be entitled to assessment of rehabilitation needs – physical, psychological, social and existential – repeatedly from diagnosis throughout treatment. This means that rehabilitation assessments should be performed in connection with every major change in care, such as altered treatment, altered healthcare provider, or notifications of post-treatment results or disease progression/regression. A rehabilitation plan should be established as part of the care plan. The contact nurse establishes this plan, and in the plan interventions are documented continuously and evaluated in relation to stated goals (RCC, 2016). According to the current care program for cancer rehabilitation, the physician and contact nurse are supposed to map a patient's need for rehabilitation in consultation with the patient. The contact nurse is responsible for the nursing care in the rehabilitation plan. This means following up symptoms, acknowledging resources and catering to elementary rehabilitation needs as regards nursing care, such as motivating the patient, educating and giving information based on evidence, and listening to the patient's and family's wishes and needs (RCC, 2017).

Subjective recovery

In addition to clinical recovery, the concept of recovery has another profound meaning, which is subjective recovery, also called personal recovery (Slade et al., 2008) or life recovery (Collier, 2010). Subjective recovery refers to the voice of the person, implying a journey of development, change and experiencing satisfaction in life despite the limitations of illness (Slade et al., 2008; Collier, 2010). In subjective recovery, the focus is not on finding a cure, but rather on acceptance of a changed life. This approach to recovery has its roots in mental healthcare, but is applicable in somatic care as well. Characteristics of subjective recovery are that it is a personal, active, nonlinear, and multidimensional process as well as a life-changing journey. Changes that typically occur in recovery are changes in connectedness, hope, identity, meaning in life, and empowerment (Leamy et al., 2011).

The modern preoperative and perioperative care regimen aims to improve the post-treatment period by helping the patient quickly regain bowel function and reduce hospital time after colorectal surgery (Basse et al., 2002). This means that the major part of subjective recovery following CRC surgery takes place at home after discharge. The majority of persons undergoing CRC surgery experienced themselves as not recovered or only partially recovered at discharge. Fatigue, muscle weakness and depressed mood also increased for persons who had undergone abdominoperineal resection the first month after discharge, and gastrointestinal symptoms increased later in the recovery for persons who had undergone rectal resection (Jakobsson et al., 2014). When recovering from cancer, the body may become a constantly present reminder of cancer, and the cancer then becomes incorporated into the ill person's identity. In other words, cancer survivors and those close to them must learn to manage and live with the cancer disease the rest of their lives (McCorkle et al., 2011). In the process of subjective recovery, the dynamics between the person treated for cancer and the partner may change, the roles may assume new guises, and the partner may feel compelled to support and encourage, while the person with cancer may hide concerns and worries about care for the partner's wellbeing (Emslie et al., 2009; Houldin, 2007).

Survivor

In cancer care, the terms cancer survivor and cancer survivorship are commonly used to describe persons experiencing the illness trajectory of a cancer disease. The concepts cancer survivor and cancer survivorship are often used interchangeably in the literature. However, survivor can be distinct from survivorship, the survivor being an individual person and survivorship being a phase of treatment follow-up and surveillance (Kazanjian, Smillie, Howard, Ward & Doll, 2012). Fitzhugh Mullan (1985) actualized the concept of cancer survivor, suggesting that the biomedical model of cure versus non-cure as a perspective for understanding cancer and cancer treatment was insufficient. According to him, only one path existed to understand this disease, and it was through survival: survival in the sense of being someone who had to deal with the consequences of the cancer diagnosis and its treatment for the rest of his/her life. The concept of cancer survivor was thus born. A recent concept analysis by Hebdon and colleagues (2015) stipulated the following conceptual meaning of cancer survivor:

> An individual who: is living with a history of malignancy; has lived through a difficult experience such as cancer treatment; has been impacted in positive and negative ways by the experience; is in the follow-up phase of their cancer treatment; and whose experience is personal and contextual. (p.p 1777).

Persons with close relationships to cancer survivors, such as family members and partners, are affected by the cancer experience and are therefore included in the survivor concept (Bell & Ristovski-Slijepcevic, 2013). The cancer survivorship concept concerns a process that begins with the cancer diagnosis and runs through treatment and survivorship, where all parts of the process have consequences for health. The process involves uncertainty, fear of recurrence and loss of control. It is a life-changing experience that may include positive aspects, such as a sense of improvement of self and improved relations, appreciation of life and personal growth, as well as negative aspects related to symptoms and loss of function (Doyle, 2008). The survivorship phase has been described as consisting of three periods: reentry, early survivorship, and long-term survivorship. Reentry begins with completion of treatment and continues for the first couple of months; patients are often unprepared for this period, having expected a rapid recovery. The early survivorship period extends from months after diagnosis to five years post-diagnosis, and in this period some treatment-related physical and psychological effects are often resolved. Finally, the long-term survivorship period takes over, and this period constitutes the time after 5 years post-diagnosis (Stanton, Rowland & Ganz, 2015).

Illness consequences

The present thesis focuses on illness consequences in terms of physical fatigue and mental health (which here refers to symptoms of anxiety and depression) as well as gastrointestinal health (which here refers to the symptoms diarrhea and constipation).

Symptoms can be described in terms of suffering and as being associated with discomfort, inconvenience and restrictions in life. Symptoms may sometimes be connected to biomedical signs of disease, but can just as well exist without any such connections. Symptoms are a personal experience, to which a cultural and a personal meaning are attached (Good & Good, 1981; Brink & Skott, 2013). Research shows that symptoms are prevalent the first six months following CRC diagnosis in all stages and in association with all treatments, as well as among untreated patients (Walling et al., 2015). Additionally, the first year after surgical treatment is marked by changes and illness consequences that may negatively influence day-to-day activities for survivors and partners (Hodgkinson, Butow, Hobbs, & Wain, 2007).

Personal beliefs and thoughts about illness, self and capability – such as illness perceptions (Leventhal et al., 1999), self-perception (Petrie & Weinman, 1997), and self-efficacy (Clarke & Dodge, 1999) – influence how persons manage symptoms and other illness consequences. While exploring the impact of different personal aspects and resources on illness and symptom management, healthcare professionals must make a distinction between the concepts disease and illness, because these concepts represent two different voices. The concept of disease tells us about the disease from a biomedical perspective, while illness speaks from within the person experiencing the disease. Therefore, disease is a concept that represents pathology and biomedical markers, while illness is a concept that concerns the subjective experience and biopsychosocial consequences (Bhugra & Mali, 2013; Eisenberg, 1977). In this sense, these concepts are explanatory and do not necessarily contradict each other. Disease can exist without illness, and illness can exist without disease. Because there is always an orientation toward understanding the social, psychological and moral world in which the individual lives when exploring and trying to understand an illness experience (Frank, 1995; Kleinman, 1995), nurses need to listen to the individual's narrative to understand illness. In the narrative, a personal experience can be found, and as nurses we can interpret and translate this experience into something comprehensible.

Fatigue

Fatigue related to cancer or cancer treatment is sometimes referred to as cancer-related fatigue (CRF). CRF is multidimensional, and the National Comprehensive Cancer Network, which designs and updates guidelines on cancer-related symptoms, defines CRF as ”a distressing, persistent, subjective sense of physical, emotional, and/or cognitive tiredness or exhaustion related to cancer or cancer treatment that is not proportional to recent activity and interferes with usual functioning" (National Comprehensive Cancer Network [NCCN], 2015). CRF, as described by those experiencing such fatigue, is referred to as a distressing sensation of total physical and mental exhaustion without relief (Horng-Shiuann & McSweeney, 2007). The CRF experience, with lost energy as its hallmark, has a major impact on every aspect of daily life (Scott, Lasch, Barsevick, & Piault-Louis, 2011). Other illness consequences may worsen CRF, such as nutritional problems, decreased physical activity, side effects of medications, and anxiety (NCCN, 2015; Koornstra, Peters, Donofrio, van den Borne & de Jong, 2014), as well as anemia and electrolyte abnormalities, among others (Koornstra et al., 2014). Measuring CRF requires a multidimensional questionnaire (Strasser, Müller-Käser & Dietrich, 2009), and in advanced cancer, such as metastatic cancer or in palliative stages of cancer disease, multidimensional measurements are needed (Knobel et al., 2003). In the present thesis, physical fatigue is measured. Fatigue is strongly associated with poor HRQoL in persons with CRC (Marventano et al., 2013). The prevalence of fatigue among persons with CRC after surgery and before chemotherapy varies between 52% and 68%, where the higher figure applies to people with metastatic disease (Vardy et al., 2014). Fatigue is most prevalent among short-term survivors (41-43%); short term in this case refers to <5 years post-diagnosis, though the prevalence of fatigue can remain high up to 10 years post-diagnosis (34-40%) (Thong et al., 2013). Treatment with chemotherapy and radiotherapy is strongly associated with fatigue among survivors of CRC (Thong et al., 2013). In fact, pelvic radiotherapy has been shown to increase fatigue during treatment, indicating a possible connection between intestinal tissue damage and fatigue (Jakobsson, Ahlberg, Taft & Ekman, 2010). Pain and disturbed sleep are symptoms that often occur along with fatigue, and research shows that these symptoms constitute a cluster that mutually affect each other negatively (Beck, Dudley, & Barsevick, 2005). The association between depression and fatigue has been well researched, and depression is known as vary in correlation with fatigue, which makes it necessary to exclude depression when addressing fatigue (Brown & Kroenke, 2009).

Mental health

A fairly recent review showed that the prevalence of anxiety and depression the first 2 years post-CRC diagnosis was low and that most patients tended to be within the normative range, compared to long-term survivors, who instead experienced high levels of anxiety and depression (Mosher, Winger, Given, Helft, & O'Neil, 2015). However, the results vary from study to study. Another study exploring the prevalence of anxiety and depression symptoms among CRC survivors within 2 years post-diagnosis showed that the prevalence of these symptoms was quite high (20% had probable anxiety and depression) (Gray et al., 2014). And among persons in palliative stages of disease, depressive symptoms were very common (79%) (Walling et al., 2015). Results also suggest that anxiety and depression vary with treatment regimen. Persons receiving only surgery have demonstrated lower levels of anxiety and depression, compared to persons who received additional chemotherapy or radiotherapy (Pereira Figueiredo, Fincham, 2011).

