HEALTH-RELATED QUALITY OF LIFE AFTER COLORECTAL CANCER

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UNIVERSITY OF EASTERN FINLAND **ABSTRACT**
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The purpose of this study was to assess health-related quality of life (HRQoL) in colorectal cancer (CRC) survivors and to identify factors associated with health-related quality of life among colorectal cancer survivors.

171 individuals from the Finnish colorectal cancer association and Association of ostomy and anal incontinence patients in Finland participated in this cross-sectional study. HRQoL was assessed using the European Organisation for Research and Treatment of Cancer Quality of life Core Questionnaire and the European Organization for Research and Treatment of Cancer Quality of Life Module-Colorectal Cancer. Data were collected from June 2015 through February 2016. Descriptive statistics and statistical procedures including Mann-Whitney U tests, Kruskal-Wallis tests, and multiple regression analyses were used to analyse data.

The mean respondent age was 67.4 years and 66% were female. CRC survivors at the extremes of the age groups (≤55 and ≥76 years) had lower overall HRQoL (p=.045) and physical functioning (p=.010) than other age groups. Female CRC survivors had lower emotional functioning (p=.004), poorer body image (p=.050), and more financial difficulties (p=.034), diarrhoea (p=.004) and sexual dysfunction (p<.0001) than men. CRC survivors with an ostomy had poorer body image (p=.027), experienced more abdominal pain (p=.025), and reported lower levels of social (p=.011) and role functioning (p=.015) than those without an ostomy. CRC survivors with at least one long-term medical condition experienced more pain (p=.007), fatigue (p=.037), anxiety (p=.014), insomnia (p=.033) and problems with ostomy care (p=.027), as well as reported lower overall HRQoL (p=.003), physical (p=.001) and role functioning (p=.020) than those without a long-term medical condition. CRC survivors married, cohabiting or in a civil partnership reported higher overall HRQoL (p=.003) and physical functioning (p=.012), as well as had less problems with body image (p=.017), sexual functioning (p=.002), and fatigue (p=.048) than those without a spouse/partner. Multiple regression analyses revealed physical functioning (p<.0001), sexual interest (p<.0001), body image (p=.022), and fatigue (p=.028) as factors most strongly associated with overall HRQoL among CRC survivors. Higher level of physical functioning, lower level of body image disturbance, and lesser severity of problems with sexual interest were related to better overall HRQoL, whereas higher level of fatigue and was related to poorer overall HRQoL.

Increased alertness and greater effort to identify and alleviate CRC-related symptoms/concerns and diminished physical functional capacity among CRC survivors are warranted in an attempt to improve their HRQoL. In particular, specific attention should be placed on women, the elderly, those with an ostomy, those at 6-10 years post-diagnosis of CRC, those without a spouse/partner, and those with other long-term medical conditions in the care of CRC survivors.

Keywords: colorectal cancer, health-related quality of life, well-being and functioning.

ITÄ-SUOMEN YLIOPISTO **TIIVISTELMÄ**
Terveystieteiden tiedekunta
Hoitotieteen laitos
Hoitotiede
Preventiivinen hoitotiede

Genesis, Olusola Paksu- ja peräsuolen syövän sairastaneiden terveyteen liittyvä elämänlaatu
Pro gradu-tutkielma 50 sivua, 5 liitettä (14 sivua)
Ohjaajat: Dosentti, yliopistonlehtori, TtT Päivi Kankkunen
Kliinisen hoitotyön asiantuntija, TtT Anne Vaajoki
Joulukuu 2016

Tutkimuksen tarkoituksena oli kuvata ja selittää paksu- ja peräsuolen syövän sairastaneiden terveyteen liittyvää elämänlaatua.

Aineisto kerättiin paksu- ja peräsuolen syövän sairastaneilta (n=171), FinnIlco- tai Colores -järjestöjen jäseniltä sähköisellä tai paperisella kyselyllä. Terveyteen liittyvää elämänlaatua mitattiin kahdella mittarilla: The European Organisation for Research and Treatment of Cancer Quality of life Core Questionnaire (EORTC QLQ-C30) ja the European Organization for Research and Treatment of Cancer Quality of Life Module-Colorectal Cancer (EORTC QLQ-CR29). Aineisto analysoitiin kuvailevien tunnuslukujen, parametrittomien keskiarvotestien, sekä regressioanalyysin avulla.

Vastaajista kaksi kolmannesta oli naisia ja keski-ikä oli 67.4 vuotta. Alle 55-vuotiaat ja yli 76-vuotiaat kuvasivat yleisen terveyteen liittyvän elämänlaatunsa (p=.045) ja fyysisen toimintakykynsä (p=.010) muita vastaajia heikommaksi. Naiset kuvasivat miehiä useammin alentunutta emotionaalista toimintakykyä (p=.004), oman kehonkuvan ongelmia (p=.050), heikentynyttä seksuaalista toimintakykyä (p<.0001), ripulointia (p=.004) ja taloudellisia ongelmia (p=.034). Tehty avanneleikkaus oli yhteydessä heikompaan kehonkuvaan (p=.027), useammin vatsan alueen kipuihin (p=.025), heikompaan sosiaaliseen toimintakykyyn (p=.011) ja roolitoimintoihin (p=.015) verrattuna niihin, joille ei ollut tehty avannetta. Paksu- ja peräsuolen syövästä selvinneet, joilla oli ainakin yksi muu pitkäaikaissairaus, kokivat enemmän kipua (p=.007), väsymystä (p=.037), ahdistusta(p=.014), unettomuutta (p=.033) ja ongelmia avanteen kanssa (p=.027). Lisäksi heidän yleinen terveyteen liityvä elämänlaatunsa oli heikompi (p=.003), fyysinen toimintakyky (p=.001) ja roolitoiminnot (p=.020) alentuneemmat kuin niillä, joilla sairaus ei ollut yhtä pitkäaikainen. Paksu- ja peräsuolensyövästä selviytyneet, naimisissa, avoliitossa tai parisuhteessa olevat raportoivat yleisen terveyteen liityvän elämänlaatunsa (p=.003) ja fyysisen toimintakykynsä (p=.012) paremmaksi sekä vähemmän ongelmia kehonkuvassaan (p=.017), seksuaalisessa toiminnassa (p=.002) ja väsymyksessä (p=.048) verrattuna niihin, joilla ei ollut puolisoa tai kumppania. Koettu yleinen terveyteen liittyvä elämänlaatu oli yhteydessä vastaajien fyysiseen toimintakykyyn (p<.0001), seksuaaliseen kiinnostukseen (p<.0001), omaan kehonkuvaan (p=.022) ja väsymykseen (p=.028).

Entistä tehokkaammin tulisi tunnistaa ja lievittää toimintakykyyn vaikuttavia oireita ja ongelmia, että voidaan edistää paksu- ja peräsuolen syövästä selvinneiden terveyteen liittyvää elämänlaatua. Erityistä huomiota tulisi kiinnittää naisiin, vanhuksiin, ja heihin, joilla on avanne, joilla paksu- ja peräsuolen syövän diagnoosista on kulunut 6-10 vuotta, jotka ilman puolisoa tai kumppania, ja joilla on pitkäaikainen sairaus.

Asiasanat: paksu- ja peräsuolen syöpä, terveyteen liittyvä elämänlaatu, hyvinvointi ja toimintakyky.

ABBREVIATIONS

CRC	Colorectal cancer
CINAHL	Cumulative Index to Nursing and Allied Health Literature
COLORES	Finnish Colorectal Cancer Association
DNA	Deoxyribonucleic acid
EORTC	European Organization for Research and Treatment of Cancer
EORTC QLQ-C29	European Organization for Research and Treatment of Cancer Quality of Life Module-Colorectal Cancer
EORTC QLQ-C30	European Organisation for Research and Treatment of Cancer Quality of life Core Questionnaire
FINNILCO	Association of ostomy and anal incontinence patients in Finland
HRQoL	Health-related quality of life
NORDCAN	Association of the Nordic Cancer Registries
QoL	Quality of life
PubMed Central	U.S National Institutes of health's National Library of Medicine
PsycINFO	American Psychological Association
SPSS	Statistical Package for Social Sciences
TME	Total mesorectal excision
WHO	World Health Organisation

1 INTRODUCTION

Colorectal cancer (CRC) is among the most prevalent malignancies globally. It is the second leading cause of death from cancer in Europe (Ferlay et al. 2013) and affects men slightly more than women (Scholefield & Eng 2014). An estimated 694,000 individuals died as a result of the disease worldwide in 2014 (World Health Organisation 2015). Although CRC is a fatal disease, survival rates have increased over the years (Cancer society of Finland 2015) as a result of awareness, early detection and improvements in cancer treatment (American Cancer Society 2015). In view of the rising number of colorectal cancer survivors, investigation of their health-related quality of life (HRQoL) becomes paramount in order to evaluate the effects of the disease and its treatment on survivors. The information obtained from such investigation can be used to inform interventions to meet CRC survivors' support needs in an effort to improve aftercare for CRC survivors.

Evidence from previous studies justify including health as a dimension of quality of life. Health-related quality of life is derived from the concept of health and quality of life (QoL) (Bowling 2001). Being broad ranging concepts, several definitions of QoL and HRQoL have been offered. The World Health Organisation (WHO) defines QoL as "an individual's perception of their position in life in the context of the culture and value systems in which they live and in relation to their goals, expectations, standards and concerns" (WHOQoL group 1994 cited in Skevington et al. 2004). Whereas, HRQoL refers to an individual's assessment of physical, social, and psychological functioning, as well as perception of well-being, fitness, health, and life satisfaction, including assessment of the impact of a health condition and its treatment on different aspects of an individual's life (Bowling 2001.) This definition is adopted for the current study.

In treatment of disease, the main intents of medical intervention are prolongation of life and improvement quality of life through resolution of symptoms. In considering treatment choices for life-threatening diseases, such as cancer, assessment of health outcomes is not only based on lives saved but also on the quality of life of the saved lives (Arndt et al. 2006, Byrne 2007). According to Sun et al. (2013), the concept of quality of life is of great significance in health care because the amount of people living with chronic illness is rising and health advances have increased survival from various diseases. On the other hand, the lives of individuals with cancer are not only at risk from effects of the disease itself but also from the side effects of treatment for the disease, making an individual’s subjective report of the impact of a disease and its treatment a crucial health assessment that should be conducted (Bowling 2001).

The effectiveness of various CRC treatment modalities is evident through more patients surviving longer, however individuals may respond differently to treatments. An increasing body of evidence highlights that individuals diagnosed with CRC often have various problems which can affect HRQoL due to the changes brought on by the disease and nature of its treatment which can cause several effects that negatively impact HRQoL. Studies to date report the adverse effects of CRC treatment including urinary, bowel, and sexual dysfunction (Bregendahl et al. 2013, Wiltink et al. 2014, Chen et al. 2015, Adam et al. 2016, Benedict et al. 2016, Huang et al. 2016, Sun et al. 2016). Concerns about HRQoL can be major with individuals diagnosed with CRC since some of the side effects of treatment may persist after the treatment is completed and other problems can arise several years later. (Arndt et al. 2006, Jansen et al. 2011a, Hornbrook et al. 2011.) In addition to extension of life by treatments, assessment of HRQoL of CRC survivors is an important health outcome in CRC survivorship care. This assessment may help identify CRC survivors who need additional support and hence, enhance CRC survivorship care.

According to the Association of the Nordic Cancer Registries (NORDCAN 2015), CRC is on a rising trend in Finland due to the ageing population. Among the aims of the Finnish National Development Programme for Social Welfare and Health Care (KASTE -ohjelma 2012-2015) and Health 2015 programme (Terveys 2015 -ohjelma) is implementation of preventive healthcare; including identification of risk groups for improvement of health and well-being in order to reduce health disparities and enable the Finnish population live longer active lives. Risk group identification is essential as it provides direction to the most critical areas where intervention is needed and resources could be channelled. While CRC and its treatment pose risks to HRQoL of individuals, interventions to address these risks can improve quality of care and protect these individuals from further morbidity.

The purpose of this study was to assess health-related quality of life in colorectal cancer survivors and to identify factors associated with health-related quality of life among colorectal cancer survivors.

2 LITERATURE REVIEW

2.1 Literature search

Literature searches were conducted in December 2015 using three electronic databases, namely Cumulative Index to Nursing and Allied Health Literature (CINAHL), U.S National Institutes of health’s National Library of Medicine (PubMed Central), and American Psychological Association (PsycINFO). The searches were performed using the following search terms: (colorectal cancer) AND (quality of life OR well-being OR function*). To ensure that the information provided in the literature review is up-to-date, a concluding literature search using the same databases and search terms was undertaken in November 2016 to identify recent relevant research articles. Further relevant articles were identified by manually searching the references of the retrieved articles. In addition, books and other supporting scholarly sources were also used.

2.2 Literature selection

The literature search identified a total of 560 citations using the CINAHL database, 268 citations using PubMed Central database, and 352 citations using PsycINFO database (table 1). The titles and abstracts of research articles from the citations produced were reviewed to assess for relevancy to the study questions. Subsequently, the full texts of relevant research articles were retrieved for screening. A preliminary reading of these articles was done and only articles which met the following criteria were considered appropriate for and included in the literature review:

- Research articles that assessed HRQoL in CRC patients or survivors. HRQoL must have been measured quantitatively or qualitatively.

- Research articles published in a peer reviewed journal in English between the years from 2005 to 2016.

Table 1. Selection of literature.

Database searched and search terms used	**Number of citations revealed after literature search**	**Number of articles found relevant from the review of titles**	**Number of articles found relevant from the review of abstracts**	**Number of articles found relevant from the review of full texts**	**Number of articles that met the inclusion criteria**
CINAHL "*colorectal cancer*" AND "*quality of life*"	286	186	92	26	10
"*colorectal cancer*"AND *"function*"*	211	96	74	15	5
"*colorectal cancer*" AND "*well-being"*	38	8	1	1	1
PubMed Central (*colorectal cancer*) AND (*quality of life* OR *well-being* OR *function**)	268	104	54	11	7
PsycINFO (*colorectal cancer*) AND (*quality of life* OR *well-being* OR *function**)	352	210	106	41	7

Articles that did not examine the physical, psychological, or social domains of HRQoL in CRC patients or survivors were excluded. Additionally, the exclusion of articles was based on relevancy to the study questions. In the literature review, evidence on HRQoL outcomes in persons diagnosed with CRC was considered mainly from three types of studies: (1) Comparison group study (comparisons of CRC survivors' HRQoL with that of an age and gender-matched sample from the general population without the disease), (2) Longitudinal study (assessments of HRQoL in CRC patients or survivors over time), and (3) Cross-sectional study (assessments of HRQoL in CRC patients or survivors at one time point). Studies included in the review used validated and reliable instruments for data collection. In addition, the psychometric properties of the instruments used in the studies included in the review were discussed in some of the research articles. The review of the literature produced six articles which were published between 2005 and 2008, nine articles between 2009 and 2012, and fifteen articles between 2013 and 2016. In total, 30 research articles from 15 different countries were found to be eligible and were included in the review. Of these articles, 4 were qualitative studies, 1 was a mixed methods study, and 25 were quantitative studies. The characteristics of each publication are summarized independently in a table (appendix 1).

