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*Quality of sexual life
and colorectal cancer
Towards a dyadic approach*

Marjan Traa

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Towards a
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M.J. Traa

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Contents

- 9 **Chapter 1**
Introduction and outline of the thesis
- 25 **Chapter 2**
Sexual (dys)function and the quality of sexual life in patients with colorectal cancer: a systematic review
- 73 **Chapter 3**
Higher prevalence of sexual dysfunction in colon and rectal cancer survivors compared with the normative population: a population-based study
- 95 **Chapter 4**
The preoperative sexual functioning and quality of sexual life in colorectal cancer: a study among patients and their partners
- 113 **Chapter 5**
Biopsychosocial predictors of sexual function and quality of sexual life: a study among patients with colorectal cancer
- 135 **Chapter 6**
Dyadic coping and relationship functioning in couples coping with cancer: a systematic review
- 179 **Chapter 7**
Sexual, marital, and general life adjustment in couples coping with colorectal cancer: a dyadic study across time
- 199 **Chapter 8**
Evaluating quality of life and response shift from a couple-based perspective: a study among patients with colorectal cancer and their partners
- 223 **Chapter 9**
The sexual health care needs after colorectal cancer: the view of patients, partners, and health care professionals
- 245 **Chapter 10**
General discussion
- Appendix**
- 267 Acknowledgements (in Dutch)
- 273 List of publications
- 277 About the author

CHAPTER 1

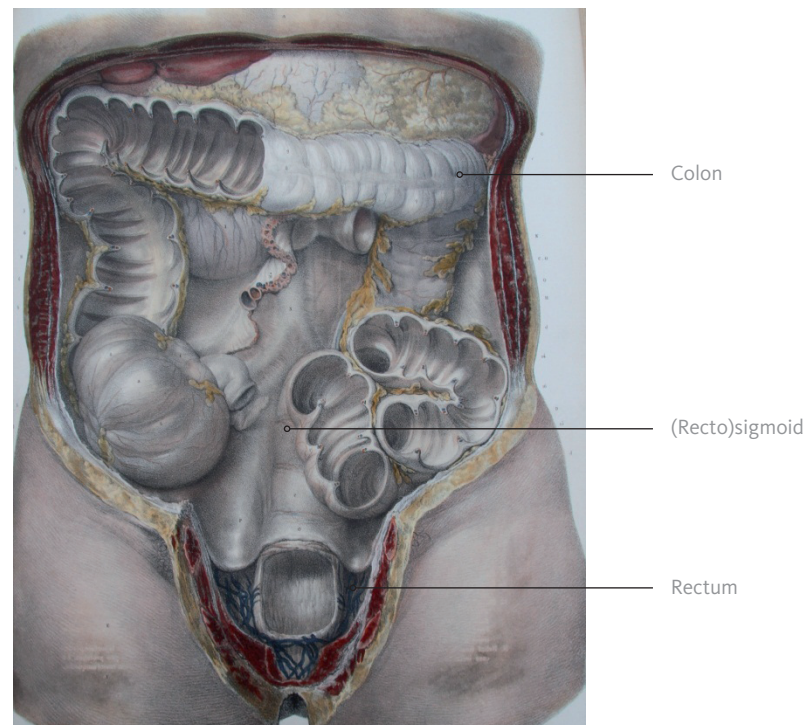
General introduction and outline of the dissertation



Colorectal cancer

Cancers located in the colon, (recto)sigmoid, or rectum are collectively known as colorectal cancer (see **Figure 1**). Colon cancer is situated in the large intestine (i.e., colon), the lower part of the digestive system. The colon starts where the small bowel ends. When stretched, the colon is 1.5 to 1.8 meters long. The rectum forms the final 10 to 15 centimeters of the large intestine and connects the colon to the anus. Cancer located in this last part is, therefore, known as rectal cancer. The (recto)sigmoid is the transitional zone between the colon and the rectum.

Figure 1 Early 19th century anatomical lithography demonstrating the colon, (recto)sigmoid, and rectum



Incidence and prevalence

In the Netherlands, colorectal cancer is the third most common cancer for both men and women.¹ About 13,000 new cases are diagnosed each year, of which approximately 30% are located in the rectum.^{1,2} The incidence of colorectal cancer is increasing.^{2,3} This rise is associated with an increasingly aging population. Currently, 75% of colorectal cancer patients are 65 years or older.⁴ Changes in lifestyle, such as dietary habits^{5,6}, smoking^{5,6}, and physical inactivity^{5,7}, are also associated with the increase in incidence. Simultaneously, the prevalence of colorectal cancer is growing rapidly. The rising prevalence is partly due to an increased five-year survival rate. Nowadays, approximately 65% of patients survive the first five years after diagnosis.⁸ In 2011 the Dutch government decided to implement a national population screening program for colorectal cancer.^{9,10} This screening program will be gradually introduced. In September 2013, a pilot has started in the south-west of the Netherlands.⁹ When the colorectal cancer screening program is nationally implemented a further growth in incidence and prevalence of colorectal cancer may be expected.

Colorectal cancer treatment

The multidisciplinary colorectal cancer treatment is mostly determined by the type, location, and extensiveness of the tumor. For colon cancer, neoadjuvant treatment is only considered if an irradical resection is to be expected.¹¹ Therefore, surgery is the first part of treatment for most patients with colon cancer. Surgery for colon cancer can be safely performed with a minimally invasive laparoscopic procedure.¹² As a result, the number of patients that are treated with laparoscopic surgery is increasing fast.¹³ Surgery is aimed at removing the tumor en bloc with the draining lymph node basin.¹⁴ If the tumor is located in the cecum, ascending colon, hepatic flexure or transverse colon, a right hemicolectomy, including a dissection of the mesenteric lymph nodes, is generally performed. Tumors located in the splenic flexure or the descending colon are treated with a left hemicolectomy and tumors located in the sigmoid colon are operated on with a sigmoid resection. In general, an anastomosis can be formed between the remaining parts of the colon in order to preserve a functioning colon.¹⁵ However, sometimes a temporary colostomy needs to be constructed.¹⁵ Finally, adjuvant chemotherapy is recommended if the tumor has spread to the lymph nodes and sometimes in high risk tumors without lymphatic spread.^{14,16-18} In contrast with colon cancer treatment, neoadjuvant therapies are often an important part of rectal cancer treatment. In rectal cancer, neoadjuvant therapies have the ability to change the tumor size and viability of the rectal tumor, which

increases the probability to perform a radical resection and sometimes even allows more limited surgery.¹⁹ Therefore, the Dutch national guidelines advice that only patients with a small, superficially growing, well or moderately differentiated tumor, without positive lymph nodes are not treated with neoadjuvant therapy.²⁰ Neoadjuvant short-term radiotherapy (5x5 Gray) is considered standard for resectable tumors with three or less involved lymph nodes but without an expected positive Circumferential Resection Margin (CRM).²⁰ For patients who are expected to have a positive CRM or four or more positive lymph nodes, long-term neoadjuvant radiotherapy (25x2 Gray) may be applied combined with chemotherapy.²⁰ Due to the challenging anatomy and location in the pelvic area (i.e., below the peritoneal fraction), complex surgical approaches are needed for rectal cancer. In line with colon cancer treatment, laparoscopic rectal cancer surgery is increasingly performed.^{12,13} The surgical approach is based on the location of the tumor in combination with the response to neoadjuvant treatment. If the tumor is small, superficially growing, and well or moderately differentiated than the tumor can be dissected with radical surgery or local excision, preferably using transanal endoscopic microsurgery.¹⁴ A (low) anterior resection, with preservation of the sphincter function, is performed for tumors located in the rectosigmoid or the upper or middle part of the rectum, provided that at least 4 to 5 centimeters of the mesorectum is removed distally from the tumor.¹⁹ For very low tumors (at the anorectal junction or below), an abdominoperineal resection is performed.¹⁹ In this procedure some parts of the pelvic floor muscles and external sphincter are removed en bloc with the rectum, hereby necessitating the formation of a permanent colostomy.^{19,21} In general, rectal cancer surgery that includes the autonomous nerve-sparing total mesorectal excision procedure offers the best oncologic results.^{14,19,22}

Quality of (sexual) life

Traditional oncological research focuses on developing treatments that increase overall and disease-free survival. For colorectal cancer, the introduction of the total mesorectal excision procedure in the early 1980's and the development of suitable (neo)adjuvant treatments are important contributions in this regard.^{14,19} Due to the increased life expectancy for patients with colorectal cancer, more awareness arose for the potential side-effects of treatments. Therefore, studies started to evaluate functional results after treatment, such as fecal incontinence, urinary function, and Sexual Function (SF).²³ In addition, the impact of colorectal cancer treatment on patients' Quality of Life (QoL) became a key outcome of interventions.²⁴ QoL is a multi-dimensional construct, incorporating at least physical, psychological, and social well-being.²⁵ Sexuality is considered central to a person's well-being and is, as such,

an important aspect of QoL.²⁶ However, sexuality itself is a broad concept which can mean different things to different people at different stages of their lives.²⁷ This is also reflected in the World Health Organization's definition of sexuality: "...a central aspect of being human throughout life encompasses sex, gender identities and roles, sexual orientation, eroticism, pleasure, intimacy and reproduction. Sexuality is experienced and expressed in thoughts, fantasies, desires, beliefs, attitudes, values, behaviours, practices, roles and relationships. While sexuality can include all of these dimensions, not all of them are always experienced or expressed. Sexuality is influenced by the interaction of biological, psychological, social, economic, political, cultural, legal, historical, religious and spiritual factors."²⁸ This definition establishes two important things. First, it shows that sexuality is more than sexual intercourse alone. Therefore, in this dissertation a distinction is made between sexual (dys)function and the Quality of Sexual Life (QoSL). SF refers to the normal performance standards of the sexual response cycle (i.e., desire, excitement, orgasm, and resolution).^{29,30} A sexual dysfunction is characterized by a disturbance in this sexual response cycle or by pain associated with intercourse.³¹ QoSL takes into account the person's subjective evaluation of his/her sexual life and, thus, concerns the extent to which someone is (dis)satisfied with their sexual life. Moreover, the definition of sexuality shows that sexuality can be influenced by different factors, which warrants the need to evaluate sexual (dys)function and QoSL from a biopsychosocial perspective.

A biopsychosocial approach

Several authors have emphasized that SF and QoSL may be best understood from an integrative biopsychosocial approach.^{29,30,32} Treatment-related factors (e.g., surgery-related autonomic nerve injury³³, temporary ileostomy or permanent colostomy³⁴⁻³⁶), demographic factors (e.g., age³⁷, sex³⁴), symptoms (e.g., fatigue³⁸), psychological issues (e.g., mood³⁹, body image⁴⁰), and social aspects (e.g., patients' and/or partners' relationship function³⁸) may have a mutual direct or indirect effect on SF and QoSL. Until now, the abovementioned factors have been mostly evaluated in separate studies. To our knowledge, only one cross-sectional study incorporated a biopsychosocial approach to evaluate the SF of patients with colorectal cancer. In this study, a higher age, having received an abdominoperineal resection, and poor social support were associated with low SF in men, while low SF in women was associated with higher age and a poor global QoL.³⁷ No study has yet evaluated QoSL from a biopsychosocial approach. Therefore, future prospective research examining SF and QoSL from a biopsychosocial perspective is warranted.

Stress-spillover

Stress-spillover may exist between QoSL, quality of the partner relationship, and QoL. QoSL can influence the quality of the partner relationship, while the quality of the partner relationship may influence quality of life. However, the reversed direction may also be true. In addition, QoSL can influence QoL and *vice versa*. Research evaluating stress-spillover between QoSL, the quality of the partner relationship, and QoL in patients with cancer is scarce. QoL was associated with the quality of the partner relationship in one study⁴¹ and with SF in another study³⁷. However, these cross-sectional studies do not allow making causal inferences. In addition, previous research has not yet evaluated all three aspects in one integrative model. Therefore, it remains interesting to prospectively evaluate the bidirectional influence of these three constructs on one another.

A dyadic perspective

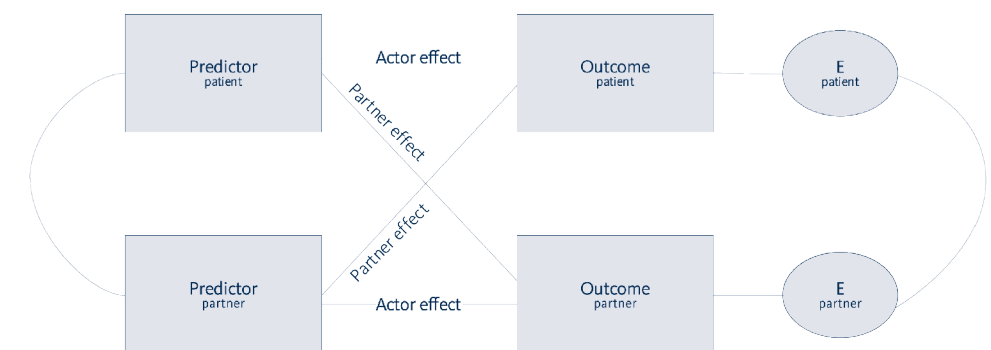
For a long time, cancer has been viewed as a disease that mainly affects patients. In this perspective, patient's individual stress demands patient's individual coping efforts. However, since the 1990's researchers have started to consider stress and coping as interpersonal processes.⁴²⁻⁴⁴ This interpersonal approach is well reflected in the definition 'dyadic stress'.⁴⁵ Dyadic stress implies that a stressful event or encounter concerns both partners directly or indirectly. Directly if both partners are confronted by the same stressor or when the stress originates inside the relationship and indirectly when the stress of one partner spills over to the relationship and in that way affects both partners. Cancer can be seen as a dyadic stressor since both partners have to incorporate ongoing cancer-related experiences and concerns into their daily lives. Therefore, an individualistic view, focused solely on patients, seems outdated. Instead, cancer may be best considered as a stressor concerning both partners simultaneously (i.e., cancer as a 'we-disease').⁴⁶ Several literature reviews have shown that a number of studies evaluated and reported interdependence between patients' and partners' psychosocial outcomes.^{47,48} This interdependence can be depicted in an Actor-Partner Interdependence Model (APIM, see **Figure 2**).⁴⁹ In this model, each person's score is an independent variable that can influence not only his/her own score on the outcome variable (Actor effect) but also the partner's score (Partner effect). Methodologically, this entails that the dyad should be the unit of analysis. The interdependence between patients and partners is also seen in the way patients and partners cope with dyadic stressors, such as cancer. Above and beyond individual coping, couples may engage in an additional form of stress management.^{50,51} This

form of coping is defined as dyadic coping and entails the attempt of one member of the dyad to help reduce stress perceived by the other member of the dyad and as a common endeavor to cope with stress that originates inside the relationship.⁴² However, as the field of dyadic research (e.g., dyadic stress, dyadic coping) is relatively new, few studies have incorporated a couple-based perspective (i.e., dyadic-perspective) to evaluate the consequences of colorectal cancer.⁵²⁻⁵⁴ While these studies showed that adequate dyadic coping is important in order to maintain a satisfying relationship, a dyadic approach to SF and QoSL has not yet been taken into account. Therefore, future research in this area is needed.

Studies in this thesis

The general aim of this dissertation was to evaluate the consequences of colorectal cancer on SF and quality of (sexual) life for patients and their partners. Data from three studies were used to achieve this goal.

Figure 2 Actor-Partner Interdependence Model



Note: E represents the unique residuals.

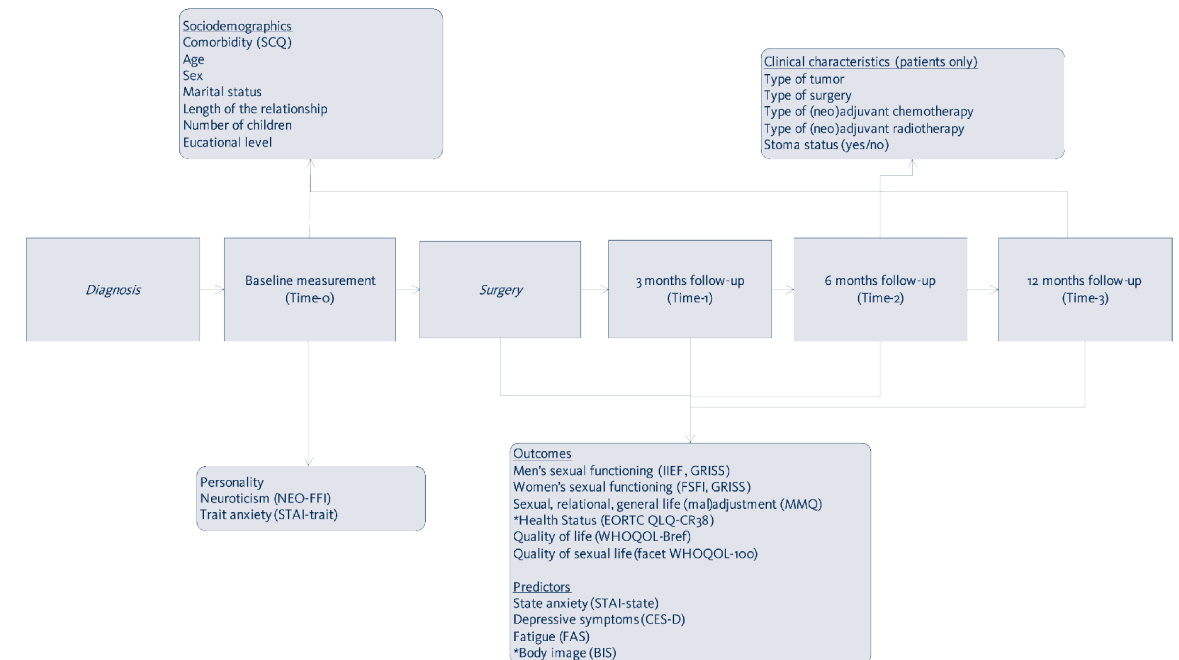
The (sexual) consequences of colorectal cancer for patients and partners

Data on the (sexual) consequences of colorectal cancer for patients and their partners was analyzed in **chapter 4,5,7, and 8**. Before surgical treatment, patients diagnosed with colorectal cancer and their partners were asked to participate. Patients were recruited between September 2010 and March 2014 from six Dutch hospitals: St. Elisabeth hospital (Tilburg), TweeSteden Hospital (Tilburg and Waalwijk), Catharina Hospital (Eindhoven), Jeroen Bosch Hospital ('s Hertogenbosch), Amphia Hospital (Breda), and Maxima Medical Centre (Eindhoven and Veldhoven). Patients and partners older than 18 years were eligible for participation. The following exclusion criteria were applied: (i) elderly age (older than 75 years), (ii) not curatively treated metastases at baseline, (iii) poor expression of the Dutch language, (iv) dementia, and/or (v) a history of psychiatric illness. When patients declined participation, the partners were still invited to participate (and *vice versa*) in order to prevent selection bias. If patients and/or their partners agreed to participate they were asked to complete a set of standardized surveys at home preoperatively (Time-0) and three (Time-1), six (Time-2) and 12 months (Time-3) postoperatively. A detailed overview of the study process is presented in **Figure 3**.

The sexual health care needs

Patients' and partners' sexual health care needs were evaluated qualitatively in **chapter 9**. For this study, participants were recruited from three Dutch hospitals: the St. Elisabeth Hospital (Tilburg), TweeSteden Hospital (Tilburg and Waalwijk), and Catharina Hospital (Eindhoven). Eligible participants had to be (i) diagnosed with colorectal cancer between January 2010 and February 2012 or be the partner of an eligible patient diagnosed with colorectal cancer within this time frame and (ii) aged between 18 and 75 years. Persons were excluded if they (i) had metastatic colorectal cancer or their partner had metastatic colorectal cancer, (ii) were physically not fit enough to attend the focus group, (iii) had a history of mental disease or cognitive problems, or (iv) had insufficient knowledge of the Dutch language. In order to ensure a wide variety of experiences to be represented, potential participants were informed that having sexual health care needs and/or being sexually active was not a prerequisite to participate. Patients and partners were selected based on their age, sex, and tumor type (if applicable) in order to attain a fair representation of the colorectal cancer patient population and their partners. To rule out selection bias, the partners were still invited to participate when patients declined participation and *vice versa*. A purposive sampling method was applied. In this study, the perspective of the health care professionals was also taken into account. Health care professionals were selected based on their level of expertise and working experience with the colorectal cancer patient population.

Figure 3 Overview of the study process



Abbreviations: BIS: Body Image scale, EORTC-QLQ-CR38: European Organization for Research and Treatment of Cancer Quality of Life Questionnaire disease specific ColoRectal 38, FAS: Fatigue Assessment Scale, FSFI: Female Sexual Function Index, GRISS: Golombok-Rust Inventory of Sexual Satisfaction, IIEF: International Index of Erectile Function, MMQ: Maudsley Marital Questionnaire, NEO-FFI: Neuroticism-Extraversion-Openness-Five Factor Inventory SCQ: Self-administered Comorbidity Questionnaire, STAI-state: Spielberger State Anxiety Inventory – state anxiety scale, STAI-trait: Spielberger State Anxiety Inventory – trait anxiety scale, WHOQOL-Bref: World Health Organization Quality of Life assessment abbreviated version, WHOQOL-100: WHOQOL-100 item version.

Note: *Only patients completed these questionnaires.

Comparison with a normative population

Data from the Eindhoven Cancer Registry (ECR), the Patient Reported Outcomes Following Initial treatment and Long term Evaluation of Survivorship registry (PROFILES), and the CentERdata panel were used in **chapter 3** to compare sexual (dys)function in colon and rectal cancer with sexual (dys)function in a normative population. The ECR records data of all newly diagnosed individuals with cancer in the southern part of the Netherlands.¹⁷ A weighted random selection of survivors based on tumor, sex, and year of diagnosis was made. Patients who had cognitive impairments were excluded. The normative sample was derived from CentERdata (an online household panel).¹⁸ An age-matched normative population, in which a similar distribution of ages as in the survivor sample was obtained, was used. A detailed description of the ECR⁵⁵, PROFILES⁵⁶, and CentERdata data⁵⁵ collection is described elsewhere.

Outline of the thesis

First, the literature was evaluated for the existing knowledge of sexual (dys)function and QoSL for patients with colorectal cancer (**Chapter 2**). The debate on whether or not sexual dysfunction in patients with colorectal cancer is normal (e.g., inherent to the often elderly age of patients) or pathological was addressed in **chapter 3**. Subsequently, insights in the preoperative SF and QoSL of patients and partners were obtained (**Chapter 4**). Biopsychosocial predictors of patients' SF and QoSL were evaluated in **chapter 5**. The association between dyadic coping and relationship functioning was systematically reviewed next (**Chapter 6**). In line with this dyadic perspective, a dyadic approach was used in **chapter 7** to evaluate how sexual (mal) adjustment, relational (mal)adjustment, and general life (mal)adjustment might spill-over between these three domains and between both members of the couple. While chapter 7 already incorporated general life (mal)adjustment, **chapter 8** focused on QoL trajectories for patients and partners and evaluated if patients and partners change their interpretation of QoL (e.g., response shift) as a consequence of the colorectal cancer diagnosis and treatment. Finally, in **chapter 9** the sexual health care needs of couples coping with colorectal cancer were examined qualitatively. In the general discussion the main findings of chapter 2 through chapter 9 are summarized and discussed and implications for research and clinical practice are presented (**Chapter 10**).

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Sexual (dys)function
and the quality of sexual
life in patients with
colorectal cancer:
a systematic review



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Abstract

Background

To determine (i) the prevalence of sexual (dys)function in patients with colorectal cancer and (ii) treatment-related and sociodemographic aspects in relation to sexual (dys)function and the quality of sexual life (QoSL). Recommendations for future studies are provided.

Method

A systematic search was conducted for the period January 1990 to July 2010 that used the databases PubMed, PsycINFO, the Cochrane Library, EMBASE, and OVID Medline.

Results

Eighty-two studies were included. The mean quality score was 7.2. The percentage of preoperatively potent men that experienced Sexual Dysfunction (SD) postoperatively varied from 5% to 88%. Approximately half of the women reported SD. Preoperative radiotherapy, a stoma, complications during or after surgery, and a higher age predicted more SD with a strong level of evidence. Type of surgery and a lower tumor location predicted more SD with a moderate level of evidence. Insufficient evidence existed for predictors of QoSL. Current studies mainly focused on biological aspects of sexual (dys)function. Furthermore, existing studies suffer from methodological shortcomings such as a cross-sectional design, a small sample size, and the use of non-standardized measurements.

Conclusion

Sexuality should be investigated prospectively from a biopsychosocial model, hereby including QoSL.

Background

Worldwide colorectal cancer is the third most common cancer in men (10%), after lung cancer (17%) and prostate cancer (14%) and the second most common cancer in women (9%) after breast cancer (22%) (www.globocan.iarc.fr). Despite improvements in the multimodality treatment of colorectal cancer, surgery remains the only treatment offering a chance of cure. For colon cancer, surgery is aimed at total resection of the tumor with adequate margins and lymphadenectomy (i.e., colectomy).¹ In general, the remaining parts of the colon are anastomosed together to create a functioning colon; however, sometimes a temporary colostomy may be constructed.² For rectal cancer, different surgical approaches are warranted. An Anterior Resection (AR), with preservation of the sphincter function, is carried out for tumors located in the middle or upper part of the rectum. For very low tumors an Abdominal Perineal Resection (APR) is carried out, hereby resecting the anal sphincter and forming a permanent colostomy.¹ In general, surgery that includes Total Mesorectal Excision (TME) offers the best results.³ Colon cancer can be safely treated by open or laparoscopic surgery⁴; however, laparoscopic rectal cancer surgery is in the experimental phase.⁵ Preoperative Radiation Therapy (PRT) or Preoperative Chemo Radiation Therapy (PCRT) leads to an additional reduction of local recurrence rates.^{6,7}

Although oncologic cure and overall survival are the main goals of treatment, functional results such as faecal incontinence, urinary function, and sexual function (SF) are also important. Furthermore, patient-reported outcomes, such as quality of life, are regarded as key measurements in assessing outcomes of interventions.⁸ Quality of life is a multi-dimensional construct, incorporating at least physical, psychological, and social well-being.⁹ Sexuality and intimacy are considered central to a person's well-being and are, as such, important aspects of quality of life.¹⁰ Poor SF and a lower sexual satisfaction are risk factors for a worse quality of life.¹¹ SF refers to the normal performance standards of the sexual response cycle¹², which consists of four phases; desire, excitement, orgasm, and resolution¹³. A Sexual Dysfunction (SD) is characterized by a disturbance in this sexual response cycle or by pain associated with intercourse.¹⁴ In line with the distinction between health status (i.e., the impact of disease on functioning) and quality of life (i.e., the subjective evaluation of this functioning)¹⁵⁻¹⁷, a similar distinction can be made between sexual (dys)function and the Quality of Sexual Life (QoSL). Sexual (dys)function refers mainly to the biological aspects of sexuality (e.g., "When you had sexual stimulation or intercourse, how often did you reach orgasm?"), while QoSL takes into account the person's subjective evaluation of his/her SF (e.g., "How satisfied were you with your ability to reach orgasm during sexual activity or intercourse?"). Several authors have emphasized the assessment of sexual (dys)function from a biopsychosocial perspective.^{12,18}

In this model, not only treatment-related aspects are important (e.g., the type of surgery and (neo)adjuvant treatments), but also psychosocial factors (e.g., mood, the partner relationship, and the subjective evaluation of the current functioning). These factors may have a direct or indirect effect on sexual (dys)function or QoSL. For instance, SF can not only be directly affected by surgical treatment¹⁹ or by PRT or PCRT²⁰⁻²², but can also be indirectly affected due to the potential loss of sphincter function, accompanied with a stoma^{20,23}.

Published research focussed on several aspects associated with sexual (dys)function in patients with colorectal cancer. To our knowledge, an overview of these studies has not yet been published. Knowledge of how colorectal cancer and its treatment affect patients will give health professionals opportunities to adequately support this patient group.

The objective of this systematic review was to provide an overview of studies that addressed sexual (dys)function and/or QoSL in colorectal cancer with regard to (i) the prevalence of sexual (dys)function and (ii) treatment-related and sociodemographic aspects in relation to sexual (dys)function and/or QoSL.

Methods

Search strategy

A search of the literature was performed in Pubmed (196 hits), Ovid Medline (328 hits), PsycINFO (7 hits), The Cochrane Library (67 hits), and Embase (534 hits). The databases were searched with combinations of colonic neoplasms, colon cancer*, colonic cancer*, rectal cancer*, colorectal cancer*, rectum cancer*, colon tumo*, colonic tumo*, rectal tumo*, colorectal tumo*, rectum tumo*, colon neoplas*, colonic neoplas*, rectal neoplas*, colorectal neoplas*, rectum neoplas*, and combinations of sexual behaviour, sexual behav*, sex behav*, sexual funct*, sex funct*, “sexual and gender disorders”, sexual disorder*, sex disorder*, sexual dysfunct*, sex dysfunct*, dyspareun*, erect*, coit*, “quality of sexual life”, “sexual quality of life”. The search was restricted to studies published from 1990 to July 2010 in English or Dutch journals. Only original reports were included. Subsequently, the reference lists of included studies were checked in order to identify studies which were not found in the computerized database searches.

Selection criteria

Studies that met the following criteria were included: (i) the studies investigated sexual (dys)function and/or QoSL as a primary or secondary objective, (ii) the study population exclusively concerned patients with colon and/or rectal cancer, (iii) sexual (dys)function and/or QoSL were measured by self-report or an interview, (iv) the studies were original full-reports published in English or Dutch, (v) studies were published in peer-reviewed journals, and (vi) studies reported on patient populations recruited after 1989 since in the past two decades substantial improvements in surgical techniques have taken place, such as the introduction of TME²⁴.

Data extraction

Combining the search results and removing duplicates resulted in 698 hits. Two authors (MJT and BLDO) applied the described inclusion criteria independently in a standardized manner. Disagreements between the two reviewers (<5%) were resolved in a consensus meeting. Altogether, 590 articles were excluded based on title and abstract. Hard copies were obtained of 108 studies, of which 81 met the selection criteria. With regard to multiple reports on the same study, only one article was included based on the highest quality score. If studies were of equal quality, only the most recent study was included. Six articles were excluded based on the multiple reports criterion. Through a hand search seven additional articles were found which met the selection criteria. Thus, a total of 82 articles remained. The flow chart of study selection is shown in **Figure 1**.

Quality assessment

The methodological quality of the selected studies was independently assessed by two reviewers (MJT and BLDO) using a criteria list (**Table 1**). This checklist was based on established criteria lists for systematic reviews, that have been previously published.^{25,26} The maximum attainable score is 15. If a criterion is not sufficiently fulfilled or not explicitly mentioned, a zero is scored. Studies scoring 70% or more of the maximum attainable score (i.e., ≥ 11 points) were considered to be of a ‘high quality’. Studies of a ‘moderate quality’ scored between 50% and 70%, while studies scoring lower than 50% (i.e., ≤ 7 points) were considered as ‘low quality’.

Levels of evidence

After the individual quality of the studies was assessed, the level of evidence was determined for predictors of SD and QoSL. Findings were considered consistent if $\geq 75\%$ of the studies that investigated a particular predictor showed the same direction of association. **Table 2** provides an overview of the four levels of evidence.