Studies exploring mental health among partners have shown more consistent results. Early research showed that emotional stress sometimes was sometimes more pronounced among partners than among survivors (Northouse, Mood, Templin, Mellon, & George, 2000). Moreover, persons close to a person with CRC, such as family members and partners, have been found to be at increased risk for developing mental illness (Sjövall et al., 2000). More recent research shows that depressive symptoms remain at a high level in partners during long-term recovery. In fact, in one study 40% of partners were considered clinically depressed (5 years post-diagnosis). Additionally the findings suggested that the survivor's health was important for the level of depressive symptoms reported by the partner at this point in recovery (Kim, Shaffer, Carver & Cannady, 2014).

Gastrointestinal health

Large resection of the colon and resections of the rectum with low anastomoses can cause frequent defecation and diarrhea. Diarrhea is a symptom that is experienced by survivors as having a pronounced impact on health and daily activities (Desnoo & Faithful, 2006; Landers McCarthy, Livingstone & Savage, 2014). In addition to diarrhea, constipation is associated with a decrease in subjective health following CRC surgery (Tsunoda, Nakao, Hiratsuka, Tsunoda & Kusano, 2007). Persons with anastomosis sometimes report more gastrointestinal symptoms compared to persons with colostomy. They may also experience uncertainty regarding their bowel function, which here means fear for experiencing urgency and fecal incontinence. Social activities outside the home are therefore often determined by access to toilet facilities, and social activities may decrease in frequency as a consequence (Desnoo & Faithful, 2006). Less social activities, in turn, may lead to poorer mental health (Kurtz, Kurtz, Stommel, Given & Given, 2002). One study by Landers and colleagues (2014) showed that as many as 86% (123 rectal cancer survivors) had diarrhea up to three years following sphincter saving surgery. Tumor Location close to the sphincter or widespread tumor growth often means amputation of the rectum with permanent colostomy and long-term phantom sensations of pain and urgency (Fingren, Lindholm & Carlsson, 2013), as well as stoma-related problems such as leakage and skin irritation (Parmar, Zammit, Smith, Kenyon, & Lees, 2011).

Self-reorientation

The self can be understood as consisting of a personal self and a social self. The personal self can be described as a highly personal and individual understanding of the self as a unique person with experiences not shared by others. The social self can be described in terms of the interpersonal being, or the personal self in interaction with other people, and the influence of this interaction on self-perception. The social self is developed and motivated by the need for belonging and coherence (Pelham & Hetts, 1998). In the context of illness, self-regulation concerns the different responses a person uses to solve the problem a health threat entails on a cognitive, emotional and behavioral level. Even though Leventhal's self-regulation theory does not explicitly refer to the self (Leventhal et al., 1999; Brink, Karlsson & Hallberg, 2006), self-regulation may still influence how the self is perceived. The ill body that is beyond recognition threatens self-perception and may give a sense of losing the person one once was. A focus on incapacities may trigger a need to reorient the self (Brink et al., 2006). Sometimes self-reorientation can be about struggling to maintain the function of the body, and to hold on to normal activities, and live life as normally as possible; in other cases, it may be about adapting to changed bodily function and limited activities (Charmaz, 1995: Brink et al., 2006). The process of self-reorientation has been described in terms of restoring the self by moving from a self that is being disrupted by symptoms and lost autonomy toward a restored self after discharge. Restoring the self has been described in terms of movement between a sense of wellness and illness. A successful recovery meant that wellness had triumphed over illness, not necessarily through restoration of physical health but through regained trust, confidence and engagement in meaningful activities (Beech, Arber, & Faithfull, 2011).

Illness perception

When health is threatened by severe disease, the ill person and persons close to him/her shape their own understanding of the illness. Illness perceptions matter for the creation of expectations in relation to disease progression and recovery. In turn, expectations affect how symptoms and other illness consequences are understood and managed (Leventhal et al., 1999). Interpretation of disease is the first stage in the common sense model of illness representations developed by Leventhal and colleagues (Leventhal, Nerenz, & Steele, 1984; Leventhal et al., 1997), a central model in Leventhal's Self-Regulation Theory (Leventhal, Meyer, & Nerenz, 1980). The model proposes that people are processing all conceivable and available information on the disease, out of which they create a mental construct consisting of cognitive representations and an emotional representation. The interpretation is mainly guided by three different sources of information. The first is incorporated layman, social and cultural information. The second source of information comes from the social local environment and authoritative sources, such as healthcare professionals. Finally, one's own experience of the disease comes into play and the mental representation can take shape based on human "common sense". The mental representation is an intuitive and automatic process where connections are made between abstract and concrete sources of information. Symptoms and bodily sensations can stimulate the search for information that connects these symptoms and sensations with diagnoses and labels, and vice versa (Leventhal et al., 1984; Leventhal et al., 1997). Based on this illness representation, one or several plans of action to manage illness consequences are selected. Finally, appraisal of these actions provides feedback that influences both the representation of the disease and the plan of action itself (Leventhal et al., 1984; Leventhal et al., 1997; Leventhal et al., 1999).

Most of the oncological research examining illness perceptions has mainly focused on cancer diagnoses other than CRC. Experiencing minor consequences has been associated with good quality of life among persons with breast cancer (Jörgensen, Fredriksen, Boesen, Elsass & Johansen, 2009), and negative emotional representations have been found to correlate with worse quality of life among persons with head and neck cancers (Scharloo et al., 2005). Cancer patients who perceived their cancer as emotionally heavy and who had more negative consequences also perceived their cancer as more chronic (Hopman & Rijken, 2015). Concerning illness perceptions in persons treated for CRC, studies have found that negative illness perceptions concerning consequences and emotional representations contributed to poorer HRQoL in recovery (Ashley, Marti, Jones, Velikova, & Wright, 2015), and was associated with higher mortality among survivors (Thong et al., 2016). In sum, research shows that consequences and emotional representations are two dimensions of illness perceptions that are of importance in cancer disease. These two dimensions are in focus in the present thesis.

Self-efficacy

General self-efficacy concerns people's beliefs of their own capability, not their actual capability (Bandura, 1997). The present thesis focuses on self-efficacy in relation to maintaining everyday activities such as social activities, activities at home, activities outside home, sexual activities and physical exercise during recovery. Recovery following CRC treatment is a time when symptoms and other illness consequences such as fatigue and mental and gastrointestinal health distress are common (Theodoropoulos et al., 2013; Tsunoda et al., 2007), and maintaining everyday activities, such as social and other activities (Kurtz et al., 2002; Hodgkinson et al., 2007) and sexual (Breukink & Donovan, 2013) and physical activity after CRC treatment has been shown to have a positive effect on wellbeing. Self-efficacy in relation to maintaining usual activities may be important for subjective health during the recovery phase.

General self-efficacy has long been known to be important for symptom and illness management in chronic disease (Clark & Dodge, 1999), and it still drives theory-based interventions in chronic diseases (Wu & Chang, 2014). In cancer recovery, self-efficacy is central to symptom management. Cancer survivors need to manage different cancer-related problems and rebuild their lives following treatment, and low beliefs on their own capability leave them ill equipped to do so (Foster & Fenlon, 2011). Among cancer survivors in general, associations between higher self-efficacy and higher wellbeing have been found (Nelson, Qian & Wenjuan, 2014). The research is consistent with regard to positive associations between higher self-efficacy in illness management and wellbeing. For example, higher self-efficacy in relation to symptom management in CRC, breast cancer and lung cancer has been associated with better wellbeing during treatment and recovery (Foster et al., 2016; Shelby et al., 2014; Porter, Keefe, Garst, McBride, & Baucom, 2008). And higher self-efficacy in relation to illness behavior in gastrointestinal cancer has been associated with fewer self-reported symptoms and better HRQoL (Kohno et al., 2010).

Health-related quality of life

Health-related quality of life (HRQoL) is a commonly used outcome measure of subjective health in oncology research (Cella & Stone, 2015). Because cancer treatment regimens such as surgery, chemotherapy, and radiotherapy will have consequences in everyday life that adversely affect human health, HRQoL is an important outcome measure after cancer treatment in early as well as later phases of survivorship and recovery (Graça Pereira, Figueiredo, & Fincham, 2012). HRQoL includes dimensions of quality of life that directly concern subjective health (Spilker & Revicki, 1996), such as physical, psychological, social and spiritual wellbeing (Haase & Braden, 2003; Vallerand & Payne, 2003), as well as symptoms (Aaronson et al., 1993). Subjective health has been shown to be a powerful predictor of mortality in cancer disease (Chase et al., 2012).

Research on HRQoL during the first 12 months after CRC surgery has shown that a gradual improvement in physical and mental health takes place regardless of whether treatment consists of laparoscopic surgery (Theodoropoulos et al., 2013) or open abdominal surgery (Tsunoda et al., 2007). Twelve months after treatment has ceased, HRQoL has usually returned to preoperative levels (Downing et al., 2015). Chemotherapy as additional treatment has been shown to provide better HRQoL six months after treatment ended compared to levels measured at baseline (Ulku, Afey, Sati, Sevgi, & Şuayib, 2014), and these favorable effects on HRQoL have also been found in advanced CRC (Maisey et al., 2002). A recent large study on former colon cancer patients (diagnosed between 2000 and 2009) showed that long-term HRQoL did not differ between those treated with surgery alone or those treated with surgery and chemotherapy (Verhaar et al., 2015). When it comes to radiotherapy, research suggests that HRQoL is neither positively nor negatively affected within 24 months after treatment has been completed (Marijnen et al, 2005). The evidence on stoma and effects on quality of life is contradictory; some studies have shown a negative impact on quality of life (Marventano et al., 2013), such as negative effects on social life with poorer quality of life compared to those without stoma (Fucini, Gattai, Urena, Bandettini, & Elbetti, 2008), though contradictory results exist showing no difference in quality of life among the groups. Besides disease and treatment-related factors, lifestyle factors, such as access to a social network, and sociodemographic characteristics, such as age, are also associated with HRQoL (Marventano et al., 2013). One lifestyle factor proven to positively affect HRQoL in persons with CRC is physical activity (Lin et al., 2014); this also applies to moderate or intense physical activity over a longer period (2-5 years after treatment) (Husson, Mols, Ezendam, Schep, & van de Poll-Franse, 2015). Concerning sociodemographic characteristics, there are studies showing that HRQoL in CRC may increase with age, as well as studies showing the opposite (Marventano et al., 2013).