2.3 Colorectal cancer and its treatment

Colorectal cancer is the merged term for cancer that develops in the colon or rectum. The various types of cancer found in the colon and rectum include carcinoid tumour, gastrointestinal stromal tumour, adenocarcinoma, lymphoma, and squamous cell cancer of the anus. Of these, adenocarcinoma is the most common type of CRC diagnosed. (Gearhart & Ahuja 2011.) Worldwide, CRC is the third most prevalent cancer in men, the second most prevalent cancer in women, and the fourth leading cause of death from cancer (Scholefield & Eng 2014). There is a vast difference in CRC incidence worldwide. Australia/New Zealand and Western Europe have the highest incidences of CRC while some parts of Africa and Asia have the lowest incidences of CRC. Of all CRC cases diagnosed, the proportion of cancers of the colon is higher than that of rectal cancers. (Souhami & Tobias 2005, Scholefield & Eng 2014.)

Factors known to increase an individual’s chance of developing CRC include older age, race/ethnicity, inherited predisposition syndromes, being male, smoking, consumption of red or processed meat, personal/family history of CRC or colorectal polyps, alcohol, and physical inactivity. In addition, several conditions such as diabetes, obesity, and inflammatory bowel disease are also major risk factors for the development of CRC. (Gearhart & Ahuja 2011, Scholefield & Eng 2014.)

Symptoms of colorectal cancer differ by site and size of the tumour in the large intestine. Generally, symptoms mainly associated with CRC include abdominal pain, change in bowel habits, rectal bleeding, (Gearhart & Ahuja 2011) fatigue, and weight loss (Scholefield & Eng 2014). The most significant prognostic factor in CRC is the pathological stage of the disease at diagnosis. As such, early detection confers survival benefit for patients. So far, screening is the most reliable method for early detection of CRC (Scholefield & Eng 2014).

Because CRC is highly age-related with the vast majority of incidences occurring in individuals aged 50 years and above, (Souhami & Tobias 2005) screening for early CRC among individuals in this age-group can reduced the mortality rate associated with CRC. To this effect, mass screening programmes have been implemented in various countries. However, due to poor participation in screening programmes, symptomatic presentation of patients remains the most common method through which CRC is suspected and eventually diagnosed (Gearhart & Ahuja 2011).

Recommended investigations in screening for early CRC in asymptomatic adults include annual faecal occult blood test, annual faecal immunochemical test, stool DNA test, double-contrast barium enema every 5 years, sigmoidoscopy every 5 years, colonoscopy every 10 years, or computed tomographic colonography every 5 years (American Cancer Society cited in Silverman 2012).

Given that different treatments for CRC may have varying effects, it is important to outline the most common types of treatments that are currently available. Generally, medical management of CRC is determined by the stage of the disease and it involves surgery to remove the tumour, supportive therapy, and adjuvant therapy. Patients who are administered some adjuvant therapy including chemotherapy, radiotherapy, immunotherapy, or multimodality therapy usually experience fewer tumour recurrences and live longer. (Smeltzer et al. 2008.)

Typically, surgery and radiotherapy are used when the cancer is localized and of favourable histological grade. Additionally, early stage small size cancer of preoperative biopsies of no adverse pathological features may be treated with surgery or radiotherapy alone for curative purpose. Chemotherapy and other systemic treatment are also used in conjunction with surgery and/or radiotherapy when the cancer has spread to other areas of the body (i.e. metastatic disease), is recurrent or inoperable. Treatments for localized colorectal cancer can result in cure, but those for metastatic disease are mainly to delay disease progression or relieve symptoms. (Silverman 2012.)

Surgery remains the primary treatment for most colon and rectal cancers. However, the technique of surgery affects patient survival and the incidence of local tumour recurrence in

CRC patients. The surgical approach in colonic tumours usually involves segmental colonic resection with anastomosis. In relation to rectal tumours, surgical procedures performed include transanal excision, anterior resection with anastomosis or abdominoperineal resection with permanent ostomy. Total mesorectal excision (TME) has been proposed as the best and most reliable technique in rectal cancer surgery. (Silverman 2012.) The type and extent of tumour removal are dependent on the site of the tumour. Surgical treatment of CRC may necessitate the formation of an ostomy for patients as part of cancer treatment or because they unwell as a result of tumour bowel obstruction or perforation since this will at least allow a reasonable quality of life or make high-dose radiotherapy for the primary tumour a possible treatment option (Souhami & Tobias 2005.)

Although a greater percentage of patients with CRC achieve total clearance of their disease after surgical resection however, about half of these patients experience cancer recurrence, possibly as a result of dispersed cancer cells and eventually die of their disease. Hence, with the intent of eliminating circulating cancer cells before they become established and less responsive to treatment, adjuvant chemotherapy is given. (McArdle et al. 2000.)

The liver is the most frequent site of metastatic spread of CRC. Surgical resection of the liver remains the primary treatment modality for cure in patients with hepatic colorectal metastases. The prognosis is poor if the metastases are left untreated. (Silverman 2012.) Although the incidence of liver metastases is high however, this surgery is only indicated in few patients with liver metastases since the outcome of the surgery is largely determined by factors related to the malignancy. Therefore, there is the general agreement that hepatic resection should only be carried out when all macroscopic cancerous tissue can be removed and adequate amount of normal liver tissue can be left in place to prevent further complications. (McArdle et al. 2000.)

Neoadjuvant chemotherapy and radiation therapy are increasingly being given before surgery to reduce the size of rectal tumours. The reduction in size of the tumour not only makes its removal easier but also helps reduce the incidence of local tumour recurrence and hence, enhance surgical outcome. So, the possibility of tumour removal increases with reduction in tumour size. CRC patients with no lymph node involvement are usually not treated with adjuvant chemotherapy as the treatment does not confer additional survival advantage in this group of CRC patients. However, administration of chemotherapy to CRC patients with lymph node-positive cancers is recommended because research provides evidence of improved survival among this patient group when they receive adjuvant chemotherapy. In patients who receive preoperative chemo-radiation therapy, surgery is usually postponed until 6 to 8 weeks following completion of the therapy so as to allow for the best possible tumour response and patient recovery from the toxicities associated at times with chemo-radiation therapy (Silverman 2012.)

Trials conducted in the United States and in Europe have respectively produced two main equally effective approaches for the optimal medical management of rectal cancer. The first approach involves total mesorectal excision (TME) surgery with selective adjuvant radiotherapy postoperatively. In addition, patients with nodal disease as well as some node-negative patients who are at greatest risk of distant metastases and as such, are recommended for adjuvant chemotherapy. In the second approach, radiotherapy is followed by surgery and chemotherapy is being given preoperatively or postoperatively. (McArdle et al. 2000.)

2.4 Cancer and health- related quality of life

Health-related quality of life is a dimension of quality of life, with the latter being a wider concept of the two (Bowling 2005). HRQoL is increasingly becoming a concept of great significance in healthcare and as such, is being used as a measure of health outcome in order to evaluate the effectiveness of clinical interventions (Bowling 2001). Health advances have delayed mortality. Hence, the proportion of people living with chronic illness has increased over years. In view of this and the importance of patient preference and satisfaction in care, it seems to be appropriate that, a comprehensive appraisal based not only clinical indicators of outcomes but also on patient-reported outcomes is needed in order to fully determine the effects and appropriateness of medical treatments (Bowling 2001). Given this argument, it would be expected that, in disease treatment, assessment of health outcomes is not only based on the extent of prolongation of life, but is also in terms of the quality of life during survival.

In considering options for treating life-threatening diseases, such as cancer, not only is it vital to be able to estimate the additional years a given treatment will provide to life but also the quality of those added years (Bowling 2001). HRQoL encompasses many aspects of life that can be especially affected by disease and its treatment.

The minimum domains for an appropriate measurement of HRQoL in patients with cancer include (a) physical well-being (encompasses symptoms and toxicities such as pain, fatigue, nausea, physical activity and work, recreation, and self-care activities); (b) psychological well-being (encompasses body image, self-esteem, emotional distress, anger, and depression); and (c) social well-being (encompasses effects on social activities, performance in social roles, isolation, social support from family and friends, and sexual relationships) (Maguire & Selby 1989, Selby 1993 cited in Bowling 2001). Therefore, HRQoL is complex concept that depicts the physical, psychological, and social aspects of health (figure 1).

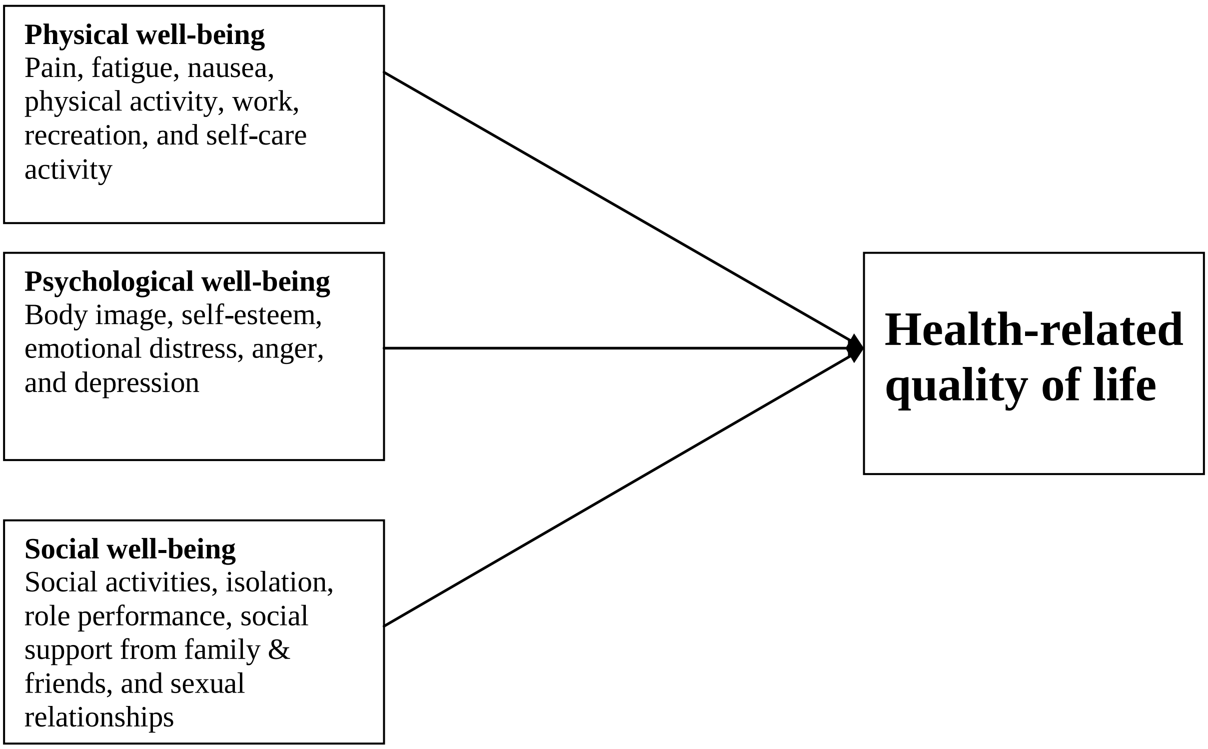


Figure 1. The minimum domains of measurement of HRQoL in cancer patients.

In addition to disease and its treatment which affect HRQoL, other factors such as the general condition of an individual, concomitant diseases, life experiences, life stage, spirituality, personality, personal activities, satisfaction with life, and goals can also impact on HRQoL. HRQoL assesses an individual's perceived physical, social, psychological health and function. Furthermore, HRQoL outcomes have become important elements of health surveillance and are generally considered valid indicators of health needs and intervention outcomes (Bowling 2001, Bowling 2005).

In individuals with cancer, assessment of HRQoL is generally done with generic-specific and disease-specific instruments. Generic instruments can be used for various patient groups irrespective of disease or disability. Disease–specific instruments are based on issues most significant to patients' health concerns and have the feature to identify small, but clinically significant changes in health status. The main purpose of disease-specific instruments is to support clinical decision making. Additionally, disease-specific instruments are also generally effective in assessing the results of specific treatments. (Bowling 2001.)

In sum, while a number of HRQoL assessment tools have been widely used and extensively validated in clinical settings and population based studies, it appears that no single HRQoL questionnaire has been proven as the gold standard instrument to measure HRQoL of cancer patients as no single measure instrument completely incorporates all the relevant domains necessary to satisfy a multidimensional model of HRQoL.

2.5 Effects of colorectal cancer and its treatment on HRQoL

2.5.1 Effects of CRC and its treatment on the physical well-being of CRC patients and survivors

Several studies have investigated physical health and functioning of CRC patients and compared it with that of controls from the general population of matched age and gender. In Germany, a longitudinal study of short-term CRC survivors (<5 years post-diagnosis) reported that younger survivors of CRC (< 60 years at diagnosis) had elevated scores in bowel problem symptoms (e.g. diarrhoea) and fatigue levels in the first few year after diagnosis, than controls from the general population. Whereas, older survivors of CRC (aged ≥70 years at diagnosis) were found to report better or comparable physical function and fewer pain symptoms up to 5 years after diagnosis when compared to controls from the general population. (Jansen et al. 2011a.) In comparison to controls from the general population, studies from France and Germany confirm worse physical functioning scores in older CRC survivors between 5 and10 years after diagnosis (Caravati-Jouvenceaux et al. 2011, Jansen et al. 2011a). Rodriguez et al. (2015) also revealed that the mean physical HRQoL score in CRC survivors was lower than that of the population norm in the United States.

When compared to controls from the general population of matched age and gender, symptoms such as diarrhoea and fatigue remained significant problems among CRC survivors (Rusell et al. 2015, Sánchez-Jiménez et al. 2015), even up to 5 years and 10 years post-diagnosis of CRC (Caravati-Jouvenceaux et al. 2011, Jansen et al. 2011a, Thong et al. 2013). Regarding CRC treatment, surgery and chemo-radiation were found to be strongly associated with fatigue (Thong et al. 2013). Furthermore, CRC patients that have undergone surgery with chemotherapy and/or radiotherapy were found to report problems related to bowel function even several years after completion of their treatment (Bregendahl et al. 2013, Chen et al. 2015, Hess et al. 2016).