Figure 1. Study selection process

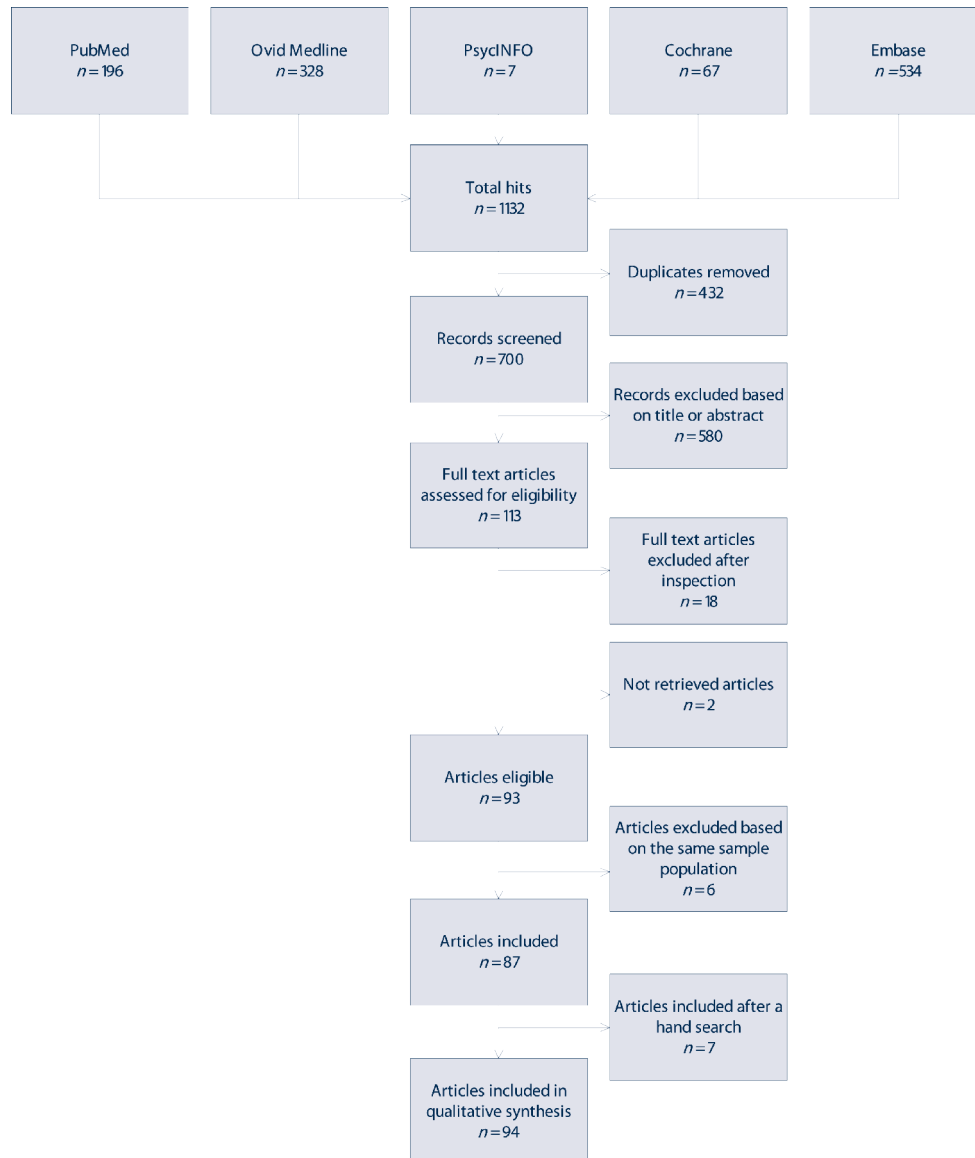


Table 1. List of criteria for assessing the methodological quality of studies on sexual (dys)function and/or QoSL in patients with colorectal cancer

Positive if	
Sexual (dys)function and/or QoSL assessment	
A.	a psychometrically sound questionnaire is used
B.	examining sexual (dys)function and/or QoSL was a primary objective of the study
Study population concerning sexual (dys)function and/or QoSL	
C.	examining both men and women
D.	description is included of at least two socio-demographic variables (e.g., age, sex, employment status, educational status, etc.)
E.	a description is present of at least two clinical variables (e.g., TNM or Dukes classification, type of surgery, tumor location etc.)
F.	inclusion and/or exclusion criteria are provided
G.	the study describes potential prognostic factors by using multivariate analyses or structural equation modelling
H.	participation rates for patient groups are described (defined as the percentage of eligible patients who gave their informed consent) and these rates are exceeding 75%
I.	the ratio non-responders versus responders is given (defined as the ratio of patients who withdrew their initial informed consent) including reasons for withdrawal
Study design concerning sexual (dys)function and/or QoSL	
J.	the study size is at least consisting of 75 patients (arbitrarily chosen)
K.	the collection of data is prospectively gathered with at least two assessment points
L.	the design is longitudinal (more than 1-year)
M.	the process of data collection is described (e.g., interview or self-report, etc.)
N.	the loss to follow-up is described and is less than < 20%
Results	
O.	the results are compared between two groups or more (e.g., healthy population, groups with different disease stages or treatment types)

Abbreviations: QoSL = Quality of Sexual Life, TNM = Tumor Nodes Metastasis.

Table 2. Levels of evidence

Level of evidence	Criteria
Strong	Consistent findings ($\geq 75\%$) in at least two high-quality studies <i>or</i> one high-quality study and at least three moderate studies
Moderate	Consistent findings ($\geq 75\%$) in one high-quality study and at least one low-quality study <i>or</i> at least three moderate studies
Weak	Findings of two moderate studies <i>or</i> consistent findings ($\geq 75\%$) in at least three <i>or</i> more low-quality studies
Inconclusive	Inconsistent findings irrespective of study quality, <i>or</i> less than three low-quality studies available

Data synthesis

The included studies investigated diverse outcomes (i.e., different phases and aspects of the sexual response cycle) in various patient populations, using different study designs. Therefore, a quantitative approach (i.e., a meta-analysis) was not possible. The information extracted from the individual reports is summarized in **Table 3, page 40**. As said, various biopsychosocial factors may have an effect on sexual (dys)function and QoSL. Unfortunately, most of the current studies focus on treatment related or sociodemographic aspects of sexual (dys)function hereby neglecting psychosocial factors that may influence sexual (dys)function and/or QoSL. In addition, in the current studies, it is difficult to identify the contribution of each aspect in the development of SD or changes in QoSL. In this review, the prevalence of SD is described for both men and women. Subsequently, treatment-related predictors and sociodemographic predictors of SD and QoSL are discussed. The main results of the prospective and cross-sectional studies are presented, which were specified for men and women when applicable

Results

Methodological quality

There was <5% disagreement between the two reviewers when scoring the articles. These disagreements were mainly due to differences in applying criterion I. The disagreements were solved through discussion in a consensus meeting. The quality scores ranged from 3 (low quality)²⁷⁻³¹ to 12 (high quality)^{20,32}. The mean quality score was 7.2 (range 3-12; standard deviation=2.2). Methodological shortcomings mainly concerned the following items: describing potential prognostic factors by using multivariate analyses or structural equation modelling (criterion G; 81%), participation rates for patient groups are described and these rates are exceeding 75% (criterion H; 73%), information is given about the ratio non-responders versus responders (criterion I; 95%), the design is longitudinal (criterion L; 82%), and the loss to follow-up is described and is < 20% (criterion N; 90%).

Study characteristics

Sample sizes ranged from 4³³ to 1437³⁴. In total, 39 (48%) studies investigated sexual (dys)function as a secondary objective (as part of clinical outcome studies, or as part of studies on health-related quality of life/health status).^{23,29,34-70} The majority of studies were cross-sectional, except for 36 (44%) studies.^{5,20,21,23,27,30-32,36,38,39,42,45,47,49,51,55,58,61,62,67,68,71-80} Of the prospective studies, seven studies failed to define the exact postoperative measurement point.^{31,49,72,74,77,81,82}

Six studies investigated the results of a randomized trial.^{20,36,38,45,47,67} The study duration ranged from three months^{30,55} up to five years²¹. Four studies used a healthy population as a control group^{33,43,64,74} and one study investigated both patients and their caregivers⁶⁵. Postoperative sexual (dys)function in men was investigated in 28 (34%) studies^{5,22,27,29-31,36,46,55,63,68,71-73,75-77,80,83-92}, seven (9%) studies investigated women^{21,28,33,93-96}, and 47 (57%) studies investigated both men and women^{20,23,32,34,35,37-45,47,49-54,56-62,64-67,69,70,74,78,79,81,82,97-103}. The results were mainly presented for sexually active patients; however, not all patients were sexually active or willing to answer questions concerning sexual (dys)function and/or QoSL.

Six different standardized self-report instruments were applied. The colorectal cancer specific European Organization for Research and Treatment of Cancer Quality of Life Questionnaire (EORTC QLQ-CR38)¹⁰⁴ was most used in 23 (28%) studies^{23,34,37,40-44,48,49,51-53,58,59,64-67,99}. Regarding sexual (dys)function and QoSL the EORTC QLQ-CR38 measures SF, Sexual Enjoyment, Male SF, and Female SF with five questions. For men, the International Index of Erectile Function (IIEF)¹⁰⁵ was most assessed in 13 (16%) studies^{5,22,46,67,69,71,74,75,77,87,98-100}. The IIEF is a 15-item questionnaire, which evaluates men's SF, including Erectile Function, Orgasmic Function, Sexual Function, Desire, Intercourse Satisfaction, and Overall Satisfaction. The most used female counterpart was the Female Sexual Function Index (FSFI)¹⁰⁶, which was used in three (4%) studies^{67,69,95,99}. The FSFI is a 19-item questionnaire addressing six domains of women's SF: Arousal, Lubrication, Orgasmic Function, Sexual Desire, Intercourse Satisfaction, and Sexual Pain.

Several studies used a combination of instruments; however, 43 (52%) studies used non-standardized assessments.^{20,21,27-32,38,39,45,47,50,54-57,61-63,68,70,73,76,78-83,85,86,88-94,96,97,101-103} One study investigated sexual (dys)function based on a single question: "Did your health status and/or treatment cause your sexual life to decline?".⁴⁷ Most studies described at least two demographic and clinical variables of interest. The most reported demographic variables were age and sex; frequently represented clinical variables were type of surgery, tumor-node-metastasis stage, distance of the tumor from the anal verge, and (neo)adjuvant therapies. Patients with rectal cancer were investigated in 66 (81%) studies^{5,20-22,27,29-32,35-55,58-63,71,72,74-81,83,85,87-89,91,93,96-100,102,103}, two (2%) studies concerned patients with colon cancer^{69,70}, and 14 (17%) studies investigated patients with colon or rectal cancer^{23,28,34,64-68,82,84,86,92,94,95}. Therefore, results presented will concern patients with rectal cancer unless explicitly mentioned.

The prevalence of sexual (dys)function in patients with colorectal cancer

Preoperatively, the percentage of sexually active men varied from 37%⁷⁹ to 79%²⁰ across studies. The percentage of preoperatively potent men that experienced SD postoperatively varied from 5%⁹⁸ to 88%⁸⁸. Compared with preoperative scores, a postoperative increase in erectile dysfunction^{5,20,27,30,72,73,79,80,82,98} and/or ejaculatory dysfunction^{20,22,30,55,79,80} was most reported. In addition, sexual desire decreased postoperative.^{5,22,77} The percentage preoperatively sexually active women ranged from 27%⁷⁹ to 78%⁶⁹. Women who were sexually active preoperatively remained sexually active postoperative.^{48,96} Women reported SD such as dyspareunia^{20,21,82} and vaginal dryness^{20,99}. Twelve months after treatment, sexual desire remained unchanged in women.⁴⁸ For both men and women, the prevalence's of sexual (dys)function found in cross-sectional studies did not deviate from the results of the above-mentioned prospective studies.

Treatment-related aspects in relation to sexual (dys)function

(P)RT predicted SD with a strong level of evidence.^{20-22,76,99} RT predicted less sexual activity in both men and women^{76,99} and erectile and orgasmic dysfunction in men⁷⁶. PRT predicted ejaculatory dysfunction in men^{20,76} and dyspareunia in women²¹. (P)RCT predicted erectile dysfunction²² and sexual desire⁷⁷ in men. Compared with scores before PRT, SD was higher at 12 months follow-up.^{20,51,72} Cross-sectional studies revealed the same direction of association; more sexual (dys)function was reported by patients who received PRT.^{53,54,90}

Having a stoma was a predictor of SD with a strong level of evidence.^{20,23} SD was more often present in patients with a stoma compared with patients without a stoma up to 24 months after surgery.^{20,23,64,87} Perioperative or postoperative complications predicted SD with a strong level of evidence.^{20,21,67} Excessive perioperative blood loss (>1500 ml) and anastomotic leakage predicted erectile dysfunction, while anastomotic leakage also predicted ejaculatory problems.²⁰ Patients with intra-abdominal sepsis had decreased ability to achieve arousal postoperatively.²¹ Conversion from laparoscopic to open surgery predicted postoperative SD in men.⁶⁷

Type of surgery predicted SD with a moderate level of evidence.^{21,22,67,97,99,102} Patients in a colonic resection group reported more sexual desire and sexual activity at three months follow-up compared with a rectal resection group, although levels were similar at six months.⁶⁷ Cross-sectional studies also found less SD after colonic versus rectal cancer surgery.^{66,95} In rectal cancer surgery, APR predicted less sexual activity⁹⁹, more erectile dysfunction in men⁹⁷, and more dyspareunia in women⁹⁷. Less SD was reported in patients who underwent

AR compared with patients who underwent APR up to 12 months after surgery.^{5,21,22,42,102} In concordance, cross-sectional studies ruled in favor of AR.^{35,52,53,97,99} Mixed results were found regarding laparoscopic versus open surgery for rectal cancer; some studies rule in favor of laparoscopic surgery^{85,98}, others for open surgery^{22,100}, and some remain inconclusive^{5,42}. Finally, Pelvic Autonomic Nerve Preservation (PANP) yielded good results in terms of sexual (dys)function^{69,71,78}. The degree of SD depended on the degree of PANP.⁷³ Cross-sectional studies confirm these results.^{63,83} A lower tumor location predicted SD with a moderate level of evidence.^{22,77,84} A lower distance between the tumor and the anal verge predicted erectile dysfunction^{22,77,84}, intercourse satisfaction⁷⁷, and orgasmic functioning⁷⁷. Inconclusive evidence was found for tumor stage⁷⁶ and time since surgery^{76,77}.

Sociodemographic aspects in relation to SD

An elderly age predicted SD with a strong level of evidence.^{20,21,76,77,81,97,99} Cross-sectional studies revealed a similar association.^{29,84,93,97,99,103,107} An increasing age predicted a loss of sexual activity^{20,21,76,81,97,99} and worse orgasmic functioning^{21,76,81}. For women, an increasing age predicted worse arousal, less dyspareunia, and less intercourse per month.²¹ For men, a higher age predicted lower sexual desire⁷⁷ and worse erectile functioning^{76,84}.

If being a man or women influences sexual (dys)function remains unclear. Women were found to be less sexually active.²⁰ Although both sexually active men and women suffered from SD, a trend revealed more SD in men compared with women up to 24 months after surgery.^{20,70}

Treatment-related and sociodemographic aspects in relation to QoSL

Insufficient evidence was found for the predictive value of treatment-related or sociodemographic factors on QoSL. Type of operation (APR versus AR or a transanal excision) and RT predicted a positive answer on the statement 'surgery made my sexual life worse'.⁹⁹ Limited changes were seen for sexual enjoyment in the first year after surgery.^{49,51,58} Patients in the colonic resection group reported more sexual enjoyment compared with patients in a rectal resection group.⁶⁷ Compared with healthy controls, patients with rectal cancer reported lower scores on sexual enjoyment.⁶⁴ A worse QoSL was found for patients with a stoma patients compared with patients without a stoma.⁶⁵

For men, sexual satisfaction decreased after surgery.^{5,39,77} Cross-sectional studies revealed the same association.^{75,86} At a median follow-up period of five years, 64% of men reported to be unsatisfied with their current SF.⁸⁸ Few studies have examined sexual satisfaction/experiences

in women. One qualitative study examined how women with permanent ostomies restructure their ideas of sexuality.⁹⁴ Some women did not present long-term challenges and were able to have intercourse with their husbands, while other women had to find other erotic activities, such as oral sex.⁹⁴ However, these women were thus able to maintain a sexual relationship. Other women chose not to be sexual active anymore due to their age or because they were unable to reconcile their own experience of disgust or the potential reactions of a sexual partner to their ostomy.⁹⁴ This study concluded that neither sexual nor intimate acts were essential to the well-being these women.⁹⁴ Sexual satisfaction was lower for patients with a stoma than for patients without a stoma in one study⁸⁶, but not in another one⁹³. No studies reported on the association between sociodemographic factors and QoSL.

Discussion

The objective of this systematic review was to provide an overview of studies that addressed sexual (dys)function and/or QoSL in colorectal cancer, with regard to (i) the prevalence of sexual (dys)function and (ii) treatment-related and sociodemographic aspects in relation to sexual (dys)function and QoSL.

This review included 82 studies. However, measuring sexual (dys)function and/or QoSL was a secondary objective in 39 (48%) studies. Since the selected studies differed regarding the targeted study population, study design, and outcome measures, definite conclusions regarding the prevalence of sexual (dys)function and clinical and sociodemographic factors associated with sexual (dys)function and QoSL cannot be made.

Methodologically, there is room for improvement. Approximately half of the studies were cross-sectional. In order to detect short-term and long-term effects it is necessary to use a prospective design with an assessment point prior to surgical treatment and measurement points up to at least one year postoperative. In addition, sample sizes of most studies were rather small. Besides, more data was collected for men, perhaps partially due to the fact that women were more reluctant to answer questions concerning sexuality.^{44,49,101} To draw meaningful conclusions on differences between men and women future large sample studies should focus on both sexes.

Furthermore, most studies used non-standardized measurements, which hampered comparisons across studies. Most studies measured sexual (dys)function and/or QoSL with a limited number of questions. Also, in several instruments (e.g., EORTC QLQ-CR38) questions are only completed if the person indicated to be sexually active. Furthermore, most

questionnaires did not provide definitions for the concepts used, such as 'sexual activity'. Some patients will interpret sexual activity as sexual intercourse, while others might feel that intimacy, touching, and kissing constitutes as sexual activity. It is therefore difficult to draw meaningful conclusions from the current data. In future studies, an explicit definition of the concept of interest is warranted. The selection of instruments should be based on systematic reasoning and will depend on how the objectives and the concepts of interest are conceptualized.²⁵ If the study objective is to measure sexual (dys)function after a colorectal cancer treatment, the use of more biomedical instruments (e.g., the FSFI for women, the IIEF for men, or physiological measurements) is satisfactory. If the objective is to describe the subjective evaluation of a patient's sexual (dys)function then instruments measuring QoSL are needed, such as the Golombok Rust Inventory of Sexual Satisfaction.¹⁰⁸ However, as pointed out by Arrington *et al.* (2004) the best way to measure SF remains uncertain.¹⁰⁹ To our knowledge there are still no questionnaires available which are suitable for both sexes of all sexual preferences in both healthy and cancer populations. In this perspective, qualitative methodologies may be a good starting point in order to examine the experience and meaning of sexuality.

The reviewed studies mostly evaluated sexual intercourse and/or the presence of a SD while other aspects of sexuality (e.g. oral sex, hugging or kissing, and QoSL) were often omitted. Moreover, having a SD may lead to a diminished QoSL, though this is not a necessity. Patients may have a SD (e.g., erectile dysfunction) without being bothered by it; in turn, they may also experience a diminished QoSL (e.g., due to a low body image) without having an apparent SD.¹² Furthermore, the current heteronormative vision of sexuality (i.e., the vision that sexual and marital relations are between a man and a woman) limits the way we think about sexuality and/or capturing its experience and meaning. For instance, the current questionnaires assessing sexuality can only be filled in by persons in a heterosexual relationship (e.g., "Do you find your vagina is so tight that your partner's penis can't enter it?" for women and "How often were you able to penetrate (enter) your partner?" for men). In addition, sexuality should be seen from a biopsychosocial perspective, hereby taken into account QoSL. Moreover, the relationship between psychosocial factors (e.g., self-esteem, body image, fatigue, loss of independence, depressive symptoms, personality characteristics, and the partners' feelings about the patients' disease or appearance) and sexual (dys)function and/or QoSL in patients with colorectal cancer should be investigated more extensively. Also, though patients with colon cancer may have better functional results, it can be expected that they suffer from psychosocial problems to the same extent as patients with rectal cancer.

Additionally, little is known on how partners of patients with colorectal cancer cope with

the changed situation and on the interaction between partners and patients, even though it is known that a SD and the lack of affection are some of the most commonly identified marital problems in couples with an ill partner.¹¹⁰ In addition, it would be interesting to investigate if there are non-sexual forms of intimacy which may replace sexual activity but still enable a couple to experience companionship and maintain a satisfactory relationship. Relationship satisfaction is an important aspect of psychological well-being and thus quality of life. A diminished marital satisfaction may therefore diminish quality of life. Overall, knowledge on these topics is a prerequisite for providing adequate support for patients with colorectal cancer and their partners.

Finally, colorectal cancer is a disease which mostly affects the elderly. There has been an on going debate on whether or not SD in a higher age is normal or pathological.¹¹¹ A recent cross-sectional study reported lower SF for patients with colorectal cancer compared with an age-matched general population.¹¹² This may indicate that colorectal cancer causes an additional negative effect on SF. Future research should investigate the effect of sociodemographic variables, such as age and sex, more extensively. There is an important task for researchers to provide more information on the potential effects of a colorectal cancer diagnosis and/or the effects of treatment to health care professionals so they in turn can inform patients on the possible outcomes of multimodality treatment. Information about the nature of treatment, including the side effects (both biological and psychosocial) that can occur, provides patients the opportunity to include sexual issues in the decision-making process.¹¹³ However, only 1 out of 10 patients remembered discussing sexual effects of treatment prior to surgery.⁹⁹ If the health care professional initiates such a discussion this may act in an empowering way to give license to patients to discuss these issues.

Conclusion

Most studies on sexual (dys)function following colorectal cancer surgery suffer from methodological problems, such as a cross-sectional design, a small sample size, and the use of non-standardized measurements. In future research, sexuality should be investigated prospectively from a biopsychosocial model. In this biopsychosocial model the subjective evaluation of sexual (dys)function, hence QoSL, and psychological factors associated with or predictive of sexual (dys)function and QoSL should be taken into account.

Table 3. Overview on studies assessing sexual (dys)function and/or QoSL in patients with colorectal cancer

Author	Site	Sex	Study population*	Design*	FU time*	A	B	C	D	E	F	G	H	I	J	K	L	M	N	O	Questionnaire used*	General conclusions*	
Bruheim <i>et al.</i> 2010 ⁹³	RC	♀	RT for rectal cancer (n=172)	CS		-	+	-	-	+	+	+	-	-	+	-	+	+	7	NS	Sexual interest was equally impaired in the RT+ compared with the RT- group. RT+ women reported more vaginal dryness, dyspareunia, and reduced vaginal dimension, they did not have more worries about their sex life.		
Celentano <i>et al.</i> 2010 ⁷¹	RC	♂	Rectal cancer (n=20)	P	24	+	+	-	-	+	+	-	-	-	-	+	+	+	-	-	7	IIEF	Erectile function was not different at 2 year follow-up. In the group with no nerve damage 13% developed erectile dysfunction. All patients in which nerve preservation was not possible developed erectile dysfunction.
Kasperek <i>et al.</i> 2010 ³⁵	RC	♀♂	Coloanal anastomosis (n=85) versus APR (n=83)	CS		+	-	+	+	+	-	-	-	-	+	-	+	+	7	EORTC QLQ-CR38	SF scores in men and women were lower for APR patients compared with patients with a coloanal anastomosis.		
Song <i>et al.</i> 2010 ⁷²	RC	♂	PRT with surgery (n=73) versus surgery alone (n=39)	P	18 (12-24)	+	+	-	-	+	+	-	-	-	+	+	+	-	+	9	IIEF-5	In both groups the total IIEF-5 score decreased postoperatively, the decline was worse for the PRT+ group compared with the surgery alone group. For the PRT+ group, APR and a lower cancer resulted in a lower total score compared with LAR and upper rectal cancer groups.	
Stephens <i>et al.</i> 2010 ³⁶	RC	♂	PRT versus PCRT (n=353)	RCT	36	+	-	-	-	+	+	-	-	-	+	+	+	-	+	8	EORTC QLQ-CR38	Male SD increased from 6 to 24 months postoperative, which was larger for the PRT group compared with the PCRT group.	
Akasu <i>et al.</i> 2009 ⁷³	RC	♂	TME with or without PANP and ELD (n=55)	P	12	-	+	-	-	+	-	-	-	-	+	-	+	-	+	5	NS	The degree of erectile function at one year follow-up depended on the extent of both PANP and ELD.	
Asoglu <i>et al.</i> 2009 ⁹⁸	RC	♀♂	LTME versus TME (n=63)	CS		+	+	+	+	+	+	-	-	-	-	-	+	-	7	IIEF	Preoperatively 92% of women and 95% of men were sexually active. Overall SD was higher in LTME versus TME with regard to the ability to ejaculate for men and with regard to vaginal secretion and dyspareunia for women. Both men and women had a reduced ability to achieve orgasm.		
Bloemen <i>et al.</i> 2009 ³⁷	RC	♀♂	Stoma (n=51) versus non-stoma (n=70)	CS		+	-	+	+	+	+	-	-	-	+	-	+	-	+	8	EORTC QLQ-CR38	The men had a higher median score on sexual problems and a lower median score on SF. Only 33% of women answered questions regarding SF.	
Ellis <i>et al.</i> 2009 ⁸⁴	CRC	♂	Above versus below the recto-sigmoid junction (n=229)	CS		+	+	-	+	+	+	+	-	-	+	-	+	-	+	9	IIEF-5	One third was sexually active in the past 6 months. Erectile problems were reported by 75%. Erectile dysfunction was associated with increased age, having a malignancy below the recto-sigmoid junction, radiotherapy, and having a stoma.	

Author	Site	Sex	Study population*	Design*	FU time*	A	B	C	D	E	F	G	H	I	J	K	L	M	N	O	Questionnaire used*	General conclusions*	
Jones <i>et al.</i> 2009 ⁸⁵	RC	♂	LTME (n=101)	CS		-	+	-	-	+	+	-	-	-	+	-	-	-	-	-	4	NS	SD was present in 11% in the APR group versus 5% in the (ultra)LAR group. Few men experienced retrograde ejaculation (n=4) or erectile dysfunction (n=2).
Lange <i>et al.</i> 2009 ²⁰	RC	♀♂	TME with or without PRT (n=757)	RCT	24	-	+	+	+	+	+	+	-	-	+	+	+	+	+	+	12	NS	Of men, >70% reported an increased general SD, erectile dysfunction, and ejaculatory problems. Risk factors were nerve damage, blood loss, anastomotic leakage, PRT, and the presence of a stoma. Women also reported SD (62%), i.e., dyspareunia and vaginal dryness. SD in women was associated with PRT and the presence of a stoma.
Morino <i>et al.</i> 2009 ²²	RC	♂	LTME (n=45)	CS		+	+	-	-	+	+	+	-	-	-	-	+	+	+	+	8	IIEF	Sexual desire was maintained by 56% of men. The ability to engage in intercourse was maintained by 58%. Ejaculation and orgasm were maintained by 37%. Distance of the tumor from the anal verge and (neo)adjuvant treatments were predicted poor postoperative SF.
Parc <i>et al.</i> 2009 ³⁸	RC	♀♂	AR with or without PRT (n=297)	RCT	24	-	-	+	-	+	+	-	+	+	+	+	+	-	+	+	10	NS	PRT+ men had worse SF compared PRT- men at 24 months follow-up. No significant differences were observed for women.
Pietrangeli <i>et al.</i> 2009 ⁷⁴	RC	♀♂	LAR with PANP (n=57) versus preoperative patients (n=67)	P	?	+	+	+	+	-	+	-	-	-	-	+	+	+	+	+	9	IIEF	SD was reported by 60% of patients. Impotence after chemoradiation was reported by 1/10 patients.
Ramirez <i>et al.</i> 2009 ⁹⁴	CRC	♀	Ostomy group (n=30)	CS		-	+	-	+	-	+	-	-	-	-	-	+	-	-	-	4	NS	Three women reported that sexual intercourse was no longer important to maintain a harmonious marital relationship. Seven women experienced long term sexual difficulties (e.g., painful intercourse or inability to have intercourse).
Stamopoulos <i>et al.</i> 2009 ⁵	RC	♂	TME versus LTME (n=56)	P	12	-	+	-	-	+	+	-	-	-	-	+	-	-	-	+	5	IIEF	The groups did not differ regarding SF. For the total group, sexual desire, erectile function, and the ability to achieve orgasm was worse at 12 months. Sexual desire was better at baseline, 3, and 6 months for the LAR group versus the APR group.

Author	Site	Sex	Study population*	Design*	FU time*	A	B	C	D	E	F	G	H	I	J	K	L	M	N	O	Questionnaire used*	General conclusions*	
Tekkis <i>et al.</i> 2009 ²¹	RC	♀	AR versus APR (n=295)	P	60	-	+	-	-	+	+	+	-	-	+	+	-	+	-	+	8	NS	The APR group had worse results: At one year follow-up they were less sexually active. Those who were active had a lower frequency of intercourse, which improved over time. At 8 and 12 months they were less likely to achieve arousal. Dyspareunia increased during the four years follow-up. At 8 months they were less likely to achieve orgasm, which improved over time. For the AR group dyspareunia became worse after 5 years. APR, PRT, intra-abdominal sepsis, and age ≥65 years were associated with significant impairments in female SF.
Trninic <i>et al.</i> 2009 ⁶⁴	CRC	♀♂	Stoma (n=25), versus no stoma (n=29), and healthy controls (n=30)	CS		+	-	+	+	-	+	-	+	-	+	-	+	-	+	8	EORTC QLQ-CR38	Sexual enjoyment was less in the colostomy and the non-colostomy group compared with the healthy population. Female SD was worse in the stoma group compared with the healthy population.	
Varpe <i>et al.</i> 2009 ³⁹	RC	♀♂	Rectal cancer (n=56)	P	12	-	-	+	+	+	-	-	-	-	+	-	+	-	+	6	NS	SD did not cause a significant worsening of quality of life. Of men, 67% reported satisfactory preoperative sex life, compared with 37% postoperatively.	
Bohm <i>et al.</i> 2008 ⁹⁵	CRC	♀	TME (n=6) versus colonic resection (n=6)	CS		+	+	-	-	+	+	-	-	-	-	-	+	-	+	6	FSFI	The TME group reported worse arousal and lubrication.	
Breukink <i>et al.</i> 2008 ³³	RC	♀	PRT and TME (n=4) versus controls (n=18)	CS		-	+	-	-	+	-	-	-	-	-	-	+	-	+	4	QSD	The changes in genital and subjective sexual excitement after erotic stimuli between female patients and healthy controls were not statistically different.	
Breukink <i>et al.</i> 2008 ⁷⁵	RC	♂	LTME (n=9)	P	15	+	+	-	-	+	+	-	-	-	+	+	+	-	+	8	IIEF	Intercourse satisfaction was the only IIEF domain which decreased significantly postoperative.	
Cotrim <i>et al.</i> 2008 ⁶⁵	CRC	♀♂	Patients (n=153) versus caregivers (n=69).	CS		+	-	+	+	+	+	-	-	-	+	-	+	-	+	8	EORTC QLQ-CR38, ISS	Only sexual satisfaction was lower for patients with a stoma than patients without a stoma.	
Di Fabio <i>et al.</i> 2008 ⁶⁶	CRC	♀♂	CRC group (n=62)	CS		+	-	+	+	+	+	-	+	-	-	-	+	-	+	8	EORTC QLQ-CR38	Of patients with colon cancer 61% reported 'no sexual problems' versus 24% of those with rectal cancer.	
Gervaz <i>et al.</i> 2008 ⁴⁰	RC	♀♂	APR (n=20)	P	12	+	-	+	+	+	+	-	-	-	+	-	+	-	+	8	EORTC QLQ-CR38	Twelve months after surgery no improvements in SF were found.	
Liang <i>et al.</i> 2008 ⁶⁹	CC	♀♂	Sigmoid cancer treated with laparoscopic PANP (n=86)	P	6	+	-	+	+	+	+	-	-	-	+	-	+	-	+	9	IIEF, FSFI	No significant changes before and after PANP were found regarding SF in both men and women.	

Author	Site	Sex	Study population*	Design*	FU time*	A	B	C	D	E	F	G	H	I	J	K	L	M	N	O	Questionnaire used*	General conclusions*	
Nitori <i>et al.</i> 2008 ⁸⁶	CRC	♂	TME (n=39) versus LTME (n=29)	CS		-	+	-	-	+	+	-	-	-	-	-	+	-	+	5	NS	Arousal, erectile function, ejaculation, and satisfaction decreased both after LTME and TME, but there were no differences between groups in terms of change. The only significant factor affecting SF was tumor location.	
Perera <i>et al.</i> 2008 ⁸²	CRC	♀♂	Rectal dissection versus segmental colectomy (n=48)	P	37 (17-4)	-	+	+	+	-	+	-	-	-	-	+	+	+	-	+	8	NS	Compared with women, men reported more SD. In men, 50% reported erectile dysfunction after rectal excision, compared with 33% in the colectomy group. In women, 6% reported dyspareunia and 19% reported reduced orgasm after rectal excision compared with none of the patients having had a colectomy.
Phipps <i>et al.</i> 2008 ⁷⁰	CC	♀♂	Long-term survivors (n=20)	CS		+	-	+	+	+	+	+	-	-	-	-	+	-	+	8	NS	Of survivors, 67% attributed their problems with SF to having had colon cancer. Of those problems attributed to colon cancer, SF was given one of the highest severity rankings by survivors.	
Segalla <i>et al.</i> 2008 ³⁴	CRC	♀♂	Patients treated with capecitabine (n=1437)	P	?	+	-	+	+	-	+	+	+	-	+	-	-	-	-	9	EORTC QLQ-CR38	Women's perception of sexual enjoyment worsened during follow-up. For men, worsening of their perception of SF and sexual enjoyment was observed.	
Zajac <i>et al.</i> 2008 ⁴¹	RC	♀♂	Stoma patients (n=50)	CS		+	-	+	+	-	-	-	-	-	-	-	+	-	-	4	EORTC QLQ-CR38	A negative influence of stoma on SF in men was reported. In women SD was significantly less expressed.	
Breukink <i>et al.</i> 2007 ⁴²	RC	♀♂	LTME and LAR (n=38) versus LTME and APR (n=13)	P	12	+	-	+	+	+	+	-	+	-	+	-	+	-	+	9	EORTC QLQ-CR38	SF, male and female SD were worse from 3 months until 12 months after surgery. Postoperative sexual enjoyment was the worst at 3 months and the best at 6 months follow-up. Patients who underwent LAR experienced less SD than patients after APR.	
Doornebosch <i>et al.</i> 2007 ⁴³	RC	♀♂	TEM (n=31), versus TME (n=31), and healthy controls (n=31)	CS		+	-	+	+	+	+	-	+	-	-	-	+	-	+	8	EORTC QLQ-CR38	Between TEM and TME no significant differences were found for SF, sexual satisfaction, male and female SD.	
Farroni <i>et al.</i> 2007 ⁴⁴	RC	♀♂	Perineal colostomy + appendicostomy (n=13) versus abdominal colostomy (n=14)	CS		+	-	+	+	-	+	-	+	-	-	-	+	-	+	7	EORTC QLQ-CR38	Patients with abdominal colostomy or a perineal colostomy with appedictostomy did not differ on SF, sexual enjoyment, and male SD. Females did not answer questions concerning female SD.	