RATIONALE

In contemporary nursing, it is essential to support persons recovering from any illness based on their own experiences as unique individuals. Given the successful treatment strategies for CRC, there will be a substantial increase in the number of survivors recovering from this cancer disease. It should not be forgotten that, in addition to every person diagnosed and treated, there is a partner or a family affected, and they are all in a broader sense cancer survivors, and thus in need of nursing support. In Sweden today, the surgical treatment for CRC is efficient and fast, and most of the recovery takes place at home after discharge. In this early survivorship and recovery period, survivors face symptoms and other illness consequences such as fatigue and mental and gastrointestinal health distress, all known to affect HRQoL and daily life in a negative way. Survivors' management of symptoms and other illness consequences is dependent on their illness perceptions, self-perception and self-efficacy, but our knowledge about how such personal aspects and resources are associated with symptoms and other illness consequences in subjective recovery is incomplete. Subjective and clinical recovery need to go hand in hand in oncology care, and therefore there is a need for knowledge about subjective recovery as a basis for developing nursing support interventions for survivors and partners, in accordance with a person-centered approach.

AIMS

The overall aim of the present thesis was to explore the first year of subjective recovery following CRC treatment. The first focus was on illness perceptions and self-reorientation in cancer care settings from the survivors' perspective, and on cancer care settings and illness perceptions from the partners' perspective. The second focus was on investigating relations between fatigue, mental health, gastrointestinal health, illness perceptions and self-efficacy in relation to maintaining everyday activities, with HRQoL as the outcome measure.

Specific aims were to:

I. Explain self-reorientation in the early phase of recovery after CRC surgery and explore how illness perceptions, symptoms and expectations for recovery influence this process of self-reorientation (Study I).

II. Explore illness perceptions in relation to experienced contemporary cancer care settings among CRC survivors and partners (Study II).

III. Explore associations between HRQoL, fatigue, mental health, gastrointestinal health, illness perceptions, i.e. consequences and emotional representations, and self-efficacy in relation to maintaining everyday activities three months after surgical CRC treatment. A further aim was to test the Maintain Function Scale in a CRC population (Study III).

IV. 1) Study changes in HRQoL, two dimensions of illness perceptions (i.e., consequences and emotional representations), fatigue and self-efficacy in persons treated for CRC during the first year after surgical treatment, and 2) study how fatigue, illness perceptions and self-efficacy measured at 3 months affect HRQoL at 12 months post-surgery (Study IV).

METHOD

Designs

To address the overall aim of the thesis, both qualitative methodology (Study I and II) and quantitative methodology (Study III and IV) were used. When the aim was to explain self-reorientation and explore illness perceptions and cancer care settings from the survivors' and partners' perspective, a qualitative comparative design, i.e. grounded theory, was selected (Charmaz, 2006). When the aim was to explore associations and changes in HRQoL, fatigue, mental health, gastrointestinal health, illness perceptions and self-efficacy in relation to maintaining everyday activities, a cross-sectional and a longitudinal quantitative design were used (Table 1).

Table 1. Overview of designs, methods and participants

Study	**I**	**II**	**III**	**IV**
Design	Qualitative Comparative Grounded Theory	Qualitative Comparative Grounded Theory	Quantitative Cross sectional Analytical statistics	Quantitative Longitudinal Analytical statistics
Data collection	Interviews	Interviews	Questionnaires QLQ-C30, HADS,IPQ-R, The Maintain Function Scale	Questionnaires QLQ-C30, IPQ-R, The Maintain Function Scale
Occasion for data collection	3-9 months after surgical treatment	3-10 months after surgical treatment	3 months after surgical treatment	3 months and 12 months after surgical treatment
Participants	17 survivors	18 (9 survivors, 9 partners)	46 survivors	39 survivors
Analysis	Constant comparative analysis	Constant comparative analysis	Exploratory factor analysis Pearson's correlation coefficients Multiple regression analysis	Independent sample t-test Paired samples t-test Path analysis

QLQ-C30=The European Organization for Research and Treatment of Cancer (EORTC) cancer specific Quality of Life Questionnaire, HADS =The Hospital Anxiety and Depression Scale, IPQ-R= The Illness Perception Questionnaire – Revised.

Sampling procedure Study I – IV

All studies are based on data from consecutive patients diagnosed with colon or rectal cancer and admitted for CRC surgery at a county hospital in western Sweden between 23 March 2011 and 25 June 2012, a period of 15 months. Patients were informed about and asked to participate in a survey and/or an interview during the admission visit at the hospital ward approximately 3 weeks prior to surgery. This task was performed by two nurses who were working at the hospital ward and were familiar with the research project. After obtaining the consent of each patient, these two nurses also registered contact details, which were used by the researcher for follow-up and for obtaining more detailed information as well as for data collection after discharge.

Of the total population consisting of 96 consecutive patients, 81 were invited to participate, 24 declined participation because they did not wish to participate. In total 57 agreed to participate, and 9 of them withdrew their participation at the 3-month follow-up; reasons given for this were: 1) the cancer was removed and there was no reason to participate or 2) they felt too ill to participate. In addition, 2 passed away during these first 3 months. Between the third and twelfth month, 4 survivors withdrew their participation because they felt 1) cured, 2) too ill to participate, or 3) because the questionnaires took too long to complete. In addition, 3 persons passed away during this 9-month period (Figure 1).

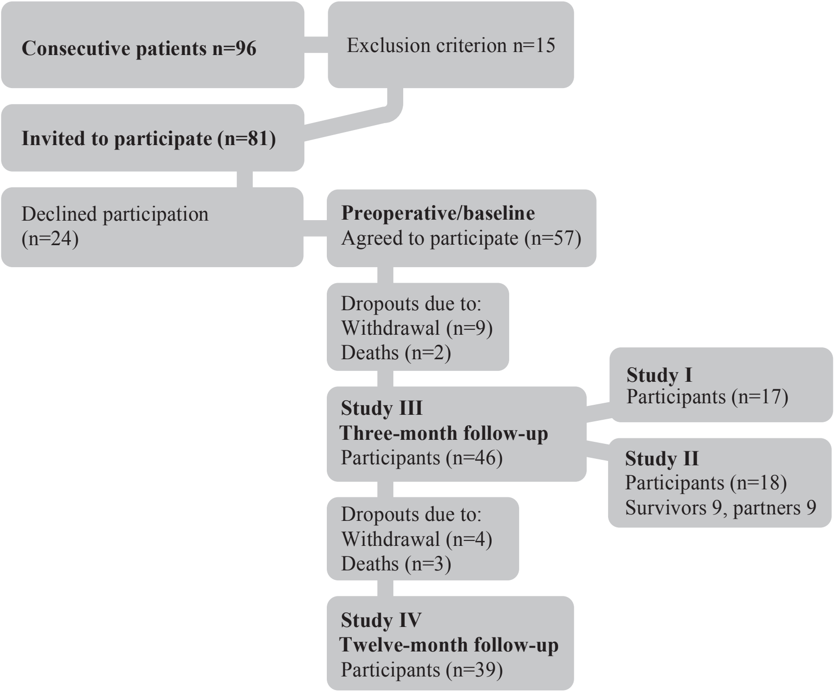

Figure 1. Flowchart of the study population

Inclusion and exclusion criteria for the total study population

Patients who were informed about their diagnosis and judged to fully understand the information provided and who were able to verbally express themselves independently and in writing were invited to participate. Patients who were not fully informed of their diagnosis were excluded (n = 7) as were patients who were unable to understand and speak Swedish (n=2), and patients with cognitive disorientation or severe communication disabilities (n=6).

Study I

The inclusion criterion was a minimum of 3 months and a maximum of 12 months since surgical treatment. The sampling was carried out with consideration to diagnosis (colon versus rectal cancer), as one way to optimize the possibility to achieve variation in the data. In total 17 survivors participated, 9 participants had received treatment for colon cancer and 8 participants had received treatment for rectal cancer.

Study II

Inclusion criteria were a minimum of 3 months and maximum of 12 months since surgical treatment and that all participants were in an active relationship, either married, cohabitant or living apart. The selection of partners was based on the survivor's consent. This meant that in some cases only the survivor (n=4) or the partner (n=4) in a couple participated, and in some cases couples participated (n=5 couples). In total 18 persons participated (9 survivors and 9 partners).

Study III

The selection was based on completed questionnaires concerning background data, HRQoL (QLQ-C30), anxiety and depressive symptoms (HADS), illness perceptions (IPQ-R), and self-efficacy in relation to maintaining everyday activities (The Maintain Function Scale), three months after surgical treatment. Nine survivors withdrew their participation, and the full sample consisted of 46 survivors.

Study IV

The selection was based on completed questionnaires concerning background data, HRQoL (QLQ-C30), illness perceptions (IPQ-R), and self-efficacy in relation to maintaining everyday activities (The Maintain Function Scale), three and twelve months after surgical treatment. After the third month following surgical treatment, 4 survivors withdrew their participation. In total 39 survivors participated at both the 3- and 12-month follow-up, and these 39 individuals constituted the total sample.

Data collection

Interviews in Study I and Study II

In Study I, interviews were conducted with survivors three to nine months after surgery, between October 2011 and June 2012. To ensure an ethical approach where the participants' comfort was ensured and prioritized in all interview situations (Kvale, & Brinkmann, 2009), the interviewer let each participant choose whether the face-to-face interview should take place in their home, at a neutral place, or at University West. Phone interviews were given as an option when no other alternative was present, i.e., when the person felt that poor health was an obstacle to leaving home and declined a home visit. In total 7 phone interviews were conducted. In 4 cases partners attended at face-to-face interviews without participating; these couples were recruited for joint interviews in Study II. Each interview lasted between 30-60 minutes, the shorter interviews were phone interviews. The data in Study I consist of interview material concerning illness perceptions, symptoms and self-perceptions among survivors. An opening question was chosen: C*an you describe an ordinary day and what it is like for you?* This question was chosen because it made the transition to the topic of the cancer illness easier for the participants. Based on the response, supplementary questions were used, such as: *What do you think about the disease today? Do you have any symptoms?* Probing questions always followed, such as: *Can you describe what you think when this occurs? What do you feel? What do you do? How has this affected you?* Each interview was recorded digitally and transcribed verbatim by the interviewer.