Age-specific differences among CRC survivors were observed by Jansen at al. (2011b); younger survivors (aged <70 years at 5 years post diagnosis) who had received chemotherapy reported significantly lower physical functioning scores and higher pain symptom levels than controls from the general population in Germany. In contrast, older survivors (aged ≥70 years at 5 years post diagnosis) reported better scores in these same domains and unlike their younger counterparts, not as much QoL scores were significantly associated with chemotherapy (Jansen et al. 2011b). To investigate functioning during chemotherapy in patients with more advanced disease, a study of metastatic CRC patients receiving chemotherapy treatment shows that both men and women reported improvement in the perception of symptoms such as pain, constipation, stoma-related problems, urination problems, defecation problems and weight loss between baseline and end of treatment (Segalla et al. 2008)**.**

Studies of CRC patients during the first year following surgery with curative intent revealed that there is temporary reduction in the HRQoL after colorectal cancer surgery. This reduction was observed in physical functioning and daily activities; scores for physical function was lower at one month after surgery compared to the preoperative levels in CRC patients (Tsunoda et al. 2007, Yoo et al. 2005). Additionally, increase in symptom scores for fatigue, pain, dyspnoea were also observed one month after CRC surgery (Tsunoda et al. 2007)

However, during the subsequent months (2-6months) following surgery, these scores had returned to the preoperative levels (Yoo et al. 2005, Tsunoda et al. 2007). Scores for other symptoms such as insomnia, appetite loss, and diarrhoea improved over time but then, these symptoms persisted during the first year following curative surgery for CRC (Tsunoda et al. 2007). Descriptive data on the lived experiences of CRC patients also provided evidence of change in physical functioning in the first 3 months and within 18 months following diagnosis of CRC; patients reported reduced physical function resulting from extreme fatigue (Dunn et al. 2006, Houldin & Lewis 2006) or sleep disturbances sometimes related their chemotherapy cycles (Houldin & Lewis 2006).

Research evidence indicates that CRC patients with an ostomy have problems with adaptation and ostomy-related concerns; they experience several challenges and have needs related to coping and adjustment even several after years after their ostomy formation (Grant et al. 2011, Sun et al. 2013). Of these include sleep disruption, dietary modification, problems with ostomy care, ostomy appliance, and bowel function (Grant et al. 2011, Sun et al. 2013) which often cause limitations in pursuit of physical activities. Women are especially affected by an ostomy. According to Grant et al. (2011), female CRC patients than their male counterparts exprience more ostomy-related concerns such as sleep disruption, gas, and odour production from the ostomy. Furthermore, CRC patients having problems adjusting to an ostomy completely gave up some activities (e.g., sports) whereas, others had to make significant changes in daily life so as to accommodate or resume activities such as sports (Grant et al. 2011, Sun et al. 2013).

2.5.2 Effects of CRC and its treatment on the psychological well-being of CRC patients and survivors

The most common form of treatment for CRC is surgery to remove the tumour. In some instances, formation of an ostomy is warranted due to the type of the surgery required to remove the cancer (Grant et al. 2011). Hence, creation of an ostomy for patients with CRC occurs most frequently (Smith-Gagen 2010). CRC patients who have a permanent ostomy are confronted with prospect of permanent faecal incontinence throughout life. Coping and adjusting to this prospect may be problematic and negatively impact on psychological well-being (Grant et al. 2011). Studies indicate that responses of individuals to an ostomy vary considerably. On the account of some research findings, CRC patients with an ostomy reported poorer scores in psychological functioning than those without an ostomy (Sharpe et al. 2011), whereas other studies have failed to confirm the negative impacts of an ostomy on psychological well-being (Hornbrook et al. 2011, Smith-Gagen et al. 2010).

The study by Grant et al. (2011) on gender differences in HRQoL in long-term CRC survivors with an ostomy provided qualitative evidence that women experience body image disturbances, depressive symptoms and a sense of loss of control due to the unpredictability of an ostomy and other problems related to living with an ostomy. However, these problems were not observed in men with an ostomy (Grant et al. 2011). Significant differences have been observed between CRC patients with an ostomy and those without an ostomy in relation to depressive symptoms and body image. The study by Sharpe et al. (2011) reported increased body image disturbances following surgery in CRC patients with an ostomy compared to those without an ostomy. In addition, the study found that there was no evidence of adjustment in body image disturbance in patients with an ostomy and body image disturbance appeared to increase over time. Furthermore, the study demonstrated that body image disturbance was strongly associated with depressive symptoms including anxiety and distress in CRC patients which confirms the findings from the study by Yoo et al. (2005) that CRC patients with an ostomy have higher psychological distress scores than those without an ostomy following CRC surgery. Body image problems are particularly common in female CRC survivors and are significantly associated with sexual function and overall HRQoL (Benedict et al. 2016).

Studies on short-term CRC survivors (<5 years post-diagnosis) revealed that clinically significant deficits were found for emotional functioning three years after diagnosis among younger CRC survivors when compared with controls from the general population of matched age and gender (Jansen et al. 2011b). Similarly, the study of long-term CRC survivors found that older patients (aged ≥70 years at diagnosis) reported significant impairments in emotional functioning 10 years after diagnosis than controls from the general population of matched age and gender (Jansen et al. 2011a). However, some studies have proved that there seems to be improvements in psychological well-being following curative surgery for CRC. The study by Tsunoda et al. (2007) on CRC patients who had undergone surgery with curative intent revealed that scores for emotional functioning measured for few months (1-4 months) following surgery were higher than the preoperative values. In addition, improvements in emotional functioning were reported by both men and women with metastatic CRC undergoing chemotherapy treatment (Segalla et al. 2008).

The link between CRC treatments and psychological symptoms has been confirmed by Thong et al. (2013); the study reported a strong association between treatments for CRC (surgery and chemo-radiation) and anxiety as well as depressive symptoms. In comparison between different modes of treatment among CRC patients, the study by Graca Pereira et al. (2012), revealed that patients who were treated with surgery alone, reported lower depression, anxiety and traumatic stress symptom scores than patients who were treated with surgery and chemotherapy or surgery and radiotherapy. In addition, patients whose CRC diagnosis took longer than 12 months reported more traumatic stress symptoms than those who received their diagnosis in less than 6 months or between 6 to12 months. Furthermore, recurrence of CRC negatively affected psychological well-being, as such patients with disease recurrence showed higher traumatic stress levels than those without recurrence. (Graca Pereira et al. 2012.)

2.5.3 Effects of CRC and its treatment on the social well-being of CRC patients and survivors

There seems to be improvements in social functioning following surgery with curative intent in CRC patients. Tsunoda et al. (2007) reported that social function scores of CRC patients measured during few months following surgery were higher than the preoperative values. However, social functioning scores were lower in CRC survivors compared to controls from the general population (Rusell et al. 2015) and in CRC patients who received adjuvant chemo- and/or radiotherapy following colorectal cancer surgery than those who did not receive such therapy (Tsunoda et al. 2007).

Differences in social well-being have also been reported in longitudinal population based studies between CRC patients and controls from the general population of matched age and gender; clinically significant declines were observed for social functioning at three years (Arndt et al. 2006), five years (Caravati-Jouvenceaux et al. 2011, Jansen et al. 2011b) and 10 years (Jansen et al. 2011a) after diagnosis especially among younger CRC survivors (aged <60 years at diagnosis) when compared to controls from the general population, whereas declines in social function among older CRC survivors (aged ≥70 years at diagnosis) were only observed 10 years post-diagnosis when compared to the general population (Jansen et al. 2011a).

The study by Den Oudsten et al. (2012) highlights the differences in sexual function between CRC survivors and controls from the general population in Netherland. The study showed that sexual function was declined in CRC survivors in comparison to the general population. This finding is supported by other studies which indicate that sexual dysfunction were more common with CRC survivors due to radiotherapy (Downing et al. 2015, Huang et al. 2016, Adam et al. 2016) or CRC surgery (Dulskas & Samalavicius 2016, Sun et al. 2016).

Over the course of treatment with chemotherapy in metastatic CRC, worsening perception of sexual enjoyment was observed in both male and female CRC patients. Additionally, men also reported worsening of their perception of sexual functioning. (Segalla et al. 2008.) Another study examining CRC patients with metastatic disease found that sexual activity declined in 3 years post-diagnosis in patients with distant metastases (Arndt et al. 2006).

Studies describing CRC patients' perspective on the experience of CRC during the first 3 months and within 18 months following their diagnosis of CRC revealed that the disease negatively impacted on the patients' sexual relationships. Younger patients (aged <60 years) especially reported to have abstained from sexual activity after their diagnosis and while they were undergoing treatment (Dunn et al. 2006), whereas others reported losing control over their sexuality (Houldin & Lewis 2006). Furthermore, a population-based study by Den-Oudsten et al. (2012) reported that CRC survivors had worse sexual function and sexual problems than individuals without CRC of matched age from the general population.

In relation to CRC survivors with an ostomy, Sun et al. (2013) confirmed that there is a continuous need to adapt and readapt to an ostomy due to the disruptions it causes to daily activities even years after its formation. According to Sun et al. (2013), CRC survivors with an ostomy have had to reorganize their lives around the ostomy. For instance, they have had to make adjustments in daily clothing and travelling; they wore loose clothing to conceal an ostomy bag and packed extra ostomy appliances when travelling in case of sudden appliance leakage. These adjustments often cause restrictions in social activities. These restrictions are in line with the findings from the study by Mols et al. (2014) in which rectal cancer survivors with an ostomy had significant and clinically relevant lower social functioning scores than those without an ostomy.

2.5.4 Summary of the literature review

A diagnosis of CRC is a threat to life, functioning and well-being of individuals. Studies support that CRC and its treatment affect patients immensely in various aspects of health across all stages of the disease. Consistent with the definition of HRQoL adopted for this study, this review comprised of research studies that assessed the several components of HRQoL. Studies show that CRC and its treatment produce physical, social, and psychological disturbances that influence HRQoL. These disturbances appear to differ across age, gender, recurrence or stage of the disease, type of treatment for the disease, and time from diagnosis of the disease. The variations between CRC patients and subjects from the general population were mostly evident in younger ages. However, functional limitations and symptoms were more rampant in older ages. In addition, CRC survivors suffer from long-lasting CRC-related symptoms and limitations even after they have achieved remission from the disease and it appears that, over the long term, deficits in HRQoL may continue for survivors of CRC even as they live prolonged lives. Healthcare professionals caring for patients with a fatal disease such as CRC have important roles to play in terms of instrumental care giving and supportive care to the affected individual. Furthermore, due to the HRQoL differences identified by age, recurrence or stage of disease, type of treatment, and time from diagnosis, healthcare professionals can significantly affect the quality of care and quality of life of CRC patients by thoroughly assessing each patient’s situation, planning and implementing interventions specifically developed to enhance social, psychological, and physical well-being of CRC patients during their first few years after diagnosis and afterwards.

3 RESEARCH PURPOSE, AIM, AND QUESTIONS

3.1 Research purpose

The purpose of this study was to assess health-related quality of life in colorectal cancer survivors and to identify factors associated with health-related quality of life among colorectal cancer survivors.

3.2 Research aim

The aim of the current study is to provide information that could be used to understand how colorectal cancer and its treatments affect the several dimensions of functioning and well-being of CRC survivors. In addition, this information could also be used to improve nursing care of colorectal cancer survivors through identification of subgroups of CRC survivors with special needs and consequently, develop interventions to address these needs or support these groups.

3.3 Research questions

1. How is the health-related quality of life of colorectal cancer survivors?

2. What factors are associated with health-related quality of life among colorectal cancer survivors?

4 METHODS AND PROCEDURES

4.1 Study design, sample, and setting

The current study is a cross-sectional study; examining at one time point (June 2015 – February 2016) HRQoL of CRC survivors who are at various time periods from a diagnosis of CRC. Individuals who are members of either the Finnish Colorectal Cancer Association (COLORES) or Association of ostomy and anal incontinence patients in Finland (FINNILCO) were screened for eligibility in the current study. Both associations are national patient organisations in Finland. The eligibility criteria for participating in the current study were: (a) individuals aged more than 18 years, (b) individuals who have been diagnosed with and have received treatment for CRC.

4.2 Procedure, data collection, instruments, and data analysis

Individuals were recruited to the current study using an information/invitation letter (appendix 2). This letter was distributed to prospective respondents through post and electronically (via e-mail). Only individuals who had not registered their postal address with the patient organisations received the information/invitation letter via e-mail. Those agreeing to participate in the study were requested to fill out socio-demographic data and questionnaire forms that were pre-attached to or accessible through an electronic link included in the sent information/invitation letter. Hence, data were collected for the current study electronically and traditionally through web-based and paper questionnaires respectively. No reminders were sent to nonrespondents. The paper questionnaire forms after they had been filled out were returned to the researcher in prepaid envelopes while the completed web-based questionnaire forms were received through a computer-based programme. A total of 171 individuals who are members of either of the two national patient organisations (COLORES and FINNILCO) were included in this study.

Respondents filled out two questionnaires: The European Organisation for Research and Treatment of Cancer Quality of life Core Questionnaire (EORTC QLQ-C30) version 3.0 (appendix 4) and the European Organization for Research and Treatment of Cancer Quality of Life Module-Colorectal Cancer (EORTC QLQ-CR29) version 2.1 (appendix 5). Respondents also completed a socio-demographic data form (appendix 3) developed by the researcher. In order to describe the study sample and make comparisons among respondents, socio-demographic data and other personal characteristics (i.e. age, gender, marital status, year of CRC diagnosis, treatment for CRC, employment status, education, and other diagnosed medical conditions) were obtained from respondents using the socio- demographic data form.

The HRQoL outcomes of CRC survivors were assessed through the EORTC QLQ-C30 and EORTC QLQ-CR29 questionnaires. The EORTC QLQ-C30 (version 3.0) is a validated cancer-specific 30-item questionnaire which comprises of a global health-status/QoL scale, five functional scales (measuring level of physical, role, cognitive, emotional and social functioning), three symptom scales (measuring severity of symptoms such as pain, fatigue, and nausea & vomiting), and six single items measuring severity of symptoms most frequently identified by patients diagnosed with cancer (i.e., insomnia, diarrhoea, dyspnoea, constipation, and appetite loss) as well as the financial effect of the disease. (Aaronson et al. 1993.) The EORTC QLQ-C29 (version 2.1) questionnaire was used as a supplement to the EORTC QLQ-C30 as recommended by the EORTC Quality of Life Group. This 29-item questionnaire was developed specifically for the evaluation of CRC symptoms and its treatment from a patient’s perspective. It incorporates four scales (measuring body image disturbance, degree of blood and mucus in stool, stool frequency, and urinary frequency) and nineteen single items measuring severity of issues such as abdominal pain, anxiety, bloating, buttock pain, dry mouth, dyspareunia, dysuria, embarrassment, faecal incontinence, flatulence, hair loss, impotence, sexual interest problems, sore skin, stoma care problems, taste problems, urinary incontinence, and weight-related concerns. (Whistance et al. 2009.)

All items in both questionnaires have a 4-point Likert-type scale (1 = not at all to 4 = very much) except the two items for global health status/QoL scale, which have a 7-point Likert-type scale (1 = very poor to 7 = excellent). To evaluate respondents’ responses in both questionnaires, at first, a preliminary score was calculated by averaging the points from the items that made up a scale. Then this score was converted into a score ranging from 0 – 100 through linear transformation as recommended in the EORTC scoring manual. All scores were analysed and missing values were handled according to the recommendations provided in EORTC scoring manual. (Fayers et al. 2001.)