Author	Site	Sex	Study population*	Design*	FU time*	A	B	C	D	E	F	G	H	I	J	K	L	M	N	O	Questionnaire used*	General conclusions*
Fazio <i>et al.</i> 2007 ⁴⁵	RC	♀♂	Coloanal anastomosis with or without a reservoir (n=297)	P	24	-	-	+	+	+	+	-	+	+	+	+	+	-	+	11	NS	Compared with baseline, male SF declined in both groups with low scores at 24 months. At 12 and 24 months more women were sexually active in the Colooplasty compared with the J-Pouch group.
Kneist <i>et al.</i> 2007 ⁴⁶	RC	♂	ANP + TME (n=26)	CS		+	-	-	-	+	+	-	-	-	-	-	+	-	+	5	IIEF	Postoperative erectile dysfunction (27%) was associated with micturition disturbance in 57%. Men with negative results on intraoperative neurostimulation or early urinary dysfunction are at greater risk.
Pietrzak <i>et al.</i> 2007 ⁴⁷	RC	♀♂	PRT (n=58), versus PCRT (n= 60)	RCT	7	-	-	+	+	+	-	-	-	+	+	+	-	+	+	8	NS	SF did not differ between patients receiving PRT and those receiving PCRT. However, patients indicated that their treatment worsened their SF.
Pocard <i>et al.</i> 2007 ⁴⁸	RC	♀♂	RC with coloanal anastomosis (n=38) versus perineal colostomy (n=12)	CS		+	-	+	-	+	+	-	-	-	-	-	+	-	+	6	EORTC QLQ-CR38	Patients with coloanal anastomosis reported equivalent results with regard to SF, sexual enjoyment, and male and female SD compared with patients with a perineal colostomy.
Ross <i>et al.</i> 2007 ²³	CRC	♀♂	Stoma (n=83) versus non-stoma (n=163) patients	P	24	+	-	+	+	+	+	+	-	-	+	+	+	-	+	11	EORTC QLQ-CR38	Only male SD was significantly worse for men with a stoma compared with men without a stoma. Having a stoma formed during follow-up was associated with the worst SF.
Arraras Urdaniz <i>et al.</i> 2006 ⁴⁹	RC	♀♂	Preoperative chemotherapy (n=81)	P	?	+	-	-	+	+	+	-	+	-	+	-	-	-	-	8	EORTC QLQ-CR38	Of patients, 63% reported to have no sexual desire nor had sexual activity 4 weeks previous to treatment. Moderate limitations were seen for SF and sexual enjoyment. None of the women answered questions regarding female SD. Male SD increased during the follow-up period.
Col <i>et al.</i> 2006 ⁸⁷	RC	♂	Resection (n=78) versus resection + ELD (n=13)	CS		+	+	-	-	+	+	-	-	-	+	-	+	-	+	7	IIEF	All IIEF domains decreased after surgical treatment. No differences were found between the treatment groups. Patients with a colostomy reported worse scores on all IIEF domains compared with patients without a colostomy.
Daniels <i>et al.</i> 2006 ⁹⁶	RC	♀	TME (n = 18)	CS		-	+	-	-	+	-	-	+	-	-	-	+	-	+	5	NS	Preoperatively, 28% of women were sexually active. Postoperatively these women remained sexually active, although all described some discomfort with penetration. Two women described that their sexual desire was reduced due to the presence of a stoma.

Author	Site	Sex	Study population*	Design*	FU time*	A	B	C	D	E	F	G	H	I	J	K	L	M	N	O	Questionnaire used*	General conclusions*	
Kyo <i>et al.</i> 2006 ²⁹	RC	♂	PANP with ELD (n=37)	CS		-	-	-	-	+	-	-	-	-	-	-	-	+	-	+	3	NS	Among sexually active men 90% with ELD and 50% without ELD maintained sexual activity, ejaculation was maintained by 90% and 70% respectively. Reduced sexual satisfaction was reported by 50% of patients who underwent LAR or Hartman procedure without LND and all patients with APR or LND.
Vironen <i>et al.</i> 2006 ⁵⁰	RC	♀♂	HAR (n=15), versus LAR (n=39) or APR (n=28)	CS		-	-	+	+	+	-	+	+	-	+	-	+	-	+	8	NS	SD was more common after APR than after LAR or HAR. Overall, 63% of men and 50% women who had been sexually active before surgery reported changes in SF.	
Ameda <i>et al.</i> 2005 ⁸⁸	RC	♂	AR (n=15) versus APR (n=13)	CS		-	+	-	+	+	-	-	+	-	-	-	-	-	+	5	NS	Of men, 88% had some deterioration in erectile function, regardless of surgical treatment. Overall, 64% of men were unsatisfied with their current SF.	
Allal <i>et al.</i> 2005 ⁵¹	RC	♀♂	PRT and surgery for LARC (n=53)	P	12	+	-	+	+	+	+	-	+	-	-	+	+	+	+	11	EORTC QLQ-CR38	Only male SD increased postoperative, to a similar degree in patients with and without a stoma.	
Gosselink <i>et al.</i> 2005 ⁵²	RC	♀♂	APR (n=51) versus LRA (n=71) versus CPA (n=45)	CS		+	-	+	+	+	+	-	+	-	-	+	-	+	+	9	EORTC QLQ-CR38	Less SD was seen after a colo-anal J-pouch anastomosis (CPA) compared with a low colorectal anastomosis (LRA) and APR. Retrograde ejaculation occurred in 10% of men, and impotence in 22%. Women reported dyspareunia in 12%.	
Guren <i>et al.</i> 2005 ⁵³	RC	♀♂	AR (n=229) or APR (n=90)	CS		+	-	+	+	+	+	-	+	-	-	+	-	+	+	9	EORTC QLQ-CR38	Only male SD increased after APR compared with AR or AR, 84% reported to have been sexually active the last 4 weeks compared with 26% of APR patients.	
Hendren <i>et al.</i> 2005 ⁹⁹	RC	♀♂	Curative surgery (n=180)	CS		+	+	+	+	+	+	+	+	-	-	+	-	+	+	11	FSFI, IIEF, EORTC QLQ-CR38	Surgical treatment deteriorated SF. Of women, 61% had a total score more than 1 SD below the normal population. 67% of men had an abnormal total IIEF score. Current age, surgical procedure, and preoperative sexual activity were independently associated with current sexual activity. Sex, surgical procedure, and RT were associated with a deteriorated SF.	
Heriot <i>et al.</i> 2005 ⁷⁶	RC	♂	PRT+ (n=101) versus PRT- (n=100)	P	48	-	+	-	-	+	+	+	-	-	+	-	-	+	+	8	NS	The patient's age, adjuvant RT, T-stage, and time of measurement predicted SF. A significant variability in SF was present among the 7 time points with a maximal deterioration at 8 months.	

Author	Site	Sex	Study population*	Design*	FU time*	A	B	C	D	E	F	G	H	I	J	K	L	M	N	O	Questionnaire used*	General conclusions*	
Jayne <i>et al.</i> 2005 ⁶⁷	CRC	♀♂	Laparoscopic rectal (n=98), open rectal (n=50), laparoscopic colonic (n=99)	RCT	18	+	-	+	+	+	+	+	-	-	+	+	+	+	-	+	11	FSFI, IIEF, EORTC QLQ-CR38	No significant differences were found on the IIEF and the FSFI domain scores between the laparoscopic versus open rectal surgery. Male SD was predicted by TME and conversion to open surgery.
Prabhudesai <i>et al.</i> 2005 ⁵⁴	RC	♀♂	PRT + TME (n=20) versus TME alone (n=10)	CS		+	-	+	+	+	+	-	-	-	-	-	+	-	+	7	NS	Patients who received PRT with TME had a higher male SD compared with the TME alone group. Female SD was not statistically different between the two treatment groups.	
Schmidt <i>et al.</i> 2005 ³²	RC	♀♂	APR, AR +/- Pouch and sigmoid resection (n=495)	P	24	+	+	+	+	+	+	-	-	+	+	+	+	-	+	12	NS	APR and AR with Pouch affected SF more than AR and resection of the lower sigmoid. Men scored lower on sexual enjoyment than women. Patients aged ≤ 69 years experienced more stress through deterioration in SF than older patients.	
Sterk <i>et al.</i> 2005 ³⁰	RC	♂	TME (n=29)	P	3	-	+	-	+	-	-	-	-	-	-	+	-	-	-	3	NS	Of the preoperatively potent men, 30% had SD postoperatively. No associations were found between postoperative impotence (n=8) and the age of patients at the time of surgery. Two men reported retrograde ejaculation.	
Platell <i>et al.</i> 2004 ²⁸	CRC	♀	RC (n=22) versus CC (n=19)	CS		-	+	-	-	-	+	-	-	-	-	-	-	-	+	3	NS	The rectal cancer group experienced more SD compared with the colonic surgery control group. They felt that their vagina was too short or less elastic and experienced more pain or fecal soiling during intercourse.	
Shirouzu <i>et al.</i> 2004 ⁵⁵	RC	♂	TME + PANP (n=49) versus TME (n=80)	P	3	-	-	-	-	+	+	-	-	-	+	+	-	+	+	7	NS	After TME with PANP the majority of men preserved erectile and ejaculatory functions (79% and 65%, respectively). Permanent damage was seen after TME without PANP.	
Maeda <i>et al.</i> 2003 ⁸⁹	RC	♂	TME (n=5) versus TME + ELD (n=37)	CS		-	+	-	-	+	+	-	-	-	-	-	+	-	+	5	NS	Of the preoperative sexually active men 27% in the TME + ELD group and 20% in the TME alone group had partial or total impotency after surgery. Retrograde ejaculation occurred in 11% and 25%, respectively.	
Bonnel <i>et al.</i> 2002 ⁹⁰	RC	♂	AR + TME with PRT (n=15) or without PRT (n=24)	CS		-	+	-	-	+	+	-	-	-	-	-	+	-	+	5	NS	Preoperatively sexually active men who received PRT were less sexually active postoperative. No differences were found for diminished libido, erectile and ejaculatory problems.	
Chatwin <i>et al.</i> 2002 ⁵⁶	RC	♀♂	LAR +PRT (n=16) versus LAR (n=27)	CS		-	-	+	+	+	-	-	-	-	-	-	+	-	+	5	NS	SD was reported by 5/84 sexually active men and 1/4 sexually active women in the surgery alone group and by 4/5 sexually active men and 1/7 sexually active women in the PRT group.	

Author	Site	Sex	Study population*	Design*	FU time*	A	B	C	D	E	F	G	H	I	J	K	L	M	N	O	Questionnaire used*	General conclusions*
Kim <i>et al.</i> 2002 ⁷⁷	RC	♂	TME with PANP (n=68)	P	8.7 ± 4.8	+	+	-	-	+	+	+	-	-	-	+	-	-	+	8	IIEF	The average IIEF score, intercourse satisfaction, orgasmic functioning, sexual desire, and overall satisfaction decreased postoperatively. An age ≥60 years predicted sexual desire, within 6 months after surgery predicted intercourse satisfaction and orgasmic function, and lower rectal cancer predicted erectile function, intercourse satisfaction, and orgasmic functioning.
Kuzu <i>et al.</i> 2002 ⁵⁷	RC	♀♂	APR (n=75), LAR (n=51), AR (n=52)	CS		+	-	+	+	+	+	-	-	-	+	-	+	-	8	NS	After APR patients were less sexually active and for those who were sexually active had a lower frequency of intercourse, compared with AR and LAR.	
Pocard <i>et al.</i> 2002 ⁷⁸	RC	♀♂	AR without PRT (n=20)	P	12	-	+	+	+	+	+	-	+	-	-	+	-	+	9	NS	Of women, 69% were sexually active before surgery. Sexual activity, sexual desire, and the ability to achieve orgasm was unchanged in these women. No dyspareunia was reported. Of men, 69% were sexually potent in the preoperative period. Sexual activity, the ability to achieve orgasm, and potency were unchanged in these men.	
Quah <i>et al.</i> 2002 ¹⁰⁰	RC	♀♂	LTME versus TME (n=21) (n=28)	CS		+	+	+	+	+	-	-	-	-	+	-	+	-	8	IIEF	LTME was associated with a higher rate erectile, ejaculatory, and overall SD in men, compared with open surgery. One woman in the TME group became sexually inactive after surgery. Another woman reported dyspareunia after LTME, but remained sexually active.	
Camilleri-Brennan <i>et al.</i> 2001 ¹¹⁴	RC	♀♂	TME (n=65)	P	12	+	-	+	+	+	+	-	+	-	-	+	+	-	9	EORTC QLQ-CR38	Compared with baseline, sexual enjoyment and male SD were worse up to one year follow-up. SF was only worse at 3 months follow-up.	
Guren <i>et al.</i> 2001 ⁵⁹	RC	♀♂	Patients with urinary diversion (n=12) and controls (n=25)	CS		+	-	+	+	+	+	-	+	-	-	+	-	+	8	EORTC QLQ-CR38	The two groups did not differ with regard to any evaluable scale or single items of the EORTC QLQ-CR38.	
Maurer <i>et al.</i> 2001 ¹⁰¹	RC	♀♂	Conventional surgery (n=29) versus TME (n=31)	CS		-	+	+	+	+	+	-	-	-	-	+	-	+	7	NS	Compared with conventional surgery, TME preserved the ability to achieve orgasm and to ejaculate. Preserved erectile function and less functional deterioration (sexual activity and interest in sex) was more common in the TME group. Few women answered the SF questions.	

Author	Site	Sex	Study population*	Design*	FU time*	A	B	C	D	E	F	G	H	I	J	K	L	M	N	O	Questionnaire used*	General conclusions*	
Mannaerts <i>et al.</i> 2001 ⁸¹	RC	♀♂	LARC (n=37) versus locally recurrent RC (n=39)	CS		-	+	+	+	+	+	+	+	-	+	-	-	+	-	+	10	NS	Patients were asked about current and preoperative functioning. Sexual desire decreased in men from 80% to 37% and in women from 63% to 26%. Both preoperative and postoperative SD was higher in women. The preoperative ability to achieve an orgasm had disappeared in 45% of patients after treatment for locally advanced primary and 57% of patients after treatment for locally recurrent rectal cancer. An age >60 years significantly reduced the ability to have an orgasm postoperatively, as well as the ability to have sexual intercourse.
Shah <i>et al.</i> 2001 ⁶⁸	CRC	♂	Rectable RC (n=31)	P	6	-	-	-	-	+	+	-	-	-	-	+	-	+	-	+	5	NS	All men, except one, were sexually active. Postoperative impotence was reported by 13% of men.
Allal <i>et al.</i> 2000 ⁶⁰	RC	♀♂	AR with PRT (n=11) versus APR with PRT (n=11)	CS		+	-	+	+	+	+	-	-	-	-	-	-	+	-	+	7	EORTC QLQ-CR38	SF was low in both the APR and the AR group. In men, SD was higher in the APR group, though this result was not significant. None of the women answered questions concerning female SF.
Chorost <i>et al.</i> 2000 ¹⁰²	RC	♀♂	Curative procedures (n=52)	CS		-	+	+	+	+	+	+	-	-	-	-	-	+	-	-	7	NS	After local excision SD was not reported. After LAR one patient reported SD. After APR 33% reported SD, whereas 75% treated with APR and postoperative RT reported SD. Only 1 woman reported SD.
Mancini <i>et al.</i> 2000 ⁶¹	RC	♀♂	RC patients with PANP (n=36)	P	24	-	-	+	+	+	-	-	-	-	-	+	+	+	-	-	6	NS	The incidence of SD related to the surgery itself was 31%.
Nesbakken <i>et al.</i> 2000 ⁷⁹	RC	♀♂	TME (n = 39) or partial TME (n=10)	P	6	-	+	+	+	+	-	-	-	-	-	+	-	+	-	+	7	NS	Men reported some reduction in erectile function (6/27) and one became impotent. Two men reported retrograde ejaculation. Women reported a reduction in sexual desire and sexual activity.
Maas <i>et al.</i> 1998 ⁶²	RC	♀♂	Patients after PANP (n=41)	P	6	-	-	+	+	+	-	-	-	-	-	+	-	+	-	+	6	NS	3/11 women and 19/30 men were sexually active. Postoperative, dyspareunia was experienced by one woman. Two men became impotent.
Havenga <i>et al.</i> 1996 ⁹⁷	RC	♀♂	TME + PANP (n=81)	CS		-	+	+	+	+	+	+	-	-	+	-	-	+	-	+	9	NS	The ability to have intercourse was maintained by 86% of patients <60 years and by 67% of patients aged ≥60 years. Age <60 years was associated with more sexual activity, while type of surgery (APR versus LAR) was related with the ability to have an erection. For women sexual activity declined with age.

Author	Site	Sex	Study population*	Design*	FU time*	A	B	C	D	E	F	G	H	I	J	K	L	M	N	O	Questionnaire used*	General conclusions*
Masui <i>et al.</i> 1996 ⁸³	RC	♂	PANP (n=134)	CS		-	+	-	-	+	+	-	-	-	+	-	-	-	+	5	NS	Patients undergoing complete PANP showed higher rates of erectile function (93%), ejaculatory function (83%), sexual intercourse (90%), and orgasm (94%) compared with patients undergoing hemilateral PANP (for which rates were 83%, 47%, 53%, and 65%, respectively) or partial pelvic plexus-preserving operation (62%, 0%, 26%, and 22%, respectively).
Sugihara <i>et al.</i> 1996 ⁶³	RC	♂	PANP (n= 64)	CS		-	-	-	-	+	-	-	+	-	+	-	-	-	+	5	NS	For men, complete SF was maintained by 33% while 37% were not able to perform sexual intercourse. The degree of SD (erection, sexual intercourse, and ejaculation) depended on type of PANP.
Leveckis <i>et al.</i> 1995 ²⁷	RC	♂	Rectal cancer group (n=16)	P	4	-	+	-	-	+	-	-	-	-	-	+	-	-	-	3	NS	Normal SF was reported by 7 men. Two men had erections but were not sexually active, 2 had partial erections and were not sexually active, and 2 were having intercourse despite only partial erections. Three men became impotent.
Cosimelli <i>et al.</i> 1994 ¹⁰³	RC	♀♂	Rectosigmoid cancer (n=246)	CS	12	-	+	+	+	+	-	-	-	-	+	+	+	+	+	8	NS	Overall, 47% of patients maintained satisfactory sexual activity. Erectile en ejaculation capacity was retained by 26% and 39% of men. A higher age and a colostomy were associated with less sexual activity.
Filiberti <i>et al.</i> 1994 ⁹¹	RC	♂	Rectal excision + coloanal anastomosis (n=23)	CS		-	+	-	-	-	+	-	+	-	-	-	+	-	+	5	NS	Sphincter preserving surgery might prevent neurogenic impotency at a higher rate. Impotency was reported by 10% of patients, ejaculation was also widely affected (90%).
Enker <i>et al.</i> 1992 ³¹	RC	♂	LAR (n=38)	P	19.6 (4-85)	-	+	-	-	+	+	-	-	-	-	-	-	-	-	3	NS	Most men remained potent (88%) and 88% of men remained normal ejaculation.
Hojo <i>et al.</i> 1991 ⁸⁰	RC	♂	Rectal cancer group (n=78)	P	12	-	+	+	+	+	-	-	-	-	+	-	-	-	-	7	NS	In men aged <60 30% recovered erectile function and 19% recovered ejaculatory function at one year follow-up. Most of these patients underwent first-degree PANP.
Koukouras <i>et al.</i> 1991 ⁹²	CRC	♂	Colorectal cancer group (n=60)	CS		-	+	-	-	+	+	-	-	-	-	-	+	-	+	5	NS	Sexual activity was suppressed in 32%. Of these, 25% had no ejaculation and penetration and 25% had no erection. A higher incidence of SD after APR (54%) compared with AR (15%) was found.

Abbreviations: CR = Rectal Cancer, CC = Colon Cancer, CRC = ColoRectal Cancer, V = Women, B = Men, P = Prospective study, CS = Cross-Sectional study, NS = Not Standardized, SD = Sexual Dysfunction, SF = Sexual Functioning, LTME = Laparoscopic Total Mesorectal Excision, TME = Total Mesorectal Excision, TEM = Transanal Endoscopic Microsurgery, AR = Anterior Resection, LAR = Low Anterior Resection, HAR = High Anterior Resection, APR = Abdominal Perineal Resection, PANP = Pelvic Autonomic Nerve Preservation, PRT = Preoperative Radiation Therapy, PRT+ = Patients who underwent preoperative radiotherapy, PRT- = Patients who did not undergo preoperative radiotherapy, PCRT = Preoperative Chemo Radiation Therapy, ELD =

Extended Lateral pelvic lymph node Dissection, EORTC QLQ-CR38 = European Organization for Research on Treatment of Cancer Quality of Life Questionnaire ColoRectal Cancer specific, IIEF = International Index of Erectile Function, IIEF-5 = International Index of Erectile Function abbreviated version, FSFI = Female Sexual Function Index, QSD = Questionnaire for Screening Sexual Dysfunction, ISS = Index of Sexual Satisfaction. Note: * Only the design, instruments and study population used to measure sexual (dys)function are mentioned. In case of a prospective study, the follow-up time in months is presented. If the follow-up measurement is not standardized, the median follow-up time and range are reported.

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Higher prevalence of sexual
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Abstract

Objectives

To compare colorectal cancer survivors with a normative population regarding erectile dysfunction, ejaculation problems, dyspareunia, dry vagina, sexual functioning (SF), and sexual enjoyment (SE). In addition, the sociodemographic, clinical, and psychological correlates of (dys)function in survivors are examined.

Methods

Sexuality subscales of the European Organization for Research and Treatment of Cancer (EORTC) module Quality of Life Questionnaire – Colorectal 38 (QLQ-CR38) were completed by survivors ($n=1371$; response rate 82%), of which 1359 received surgical treatment and were included in analysis. The normative population consisted of 400 participants (response rate 78%).

Results

Erectile problems were more often present in rectal cancer (54%) than colon cancer survivors (25%) and the normative population (27%; $p<.001$). They also had more ejaculation problems (68%) than colon cancer survivors (47%; $p<.001$). Dry vagina was common in colon (28%) and rectal cancer survivors (35%), while the normative population scored lower (5%; $p=.003$). In addition, colon (9%) and rectal cancer survivors (30%) experienced more pain during intercourse than the normative population (0%; $p=.001$). SE for men was similar across groups, while women with colorectal cancer reported lower scores than the normative population. Higher age, being a woman, not having a partner, a low educational level, rectal cancer, depressive symptoms, and fatigue were associated with lower SF. Lower SE was associated with higher age, being a woman, depressive symptoms, and cardiovascular disease.

Conclusion

SF was deteriorated in both sexes after cancer, which affected women's SE negatively. Attention towards sexual (dys)function in colorectal cancer survivors is needed.

Introduction

Colorectal cancer is the third most common cancer in men (10%), and the second most common cancer in women.¹ Due to medical advances about 62% of the patients will become long-term survivors^{2,3}, especially in younger cohorts.⁴

Conventionally, outcomes assessment in colorectal cancer included mortality, morbidity, disease recurrence, and long-term survival. However, patient-reported outcomes (e.g., quality of life) are now also regarded as key measurements in assessing outcomes of interventions.⁵ Sexuality and intimacy are considered to be important aspects of quality of life.⁶ The majority of colorectal cancer survivors remain sexually active.⁷ However, survivors do experience sexual dysfunction, which may be caused by surgical treatment, radiochemotherapy^{7,9}, or the presence of a stoma.⁷ In addition, sexual functioning and sexual satisfaction are influenced by the presence of depressive symptoms, anxiety, and fatigue.¹⁰⁻¹²

In a recent literature review ($n=82$), about half of the studies had small samples sizes ($n<75$) and presented data for both men and women.⁷ In addition, only four studies have used a healthy population as a control group.¹³⁻¹⁶ Since, the majority of studies did not include an age-matched normative population, it is often unclear whether sexual dysfunction is purely related to age or comorbidities. Therefore, the aim of this large population-based study was to examine (i) the prevalence of erectile dysfunction, ejaculation problems, dyspareunia, and dry vagina in colon and rectal cancer survivors and a normative population, (ii) to compare sexual (dys)function between these three groups, and (iii) to describe the sociodemographic, clinical and psychological correlates of sexual (dys)function in survivors.

Methods

Participants

The Eindhoven Cancer Registry (ECR) records data of all newly diagnosed individuals with cancer in the southern part of the Netherlands, an area with 2.3 million inhabitants, 10 hospitals with 18 locations and two large radiotherapy institutes.¹⁷ Registered individuals diagnosed with colorectal cancer between 1998 and 2007 were eligible for participation ($n=5580$). From these survivors, a weighted random selection of 2400 survivors based on tumor, sex, and year of diagnosis was made (Figure 1). These weights were derived from the distribution of colon and rectal cancer survivors in the normative population. Survivors with shorter duration since diagnosis were oversampled for inclusion in future follow-up assessments. After excluding survivors who had cognitive impairment or who had died, data collection started in January 2009. Survivors were informed of the study via a letter from their (ex)attending surgeon. A Medical Ethics Committee approved this study. Participants provided informed consent.

The normative sample was derived from CentERdata (an online household panel). In total, 1731 (81%) members of this panel completed questionnaires.¹⁸ The description of the data collection is given elsewhere.¹⁸ For this analysis, an age-matched normative population ($n=400$), in which a similar distribution of ages as in the survivor sample was obtained, was included. The data will be available for non-commercial scientific research, subject to study question, privacy and confidentiality restrictions, and registration (www.profilesregistry.nl).¹⁹

Measures

Survivors' sociodemographic and clinical information (i.e., date of diagnosis, Tumor-Node-Metastasis classification²⁰, clinical stage²⁰, treatment) was available from the ECR. Living situation, education, work situation, length and weight, and life style factors were completed in the questionnaire. An adapted Self-administered Comorbidity Questionnaire (SCQ) was completed.²¹ Disease-specific issues were assessed with the European Organization for Research and Treatment of Cancer (EORTC) module Quality of Life Questionnaire – Colorectal 38 (QLQ-CR38).²² The QLQ-CR38 comprises 38 questions, of which 19 are completed by all survivors and the remaining by subsets of survivors (men or women; survivors with/without a stoma). The QLQ-CR38 assesses both functioning (Weight loss, Body Image, Sexual Functioning (SF), Sexual Enjoyment (SE), Future Perspective) and symptom burden (Micturition Problems, Defecation Problems, Gastrointestinal Symptoms, Stoma-related Problems, Chemotherapy Side effects, Male SF, Female SF). The items have a 4-point rating scale ranging from 1 (*not at all*) to 4 (*very much*). Scales were linearly converted to a 0-100 scale. Higher scores on functional items/scales indicate better functioning, while higher scores on symptom item/scale indicate higher symptom burden. In this study, SF, SE, and male SF or female SF were analyzed.

Figure 1 Flow-chart of the data collection process in colorectal cancer survivors



The Fatigue Assessment Scale (FAS)²³ is a 10-item questionnaire assessing perceived fatigue and exhaustion. Five questions of the FAS reflect physical fatigue and five assess mental fatigue. The response scale is a 5-point rating scale ranging from 1 (*never*) to 5 (*always*). Scores on the FAS range from 10 to 50. The psychometric properties are good.²⁴⁻²⁷

Symptoms of anxiety and depression were evaluated with the 14-item Hospital Anxiety and Depression Scale (HADS).²⁸ This self-report questionnaire contains two 7-item subscales designed to measure symptoms of anxiety and depression. The scale was developed for use in patients suffering from bodily disease and therefore, symptoms of somatic reference such as pain and fatigue were excluded. The psychometric properties are good.^{29,30}

The normative sample completed a sociodemographic questionnaire, the SCQ, and the EORTC QLQ-CR38 sexuality questions, except for the item on ejaculation difficulties since the CentERpanel strongly advised not to include this specific item due to practical and ethical considerations.

Statistical analyses

Chi-square tests and independent student t-tests were used to compare both sexes on sociodemographic and clinical characteristics (for colon-, rectal cancer survivors, and the normative population separately) and sexually active survivors with survivors who were not sexually active. To determine the prevalence of sexual problems, the scores on the subscales were dichotomized. Participants who reported no problems or minor problems (*not at all – a little bit*) were categorized as not having sexual problems, while patients who reported quite some problems or severe problems (*quite some–very much*) were categorized as having sexual problems. Analyses of Variance (ANOVA)'s compared the sexuality subscales, for men and women separately. Post-hoc tests were corrected with the Bonferonni method. Finally, multivariate linear regression models (method: Enter) investigated whether a priori determined sociodemographic characteristics (age, sex, having a partner, educational level, Body Mass Index (BMI), being a smoker), clinical and psychological characteristics (site of cancer, type of treatment, years since diagnosis, disease progression, having a stoma, having cardiovascular disease, having diabetes mellitus, fatigue, anxiety, and depression) were associated with SF, SE, male SF and female SF. Assumptions were checked. SF was analyzed for the entire group, while the other scales were only examined for the sexually active survivors. Means and standard deviations are provided as ($M \pm SD$). Statistical differences were indicated if $p < .05$ (two-sided). A difference of > 0.5 SD was considered indicative of clinical meaningful differences between groups.³¹ All statistical analyses were performed using SPSS17.0.

Results

In total, 1371 (82%) survivors completed the questionnaire. Eventually, 1359 survivors treated with surgery (with or without (neo)adjuvant therapy) were included. Non-respondents were significantly older (72 ± 10) and more often women (55%) than respondents (70 ± 10 , 43% female) and those with non-verified addresses (69 ± 11 , 44% female). These groups did not differ on clinical aspects.

Male participants were more often partnered and more highly educated, while they less often had arthrosis and back pain than women (Table 1). In addition, female colon cancer survivors were more often depressed and less sexually active than men. Male rectal cancer survivors were more often smokers than their female counterparts.

Sexually active participants were significantly younger, more often partnered, and had a higher educational level than participants who were not sexually active. In addition, sexually active men less often had a stoma and sexually active women less often reported comorbidities (Table 2).

The normative sample consisted of 224 men and 156 women (response rate 78%). Men were older (70 ± 10) than women (67 ± 11 , $p = .009$), were more often partnered (80% versus 65%, $p = .001$), and were more often sexually active (64% versus 45%, $p < .001$). Further information is published elsewhere.³²⁻³³

Table 1 Demographic and clinical characteristics of the participating cancer survivors

	Colon		<i>p</i> -value	Rectum		<i>p</i> -value
	Men N = 468	Women N = 434		Men N = 297	Women N = 160	
	Mean±SD	Mean±SD		Mean±SD	Mean±SD	
Age at time of survey	70.4 ± 9.2	69.9 ± 10.1	.486	68.6 ± 9.4	67.6 ± 10.1	.298
Years since initial diagnosis	3.9 ± 2.4	3.9 ± 2.5	.701	3.9 ± 2.5	4.2 ± 2.6	.168
BMI	27.0 ± 3.9	27.0 ± 5.5	.961	26.4 ± 4.2	26.0 ± 4.7	.491
	N (%)	N (%)		N (%)	N (%)	
Having a partner						
Yes	382 (82)	238 (55)	<.001	248 (84)	107 (67)	<.001
Missing	15 (3)	19 (4)		7 (2)	7 (4)	
Sexually active						
Yes	243 (52)	136 (31)	<.001	140 (47)	59 (37)	.063
Missing	47 (10)	78 (18)		24 (8)	22 (14)	
Educational level^a			<.001			<.001
Low	114 (24)	45 (10)		79 (27)	15 (9)	
Medium	251 (54)	246 (57)		168 (57)	102 (64)	
High	82 (18)	116 (27)		41 (14)	35 (22)	
Missing	21 (5)	27 (6)		9 (3)	8 (5)	
Currently smoking	53 (11)	35 (8)	.099	43 (15)	12 (8)	.029
Stage of cancer			.076			.731
1	119 (25)	82 (19)		123 (41)	63 (39)	
2	198 (42)	195 (45)		88 (30)	46 (29)	
3	124 (27)	136 (31)		77 (26)	48 (30)	
4	27 (6)	21 (5)		9 (3)	3 (2)	

	Colon		<i>p</i> -value	Rectum		<i>p</i> -value
	Men N = 468	Women N = 434		Men N = 297	Women N = 160	
	N (%)	N (%)		N (%)	N (%)	
Type of treatment			.790			.102
Surgery only	334 (71)	297 (68)		67 (23)	33 (21)	
Surgery + RT	3 (1)	4 (1)		175 (59)	89 (56)	
Surgery + CT	127 (27)	129 (30)		21 (7)	7 (4)	
Surgery + RC + CT	4 (1)	4 (1)		34 (11)	31 (19)	
Disease progression	32 (7)	30 (7)	.965	26 (9)	9 (6)	.230
Stoma status			.986			.568
Stoma at time of surgery	20 (4)	21 (5)		97 (33)	62 (39)	
Missing	126 (27)	73 (17)		62 (21)	20 (13)	
Comorbidity						
Cardiovascular disease	199 (43)	175 (40)	.503	127 (43)	76 (48)	.331
Lung disease	45 (10)	46 (11)	.624	30 (10)	11 (7)	.250
Diabetes mellitus	64 (14)	58 (13)	.891	35 (12)	21 (13)	.677
Arthrosis	90 (19)	148 (34)	<.001	57 (19)	55 (34)	<.001
Back pain	92 (20)	124 (29)	.002	60 (20)	51 (32)	.006
Depression	12 (3)	34 (8)	<.001	29 (6)	13 (8)	.490

Abbreviations: SD = standard deviation, BMI = Body Mass Index, RT = Radiotherapy, CT = Chemotherapy

Note: ^a Educational level: Low (no or primary school); Medium (lower general secondary education or vocational training); High (pre-university education, high vocational training, university). A *p*-value of <.05 is considered significant.