In Study II, Interviews were conducted with survivors and partners three to ten months after surgery, between October 2011 and July 2012. Vulnerability and insecurity among the participants was considered, so as to allow an open and uncensored communication of experiences to take place (Kvale, & Brinkmann, 2009). The interviewer let each participant choose whether the face-to-face interview should take place in their home, at a neutral place, or at University West. Participants who were couples could choose to conduct the interview individually or together with the significant other. Four joint couple interviews were performed, and one couple was interviewed separately. In the other cases, 4 survivors and 4 partners whose significant others were not participants were interviewed separately. Each interview lasted between 60-90 minutes. The data in Study II consist of interview material concerning illness perceptions and healthcare experiences in survivors and partners. To gain access to these topics, questions were used such as: *What do you think about the disease today? What do you think about the healthcare and treatment given?* Corresponding questions posed to partners could be: *What do you think about your partner's disease? What do you think about the healthcare and treatment given to your partner?* Followed by probing questions such as*: Can you describe what you think when this occurs? What do you feel? What do you do? How has this affected you?* Each interview was recorded and transcribed by the interviewer.

Questionnaires and medical record data in Study III and Study IV

In Study III, a package of questionnaires and prepaid envelopes were sent to the participants' home address 3 months after surgical treatment. Reminder notifications were sent twice, two weeks apart, and non-response was followed by phone calls. Each participant who did not respond to the survey (n=9) was contacted by phone (twice) to find out the reason for non-response; of those contacted, 7 responded. After that, non-response was considered withdrawal from the study. Medical information and information concerning treatment, such as diagnosis cancer coli and cancer recti, stoma, chemotherapy, radiotherapy and complications, were gathered from the medical records. Consent from the participants to retrieve medical data was forwarded to the head of department, who collected prespecified data from the medical records.

In Study IV, a package of questionnaires and prepaid envelopes were sent to the participants' home address on two occasions – at 3 months after surgical treatment and at 12 months after surgical treatment. Before the 12 months mailing, personal data were checked by tax authorities for information on deaths. Reminder notifications were sent twice, two weeks apart; non-response was followed by phone calls. Each participant who did not respond to the survey (n=4) was contacted by phone (twice) to find out the reason for non-response; of those contacted, 3 responded. After that, non-response was considered withdrawal from the study.

Study III, IV

European Organization for Research and Treatment of Cancer's (EORTC*)* cancer-specific *Quality of Life Questionnaire* QLQ-C30 (version 3) was used to measure HRQoL (symptoms and subjective health) in the present thesis. The QLQ-C30 has been used frequently, and in recent years it has become one of the most used patient reported outcome measures on HRQoL in clinical trials in oncology. QLQ C30 has been translated into more than 60 languages, including Swedish (Velikova et al, 2012), and many studies in the 1990s examined the validity and reliability of this questionnaire, showing that it has good psychometric properties, relevant across different cancer populations and languages (Aaronsson et al., 1993; Nietzgoda &, Pater, 1993; Hjermstad, Fossa, Bjordal & Kaasa, 1995; Groenvold, Klee, Sprangers, & Aaronsson, 1997; Velikova et al., 2012). QlQ-C30 is a 30-item questionnaire that incorporates one quality of life scale called the global health status/quality of life scale (GHS/QoL), five functional scales (physical, role, cognitive, emotional, and social) and nine symptom scales (physical fatigue, nausea, pain, dyspnea, insomnia, appetite, constipation, diarrhea, and economy) (Aaronson et al., 1993). QLQ C30 is commonly used in its entirety, but subscales have also been used separately, such as the GHS/QoL subscale (Parsons, Johnston & Slutsky, 2003) and subscales measuring symptoms such as fatigue, pain and nausea (Quinten et al., 2011). In Study III and IV, the following subscales were used: the GHS/QoL (two items), the fatigue subscale (3 items), diarrhea and constipation (single items) subscales. The GHS/QoL items are rated from 1=very poor to 7=excellent. The higher the scores on the GHS/QoL scale, the better the HRQoL. The items on the symptom scales are rated from 1=not at all to 4=very much, where higher scores on the symptom scales represent greater symptom burden. Scores on each scale were transformed into scores ranging from 0 to 100 (Fayers et al., 2001). The construct validity of the multi-item subscales of the QLQ-C30 has been confirmed (Shih, Chen, Sheu, Lang & Hsieh, 2013). In the present thesis, the Cronbach's alpha reliability coefficients calculated for fatigue ranged from 0.87 at 3 months to 0.81 at 12 months; for HRQoL the coefficient was 0.97 at both 3 and 12 months.

Study III

The Hospital Anxiety and Depression Scale (HADS) was used to estimate anxiety and depressive symptoms. The Swedish version used in the present study was validated in a larger sample of the general population in 1997 (Lisspers, Nygren & Soderman, 1997). The HADS has been used for a long time, across different countries and populations, and is considered to be a valid and reliable questionnaire (Bjelland, Dahl, Haug, & Neckelmann, 2002). The scale consists of 14 items, divided into the subscales anxiety and depression. HADS only contains items that measure mental health and is therefore useful in different groups of somatic illnesses. All items are rated on a 4-point scale from 0=not at all to 3=mostly. Scores were summarized, 7 items for anxiety and 7 items for depression, ranging from 0-21 points. HADS can be used to screen for anxiety and depression in three categories: Scores 7 and below on each scale give no indication of anxiety or depression; scores between 8 and 10 on each scale give an indication of possible anxiety and/or depression; scores ≥11 indicate probable anxiety and/or depression (Zigmond & Snaith, 1983). In the present thesis, the Cronbach's alpha reliability coefficient calculated for anxiety was 0.88 and that for depression was 0.80 at 3 months.

Study III, IV

The Illness Perception Questionnaire - Revised (IPQ-R) is a generic questionnaire used for assessment of illness perceptions. The original English version of IPQ-R has been confirmed as useful in cancer populations (Dempster and McCorry, 2012), and the Swedish version used in our studies and in the thesis has been validated in persons with myocardial infarction (Brink, Alsen, & Cliffordson, 2011). IPQ-R is a 38-item questionnaire incorporating in total of eight scales of illness perception dimensions: identity, timeline, consequences, personal control, treatment control, illness coherence, timeline cyclical and emotional representations. In the present thesis, two scales containing six items each were used: consequences and emotional representations. The consequences scale measures the perceived negative influence of the disease in various domains of one's personal life, such as activities, economics, impact on close relatives/friends as well as other people's attitudes. The emotional representations scale assesses negative emotional response through negative emotions connected to the disease, such as anger, worry and fear, as well as depressing and upsetting thoughts. All items are rated on a 5-point scale ranging from 0=strongly disagree to 5=strongly agree. Scores were summarized, ranging from 0 to 30 points. High scores on consequences and emotional representations represent strongly held beliefs about the negative consequences of the illness and negative emotional response (Moss-Morris, Weinman, Petrie, Cameron & Buick, 2002). In the present thesis, the Cronbach's alpha reliability coefficients calculated for consequences ranged between 0.59 at 3 months and 0.68 at 12 months, for emotional representations the coefficients were 0.79 at 3 months and 0.91 at 12 months.

Study III, IV

The Maintain Function Scale was used to measure self-efficacy in relation to maintaining everyday activities. In the present thesis, a Swedish version validated in persons with coronary disease was used (Fors, Ulin, Cliffordson, Ekman, & Brink, 2014). The Maintain Function Scale has no connection to a specific disease, and can therefore be used in different illness groups. The maintain function scale is one dimension (Maintain functioning) of the Cardiac Self-Efficacy Scale, originally developed by Sullivan and colleagues (1998) to measure self-reported self-efficacy in persons with coronary artery disease (Sullivan, LaCroix, Russo, & Katon, 1998). The Maintain Function Scale consists of five items that assess self-reported self-efficacy to maintain usual activities of daily life. All items are rated on a 5-point scale from 0=not at all confident to 4=completely confident. Scores were summarized, ranging from 0 to 20 points. High number of points indicates strong self-efficacy in relation to maintaining everyday activities. In the present thesis, the Cronbach's alpha reliability coefficients calculated for The Maintain Function Scale were 0.59 at 3 months and 0.90 at 12 months.

Analyses

The historical underpinnings of constructivist grounded theory analysis

Grounded theory has emerged from symbolic interactionism (Denzin, 1988), and from the beginning the classical grounded theory method was developed by Barney Glaser and Anselm Strauss to reduce the impact of positivist quantitative research. They made a slight modification of the objectivist epistemology and proposed a methodology aimed at theory and verification. Abstract concepts could be generated that were applicable to different areas by using a detailed inductive research process rather than making deductive assumptions (Glaser & Strauss, 1967). Strauss and Corbin (1990) later modified the classical grounded theory method and the philosophical perspective using verification in a new way. Verification was no longer used in a positivistic manner with hypothesis testing of the analysis; instead the steps of the analysis offered verification. They introduced the abductive approach, which involves controlling the analysis of inductive data by collecting more data and connecting the interpreted with the empirically observed. They also argue that knowledge is created, not that it exists and is waiting to be discovered, as the classical method indicates. Their work moved toward uncovering constructed realities, and thereby they made an imprint on constructivist soil, an imprint that was deepened and extended by Clark (2005) and Charmaz (2006). Through their work, the creation of a contextual understanding and interpretation became the focus. In this way, they place grounded theory in postmodernism where the method is still evolving. Constructivist grounded theory implies a relativistic ontology in which multiple social realities are present, reality is fluid and indeterminate. The epistemology embraces the notion of knowledge as created in social interaction. Scientific truth is therefore relativistic, provisional and ascertained through what works in empirical practice (Charmaz, 2006).