Hence, each respondent's score was expressed as a number on a scale of 0 to 100. A high score for the global health status/QoL indicates a high quality of life. Similarly, a high score for a functional scale indicates a high/healthy level of functioning. So, a higher score for a functional scale or global health status/QoL indicates better functioning or better QoL while a lower score indicates worse functioning or worse QoL. However, a high score for a symptom scale/item indicates a high level of symptom or problems. So, a higher score for a symptom scale/item indicates a higher level of symptom/problem while a lower score indicates a lower level of symptom/problem (Fayers et al. 2001.)

Among the items evaluated, respondent's overall HRQoL (i.e. global health status/QoL score) was assessed in the EORTC QLQ-C30. All statistical analyses were executed using the Statistical Package for Social Sciences software programme, SPSS version 23.0 (SPSS Inc., Chicago, IL, USA). Descriptive statistics including frequency and percentages were used to describe variables and reveal characteristics of the respondents. Other forms of descriptive statistics such as mean, standard deviation, and range were used to report HRQoL outcomes' scores.

Data were compared within the sample in relation to gender, age, time from colorectal cancer diagnosis, ostomy status, marital status and presence of other diagnosed long term medical conditions. Regarding age, respondents were divided into four groups: a group ≤ 55 years; a second group between 56-65 years; a third group between 66-75 years, and the fourth group ≥76 years. In relation to time from CRC diagnosis, respondents were divided into three groups: those at 0-5 years post-diagnosis; those at 6-10 years post-diagnosis, and those at ≥11 years post-diagnosis. The level of symptoms reported by respondents were divided into two categories representing those who reported no symptoms at all ("not at all") and those with mild or moderate or severe symptoms ("a little/quite a bit/very much") in the analyses of proportion of symptoms among respondents.

Variables did not show normal distribution across all groups hence, Mann-Whitney U tests or Kruskal-Wallis tests were conducted to assess differences between or within groups in the sample respectively. Assumptions for using the Pearson's correlation coefficient to test for associations between variables were not all met. Hence, bivariate correlational analyses using Spearman's rank correlation coefficient were performed to establish evidence of relationship between overall HRQoL and other variables, taking into account that a correlation coefficient value from ±0.3 to ±0.5 indicates a moderate relationship between variables while a value greater than ±0.5 indicates a strong relationship between variables. Stepwise multiple regressions were used to identify variables as a group explaining overall HRQoL in CRC survivors. Statistical significance was defined by a *p* value of ≤0.05 through all the statistical analyses conducted in the current study. (Groove et al. 2013.)

5 RESULTS

5.1 Respondents

In total, 171 CRC survivors were included in this study. Of these 171 CRC survivors evaluated, 113 (66%) were females and the mean respondent age was 67.4 years (standard deviation (SD): ± 9.7, range: 44-88 years). Respondents were at different time periods since the diagnosis of CRC, this time period ranged from 0-26years (table 2). 67% of respondents reported to have been diagnosed with other long-term medical conditions. Of these, hypertension, heart disease and diabetes mellitus were the most prevalent conditions (21%, 11%, and 10% respectively). An ostomy was present in 47% of respondents. Overall, 36% of respondents reported having multimodal CRC treatment with surgery, radiotherapy and chemotherapy.

Table 2. Demographics and characteristics of the respondents.

Demographic or characteristic	**No. of Respondents N=171**	**(%)**
Age (years)		
≤ 55	20	(12)
56-65	51	(30)
66-75	65	(38)
≥ 76	35	(20)
Gender		
Female	113	(66)
Male	58	(34)
Employment		
Retired	133	(78)
Employed	35	(20)
Unemployed	3	(2)
Marital status		
Married/cohabiting/civil partner	101	(59)
Single/divorced/widowed/separated	70	(41)
Level of education		
Higher education	56	(33)
Less than higher education	78	(46)
Not reported	37	(21)
Time from the diagnosis of colorectal cancer (years)		
0- 5	81	(47)
6-10	61	(36)
≥ 11	29	(17)
Treatment for colorectal cancer		
Surgery, chemotherapy, and radiotherapy	61	(36)
Surgery	55	(32)
Surgery and chemotherapy	38	(22)
Surgery and radiotherapy	15	(9)
Chemotherapy	2	(1)
Ostomy status		
No ostomy	90	(52)
Present	80	(47)
Not reported	1	(1)
Other diagnosed medical conditions		
Present	114	(67)
None	57	(33)

5.2 HRQoL outcomes in colorectal cancer survivors

HRQoL mean scores of respondents are shown in the tables below (tables 3 and 4). In the EORTC QLQ-C30, the overall HRQoL mean score was 68.3 for respondents. In addition, for the functional scales of the EORTC QLQ-C30, the mean score was highest for cognitive functioning and lowest for physical functioning. For the symptom scales/items on the EORTC QLQ-C30, the mean score was highest for fatigue and lowest for nausea and vomiting.

Table 3. EORTC QLQ-C30 mean scores of CRC survivors.

Total number of respondents: N=171				
	Mean Score	**No. of respondents**	**± Standard Deviation**	**(range)**
Global health status/QoL				
Global health status/QoLǂ	68.3	170	±21.1	(8.3-100)
Functional scales				
Cognitive functioning ǂ	85.5	170	±19.1	(0-100)
Emotional functioning ǂ	81.3	170	±21.1	(8.3-100)
Social functioning ǂ	80.1	170	±25.5	(0-100)
Role functioning ǂ	77.6	170	±25.1	(0-100)
Physical functioning ǂ	77.5	170	±20.4	(13.3-100)
Symptom scales/items				
Fatigue *	29.1	170	±23.4	(0-100)
Insomnia *	25.3	170	±27.9	(0-100)
Pain *	18.6	170	±26.5	(0-100)
Financial difficulties *	17.3	170	±30.4	(0-100)
Diarrhoea *	17.2	169	±25.7	(0-100)
Dyspnoea *	12.2	169	±23.1	(0-100)
Constipation *	10.4	170	±19.6	(0-100)
Appetite loss *	7.7	169	±19.6	(0-100)
Nausea and vomiting *	4.6	170	±13.1	(0-83.3)

ǂ Higher scores indicate better level of functioning
*Higher scores indicate worse level of problems

For the functional scales of the EORTC QLQ-C29, the mean score was highest for weight and lowest for sexual interest. For the symptom scales/items on the EORTC QLQ-C29, the mean score was highest for impotence and lowest dysuria.

Table 4. EORTC QLQ-C29 mean scores of CRC survivors.

Total number of respondents: N=171				
	Mean Score	**No. of respondents**	**±Standard Deviation**	**(range)**
Functional scales				
Weight ǂ	75.5	170	±27.5	(0-100)
Body Image ǂ	70.8	170	±26.6	(0-100)
Anxiety ǂ	64.1	170	±28.1	(0-100)
Sexual interest ǂ	32.1	169	±30.1	(0-100)
Symptom scales/items				
Impotence *	59.2	58	±39.0	(0-100)
Urinary frequency *	41.3	170	±23.6	(0-100)
Flatulence (with an ostomy) *	34.6	80	±28.8	(0-100)
Flatulence (without an ostomy)*	33.1	87	±27.1	(0-100)
Dry mouth *	24.7	170	±28.6	(0-100)
Sore skin *	24.1	167	±26.3	(0-100)
Bloating *	23.1	170	±26.9	(0-100)
Stool frequency *	23.1	167	±22.2	(0-83.3)
Faecal incontinence (with an ostomy) *	22.5	80	±24.7	(0-100)
Dyspareunia *	21.6	97	±28.6	(0-100)
Embarrassment *	20.6	167	±29.2	(0-100)
Urinary incontinence *	18.2	170	±24.9	(0-100)
Hair loss *	18.1	169	±28.2	(0-100)
Abdominal pain *	17.8	170	±23.5	(0-100)
Buttock pain *	17.6	169	±25.5	(0-100)
Stoma care problems *	17.5	80	±22.4	(0-66.7)
Faecal incontinence (without an ostomy) *	16.1	87	±24.8	(0-100)
Taste *	10.6	170	±21.6	(0-100)
Blood and mucus in stool *	5.9	169	±12.1	(0-66.7)
Dysuria *	3.6	168	±10.3	(0-33.3)

ǂ Higher scores indicate better level of functioning
*Higher scores indicate worse level of problems

5.3 Differences in HRQoL outcomes in colorectal cancer survivors and correlated variables

Regarding gender, when evaluating the results of the EORTC QLQ-C30 questionnaire, it was observed that women reported lower emotional functioning (p = .004), had more diarrhoea (p = .004), and financial difficulties (p = .034) than men. When the responses in the EORTC QLQ-CR29 questionnaire were assessed, women had worse body image (p = .050), rated their sexual interest lower (p < .0001), and experienced higher level of symptoms such as bloating (p =.010), hair loss (p = .001), and stool frequency (p =.026) than men.

In relation to age, global health status/QoL (p = .045) and physical functioning (p = .010) were lower in CRC survivors at the extremes of the age groups (≤55 and ≥76 years) compared to other age groups. In addition, this sub-group of CRC survivors also experienced more dryness in mouth (p = .007) than other age groups. Those ≥76 years of age had the least sexual interest score (p = .032) and worst problem in relation urinary frequency (p = .005) compared to other age groups. Those ≤55 years of age perceived worst appetite loss (p = .011) and nausea and vomiting (p = .021) than other age groups.

In terms of ostomy status, when assessing the results of the EORTC QLQ-C30 and EORTC QLQ-C29 questionnaires, CRC survivors with an ostomy reported a lower level of social functioning (p = .011), role functioning (p = .015), had poorer body image (p = .027), and more abdominal pain (p = .025) than those without an ostomy. CRC survivors without an ostomy experienced more bowel problems, including constipation (p = .013) and stool frequency (p = .012) than those with an ostomy.

Problem with sexual interest was lowest among CRC survivors at 0-5 years post-diagnosis followed by CRC survivors at ≥11 years post-diagnosis while CRC survivors at 6-10 years post-diagnosis had worst problem with sexual interest (p = .048). There were no other statistically significant differences among these groups in relation to other items assessed in the EORTC QLQ-C30 and EORTC QLQ-C29 questionnaires.

Across the sample, CRC survivors that reported to have been diagnosed with at least one other medical condition in addition to CRC were worse off in global health status/QoL (p = .003), physical (p = .001), and role functioning (p = .020). This sub-group of respondents also reported a higher level of pain (p = .007), dyspareunia (p = .030), fatigue (p = .037), insomnia (p = .033), and anxiety (p =. 014), as well as experienced more problems with urinary frequency (p = .016), mouth dryness (p = .004), and ostomy care (p = .027).

When evaluating responses in both questionnaires in terms of marital status, those married, cohabiting or in civil partnership reported better global health status/QoL (p = .003) and physical functioning (p = .012), whereas those single, divorced, widowed or separated reported worse body image (p = .017) and sexual interest (p = .002), as well as had more problems with symptoms such as fatigue (p = .048), dyspnoea (p = .017), hair loss (p = .038), taste (p = .042), and flatulence; without an ostomy (p = .036).

Within the sample, only 15 respondents (8.8%) rated their overall HRQoL as “excellent”; (i.e. had a global health status/QoL score of 100). On evaluation, a moderate to strong positive significant correlation was observed between overall HRQoL and all functional domains in the EORTC QLQ-C30 including physical (r = .748, p < .0001), role (r = .646, p < .0001), emotional (r = .540, p < .0001), cognitive (r = .361, p < .0001), and social functioning (r = .474, p < .0001) (table 5).

Table 5. Correlation coefficients (r) between overall HRQoL and other measured variables.

	Physical functioning	**Role functioning**	**Emotional functioning**	**Social functioning**	**Cognitive functioning**
Global health status / QoL (overall HRQoL)	.748**	.646**	.540**	.474**	.361**

**Correlation is significant at the 0.01 level (2-tailed)

Similarly, overall HRQoL was also positively and significantly correlated with all functional scales of the EORTC QLQ-C29 including, body image (r = .483, p < .0001), anxiety (r = .502, p < .0001), weight (r = .394, p < .0001), and sexual interest (r = .395, p < .0001) (table 6).

Table 6. Correlation coefficients (r) between overall HRQoL and other measured variables.

	Anxiety	**Body image**	**Sexual interest**	**Weight**
Global health status / QoL (overall HRQoL)	.502**	.483**	.395**	.394**

**Correlation is significant at the 0.01 level (2-tailed)

Furthermore, a moderate to strong significant negative correlation was observed between overall HRQoL and most of the symptom scales/items of the EORTC QLQ-C30 such as, fatigue (r = -.674, p < .0001), nausea and vomiting (r = -.330, p < .0001), pain (r = -.439, p < .0001), dyspnoea (r = -.303, p < .0001), insomnia (r = -.355, p < .0001), appetite loss (r = -.370, p < .0001), and financial difficulties (r = -.422, p < .0001) (table 7).

Table 7. Correlation coefficients (r) between overall HRQoL and other measured variables.

	Fatigue	**Pain**	**Financial difficulties**	**Appetite loss**	**Insomnia**	**Nausea & vomiting**	**Dyspnoea**
Global health status / QoL (overall HRQoL)	-.674**	-.439**	-.422**	-.370**	-.355**	-.330**	-.303**

**Correlation is significant at the 0.01 level (2-tailed)

A moderate significant negative correlation was observed between overall HRQoL and most of the symptom scales of the EORTC QLQ-C29 such as urinary frequency (r = -.314, p < 0.0001), abdominal pain (r = -.375, p < .0001), bloating (r = -.337, p < .0001), dry mouth (r = -.327, p < .0001), faecal incontinence; without an ostomy (r = -.360, p = .001), sore skin (r = -.303, p < .0001); embarrassment (r = -.306, p < .0001), and stoma care problems (r = -.410, p < .0001) (table 8 to table 9).

Table 8. Correlation coefficients (r) between overall HRQoL and other measured variables.

	Stoma care problems	**Abdominal pain**	**Faecal incontinence (without an ostomy)**	**Bloating**	**Dry mouth**
Global health status / QoL (overall HRQoL)	-.410**	-.375**	-.360**	-.337**	-.327**

**Correlation is significant at the 0.01 level (2-tailed)

Table 9. Correlation coefficients between overall HRQoL and other measured variables.

	Urinary frequency	**Embarrassment**	**Sore skin**
Global health status / QoL (overall HRQoL)	-.314**	-.306**	-.303**

**Correlation is significant at the 0.01 level (2-tailed)

5.4 Factors related to overall HRQoL in colorectal cancer survivors

To develop a predictive model of overall HRQoL in CRC survivors, the multivariate relationships among overall HRQoL and function, symptom, item variables were examined. Some variables which were used as independent variables (predictors for overall HRQoL) were identified through the bivariate correlational analyses presented above. Variables in the correlational analyses which had moderate to strong association with overall HRQoL including demographic and other character variables were entered into multiple regression models to identify which factors remained independent predictors of overall HRQoL score in CRC survivors.