Table 2 Demographic and clinical characteristics according to sexual activity and sex

	Men			Women		
	Not sexually active N = 311	Sexually active N = 383	<i>p</i> -value	Not sexually active N = 299	Sexually active N = 195	<i>p</i> -value
	Mean±SD	Mean±SD		Mean±SD	Mean±SD	
Age at time of survey	72.0 ± 8.5	66.9 ± 9.4	<.001	71.8 ± 8.8	62.8 ± 9.6	<.001
Years since initial diagnosis	3.8 ± 2.4	3.9 ± 2.4	.480	3.9 ± 2.5	3.9 ± 2.5	.729
BMI	26.9 ± 4.0	26.8 ± 4.2	.703	27.0 ± 5.7	26.2 ± 4.7	.164
	N (%)	N (%)		N (%)	N (%)	
Having a partner						
Yes	239 (77)	348 (91)	<.001	148 (51)	168 (87)	<.001
Missing	6 (2)	4 (1)		11 (4)	1 (1)	
Educational level^a			<.001			<.001
Low	65 (22)	38 (10)		99 (35)	26 (14)	
Medium	167 (56)	223 (59)		158 (55)	142 (74)	
High	69 (23)	115 (31)		28 (10)	24 (13)	
Missing	10 (3)	7 (2)		14 (5)	3 (2)	
Currently smoking	36 (12)	57 (15)	.203	24 (8)	19 (10)	.508
Rectal cancer	133 (43)	140 (37)	.096	79 (26)	59 (30)	.353
Stage of cancer			.595			.711
1	105 (34)	112 (29)		67 (22)	47 (24)	
2	113 (36)	145 (38)		127 (43)	73 (37)	
3	77 (25)	107 (28)		92 (31)	67 (34)	
4	16 (5)	19 (5)		13 (4)	8 (4)	
Type of treatment			.055			.188
Surgery only	157 (51)	195 (51)		169 (57)	91 (47)	
Surgery + RT	86 (28)	77 (20)		46 (15)	34 (17)	
Surgery + CT	55 (18)	88 (23)		66 (22)	55 (28)	
Surgery + RC + CT	13 (4)	23 (6)		18 (6)	15 (8)	

	Men			Women		
	Not sexually active N = 311	Sexually active N = 383	<i>p</i> -value	Not sexually active N = 299	Sexually active N = 195	<i>p</i> -value
	N (%)	N (%)		N (%)	N (%)	
Disease progression	28 (9)	26 (7)	.279	20 (7)	14 (7)	.833
Stoma status			.037			.997
Stoma at time of surgery	60 (25)	53 (17)		43 (17)	31 (17)	
Missing	68 (22)	79 (21)		44 (15)	11 (6)	
Comorbidity						
Cardiovascular disease	147 (48)	158 (41)	.112	142 (48)	70 (36)	.011
Lung disease	37(12)	30 (8)	.071	35 (12)	14 (7)	.100
Diabetes mellitus	49 (16)	42 (11)	.063	54 (18)	14 (7)	.001
Arthrosis	69 (22)	72 (19)	.270	118 (40)	57 (29)	.020
Back pain	67 (22)	79 (21)	.768	92 (31)	63 (32)	.719
Depression	14 (5)	15 (4)	.702	28 (9)	15 (8)	.519

Abbreviations: SD = standard deviation, BMI = Body Mass Index, RT = Radiotherapy, CT = Chemotherapy.

Note: ^aEducational level: Low (no or primary school); Medium (lower general secondary education or vocational training); High (pre-university education, high vocational training, university). A *p*-value of <.05 is considered significant.

Sexual dysfunction

Male colon (58%) and rectal cancer survivors (51%) were less sexually active than men from the normative population (64%, $p=.018$). For women, 54% of colon cancer survivors were sexually active compared with 23% for both rectum cancer survivors and the normative population ($p=.345$). Male rectal cancer survivors had more problems with erectile functioning (54%) than colon cancer survivors (25%) and the normative population (27%, $p<.001$). Furthermore, male rectal cancer survivors reported more ejaculation problems (68%) than colon cancer survivors (47%, $p<.001$). Lubrication problems were more common in female colon (28%) and rectal cancer survivors (35%) than the normative population (5%, $p=.003$). In addition, female colon (9%) and rectal cancer survivors (30%) experienced more dyspareunia than the normative population (0%, $p<.001$).

Compared with male colon (29 ± 25) and rectal cancer survivors (26 ± 23), men from the normative population had higher scores on SF (38 ± 24 , $p<.001$; **Figure 2^a**). However, SE was similar in these groups. Finally, rectal cancer survivors (52 ± 39) reported more problems with erectile functioning than colon cancer survivors (31 ± 35 , $p<.001$) and the normative population (29 ± 34 , $p<.001$). Female colon (15 ± 19) and rectal cancer survivors (15 ± 18), reported lower SF than the normative population (22 ± 24) ($p=.020$ and $p=.010$ respectively; **Figure 2^b**), as well as lower SE than the normative population (51 ± 29 , 49 ± 26 and 66 ± 28 , respectively). Female colon (23 ± 26) and rectal cancer (30 ± 33) survivors reported significantly more problems with female SF than the normative population (11 ± 17 ; $p=.002$). The differences in SF and SE in both sexes were clinically meaningful.

Correlates of SF in colorectal cancer survivors

Lower SF was significantly associated with higher age, female sex, not having a partner, low educational level, rectal cancer, depressive symptoms, and fatigue, explaining 32% of the variance (R^2 ; $p<.001$) (**Table 3**). Lower SE was associated with higher age, female sex, depressive symptoms, and cardiovascular disease ($R^2=23\%$; $p<.001$). A lower male SF was associated with a higher age and having a stoma ($R^2=28\%$; $p<.001$). Fatigue was associated with a lower SF for women ($R^2=24\%$; $p<.001$).

Secondary analyses, stratified by sex, were conducted in order to determine the sex-specific correlates of SF and SE. For men, the results remained comparable; however, a higher BMI was also related with a lower SF ($R^2=32\%$, $p<.001$). For women, only a higher age and having a partner remained significantly associated with SF ($R^2=29\%$; $p<.001$). For men, lower SE was associated with a higher age and depressive symptoms ($R^2=20\%$; $p<.001$). For women, lower SE was associated with having cardiovascular disease and surgery in combination with radiotherapy and chemotherapy ($R^2=26\%$; $p=.05$).

Figure 2 Comparison of sexual problems (mean scores) in men between (i) colon cancer survivors compared with the normative population, (ii) rectal cancer survivors compared with the normative population, and (iii) colon versus rectal cancer survivors

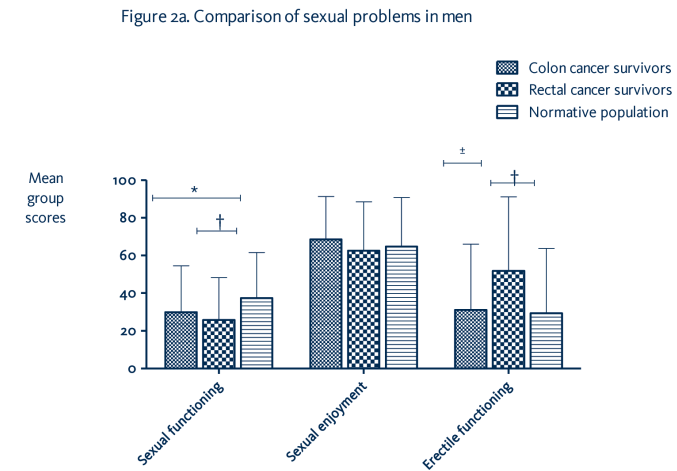
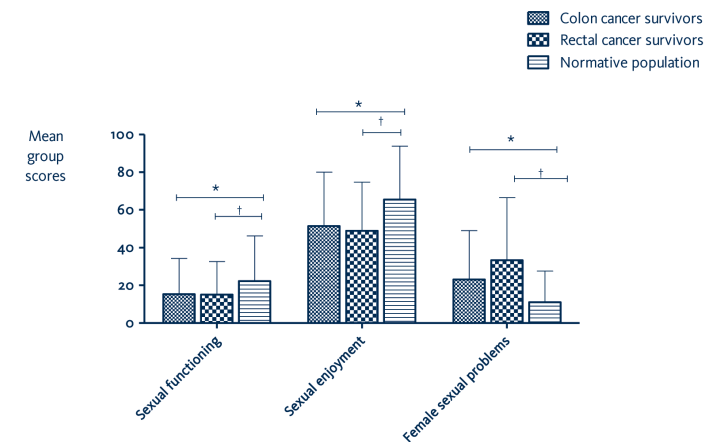


Figure 2b. Comparison of sexual problems in women



* The contrast is significant between patients with colon cancer and the normative population.
 † The contrast is significant between patients with rectal cancer and the normative population.
 ‡ The contrast is significant between patients with colon cancer and patients with rectal cancer.

Table 3 Multivariate regression analyses of sexual functioning, sexual enjoyment, and male/female sexual problems in colorectal cancer survivors

	Sexual functioning (n=829)		Sexual enjoyment (n=370)		Male sexual functioning (n=258)		Female sexual functioning (n=144)	
	β -value	p-value	β -value	p-value	β -value	p-value	β -value	p-value
Age at time of survey	-.274	<.001	-.175	.001	.316	<.001	.003	.975
Men (vs women)	.242	<.001	.286	<.001	NA	NA	NA	NA
Years since diagnosis	.038	.197	.048	.321	.047	.426	.063	.473
Having a partner	.148	<.001	NA	NA	NA	NA	NA	NA
Educational level								
Low*	-.110	.004	-.053	.341	-.066	.294	.046	.670
Middle*	-.070	.057	-.021	.697	-.027	.653	.110	.269
BMI	-.051	.087	-.020	.693	-.042	.474	-.082	.373
Smoker	.037	.218	-.028	.586	.095	.118	.046	.609
Rectum (vs colon)	-.133	.006	-.054	.483	.088	.322	.028	.844
Type of treatment								
Surgery + RT †	.042	.364	-.029	.695	.133	.129	.224	.095
Surgery + CT †	.008	.792	.036	.490	-.045	.483	.163	.070
Surgery + RT + CT †	-.005	.891	.053	.404	.102	.163	.084	.475
Disease progression	-.027	.369	-.014	.771	.060	.300	-.060	.483
Stoma	-.016	.628	-.022	.677	.232	<.001	.146	.137
Cardiovascular disease	-.006	.856	.141	.005	-.043	.472	-.090	.295
Diabetes mellitus	-.046	.128	-.002	.966	.062	.282	-.089	.305
Anxiety	.066	.087	.064	.316	-.118	.089	.157	.185
Depression	-.132	.001	-.271	<.001	.058	.450	-.200	.095
Fatigue	-.175	<.001	-.030	.639	.067	.362	.257	.048

Abbreviations: BMI = Body Mass Index, RT = Radiotherapy, CT = Chemotherapy, NA = not applicable.

Note: A *p*-value of <.05 is considered significant. For the sexual functioning and enjoyment scale a positive β -value indicates better functioning, while for the male and female sexual functioning scales a positive β -value indicates more problems. *The middle and low educational level were compared with a high educational level. †These treatments were compared with surgery only.

Discussion

Male colon- and rectal cancer survivors were less sexually active and reported worse SF compared with the normative population. These differences were clinically meaningful.

The findings on the prevalence of sexual dysfunction fall within the range of previous studies.³⁴ However, it is not clear how to define the presence of sexual dysfunction, sexual problems, and sexual disorders.^{35,36} In line with the recent literature^{35,37}, we have excluded the score 'a little bit' from the definition of a sexual problem. As a consequence, sexual dysfunction is only present when dysfunction is severe. Moreover, it is important to know to which extent patients are bothered by their sexual problems (i.e., their quality of sexual life). Having a sexual dysfunction may lead to a diminished quality of sexual life, though this is not a necessity. In this light, the Diagnostic and Statistical Manual of Mental Disorders (DSM-IV) formulated two separate categories to describe sexual disorders.³⁷ The A category focuses on defining sexual disorders per se, with the common denominator being: "persistent or recurrent", while the B category adds a distress dimension to all dysfunctions "the disturbance causes marked distress or interpersonal difficulty".^{36,37} These definitions are a prerequisite to distinguish a dysfunction from its emotional impact.³⁶ The current research focussed on the A category (defining sexual disorders per se). However, future research should also include the B category in order to provide a complete picture.

Consistent with previous studies, this study showed a strong relationship between male SF and age^{38,39} and the presence of a stoma.^{7,40} Rather unexpected were the findings that radiotherapy, chemotherapy, and having a stoma were not significantly associated with SF. Especially, since the role of radiotherapy is one of the most robust findings in the literature.⁴¹ Perhaps, the QLQ-C38 is not the most appropriate instrument to assess this theme (see below). This study also examined the relationship between psychological factors and SF and SE, since it has been suggested that depression may be a more important factor in sexual dysfunction than clinical factors.^{41,42} However, only a few studies have included this aspect.¹⁰⁻¹² We showed that depression was negatively associated with SF and SE. Moreover, fatigue was negatively associated with SF and female SF. These findings show that the existence of sexual problems in colorectal cancer patients should not merely be attributed to treatment damage, since sexual dysfunction is often multifactorial with biological, psychological, and/or social causes.

Strengths of the current study are the fact that a normative population with a similar age distribution is included. Up to date, no large population-based studies comparing sexual (dys)function in colorectal cancer survivors and a normative population are available. This study contributes to the debate on whether sexual dysfunction in a higher age is normal or pathological. The current study achieved a high response rate for both men (76%) and women

(70%). Moreover, most studies on sexual function focus on rectal cancer survivors³⁴, since it is expected that especially they will report more functional problems due to surgery and/or radio(chemo)therapy. This study consisted of both rectal- and colon cancer survivors. We have shown that colon cancer survivors and women also need attention for their potential sexual problems. Finally, this study had few missing data on sexual questions compared with other studies.^{43,44} For instance, Bloemen *et al.*⁴³ reported that 33% of the women did not complete the sexuality items, while another study reported an even higher percentage (58%).⁴⁴ In our study, less than 10% of the men did not complete the items on sexuality, with exception of item on SE (17% was missing). Missing data in women ranged from 12% (dry vagina) to 17% (sexually active).

There are also some limitations that need to be acknowledged. First, this study is cross-sectional. As a consequence, this design does not allow making causal inferences or displaying short-term and long-term changes in SF over time. However, knowledge about the course of sexual (dys)function will help health care professionals informing their patients in what to expect during and after treatment. Second, no information was known about sexual (dys)function before diagnosis/treatment of cancer, which limits the determination of the effect of a cancer diagnosis and treatment on functioning or being able to correct for baseline functioning. Prospective studies with an assessment point prior to surgical treatment are warranted. Third, even though the EORTC QLQ-CR38 is one of the most commonly used questionnaire to assess SF, it provides only limited information. The question ‘Did you experience difficulties ejaculating?’ for men may be inadequate, since some men with colon or rectal cancer end up with nerve damage or changes from surgery, pelvic (chemo)radiotherapy or a combination so that they essentially have ‘dry orgasms’, with pleasurable sensation and muscle contractions but no semen. As a consequence, it is unknown if men had dry orgasms or were not been able to reach orgasm. Finally, men from the normative population did not complete the question regarding ejaculation. Therefore, comparison with survivors was not possible on male SF.

Future prospective studies should investigate sexuality from a biopsychosocial model, in which the subjective evaluation of sexual (dys)function is taken into account. Thus, it would be interesting to assess the extent to which patients are bothered by sexual problems, since the presence of dysfunction may lead to a diminished quality of sexual life, though this is not a necessity.³⁴

Conclusion

This study showed that male colorectal cancer survivors were less sexually active and reported worse SF compared with the normative population. These results imply that attention towards sexual (dys)function in colorectal cancer survivors, in both research and clinical practice is needed.

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The preoperative sexual
functioning and quality of
sexual life in colorectal cancer:
a study among patients
and their partners



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Abstract

Introduction

Even though the body of literature on Sexual Function (SF) is growing, information on the preoperative SF and the Quality of Sexual Life (QoSL) after colorectal cancer is lacking. Research focusing on female patients and on partners is also rather scarce.

Aim

This cross-sectional study aimed to describe the preoperative SF, QoSL, and relationship functioning for male and female patients with colorectal cancer and their partners. In addition, the mean scores of the patients and partners were compared with mean norm scores.

Methods

Patients diagnosed with colorectal cancer ($n=136$) and their partners ($n=106$) were recruited before surgical treatment in six Dutch hospitals.

Main outcome measures

Men completed the International Index of Erectile Functioning, while women completed the Female Sexual Function Index. All partnered participants completed the Golombok-Rust Inventory of Sexual Satisfaction and the Maudsley Marital Questionnaire. The mean scores were compared with mean norm scores derived from the manuals of the questionnaires.

Results

All participants were in a heterosexual relationship. Female patients reported a lower QoSL compared with male patients. Male partners reported a lower SF and a lower QoSL compared with male patients. Patients with colorectal cancer and partners (both sexes) reported a lower SF and a lower QoSL compared with norm populations, but scored similar on relationship functioning.

Conclusion

A lower SF and a lower QoSL are already reported preoperatively; however, relationship functioning was comparable with a norm population. Therefore, all the impairment seen after treatment should not be solely attributed to the effects of treatment.

Introduction

Worldwide, colorectal cancer is the third most common cancer in men and the second most common cancer in women.¹ Fortunately, the improved multidisciplinary treatment has led to a substantial improvement in prognosis.^{2,3} An increasing incidence combined with an improving prognosis will result in a significant incline in the prevalence of colorectal cancer.

Over the past three decades, research on colorectal cancer showed a negative effect of colorectal treatment on Sexual Function (SF).⁴ A recent review reported that the current studies predominantly investigated the sexual response cycle. These studies found a high percentage erectile and/or ejaculatory dysfunction in men (range 5-88%) and that approximately half of the women reported pain during intercourse and/or dyspareunia.⁴ Sexual (dys)function is often investigated as part of clinical outcome studies (in combination with urological and/or bowel functioning) or as part of studies on health-related quality of life/health status.⁴ Currently, less is known about to which extent patients are bothered by their sexual problems (i.e., their Quality of Sexual Life – QoSL). However, it is important to evaluate the level of SF and QoSL, since having a sexual dysfunction does not necessarily lead to a diminished QoSL.⁵ Less than half of the men and women with a sexual dysfunction were actually bothered by this dysfunction.⁶ Furthermore, a cancer diagnosis and its subsequent treatment not only affect patients but also partners. Moreover, there may be interdependence between both members of the couple.^{7,8} In general, the existing studies paid little attention to the preoperative SF and/or QoSL.

Therefore, the aim of the current study was to describe the preoperative SF, QoSL, and relationship functioning for male and female patients with colorectal cancer and their partners. In addition, the mean scores of patients and partners were compared with mean norm scores derived from the manuals of the questionnaires.

Methods

Patients

Before surgical treatment, patients diagnosed with colorectal cancer and their partners were asked to participate in this study. However, according to the Dutch guidelines, patients with rectal cancer received neoadjuvant treatments (i.e., radio(chemo)therapy) that may already started by the time the participants completed the questionnaire.⁹ Patients were recruited between September 2010 and December 2011 from six Dutch hospitals: the St. Elisabeth hospital (Tilburg), TweeSteden Hospital (Tilburg and Waalwijk), Catharina Hospital

(Eindhoven), the Jeroen Bosch Hospital ('s Hertogenbosch), Amphia Hospital (Breda), and Maxima Medical Centre (Eindhoven and Veldhoven). Patients and partners older than 18 years were eligible for participation. The following exclusion criteria were applied: (i) elderly age (older than 75 years), (ii) not curatively treated metastases at baseline, (iii) poor expression of the Dutch language, (iv) dementia, and (v) a history of psychiatric illness. When patients declined participation, the partners were still invited to participate (and vice versa) in order to prevent selection bias. Patients and partners were asked by their treating physician during a preoperative visit if they could be approached by a member of the research group who would explain the study design and purpose of the study. Subsequently, a member of the research group contacted the participants and explained the study details. If patients and/or their partners agreed to participate they were asked to complete the set of standardized surveys at home, prior to the patients' surgery. Participants returned the surveys in sealed postage-paid envelopes. Participants who consented but who did not return the surveys within two weeks after consenting received a reminder (a phone call or a reminder letter). The institutional review board approved the study. All participants gave written informed consent.

Measures

Questions assessing socio-demographic factors (age, sex, marital status, length of the relationship, number of children, paid work, and educational level) and an adapted Self-administered Comorbidity Questionnaire¹⁰, which evaluates comorbidity at the time of questionnaire completion, were completed by all participants.

All male patients and male partners completed the International Index of Erectile Function (IIEF).¹¹ The IIEF is a well-validated 15-item instrument with good psychometric properties.¹² The IIEF consists of five domains and a total score. The domains Erectile Function, Orgasmic Function and Sexual Desire evaluate sexual (dys)function, while the domains Intercourse Satisfaction and Overall Satisfaction measure QoSL. Higher scores indicate fewer problems with SF and a better QoSL. Men scoring less than or equal to 25 were classified as having erectile dysfunction.¹²

All female patients and female partners completed the Female Sexual Function Index (FSFI).^{13,14} The FSFI¹⁴, Dutch version¹³ is a 19-item validated questionnaire that addresses five domains of women's sexual (dys)function: Arousal, Lubrication, Orgasmic Function, Sexual Desire, and Sexual Pain. In addition, the sixth domain Intercourse Satisfaction evaluates the women's QoSL. All responses were summed to provide a total score. Higher scores indicate fewer problems with SF and a better QoSL. The psychometric properties of the FSFI were found satisfactory to good.^{13,14}

The participants with a partner (both men and women) completed the Golombok-Rust Inventory of Sexual Satisfaction (GRISS)¹⁵, since most of the GRISS questions are intercourse orientated. The GRISS has separate versions for men and women, each consisting of 28 items. The GRISS assesses seven domains. Four domains which evaluate the QoSL: Avoidance (i.e., the extent to which the person is actively avoiding having sex), Satisfaction, Non-Communication (i.e., the extent to which a couple is able to talk about their sexual problems), Non-Sensuality (i.e., the extent to which a person gains pleasure from touching and caressing), and the sexual (dys)function domain Infrequency of Intercourse. In addition, women completed the sexual (dys)function domains Vaginismus and Anorgasmia, while men completed the sexual (dys)function domains Premature Ejaculation and Impotence. Finally, for both sexes all responses were summed to obtain a total score. Items were answered on a 5-point Likert scale ranging from 1 (*never*) to 5 (*every time*). High scores indicate more problems with SF and lower QoSL. The psychometric qualities of the Dutch version of the GRISS are good.^{16,17}

Finally, the participants with a partner (both men and women) completed the Maudsley Marital Questionnaire (MMQ).¹⁸⁻²⁰ The MMQ evaluates the relationship in general, the sexual relationship, and life in general. The MMQ consists of 20 items with a 9-point response scale (0-8). The items in each subscale were summed. Scores on the Marital Maladjustment subscale could range from 0 to 80, while the Sexual Maladjustment subscale and General Life Maladjustment could range from 0 to 40. For all subscales, a higher score indicates more maladjustment. A cutoff score of ≥ 20 on the Marital Maladjustment subscale was used to identify individuals who experienced marital maladjustment.^{21,22} The MMQ has good reliability and validity. The psychometric qualities of the Dutch version of the MMQ were also found to be satisfactory.^{18,20}

Medical records

Data concerning type of tumor (colon or rectum) was obtained from the medical records of the patients.

Statistical analysis

Frequencies were used to present the available sociodemographic and clinical data. First, it was determined whether patients with colon and rectal cancer differed in their SF and QoSL. Independent samples *t*-tests were used to compare patients with colon and rectal cancer on the IIEF (men) and the FSFI (women). Analyses of variance (ANOVAs) compared the mean scores on the GRISS and MMQ for the partnered participants (four subgroups: male patients with colon cancer, male patients with rectal cancer, female patients with colon cancer, and

female patients with rectal cancer). Next, the total group of patients with colorectal cancer (thus patients with colon and rectal cancer combined) and their partners were compared on the IIEF (men), and the FSFI (women) with independent samples *t*-tests. For the participants with a partner the mean scores on the GRISS and MMQ were compared with ANOVA's (four subgroups: male patients, male partners, female patients, female partners). Post-hoc tests were corrected with the Bonferroni method; missing data was excluded from the analysis. The mean scores obtained in the present study were compared with the mean scores from norm populations as described in the questionnaire manuals of the GRISS¹⁶, the IIEF¹¹, the FSFI¹⁴, and the MMQ¹⁸, with the one-samples *t*-test. In the text, mean scores and standard deviations are provided as (mean \pm standard deviation). Statistical differences were indicated if $p < .05$ and reported *p*-values were two-sided. All statistical analyses were performed using the Statistical Package for the Social Sciences (version 17.0, SPSS Chicago, IL, USA).

Results

In total, 259 eligible participants agreed to be contacted by a member of the research group, who subsequently informed them about the study. Of this group, 136 (54%) patients agreed to participate and completed the preoperative set of questionnaires. In addition, 123 patients had a partner of which 106 (86%) participated in this study. There were no partners who participated if the patient did not. Although not a prerequisite, all participants were in a heterosexual relationship. Several couples declined participation for various reasons. The most reported reasons for non-participation were (i) the intimate nature of the questionnaires, (ii) the length of the questionnaires, and (iii) the amount of experienced stress at that time. The demographic and clinical characteristics of the participants are reported in **Table 1**. No differences were found between patients with colon patients and patients with rectal cancer on the mean scores on the IIEF (men), FSFI (women), and the GRISS and MMQ (partnered men and women) ($p > .05$). Therefore, the colon and rectal cancer groups were combined in the subsequent analyses. The mean scores of the patients with colorectal cancer and their partners on the IIEF (for men), the FSFI (for women), and the GRISS and MMQ (for partnered men and women) are reported in **Table 2**.

Table 1 Demographic and clinical characteristics of patients and their partners

	Men		Women	
	Patients (n=91)	Partners (n=32)	Patients (n=45)	Partners (n=74)
	Mean \pm SD		Mean \pm SD	
Age at time of survey	64.3 \pm 11.3	65.4 \pm 10.5	64.1 \pm 13.6	60.3 \pm 12.7
BMI	82.3 \pm 13.6	84.2 \pm 10.5	69.0 \pm 10.3	71.5 \pm 11.8
Relationship in years	33.8 \pm 13.5	39.9 \pm 9.5	39.0 \pm 10.0	34.2 \pm 13.9
	N (%)		N (%)	
Educational level				
Low	5 (5.5%)	3 (9.4%)	6 (13.3%)	6 (8.1%)
Medium	49 (35.8%)	15 (46.9%)	26 (57.8%)	53 (67.1%)
High	32 (35.2%)	12 (37.5%)	7 (15.6%)	9 (12.2%)
Missing	5 (5.5%)	2 (6.3%)	6 (13.3%)	6 (8.1%)
Marital status				
Partnered	84 (92.3%)	-	39 (86.7%)	-
Widow/no partner	7 (7.7%)	-	6 (13.3%)	-
Missing	0 (0.0%)	-	0 (0.0%)	-
Type of cancer				
Colon	26 (28.6%)	-	10 (26.3%)	-
Rectum	65 (71.4%)	-	28 (73.7%)	-
Comorbidity				
Cardiovascular disease	11 (12.1%)	7 (21.9%)	5 (11.1%)	6 (8.1%)
Lung disease	6 (6.6%)	0 (0.0%)	2 (4.4%)	8 (10.8%)
Diabetes mellitus	7 (7.7%)	6 (18.8%)	2 (4.4%)	7 (9.5%)
Artrose	11 (12.1%)	6 (18.8%)	7 (15.6%)	18 (24.3%)
Back pain	17 (18.7%)	8 (25.9%)	6 (13.3%)	7 (9.5%)

Note: Low = up to ten years of education; middle = 10-14 years of education; high = more than 14 years of education.

Table 2 Mean values on the questionnaires

	Men			Women			
	Patients (n=67)	Partners (n=29)	p-value	Patients (n=38)	Partners (n=56)	p-value	p-value*
IIEF (♂ only; higher scores indicate better SF/better QoSL)							
Erectile functioning	8.6±5.6	7.6±6.3	ns	-	-	-	-
Orgasmic functioning	1.8±2.7	1.1±2.5	ns	-	-	-	-
Sexual desire	7.2±2.1	7.4±2.3	ns	-	-	-	-
Intercourse satisfaction	2.0±2.7	1.7±2.9	ns	-	-	-	-
Overall satisfaction	5.8±2.4	6.0±2.7	ns	-	-	-	-
FSFI (♀ only; higher scores indicate better SF/QoSL)							
Total	-	-	-	14.7±6.5	14.8±5.2	ns	-
Desire	-	-	-	5.4±1.0	4.4±1.1	<.001	-
Arousal	-	-	-	2.5±2.8	1.9±2.1	ns	-
Lubrication	-	-	-	1.3±1.5	2.0±1.4	.040	-
Orgasm	-	-	-	1.2±1.5	1.6±1.3	ns	-
Pain	-	-	-	1.7±2.2	2.3±2.4	ns	-
Satisfaction	-	-	-	2.6±1.4	2.2±1.1	ns	-
GRISS (higher scores indicate lower SF/ QoSL)							
Total	64.0±71.6	15.3±19.5	ns	72.7±20.9	62.9±15.8	ns	ns
Infrequency of intercourse	7.3±1.5	8.4±1.7	.023	7.7±1.8	7.2±1.7	ns	ns
Impotence	10.1±4.2	11.0±4.8	ns	-	-	-	-
Premature ejaculation	10.2±2.5	10.7±3.0	ns	-	-	-	-
Vaginismus	-	-	-	8.9±4.5	7.3±4.0	ns	-
Anorgasmia	-	-	-	12.1±2.6	10.8±2.9	.035	-
Non-sensuality	6.6±2.8	7.3±3.8	ns	8.7±4.4	6.7±2.6	ns	<.001
Avoidance	4.8±1.5	5.5±2.9	ns	7.8±4.3	6.0±2.7	ns	<.001

	Men			Women			
	Patients (n=67)	Partners (n=29)	p-value	Patients (n=38)	Partners (n=56)	p-value	p-value*
GRISS (higher scores indicate lower SF/ QoSL)							
Dissatisfaction	10.0±3.6	10.9±3.2	ns	9.6±3.8	8.6±3.9	ns	<.001
Non-communication	4.8±1.7	6.0±2.4	.038	6.0±2.2	5.6±1.9	ns	.026
MMQ (higher scores indicate more maladjustment)							
Marital maladjustment	10.8±10.5	9.6±9.0	ns	11.4±11.3	11.8±10.0	ns	ns
Sexual maladjustment	16.5±9.6	21.6±9.3	ns	17.8±9.5	16.4±9.4	ns	ns
General life maladjustment	7.7±5.0	7.8±5.2	ns	7.7±5.0	7.2±4.5	ns	ns

Abbreviations: GRISS=Golombok-Rust Inventory of Sexual Satisfaction, IIEF=International Index of Erectile Function, FSFI=Female Sexual Function Index, MMQ=Maudsley Marital Questionnaire, QoSL=Quality of Sexual Life, SF=Sexual Function.

Note: A *p*-value <.05 was reported statistically significant. ns = not statistically significant. The quality of life subscales are marked in bold. For the GRISS and the MMQ the post hoc Bonferroni corrected *p*-values are reported. For each question, more than 75% of the participants completed the question.**p*-value represents the comparison between male and female patients.

Sexual functioning

Male patients and male partners did not differ on the IIEF SF domains ($p>.05$). However, male patients reported less problems with Infrequency of Intercourse compared with male partners, (GRISS subscale, $p=.023$). Female patients reported a lower SF on the FSFI subscale Lubrication ($p=.040$), but a higher score on the subscale Desire ($p<.001$) compared with female partners. Furthermore, female patients reported more Anorgasmia compared with the female partners (GRISS subscale, $p=.035$).

Quality of Sexual Life

Both patients and partners scored similar on the Satisfaction subscale of the IIEF (men) and FSFI (women) ($p>.05$). Female patients had more problems with Non-sensuality ($p<.001$), Avoidance ($p<.001$), and Non-communication ($p=.026$) compared with male patients. Male patients reported more Dissatisfaction than female patients ($p<.001$). However, male patients reported less problems with Non-communication ($p=.021$) and with Infrequency of intercourse ($p=.003$) compared with male partners. The four groups did not differ on Sexual Maladjustment (MMQ, $p>.05$).

Relationship Maladjustment and General Life Maladjustment

For the MMQ, no significant differences were found between the four subgroups on Marital Maladjustment and General Life Maladjustment ($p>.05$). When marital maladjustment was dichotomized, 10 (13%) male patients, 10 (29%) female patients, 5 (17%) male partners, and 11 (17%) female partners reported marital maladjustment ($p=.253$). In four cases both members of the dyad reported marital maladjustment.

Comparison of patients with colorectal and their partners with previous described normative populations

Comparing the abovementioned results with norm scores revealed that both male patients and male partners reported significantly lower scores on the IIEF ($p<.05$), with exception of the subscale Sexual Desire for both male patients and male partners ($p=.436$ and $p=.409$, respectively). In addition, female patients and female partners reported significantly lower scores on all subscales of the FSFI ($p<.05$). The GRISS norm scores were lower for all subscales for the four groups except for the subscale Avoidance for male patients ($p=.251$) and male partners ($p=.414$). Finally, for the MMQ, no significant differences were reported between the four groups and the norm scores with regard to Marital Maladjustment ($p>.05$). However, all four groups differed significantly on Sexual Maladjustment ($p<.05$). Male patients and female partners reported more General Life Maladjustment ($p=.017$, and $p=.001$, respectively).