Study I and II, constant comparative analysis

The data in Study I and II were analyzed using grounded theory, according to the method presented by Charmaz (2006). The analysis aims to develop a theoretical understanding of personal processes and interactions in relation to a given situation or circumstance. With research interest and sensitizing concepts as the point of departure, systematic coding and constant comparisons of the data and codes form the basis for analysis progression. In the work with the analysis, codes and categories as well as relations are identified and explained by posing questions to the data, such as “What is expressed?” and “What does that mean?” A constant comparative methodology combined with memo-writing and theoretical sampling results in an increased level of abstraction and the growth of a theoretical model. Constant comparative methodology involves analyzing the material by comparing all the data at each level of analysis, i.e., comparing data with data, events with events, codes with codes and so on. Memo-writing involves making notes on the observations and ideas that emerge when performing comparative methods. These notes help in making analytical sense of the material, especially notes that challenge the immediate understanding. Memo-writing is also necessary to making one’s own preconceptions visible. Memo-writing leads directly to theoretical sampling, which is focused on illuminating the categories one has created to make sense of the material. Theoretical sampling leads to tight and robust categories and clear associations between them (Charmaz, 2006).

Analyzes performed in Study I and II was initiated by line-by-line coding of the transcribed interviews. Nvivo software was used to sort and categorize the data (Edhlund, 2011). Analyses were meant to uncover processes that took place during the early survivorship and recovery period following CRC treatment. Illness perceptions and self-perceptions in Study I, and illness perceptions and cancer care settings in Study II, were used as sensitizing concepts and the point of departure. The steps of the analyses eventually led to acting upon the data and developing focused codes that could explain larger segments of the line-by-line codes. Focused codes were in turn explained and some of them were abstracted to categories that synthesized larger portions of data and more of the focused codes. A constant comparative method and mind mapping, i.e. clustering, were used to clarify connections. During this later part of the research process, a review of the literature and a theoretical deepening of the areas of concern also began. In Study I, theoretical sampling included performing two final interviews intended to refine the properties of the categories. Categories were then abstracted further, and presented in conceptual categories and a core category that described the results. Preconceptions were handled by extensive memo-writing about the data as well as knowledge and thoughts emerging throughout the entire analysis (Charmaz, 2006).

Study III and IV, descriptive and analytical statistics

The data in Study III, IV were analyzed using descriptive and analytical statistics. In SPSS version 21 for Windows, Cronbach's alpha reliability coefficients for the scales used in both studies were calculated, as well as descriptive statistics including frequencies, percentages, mean scores and standard deviations (SD) for the samples and variables investigated in both studies (Pallant, 2013).

In Study III, an exploratory factor analysis of the Maintain Function Scale was performed in order to get an indication of the suitability of this scale in the investigated population (Pallant, 2013). If one underlying factor can be identified that explains 60% of the variation of the items in the scale, this suggests that self-efficacy in relation to maintaining everyday activities is measured in the investigated population. The factor analysis involved 2 steps: 1) Assessment of the suitability of the data by the sample size and the inter-item relationship. A sample size of 5 cases per item and inter-item correlation coefficients above 0.3 are sufficient for performing a factor analysis (Tabachnick & Fidell, 2013). 2) Factor extraction was performed using Kaiser's criterion or the rule of eigenvalue greater than one, meaning that only factors with an eigenvalue of one or more are kept. Associations between the investigated variables were identified by Pearson's correlation coefficients, and all independent variables associated with HRQoL ($p < 0.01$) were included in a multiple regression analysis model (Pallant, 2013).

In Study IV, the differences in HRQoL and fatigue between persons treated for CRC and the general population (Scott et al., 2008) were examined using independent sample t-tests. To evaluate changes in variables between 3 and 12 months in Study IV, means (SD) were compared using paired samples t-tests. To identify relationships between variables and to determine whether two dimensions of illness perceptions (consequences and emotional representations) qualified as mediators, Pearson's correlation coefficients were used.

In addition, using Baron and Kenny's definition of a mediating variable as the point of departure (Baron & Kenny, 1986) to test whether the relationship between self-efficacy (at 3 months) and HRQoL (at 12 months) could be partly or completely explained by emotional representations and fatigue (at 3 months) as mediators, a path analysis was performed using Mplus (version 5) (Muthén & Muthén, 2009) under the STREAMS (Gustafson & Stahl, 2005) environment. One path model was constructed with HRQoL (at 12 months) as the dependent variable, self-efficacy (at 3 months) as the independent variable and emotional representations and fatigue (at 3 months) as the mediating variables. The following causal relations were expected: the direct relationship between self-efficacy and HRQoL was expected to subside or disappear (direct effect). Self-efficacy was expected to affect emotional representations and fatigue. Emotional representations were expected to affect fatigue and, in turn, emotional representations, and fatigue was expected to affect HRQoL (mediating effects).

ETHICAL CONSIDERATIONS

The studies were conducted in collaboration with a cancer unit at a county hospital in western Sweden. Permission to carry out the project was obtained from the head of department as well as from the operation manager of the cancer unit. Each participant was informed verbally and in writing about the project's purpose, voluntary participation, confidentiality and what participation would mean in terms of time, and sometimes sharing sensitive and medical information (patients only). Each participant gave his/her written informed consent to participate under these conditions. Participants were also informed that their participation could be discontinued at any time without affecting their care or treatment, or the care or treatment given to their partner. The research has been conducted in accordance with medical ethical principles stipulated in the Declaration of Helsinki (World Medical Association, 2013), and by Swedish law concerning ethical review of research involving humans (SFS 2003:460; SFS 2008:192) and management of personal data (SFS 1998:204). The studies performed within this project were approved by the Regional Ethical Review Board of Gothenburg (reg. no. 753-10) before the data were collected.

RESULTS

Self-reorientation and the influence of illness perceptions, symptoms and expectations, Study I

The study population in Study I consisted of 17 survivors (12 females and 5 males; 61-85 years of age). Eight participants were treated for colon cancer, 6 for rectal cancer. The analysis in Study I gave rise to the core category *striving for a congruent self,* which explained self-reorientation as the person trying to achieve congruence in self-perception by bringing closer together the perceived self and the self that is mirrored by others. The core of self-reorientation consisted of cumulative questions without clear answers. Not knowing what caused the disease and not being able to understand why one's body reacted in a certain way meant being in a body and a life situation that felt unsafe and unpredictable. It meant losing one's expectations and former sense of self. The person was in limbo, with an incoherent and unrecognizable self-perception. The core category was presented as different attempts to get answers through personal explanations. These attempts illustrated different strategies and are described in the content of the conceptual categories *self-strengthening through thankfulness, self-sheltering through guilt reduction* and *self-exposing through blame.* The first conceptual category *self-strengthening through thankfulness* was based on expressed thankfulness, which was associated with the perception of aging and the perception of negative attributes associated with cancer disease, which lowered expectations for life and produced the need to express thankfulness for everyday life, regardless of symptoms and obstacles. *Self-sheltering through guilt reduction* concerned the commonality of CRC, the role of coincidence in causing it, as well as genetic inheritance of cancer disease, and how these aspects offered consolidation and reduced feelings of responsibility for the CRC. The last conceptual category, *self-exposing through blame,* illustrated the search within personal lifestyle factors and own actions when commonality, coincidence or genetic inheritance no longer provided sufficient explanations for the development of the cancer.

Illness perceptions in relation to experienced cancer care settings among survivors and partners, Study II

The study population in Study II consisted of 18 survivors and partners (12 females and 6 males). The survivors were between 61 and 85 years of age and the partners between 58 and 87 years; 3 survivors were treated for colon cancer and 6 for rectal cancer. The analysis in Study II resulted in the core category *outlook on the cancer diagnosis when quickly informed, treated, and discharged*, which exemplified the illness perceptions of survivors and partners and the care environment where they were found. The core category was created based on the conceptual categories *experiencing contemporary cancer care settings* and *outlook on the cancer diagnosis.* The conceptual category *experiencing contemporary cancer care settings* presented the cancer care environment. Survivors and partners experienced treatment as quick, without waiting and as a positive experience; however partners experienced the information given as massive and troublesome, and they were concerned about forgetting, feeling they had to take charge over the care situation. Partners also experienced non-continuity in care as more problematic than the survivor did, because they did not have a specific healthcare professional to contact if needed. The time after discharge was also characterized by uncertainty and loneliness for both survivors and partners. They did not know what to expect and they felt abandoned. *Outlook on the cancer diagnosis* was a conceptual category that displayed the illness perceptions found in the present findings. There was a mismatch between survivors' and partners' perceptions. Survivors tended to minimize the seriousness and were more focused on leaving the cancer diagnosis in the past and moving forward, which implied focusing on words that did not confirm or refute the cancer disease as well as shielding from unnecessary information and having faith. Partners tended to be more focused on the cancer word, and on seeing the cancer diagnosis as a permanent life-changing event. They were prepared to face severe consequences and displayed active information-seeking behavior.

Associations between variables 3 months into recovery and the suitability of the Maintain Function Scale, Study III

The study population in Study III consisted of 46 survivors (20 females and 26 males; mean age 72.6 years). Twenty-four participants were treated for cancer coli and 22 for cancer recti. The majority did not have chemotherapy (84.8 %), radiotherapy (76.1 %) or experience complications (76.1%). Fatigue, depression, anxiety, diarrhea, and illness perceptions were negatively associated with HRQoL, meaning that persons who were more fatigued, depressed, anxious, or had more diarrhea were more likely to report lower HRQoL. Regarding illness perceptions, the results showed that those who reported more negative emotions and negative consequences of CRC were more likely to report lower HRQoL. Self-efficacy in relation to maintaining everyday activities was positively associated with HRQoL, meaning that those who scored higher were more likely to report higher HRQoL. The result of the multiple regression model identified fatigue and diarrhea as negative predictors, implying that improvement in these variables improved HRQoL. Self-efficacy in relation to maintaining everyday activities was identified as a positive predictor, implying that an improvement in this variable improved HRQoL. The results of the factor analysis showed that the Maintain Function Scale was suitable for assessing self-efficacy in relation to maintaining everyday activities in the present study population. The result of the analysis was based on an eigenvalue >1, confirming a one-factor solution. This one factor explained 79.16% of the variance in the total sample.