In the first phase of the stepwise multiple regression analysis, socio-demographic and other personal characteristics variables such as gender, age, ostomy status, time from CRC diagnosis, other diagnosed medical conditions, and marital status were modelled together. This multivariate analysis yielded “marital status” (p = .003) and “presence of other diagnosed medical conditions” (p = .008) as significantly predictive of overall HRQoL among CRC survivors (table 10).

Table 10. Predictors of overall HRQoL using socio-demographic and other personal characteristics variables.

Global health status/QoL (overall HRQoL score)		
Independent variables included in model	**Beta (standardized coefficient)**	***P*-value**
Single/divorced/widowed/ separated	-.221	.003
Presence of other diagnosed medical conditions	-.197	.008

Model $R^2 = .088$, *F*-test $p < .0001$

In the second phase of the stepwise multiple regression analysis, variables in the EORTC QLQ-C30 questionnaire (physical functioning, role functioning ,emotional functioning, cognitive functioning, social functioning, fatigue, nausea and vomiting, pain, dyspnoea, insomnia, appetite loss, and financial difficulties) found to be moderately to strongly correlated with overall HRQoL were modelled together. This analysis produced “physical functioning” (p < .0001), “emotional functioning” (p < .0001), and “fatigue” (p = .039) as significant unique predictors of overall HRQoL among CRC survivors (table 11).

Table 11. Predictors of overall HRQoL using variables in the EORTC QLQ-C30.

Global health status/QoL (overall HRQoL score)		
Independent variables included in model	**Beta (standardized coefficient)**	***P*-value**
Physical functioning ⱡ	.486	<.0001
Emotional functioning ⱡ	.239	<.0001
Fatigue*	-.184	.039

Model $R^2 = .620$, *F*-test *p* < .0001
ⱡ Higher scores indicate better level of functioning
*Higher scores indicate worse level of problems

In the third phase of the stepwise multiple regression analysis, variables in the EORTC QLQ-C29 questionnaire (body Image, anxiety, weight, sexual interest, urinary frequency, abdominal pain, bloating, dry mouth, faecal incontinence; without an ostomy, sore skin, embarrassment, and ostomy care problems) which have moderate to strong correlation with overall HRQoL were modelled together. The result of this analysis revealed that “anxiety” (p = .002), “body image” (p = .001), and “sexual interest” (p = .002) were significant independent predictors of overall HRQoL score (table 12).

Table 12. Predictors of overall HRQoL using variables in the EORTC QLQ-C29.

Global health status/QoL (overall HRQoL score)		
Independent variables included in model	**Beta (standardized coefficient)**	***P*-value**
Anxiety ⱡ	.310	.002
Body image ⱡ	.326	.001
Sexual interest ⱡ	.280	.002

Model $R^2 = .437$, *F*-test *p* < .0001
ⱡ Higher scores indicate better level of functioning

In the last phase of the stepwise multiple regression analysis, all the eight independent predictor variables of overall HRQoL identified in the three previous phases were tested with a final stepwise multiple regression analysis to determine which factors remained unique predictors of overall HRQoL score in CRC survivors. These eight predictors modelled together were marital status, presence of other diagnosed medical conditions, physical functioning, emotional functioning, fatigue, anxiety, body image, and sexual interest. The final analysis revealed that four variables namely physical functioning ($p < .0001$), sexual interest ($p < .0001$), body image ($p = .022$), and fatigue ($p = .028$) remained significant independent predictors of overall HRQoL score in CRC survivors (table 13). These four variables accounted for 67.4% of the variation in overall HRQoL score among CRC survivors. Among the four variables, physical functioning made the strongest contribution to explaining the level of overall HRQoL in CRC survivors. In sum, higher level of physical functioning, lower level of body image disturbance and lesser severity of problems with sexual interest were related to better overall HRQoL, whereas higher level of fatigue was related to poorer overall HRQoL.

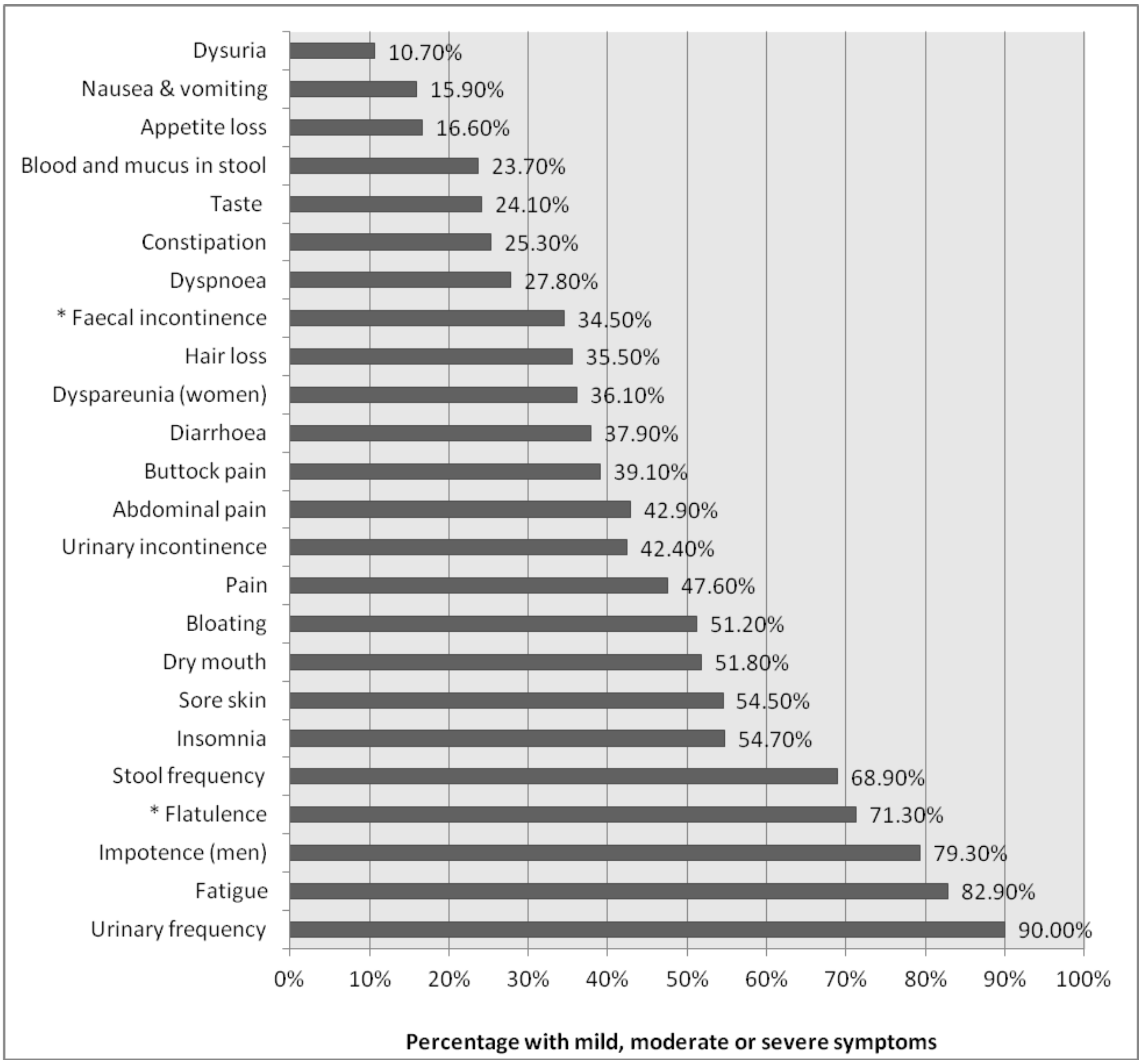
Table 13. Predictors of overall HRQoL using all factors from socio-demographic, EORTC QLQ-C30, and EORTC QLQ-C29 models.

Global health status/QoL (overall HRQoL score)		
Independent variables included in model	**Beta (standardized coefficient)**	***P*-value**
Physical functioning ǂ	.388	<.0001
Sexual interest ǂ	.177	<.0001
Body image ǂ	.133	.022
Fatigue*	-.188	.028

Model $R^2 = .674$, *F*-test $p < .0001$
ǂ Higher scores indicate better level of functioning
*Higher scores indicate worse level of problems

5.5 Prevalence of symptoms among colorectal cancer survivors

Different severities of problem were reported in each of the symptom/item domains in the EORTC QLQ-C30 and EORTC-QLQ-C29. However, none of the respondents reported having problems in all the symptom/item domains. Analysis of question-items relating to bowel incontinence was restricted to respondents without an ostomy. The proportion of respondents that reported any degree of problem (ranging from “a little” to “very much”) in the symptom domains in both questionnaires are shown in the figure below (figure 2).



*Respondents reporting they had an ostomy present were excluded from this analysis

Figure 2. Percentage of respondents reporting mild to severe symptoms (using the EORTC QLQ-C30 and EORTC QLQ-C29).

Problems relating to bowel, urinary and sexual function were among the 5 most prevalent symptoms, with urinary frequency (90.00%), fatigue (82.90%), and impotence (79.30%) being the 3 most reported symptoms among respondents respectively. The 3 least reported symptoms were appetite loss (16.60%), nausea and vomiting (15.90%) and dysuria (10.70%) respectively. Furthermore, it was found that more than half of the respondents, that is, 51.80% reported having dry mouth, 54.50% reported having sore skin and 54.70% reported having insomnia. Respondents reported having “a little” or “quite a bit” or ”very much” of the symptoms included in the figure above (figure 2).

6 DISCUSSION

6.1 Review of the major findings

As the prevalence of CRC increases, understanding the perspective of CRC survivors on the effect of the disease and its treatment on their health are important. Alongside effective disease treatment, the factors that influence HRQoL of CRC survivors should be progressively investigated and identified in an effort to modify them towards improving HRQoL for CRC survivors. The current study shows that CRC survivors experience impairments in functioning, well-being and overall HRQoL. These impairments appear to differ especially across gender, age, ostomy status, marital status, and comorbidity status in CRC survivors. In addition, this study also revealed CRC survivors who are at greater risk for diminished HRQoL and may be experiencing ongoing health problems and concerns needing further support and services. Notably women, those at the extremes of the age groups (≤55 and ≥76years), those with an ostomy, those without a spouse/partner, and those that have been diagnosed with at least one other medical condition in addition to CRC reported poorer functioning, symptoms, or overall HRQoL. Similar findings were reported in previous studies of CRC survivors' HRQoL outcomes (Tsunoda et al. 2007, Hornbrook et al. 2011, Grant et al. 2011, Färkkilä et al. 2013, Downing et al. 2015, Rodriguez et al. 2015).

In the current study, women reported poorer emotional functioning, body image, and experienced more symptoms than men. These problems were confirmed in a prior study on gender differences among CRC survivors (Krouse et al. 2009). The disparity in functioning and well-being between male and female CRC survivors may be explained by the effects of functional status on well-being as confirmed by Krok et al. (2013) that female cancer patients report worse functional impairment and are more likely to be dissatisfied with their body image than men.

Overall HRQoL and physical functioning were lower in those at the extreme of the age groups (≤55 and ≥76 years) among CRC survivors and younger CRC survivors (≤55years) had more symptoms than any other age group. These findings concur with previous studies that have compared HRQoL outcomes of CRC survivors with that of controls from the general population of matched age and gender (Jansen et al. 2011b, Downing et al. 2015).

Differences in symptoms between older and younger CRC survivors may be due to variations in treatment for CRC for each group since younger patients are known to be administered chemotherapy more than older patients (Jansen et al. 2011b).

In regard to the impact of an ostomy on well-being and functioning of CRC survivors, the current study showed that social and role function were significantly reduced in CRC survivors with an ostomy than those without an ostomy. In addition, CRC survivors with an ostomy perceived their body image more negatively than those without an ostomy. The studies by Sharpe et al. (2011), Grant et al. (2011), Sun et al. (2013) and Mols et al. (2014) of CRC survivors with an ostomy provide evidence for the findings and highlight that ostomy negatively affect psychological well-being and social function by causing disturbances to body image, as well as restrictions in physical and social activities.

As expected, significant deficits in overall HRQoL, physical and role function including, other problems were more prevalent in CRC survivors with other diagnosed medical conditions than those without other diagnosed medical conditions. These findings are consistent with those of prior studies of CRC survivors which noted that CRC survivors with one or more other long-term conditions reported more problems in several domains of HRQoL (Downing et al. 2015), have lower physical function, and lower overall HRQoL (Rodriguez et al. 2015) than CRC survivors with no long-term condition(s).

Decline in sexual interest was worst for CRC survivors at 6-10 years post-diagnosis followed by those at ≥11 years post-diagnosis. This finding supports the studies by Arndt et al. (2006) and Sun et al. (2013) which both reported that prominent changes were found for sexual activity in CRC patients. As such, a significant decrease in sexual activity over several years after CRC diagnosis was observed in both studies.

Contrary to the author’s findings, several longitudinal studies have found differences in HRQoL outcomes among CRC survivors in relation to the time from diagnosis of CRC; indicating likelihood toward higher symptom scores and more limitations in daily life as the time from diagnosis of CRC progresses. Specific symptoms such as insomnia, dyspnoea, constipation (Arndt et al. 2006, Jansen et al. 2011b) and diarrhoea (Arndt et al. 2006, Caravati-Jouvenceaux et al. 2011, Jansen et al. 2011a) were found to persist and gradually worsen with time, between 3 and 15 years post-diagnosis of CRC. However, in the current study, no significant differences were observed in symptoms experienced among CRC survivors even though the time period from CRC diagnosis among respondents ranged from 0-26 years. In comparison with a large study of cancer survivors by Benett et al. (2010), findings from the study supported that symptoms, physical and emotional health were not related to time since diagnosis of cancer. It is worth noting however, that the study by Benett et al. (2010) and this study are both cross-sectional studies, lacking baseline data and this may explain for the disparity between findings.

The health-promoting benefit of marriage and similar relationships has been documented among cancer survivors (Goldzweig et. al. 2009, Morgan et al. 2011, Färkkilä et al. 2013). CRC survivors who were single, divorced, widowed or separated had lower overall HRQoL, physical function and higher symptom scores compared to CRC survivors who had a spouse/partner. These findings concur with the study by Chambers et al. (2012) which revealed that being single is a risk factor for poor HRQoL and psychological distress post-diagnosis of CRC.

Problems relating to bowel, urinary and sexual function were common in the respondents although, with relatively varying degrees. Downing et al. (2015) reported a similar category of prevalent symptoms, however, compared to the English study, greater frequencies of these problems were reported among CRC survivors in the current study. The high prevalence of symptoms such as urinary frequency, fatigue, impotence, flatulence, and stool frequency among respondents is a significant finding of the current study and is supported by other studies among CRC survivors (Bregendahl et al. 2013, Chen et al. 2015, Sánchez-Jiménez et al. 2015, Adam et al. 2016, Hess et al. 2016). These findings highlight the importance of extensive implementation of interventions for symptoms management among CRC survivors. The problems relating to bowel, urinary and sexual function must be acknowledged, assessed and addressed in order to prevent further morbidity among CRC survivors.