Discussion

Even though the negative effect of colorectal cancer treatment on the SF of patients is a robust finding in the literature, this study points out that both patients with colon and rectal cancer may already experience a lower SF and QoSL before surgical treatment. Therefore, surgical interventions may not be solely responsible for the high percentage of sexual dysfunction after colorectal cancer. No differences were found between patients with colon cancer (who did not receive neoadjuvant treatment) and patients with rectal cancer (who received neoadjuvant treatment). Compared with previously described populations, patients with colorectal cancer reported significantly lower scores on SF and the QoSL, regardless of gender. In addition, female patients reported a lower SF and a lower QoSL compared with male patients. Another important finding is the fact that not only patients but also their partners (men and women) reported a lower SF and QoSL compared with formerly described populations. In addition, male partners reported a lower SF and a lower QoSL compared with male patients. These findings may be partially explained by the low scores on SF for the female patients, as interdependence between the female patients and their male partners may play a role.

Earlier studies have already reported high levels of psychological distress in patients awaiting a possible cancer diagnosis²³ and recently diagnosed cancer patients²⁴⁻²⁶. Moreover, psychological distress, such as anxiety and depression, is found to be negatively associated with SF²⁷⁻²⁹. In this study, psychosocial factors may also provide the main explanation for the low levels of functioning and QoSL, especially since there was a lack of differences between colon and rectal cancer survivors.

However, even though both patients and their partners reported a lower SF and a lower QoSL, the levels of relationship functioning found in this population did not deviate from the levels reported by the norm population. This study therefore potentially shows that a lower SF and a lower QoSL do not necessarily influence the relationship as a whole.

All in all, this study provides an in depth view of the preoperative SF, QoSL, and relationship functioning in both patients and partners of both sexes. To our knowledge, this has not been done before. In addition, the objectives were assessed with standardized, psychometrically sound questionnaires. Adequate quantitative measures, such as those used in this study, make the results more objective, more reliable, and more replicable.³⁰ Furthermore, 54% of eligible patients agreed to participate which is a good response rate compared with other studies.³¹⁻³³

There are also some limitations that need to be acknowledged. Patients completed the questionnaires after diagnosis; therefore, we cannot make any statements about the SF or QoSL prior to diagnosis. Moreover, as part of the standard care, patients with rectal cancer may already started with neoadjuvant treatments, since not all participants completed the questionnaire immediately after receiving it. Since the time between diagnosis and completing the questionnaires varied, we cannot determine the additional effect of neoadjuvant radio(chemo)therapy on the results of the patients with rectal cancer. However, as mentioned above no difference between patients with colon and rectal cancer was found, therefore, we expect that the specific effect of radio(chemo)therapy on the results was not substantial. Furthermore, important reasons for declining participation were the high levels of experienced stress and the intimate nature of the questions. It is plausible that participants who experienced impairments were inclined to decline participation, which may lead to an underestimation of the current problems. Since the objective was to examine both SF and QoSL, multiple sexuality questionnaires had to be completed. The IIEF and the FSFI were assessed as they focus predominantly on functioning. The GRISS was added since this questionnaire focuses more broadly and gives more weight to the subjective evaluation of the reported functioning. To our knowledge, there is no questionnaire available that adequately measures both SF and QoSL in one questionnaire. Furthermore, the questionnaires lacked clear cutoff scores (for both the different domains as for the total score) which prohibited the stratification of scores in terms of severity. There were only cut-off scores available for the Erectile Functioning scale of the IIEF and the Marital Maladjustment scale of the MMQ. However, there has been a debate on whether or not the cutoff score of ≥ 25 for the IIEF is optimal.³⁴ In order to get some impression of the severity of the impairments, the results were compared with previously described populations. However, these comparison groups were relatively young while colorectal cancer mostly affects the elderly. Satisfactorily assessing

whether colorectal cancer causes an additional negative effect on sexuality requires age- and sex- matched normative data for the questionnaires used; unfortunately, this data is not yet available. However, a recent cross-sectional study analysed the sexuality questions of the European Organization for Research and Treatment of Cancer (EORTC) module Quality of Life Questionnaire – Colorectal 38 (QLQ-CR38) and reported lower SF for colon and rectal cancer survivors compared with an age-matched normative population.²⁸ Based on these results it may be expected that age does not fully explain the lower levels of SF and QoSL in our population compared with the comparison groups.

Future research is needed to make the results obtained in this study more valid (e.g., through the availability of clear cutoff scores and good normative data). In addition, prospective research with a pretreatment or even pre-diagnosis baseline assessment is needed to address the course of SF, relationship functioning, and QoSL over time and to assess the biopsychosocial determinants of impairments. Finally, this study shows that couples experience problems prior to surgery. More information provision and/or psychosexual guidance may be needed preoperatively in order to give license to couples to discuss sexual problems and to search for adequate professional support during any point in treatment. Especially, since the majority of patients do not take the initiative to discuss the treatment options for possible sexual dysfunction.³⁵ In this perspective, qualitative methodologies may also provide helpful insights in the experience and meaning of sexuality during the sequelae of cancer.

Conclusion

A lower SF and a lower QoSL are already reported preoperatively. However, relationship functioning was comparable with a norm population. Consequently, all the impairment seen after surgery should not be solely attributed to the effects of surgery. Therefore, it is a prerequisite that health professionals already address this topic with both the patients and their partners before initiating treatment.

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Biopsychosocial predictors
of sexual function and
quality of sexual life:
a study among patients
with colorectal cancer



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Abstract

Objective

To evaluate (i) relatedness between Sexual Function (SF) and the Quality of Sexual Life (QoSL), (ii) the course of SF and QoSL, and (iii) biopsychosocial predictors of SF and QoSL.

Methods

Patients completed questionnaires assessing sociodemographic factors and personality characteristics before surgery. Questionnaires assessing psychosocial aspects were measured preoperative and three, six, and 12 months after surgery. Clinical characteristics were obtained from the Eindhoven Cancer Registry. Linear mixed-effects models were examined.

Results

SF and QoSL are related constructs ($r=.206$ to $r=.642$). Compared to preoperative scores, SF did not change over time ($p>.05$). Overall, patients' QoSL decreased postoperatively ($p=.001$). A higher age ($\beta=-.02$), fatigue ($\beta=-.02$), not being sexually active ($\beta=-.081$), and having a stoma ($\beta=.37$) contributed to a lower SF ($p's<.05$). Having rectal cancer ($\beta=-1.64$), depressive symptoms ($\beta=-.09$), lower SF ($\beta=1.05$), and more relationship maladjustment ($\beta=-.05$) contributed to a lower QoSL ($p's<.05$). In addition, partners' SF ($\beta=.24$) and QoSL ($\beta=.30$) were predictive for patients' SF and QoSL, respectively. A significant interaction between time and gender was reported for both outcomes ($p's=.002$).

Conclusion

SF and QoSL are related but distinctive constructs. The course of SF and QoSL differed. Different biopsychosocial predictors were found for SF and QoSL. The contribution of partner-related variables to patients' outcomes suggests interdependence between patients and partners. Men and women showed different SF and QoSL trajectories. We recommend that health care professionals pay attention to both SF and QoSL. More in depth research of gender effects and interdependence between patients and partners is needed.

Introduction

Multidisciplinary colorectal cancer treatment may influence patients' SF (e.g., erectile or ejaculatory dysfunction in men and dyspareunia and lubrication problems in women).¹ However, demographic factors (e.g., age, sex), psychological issues (e.g., mood, body image), and social aspects (e.g., patients' and partners' relationship adjustment) may also have a direct or indirect effect on patients' Sexual Function (SF). Therefore, SF may be best understood from an integrative biopsychosocial model.^{2,3}

One may assume that if patients experience sexual dysfunction after colorectal cancer treatment they would also report a lower Quality of Sexual Life (QoSL), since these concepts are related. However, this is not necessarily true. Sexual (dys)function refers to (dys)function in a part of the sexual response cycle³ (i.e., desire, excitement, orgasm, and resolution)^{4,5} or pain associated with intercourse⁵, while the QoSL takes the person's subjective evaluation of this functioning into account.^{1,3} Patients may not be bothered with sexual dysfunction if they employ other ways to establish a satisfactory sexual relationship.^{2,4} For instance, intimacy (e.g., hugging/kissing) has been reported as more important than being able to have sexual intercourse.⁶ On the other hand, patients may report a low QoSL without an apparent sexual dysfunction.^{2,4}

To our knowledge, no study has yet evaluated to what extent SF and QoSL are related. Furthermore, only one cross-sectional study examined SF using a biopsychosocial approach.⁷ In this study, older age, having received an abdominoperineal resection, and poor social support were associated with low SF in men, while low SF in women was associated with higher age and poor global quality of life.⁷ Finally, while treatment-related factors were related to sexual satisfaction and/or sexual enjoyment¹, no study has evaluated biopsychosocial predictors of QoSL.¹

Therefore, this study aimed to evaluate (i) relatedness between SF and QoSL, (ii) the course of SF and QoSL, and (iii) biopsychosocial predictors of SF and QoSL during the first year after colorectal cancer surgery.

Methods

Patients

Data were drawn from a larger study examining the (sexual) consequences of colorectal cancer for patients and their partners (NCT01234246). For this study, patients were recruited from six Dutch hospitals: St. Elisabeth hospital (Tilburg), TweeSteden Hospital (Tilburg and Waalwijk), Catharina Hospital (Eindhoven), Jeroen Bosch Hospital ('s Hertogenbosch), Amphia Hospital (Breda), and Maxima Medical Centre (Eindhoven and Veldhoven). To be eligible for participation, patients and partners had to be older than 18 years. Patients were excluded if one or more of the following criteria was applicable: (i) elderly age (>75 years), (ii) non-curatively treated metastases at baseline, (iii) poor expression of the Dutch language, (iv) dementia, and/or (v) a history of psychiatric illness. In order to prevent a selection bias, all partners with sufficient knowledge of the Dutch language and without dementia or a history of psychiatric illness were still invited to participate even if patients declined participation (and *vice versa*). During a preoperative visit eligible patients and partners were asked, by their treating physician, if they gave permission to be approached by a member of the research team. Subsequently, this member contacted the potential participants by phone to explain the design and purpose of the study. If patients and/or partners agreed to participate they were asked to complete a set of questionnaires at home before surgery (Time-0) and three (Time-1), six (Time-2), and 12 months (Time-3) postoperative. However, the Dutch guidelines recommend that rectal cancer patients, except those with a clinical T1 stage without positive lymph nodes, receive neoadjuvant treatments (i.e., radio(chemo)therapy; www.oncoline.nl). Therefore, a subset of patients completed the first set of questionnaires prior to surgery, but potentially during or after the time patients received neoadjuvant therapy. Participants returned the surveys in sealed postage-paid envelopes. Participants who did not return the questionnaires within two weeks received reminders (phone call(s) and/or a reminder letter). This study was approved by the institutional review board. All participants gave written informed consent.

Measures

The patient's clinical information was retrieved from the Eindhoven Cancer Registry (ECR). The ECR routinely collects data on tumor characteristics and treatment. If needed, additional clinical information was retrieved from the patient's medical records. Patients also completed questions regarding their age, sex, and length of the relationship with their partner.

Two aspects of the patients' personality were assessed. Neuroticism was assessed with the Neuroticism facet of the Neuroticism-Extraversion-Openness-Five Factor Inventory (NEO-FFI).⁸⁻¹⁰ This factor assesses six aspects belonging to neuroticism (i.e., anxiety, hostility,

depression, self-consciousness, impulsiveness, vulnerability to stress). Trait anxiety was evaluated with the Dutch short form trait scale of the Spielberger State-Trait Anxiety Inventory (STAI).¹¹ The trait anxiety scale describes how persons generally feel and conceives anxiety as a personality disposition.

Patients' psychological function was assessed with four constructs, specifically, body image, state anxiety, depressive symptoms, and fatigue. Body image was evaluated with the Body Image scale.^{12,13} Depressive symptoms were evaluated with the 16-item version of the Center for Epidemiological Studies- Depression Scale (CES-D).¹⁴ State anxiety was assessed with the short form (6-items) of the STAI state anxiety scale.¹⁵ State anxiety is a momentary emotional condition characterized by subjective feelings of apprehension and tension, and heightened autonomic nervous system activity and may thus vary in intensity and fluctuate over time.¹⁶ Fatigue was evaluated with the Fatigue Assessment Scale (FAS).¹⁷ The FAS assessing perceived fatigue and exhaustion. NB: Fatigue was in this study for clarity purposes seen as a psychological factor, even though we know that fatigue is a multidimensional construct encompassing both physical and psychological aspects.

Social characteristics (i.e., sexual activity, SF, non-sensuality, avoidance, non-communication, relationship adjustment,) were completed by both patients and partners, except for sexual activity, which was only completed by patients due to redundancy. Patients' sexual activity was assessed with the question 'To what extent were you sexually active (with/without sexual intercourse)?' from the European Organization for Research and Treatment of Cancer (EORTC) disease specific ColoRectal 38 (QLQ-CR38).¹⁸ QoSL was evaluated with the Sexual Activity facet of the World Health Organization Quality of Life assessment (WHOQOL-100).^{19,20} This facet contains the following items: 'How would you rate your sex life?', 'How well are your sexual needs fulfilled?', 'How satisfied are you with your sex life?', and 'Are you bothered by any difficulties in your sex life?' SF was evaluated with two sex-specific questionnaires. Men completed the Erectile Function, Orgasmic Function, and Sexual Desire domains of the International Index of Erectile Function (IIEF).²¹ Women completed the Arousal, Lubrication, Orgasmic Function, Sexual Desire, and Sexual Pain domains of the Female SF Index (FSFI).^{22,23} If needed, patients could indicate that an item was not applicable. For the IIEF the total score was computed as the sum of at least five items and, thus, up to five items were person-mean imputed. For the FSFI, domain scores were obtained following the standard scoring instruction. The IIEF and FSFI total scores were transformed into standardized z-scores. The z-scores were subsequently combined to obtain one SF score. Next, patients and partners completed the Avoidance, Non-Communication, and Non-Sensuality domains of the Golombok-Rust Inventory of Sexual Satisfaction (GRISS).²⁴ The GRISS has

separate versions for men and women; however, the Avoidance, Non-Communication, and Non-Sensuality domains are comparable for both sexes. Finally, relationship (mal)adjustment was assessed with the Marital (Mal)adjustment scale of the Maudsley Marital Questionnaire (MMQ).²⁵⁻²⁷ Sociodemographic factors and personality characteristics were assessed only at Time-0, while all other questionnaires were completed at each time point (Time-0 – Time-3). The psychometric properties of all questionnaires were satisfactory.

Statistical Analyses

An independent *t*-test and Chi-square tests were used to examine potential differences in age, sex, and type of tumor for participants and non-participants. Bivariate correlations between SF and QoSL were at each time point assessed with the Pearson correlation coefficient. Correlations were grouped into small ($r < .30$), moderate ($r = .30-.49$), or high ($r > .49$).²⁸ Linear mixed-effects models with an unspecified covariance pattern model were used to examine (i) the course of SF and QoSL and (ii) identify predictors for both constructs. Linear mixed-effects models has a comparable purpose as repeated measures (multivariate) analysis of variance ((M)ANOVA) and can be seen as a linear regression analysis that takes into account the correlational structure of repeated measures.²⁹ However, mixed-effects models uses all complete time points whereas in repeated measures (M)ANOVA patients with any missing observation are omitted from the analysis entirely.²⁹ Therefore, mixed-effects models are more efficient and more robust to missing data.²⁹ Time was analysed as a categorical predictor with four levels (i.e., Time-0, Time-1, Time-2, and Time-3). The fixed-effects parameters of the models were estimated with maximum likelihood. Sociodemographic variables (i.e., age, sex), clinical variables (i.e., tumor type, type of surgery, type of radiotherapy, chemoradiation (yes/no), type of chemotherapy, stoma status), and personality characteristics (i.e., trait anxiety and neuroticism) were analysed as time-invariant predictors as they were only assessed at baseline. Psychological variables and symptoms (i.e., anxiety, depressive symptoms, body image, and fatigue), patient-related social variables (i.e., sexual activity, relationship adjustment, SF, non-sensuality, avoidance, non-communication), and partner-related social variables (i.e., SF, relationship adjustment, QoSL, non-sensuality, avoidance, non-communication), were measured at each time point and thus analysed as time-varying predictors.²⁹

Analyses proceeded in three steps. In order to obtain an acceptable number of variables entered in the final model a selection procedure was performed first. This selection procedure entailed that a basic set of predictors (i.e., age, sex, and type of tumor, Block 1) was formed to which, in separate analyses, a specific block of predictors was added. Thus, a forward selection method was chosen. The following sets were formed: basic set of predictors (Block 1), basic set

+ personality characteristics (Block 2), basic set + psychological variables (Block 3), basic set + patient-related social factors (Block 4), basic set + partner-related social factors (Block 5), and basic set + clinical characteristics (Block 6). These sets were formed based on content. To minimize data-driven choices and to identify a parsimonious model, a $p < .10$ was used during the selection procedure. Significant predictors were subsequently evaluated in a final model. If the effect of time-varying predictors was significant in the final model, then the effect was split into two effects in the second part of the analysis: between-subjects effects (e.g., the degree to which patients' SF/QoSL is related to their average level on a predictor) and within-subjects effects (e.g., the degree to which variation in patients' SF/QoSL over time is associated with a change in their levels on a predictor). Finally, in the third part of analyses, the interaction between time and gender and time and type of tumor was evaluated for both outcomes.

In order to correctly interpret all model parameters, all time-varying variables have been grand-mean centered. Analyses were performed in IBM SPSS 19.0, using a significance level of $p \leq .05$ (with exception of the selection procedure).

Results

Participants

In total, 672 eligible patients agreed to be contacted by a member of the research group, who informed them about the study. Of them, 313 (47%) patients agreed to participate; 64% of patients with rectal cancer participated and 50% of the patients with colon cancer participated ($p = .001$). Fewer women (38%) than men (62%) were approached for this study. In addition, women less often participated (43%) than men (66%). Of the 313 patients, 279 (89%) had a partner of which 205 (74%) participated. Since partner-related variables were taken into account in this paper, only couples were included in the analyses ($n = 205$). Of these 205 couples, 42 patients and 40 partners did not complete Time-0 since the time between study recruitment and surgery was too short. At Time-1, 148 patients and 141 partners participated (missing: 10/10; dropout: 23/28; not yet completed Time-1: 25/27, respectively). At Time-2, 123 patients and 114 partners participated (missing: 14/14; dropout: 35/35; ongoing: 35/35, respectively). Finally, at Time-3, 104 patients and 89 partners participated (missing: 3/7; dropout: 49/60; ongoing: 49/49, respectively). For patients, time-invariant characteristics are presented in **Table 1** while time-varying factors are presented in **Table 2**.

Table 1 Descriptives for the time-invariant predictors

	Patients (n=205)
	Mean±SD
Age at time of survey	62.0±8.6
Relationship in years	35.9±16.3
Neuroticism	27.1±6.7
Trait anxiety	16.6±4.8
	N (%)
Male sex	146 (71.2%)
Type of cancer	
Colon	125 (61.0%)
Rectum	80 (39.0%)
Type of surgery	
Low anterior resection	84 (41.0%)
Abdominoperineal resection	35 (17.1%)
Hemicolectomy/ileocecal resection	29 (14.1%)
Sigmoid resection	27 (13.2%)
Other	27 (13.2%)
Unknown type of surgery	3 (1.5%)
Type of radiotherapy (RT)	
No RT	135 (65.9%)
Preoperative RT	42 (20.5%)
Intra-Operative RT	19 (9.3%)
Other RT	5 (2.5%)
Unknown	4 (2.0%)
Chemoradiation	
No	125 (61.0%)
Yes	74 (36.1%)
Unknown	5 (2.4%)

	Patients (n=205)
	N (%)
Type of chemotherapy (CT)	
No CT	145 (70.7%)
Postoperative CT	50 (24.4%)
Other CT	7 (3.5%)
Unknown	3 (1.5%)
Stoma	
Yes	122 (59.5%)
No	79 (38.5%)
Unknown	4 (2.0%)

Note: Neuroticism range = 12-60. Trait anxiety range = 10-40.

Table 2 Descriptives for the time-varying predictors

	Time-0	Time-1	Time-2	Time-3
	Mean±SD	(M±SD)	(M±SD)	(M±SD)
QoSL (WHOQOL-100)				
patients	13.4±3.6	12.1±3.6	12.1±6.0	12.5±3.9
partners	13.6±3.4	12.1±3.2	12.1±3.3	12.4±3.4
Relationship (mal)adjustment (MMQ)				
patients	13.3±7.2	13.7±9.2	14.7±8.4	14.9±8.4
partners	14.5±8.2	15.7±8.5	16.0±8.9	15.8±10.3
SF (z-score)				
patients	-2.5±1.0	-2.1±1.0	-1.3±1.0	-1.4±1.0
partners	-2.4±1.0	-1.7±1.0	-1.3±1.0	-1.3±1.0
Non-sensuality (GRISS)				
patients	6.4±2.9	7.1±2.8	7.3±3.2	7.1±3.1
Avoidance (GRISS)				
patients	5.3±2.6	5.8±2.8	5.8±2.5	5.7±2.7
Non-Communication (GRISS)				
patients	5.1±1.8	5.6±2.8	5.2±1.8	5.2±1.9
Depressive symptoms (CES-D)				
patients	5.9±6.7	5.64±5.6	5.8±6.5	4.8±6.1
Body Image (BIS)				
patients	24.5±13.4	18.7±8.3	17.8±7.2	18.5±8.0
Fatigue (FAS)				
patients	19.5±5.7	22.2±6.6	21.8±7.1	20.3±6.3

Abbreviations: Time-0: Preoperative measurement, Time-1: 3 months follow-up, Time-2: 6 months follow-up, Time-3: 12 months follow-up. BIS: Body Image Scale [range 10-40], CES-D: Center for Epidemiological Studies-Depression Scale [range 0-48], FAS: Fatigue Assessment Scale [range 10-50], GRISS: Golombok-Rust Inventory of Sexual Satisfaction, MMQ: Maudsley Marital Questionnaire [range 0-80], QoSL: Quality of Sexual Life, SF: Sexual Function, STAI: Spielberger State-Trait Anxiety Inventory [range 4-24], WHOQOL-100: World Health Organization Quality of Life assessment [range 4-20].

Note: Higher scores indicate more problems, except for the QoSL and SF domains. For these domains higher scores indicate a higher QoSL or SF, respectively.

Relationship between SF and QoSL

At each time point a significant association was reported between SF and QoSL. At Time-0 a moderate correlation was reported ($r=.47, p=.01$), while at Time-1 a high association was noted ($r=.64, p=.01$). The correlation decreased at Time-2 ($r=.21, p=.05$), but subsequently increased to the baseline level at Time-3 ($r=.45, p=.01$).

Course and predictors of patients' SF

The selection procedure showed that a higher age ($p=.002$, Block 1), having rectal cancer ($p=.001$, Block 1), more anxiety ($p=.009$, Block 3), more depressive symptoms ($p=.004$, Block 3), more fatigue ($p=.001$, Block 3), not being sexually active ($p<.001$, Block 4), more non-sensuality ($p=.006$, Block 4), higher levels of partners' SF ($p<.001$, Block 5), and not having a stoma ($p=.011$, Block 6) predicted the course and level of patients' SF and were, therefore, included in the final model (Table 3, Part I).

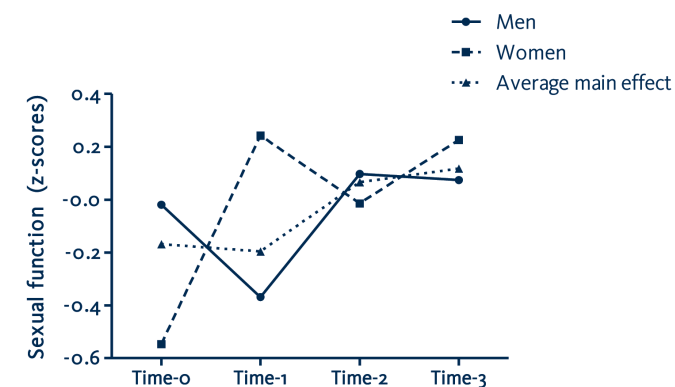
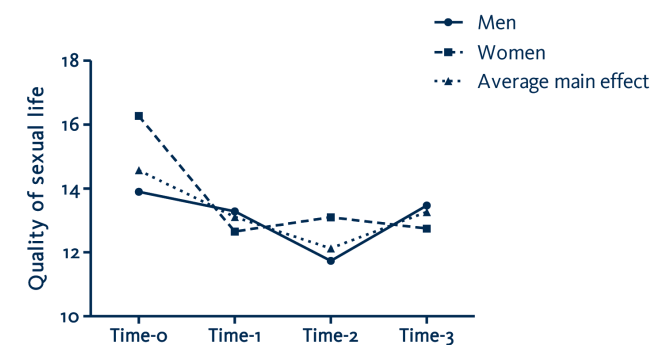
In this final model the Estimated Marginal Means (EMM) showed a non-significant change in SF over time ($p>.05$). A higher age ($\beta=-.02$), more fatigue ($\beta=-.02$), no sexual activity ($\beta=-.81$), higher partners' SF ($\beta=.24$), and having a stoma ($\beta=.24$) contributed significantly to patients' lower SF ($p<.05$). For the significant time-varying predictors, the between- and within-subject analyses showed that patients who on average reported not to be sexually active had on average lower levels of SF (between-subjects effect, $\beta=1.03, p<.001$, Table 3, Part II). Moreover, patients that showed a positive change in sexual activity on a time point also showed a positive change in SF (within-subjects effect, $\beta=.62, p=.001$). Patients that on average were more tired scored on average lower on SF (between-subjects effect, $\beta=-.03, p=.012$). Finally, if the partners reported on average higher SF this predicted on average better SF for the patients (between-subjects effect, $\beta=.32, p=.001$).

Finally, there was a significant interaction effect between time and gender ($p=.002$, see Figure 1^a and Table 3, Part III). Overall, the scores on SF fluctuated across time, but the difference between men and women was only significant at Time-1. At this time point women reported significantly higher SF (EMM=.24) than men (EMM=-.37, $p=.005$). The interaction between time and type of tumor was not significant (results not shown).

Table 3 Estimates of fixed effects for SF

Predictor ^a	B	SE	Sig.	95% CI	
				Lower Bound	Upper Bound
Part I					
Time^b			.093		
Time-0 (intercept)	0.05	0.23	.838	-0.41	0.50
Time-1 – Time-0	-0.04	0.16	.815	-0.36	0.28
Time-2 – Time-0	0.22	0.15	.164	-0.09	0.52
Time-3 – Time-0	0.29	0.16	.070	-0.02	0.59
Age	-0.02	0.01	.006	-0.04	-0.01
Male sex	-0.05	0.13	.731	-0.31	0.22
Having rectal cancer	-0.12	0.17	.474	-0.46	0.22
Anxiety	-0.01	0.02	.626	-0.05	0.03
Depressive symptoms	0.01	0.01	.505	-0.01	0.03
Fatigue	-0.02	0.01	.034	-0.04	0.00
Not being sexual active	-0.81	0.15	<.001	-1.11	-0.51
Non-sensuality	-0.04	0.02	.065	-0.08	0.00
Not having a stoma	0.37	0.17	.035	0.03	0.71
Partners SF	0.24	0.07	<.001	0.10	0.38
Part II					
1. Fatigue: between	-0.03	0.01	.012	-0.06	-0.01
Fatigue: within	-0.01	0.01	.548	-0.03	0.02
2. Not being sexual active: between	1.03	0.22	<.001	0.60	1.46
Not being sexual active: within	0.62	0.18	.001	0.25	0.98
3. Partners' SF: between	0.32	0.09	.001	0.14	0.49
Partners' SF: within	0.16	0.09	.099	-0.03	0.34
Part III					
Interaction effect Sex*Time^b			.002		
Sex at Time-0	0.53	0.27	.054	-0.01	1.06
Sex at Time-1 ^c	-0.61	0.22	.005	-1.04	-0.19
Sex at Time-2 ^c	0.11	0.17	.519	-0.23	0.46
Sex at Time-3 ^c	-.157	0.19	.427	-0.52	0.22

Note: Time-0: Preoperative measurement, Time-1: 3 months follow-up, Time-2: 6 months follow-up, Time-3: 12 months follow-up. Statistically significant results ($p < .05$) are shown in bold. ^a All predictors (except Time) are grand-mean centered. ^b Analysis of Variance (ANOVA) type III test. ^c Post-hoc test of simple effects.

Figure 1 Interaction effects for time and gender**1a. Interaction between time and gender for sexual function****1b. Interaction between time and gender for the quality of sexual life**

Course and predictors of patients' QoSL

The selection procedure showed that having rectal cancer ($p < .001$, Block 1), higher levels of neuroticism ($p = .037$, Block 2), more depressive symptoms ($p = .003$, Block 3), lower body image ($p = .019$, Block 3), better SF ($p < .001$, Block 4), better relationship adjustment ($p = .001$, Block 4), more avoidance ($p = .009$, Block 4), better partners' SF ($p = .005$, Block 5), higher partners' QoSL ($p < .001$, Block 5), and not having a stoma ($p = .020$, Block 6) predicted the course and levels of QoSL.

The EMM of the final model showed that QoSL at Time-0 was 15.8 which decreased 1.4 points to 14.4 at Time-1, then decreased a little further to 13.4 at Time-2, and finally increased slightly to an EMM of 14.4 at Time-3 ($p < .001$, **Table 4, Part I**). In this model, having rectal cancer ($\beta = -1.64$), more depressive symptoms ($\beta = -.09$), lower SF ($\beta = 1.05$), more relationship (mal) adjustment ($\beta = -.05$), and lower partners' QoSL ($\beta = -.30$) contributed significantly to a lower QoSL for the patients ($p < .05$).

The between- and within-subjects analyses (**Table 4, Part II**), showed that patients with more depressive symptoms or higher relationship maladjustment on a time point also reported a negative change in QoSL on that time point (within-subject effects, $\beta = -.11$ ($p = .009$) and $\beta = -.07$ ($p = .047$), respectively). Patients who on average reported a lower SF had on average lower levels of QoSL (between-subjects effect, $\beta = 1.36$, $p < .001$). Moreover, patients who showed change in SF on a time point also showed a change in the QoSL (within-subjects effect, $\beta = .67$, $p = .039$). If partners on average reported higher QoSL then patients, on average, also scored higher on QoSL (between-subjects effect, $\beta = 0.30$, $p = .001$). Also, if partners changed in their QoSL, then patients' QoSL also changed (within-subjects effect, $\beta = .30$, $p = .001$).

The interaction between time and gender was significant ($p = .002$, see **Figure 1^b** and **Table 4, Part III**). Compared with Time-1, women showed lower but comparable QoSL scores at the subsequent time points. However, the pattern for men differed. Men's QoSL decreased at Time-1 and continued to drop at Time-2, but finally increased somewhat at Time-3. At Time-0, women had a significantly higher QoSL than men ($p = .002$, EMM=16.3 and 13.9, respectively). In addition, men scored significantly lower (EMM=11.7) than women (EMM=13.1) at Time-2 ($p = .035$). Again, the interaction between time and type of tumor was not significant (results not shown).

Table 4 Estimates of fixed effects for QoSL

Predictor ^a	B	SE	Sig.	95% CI	
				Lower Bound	Upper Bound
Part I					
Time^b			<.001		
Time-0 (intercept)	15.78	0.68	<.001	14.42	17.13
Time-1 – Time-0	-1.44	0.43	.003	-2.31	-0.56
Time-2 – Time-0	-2.38	0.50	<.001	-3.38	-1.37
Time-3 – Time-0	-1.41	0.45	.002	-2.32	-0.49
Age	0.02	0.02	.377	-0.03	0.07
Male sex	-0.78	0.42	.066	-1.61	0.05
Having rectal cancer	-1.64	0.53	.003	-2.70	-0.58
Neuroticism	-0.03	0.03	.391	-0.09	0.04
Depressive symptoms	-0.09	0.03	.001	-0.15	-0.04
Body image	-0.05	0.03	.081	-0.11	0.01
SF	1.05	0.22	<.000	0.61	1.48
Relationship maladjustment	-0.05	0.02	.027	-0.09	-0.01
Avoidance	-0.04	0.08	.670	-0.20	0.13
Partners' SF	0.20	0.24	.392	-0.26	0.67
Partners' QoSL	0.30	0.06	<.001	0.17	0.43
Not having a stoma	-0.12	0.53	.815	-1.17	0.93
Part II					
1. Depressive symptoms: between	-0.08	0.04	.073	-0.02	0.01
Depressive symptoms: within	-0.11	0.04	.009	-0.18	-0.03
2. SF: between	1.36	0.28	<.001	0.79	1.92
SF: within	0.67	0.31	.039	0.03	1.28
3. Relationship maladjustment: between	-.03	0.03	.232	-0.09	0.02
Relationship maladjustment: within	-0.07	0.04	.047	-0.14	-0.00
4. Partners' QoSL: between	0.30	0.08	.001	0.13	0.47
Partners' QoSL: within	0.30	0.09	.001	0.12	0.49
Part III					
Interaction effect Sex*Time^b			.002		
Sex at Time-0	-2.37	0.69	.002	-3.78	-0.95
Sex at Time-1 ^c	0.63	0.61	.301	-0.59	1.85
Sex at Time-2 ^c	-1.36	0.63	.035	-2.62	-0.10
Sex at Time-3 ^c	0.73	0.89	.411	-1.03	2.48

Note: Time-0: Preoperative measurement, Time-1: 3 months follow-up, Time-2: 6 months follow-up, Time-3: 12 months follow-up. Statistically significant results ($p < 0.05$) are shown in bold. QoSL: Quality of Sexual Life. ^a All continuous predictors (except Time) are grand-mean centered. ^b Analysis of Variance (ANOVA) type III test ^c Post-hoc test of simple effects

Discussion

Compared to the preoperative scores, patients' SF did not change significantly during the first year after surgery. However, the course of patients' QoSL did change. Compared to the preoperative assessment, patients' QoSL was significantly lower at three, six, and 12 months postoperative. Evaluating biopsychosocial predictors of patients' SF and QoSL revealed that a higher age and having a stoma contributed to lower scores on SF, but did not contribute to QoSL. The association between sexual dysfunction and a higher age^{1,2} and having a stoma^{1,30,31} has been previously reported. Furthermore, patients who on average were more tired scored on average lower on SF, but this association was not found for the QoSL. This result is in line with a previous cross-sectional among colorectal cancer survivors.³² Moreover, mood (i.e., anxiety and depressive symptoms) did not predict SF, but depressive symptoms on a time point did predict a negative change in QoSL on that time point. In previous research, results are mixed. Milbury *et al.*, 2013⁷ did not find a significant association between depressive symptoms and SF, while depressive symptoms were associated with both SF and sexual enjoyment in the study of Den Oudsten *et al.*, 2012³². Therefore, more research examining the relationship between fatigue and SF and QoSL is still needed.