Changes in variables between 3 and 12 months into recovery and the results of the path model, Study IV

The study population in Study IV consisted of 39 survivors (16 females and 23 males; mean age 71.7 years). Eighteen participants were treated for cancer coli and 21 for cancer recti. The majority did not have chemotherapy (84.6), radiotherapy (71.8), or experience surgical complications (74.4%). Comparisons between the two measurements over time showed a significant decrease in level of self-efficacy at 12 months (p=0.003). No significant changes in levels of HRQoL (p=0.456), fatigue (p=0.939), illness perceptions (i.e., consequences (p=0.547) or emotional representations (p=0.728) were found. To test whether illness perceptions and fatigue mediated the effect between self-efficacy and HRQoL, bivariate associations between the variables were studied. All variables were associated, except for the illness perception dimension consequences, which was not associated with self-efficacy. Because established associations between the variables were necessary for performing a path analysis, consequences was discarded from additional analyses.

The results of the path model showed that the effect of self-efficacy on HRQoL was not significant (standardized relation = .059, p>0.05), showing no direct effect. Therefore the model had three paths containing emotional representations and fatigue as mediators: 1) Self-efficacy influenced emotional representations, and emotional representations influenced HRQoL (standardized relations: - .504 x -.316 = .159). Consequently, emotional representations had a significant (p<0.05) mediating effect on HRQoL. 2) Self-efficacy influenced emotional representations, emotional representations influenced fatigue, and in addition fatigue influenced HRQoL (standardized relations: -.504 x .132 x-.402 = .027). 3) Self-efficacy influenced fatigue and fatigue influenced HRQoL (standardized relations: -.629 x -.402 = .253). Hence, fatigue had a significant (p<0.05) mediating effect of self-efficacy on HRQoL. The path between emotional representations and fatigue was not significant (p>0.05) and did not mediate the effect of self-efficacy on HRQoL. The results of the path model showed that emotional representations and fatigue, respectively, mediated the effect of self-efficacy on HRQoL.

DISCUSSION

Self-reorientation and Illness perceptions in relation to cancer care settings

With reference to the results of the present thesis, healthcare environment, i.e. cancer care settings, seems to be important for self-reorientation and illness perceptions. Earlier studies have shown how the healthcare environment in a broader perspective, including physical and psychosocial aspects, influences care experience (Browall, Koinberg, Falk, & Wijk, 2013; Edvardsson, Sandman, & Rasmussen, 2006). The results of Study II indicate that healthcare environment not only influenced the care experience, but also contributed to the illness perception *outlook on the cancer diagnosis*. The environment in which *outlook on the cancer diagnosis* was found was a quick and medically effective healthcare context, where some aspects caused concern, such as information, lack of continuity and loneliness after discharge. Two different perceptions were found, one focused on the cancer diagnosis and the difficulties and setbacks brought along with the diagnosis, common among partners, and another focused on leaving the cancer diagnosis behind, more common among survivors. Partners reacted more negatively to information and lack of continuity than survivors did, which indicates that partners take on a caregiver role, but also that the healthcare environment in its current form is likely to burden partners more than they are prepared for. The strain on partners indicated here is in line with early research showing high pressure on partners and a negative impact on their health (Northhouse et al., 2000: Sjövall et al., 2009). The results of Study I indicate that self-reorientation after CRC treatment depends on illness perceptions, a finding suggesting that illness perceptions are of vital importance for subjective recovery in cancer illness. Further, the results of Study II indicate that the healthcare environment, as it appeared in the present research, may make it more difficult for survivors to reorient and understand their illness, which may in turn contribute to prolonged subjective recovery.

Illness perceptions, self-efficacy, symptoms and HRQoL

In the present thesis, illness perceptions (emotional representations) was found to be a key component that functions as a mediator between self-efficacy and HRQoL. Self-efficacy proved to play a prominent role in subjective recovery following CRC treatment in several respects, not only by influencing illness perceptions, but also by influencing fatigue. It was also apparent from the results in Study IV that self-efficacy deteriorated during the first year of recovery. The prominent role of self-efficacy in subjective recovery found in the present results is supported by the conceptual framework developed by Foster and Fenlon

(2011), who suggested that self-efficacy is central to cancer recovery. Therefore, and with reference to the present results, cancer nursing should be developed in a manner that strengthens survivors' self-efficacy early on in recovery. It is reasonable to believe that strengthening self-efficacy would also reduce the uncertainty found in Study I and II, which in turn would positively influence illness perceptions and self-reorientation.

In contrast to previous research showing increased fatigue (Vardy et al., 2014; Thong et al., 2013) and worse HRQoL followed by improvements between 3 and 12 months into recovery (Theodoropoulos et al., 2013; Tsunoda et al., 2007), the present thesis showed that there were no differences in fatigue and HRQoL at the group level among survivors compared to healthy controls (Scott et al., 2008). It also showed that there were no statistically significant changes in fatigue or HRQoL between the two measurements over time. It is possible that the early increase in HRQoL seen here indicates relief related to ending treatment, suggesting that such early improvements might not last. The lack of statistically significant changes in HRQoL and fatigue between the two measurements over time may indicate that survivors have adapted to symptoms and other illness consequences at 12 months into recovery and changed their perception of what HRQoL and fatigue mean to them. This circumstance is often referred to as response shift (Sprangers & Schwartz, 1999). Of the symptoms examined in the present thesis, fatigue was characterized as a more significant symptom for the experience of HRQoL, which is in line with previous research findings (Marventano et al., 2013). Another symptom that was important to the experience of HRQoL and that has had a negative impact on wellbeing in other studies was diarrhea (Desno & Faithful, 2006; Landers et al., 2014), a symptom that here, as seen in Study III, had a direct impact on HRQoL during the early part of recovery. Fatigue and diarrhea have long been known to be important symptoms to address after CRC treatment, and the present results support their continued importance. The thesis confirms that depression and anxiety are negatively correlated with HRQoL, meaning that survivors who are more depressed or worried during recovery are more likely to have lower HRQoL. Although the findings from Study III did not support the notion that depression and anxiety predict HRQoL, as suggested by previous research (Pereira et al., 2011), nurses need to be attentive to mental health issues following CRC treatment.

HRQoL in relation to age

Age has been associated with HRQoL in colorectal cancer. In some studies, HRQoL increases with age, while other studies show the opposite (Marventano et al., 2013). In the present thesis, HRQoL at the group level was consistent with the HRQoL of healthy controls (Study IV), and age was found to be an important factor for the experience of HRQoL (Study III). The present results indicate that HRQoL may increase during mature age. Positive associations between wellbeing and mature age, despite declining health, have previously been acknowledged in the research (Steptoe, Deaton & Stone, 2015). Regarding CRC, early studies have shown that persons over 60 report better quality of life on short-term follow-ups than younger persons do (Arndt, Merx, Stegmaier, Ziegler, & Brenner, 2004; Jansen et al., 2011), and wellbeing and positive experiences in the present are given more space even in the presence of illness and difficulties (Carstensen, Fung & Charles, 2003). In Study I, beliefs about aging and cancer manifestations enabled comparisons that lowered expectations regarding health and activity, so it may be that self-reports showing better HRQoL in mature age reflect lower health expectations. Deeper knowledge about aging and HRQoL would most likely be beneficial in improving illness perceptions and bolstering self-efficacy during recovery following CRC. More research in the area of aging and HRQoL is warranted.

Findings in relation to nursing

Subjective recovery emphasizes the personal journey of change and wellbeing despite presence of illness (Slade et al., 2008; Collier, 2010). This type of recovery does not mean that there is an end or a cure, but rather a change and an acceptance of a life, a body, and a self that is forever changed (Leamy et al., 2011). With reference to Study I, subjective recovery is about recovering a new sense of self and purpose in an overwhelming situation. Subjective recovery belongs to those experiencing it, that is, they decide what subjective recovery means to them. With reference to the present thesis, nursing needs to be more focused on supporting cancer survivors and nurturing their subjective recovery after CRC treatment. Considering that many CRC survivors will never be able to clinically recover, subjective and clinical recovery need to go hand in hand in oncology care.

With reference to the results of Study II, survivors, partners included, were left in silence after discharge. They felt lonely and abandoned and did not know what to expect. These results suggest that nurses, the contact nurse in particular, needs to be educated in advanced oncology nursing to be able to identify and address the complex physical, psychological and social needs that arise during recovery (Beets et al., 2017). With further reference to Study IV, it is recommended that self-efficacy and illness perceptions be emphasized in advanced oncology nursing education and incorporated into the core competence: patient-centered care for advanced practice (APN) (Cronenwett et al., 2007; Cronenwett et al., 2009). Additionally, the present results indicate that the healthcare environment, as it appeared here, may prolong subjective recovery in survivors and burden partners more than they are prepared for. This, in turn, indicates the need for an expanded cultural awareness among healthcare professionals, which involves avoiding generalizations based on cultural features (Hogg, 2010) and identities. An example of cultural awareness may be to treat every patient and every partner as unique individuals, and not to act based on stereotypical expectations. Nurses need to have an intersectional perspective and be aware of their position and the position of the survivor and partner, as well as power structures and how they may interact to affect the patient, partner and nursing care (Weber, 2006).

The results of the present thesis show that nursing care after treatment and discharge needs to be prioritized. It was indicated that subjective recovery was not seen as an essential part of cancer care, which may be related to cancer being assessed from a biomedical perspective, where the effectiveness of diagnosis and therapy in relation to cure versus non-cure is emphasized. The current thesis shows that, in addition to effective medical treatment, an effective nurse-led follow-up after treatment would be beneficial. Follow-up should be focused on the needs of the survivor and partner. We need to recognize these people as survivors entering survivorship, meaning that they are persons who have lived through a difficult and personal experience of cancer treatment (Hebdon et al., 2015), and who now stand on the threshold of post-treatment life. Early reentry has previously been described as a time when survivors expect rapid recovery and confront a life for which they were not prepared (Stanton et al., 2015). This unpreparedness was also found in the present results. Nurses may help by supporting self-efficacy early on in recovery. To be able to emphasize subjective recovery during nursing follow-up consultations, nurses need to acknowledge that even though cancer treatment has ended, the cancer trajectory and the cancer experience have not ended. Survivors have to live with the consequences of cancer for the rest of their life. Nurses supporting survivors in their subjective recovery need to adopt the meaning of survivor and survivorship in their everyday practice and use these concepts to acquire a deeper understanding of the treated person and partner. In the end, every patient, every survivor and those close to them are first and foremost persons. For this reason, I believe that the concepts survivor and survivorship can be regarded as an extension of, or an addition to, the concept of person-centeredness, specific to oncology nursing.