Different variables as a group affected the overall HRQOL of CRC survivors. Multivariable analysis revealed a significant relationship between overall HRQoL and other factors such as physical functioning, sexual interest, body image and fatigue. The analysis provided evidence to suggest that these four factors significantly affect CRC survivors’ perception of their overall HRQoL. The finding is consistent with those of previous studies demonstrating the effect of fatigue (Gray et al. 2011, Färkkilä 2013, Ness et al. 2013, Sanin et al. 2015), body image (Benedict et al. 2016) and physical function/activity (Tsunoda et al. 2007, Lynch et al. 2008, Lee et al. 2015) on overall HRQoL in CRC survivors. CRC survivors' overall HRQoL scores were not associated with age when other variables were factored in. Similarly, gender, time since CRC diagnosis, including ostomy status did not account for changes in overall HRQoL among CRC survivors in the current study.

The findings from this study have potential implications for the care of CRC survivors. Because higher levels of physical function, lower levels of problems with sexual interest and better perception of body image were associated with higher overall HRQoL scores, healthcare providers should assess for and address disturbances in body image, problems with physical, and sexual functioning in CRC survivors. This assessment could help identify risk groups for poor overall HRQoL requiring additional support, resources, and/or services. Early intervention including linking CRC survivors with appropriate services or referrals targeted at addressing poor body image, physical and sexual function could be pivotal in improving overall HRQoL in CRC survivors. For instance, recent studies have suggested that physical activity even at a moderate level improves physical function and overall HRQoL in CRC survivors (Husson et al. 2015, Rodriguez et al. 2015). Higher levels of fatigue were also associated with lower overall HRQoL scores. The implementation of long-term care and support strategies to manage persistent cancer-related symptom such as fatigue could directly or indirectly improve overall HRQoL in CRC survivors.

6.2 Reliability and validity of the study

Literature search was conducted using three electronic databases (CINAHL, PubMed Central and PsycINFO) in order to identify relevant research articles on HRQoL in CRC patients or survivors, as well as instruments with proven reliability and validity that have been previously used to assess HRQoL in individuals diagnosed with CRC. Although research articles included in review of the literature present results from studies conducted from several parts of the world, several limitations of the review require consideration. Some conflicting findings and the use of different HRQoL measures in the studies made it harder to generalize HRQoL outcomes among persons diagnosed with CRC. The majority of the studies employed a quantitative approach, leaving little or no chance for CRC patients or survivors to explain in-depth opinions about their HRQoL. The lack of representative and randomized samples, including the low response rate in some studies are also issues of concern, as it limits generalizations from the findings of those studies. In addition, many of the studies included in the review lacked racial and/or ethnic diversity within the study population, restricting findings to specific racial or ethnic groups.

Furthermore, during the process of electronic retrieval of articles, some articles were found relevant for the literature review after reading the abstracts. However, these articles were not included in the review because the full texts of these publications were subject to market availability and as such, the researcher had no access to these. In addition, only studies in English were included the literature review, which might have also resulted in important findings being excluded. Despite these problems, it was possible to identify major HRQoL outcomes among CRC patients or survivors.

The literature search revealed that the EORTC QLQ-C30 (generic instrument) and EORTC QLQ-C29 (disease-specific instrument) were among the most frequently used, most tested and most recommended HRQoL instruments in CRC research. Generic-specific instruments aim to assess the primary dimensions of quality of life. However, in relation to individuals diagnosed with a particular disease, measurement of HRQoL with a generic instrument may need supplementation with a disease-specific instrument in order to measure the multiple domains of HRQoL (Bowling 2001) and to assess important issues relevant to these individuals (Byrne 2007, Tsunoda et al. 2007, Whistance et al. 2009, Yoo et al. 2005). Hence, the two instruments (EORTC QLQ-C30 and EORTC QLQ-C29) were chosen and used as the instruments of measure for the current study. Both instruments have been widely used, tested and proven in international clinical settings and population based studies to demonstrate adequate reliability and validity (Aaronson et al. 1993, Whistance et al. 2009).

Reliability of an instrument refers to the consistency of the results obtained in a study while validity of an instrument determines the accuracy of the results obtained in a study. The degree of reliability of an instrument can be determined by testing the internal consistency of subscales in the instrument, whereas one of the methods of determining the degree of validity of an instrument is by testing the instrument’s construct validity from factor analysis. (Groove et al. 2013.) Previous assessment of internal consistencies of both instruments revealed that almost all the instruments’ scales met the minimal criteria for internal reliability which according to Groove et al. (2013) is a Cronbach's alpha coefficient value ≥0.70. According to Groove et al. (2013), assessments of instrument reliability and validity are unique to the population and sample being studied. In this study, the degree of internal consistency of each of the two questionnaires was determined through calculation of Cronbach’s alpha coefficient for each of the subscales in the questionnaires.

The international study by Aaronson et al. (1993) which consisted patients from 13 Countries tested the psychometric properties of the EORTC QLQ-C30 and reported that Cronbach's alpha coefficients for eight of the nine subscales in EORTC QLQ-C30 exceeded the 0.70-value criterion for adequate scale reliability at one or the two periods the values were assessed in the study. Only the role functioning scale demonstrated low reliability with Cronbach's alpha coefficients for this particular scale ranging from 0.52 to 0.54 during the two periods of assessment. Regarding the EORTC QLQ-C30 subscales in the current study, Cronbach's alpha coefficients for the nine subscales are shown in the table below (table 14).

Table 14. Cronbach's alpha coefficients for the EORTC QLQ-C30 subscales.

EORTC QLQ-C30 subscales	**Cronbach's alpha coefficients**
Pain	0.91
Global health status/QoL	0.89
Emotional functioning	0.87
Fatigue	0.85
Physical functioning	0.83
Social functioning	0.83
Role functioning	0.78
Cognitive functioning	0.66
Nausea and vomiting	0.64

Whistance et al. (2009) conducted an international study which comprised of patients from 7 Countries to test the reliability and validity of the EORTC QLQ-C29. The results of the study showed that, for the total sample, Cronbach's alpha coefficients for three of the four EORTC QLQ-C29 subscales met the 0.70-value criterion for adequate scale reliability. Regarding the

EORTC QLQ-C29 subscales in the current study, Cronbach's alpha coefficient for the four subscales are shown in the table below (table 15).

Table 15. Cronbach's alpha coefficients for the EORTC QLQ-C29 subscales.

EORTC QLQ-C29 subscales	**Cronbach's alpha coefficients**
Body image	0.86
Urinary frequency	0.77
Blood and mucus in stool	0.41
Stool frequency	0.64

Previous studies have established the scale structure and construct validity of both the EORTC QLQ-C29 and EORTC QLQ-C30 through procedures that tested for and confirmed (1) correlations among scales in each instrument; (2) sensitivity of the instruments to change in clinical health status of patients over time; and (3) capacity of the instruments to distinguish between clinically distinct groups of patients (Aaronson et al. 1993, Whistance et al. 2009).

6.3 Ethical considerations

Organisational approval for the current study was obtained from the Executive Directors of the two patient organisations from which respondents were recruited. Recruitment of individuals to the study began after the approval was granted. Effort was made to ensure that prospective respondents understood the nature, purpose and scope of the current study before participating in the study. To this end, a mail consisting of an information/invitation letter informing about the purpose of the study, voluntary participation and confidentiality of the data resulting from participation was sent to prospective respondents. They were also informed of their right to decline to participate in the study without any penalty or loss of benefit, and that their identity will not revealed while the study is being conducted, reported or published. Furthermore, permission to use the EORTC QLQ-C30 (version 3.0) and EORTC QLQ-CR29 (version 2.1) for this study was authorized by the EORTC Quality of Life Group.

The researcher acknowledges that the current study might have caused some discomfort or embarrassment for some respondents due to the length of the questionnaire forms and the intimate nature of certain questions in these forms respectively. Regular contact was maintained with each of the Executive directors of the patient organisations in order to answer any questions that their members participating in the study may have. The researcher received few e-mails from the Executive directors to this effect. In addition, the contact information of the researcher and her supervisors were included in the invitation/information letter that was sent respondents so that they could freely contact the researcher and her supervisors and ask any questions they may have related the study. Several phone calls were received to this effect.

6.4 Limitations of the study

Although this study answers the research questions set, several limitations of this study need to be acknowledged. Firstly, there is a possible bias selection regarding CRC survivors that provided information about HRQoL in this study because other CRC survivors who are not members of either of the two patient organisations were not included in this study. A more representative sample could have been identified at a national level through the Finnish Cancer registry. In addition, nonrespondent characteristics analysis was not undertaken as the researcher did not have access to information or other sources relating to nonrespondents. Consequently, it was not possible to determine if nonrespondents differed from the respondents. As to whether this has had any effect on the results of the current study remains unknown.

Secondly, given the cross-sectional design of this study, there are limitations regarding the type of information that can be achieved and in interpreting the established relationship between or within variables. Groove et al. (2013) noted that relationship between or within variables does not mean causal link. Furthermore, being a cross-sectional study, neither baseline nor longitudinal data were obtained; baseline data such as HRQoL outcomes before treatment for CRC and longitudinal data such as HRQoL outcomes over time after treatment for CRC could have provided more important information on the effects of CRC and its treatment on HRQoL of CRC survivors.

Thirdly, it was not possible to estimate the response rate in this study because the electronic link to the web-based questionnaires was e-mailed on behalf of the researcher to all the members of the FINNILCO-association irrespective of their diagnosis because the association does not have a record from which they could differentiate individuals with a diagnosis of CRC from those without. Hence, individuals who have not been diagnosed with and treated for CRC were part of the recipients of the e-mail containing the link to the web-based questionnaires. Nevertheless, screening for eligibility for participating in the current study was undertaken by the researcher through the socio-demographic data form that respondents were required to fill out. This form contains information about the respondent's year of CRC diagnosis and the treatment(s) received for CRC. Early on, the researcher decided that individuals who responded to the web-based questionnaires and did not indicate the year they were diagnosed with CRC and the treatment they receive for CRC will be excluded from this study. Surprisingly though, there were none of such cases; the researcher believes the information/invitation letter (detailing the nature, purpose and scope of the study) that respondents received prior to participating in this study guided respondents in regards to eligibility for enrolling in the study. This, perhaps, explains why individuals that have not been diagnosed with CRC did not accidentally enrol in the study.

Fourthly, the EORTC QLQ-C29 questionnaire is not available in the Finnish language and it had to be translated from the English language to Finnish language for this study. The translation was done by a native speaker of the Finnish language who understands English. This translated version was then checked for wording and correctness by the two supervisors of the researcher. The supervisors have vast experience in healthcare research and are also native speakers of the Finnish language. However, a backward translation of the Finnish version was not done which could have fully confirmed that the all concepts addressed in the original questionnaire were completely reproduced in the translated version. In addition, respondents received questionnaires in electronic or paper version. The inconsistency in questionnaire administration to respondents and lack of backward translation of one of the questionnaires could have had effects on the quality of data collected for this study. (Bowling 2005, Groove et al. 2013). Furthermore, the EORTC QLQ-C30 and EORTC QLQ-C29 data were skewed making multivariable analysis complex.

Lastly, this study is based on subjective information from individuals that was not confirmed through verification from medical records as the researcher had no access to these.

In spite of these limitations, the findings from the current study are additional significant information to the body of research on HRQoL of CRC survivors. Another contribution of this study is that it provides direction to areas where increased intervention is needed in CRC survivorship care. The findings are applicable in Finland and could benefit any organisation that seeks to develop services and interventions to address the needs and improve HRQoL of CRC survivors.

6.5 Implications for nursing practice

The study findings have implications for educating patient organisations, health care providers, and informing development and implementation of effective interventions. The findings may serve as a guide in educating patient organisations and health care providers about the health challenges faced by CRC survivors. The findings can also be used by healthcare professionals and patient organisations to initiate and develop tailored support and services to meet the needs of CRC survivors. Due to the differences in HRQoL outcomes among CRC survivors as identified by gender, age, ostomy status, marital status, and comorbidity status in this study, healthcare professionals can significantly affect the quality of care and HRQoL of CRC survivors by thoroughly assessing each survivor’s health situation, including planning and implementing interventions to enhance physical function and address disturbances in body image, problems with sexual functioning, and fatigue in CRC survivors. Offering support early in CRC survivorship care may increase function, provide symptom relief, and improve HRQoL.

6.6 Suggestions for future research

More research analysing racial/ethnic differences in HRQoL among CRC survivors is necessary since culture/ethnicity can influence an individual’s perception of health, illness, and well-being. This information will provide healthcare professionals with knowledge about the variations in HRQoL that exist among CRC survivors of different racial/ethnic groups and thereby, enable them to develop culturally relevant interventions not only to address the needs of these individuals but that also have the potential to improve their HRQoL. In addition, further research aimed at investigating the support needs of CRC survivors and the effects of interventions to alleviate fatigue, enhance body image, physical and sexual function on HRQoL of CRC survivors are equally essential.

6.7 Conclusions

The current study identifies factors associated with overall HRQoL among CRC survivors. Functional capacity and CRC-related problems were most strongly associated with overall HRQoL among CRC survivors and as such, specific factors such as physical function, sexual interest, body image and fatigue significantly influenced overall HRQoL of CRC survivors. Hence, increased alertness and greater effort to identify and alleviate CRC-related symptoms/concerns and diminished physical functional capacity among CRC survivors are warranted in an attempt to improve their overall HRQoL. In particular, specific attention should be placed on women, the elderly, those with an ostomy, those without a spouse/partner, those at 6-10 years post-diagnosis of CRC, and those with other long-term medical conditions in the care of CRC survivors, as these were the subgroups of CRC survivors that experienced most problems with the specific factors that significantly influenced overall HRQoL in the current study.

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Appendix 1.Characteristics of included studies in the literature review (1/10)

Author(s), year of publication, and country	**Purpose of the study**	**Sample/Data and Method**	**Main results**
Adam JP, Denost Q, Capdepont M, van Geluwe B & Rullier E 2016 France	To evaluate changes in urogenital function over time after rectal cancer treatment.	Rectal cancer patients (n= 169; response rate : 68%) Questionnaire	After radiotherapy, urinary function temporarily declined in men and sexual function significantly declined in women. Sexual function significantly decreased in both sexes after surgery and worsened 12 months post treatment.
Arndt V, Merx H, Stegmaier C, Ziegler H & Brenner H 2006 Germany	To determine the QoL of CRC patients at 1-3 years after diagnosis and treatment for CRC.	CRC patients (n = 309; response rate: 82% at follow-up, 1 year post-diagnosis) (n = 222; response rate: 92% at follow-up, 3 years post-diagnosis) & an age and gender subjects from the general population (n=2028) Questionnaire	Compared to the normative population CRC patients reported high overall QoL and experienced only few problems in physical functioning but problems in emotional and social functioning lasted over the years.
Benedict C, Philip EJ, Baser RE, Carter J, Schuler TA, Jandorf L, DuHamel K & Nelson C, 2016, USA	To assess body image problems and determine relationship between body image and sexual function among female rectal cancer patients.	Rectal cancer patients (n= 70) Questionnaire	86% of respondents reported at least one body image problem. Younger age, lower overall HRQoL, higher severity of symptoms were significantly associated with poorer body image. Poor body image had a negative impact on all aspects of sexual function, except pain.
Bregendahl S, Emmertsen KJ, Lous J & Laurberg S, 2013, Denmark	To assess bowel function after rectal cancer surgery with or without neoadjuvant therapy	Rectal cancer patients (n= 938; response rate : 96%) Questionnaire	Major bowel dysfunction was observed in 41% of respondents. Chemo-radiation, total mesorectal excision, female gender, anastomotic leakage, and age ≤64 years at surgery were factor strongly associated with major bowel dysfunction.