Several observations regarding the relatedness between SF and QoSL can be made. Patients that on average reported a lower SF had on average lower levels of QoSL and a change in SF on a time point also predicted a change in QoSL at the that time point. This finding supports the idea that the constructs SF and QoSL are inter-related. However, a high correlation between SF and QoSL was only reported at Time-1. Thus, even though these concepts are related, they may be best viewed as separate constructs. The distinction between both constructs is further supported by the fact that different predictors were found for the QoSL and SF (see above). Finally, this study indicates that SF, relationship (mal)adjustment, and QoSL can be conceptualized as constructs ranging from narrow to broad: Being sexually active (with or without sexual intercourse) was both between- and within-subjects associated with SF, but not with the QoSL. Additionally, higher relationship maladjustment on a time point predicted a negative change in QoSL on that time point, but relationship maladjustment did not predict SF.

Another interesting finding is that partners' SF and QoSL were predictive for patients' SF and QoSL, respectively. Therefore, interdependence between patients and partners seems present. While previous research has already addressed the importance of evaluating and addressing the consequences of cancer from a couple-based perspective³³⁻³⁵, this is the first study that incorporated partner-related variables as predictors for patients' SF and QoSL. Future studies are required to more specifically evaluate interdependence between patients' and partners' SF and QoSL.

Few clinical variables were significant predictors of patients' SF and QoSL. Not having a stoma was predictive for better SF while having rectal cancer predicted a lower QoSL. The lack of other significant clinical predictors may seem remarkable as earlier studies have shown that radiotherapy³⁶⁻³⁸, but especially surgical nerve damage (which can be roughly estimated based on type of surgery) seems to play an important role in the occurrence of sexual dysfunction.³⁸ However, type and location of the tumor leads to a protocolled treatment schedule. The presence of inherent multicollinearity between the treatment related variables makes it difficult to find significant unique effects of each variable separately, especially since the number of patients included in the analyses was limited.

An important methodological consideration that needs to be acknowledged concerns the questionnaires used in the current study. While validated and reliable questionnaires were used, a difficulty lied in obtaining one SF score (regardless of gender). For men, aspects such as erectile and ejaculatory (dys)function were measured while women answered questions regarding problems with lubrication or pain during intercourse. Therefore, sex-specific sum scores were transformed into z-scores and combined in one SF score. This resulted in a loss of information. Unfortunately, it was not possible to evaluate the specific effects of each SF domain on the QoSL for men and women separately, due to a limited sample size. However, the significant interaction between time and gender showed that the SF and QoSL trajectories are different for men and women. Therefore, future more in-depth studies in this area are still warranted.

Conclusion

This study shows that SF and QoSL are related but distinctive constructs, for which different biopsychosocial predictors were identified. SF did not change significantly over time, while the QoSL decreased from Time-0 to Time-1 and Time-2 and finally increased somewhat at Time-3. Therefore, it is important that health care professional not only pay attention to the patient's SF, but also to his/her QoSL. The significant contribution of partners' SF and QoSL to patients' SF and QoSL suggests interdependence between patients and partners. Finally, the significant interaction between time and gender suggest that SF and QoSL trajectories differ for men and women. Future research is needed in order to evaluate gender effects and interdependence between patients and partners more in depth.

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Dyadic coping and
relationship functioning in
couples coping with cancer:
a systematic review



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Abstract

Objectives

Cancer not only affects the patient but also the partner. In fact, couples may react as a unit rather than as individuals while coping with cancer (i.e., dyadic coping). We assessed (i) the relationship between dyadic coping and Relationship Function (RF) in couples coping with cancer and (ii) whether intervention studies aimed at improving dyadic coping were able to enhance the RF of these couples. Recommendations for future studies are provided.

Method

A systematic search was conducted to identify all eligible papers between January 1990 and September 2012. The databases PubMed, PsycINFO, the Cochrane Library, and EMBASE were screened.

Results

Most studies ($n=33$) used an appropriate study design, adequate measurements, adequate analytical techniques, and a sufficient number of included participants to answer addressed research questions. However, the definition and assessment of dyadic coping strategies differed, which hampered comparison. Coping styles characterized by open and constructive (cancer-related) communication, supportive behaviors, positive dyadic coping, and joint problem solving were related with higher RF, whereas dysfunctional communication patterns (e.g., protective buffering, demand-withdraw communication), unsupportive behaviors, and negative dyadic coping were related with RF. The results of the intervention studies were inconsistent: while some studies reported a beneficial effect on RF, other studies report no such effect, or only found a positive effect in couples with fewer personal relationship resources.

Conclusions

This review showed that adequate dyadic coping may improve RF, while dysfunctional dyadic coping may impede RF. In order to increase the comparability of the reported findings, a more uniformly conceptualized perspective on dyadic coping is needed. A better understanding of the dyadic challenges couples coping with cancer may face and more insight on how to expand the dyadic coping of these couples may facilitate improvements in the quality of cancer care. Couple-based intervention studies may increase the couples' RF. However, future research is needed to examine more specifically which couples may benefit from such interventions.

Statement of contribution

'What is already known on this subject?'

Dyadic coping may influence the distress experienced by both members of the couple and their Relationship Function (RF). Several reviews already reported on the potential of couple-based interventions to improve the dyadic coping of couples coping with cancer and on the beneficial effects of this coping on the psychosocial adjustment and RF of patients and partners.¹³ However, even though we now know that couple-based intervention might be useful, no systematic review has been conducted that focuses specifically on the mechanisms of dyadic coping itself.

'What does this study add?'

This review showed the importance of stress communication, supportive behaviors, and positive dyadic coping for the maintenance or enhancement of RF in couples coping with cancer. In addition, the dyadic intervention studies send an important message that encourages to further examine the potential benefit of such interventions in the future. However, more consensus in the conceptualization and assessment of the dyadic coping styles is needed in order to increase the comparability of the reported findings.

Introduction

There is a growing awareness that a cancer diagnosis and its subsequent treatment not only affects the patient, but also the partner. Patients with cancer and their partners experience great levels of psychosocial distress⁴, which are higher than the levels of psychosocial distress in the general population.⁵⁻⁸ Having to incorporate ongoing cancer-related experiences may also influence the quality of life of patients and partners.⁹

Cancer and other chronic illnesses were for a long time viewed as individual stress experiences demanding individual coping efforts. However, since the 1990's researchers started to consider stress and coping as interpersonal processes¹⁰⁻¹² Consequently, the partner's burden caused by the patient's illness started to be considered.^{13,14} The interdependence between patients and partners was further supported by a meta-analysis indicating a relevant intercorrelation between the psychological distress of patients and partners.¹⁵ Therefore, a solely individualistic view, where patient and partner experience cancer separately and deal with it in a role-related perspective (as patient and caregiver), seems outdated. Instead, cancer or other severe chronic illnesses may be best considered as stressors concerning both partners simultaneously (cancer as a "we-disease"^{16,17}).

In 2005, Bodenmann defined 'dyadic stress' implying that a stressful event or encounter always concerns both partners either directly, if both partners are confronted by the same stressor or when the stress originates inside the relationship, or indirectly when the stress of one partner spills over to the relationship and in that way affects both partners.¹⁸ Cancer represents such a dyadic stressor; cancer not only threatens the patients' life, which demands restoring his/her physical, psychological, and social homeostasis, but is also stressful for the other partner. The partner has to adapt to the patients' illness, has worries about the patient, is burdened by taking over the patient's tasks and by providing support and caring, experiences important restrictions in his/her social life, might suffer from economic consequences, and/or is threatened by an insecure future.

Beyond and above individual coping, dyadic coping is an additional form of (dyadic) stress management.^{19,20} Dyadic coping can be defined as the attempt of one member of the dyad to help reduce the stress perceived by the other member of the dyad and as a common endeavor to cope with stress that originates inside the relationship.¹⁰ This coping process is regarded as a circular bidirectional sequence that is influenced by interdependence of partners.^{21,22} There is empirical evidence that dyadic coping involves stress communication and support exchange, but is more than social support.²³ Dyadic coping entails that both partners are mutually involved in the stress coping process; providing and receiving support from each other and engaging in joint problem-solving activities and shared emotion regulation.^{10,23} Therefore, couples may react as a unit rather than as individuals in the face of cancer.^{15,24,25}

Different dyadic coping theories have emerged, which all recognize interdependence between both members of the dyad.^{10,11,25-28} Most dyadic coping theories emphasize that dyadic coping does not only entail congruence in the individual coping of both members of the dyad, but represents an interpersonal form of coping that goes beyond individual coping congruence or discrepancy.^{10,11,21,25} According to the Systemic-Transactional Model^{10,28} (STM), the dyadic coping process is an interplay between (non) verbal stress signals of one or both members of the dyad (e.g., stress communication), the perception and decoding of these signals by the other partner and his/her reactions (e.g., (un)supportive behaviors), and joint dyadic coping efforts. Joint (or common) dyadic coping will be likely when both partners are similarly concerned by the stressor and perceive it as a 'we-stress'. Hereby, the level of distress and Relationship Function (RF) not only depends on the extent to which both partners cope together but also on the quality and effectiveness of their coping attempts.²⁹

As mentioned above, dyadic coping has two primary objectives: the reduction of distress for both members of the dyad and the preservation or enhancement of RF.²¹ In this review, we chose to focus on the latter objective of dyadic coping (i.e., RF). Conceptually RF refers to an ever-changing process with a qualitative dimension which can be evaluated in any point in time

on a dimension ranging from adjusted to maladjusted.³⁰ Deterioration of RF is often presumed to be related with chronic everyday stress or major stress events, such as cancer, that have an important impact on the couple or are poorly handled.³¹ However, maintaining a satisfying RF during and after the treatment of cancer is important, because RF is a key predictor of a person's well-being.^{32,33} Dyadic coping may reduce stress in both partners 'a sorrow shared is a sorrow halved' but, and even more importantly, increases mutual confidence, intimacy, and cohesion.^{18,34}

In sum, couples may react as a unit rather than as individuals when coping with cancer, which influences the distress experienced by both members of the couple and might impact their RF. The importance of adopting a couple-based perspective to coping with cancer has been acknowledged by several systematic reviews and meta-analyses.^{1-3,15} These reviews reported on the benefits of couple-based interventions to improve quality of life.¹⁻³ In addition, they reported potential beneficial effects of this dyadic coping on the psychosocial adjustment and RF of patients and partners.¹⁻³ However, even though we know that couple-based intervention might be useful, no systematic review has been conducted that focuses specifically on dyadic coping itself.

Therefore, the primary aim of the current systematic review was to examine which forms of dyadic coping are related with RF in couples coping with cancer. In order to provide a complete view we additionally described if intervention studies aimed at improving dyadic coping were able to enhance the RF of these couples.

Methods

Search strategy

A systematic computerized search was performed in Pubmed, EMBASE, PsycINFO, and the Cochrane Library. All searches were performed on 3 September 2012. The databases were searched with combinations of (i) neoplasms [Mesh], neoplasm* OR tumor* OR tumour* OR cancer* OR lymphoma* OR malignan* OR oncolog* OR carcinom* OR melanom*, (ii) partners [Mesh] OR couple* OR partner* OR marit* OR dyad*, (iii) intimacy OR distress OR communication [Mesh] OR support* OR sexuality [Mesh] OR adjustment, and (iv) psychological OR psychosocial OR "quality of life" [Mesh]. The search was restricted to studies published between January 1990 and September 2012 because the concept of dyadic coping has been evaluated in couples coping with cancer since the early 1990's. The reference lists of the retrieved studies and other key reviews^{1-3,25,35} were checked in order to capture other relevant publications, which were not found in the computerized database searches.

Selection criteria

All studies that met the following criteria were included: (i) the primary or secondary objective of the article was to evaluate the relationship between dyadic coping and RF, (ii) the population studied consisted of both patients and their partners (studies including children or other family members, without separate partner analyses, were excluded), (iii) the cancer was diagnosed in adulthood, (iv) the article was a full report published in English or Dutch, (v) the article presented an original report with either a quantitative or a qualitative design (e.g., reviews and letters to the editor were excluded), and (vi) the studies were published in peer-reviewed journals.

Data extraction

First, the search results from the separate databases were combined. Next, duplicates were removed. After removing duplicates one author (MJT) applied the described inclusion criteria in a standardized manner. First, the titles of the manuscripts were evaluated to assess suitability. For the studies that were not excluded based on the title, the abstract was screened to evaluate if the manuscript might fit the inclusion criteria. If suitability was expected, hard copies of the manuscripts were obtained. If during each of these steps there was doubt about the suitability of the manuscript, then the manuscript was included in the next, more specific, step. For the remaining studies, the manuscripts were read to examine if the article fitted the inclusion criteria. If there was doubt about the suitability of the manuscripts during this phase then this article was discussed with another author (BLDO). Finally, the reference lists of the retrieved studies and other key reviews were checked. If there were multiple reports of the same study with a similar study objective, only the most recent study was included. For the selected articles ($n=33$), the results regarding the association between one or more aspects of dyadic coping and RF were included in this review.

Data synthesis

The included studies relied on different study designs to examine the relationship between one or more aspects of dyadic coping and RF in various cancer populations. In addition, the studies differed with regard to the theory/model used to evaluate dyadic coping (for an overview of the different theories and models we refer to Revenson & Lepore, 2012²²). The different dyadic coping approaches led to heterogeneity in the operationalization of (aspects of) dyadic coping, which, however, reflects the current status quo in this field. Due to this heterogeneity, it was not possible to perform a meta-analysis. Furthermore, various definitions of RF and different measures assessing this variable complicated the analysis further (e.g., relationship (mal)

adjustment, relationship satisfaction, and/or relationship quality). Because the definitions all reflect the subjective evaluation of the relationship at a certain point in time, we reframed these different definitions into RF to have a more comprehensible outcome measure.

The results of the prospective and intervention studies will be described in more detail, while the results of cross-sectional and qualitative studies will only be used to evaluate if they confirm the findings of the prospective and intervention studies. These descriptions will be brief. The results of the observational studies are for clarity purposes presented in three separate paragraphs based on the STM model^{10,21}: (i) communication patterns related with RF, (ii) (un)supportive behaviors or (dys)functional behaviors related with RF, and (iii) the relationship between common/joint dyadic coping and RF.

Data allocation was performed based on the constructs examined in the studies: studies focussing solely on communication patterns are described in the first paragraph, studies that examined a broader perspective (e.g., communication patterns in combination with support exchange) are listed in the second paragraph, and studies focussing on dyadic coping are presented in the third paragraph. However, an important note is that the paragraphs are interconnected as most (un)supportive behaviors can be seen as communicative since they symbolize the extent of commitment to the relationship and to their partner.^{36,37} In addition, the reversed direction can be applied as well: negative communication behaviors can also be viewed as unsupportive behaviors.

Additionally, different checklists were used to evaluate the included studies: (i) a checklist for observational studies (STROBE: STrengthening the Reporting of OBservational studies in Epidemiology³⁸), (ii) a checklist for qualitative studies (COREQ: CONsolidated criteria for REporting Qualitative research³⁹), and (iii) a checklist for experimental studies (CONSORT: CONSolidated Standards Of Reporting Trials⁴⁰). In case of disagreements between raters, the authors discussed the differences in opinions and carefully selected the most appropriate one.

An overview of the dyadic coping strategies analyzed and the association of these strategies with RF is presented in **Table 1 (page 150)** for the observational studies and **Table 2 (page 162)** for the intervention studies. An overview of the checklist items for each study is available as Supporting Information.

Results

Study selection process

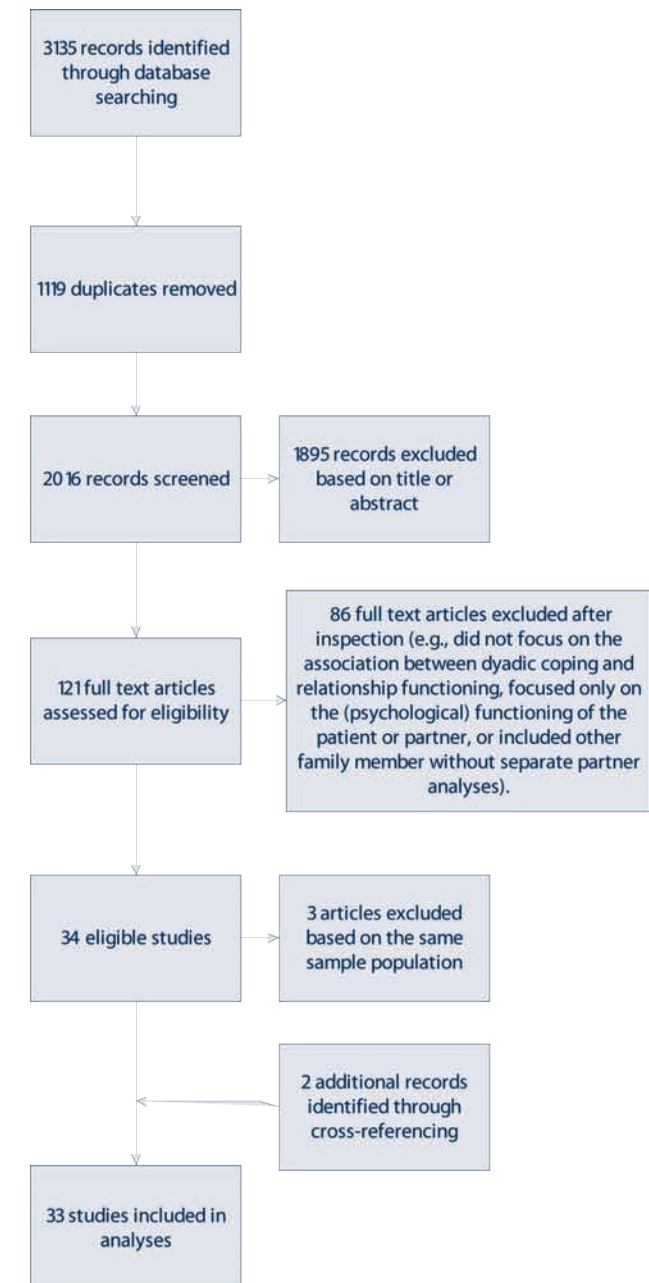
Combining the search results resulted in 3135 hits. After removing duplicates 2016 hits remained out of which 1875 articles were excluded, based on the evaluation of titles and abstracts. Hard copies were obtained of 121 articles, of which 34 met the inclusion criteria. The excluded studies did not focus on the association between dyadic coping and RF, focused only on the (psychological) functioning of the patient or partner, or included other family members without separate partner analyses. Three articles were excluded based on the multiple reports criterion. Two additional articles were found by means of cross-referencing. Thus, a total of 33 studies were included in this review (see Figure 1).

Study characteristics

Based on the checklists, improvements in the reporting quality of the studies are needed in order to be able to assess the risk of bias more adequately (see Supporting Information). All in all, studies varied considerably with regard to their study characteristics (see Tables 1 and 2). In total, there were 14 (43%) cross-sectional studies of which six were (18%) qualitative studies. In addition, there were 10 (30%) observational prospective studies, and nine (27%) intervention studies. For the prospective studies, the study duration ranged from seven days up to 12 months. Fifteen studies (46%) examined couples coping with breast cancer, 6 (18%) studies concerned prostate cancer, 3 (9%) studies concerned lung cancer, three (9%) studies examined couples coping with gastrointestinal cancer, one study (3%) evaluated coping after a hematopoietic stem cell transplantation, and five studies (15%) investigated a range of cancer types. Sample sizes varied greatly in the different studies and ranged from 10 to 282 participants. Nevertheless, most studies included a sufficient number of patients and partners to answer their research questions. Especially the more recent studies included analyses comparing responders with non-responders and/or study completers with study non-completers (if applicable).

However, the way researchers handled missing data and loss to follow-up (if applicable) was often unclear. In most studies, the majority of the participants were middle-aged, while elderly patients (i.e., >75 years) were included and/or participated to a lesser extent. Not all studies yielded information on the ethnic background of the participants. However, the studies that did provide this information reported that more than 70% of the included participants were Caucasian, with exception of one study. In this study only 62% of the participants were Caucasian, however, this study had a low sample size ($n=36$, Ptacek *et al.*, 1994⁴¹). All studies

Figure 1 Study selection process



were conducted with heterosexual couples. Thus, the generalizability of most studies was limited. Based on the objectives of the studies, adequate study designs were chosen. The studies used psychometrically sound questionnaires or used adequate qualitative techniques. Overall, adequate techniques were used to analyze the data. The Dyadic Adjustment Scale (DAS) was most frequently used to assess dyadic adjustment ($n=12$; 36%). Moreover, in the last few years statistical techniques designed to measure the interdependence between both members of the couple, such as the Actor-Partner Interdependence Model, have been frequently applied.^{24,37,42-44} Study findings were generally well summarized. However, many studies could benefit from a more deepened discussion of sources for potential bias and/or imprecision and a better integration of the work in the existing literature (not limited to studies that support the results of the conducted study).

The possible bonding effect of cancer

Facing cancer as a 'we-disease' may result in a strengthening of the relationship between partners. For instance, 42% of couples facing non-metastatic breast cancer reported that illness experience and its treatment had increased cohesion among partners, up to one year after diagnosis.⁴⁵ Occasionally, only the patient or the partner reported getting closer, with no effect found in the other partner (14% and 20%, respectively). Finally, 6% of the couples had one partner reporting emotional distance, and in <1% of couples this was the case for both partners. An increased cohesion was also reported in the majority of qualitative studies^{16,46-51}, except for one study in which no such effect was found⁵².

The association between communication patterns and RF

How both partners communicate with each other has important implications for RF. Manne *et al.* (2006)⁵³ reported that for both members of the dyad, mutual constructive communication about breast cancer-related issues was related with higher RF, while demand-withdraw communication was related with lower RF. Mutual avoidance of discussing problems was not related with RF at all.⁵³ Breast cancer-related relationship communication was stable within a nine month follow-up period.⁵³ These results were expanded by Badr *et al.* (2008)⁴² who examined if communication about the relationship, instead of talking about cancer-related concerns, influenced relationship satisfaction. They found that patients and partners who reported more frequent discussions about their relationship reported higher RF over a 6-month period after diagnosis and/or treatment, regardless of gender.⁴² The positive relationship between constructive communication and RF was consistently supported by cross-sectional^{43,46,54-57} and qualitative studies^{47,49,51,52}.

The association between (un)supportive or (dys)functional behaviors and RF

Badr and Taylor (2008)³⁷ examined relationship maintenance behaviors (i.e., positivity, openness, assurances, social networks, and shared tasks) in couples coping with lung cancer. Their results showed that if both partners were more engaged in relationship maintenance behaviors they both reported better RF up to six months after treatment.³⁷

The importance of adequate spousal support was further established by Langer, Brown, and Syrjala (2009)⁵⁸ and Pasipanodya *et al.* (2012)⁵⁹. Langer *et al.* (2009) showed that protective buffering (i.e., hiding concerns, denying worries, and avoiding discussions) reduced RF in a 50-days follow-up study among couples coping with a stem cell transplantation.⁵⁸ The more participants buffered their partner (and felt buffered by their partner), the lower their RF was.⁵⁸ In addition, the partners buffered patients more than *vice versa*.⁵⁸ The 7-day diary study of Pasipanodya, *et al.*, (2012) focused on couples coping with breast cancer and showed that greater patient-reported and partner-reported social constraints to a reciprocal disclosure of thoughts, feeling, and concerns was related with lower levels of each partner's own reports of average daily intimacy and RF.⁵⁹

Two studies focused more explicitly on support exchange.^{44,60} One of these studies, a 12-month prospective study among various cancer types, showed that both the provision of adequate support and support concordance between patients and partners were related with higher RF.⁶⁰ In the second study, the role of past spousal supportiveness (i.e., the degree to which the spouse was generally responsive to the individual's needs before the couple was confronted with cancer) has been evaluated.⁴⁴ Three months after treatment RF was maintained if past spousal supportiveness was high, even if the partner was currently not very responsive to the individual's needs.⁴⁴ However, at nine months follow-up, hiding concerns and minimizing the other partner's concerns was negatively related with future RF.⁴⁴ Again, the cross-sectional^{47,50,54,57,61} and qualitative studies^{16,48,51} confirmed the prospectively obtained results.

The association between joint dyadic coping and RF

Finally, one prospective study included behaviors beyond support exchange (i.e., stress communication and/or (un)supportive coping).²⁴ This study, among couples coping with metastatic breast cancer, examined the degree to which both partners worked together to manage dyadic stress and restore or maintain the balance in their relationship.²⁴ They found that the couples that were using joint positive dyadic coping (i.e., joint problem solving, joint information seeking, sharing of feelings, mutual commitment, and relaxing together)

experienced higher RF than patients and partners who used joint negative dyadic coping (i.e., hiding concerns from each other, mutual denying of worries, and avoidance of shared discussion).²⁴ Furthermore, individuals who perceived their partners as more supportive and less unsupportive had better RF up to six months after breast cancer treatment, regardless of their role.²⁴ Joint dyadic coping was also examined in three qualitative studies who all found that this form of coping was beneficial for RF.^{16,48,50}

Intervention studies aimed at improving RF

In the past 10 years, several intervention studies aimed at improving the dyadic coping and RF of couples coping with cancer have been conducted (see **Table 2, page 162**). At 1-year follow-up an increase in RF was reported after couple therapy.⁶² Another intervention study aimed at restoring perceptions of equity reduced the levels of perceived underinvestment and overbenefit and improved RF.⁶³ In addition, partner-assisted emotional disclosure, instead of a couples' education/support condition, yielded improvements in RF and intimacy for couples in which the patient initially reported high levels of holding back.⁶⁴ Furthermore, comparing a couple-skills intervention (*Side by Side*) with a psycho-education program (*Couples Control Program*) showed that women in the couple skills intervention scored higher on RF after treatment.⁶⁵ Finally, couples in a psychosexual intervention group reported higher RF three months after mastectomy compared with baseline and compared with the control group.⁶⁶ However, in another study no differences were found between a telephone-intervention and a face-to-face intervention, perhaps due to a limited sample size. Compared with care as usual, a trend towards higher RF was noted in favor of both interventions.⁶⁷ A sexual rehabilitation program found improvements in male distress and male and female global sexual functioning, in both the counseling together and the men-attend alone group.⁶⁸ However, RF did not improve, most likely because the couples already reported high RF at baseline.⁶⁸ Moreover, pre-intervention psychological and relationship factors largely moderated the effects of intimacy-enhancing therapy.⁶⁹ Intimacy-enhancing therapy was only effective in couples with fewer personal relationship resources.⁶⁹

Discussion

This review shows the importance of stress communication, supportive behaviors, and adequate dyadic coping for the maintenance or even enhancement of RF. More specifically, couples who were able to express their worries, feelings, and needs regarding cancer-related issues or their relationship reported higher RF. There are several reasons why stress communication might be beneficial. First, talking about one's worries and needs allows couples to share the experience more adequately, building the basis for a definition of cancer as a 'we-disease'¹⁶ and allowing joint coping efforts²⁴. Second, according to the optimal matching model of social support, sharing experiences by mutual emotional stress communication (self-disclosure of both partners) allows a better matching of needs and mutual support⁷⁰, which covaries with higher relationship satisfaction⁷¹. Third, adequate self-disclosure of both partners may also indicate that the couples' relationship is characterized by mutual trust and intimacy and that partners are used to rely on each other. Even though cancer may affect both partners' lives significantly, they can build on previous experiences of mutual support and investment in the relationship.⁴⁴ Fourth, it seems relevant that open and constructive dyadic communication not only concerns cancer-related issues but also the couple's life in general (e.g., Badr *et al.*, 2008⁴²). Therefore, enlarging the scope of communication and framing it in the general context of ongoing daily experiences of both partners is important.^{42,49} Since (stress) communication was found to be beneficial, it is not surprising that demand-withdraw communication or avoiding communication revealed to be dysfunctional.^{24,53,58,59} Not only communication strategies, but also supportive or dysfunctional behaviors and dyadic coping itself have been identified as highly relevant for relationship outcome in couples dealing with cancer. Couples' coping characterized by supportive behaviors, active engagement, joint positive dyadic coping, and joint problem solving was related with higher RF, whereas unsupportive or dysfunctional behaviors (e.g., overprotection) were related with lower RF. These findings make sense. For the patient both protective buffering as well as overprotection do not reflect a thoughtful, respectful, and esteeming attitude towards the patient but attribute him/her the role of the impaired, deficient subject in need, ignoring or not valuing the patient's self-efficacy, resources, and strengths. The findings emphasize the importance of addressing unsupportive behaviors and dysfunctional dyadic coping in both cancer research and treatment since these aspects coexists regularly with lower RF. Our results corroborate the findings of previous non-systematic overviews which also noted that high RF during or after the treatment for cancer may, from a dyadic perspective, depend on how well the couple integrated cancer into their lives.^{25,35} Finally, our review indicates that couple-based interventions may have beneficial effects on RF.

Dyadic coping research is a relatively new field of expertise (i.e., the majority of studies has been conducted since 2000). Therefore, some additional notes regarding the progress and current-status of the field are important. The earlier studies were mainly addressing the patient and the partner as separate entities while the more recent ones were able to apply statistical techniques equipped to focus on the dyad as the unit of analysis (i.e., Actor-Partner Interdependence Model⁷²). In addition, the earlier, mostly cross-sectional, studies often reported RF as a state condition. In the more recent studies mostly prospective designs were applied, sometimes combined with an intervention. In these prospective studies, stress communication, supportive behaviors, and dyadic coping in couples dealing with cancer are no longer evaluated solely as a 'snapshot' of the continuum of (mal)adjustment at one point in time, but more accurately as a dynamic process. However, the studies included in this review differed with regard to the underlying theory/model. This theoretical heterogeneity reflected two lines of research (dyadic coping research originating from coping literature and social support research rooted in social support approaches). The different theoretical grounding inspired researchers in defining and selecting instruments and the design of the studies. This heterogeneity made it difficult to clearly summarize and categorize the results. For each outcome variable there was often an insufficient number of studies which did not allow meta-analysis or subgroup analyses. One of the main challenges for future research will, therefore, be to more uniformly conceptualize the couples' role in the context of cancer and how both partners are concerned and enrolled in the process of dealing with the disease. For this purpose a meta theory linking the dyadic coping approaches with the social support models is needed. This would require that researchers conducting dyadic coping research and social spousal support research are more aware of the work of each other and form collaborations in order to overcome gaps and discrepancies in theory and methods. The dyadic coping field has recently turned their attention to the potential benefits of interventions to increase dyadic coping. Future research is warranted to more specifically evaluate which couples may benefit from such interventions and whether or not these interventions can be more cost-effective. Furthermore, most studies focused on the association between dyadic coping and cancer-related stress. However, as cancer-related stress adds to general life stress and daily hassles, researchers should be more aware of this pile-up of stress and the role of contextual variables. Couples dealing with cancer are not only exposed to the challenges of the illness but to all requirements of everyday life. Dyadic coping is, therefore, needed for both demands. The outcomes (e.g., psychosocial adjustment, RF) probably covary with the quality of handling the disease as well as daily life and the interplay between disease and daily life. This aspect also requires further attention. With regard to the generalizability of findings, it is unfortunate that the majority of the included studies consisted of middle-aged,

heterosexual, and Caucasian participants. Therefore, future studies should also include same-sex couples, elderly participants, and ethnic minorities in order to increase the external validity of the current findings. Finally, based on the checklists, improvements in the reporting quality of the studies is needed in order to be able to assess the risk of bias (e.g., handling of missing data, lack of flow charts, imprecise description of sample, recruitment, methods) more adequately. With regard to our review, an important limitation lies in the fact that we did not consider non-published studies (e.g., grey-literature, dissertations, master thesis); therefore, some relevant but not published studies may potentially be missed. In addition, as stated above we were not able to perform a meta-analysis due to the theoretical and methodological heterogeneity of studies. Another challenge lied in the fact that not a single checklist could be used. Therefore, a variety of different lists had to be applied according to the study design. The checklists incorporated in this review evaluate the extent to which the studies report important aspects of the research process. Even though scoring negatively on many items might be indicative for presumed (or evidence of) association with susceptibility of bias it does not justify classifying studies into low/medium/high quality since reporting quality can differ from study quality.⁷³

Conclusion

There is an increasing awareness of viewing cancer as a dyadic affair (we-disease). This review showed the importance of adequate dyadic coping in order to maintain or even improve RF in couples dealing with severe illness such as cancer. However, a more uniformly conceptualized perspective on dyadic coping is needed in order to adequately compare the results and formulate general conclusions. Future research is needed to more specifically examine benefits of common dyadic coping compared with spousal support and under which conditions (individual-, dyadic-, and contextual variables) and for whom this approach is beneficial or harmful. Based on these more detailed findings, future more personalized psychological interventions for couples dealing with cancer can be developed which can emphasize best practice for defined types of couples, individuals, and types of cancer. Thus thorough basic research on dyadic coping and dynamics in couples with cancer is still needed to stimulate new theoretical insights that allow the development of specific interventions for these couples with the aim of improving quality of life for both partners as well as a more favorable dealing with cancer, in the best case resulting in better (relational) adjustment and recovery from the disease.