In an early publication of Basic Principles of Nursing Care (1969), Virginia Henderson emphasized recovery as a fundamental nursing concern. Furthermore, Henderson meant that the fundamentals of nursing did not vary by medical diagnosis, only by person. Although Henderson's outlook on nursing originates from a bygone era when concepts such as cultural competence and intersectionality were unknown, her ideas show person-centeredness in its infancy. The term person-centered can be used interchangeably with related terms such as patient-centered, family-centered or personalized (McCance, McCormack, & Dewing, 2011). Regardless of the term used, the following key components are shared: establishing a restorative relationship or partnership with the patient, getting to know the person behind the disease and including those close to the patient and family members according to the patient's preference, recognizing the role family members play in home-care and care-giving, exploring and listening to goals and wishes regarding care, acknowledging the level of involvement the patient wants in decision-making, and providing information to meet identified needs (Clay & Parsh, 2016; Sharma, Bamford & Dodman, 2015). In person-centered care, one strives to see every person's uniqueness and emphasizes these aspects when planning care (Ekman et al., 2011). This means that different persons with the same disease or with the same experience of symptoms should not be treated in the same way (Brink & Skott, 2013), and this also applies their those close to them.

Subjective recovery can be viewed as a transition. Transition, as a framework, has long been well anchored in the area of psychosocial oncology nursing studies (Berterö, 1998; Sarenmalm, Thoren-Jönsson, Gaston-Johansson, & Öhlen, 2009). Transition places the present results in the context of transition conditions, highlighting the different circumstances that can facilitate or prevent a healthy transition. A healthy transition occurs when a person incorporates new knowledge, change behavior and redefines the self in a social context. The concept of transition consists of a separate or parallel change from one state to another. A transition does not take a certain amount of time, but is a process that develops over time and involves disruption of life with changes in development, the situation and/or health status. Transitions begin with the first signs of change, continue through a phase of instability, and reach their endpoint with a new beginning or a stable phase. Critical points of importance from a transitional perspective are diagnosis and completion of treatment. Transitions have universal characteristics, such as the transformation of identity, abilities, roles and behavior patterns on the individual and family level (Meleis, Sawyer, Hilfinger Messias, & Schumacher, 2000). In the early period following surgical treatment for CRC, the person is in a transitional phase of instability, which is characterized by feelings of being lost and of having a fragile identity and structure. With reference to the results of Study I and II, change begins in this phase of instability. Illness perceptions affect self-reorientation and relationship dynamics, and the transition from cancer patient and partner to cancer survivors begins.

METHODOLOGICAL CONSIDERATIONS

Grounded theories are substantive or formal in nature, meaning that they claim to understand a certain phenomenon in a defined situation or to deliver understanding at a higher level of abstraction that is applicable across different areas (Charmaz 2006). The grounded theory studies (Study I and II) in the present thesis were conducted to try to understand self-reorientation and illness perceptions following CRC treatment, and owing to their purposes and their delimitations they are considered to be substantive models. Interviews dealing with sensitive topics, such as in grounded theory Study I and II, need to be thoughtfully prepared. To be able to communicate concern and understand the feelings and experiences of others without becoming to involved is sometimes referred to as empathetic distance in a researcher (Valentine, 2007); empathic distance allows rapport to develop, meaning achieving a good understanding of each other, which in turn facilitates the end of the interview (Hennink, Hutter & Bailey, 2011). Being a researcher and a nurse may cause ethical conflict to arise when undertaking interviews on sensitive themes (Ashton, 2014). I found it difficult to identify the right level of involvement. At times I was torn between the desire to step in as a nurse and to step back as a researcher. My way of balancing the ethical dilemma of being a researcher and a nurse was to make priorities. The convenience and wellbeing of the participants was always my highest priority, access to rich data came in second, and these priorities framed where and how the interviews were performed.

In Study I and II, some aspects of data collection may have influenced the credibility. In Study I, diagnosis (colon versus rectal cancer) initially played role in decision-making regarding the recruitment of participants. This was done to optimize the possibility of including variation in self-reorientation from the outset and to ensure that the categories developed later would be derived from data applicable to all patients in the early recovery phase following CRC surgery. This initial decision does not mean that the diagnosis as such was a focus in the analysis.

Other aspects that should be mentioned as potential influencers on credibility were the length of the interviews and the use of phone interviews. Interviews lasted between 30-60 minutes. This might be considered a short period of time for achieving depth and sufficient data in grounded theory (Charmaz, 2006). But after each interview there was room for discussion. Many participants said they appreciated being listened to and bringing their thoughts and feelings out into the open. I like to believe that this kind of feedback from the participants indicates the honesty and depth of their stories. Phone interviews were given as a option when face-to-face interviews were impossible, meaning that phone interviews gave voice to patients whose voices would otherwise not have been heard. As the core of grounded theory is to see participants act in their social setting (Charmaz, 2006), the use of phone interviews can be viewed as incompatible. However, people's relationship to their phone has changed so radically in recent years that the use of telephone interviews should not only be seen as a limitation. Phone interviews could in fact add value. Concentrating on the voice instead of the face may give access to non-visual cues that are highly useful in grounded theory analysis (Ward, Gott & Hoare, 2015).

The study population size may have influenced the generalizability of the results in Study III and IV. The study population was estimated to be around 120 persons, a figure found to be adequate for addressing the research question, and a reliable figure considering the number of patients eligible for this project passing through the clinic every year. Although, the time for data collection was extended from 12 to 15 months, the estimated study population was reduced by 39 persons. During data collection for this project, an additional study began recruiting patients treated for CRC at the clinic, which may have resulted in fewer available patients. In addition, there were problems with loss of participants. Some persons declined participation from the start, and for ethical reasons a non-response analysis was not performed among these persons. In retrospective, it is possible that some of those who declined participation might have participated if the initial recruitment had been handled in person by the researcher instead of using a gatekeeper, as face-to-face recruitments are typically more effective (Polit & Beck, 2017).

In addition to those who declined participation, others dropped out during the studies. Participants who dropped out consisted of individuals who had died or who felt too healthy or too ill to participate. Therefore, it is possible that those suffering from more severe illness were not represented in the material. When comparing age between dropouts and participants in Study IV, a statistically significant difference was found (dropouts: mean 77.9, SD 6.50; participants: 71.7, SD 7.38; p=.003), meaning that the oldest patients were not represented in the material. Some persons who dropped out indicated that the questionnaires were too comprehensive. It is known that comprehensive questionnaires can lead to lower response rates (Edwards et al., 2009), and it is possible that a less extensive questionnaire may have led to a higher response rate. The differences between dropouts and participants could have affected the generalizability of the results (Polit & Beck 2017), but this cannot be determined conclusively.

Given the small study population, the use of detailed statistical analysis such as factor analysis and path analysis in Study III and IV may be questioned. However, it should be said that using a minimum sample size may not always be the most beneficial approach. In factor analysis, high values on communalities are of interest as well, because high values can outweigh a small sample size (Preacher & MacCallum, 2002). In path modeling, there is no consensus regarding sample size (Wang & Wang, 2012), instead it is the strength of the associations calculated prior to conducting the path model that is important, and according to Wolf and colleagues (2013), it is recommended to tailor the sample size to the model. Finally, if one can theoretically justify the statistical analyses conducted, this may further compensate for a small study population (Preacher & MacCallum, 2002).

Besides limitations related to the size of the study population, other aspects concerning data collection may have influenced the validity of Study III and IV. The concept HRQoL used in the present thesis refers to symptoms and subjective health. Accordingly, the results concerning HRQoL in Study III and IV do not cover all dimensions of the HRQoL concept. In addition, using the QLQ C30 for assessing fatigue means measuring physical fatigue. Other domains of fatigue that may be of importance here, such as the mental dimension, were not covered. Future studies exploring HRQoL in subjective recovery following CRC treatment should therefore include functional dimensions, and fatigue should preferably be assessed using a multidimensional approach. Making comparisons between a stoma group and a non-stoma group, or between groups of different disease severity, was not an aim in the present thesis. However, it cannot be ruled out that HRQoL and illness perceptions may change depending on the presence/absence of stoma and disease prognosis. Although the presence of stoma was relatively evenly distributed in the sample, the sample size was too small to allow for such comparisons. Future studies with larger sample sizes should include comparisons between groups with and without stoma and groups with different disease severity.

In Study IV, longitudinal measurements were performed, and response shift can be considered a measurement bias (Salmon, Blanchin, Rotonda, Guillemin, & Sébille, 2017). To rule out that the results have been affected by response shift, and to distinguish response shift effects from other changes, analyses at the sample level, such as structural equation modeling, are required (Cort, 2005), but because response shift as such was not the focus of the present thesis, these kind of analyses were not performed.

CONCLUSIONS AND CLINICAL IMPLICATIONS

Nursing care after treatment and discharge needs to be prioritized. Survivors and partners must not be left in silence after CRC treatment. Results such as those seen in the present thesis suggest that there is an urgent need to establish a clearly formulated care contact person for survivors and partners who is accessible during recovery. It is of vital importance that survivors and partners know where to turn with their questions and problems. In addition to prioritizing nursing care after discharge, massive amounts of information, lack of continuity and the strain on partners, as found in the present results, need to be addressed by the contact nurse during CRC treatment.