Appendix 1.Characteristics of included studies in the literature review (2/10)

Author(s), year of publication, and country	Purpose of the study	Sample/Data and Method	Main results
Caravati-Jouvenceaux A, Launoy G, Klein D, Henry-Amar M, Abeilard E, Danzon A, Pozet A, Velten M & Mercier M, 2011, France	To compare CRC survivors' QoL at 5, 10, and 15 years after diagnosis with that of healthy subjects from the general population.	CRC survivors (n = 542; response rate: 37%) & An age and gender matched subjects from the general population (n = 1181; response rate: 28%). Questionnaire	CRC survivors had clinically and statistically significant lower social functioning scores 5 years post-diagnosis and more diarrhoea 5 and 10 years post diagnosis. Rectal cancer influenced physical functioning at 5 years and fatigue levels at 5 and 10 years post-diagnosis.
Chen TY, Wiltink LM, Nout RA, Meershoek-Klein Kranenbarg E, Laurberg S, Marijnen CA & Van de Velde CJ, 2015, Nethelands	To investigate long-term bowel function after surgery (TME) with or without preoperative radiotherapy for rectal cancer and also to examine the risk factors for bowel dysfunction, and the relations between bowel dysfunction and HRQoL.	Rectal cancer survivors (n= 478; response rate : 82%) Questionnaire	Major bowel dysfunction was reported by 46% of all respondents, of which 56% received preoperative radiotherapy and surgery for treatment and 35% underwent surgery alone for treatment. Preoperative radiotherapy and age ≤75 years at the follow-up increased the risk of major bowel dysfunction. Survivors with major bowel dysfunction were worse off in many HRQoL outcomes.
Den Oudsten BL, Traa MJ, Thong MS, Martijn H, De Hingh IH, Bosscha K & Van de Poll-Franse LV, 2012, Netherlands	To compare CRC survivors' sexual functioning and sexual enjoyment to that of subjects from the general population.	CRC survivors (n = 1371; response rate: 82%) & An age and gender matched subjects from the general population (n =400; (response rate: 78%). Questionnaire	Sexual function was diminished in CRC survivors compared to that of the general population. Sexual enjoyment was similar within groups for men, whereas female CRC survivors scored lower than the general population. Lower sexual function was linked to fatigue, female sex, rectal cancer, older age, being without a spouse, low educational level, and depressive symptoms. Older age, female sex, depressive symptoms, and cardiovascular disease were linked to lower sexual enjoyment.

Appendix 1.Characteristics of included studies in the literature review (3/10)

Author(s), year of publication, and country	**Purpose of the study**	**Sample/Data and Method**	**Main results**
Dulskas A & Samalavicius NE, 2016 Lithuania	To evaluate urogenital dysfunction after surgical rectal cancer treatment.	Rectal cancer patients (n= 54; response rate : 50%) Questionnaire	Urinary and sexual function declined in both sexes postoperatively. Female patients reported higher levels of sexual dysfunction than males.
Downing A, Morris EJ, Richards M, Corner J, Wright P, Sebag-Montefiore D, Finan P, Kind P, Wood C, Lawton S, Feltbower R, Wagland R, Vernon S, Thomas J & Glaser AW, 2015, England	To assess the HRQoL of CRC survivors and determine factors related to poor health outcomes.	CRC survivors (n = 21,802; response rate: 63.3%) Questionnaire	CRC survivors reported more health problems than in the general population, notably CRC survivors <55 years of age reported most problems. CRC survivors with long-term disease(s), those with active or recurrent CRC, those with an ostomy, and those <55 and >85 years of age reported higher level of problems. 25.1% of rectal cancer survivors had problems with sexual matters compared to only 11.2% of colon cancer survivors.
Dunn J, Lynch B, Rinaldis M, Pakenham K, McPherson L, Owen N, Leggett B, Newman B & Aitken J, 2006, Australia	To the QoL of CRC patients and psychosocial issues most important to CRC patients.	CRC patients (n= 19) Focus group discussions Interviews	Satisfaction with diagnosis and treatment; provision of supportive information; benefits of diagnosis; quality of life; making sense of the cancer experience; and coping strategies emerged as core themes from the data collected

Appendix 1.Characteristics of included studies in the literature review (4/10)

Author(s), year of publication, and country	**Purpose of the study**	**Sample/Data and Method**	**Main results**
Graca Pereira M, Figueiredo AP & Fincham FD, 2012, Portugal	To assess the effect of different treatment strategies on depression, anxiety, traumatic stress, and QoL in CRC patients and their partners.	CRC patients (n= 114) and 67 partners. Questionnaire	CRC patients treated with surgery only reported lower depression, anxiety and traumatic stress symptom levels than CRC patients that underwent surgery and chemotherapy or surgery and radiotherapy for treatment. Traumatic stress was associated with adverse symptoms, that is, pain/bowel pattern. Anxiety and depression were significantly linked to CRC patient's QoL.
Grant M, McMullen CK, Altschuler A, Mohler MJ, Hornbrook MC, Herrinton LJ, Baldwin CM & Krouse RS 2011, USA	To describe gender differences in relation to concerns and adaptations of long-term CRC survivors with an ostomy.	CRC survivors Four female & four male focus groups (n = 33) Focus group discussions	Both sexes reported difficulties with sexuality and intimacy. Problems with coping and adjusting with an ostomy were mostly reported by women. Sleep problems were mostly reported by female CRC survivors with low HRQoL. Body image disturbance and depression were reported only by female CRC survivors with low HRQoL.
Hess V, Winterhalder R, Von Moos R, Widmer L, Stocker P, Jermann M, Herrmann R & Koeberle D, 2016, Switzerland	To investigate the long-term outcomes of combined modality treatment of locally advanced rectal cancer.	Rectal cancer patients (n= 51; response rate : 94%) Questionnaire	Multimodality treatment of locally advanced cancer results in a high five-year disease progression-free and survival rate (61% and 78% respectively). Up to one-third of patients reported high levels of problems related to bowel function and about 28% of patients were not satisfied with their urinary, bowel or ostomy function during at least one evaluation period.

Appendix 1.Characteristics of included studies in the literature review (5/10)

Author(s), year of publication, and country	**Purpose of the study**	**Sample/Data and Method**	**Main results**
Hornbrook MC, Wendel CS, Coons SJ, Grant M, Herrinton LJ, Mohler MJ, Baldwin CM, McMullen CK, Green SB, Altschuler A, Rawl SM & Krouse RS, 2011, USA	To investigate the impacts of living with a permanent ostomy compared to a major intestinal resection among long-term CRC survivors.	CRC survivors (n= 640; response rate: 52%) Questionnaire	CRC survivors' HRQoL scores were not related to having a permanent ostomy after other variables were taken into consideration. Complications from surgery, concomitant diseases, and metastatic CRC were negatively associated with HRQoL scores, while financial income was positively associated with HRQoL scores.
Houldin A, Lewis FM, 2006, USA	To describe the experiences of patients newly diagnosed with late stage CRC	CRC patients (n= 14) Interviews	Feelings of disruption of life, unpreparedness, rethinking parenting, wondering "why me?", experiencing physicians, and dealing with it were the core themes that emerged from the data collected. The major category that significantly described CRC patients' experiences was "salvaging their normal lives."
Huang M, Lin J, Yu X, Chen S, Kang L, Deng Y, Zheng J, Luo Y, Wang L, Lan P & Wang J, 2016 China	The assess erectile and urinary function in male rectal cancer patients treated with neoadjuvant chem-radiation or neoadjuvant chemotherapy only.	Rectal cancer patients (n= 108) Questionnaire	Compared to rectal cancer patients who received neoadjuvant chemotherapy alone before surgery, erectile and urinary function was significantly affected in patients who received noeadjuvant chemo-radiation. Age, ostomy, tumor location and size were associated with erectile dysfunction in the patients treated with chemo-radiation.

Appendix 1.Characteristics of included studies in the literature review (6/10)

Author(s), year of publication, and country	**Purpose of the study**	**Sample/Data and Method**	**Main results**
Jansen L, Herrmann A, Stegmaier C, Singer S, Brenner H & Arndt V, 2011a, Germany	To compare the QoL of CRC survivors at 1, 3, 5, and 10 years after diagnosis with that of subjects from the general population and determine changes in QoL of CRC survivors during the 10 years post-diagnosis	CRC survivors (n=439; at baseline) (n = 178; response rate: 76% at follow-up, 5 years post-diagnosis) (n = 133; response rate: 68% at follow up, 10 years post-diagnosis) Questionnaire	CRC survivors aged <60 years at diagnosis reported worse limitations in social, role, cognitive, and emotional functioning as well as worse symptom levels regarding diarrhoea, fatigue, constipation, and insomnia than subjects from the general population. CRC survivors aged ≥70 years at diagnosis reported similar to better QoL at 3 to 5 years post-diagnosis and similar to worse QoL at 5-10 years post diagnosis than subjects from the general population. Whereas, younger CRC survivors repeatedly experienced deficits in different QoL outcomes during the 10-years post-diagnosis, deficits in older CRC survivors only became apparent in the long term.
Jansen L, Hoffmeister M, Chang-Claude J, Koch M, Brenner H & Arndt V, 2011b, Germany	To determine the age-related pattern of administering chemotherapy and how it is associated with long-term survival and QoL of CRC patients.	CRC survivors (n= 562; at baseline) (n=327; response rate: 90% at the 5 year follow-up) Questionnaire	Chemotherapy was significantly associated with longer survival time in stage III CRC patients only. Chemotherapy was significantly associated with worse long-term overall QoL in CRC survivors aged <70 years. Conversely, in older CRC survivors aged >70 years, only hair loss and dry mouth were significantly associated with chemotherapy. CRC survivors treated with chemotherapy and aged <70 years at an average of 5 years post-diagnosis reported significantly worse cognitive, role, and physical functioning including higher level of symptoms as regards hair loss, appetite loss, pain, and problem with taste.

Appendix 1.Characteristics of included studies in the literature review (7/10)

Author(s), year of publication, and country	**Purpose of the study**	**Sample/Data and Method**	**Main results**
Mols F, Lemmens V, Bosscha K, van den Broek W & Thong MS, 2014, Netherlands	To investigate the physical and mental effects of an ostomy among 1 to10-year rectal cancer survivors.	Rectal cancer survivors (n = 1019; response rate 76%) Questionnaire	Rectal cancer survivors had a statistically and clinically relevant lower social, role, and physical functioning, as well as lower global health status/QoL but lesser bowels problems as regards constipation and diarrhoea compared to those without an ostomy. They also reported significantly worse male sexual problems and body image than those without an ostomy.
Russell L, Gough K, Drosdowsky A, Schofield P, Aranda S, Butow PN, Westwood JA, Krishnasamy M, Young JM, Phipps-Nelson J, King D & Jefford M, 2015, Australia	To assess psychological problems, QoL, CRC-related symptoms and supportive care needs among CRC survivors.	CRC survivors (n = 152; response rate 69%) Questionnaire	Compared to the normative population, CRC survivors reported lower depression and anxiety scores but worse social, cognitive and role functioning scores. CRC survivors reported worse levels of nausea/vomiting, fatigue, appetite loss, diarrhoea, constipation, financial difficulties and pain. CRC- related psychological scores were positively associated with the 3 BSI-questionnaire domain scores, including fatigue and pain scores in the QLQ-C30-questionnaire while negatively associated with the 5 functional scales in the QLQ-C30-questionnaire.
Rodriguez JL, Hawkins NA, Berkowitz Z & Li C, 2015, USA	To investigate socio-demographic and medical variables correlated with HRQoL of CRC survivors including factors that predispose survivors to poor functioning.	CRC survivors (n= 593; response rate: 46.3%) Questionnaire	In comparison to the normative population, CRC survivors had lower physical and mental HRQoL scores. Older age, comorbidities, and CRC recurrence correlated with lower physical and overall HRQoL, while better physical and overall HRQoL correlated with being physically active.

Appendix 1.Characteristics of included studies in the literature review (8/10)

Author(s), year of publication, and country	**Purpose of the study**	**Sample/Data and Method**	**Main results**
Sánchez-Jiménez A, Cantarero-Villanueva I, Delgado-García G, Molina-Barea R, Fernández-Lao C, Galiano-Castillo N & Arroyo-Morales M, 2015, Spain	To investigate physical performance, QoL and fatigue among CRC survivors compared with healthy subjects.	CRC survivors (n = 23) & An age and gender matched healthy subjects (n = 22) Questionnaire	CRC survivors reported significantly higher levels of symptoms as regards dyspnoea, fatigue, and diarrhoea than the healthy subjects. In comparison to the healthy subjects, objective and subjective worsening of health-related fitness level, and diminished perceived QoL were observed in CRC survivors.
Segalla JG, Van Eyll B, Federico MH, Skare NG, Franke FA, Perdicaris MR, Filho Ude P, Gampel O, Cabral S & Ribeiro Rde A, 2008, Brazil	To investigate the effects of oral capecitabine on QoL of patients with metastatic CRC.	CRC patients (n=1437) Questionnaire	Female CRC patients reported statistically significant improvements in overall HRQoL, emotional functioning, body image perception, future perspective, financial difficulties, and in symptoms such as weight loss, pain, nausea/vomiting, including ostomy-related problems, urination problems, and bowel problems. Male CRC patients reported statistically significant improvements in overall HRQoL in emotional and social functioning, future perspective, financial difficulties, and in symptoms such as appetite loss, pain, insomnia, weight loss, including ostomy-related problems, urination problems, and bowel problems. Both sexes reported statistically significant deterioration of sexual function/enjoyment.