Table 1 Overview of the cross-sectional and prospective studies assessing dyadic coping in couples coping with cancer

Author	Couples coping with	No. Of dyads	Design	Measurement intervals	Independent variables	Dependent variables	Main conclusions
Pasipanodya <i>et al.</i> , 2012 ⁵⁹	Breast cancer	45	Prospective; Questionnaires	7 consecutive days	Daily event sharing (e.g., social constrains on disclosure)	Daily RF (NVQ)	Greater patient-reported and spouse-reported social constrains were associated with lower levels of each partner's own reports of average daily intimacy and RF.
Walker & Robinson, 2012 ⁵¹	Prostate cancer	18	Cross-sectional; Unstructured interview	4 months-13 years after androgen deprivation therapy	Strategies couples used when trying to adapt sexually to the side effects of androgen deprivation therapy	Satisfying sexual relationship	Some couples did find ways to have a satisfying sexual relationship despite the man's castrate level of testosterone.
Hagedoorn <i>et al.</i> , 2011 ⁴⁴	Colorectal cancer	88	Prospective; Questionnaires	3 and 9 months after diagnosis	Spousal active engagement and protective buffering (NVQ's); Past spousal supportiveness (MCBS)	Relationship functioning (MMQ)	Three months after treatment, spousal active engagement was positively associated with RF in patients and partners. Spousal protective buffering was negatively associated with RF in patients. However these results only applied when past spousal support was relatively low. If past spousal support was high, participants rated their RF relatively high, regardless of their partner's current support behavior. Over time, past spousal supportiveness did not mitigate the negative association between spousal protective buffering and RF.
Badr, Carmack, Kashy, Cristofanilli, & Revenson, 2010 ²⁴	Breast cancer	191	Prospective; Questionnaires	At the start of treatment and 3 and 6 months after treatment	Stress communication, support responses, mutual or common dyadic coping (FDCT-N); Cancer-related stress communication, supportive coping, unsupportive coping, common positive dyadic coping, common negative dyadic coping (NVQ's)	RF (DAS)	Couples using common positive dyadic coping experienced better RF than patients and partners who used common negative dyadic coping. Individuals who perceived their partners as more supportive and less unsupportive had better RF up to 6 months after breast cancer treatment, regardless of role (i.e., patient or partner).
Badr & Taylor, 2009 ⁴³	Prostate cancer	116	Cross-sectional; Questionnaires	±4.6 years (SD=3.8 years)	Male sexual function (IIEF); Female sexual function (FSFI); Communication patterns (CPQ)	RF (DAS)	When patients had poor erectile function, their partners were more likely to report that the couple avoided open spousal discussions; this was associated with partners' lower RF. Patients and partners who reported high levels of mutual constructive communication reported greater RF, regardless of their own sexual satisfaction. In contrast, greater sexual dissatisfaction was associated with poorer RF in patients and partners who reported low levels of mutual constructive communication. Mutual constructive communication and mutual avoidance partially mediated the association between patients' erectile function and their partners' RF.

Author	Couples coping with	No. Of dyads	Design	Measurement intervals	Independent variables	Dependent variables	Main conclusions
Fergus & Gray, 2009 ⁴⁷	Breast cancer	19	Cross-sectional; Focus group, combined couples and individual interviews	?	Communication barriers and challenges	Relationship dynamics	The relationship dynamics were divided into pitfalls (i.e., communication barriers, withholding-withdrawing, under-burdening, and conflictual intentions) and challenges (i.e., negotiating support, accommodating changes in other, coping with sexual disruption, and incorporating death and separation) associated with coping with breast cancer as a couple.
Langer, Brown, & Syrjala, 2009 ⁵⁸	Stem cell transplantation	87	Prospective; Questionnaires	Before and 50 days post transplantation	Protective buffering (NVQ)	RF (DAS)	Partners buffered patients more than vice versa, especially at 50 days post transplantation. The more participants buffered their partners at 50 days post transplantation and the more they felt buffered, the lower their RF. Patients who buffered primarily to protect their partner before transplantation reported increases in RF over time; however, when they did so at 50 days post transplantation, their partner reported decreases in RF.
Badr, Acitelli, & Carmack Taylor, 2008 ⁴²	Lung cancer	169	Prospective; Questionnaires	Within 1 month of treatment and 3 and 6 months later	Relationship talk (NVQ)	RF (DAS)	Patients and partners who reported more frequent discussions of their relationships reported greater RF over the six month period after diagnosis and/or treatment, regardless of gender.
Badr & Taylor, 2008 ³⁷	Lung cancer	158	Prospective; Questionnaires	Within 1 month of treatment and 3 and 6 months later	Relationship maintenance strategies (RMSM)	RF (DAS)	Regardless of gender or role (i.e., patient or partner) it was reported that own and partner engagement in each of the five maintenance strategies (i.e., Positivity, Openness, Assurances, Social networks, and Shared tasks) helped to enhance patient and partner reported RF at baseline and over time.
Kayser, Watson, & Andrade, 2007 ¹⁶	Breast cancer	10	Cross-sectional; Couples interviews	Within 3 months after diagnosis	Mutual responsiveness and disengaged avoidance	Relationship growth	The mutual responsive couples had the relational qualities of relationship awareness, authenticity, and mutuality. These factors were identified as important ingredients for a good RF and facilitated the participation of both partners in the coping process. Through mutually response coping there was relationship growth. Couples who used a disengaged avoidant style of coping seemed to have developed a mutual respect for each other's individual response to the cancer.

Author	Couples coping with	No. Of dyads	Design	Measurement intervals	Independent variables	Dependent variables	Main conclusions
Norton & Manne, 2007 ⁶⁰	A range of cancer types	239	Prospective; Questionnaires	Baseline (±12 months, SD = 27) and 3 months later	Support concordance (CSI); Psychological distress (MHI); Affiliative need (IOS); Patient physical impairment (CARES)	RF (DAS)	Couples had high agreement and showed greater concordance on unsupportive behaviors than supportive behaviors. Both partners' reports on RF were associated with greater support concordance and spouses' need for attention was related with lower support concordance. Neither length of marriage nor psychological distress was related with support concordance. Greater patient physical impairment was not significantly related with concordance for supportive behaviors but was related with lower concordance for unsupportive behaviors.
Badr & Taylor, 2006 ⁴⁶	Lung cancer	25	Cross-sectional; Individual semi-structured interviews	±7.2 months (range 3.2-13.4)	Spousal communication; denial, avoidance/ protective buffering, and conflict	RF	The couples experienced a wide variety of social constraints; including denial, avoidance, and conflict that can hinder open spousal communication. These factors can negatively affect RF. Participants who reported talking with their partners about their relationships reported fewer constraints and better communication about cancer. Participants talked about how relationship talk was beneficial for their RF.
Manne <i>et al.</i> , 2006 ⁵³	Breast cancer	127	Prospective; Questionnaires	±4.5 months (SD=2.2) and at 9 months	Mutual constructive communication, mutual avoidance, demand-withdraw communication (CPQ)	RF (DAS)	For both members of the dyad, mutual constructive communication about breast cancer-related issues was associated with better RF, while demand-withdraw communication was associated with worse RF. A mutual avoidance of discussing problems was not associated with relationship quality. Patients' perceptions of mutual constructive and demand/withdraw communication were associated with partners' marital satisfaction, but not vice versa. The cancer-related relationship communication did not change over nine months follow-up.

Author	Couples coping with	No. Of dyads	Design	Measurement intervals	Independent variables	Dependent variables	Main conclusions
Dorval <i>et al.</i> , 2005 ⁴⁵	Breast cancer	282	Prospective; Individual interviews	2 weeks and 3 and 12 months after treatment start	Characteristics related with couple interactions	Relationship growth	Overall, 42% said breast cancer brought them closer. In some cases only the patient or the spouse reported getting closer, with no effect found in the other partner (14% and 20%, respectively). 6% of couples had one or other partner reporting feeling distanced and <1% of couples had both partners reporting feeling distanced. After taking into account partners' pre-diagnosis characteristics and the patient's treatment, the spouse reporting the patient as confidant, getting advice from her in the first 2 weeks about coping with breast cancer, accompanying her to surgery, the patient's reporting more affection from her spouse at 3 months since diagnosis predicted both partners saying the disease brought them closer.
Picard, Dumont, Gagnon, & Lessard, 2005 ⁵⁰	Breast cancer	16	Cross-sectional; Semi-structured couple interviews	Between the 10 th and 12 th month after diagnosis	Couple adjustment processes	RF	The couples' adjustment processes seemed to be structured around 5 major axes: building up shared knowledge, mutuality, intimacy, constructing meaning, and solidarity with the social network.
Porter, Keefe, Hurwitz, & Faber, 2005 ⁵⁷	Gastrointestinal cancer	45	Cross-sectional; Questionnaires	?	Caregiver strain (CSI*); Perception of empathy (RBLRI); Disclosure and holding back (NVQ)	RF (MSIS)	Patients and spouses reported moderately high levels of disclosure and low levels of holding back, with patients reporting higher levels of disclosure than spouses. Patient and spouse disclosure was positively associated with RF (e.g., intimacy and empathy) and negatively associated with negative partner behaviors.
Henselmans, Hagedoorn, Buunk, & Sanderman, 2004 ⁵⁵	A range of cancer types	106	Cross-sectional; Questionnaires	±4.2 (SD=4.8)	Stress communication (CSI**)	RF (MMQ)	The communication style of the couples was characterized by a high degree of intimacy and in a lesser degree by successively avoidance, destructive, and incongruent communication. The negative correlation between destructive communication and RF appeared to be stronger for women than for men, irrespective of their role (i.e., patient or partner). The negative relationship between incongruent communication and RF was found to be stronger for healthy female partners than for male partners.

Author	Couples coping with	No. Of dyads	Design	Measurement intervals	Independent variables	Dependent variables	Main conclusions
Manne <i>et al.</i> , 2004 ⁵⁶	Breast cancer	85	Cross-sectional; Questionnaires	?	Cancer-related issues (CII); Perceived self disclosure, partner disclosure, partner responsiveness, and intimacy (NVQ's)	RF (e.g., intimacy)	For patients, perceived responsiveness partially mediated the association between partner disclosure and intimacy, but self-disclosure was not significantly associated with responsiveness or intimacy. For partners, perceived responsiveness mediated the association between self-disclosure and perceived partner disclosure and intimacy. Partner disclosure predicted patient feelings of intimacy; because this type of disclosure was associated with greater feelings of acceptance, understanding, and caring.
Kuijer, Buunk, Ybema, & Wobbles, 2002 ⁶¹	A range of cancer types	68	Cross-sectional; Questionnaires	±2.8 years since diagnosis (range=1-24, SD=4.1)	Perceived equity and emotions (NVQ's)	RF (MMQ)	On average, only male patients felt overbenefited in their relationship, whereas female patients felt equally treated. The partners of these patients did not feel underbenefited in their relationship. In general patients seemed most sensitive to underbenefit (i.e., reported the lowest RF) and experienced on average least positive and most negative affect when they felt underbenefited. Particularly, patients who were physically impaired felt dissatisfied and angry when underbenefited. The partners of these patients were in general equally sensitive to inequity in both directions, regardless of their ill partner's physical condition.
Gray, Fitch, Phillips, Labrecque, & Fergus, 2000 ⁴⁸	Prostate cancer	34	Prospective; Semi-structured interviews	Pre-surgery, 8-10 weeks post-surgery, and 11-13 months post-surgery	Facing illness as a team, reassuring that things will be OK, letting people help; keeping relationships normal	Keeping relationships working	Keeping relationships working was one of the main themes. Important issues were facing illness as a team, reassuring that things will be OK, letting people help, and keeping relationships normal. The couples not only had to deal with their individual reactions, but also with each other's reaction and the mutual reaction.
Hagedoorn <i>et al.</i> , 2000 ⁵⁴	A range of cancer types	68	Cross-sectional; Questionnaires	±2.8 years (SD=4.1)	Active engagement, protective buffering, and overprotection (NVQ's); Depression (CES-D); Health Status (RAND-36)	RF (MMQ)	The positive association between active engagement and the patient's RF was stronger for patients with a rather poor psychological and physical condition than for those with a rather good condition. Protective buffering and overprotection were negatively associated with RF, only when patients experienced relatively high levels of psychological distress or physical limitations.

Author	Couples coping with	No. Of dyads	Design	Measurement intervals	Independent variables	Dependent variables	Main conclusions
Lavery & Clarke, 1999 ⁴⁹	Prostate cancer	12	Cross-sectional; Semi-structured individual interviews	±24 months (range 5-42 months)	Active engagement, protective buffering	RF	The partners were more actively engaged in meeting the demands of the illness than the patients. Patients employed more protective buffering than partners by avoiding discussions about their cancer or by denying their cancer-related anxieties and concerns. The majority of patients reported that their RF had remained the same or had improved since their diagnoses, although a few men reported negative changes.
Lewis & Deal, 1995 ⁵²	Recurrent breast cancer	15	Cross-sectional; Questionnaires and couple interviews	±12.7 months (SD=8.9)	Balancing lives (MDI)	RF (DAS)	The couples were actively working to balance two realities: their life as couple and their cancer-related life. Even when the couples were jointly discussing aspects of the cancer, they appeared to avoid potentially sensitive areas related with the cancer recurrence.
Ptacek, Ptacek, & Dodge, 1994 ⁴¹	Breast cancer	36	Cross-sectional; Questionnaires	±15 months (SD=9)	Self-reported coping and other-reported coping i.e., problem-focused coping, social support, self-blame, wishful thinking and avoidance (WCCL)	RF (DAS)	The patients' self reported coping related significantly to the RF of their partners, particularly the use of problem-focused coping and avoidance. Partners whose wife reported using more problem focused coping and less avoidance while undergoing radiation therapy reported a better RF.

Abbreviations: CARES = Cancer Rehabilitation Evaluation System, CES-D = Center for Epidemiological Studies – Depression Scale, CII = Cancer Issue Inventory, CPQ = Communications Pattern Questionnaire, CSI = Cancer Support Inventory, CSI* = Caregiver Strain Index, CSI** = Communication Skill Inventory, DAS = Dyadic Adjustment Scale, FDCT-N = Dyadic coping questionnaire, FSFI = Female Sexual Function Index, IIEF = International Index of Erectile Function, IOS = Interpersonal Orientation Scale, MCBS = Mutual Communal Behaviors Scale, MDI = Marital Dyad Interview, MHI = Mental Health Inventory, MMQ = Maudsley Marital Questionnaire, MSIS = Miller Social Intimacy Scale, NVQ = non-validated questionnaire, RAND-36 = Health Related Quality of Life, RBLRI = Revised Barrett-Lennard Relationship Inventory, RMSM = Relationship Maintenance Strategies Measure, SD = Standard Deviation, SF-36 = Medical Outcomes Study General Health Survey, PCI = Prostate Cancer Index, WCCL = Ways of Coping Checklist Revised.

Table 2 Overview of the intervention studies aimed at improving dyadic coping and RF in couples coping with cancer

Author	Couples coping with	No. of dyads	Design	Measurement interval	Intervention	Dependent variables	Main conclusion
Decker, Pais, Miller, Goulet, & Fifea, 2012 ⁶⁷	Breast cancer	65	Prospective; Questionnaires	Prior to the intervention, at the end of the intervention, 6 months after the intervention	Care as usual, a face-to-face intervention, or the intervention by telephone	RF (DAS)	There was an equal level of RF among those in the telephone and face-to-face groups. Interesting trends in differences between the intervention and comparison groups on the relationship variables of intimacy and RF were obtained; however, given the sample size, power was not sufficient to reach statistical significance.
Heinrichs <i>et al.</i> , 2012 ⁶⁵	Breast and gynecological cancer	72	Prospective randomized controlled trial; Questionnaires	Before randomization, at the end of intervention, and 6 and 12 months after the intervention	Four bi-weekly face-to-face sessions	RF (QMI)	Comparing a couple-skills intervention (<i>Side by Side</i>) with education (<i>Couples Control Program</i>) showed that women in the side by side intervention reported better relationship skills. However, all differences favoring <i>Side by Side</i> disappeared by 16 months after the diagnosis.
Manne <i>et al.</i> , 2011 ⁶⁹	Prostate cancer	71	Prospective pilot intervention study; Questionnaires	At baseline and 8 weeks follow-up	Five 90 minute couples' sessions of intimacy enhancing therapy (IET) or care as usual (no treatment)	RF (DAS)	IET effects were largely moderated by pre-intervention psychosocial and relationship factors. Those who had higher levels of cancer concerns at pretreatment had significantly reduced concerns following IET. Similar moderating effects for pre-intervention levels were reported for the effects of IET on self-disclosure, perceived partner disclosure, and perceived partner responsiveness. Among partners beginning the intervention with higher cancer-specific distress, lower RF, lower intimacy, and poorer communication, IET improved these outcomes.
Baucom <i>et al.</i> , 2009 ⁶²	Breast cancer	14	Prospective pilot intervention study; Questionnaires	Before treatment, post treatment, and 12 months follow-up	Couple-based relationship enhancement (RE) condition (6 bi-weekly face-to-face sessions) or treatment-as-usual.	RF (QMI)	Compared with couples receiving treatment-as-usual, both patients and partners in the RE condition experienced improved RF at posttest and 1-year follow-up. In addition, women in RE showed fewer medical symptoms at both time periods.
Porter <i>et al.</i> , 2009 ⁶⁴	Gastrointestinal cancer	130	Prospective randomized controlled trial; Questionnaires	Before randomization and at the end of the intervention sessions	4 face-to-face sessions of either partner-assisted emotional disclosure or a couple's cancer education/support intervention	RF (QMI); Intimacy (MSIS)	Compared with an education/support condition, the partner-assisted emotional disclosure intervention led to improved RF and intimacy for couples in which the patient initially reported higher levels of holding back from discussing cancer-related concerns.

Author	Couples coping with	No. of dyads	Design	Measurement interval	Intervention	Dependent variables	Main conclusion
Kalaitzi <i>et al.</i> , 2007 ⁶⁶	Breast cancer	40	Prospective intervention study	2 days before mastectomy and after the intervention (3 months later)	6 sessions of a combined brief psychosexual intervention and a control group	RF (NVQ)	Couples in the intervention study reported better RF 3 months after mastectomy compared with baseline and compared with the control group.
Shands, Lewis, Sinsheimer, & Cochrane, 2006 ⁷⁴	Breast cancer	29	Cross-sectional intervention study; Qualitative analyses	±5.7 months after diagnosis (SD=2.6) range 2-11 months	1.5-2 hour home intervention consisting of 3 parts: (i) the couple was asked about the impact of cancer on them as a couple and cancer-related concerns they had as a couple (ii) individual session about how the illness impacted both members individually; (iii) the couple further elaborated on their primary concerns together	RF	Sixty-six percent of the couples wanted to work in a single case occasion intensive session on resolving the tension in their relationship or to find better ways to be together as a couple. Four core concerns were reported: dealing with tension in the relationship; needing to be together as a couple; wondering about the children; and managing the threat of breast cancer.
Canada, Neese, Sui, & Schover, 2005 ⁶⁸	Prostate cancer	51	Prospective pilot intervention study; Questionnaires	At baseline, post treatment and at 3-month and 6-month follow-up	4 sessions of counseling together or a man attend alone (i.e., education on prostate carcinoma and sexual function and options to treat erectile dysfunction as well as sexual communication and stimulation skills, psychological distress, and utilization of treatments for erectile dysfunction)	RF (DAS)	The sexual rehabilitation program reported no improvements in RF, most likely because the couples reported good RF at baseline.
Kuijjer, Buunk, De Jong, Ybema, & Sanderman, 2004 ⁶³	Various cancer types		Prospective intervention study; Questionnaires	Before intervention, one week, and three months post intervention	5 bi-weekly sessions by a psychologist designed to stimulate the provision of adequate support and help by the partner to the patient and vice versa in order to reduce feelings of inequity	RF (NVQ)	After the intervention, both patients and their partners reported higher levels of RF.

Abbreviations: DAS = Dyadic Adjustment Scale, MSIS = Miller Social Intimacy Scale, NVQ = Non validated questionnaire, QMI = Quality of Marriage Index

Supplementary Table 1 Scores of the observational studies on the STROBE checklist

Author	STROBE Checklist Items																																	
	1 ^a	1 ^b	2	3	4	5	6 ^a	6 ^b	7	8	9	10	11	12 ^a	12 ^b	12 ^c	12 ^d	12 ^e	13 ^a	13 ^b	13 ^c	14 ^a	14 ^b	14 ^c	15	16 ^a	16 ^b	16 ^c	17	18	19	20	21	22
Pasipanodya <i>et al.</i> , 2012 ⁵⁹	-	-	+	+	+	-	-	NA	-	+	-	-	-	-	NA	-	NA	NA	-	-	-	+	-	NA	+	+	NA	NA	NA	+	-	-	+	-
Hagedoorn <i>et al.</i> , 2011 ⁴⁴	-	-	+	+	+	-	-	NA	-	+	+	-	-	-	-	-	NA	NA	-	-	-	+	-	NA	+	-	NA	NA	+	+	-	-	-	-
Badr, Carmack, Kashy, Cristofanilli, & Revenson, 2010 ²⁴	+	-	+	+	+	-	+	NA	+	+	+	-	+	-	-	-	NA	NA	-	-	-	+	-	NA	+	-	NA	NA	+	+	-	-	+	-
Badr & Taylor, 2009 ⁴³	+	-	+	+	-	-	+	NA	+	+	+	-	-	-	-	-	NA	NA	-	-	-	+	-	NA	+	-	NA	NA	+	+	-	-	+	-
Langer, Brown, & Syrjala, 2009 ⁵⁸	-	-	+	+	+	-	+	NA	-	+	+	+	-	-	-	-	NA	NA	-	-	-	+	-	NA	+	-	NA	NA	+	+	-	-	-	-
Badr, Acitelli, & Carmack Taylor, 2008 ⁴²	+	+	+	+	+	-	+	NA	-	+	+	-	-	-	-	-	NA	NA	-	-	-	+	-	NA	+	-	NA	NA	+	+	-	-	+	-
Badr & Taylor, 2008 ³⁷	+	-	+	+	+	-	+	NA	-	+	+	-	-	-	-	-	NA	NA	-	-	-	+	-	NA	+	-	NA	NA	+	+	-	-	+	-
Norton & Manne, 2007 ⁶⁰	-	-	+	+	+	-	-	NA	+	+	-	-	-	-	NA	-	NA	NA	-	-	-	+	-	NA	+	-	NA	NA	NA	+	-	-	+	-
Manne <i>et al.</i> , 2006 ⁵³	+	-	+	+	+	-	-	NA	+	+	+	-	+	-	-	-	NA	NA	-	-	-	+	-	NA	+	-	NA	NA	+	+	-	-	+	-
Porter, Keefe, Hurwitz, & Faber, 2005 ⁵⁷	-	+	+	+	-	-	-	NA	-	+	-	-	-	-	-	-	NA	NA	-	-	-	+	-	NA	+	-	NA	NA	NA	+	-	-	+	-
Henselmans, Hagedoorn, Buunk, & Sanderman, 2004 ⁵⁵	-	-	+	+	-	-	+	NA	-	-	-	-	-	-	-	-	NA	NA	-	-	-	+	-	NA	+	-	NA	NA	+	+	-	-	-	-
Manne <i>et al.</i> , 2004 ⁵⁶	-	-	+	+	-	-	-	NA	-	-	+	-	+	-	-	-	NA	NA	-	-	-	+	-	NA	+	-	NA	NA	+	+	-	-	+	-
Kuijer, Buunk, Ybema, & Wobbles, 2002 ⁶¹	-	+	+	+	-	-	-	NA	+	-	-	-	-	-	-	-	NA	NA	-	-	-	+	-	NA	+	-	NA	NA	+	+	-	-	-	-
Hagedoorn <i>et al.</i> , 2000 ⁵⁴	+	-	+	+	-	-	-	NA	+	+	-	-	-	-	-	-	NA	NA	-	-	-	+	-	NA	+	-	NA	NA	+	+	-	-	+	-
Lewis & Deal, 1995 ⁵²	+	-	+	-	-	-	-	NA	-	+	-	-	-	-	-	-	NA	NA	-	-	-	+	-	NA	+	-	NA	NA	NA	+	-	-	+	-
Ptacek, Ptacek, & Dodge, 1994 ⁴¹	+	-	+	+	-	-	+	NA	-	+	-	-	-	-	-	-	NA	NA	-	-	-	+	-	NA	+	-	NA	NA	NA	+	-	-	+	-

Note: + = The criteria of the item were sufficiently reported, - = The criteria of the item were not/insufficiently reported, NA = Not Applicable.

Supplementary Table 2 Scores of the qualitative studies on the COREQ checklist

COREQ Checklist Items																																	
Author	1	2	3	4	5	6	7	8	9	10	11	12	13	14	15	16	17	18	19	20	21	22	23	24	25	26	27	28	29	30	31	32	
Walker & Robinson, 2012 ⁵¹	+	+	+	+	-	-	-	+	-	-	+		-	-	-	+	-	-	+	-	+	+	-	-	+	+	+	+	+	+	+	+	-
Fergus & Gray, 2009 ⁴⁷	+	-	-	+	-	-	-	-	+	+	+	+		+	-	-	+	+	-	+	-	-	-	-	+	+	+	+	-	+	+	+	-
Kayser, Watson, & Andrade, 2007 ¹⁶	+	+	-	+	-	-	-	-	+	+	+	+		-	-	-	+	-	-	+	-	+	-	-	+	+	+	+	-	+	+	+	-
Badr & Taylor, 2006 ⁴⁶	-	-	-	+	-	-	-	-	+	+	+	+		+	-	-	+	-	-	+	-	+	-	-	+	+	+	-	-	+	+	+	+
Dorval <i>et al.</i> , 2005 ⁴⁵	-	-	-	+	-	-	-	-	-	+	+	+		+		-	+	+	+	-	-	-	-	NA	-	+	+	+	NA	NA	+	NA	NA
Picard, Dumont, Gagnon, & Lessard, 2005 ⁵⁰	-	+	+	+	+	-	-	-	+	+	+	+		-	-	-	+	-	-	+	-	+	-	-	-	-	-	-	+	-	+	+	-
Gray, Fitch, Phillips, Labrecque, & Fergus, 2000 ⁴⁸	-	-	-	+	-	-	-	-	+	-	+	+		+	+	-	+	-	+	+	+	+	+	-	-	+	+	+	-		+	+	-
Lavery & Clarke, 1999 ⁴⁹	+	-	-	-	-	-	-	-	-	-	+	+		-	+	-	+	-	-	+	-	+	-	-	+	+	+	-	-	+	+	+	-

Note: + = The criteria of the item were sufficiently reported, - = The criteria of the item were not/insufficiently reported, NA = Not Applicable.

Supplementary Table 3 Scores of the intervention studies on the CONSORT checklist

CONSORT Checklist Items																																								
Author	1 ^a	1 ^b	2 ^a	2 ^b	3 ^a	3 ^b	4 ^a	4 ^b	5	6 ^a	6 ^b	7 ^a	7 ^b	8 ^a	8 ^b	9	10	11 ^a	11 ^b	12 ^a	12 ^b	13 ^a	13 ^b	14 ^a	14 ^b	15	16	17 ^a	17 ^b	18	19	20	21	22	23	24	25			
Decker, Pais, Miller, Goulet, & Fifea, 2012 ⁶⁷	-	-	+	+	-	NA	+	+	+	-	NA	-	NA	NA	NA	NA	NA	NA	NA	+	+	+	-	-	-	+	-	-	-	-	-	-	-	-	-	-	-	NA	-	
Heinrichs <i>et al.</i> , 2012 ⁶⁵	+	-	+	+	+	NA	+	-	+	-	NA	-	NA	+	+	+	+	NA	NA	+	NA	+	+	+	+	+	-	-	NA	NA	+	-	+	-	+	-	+	+	-	
Manne <i>et al.</i> , 2011 ⁶⁹	-	-	+	+	-	NA	+	-	+	-	NA	-	NA	-	-	-	-	NA	NA	+	NA	+	-	-	-	+	-	-	NA	NA	+	-	+	+	-	-	-	-	-	
Baucom <i>et al.</i> , 2009 ⁶²	-	-	+	+	-	NA	+	-	+	-	NA	-	NA	+	-	-	-	NA	NA	+	NA	+	-	-	-	+	-	-	NA	NA	-	-	+	+	-	-	-	-	-	
Porter <i>et al.</i> , 2009 ⁶⁴	+	-	+	+	-	+	+	-	+	-	NA	-	NA	-	+	-	-	NA	NA	+	+	+	-	-	-	+	-	-	-	+	+	-	+	+	-	+	+	-	-	-
Kalaitzi <i>et al.</i> , 2007 ⁶⁶	-	-	-	+	-	NA	+	-	+	-	NA	-	NA	-	-	-	-	NA	NA	+	NA	-	-	+	-	-	-	-	NA	NA	-	-	+	-	-	-	-	-	-	
Shands, Lewis, Sinsheimer, & Cochrane, 2006 ⁷⁴	-	-	+	-	-	NA	+	+	-	-	NA	-	NA	-	-	-	-	NA	NA	-	NA	-	-	-	-	+	-	-	NA	NA	-	-	-	-	-	-	-	-	-	
Canada, Neese, Sui, & Schover, 2005 ⁶⁸	-	-	+	+	+	NA	+	-	+	-	NA	-	NA	+	+	-	-	NA	NA	+	NA	+	+	-	-	+	-	-	NA	NA	-	-	-	-	-	-	-	-	-	
Kuijjer, Buunk, De Jong, Ybema, & Sanderman, 2004 ⁶³	-	-	+	+	+	NA	+	-	+	-	NA	-	NA	-	-	-	-	NA	NA	+	NA	+	-	-	-	+	-	-	NA	NA	-	-	-	+	-	-	-	-	-	

Note: + = The criteria of the item were sufficiently reported, - = The criteria of the item were not/insufficiently reported, NA = Not Applicable.

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Sexual, marital, and
general life adjustment
in couples coping with
colorectal cancer:
a dyadic study across time



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Abstract

Objectives

This study evaluated: (i) levels of sexual, marital, and general life (mal)adjustment for patients with colorectal cancer and partners, (ii) stress-spillover between the three domains for patients and partners separately, (iii) interdependence between patients and partners, and (iv) longitudinal change in (mal)adjustment and longitudinal stress-spillover from a dyadic perspective.

Methods

Couples coping with colorectal cancer ($n=102$) completed the Maudsley Marital Questionnaire (MMQ) preoperatively and three and six months postoperatively. Mean scores were compared with mean norm scores. A multivariate general linear model and a multivariate latent difference score model (LDS-SEM), which took into account Actor- en Partner effects, were evaluated.

Results

Patients and partners reported more sexual maladjustment, similar marital maladjustment (except patients' higher maladjustment at six months), and more general life adjustment compared with norm scores. Moderate to high within-dyad associations were found. The LDS-SEM model mostly showed Actor effects. A partner effect was reported for the longitudinal change in the partners' sexual maladjustment. Sexual maladjustment did not spill over to the other domains, while the patients' preoperative general life maladjustment influenced the postoperative marital and sexual domains.

Conclusion

Patients and partners report sexual maladjustment. Therefore, clinicians should examine potential sexual maladjustment. But, they have to be aware that this (mal)adjustment may not spill over to the marital and general life domains. However, maladjustment in the general life domain may spill over to the marital and sexual domains. The interdependence between patients and partners supports the notion that a couple-based perspective (e.g., couple-based interventions/therapies) to coping with cancer is needed.

Introduction

Having cancer and undergoing cancer treatment can influence sexual (mal)adjustment^{1,2}, marital (mal)adjustment³, and general life (mal)adjustment⁴. Furthermore, since these domains are interconnected, maladjustment in one of these domains may spill over to the other domains (i.e., stress-spillover). However, for patients with cancer, this form of stress-spillover has only been examined to some extent for the general life domain. One study reported that having a well-adjusted relationship is important as it influences general life (mal)adjustment⁵, which may indicate that a spillover effect from a less broadly defined domain to a more broadly defined domain is present. However, another study found that the experienced general life (mal)adjustment influenced sexual (mal)adjustment, which may suggest stress-spillover from a broad domain to a less broadly defined domain.⁶ Therefore, there may be a complex bidirectional influence of the domains on one another. However, these cross-sectional studies do not allow drawing causal interferences.