Illness perceptions and self-efficacy in relation to maintaining everyday activities are of vital importance for subjective recovery, because illness perceptions not only influence self-reorientation but also function as a mediator between self-efficacy, in relation to maintaining everyday activities, and HRQoL. As low self-efficacy in relation to maintaining everyday activities was associated both with more negative emotional representations and with increased fatigue in survivors, and because self-efficacy decreased during the first year of recovery, complicating illness and symptom management for survivors, self-efficacy strengthening interventions need to be in focus after CRC treatment. In addition to self-efficacy strengthening interventions, symptoms and survivors' and partners' illness perceptions need to be addressed separately as part of facilitating self-reorientation and avoiding a decrease in subjective health and wellbeing.

The results of the present thesis provide a base of knowledge, which could serve as a guideline for designing early nursing support interventions in recovery. To identify the needs of the survivor and partner early on, nurse-led follow-up consultations after CRC treatment are needed. A nurse-led follow-up consultation should focus on: establishing a clear care contact person; identifying fatigue and diarrhea and using care plans to address them; helping the survivor and partner to recognize different illness perceptions and adapt information accordingly; identifying survivors with negative illness perceptions by asking how they are managing after their treatment, and asking additional questions about emotions and thoughts concerning their illness; addressing questions and concerns to ease uncertainty and facilitate self-reorientation; using the Maintain Function Scale to identify survivors with low self-efficacy in relation to maintaining everyday activities; and for those in need, initiating self-efficacy strengthening support.

IMPLICATIONS FOR FUTURE RESEARCH

First, with regard to the results of Study I and II, implications for future research include to further research illness perceptions in cancer survivors and partners in relation to their informational needs. With regard to the results of Study III and IV, implications for future research include conducting a larger study comprising variables such as functional dimensions of HRQoL and multidimensional fatigue, in addition to making comparisons between groups with and without stoma and groups with different disease severity.

Second, the finding concerning the importance of self-efficacy in relation to maintaining everyday activities in subjective recovery following CRC treatment adds new and valuable knowledge. Using the Maintain Function Scale to measure such self-efficacy in the present thesis was an exploration. But because the Maintain Function Scale is well-suited to the study population and because it is short and probably useful in clinical cancer settings as well, studying this scale further would be worthwhile. The Maintain Function Scale should preferably be tested and validated in larger CRC populations, and further developed into a cancer-specific scale.

Development of interventions and nurse-led follow-up consultations in recovery is a third implication for future research generated from this thesis. Because nurse-led follow-up telephone consultations have been shown to have good patient satisfaction outcomes, designing and testing other cost effective alternatives, such as nurse-led digital receptions for communication and counseling in recovery following CRC treatment, should be encouraged. In addition to such follow-up consultations, the results of the present thesis encourage equal emphasis on developing self-efficacy enhancing interventions for use in recovery following CRC treatment.

SVENSK SAMMANFATTNING

Subjektiv återhämtning efter kolorektal cancerbehandling handlar om att lära sig att leva med en cancersjukdom i sin livshistoria, att hantera olika sjukdomskonsekvenser och att erfara ett välbefinnande. Tidigare forskning har identifierat symptom och andra konsekvenser, efter behandlingsavslut, som påverkar hälsan och det dagliga livet negativt för både personen som behandlats och närstående. Det direkta stödet från hälso- och sjukvården upphör efter utskrivning, vilket innebär att personer som behandlats och deras närstående själva måste finna vägar för att hantera sjukdoms- och behandlingsrelaterade symptom och konsekvenser. Tidigare forskning i annan sjukdomskontext har visat att de övertygelser och tankar en person har om sin sjukdom, om sig själv, och om sin förmåga, har samband med symptom och konsekvenshantering, dock saknas tillräcklig kunskap om sådana samband under återhämtningsfasen efter kolorektal cancerbehandling. För att erhålla en kunskapsgrund för stödjande omvårdnadsinterventioner var avhandlingens övergripande syfte att undersöka det första året av subjektiv återhämtning. Dels med fokus på sjukdomsuppfattning och självbild mot bakgrund av vårdmiljön från den behandlade personens perspektiv, och sjukdomsuppfattning mot bakgrund av vårdmiljön från partnerns perspektiv. Dels att undersöka sambanden mellan trötthet, mental hälsa, gastrointestinal hälsa, sjukdomsuppfattning, och tilltro till egen förmåga att bibehålla vardagliga aktiviteter med hälso-relaterad livskvalitet som utfallsmått.

Deltagarna som inkluderades i de fyra delstudier som ligger till grund för avhandlingen bestod av personer som genomgått kirurgi för kolorektalcancer vid ett länssjukhus i Västsverige och deras partners. I studie I (n=17), III (n=46) och IV (n=39) bestod deltagarna av personer som genomgått kirurgisk behandling, och i studie II (n =18) bestod deltagarna av personer som genomgått kirurgisk behandling och partners. Studie I och II, var intervjustudier, vilka genomfördes enligt konstruktivistisk Grounded Theory metodologi, som syftar till att utveckla en teoretisk förståelse för processer och interaktioner. Med utgångspunkt i konstant jämförande metod där data jämförs vid varje analysnivå, identifieras tankar och idéer som ger en analytisk innebörd åt data. Med hjälp av teoretisk förfining resulterar analysen i en ökad abstraktionsnivå och framväxten av en teoretisk modell. Studie III och IV var enkätstudier där deltagarna svarade på frågeformulär 3 månader och 12 månader efter kirurgisk behandling. I studie III, användes exploratorisk faktor analys för att undersöka användbarheten hos skalan the Maintain Function Scale, för att skatta tilltro till egen förmåga i relation till att bibehålla vardagliga aktiviteter. Vidare undersöktes samband mellan variabler med korrelations och regressionsanalyser. I studie IV, användes t-test för att undersöka skillnader i medelvärden mellan studiepopulation och jämförelsegrupp, samt för att undersöka skillnader mellan 3 månader och 12 månaders rapportering inom studiepopulationen. Vidare undersöktes samband med hjälp av korrelationsanalyser, och därtill undersöktes medierande faktorer med path analys.

Det specifika syftet med studie I var att förklara självreorientering, samt att undersöka hur sjukdomsuppfattning, symptom och förväntningar påverkade processen. Den teoretiska modellen i studie 1 förklarade självreorientering som ett försök att finna överenstämmelse i självbilden. Kärnan i självreorienteringsprocessen var frågor utan tydliga svar. Att inte veta vad som orsakade sjukdomen, och att inte förstå kroppsliga reaktioner innebar att livet kändes osäkert och oförutsägbart. Det innebar att förlora känslan av sitt forna jag. Kärnkategorin presenterades genom personliga förklaringar som illustrerades av självstärkande, självskyddande och självexponerande strategier. I studie II illustrerade den teoretiska modellen sjukdomsuppfattningar hos behandlade personer och partners samt vårdmiljön där dessa återfanns. Behandlingen upplevdes som snabb och positiv. Partners upplevde dock en massiv informationsbörda, och de kände att de behövde ta ansvar för vårdsituationen. Partners upplevde även att bristande kontinuitet var problematiskt, eftersom de inte visste vem de skulle kontakta vid behov av stöttning och rådgivning. Tiden efter utskrivning upplevdes som en ensam och osäker tid av både behandlade personer och partners. Deras sjukdomsuppfattningar skilde sig dock åt. Behandlade personer tenderade att i större utsträckning minimera allvaret i cancerdiagnosen. De fokuserade på att lämna diagnosen i det förgångna, vilket innebar att skydda sig från onödig information och ha tillit. Partners fokuserade istället mer på cancerdiagnosen och såg den som en permanent livsförändrande händelse. De var förberedda på svåra konsekvenser och uppvisade ett informationssökande beteende. Studie III visade att the Maintain Function Scale var användbar för att skatta tilltro till egen förmåga att bibehålla vardagliga aktiviteter i studiepopulationen. Korrelationsanalyser visade att personer som var fysiskt tröttare, mer deprimerade, oroliga, eller som hade mer diarré var mer benägna att uppge lägre hälsorelaterad livskvalitet. När det gäller sjukdomsuppfattning så visade korrelationsanalyser att de som uppgav mer negativa känslor och negativa konsekvenser var mer benägna att uppge lägre hälsorelaterad livskvalitet. Vidare framkom att de som skattade högre i tilltro till egen förmåga att bibehålla vardagliga aktivitet var mer benägna att uppge högre hälsorelaterad livskvalitet. Av regressionsanalysen framkom att fysisk trötthet och diarré predicerade hälsorelaterad livskvalitet negativt, medan tilltro till egen förmåga att bibehålla vardagliga aktiviteter predicerade positivt, vilket antyder att en förbättring av dessa symptom samt en förbättring av den här typen av tilltro till egen förmåga förbättrar den hälsorelaterade livskvaliteten för den här gruppen. Resultatet av t-test i studie IV visade en signifikant nedgång i tilltro till egen förmåga att bibehålla vardagliga aktiviteter 12 månader efter operation. Av path analysen framkom därtill att sjukdomsuppfattning i form av negativa känslor samt fysisk trötthet, medierade effekten mellan tilltro till den egna förmågan att bibehålla vardagliga aktiviteter vid 3 månader, och den hälsorelaterade livskvaliteten vid 12 månader. Resultatet av path analysen stödjer därmed uppfattningen att personer som upplever fysisk trötthet eller som har negativ sjukdomsuppfattning i form av negativa känslor, kommer att ha mindre tilltro till sin egen förmåga att bibehålla vardagliga aktiviteter, vilket i sin tur kommer att ha en negativ påverkan på deras hälsorelaterade livskvalitet.

Föreliggande avhandling visar att det finns behov av att prioritera sjuksköterskeledda uppföljningskonsultationer efter utskrivning för den gruppen. Eftersom sjukdomsuppfattning inte bara påverkar självreorientering, utan även fungerar som en mediator mellan tilltro till egen förmåga att bibehålla vardagliga aktiviteter och hälsorelaterad livskvalitet, behöver sjukdomsuppfattning och tilltro till egen förmåga vara i fokus när sjuksköterskor stödjer symptomhantering. Förutom att prioritera omvårdnadsinterventioner efter utskrivning behöver även den informationsbörda, bristande kontinuitet och belastning på partners som framkom i resultaten adresseras under behandlingstiden.

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