Appendix 1.Characteristics of included studies in the literature review (9/10)

Author(s), year of publication, and country	**Purpose of the study**	**Sample/Data and Method**	**Main results**
Sharpe L, Patel D & Clarke S, 2011, Australia	To assess the impact of having an ostomy on body image in CRC patients and to examine if body image disturbances predicted distress.	CRC patients (n=79) Questionnaire	CRC patients living with an ostomy reported poorer body image that got worse over time. Body image strongly predicted anxiety, distress, and depression levels among CRC patients.
Smith-Gagen J, Cress RD, Drake CM, Romano PS, Yost KJ & Ayanian JZ, 2010, USA	To assess rectal cancer patients' HRQoL after surgery.	Rectal cancer patients (n=160) Questionnaire	Lower social well-being scores were observed in male CRC patients. Younger CRC patients reported lower emotional and physical well-being, and CRC-related adverse issues. CRC patients that were treated with adjuvant therapy reported worse physical well-being and more CRC-related adverse issues at 9 months post-diagnosis but, only CRC-related adverse issues continued over time.
Sun V, Grant M, McMullen CK, Altschuler A, Mohler MJ, Hornbrook MC, Herrinton LJ, Baldwin CM & Krouse RS, 2013, USA	To generate descriptive data on persistent ostomy-related concerns and adaptations in long-term CRC survivors with an ostomy.	CRC survivors 8 focus groups (n= 33) & Study survey (n=130) Focus group discussions and open-ended questionnaire	Long-lasting (persisting more than 5 years from ostomy creation) ostomy-related issues were prevalent among CRC survivors. Of these were clothing limitations, dietary matters, issues related to ostomy appliance and self-care, and continuously needing to find means to adapt and readapt to living with an ostomy.
Sun V, Grant M, Wendel CS, McMullen CK, Bulkley JE Herrinton LJ, Hornbrook MC & Krouse RS, 2016, USA	To describe changes in sexual function and HRQoL in long-term (≥5 years) rectal cancer survivors.	Rectal cancer survivors (n=575) Questionnaire & Open-ended questionnaire	In comparison to survivors of rectal cancer without an ostomy, higher rates of sexual dysfunction was observed in rectal cancer survivors with an ostomy especially females. Themes that emerged qualitative data were loss of and decreased sexual activity, psychological issues with sexual activity, physical issues with sexual activity, partner rejection, ostomy interference with sexual activity, and positive experiences with sexuality.

Appendix 1.Characteristics of included studies in the literature review (10/10)

Author(s), year of publication, and country	**Purpose of the study**	**Sample/Data and Method**	**Main results**
Thong MS, Mols F, Wang XS, Lemmens VE, Smilde TJ & Van de Poll-Franse LV. 2013 Netherlands	To compare fatigue levels of CRC survivors (up to 10-years post-diagnosis) with that of the normative population.	CRC survivors (n = 3739; (response rate: 79%) & an age- and gender-matched subjects from the general population (n = 338) Questionnaire	The reporting of fatigue was higher in CRC survivors than in the general population. CRC survivors at <5 years post-diagnosis reported the highest fatigue levels compared to CRC survivors at ≥5 years post-diagnosis or the general population. Anxiety, fatigue, and depressive symptoms independently correlated with surgery and chemo-radiation.
Tsunoda A, Nakao K, HIhratsuka K & Kusano M, 2007, Japan	To investigate monthly variations in QoL of CRC patients up to 1 year after surgery.	CRC patients (n=100) Questionnaire	Physical and role functioning, pain, fatigue, and dyspnoea declined significantly from the preoperative levels at 1 month after surgery and went back to the preoperative levels at 3 months after surgery. Improvements were observed in overall HRQoL, emotional and social functioning, financial difficulties, and in symptoms such as diarrhoea, insomnia, and appetite loss at 3 months after surgery. Scores for cognitive functioning, nausea/vomiting, and constipation remained constant. Multiple regression analyses indicated that preoperative performance status was a predicator of various QoL outcomes.
Yoo HJ, Kim JC, Eremenco S & Han OS, 2005 Korea	To investigate the validity of the FACT-C – questionnaire as an assessment tool to determine changes in QoL of CRC patients.	CRC patients (n= 98; at baseline) (n=52; at 1 month and 6 months after surgery) Questionnaire	FACT-C –questionnaire demonstrated good reliability and convergent and divergent validity. Lower overall QoL were observed among CRC patients at 1 month following surgery but returned to the preoperative level at 6 months following surgery.

Appendix 2. Invitation/information letter

Arvoisa vastaanottaja,

Pyydän Teitä osallistumaan paksu- ja peräsuolen syöpään sairastuneiden terveyteen liittyvään elämänlaatu-tutkimukseen. Opiskelen Itä-Suomen yliopiston hoitotieteen laitoksella ja teen progradu -tutkimusta aiheesta.

Tämän tutkimuksen tarkoituksena on kuvata ja selittää, miten paksu- ja peräsuolen syöpään sairastuminen on vaikuttanut terveyteen liittyvään elämän laatuun. Mikäli haluatte osallistua tähän tutkimukseen, pyydän Teitä vastaamaan taustatietoihin ja kahteen elämänlaatua mittaavaan kyselylomakkeeseen mitkä olette saaneet tämän kirjeen kanssa ja palauttamaan ne oheisessa palautuskuoressa. Kyselylomakkeiden täyttäminen kestää noin 30 minuuttia.

Vastaamalla kyselyyn saamme tietoa siitä, miten paksu- ja peräsuolen syöpä ja sen hoito ovat vaikuttaneet Teidän hyvinvointiinne. Tutkimuksesta saatavaa tietoa voidaan hyödyntää arvioitaessa paksu- ja peräsuolen syövän sairastaneiden erityistarpeita.

Tutkimukseen osallistuminen on vapaaehtoista eikä siitä makseta palkkiota. Tutkimuksesta saatavat tiedot koodataan niin, etteivät ne yhdisty nimeenne eikä henkilöllisyytenne paljastu tutkimuksen teon tai raportoinnin missään vaiheessa.

Voitte lähettää tähän tutkimukseen liittyvät kysymyksenne tutkijalle: Olusola Genesis (puh:xxx, sähköposti: olusolg@student.uef.fi tai tutkimukseni ohjaajille Päivi Kankkuselle (puh:xxx, sähköposti: paivi.kankkunen@uef.fi tai Anne Vaajoelle (puh:xxx, sähköposti: Anne.Vaajoki@kuh.fi).

Ystävällisin terveisin
Olusola Genesis
Sairaanhoitaja, terveystieteiden maisteriopiskelija

Appendix 3. Socio-demographic data form

A. Ikä ___________

B. Sukupuoli ______________

C. Siviilisääty (naimaton, naimisissa, avoliitossa, eronnut, leski, rekisteröidyssä parisuhteessa, eronnut rekisteröidystä parisuhteesta, leski rekisteröidyn parisuhteen jälkeen)_____________

D. Paksu- tai peräsuolen syöpä todettu vuonna _______________

E. Muut sairaudet _______________________________

F. Paksu -tai peräsuolen syövän hoito/terapia (Sädehoito, Solunsalpaajahoito, Leikkaus, Sädehoito ja leikkaus, Solunsalpaajahoito ja leikkaus, Sädehoito, Solunsalpaajahoito ja leikkaus) ____________________

G. Työllisyys (työssä, työtön, opiskelija, eläkeläinen) _____________________

H. Koulutusaste (esiaste, alempi perusaste, ylempi perusaste, keskiaste, alin korkea-aste, alempi korkeakouluaste, ylempi korkeakouluaste, tutkijakoulutusaste, koulutusaste tuntematon)_____________

EORTC QLQ-C29 (versio 2.1)

Potilaat raportoivat toisinaan seuraavia oireita ja ongelmia. Olkaa hyvä ja kertokaa missä määrin olette kokenut seuraavia oireita viimeisen viikon aikana. Vastatkaa ympyröimällä numero, joka parhaiten kuvaa tilannettanne.

Kuluneella viikolla:	**Ei lainkaan**	**Vähän**	**Melko Paljon**	**Hyvin Paljon**
31. Jouduitteko virtsaamaan usein päivisin?	1	2	3	4
32. Jouduitteko virtsaamaan usein öisin?	1	2	3	4
33. Onko teillä ollut tahatonta virtsankarkailua?	1	2	3	4
34. Oletteko tuntenut kipua virtsatessa?	1	2	3	4
35. Onko teillä ollut vatsakipuja?	1	2	3	4
36. Oletteko tuntenut kipua pakaroissa/anaalialueella/peräsuolessa?	1	2	3	4
37. Onko teillä ollut turvotusta vatsan seudulla?	1	2	3	4
38. Onko teillä ollut verta ulosteessa?	1	2	3	4
39. Onko teillä ollut limaa ulosteessa?	1	2	3	4
40. Oletteko kärsinyt suun kuivuudesta?	1	2	3	4
41. Onko teillä ollut hiusten lähtöä hoidon jälkeen?	1	2	3	4
42. Onko makuaistinne huonontunut?	1	2	3	4

Kuluneella viikolla:	**Ei lainkaan**	**Vähän**	**Melko Paljon**	**Hyvin Paljon**
43. Onko terveydentilanne huolestuttanut teitä?	1	2	3	4
44. Oletteko ollut huolissanne painostanne?	1	2	3	4
45. Oletteko tuntenut itsenne ulkoisesti vähemmän viehättäväksi sairaudesta/hoidosta johtuen?	1	2	3	4
46. Oletteko tuntenut itsenne vähemmän naiselliseksi/miehekkääksi sairaudesta tai hoidosta johtuen?	1	2	3	4
47. Oletteko ollut tyytymätön kehoonne?	1	2	3	4

48. Onko teillä avannepussi (paksusuoli-/ohutsuoliavanne)?

(Ympyröikää oikea vastaus) Kyllä Ei

Jatkuu seuraavalle sivulle

Appendix 4. EORTC QLQ–C29 (2/2)

Kuluneella viikolla:	**Ei lainkaan**	**Vähän**	**Melko paljon**	**Hyvin paljon**
Vastatkaa seuraaviin kysymyksiin VAIN JOS TEILLÄ ON AVANNEPUSSI. Mikäli ei, siirtykää seuraavaan kohtaan:				
49. Onko avannepussistanne päässyt tahattomasti suolistokaasuja/ilmaa?	1	2	3	4
50. Onko teillä ollut ulostevuotoa avannepussistanne?	1	2	3	4
51. Onko ihoanne aristanut avanteen ympärillä?	1	2	3	4
52. Jouduitteko vaihtamaan pussia useita kertoja päiväsaikaan?	1	2	3	4
53. Jouduitteko vaihtamaan pussia useita kertoja öisin?	1	2	3	4
54. Onko teillä ollut häpeän tunteita avannepussinne vuoksi?	1	2	3	4
55. Onko teillä ollut ongelmia avannepussinne huollossa?	1	2	3	4

Vastatkaa seuraaviin kysymyksiin VAIN JOS TEILLÄ EI OLE AVANNEPUSSIA:				
49. Onko teillä ollut tahatonta suolistokaasujen/ilman päästelyä peräaukosta?	1	2	3	4
50. Onko teillä ollut ulostevuotoa peräaukostanne?	1	2	3	4
51. Onko ihoanne aristanut peräaukon ympärillä?	1	2	3	4
52. Jouduitteko ulostamaan useita kertoja päiväsaikaan?	1	2	3	4
53. Jouduitteko ulostamaan useita kertoja öisin?	1	2	3	4
54. Onko teillä ollut häpeän tunteita suolenne toiminnan vuoksi?	1	2	3	4

Viimeisen neljän viikon aikana:	**Ei lainkaan**	**Vähän**	**Melko paljon**	**Hyvin paljon**
Vain miehille:				
56. Kuinka kiinnostunut olette ollut seksistä?	1	2	3	4
57. Onko teillä ollut erektio-ongelmia?	1	2	3	4
Vain naisille:				
58. Kuinka kiinnostunut olette ollut seksistä?	1	2	3	4
59. Onko teillä ollut kipua tai epämukavuutta yhdynnän aikana?	1	2	3	4

Appendix 5. EORTC QLQ–C30 (1/2)

EORTC QLQ-C30 (version 3.0.)

Selvitämme kyselyssämme joitakin teitä ja terveyttänne koskevia asioita. Pyydämme teitä vastaamaan itse kaikkiin kysymyksiin ympyröimällä parhaiten sopivan numeron. Tässä kyselyssä ei ole "oikeita" eikä "vääriä" vastauksia. Pidämme antamanne tiedot ehdottoman luottamuksellisina.

Täyttäkää tähän nimikirjaimenne:
Syntymäaika (päivä, kk, vuosi):
Kyselyn täyttöpäivä (päivä, kk, vuosi):

	Ei Lainkaan	**Vähän**	**Melko paljon**	**Hyvin paljon**
1. Tuntuvatko rasittavat työt kuten painavan ostoskassin tai matkalaukun kantaminen teistä työläältä?	1	2	3	4
2. Tuntuvatko pitkät kävelymatkat työläiltä?	1	2	3	4
3. Tuntuvatko lyhyet kävelymatkat kotinne ulkopuolella työläiltä?	1	2	3	4
4. Pitääkö teidän pysytellä levolla tai istumassa päivän mittaan?	1	2	3	4
5. Tarvitsetteko apua ruokaillessanne, pukeutuessanne, peseytyessänne tai WC:n käytössä?	1	2	3	4

Kuluneella viikolla:

6. Oliko teillä vaikeuksia suoriutua työstänne tai muista päivittäisistä toimistanne?	1	2	3	4
7. Oliko teillä rajoituksia harrastus- tai muissa vapaa-ajan toiminnoissanne?	1	2	3	4
8. Oliko teillä hengenahdistusta?	1	2	3	4
9. Oliko kipuja?	1	2	3	4
10. Tunsitteko levontarvetta?	1	2	3	4
11. Oliko unettomuutta?	1	2	3	4
12. Tunsitteko heikotusta?	1	2	3	4
13. Oliko ruokahaluttomuutta?	1	2	3	4
14. Oliko pahoinvointia?	1	2	3	4
15. Oksensitteko?	1	2	3	4

Jatkuu seuraavalle sivulle

Appendix 5. EORTC QLQ–C30 (2/2)

Kuluneella viikolla:

	Ei Lainkaan	**Vähän**	**Melko paljon**	**Hyvin paljon**
16. Oliko ummetusta?	1	2	3	4
17. Oliko ripulia?	1	2	3	4
18. Olitteko väsynyt?	1	2	3	4
19. Häiritsikö kipu päivittäisiä toimianne?	1	2	3	4
20. Oliko teillä keskittymisvaikeuksia esim. sanomalehteä lukiessanne tai televisiota katsellessanne?	1	2	3	4
21. Olitteko jännittynyt?	1	2	3	4
22. Olitteko huolestunut?	1	2	3	4
23. Olitteko ärtynyt?	1	2	3	4
24. Olitteko masentunut?	1	2	3	4
25. Oliko teidän vaikea muistaa asioita?	1	2	3	4
26. Häiritsikö hoito tai fyysinen kuntonne perhe-elämäänne?	1	2	3	4
27. Häiritsikö hoito tai fyysinen kuntonne sosiaalista kanssakäymistä?	1	2	3	4
28. Aiheuttaako fyysinen kuntonne tai hoito taloudellisia vaikeuksia?	1	2	3	4

Vastatkaa seuraaviin kysymyksiin ympyröimällä numerosarjasta 1-7 teihin parhaiten sopiva vaihtoehto

29. Millainen yleinen terveydentilanne oli kuluneella viikolla?

1	2	3	4	5	6	7
Erittäin huono						Erinomainen

30. Millainen yleinen elämänne laatu oli kuluneella viikolla?

1	2	3	4	5	6	7
Erittäin huono						Erinomainen