Furthermore, several reviews established emotional interdependence between both members of a couple when coping with cancer.⁷⁻⁹ Therefore, it is important to evaluate the interplay between sexual, marital, and general life (mal)adjustment from a dyadic perspective. This perspective postulates an Actor-Partner interdependence in which the dyad is the unit of analysis and each person's score is an independent variable that can influence not only his/her own score on the outcome variable (Actor effect) but also the partner's score (Partner effect).¹⁰ Although the number of studies that have taken a couple-based perspective to coping with cancer is increasing, most studies focused on distress or relationship functioning in patients with breast, prostate, or gynecological cancers.⁷⁻⁹ To our knowledge, only a few studies focused on patients with colorectal cancer.¹¹⁻¹⁴ While these studies focused on dyadic aspects of the (mal)adjustment domains separately^{11,13,14} or on stress-spillover between two (mal)adjustment domains¹², no study has yet analyzed both objectives in an integrative, prospective, and dyadic model.

Therefore, this study evaluated the (i) preoperative (Time-0) and three (Time-1) and six months (Time-2) postoperative levels of sexual, marital, and general life (mal)adjustment for both patients and partners, (ii) stress-spillover between the three (mal)adjustment domains for patients and partners separately, (iii) interdependence between both members of the couple, and (iv) longitudinal change in sexual, marital, and general life (mal)adjustment and longitudinal stress-spillover effects in these three domains, from a dyadic perspective.

Method

Patients

Data were drawn from a larger study examining the (sexual) consequences of colorectal cancer for patients and their partners (NCT01234246). Before surgical treatment, patients diagnosed with colorectal cancer and their partners were asked to participate in this study. Patients were recruited from six Dutch hospitals: St. Elisabeth hospital (Tilburg), TweeSteden Hospital (Tilburg and Waalwijk), Catharina Hospital (Eindhoven), Jeroen Bosch Hospital ('s Hertogenbosch), Amphia Hospital (Breda), and Maxima Medical Centre (Eindhoven and Veldhoven). Patients and partners older than 18 years were eligible for participation. The following exclusion criteria were applied: (i) elderly age (older than 75 years), (ii) non-curatively treated metastases at baseline, (iii) poor expression of the Dutch language, (iv) dementia, and/or (v) a history of psychiatric illness. When patients declined participation, the partners were still invited to participate (and *vice versa*) in order to prevent selection bias. During a preoperative visit patients and partners were asked, by their treating physician, if they could be approached by a member of the research team who would explain the study design and purpose. Subsequently, this member (MJT) contacted the potential participants and explained the study details. If patients and/or their partners agreed to participate they were asked to complete a set of standardized questionnaires at home at each time point (i.e., Time-0, Time-1, and Time-2). The Dutch guidelines recommend that all rectal cancer patients, except those with a clinical T1 stage without positive lymph nodes, receive neoadjuvant treatments (i.e., radio(chemo) therapy; www.oncoline.nl). Therefore, a subset of patients in this study completed the first set of questionnaires before surgery, but potentially while already receiving or after neoadjuvant therapy. Participants returned the surveys in sealed postage-paid envelopes. Participants who consented but who did not return the surveys within two weeks after consenting received a reminder (phone call(s) or a reminder letter). This study was approved by the institutional review board. All participants gave written informed consent.

Measures

Participants completed items on sociodemographic factors (age, sex, marital status, length of the relationship with their partner, and educational level) and the Maudsley Marital Questionnaire (MMQ)^{15,16}. The MMQ evaluates three domains of (mal)adjustment: Sexual (Mal) adjustment (5 items), Marital (Mal)adjustment (10 items), and General Life (Mal)adjustment (5 items). The 20 items of the MMQ are answered on a 9-point response scale (0–8). The items in each domain were summed. Scores on the Marital (Mal)adjustment domain could range from 0 to 80, while the Sexual (Mal)adjustment and General Life (Mal)adjustment domains could

range from 0 to 40. For all domains, a higher score indicates more maladjustment. A cutoff score of ≥ 20 on the Marital (Mal)adjustment subscale was used to identify individuals who experienced marital maladjustment.^{17,18} The psychometric qualities of the Dutch version of the MMQ were found to be satisfactory.^{15,16}

Statistical analysis

A multivariate General Linear Model (GLM) was conducted using an unstructured covariance matrix for the outcome variables (i.e., three (mal)adjustment domains \times three time points) with role (i.e., patient/partner) as within-subjects factor. The term 'subjects' refers here to dyads, as the patient-partner dyad is the unit of analysis.¹⁰ Type of tumor (i.e., colon/rectum) and the patients' gender were included as covariates. The GLM analysis allows characterizing the level of (mal)adjustment in the sample (i.e., descriptive statistics) and assessing within-dyad differences between patients and partners through the use of planned pairwise contrasts. Furthermore, the estimated covariance-matrix evaluates the association within dyads (i.e., patient-partner interdependence) as well as the inter-correlation between the three (mal)adjustment domains for both patients and partners (i.e., stress-spillover). Across time, stability of the MMQ domains was assessed with the IntraClass Correlation coefficient. For all correlations, a correlation of .5 was defined as strong, a correlation of .30 as moderate, and a correlation of .10 as weak.¹⁹ One-sample *t*-tests were used to compare the mean scores obtained in the present study with the mean scores of norm populations as described in the MMQ questionnaire manual.²⁰ Finally, Structural Equation Modeling (SEM) was used to evaluate the longitudinal change in sexual, marital, and general life (mal)adjustment and longitudinal stress-spillover between these three domains, from a dyadic perspective. A multivariate Latent Difference Score Model (LDS-SEM)^{21,22} was conducted in which the change in (mal)adjustment from preoperative to postoperative was explicitly formalized as a latent outcome variable. These latent difference scores were defined as implicit contrasts between (i) Time-1 and Time-0 and (ii) Time-2 and Time-0. On these contrasts a common factor was superimposed that captured the common preoperative to postoperative transition. Thus, it is the latter common change factor that is being predicted based upon the preoperative maladjustment levels of both patients and their partners. This model takes into account the dyadic data structure by allowing both Actor- and Partner effects and by allowing the outcome residuals to be correlated.²³ Again, type of tumor and the patients' gender were included as covariates. In order to use all available information for each individual under the missing at random assumption, the GLM and the LDS-SEM were estimated by means of full-information Maximum Likelihood.²⁴ Model fit was evaluated using the following fit indices^{24,25}: (i) The chi-

square with the associated p -value, (ii) The Root Mean Square Error of Approximation (RMSEA; $<.08$ = acceptable; $<.05$ = good fit), and (iii) The Comparative Fit Index (CFI; $.90-.95$ = acceptable; $\geq.95$ = good fit).

Results

Sample characteristics

In total, 374 eligible patients agreed to be contacted by a member of the research group, who informed them about the study. Of this group, 182 (49%) patients agreed to participate. Of these patients, 160 (87%) had a partner of which 123 (77%) participated. The non-responders had a higher age and were more often female compared with the responders ($p < .05$). In addition, three partners participated even though the patient did not. This resulted in a total of 182 participating patients and 126 participating partners. However, due to the dyadic nature of the study, the patients without a (participating) partner were excluded, resulting in 123 couples. In addition, to be included in the analyses, patients and partners had to complete at least two assessments. Based on this criterion, 21 (17%) couples were excluded. Therefore, the studied population consisted of 102 couples. Various reasons for declining or terminating participation were reported. The most reported reasons for non-participation were (i) the intimate nature of the questionnaires, (ii) the length of the questionnaires, and (iii) the amount of experienced stress at that time. The average age of patients and partners was 63.2 years (standard deviation=7.7) and 61.7 years (standard deviation=9.0), respectively. The male to female ratio of patients was 72 (70.6%) to 30 (29.4%). Thirty-nine (38%) patients had a colon tumor and 63 (62%) patients had a rectum tumor. The average length of the partner relationship was 36 years (standard deviation = 11.1; range 4 – 51 years). Although not a prerequisite, all couples were in a heterosexual relationship.

(Mal)adjustment levels for the sexual, marital, and general life domains

The levels of (mal)adjustment, differences between patients and partner on these (mal)adjustment scores, and a comparison with norm scores are presented in **Table 1**. In general, no significant differences were reported between patients, partners, and norm scores with regard to marital (mal)adjustment. Only at Time-2, partners reported more marital maladjustment compared with the norm. Moreover, at each time point both patients and partners reported more sexual maladjustment but better general life adjustment compared

with norm scores. However, for all domains, large standard deviations and a broad range in (mal)adjustment scores were reported, especially for the sexual (mal)adjustment domain. No significant differences were found between the patients' and partners' adjusted mean scores on the MMQ. When the scores on marital (mal)adjustment were dichotomized, it was noted that 17 (20%) patients and 17 (20%) partners reported marital maladjustment at Time-0. Postoperatively these results remained relatively stable: 16 (18%) patients and 18 (21%) partners reported marital maladjustment at Time-1 and 19 (24%) patients and 19 (24%) partners reported marital maladjustment at Time-2. In three (Time-0), two (Time-1), and seven (Time-2) cases both members of the dyad reported marital maladjustment. Thus, in most cases only the patient or the partner reported marital maladjustment. In addition, different participants reported marital maladjustment across the assessment points.

Stress-spillover between sexual, marital, and general life (mal)adjustment

Table 2 presents, for patients and partners separately, the association between the (mal)adjustment domains at each time point (i.e., Time-0, Time-1, Time-2). For patients, strong correlations are observed between the Marital (Mal)adjustment domain and the Sexual and General Life (Mal)adjustment domains at Time-0, but the strength of the correlations decreases over time. However, the reversed pattern is observed for the across time correlations between the Sexual and General Life (Mal)adjustment domains. The correlation is moderate at Time-0 and Time-1, while a strong correlation is observed at Time-2. For partners, the correlation between the Sexual and Marital (Mal)adjustment domains are moderate to weak at Time-0 and Time-1 and even non-significant at Time-2. The correlation between the Sexual and General Life (Mal)adjustment domains is moderate at Time-0, but also becomes insignificant at the subsequent time points. However, a moderate correlation between the Marital and General Life (Mal)adjustment domains is observed at Time-0, which even increases slightly over time.

Interdependence between patients and partners

Across time, the within-dyad associations are high for sexual (mal)adjustment and moderate for marital (mal)adjustment (see **Table 3**). For general life (mal)adjustment, the correlation decreases from high to insignificant across time. Thus, at each assessment point all three domains correlate within-dyads, with exception of general life (mal)adjustment at Time-2.

Table 1 Adjusted mean (mal)adjustment scores on the Maudsley Marital Questionnaire, differences in the levels of (mal)adjustment between patients and partners, and the comparison with norm scores

	Patients (n=102)	Partners (n=102)	<i>p</i> -value difference test
Sexual (Mal)adjustment			
Time-0	16.3±9.3 [1-36]**	17.2±8.2 [2-34]**	.424
Time-1	19.2±9.4 [0-38]**	19.0±8.8 [2-40]**	.847
Time-2	19.8±9.9 [0-40]**	20.1±8.9 [2-37]**	.692
Marital (Mal)adjustment			
Time-0	14.8±7.5 [0-44]	15.5±8.0 [2-52]	.525
Time-1	14.8±10.0 [0-62]	15.9±8.4 [2-48]	.362
Time-2	15.1±8.5 [0-38]	16.6±9.3 [0-47]**	.213
General Life (Mal)adjustment			
Time-0	6.3±4.4 [0-24]*	7.1±4.4 [0-21]*	.162
Time-1	8.0±4.9 [0-22]*	7.8±4.5 [0-22]*	.692
Time-2	8.7±5.5 [0-24]*	8.6±4.8 [0-24]*	.851

Note: Higher scores indicate more maladjustment. Scores on the Marital (Mal)adjustment subscale could range from 0 to 80, while the Sexual (Mal)adjustment subscale and General Life (Mal)adjustment could range from 0 to 40. Means ± standard deviations are reported adjusted for type of tumor and gender within a multivariate general linear model framework. The range in reported (mal)adjustment scores is reported between brackets. *P*-values based upon planned paired difference contrasts comparing patients with partners. Significantly less maladjustment compared with the norm scores is indicated with *, while ** indicates significantly more maladjustment compared with the norm scores. Time-0 = postoperative, Time-1 = three months postoperative, Time-2 = six months postoperative.

Table 2 Within-patient and within-partner correlation coefficients for the Maudsley Marital Questionnaire at each time point (i.e., stress-spillover between the three maladjustment domains)

		Time-0			Time-1			Time-2		
		1.	2.	3.	1.	2.	3.	1.	2.	3.
Patient	1. Sexual (Mal)adjustment	1.0	.48***	.36***	1.0	.36***	.37***	1.0	.28**	.48***
	2. Marital (Mal)adjustment		1.0	.49***		1.0	.26**		1.0	.26*
	3. General Life (Mal)adjustment			1.0			1.0			1.0
Partner	1. Sexual (Mal)adjustment	1.0	.26*	.28*	1.0	.22*	.16	1.0	.18	.17
	2. Marital (Mal)adjustment		1.0	.37***		1.0	.39***		1.0	.43***
	3. General Life (Mal)adjustment			1.0			1.0			1.0

Note: *** $p \leq .001$, ** $p \leq .010$, * $p \leq .050$; Reported correlations are partialled for type of tumor and gender within a multivariate general linear model framework. Time-0 = postoperative, Time-1 = three months postoperative, Time-2 = six months postoperative.

Table 3 Within-dyad correlations for the Maudsley Marital Questionnaire (i.e., interdependence between patients and partners)

(n=102)	<i>r</i>	95% CI	<i>p</i> -value
Sexual (Mal)adjustment			
Time-0	.60	[.44, .75]	<.001
Time-1	.51	[.35, .68]	<.001
Time-2	.72	[.61, .83]	<.001
Marital (Mal)adjustment			
Time-0	.46	[.29, .63]	<.001
Time-1	.34	[.14, .54]	.001
Time-2	.35	[.16, .55]	<.001
General Life (Mal)adjustment			
Time-0	.50	[.34, .66]	<.001
Time-1	.23	[.03, .44]	.025
Time-2	.04	[-.18, .25]	.733

Note: Reported correlations are partialled for type of tumor and gender within a multivariate general linear model framework. Time-0 = postoperative, Time-1 = three months postoperative, Time-2 = six months postoperative.

Longitudinal change and longitudinal stress-spillover from a dyadic perspective

For both patients and partners scores on marital (mal)adjustment were stable across time, as indicated by the high intraclass correlations and the non-significant average level differences across the three time points (see Table 4). For patients, there is support for average level differences for the other two domains. This indicates that more sexual and more general life maladjustment is reported at Time-1 and Time-2 compared with Time-0. For partners there is a similar pattern, but the difference is only significant at Time-2.

The LDS-SEM model evaluating the pre- to postoperative change had a good model fit ($\chi^2(df=93) = 127.42, p = .010$; CFI = .944; RMSEA = .060, $p = .252$; Table 5), however, based on the R^2 the model was better in predicting partner than patients' scores. For both patients and partners autoregressive effects were reported for all domains, except for the partners' marital (mal)adjustment. These autoregressive Actor effects entail that relatively more preoperative maladjustment in a certain domain lead to less worsening in the postoperative maladjustment of that domain. Furthermore, some pre- to postoperative cross-domain effects were found. Patients who were preoperatively relatively maladjusted in the general life domain showed a more steep increase in their postoperative sexual maladjustment, but a less steep increase in their postoperative marital maladjustment. For partners, their relatively high levels of preoperative marital maladjustment lead to a more steep increase in their postoperative general life maladjustment. Finally, the autoregressive effect of sexual (mal)adjustment was slightly compensated when their patients reported to be preoperatively sexually maladjusted (i.e., Partner effect). This effect indicated that if not only the partner but also the patient reported relatively high levels of preoperative sexual maladjustment, then the partner showed a steeper worsening of his/her postoperative sexual maladjustment even though he/she was already relatively maladjusted postoperatively. There was no significant influence of gender or type of tumor on the abovementioned results.

Table 4 Stability of scores on the Maudsley Marital Questionnaire over time and changes in the participants' scores over time

	Patients (n=102)	p-value	Partners (n=102)	p-value
Sexual (Mal)adjustment				
IntraClass Correlation	.71		.47	
Level differences across time				
Time-0-> Time-1	2.9	.004	1.8	.167
Time-1-> Time-2	0.5	.526	1.1	.227
Time-2-> Time-0	3.4	.001	2.9	.023
Marital (Mal)adjustment				
IntraClass Correlation	.84		.78	
Level differences across time				
Time-0-> Time-1	-0.4	.966	0.4	.554
Time-1-> Time-2	0.3	.749	0.7	.450
Time-2-> Time-0	0.2	.761	1.1	.246
General Life (Mal)adjustment				
IntraClass Correlation	.54		.65	
Level differences across time				
Time-0-> Time-1	1.8	.005	0.7	.143
Time-1-> Time-2	0.7	.257	0.8	.163
Time-2-> Time-0	2.5	.001	1.5	.005

Note: P-values based upon planned paired difference contrasts between time points. Analyses adjusted for type of tumor and gender within a GLM framework. Time-0 = postoperative, Time-1 = three months postoperative, Time-2 = six months postoperative.

Table 5 Latent Difference Score Model: longitudinal change in sexual, marital, and general life (mal) adjustment and longitudinal stress-spillover between these three domains, from a dyadic perspective

	Patients' postoperative (mal)adjustment scores									Partners' postoperative (mal)adjustment scores									
	Sexual (Mal)adjustment			Marital (Mal)adjustment			General Life (Mal)adjustment			Sexual (Mal)adjustment			Marital (Mal)adjustment			General Life (Mal)adjustment			
Preoperative predictor	β	S.E.	<i>p</i> -value	β	S.E.	<i>p</i> -value	β	S.E.	<i>p</i> -value		β	S.E.	<i>p</i> -value	β	S.E.	<i>p</i> -value	β	S.E.	<i>p</i> -value
Patients' Sexual (Mal)adjustment	-.29	.14	.031	.14	.12	.247	-.09	.09	.320		.48	.14	.001	.10	.10	.318	.02	.06	.742
Partners' Sexual (Mal)adjustment	-.07	.14	.607	-.09	.12	.415	.04	.10	.701		-.92	.14	<.001	-.10	.11	.341	-.05	.06	.387
Patients' Marital (Mal)adjustment	-.07	.15	.618	-.05	.11	.691	.12	.09	.160		-.17	.16	.274	.06	.11	.600	-.00	.06	.939
Partners' Marital (Mal)adjustment	-.06	.12	.604	-.00	.10	.976	.01	.07	.918		.05	.12	.668	-.25	.08	.004	.16	.05	.001
Patients' General Life (Mal)adjustment	.54	.23	.022	-.56	.20	.004	-.62	.14	<.001		.38	.27	.158	.13	.18	.453	.06	.09	.548
Partners' General Life (Mal)adjustment	.00	.21	.989	.16	.17	.370	.07	.13	.618		.01	.23	.981	.03	.17	.883	-.45	.08	<.001
Patients' gender	.66	.81	.415	.35	.66	.599	.92	.49	.060		.30	.89	.734	.58	.63	.352	.21	.33	.523
Patients' tumor	-1.0	.74	.161	-.04	.61	.953	-.27	.46	.563		-.86	.81	.288	-.32	.63	.608	.10	.31	.760
Intercept T0 ->T2	7.51			2.07			4.07				9.97			2.59			1.73		
Intercept T0 -> T3	8.47			3.08			4.71				10.09			3.42			2.67		
R ²	.34			.24			.42				.57			.31			.86		

Model fit: $\chi^2(df=93) = 127.42, p = .010$; CFI = .944; RMSEA = .060, $p = .252$.

Discussion

Across time, patients with colorectal cancer and their partners reported more sexual maladjustment, similar marital maladjustment (with exception of patients' higher maladjustment at Time-2), and even better general life adjustment compared with norm scores. These findings may indicate that even though the sexual maladjustment of patients and partners may be high, this stress does not necessarily spill over to the marital and general life domains. Moreover, the scores on marital (mal)adjustment were not only comparable with norm scores, but were also stable across time for both patients and partners. The fact that the studied population consisted mostly of couples in long-term relationships may have attributed to this. A U-shaped pattern of marital happiness across the life time has been previously reported.²⁶ These high levels of marital adjustment found in couples in long-term relationships may be explained by their reported high quality of dyadic interaction (i.e., dyadic coping), which was found to be positively associated with marital satisfaction.^{27,28}

In line with previous studies, the within-dyad correlations were moderate to high.^{29,30} These within-dyad correlations and the lack of mean level differences between patient and partners are indicative for interdependence and congruence in the experienced (mal)adjustment between patients and partners. The within-dyad associations were the highest for the Sexual (Mal)adjustment domain and the lowest for the General Life (Mal)adjustment domain. Intuitively, this is what might be expected, since the domains are ordered from narrow to broad: general life (mal)adjustment can be influenced by a broader range of factors, with larger individual differences between both members of the dyad, than patients' and partners' sexual (mal)adjustment.

The LDS-SEM model took into account actor-partner interdependence to examine the longitudinal change in sexual, marital, and general life (mal)adjustment and longitudinal stress-spillover in these three domains. For both patients and partners, autoregressive effects were reported for all domains, except for the Marital (Mal)adjustment domain for partners. These Actor effects reflect the intuitive notion that when someone is already highly maladjusted preoperatively, he/she will have less relative space to worsen postoperatively compared with someone who is more adjusted preoperatively. Another important observation was that the patients' preoperative general life maladjustment affected the postoperative change in all three domains, while sexual (mal)adjustment did not affect the postoperative change in the other two domains. This again shows that sexual maladjustment does not necessarily spill over to the other two domains. Moreover, the reversed direction may be applied. Maladjustment in the more broad general life domain may spill over to the smaller marital and sexual domains. Finally, both Actor- and Partner effects were reported for the longitudinal change in the

partners' sexual maladjustment. These effects implicate, in line with the high within-dyad associations for this domain, interdependence between patients and partners sexual (mal) adjustment.

The lack of gender effects in this study seems counterintuitive since the literature reports that women tend to experience more distress than men, regardless of their role.^{8,31,32} In our patient population, the ratio male to female patients was uneven (i.e., more male than female patients participated), which makes it difficult to formulate definitive conclusions. Nevertheless, Badr and Taylor (2008)³³ were also unable to detect a gender effect for the relationship between dyadic coping behaviors and marital adjustment. Therefore, it may be that an effect of gender is less prominent when it concerns dyadic/relational processes as opposed to mood-related distress, such as anxiety and depressive symptoms. Type of tumor (colon versus rectum) was also a non-significant covariate. This non-significance may be due to the fact that both colon and rectal cancer patients report more sexual dysfunction compared with a normative population, regardless of treatment differences.³⁴ In addition, both patient groups have to cope with cancer and incorporate the consequences of the disease and treatment in their life.

While the interdependence between patients and partners reported in this study is consistent with the literature, our study has provided new insights regarding (longitudinal) stress-spillover in the sexual, marital, and general life domains. However, there is also a need for future research. First of all, our sample size did not allow us to incorporate more specific treatment-related or psychosocial variables. A larger cohort of patients and partners, including more equally divided numbers of participating men and women, is needed in order to test the influence of additional treatment-related and psychosocial covariates on (mal)adjustment. In addition, a longitudinal prospective study could examine the association between dyadic processes and the course of sexual, marital, and general life adjustment in (older) couples coping with cancer more extensively. Furthermore, our study consisted solely of heterosexual couples who were not older than 75 years. In order to increase the generalizability of our findings, future studies should also include same-sex and elderly couples. Finally, a response rate of 49% was obtained. Even though this is a fairly good result compared with previous research focusing (partly) on sexuality after colorectal cancer¹¹, there still were considerable refusal rates. Some patients and partners felt reluctant to participate in a study that assesses relational and sexual aspects. Unfortunately, this may also entail that the patients and partners who experience the most maladjustment are the most likely to decline or terminate participation, which may have led to an underestimation of the experienced maladjustment.

Conclusion

Health care professionals have to be aware of potential sexual maladjustment after colorectal cancer surgery. However, they should evaluate if this sexual maladjustment influences the marital and general life adjustment of the couples and if patients and partners are bothered by sexual issues; there may not always be a need for help. Moreover, the reversed direction may be applied. Maladjustment in the more broad general life domain may spillover to the smaller marital and sexual domains. The moderate to high within-dyad associations and the similar levels of (mal)adjustment between patients and partners are indicative for interdependence between both partners. This supports the notion that a couple-based perspective to coping with cancer (e.g., couple-based interventions/therapy) is needed in both research and clinical practice. However, as mentioned above, future studies are needed to provide more specific insights in the course of the (dyadic) development of sexual, marital, and general life adjustment in older couples and to evaluate more specific treatment-related and psychosocial factors associated with this development.

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Evaluating quality of life
and response shift from a
couple-based perspective:
a study among patients
with colorectal cancer
and their partners



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Abstract

Objectives

To examine (i) measurement invariance of Quality of Life (QoL) domains over time for patients with colorectal cancer and partners (i.e., response shift - recalibration, reprioritization, and reconceptualization); (ii) between dyad-members measurement invariance; (iii) QoL trajectories.

Methods

Participants completed the WHOQOL-Bref preoperative (Time-0) and three (Time-1) and six months (Time-2) postoperative. A stepwise procedure, using nested factor models, examined the viability of restricting specific model parameters to be equal across measurements and between dyad members.

Findings

No reconceptualization and reprioritization occurred, but indications for recalibration were present. Therefore, comparisons were restricted to group-level statistics at factor level. For patients, a decrease in the Physical Health domain occurred at Time-1 ($p < .001$), with partial recovery to baseline at Time-2 ($p = .055$). For partners, factor means in this domain remained constant ($p > .05$) and were at each time point higher than patients' factor means ($p < .05$). Patients' and partners' Psychological Health decreased at Time-1 ($p < .05$), with stabilization at Time-2 ($p > .05$). Patients and partners factor means were comparable ($p > .05$). Patients' and partners' Social Relationship factor means decreased at Time-1 ($p < .05$), which decreased further for patients ($p = .011$) but stabilized for partners ($p = .214$). Partners' factor means were only lower than patients' factor means at Time-1. A similar decrease in the Environmental Domain factor means occurred for both patients and partners at Time-1 ($p < .05$), with stabilization at Time-2 ($p > .05$).

Conclusion

Since both patients and partners are affected by the patients' disease and treatment we recommend that attention is paid to the couple instead of solely the patient.

Introduction

There is an increasing awareness that not only oncological outcomes, but also patient-reported outcomes, such as Quality of Life (QoL), must be taken into account when evaluating the consequences of disease and treatment. However, QoL standards may change over the course of the disease trajectory.^{1,3} This may be inherent to the process of adapting to the disease.^{1,2} Within chronic disease research, Sprangers and Schwartz were the first to theoretically and methodologically address changes in QoL standards.^{1,2} Theoretically, they operationalized the term response shift as a 'meta-construct' which includes three interrelated constructs: Response shift is a change in the meaning of one's self-evaluation of QoL as a result of (i) recalibration: a change in the respondent's internal standards, (ii) reprioritization: a change in the respondent's values (i.e., the relative importance of an item on a QoL domain changed or the relative importance of the component domains constituting QoL changed), or (iii) reconceptualization: a redefinition of QoL.^{1,2} Response shift poses methodological challenges for QoL research: In order to adequately compare assessments completed over time, the questionnaire has to be measurement invariant.⁹ However, if response shift occurs, then this is not applicable. Therefore, evaluating response shift is necessary to allow adequate interpretation of QoL findings over time.

To our knowledge, only three studies examined response shift among patients with colorectal cancer^{4,6}, even though colorectal cancer is among the most prevalent cancer types.⁷ A qualitative study found recalibration and reconceptualization in patients with a temporary stoma.⁴ In addition, indications for recalibration were found in patients with colon cancer⁵ and a definitive colostoma.⁶ However, the latter two studies used the Then Test to evaluate response shift.^{5,6} Unfortunately, this test is not without criticism due to its proven susceptibility to recall bias.⁸ Therefore, more insight in the occurrence of response shift in patients with colorectal cancer is needed.

Furthermore, it is interesting to evaluate whether response shift occurs in partners of patients with colorectal cancer. These partners also have to incorporate ongoing cancer-related experiences into their lives, which may lead to changes in their QoL standards, values, and conceptualization. To our knowledge, this has not yet been evaluated. Incorporating both patients and partners in analyses can not only show if the QoL measurement is invariant over time for patients and partners separately, but also if measurement of QoL is invariant between both members of the couple. If this is true, then QoL findings of both patients and partners can be compared over time and between both dyad members.

Therefore, the aim of the current study was to examine (i) measurement invariance of QoL domains over time for patients with colorectal cancer and their partners (i.e., response shift - recalibration, reprioritization, and reconceptualization), (ii) between dyad-members measurement invariance and (iii) QoL trajectories for patients and partners in which the measurement invariance is taken into account.

Methods

Patients

Data were drawn from a larger study examining the (sexual) consequences of colorectal cancer for patients and their partners (NCT01234246). Before surgical treatment, patients diagnosed with colorectal cancer and their partners were asked to participate in this study. Patients were recruited from six Dutch hospitals: St. Elisabeth hospital (Tilburg), TweeSteden Hospital (Tilburg and Waalwijk), Catharina Hospital (Eindhoven), Jeroen Bosch Hospital ('s Hertogenbosch), Amphia Hospital (Breda), and Maxima Medical Centre (Eindhoven and Veldhoven). Patients and partners older than 18 years were eligible for participation. The following exclusion criteria were applied: (i) elderly age (older than 75 years), (ii) non-curatively treated metastases at baseline, (iii) poor expression of the Dutch language, (iv) dementia, and/or (v) a history of psychiatric illness. In order to prevent selection bias, partners were still invited to participate if the patients declined participation (and *vice versa*). During a preoperative visit patients and partners were asked, by their treating physician, if they gave permission to be approached by a member of the research team. This member would subsequently explain the study design and purpose. If patients and/or their partners agreed to participate they were asked to complete a set of standardized questionnaires at home at preoperatively (Time-0) and three (Time-1) and six months (Time-2) postoperative. However, the Dutch guidelines¹⁰ recommend that all rectal cancer patients, except those with a clinical T1 stage without positive lymph nodes, receive neoadjuvant treatments (i.e., radio(chemo)therapy). Therefore, a subset of patients completed the first set of questionnaires before surgery, but potentially while already receiving or after neoadjuvant therapy. Participants returned the surveys in sealed postage-paid envelopes. Participants who consented but who did not return the surveys within two weeks after consenting received reminders (phone call(s) or a reminder letter). The institutional review board approved this study. All participants gave written informed consent.

Measures

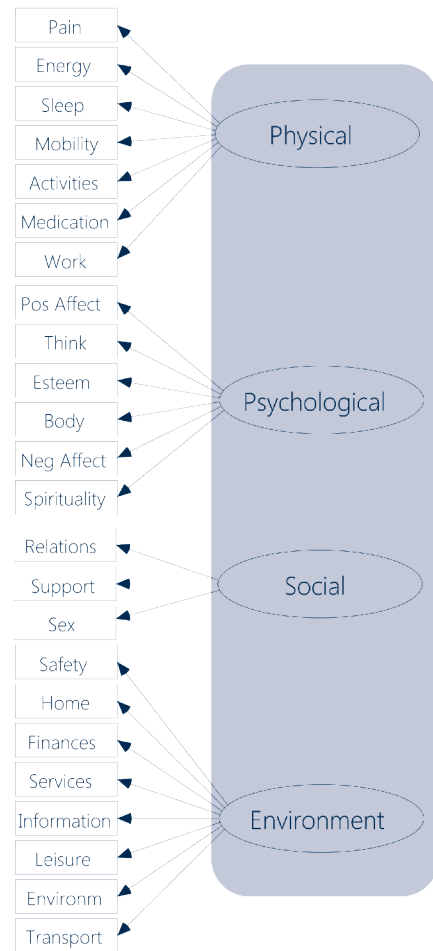
Participants preoperatively completed questions assessing sociodemographic factors (age, sex, marital status, length of the relationship with the partner, and educational level) and an adapted Self-administered Comorbidity Questionnaire (SCQ)¹¹, which evaluates comorbidity at the time of questionnaire completion.

The cross-culturally developed World Health Organization Quality of Life assessment instrument-abbreviated version (WHOQOL-Bref) is a generic multi-dimensional QoL measure.¹² The participants completed this questionnaire at each time point. The WHOQOL-Bref consists of 26 items of which 24 cover four domains: Physical Health, Psychological Health, Social Relationships, and Environment (see **Figure 1**). Furthermore, two items constitute the facet Overall Quality Of Life and General Health. However, since this facet only consists of two items it was not included in the response shift analyses. The WHOQOL-Bref provides a valid and reliable alternative for the WHOQOL-100.¹² Higher scores on a domain or the general facet indicate better QoL. Psychometric properties, such as discriminant validity, content validity, internal consistency, and test-retest reliability of the WHOQOL-Bref have been examined on multiple occasions and appeared to be good.¹³⁻¹⁵

The patient's clinical information was retrieved from the Eindhoven Cancer Registry (ECR). The ECR routinely collects data on tumor characteristics including date of diagnosis, tumor grade according to the Tumor-Node-Metastasis clinical classification, clinical stage, and treatment. If the ECR had not yet registered all clinical information, then the missing clinical information was retrieved from the patient's medical records.

Figure 1 WHOQOL-Bref structure for patients and partners

Figure 1. WHOQOL-Bref structure for patients and partners



Note: Variables within the gray box are allowed to intercorrelate.

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Statistical analysis

Chi-square tests and independent student *t*-tests were used to compare participants who declined participation with the participants on age, sex, and tumor type (if applicable). For the participants, descriptive statistics of the sociodemographic and clinical data were calculated. Pairwise difference tests were used to determine whether differences in QoL were noted between colon and rectal cancer for (i) patients and (ii) partners.

The equivalence of the QoL domains at different time points and between both members of the dyad (patients-partners) was evaluated. This so called factorial measurement invariance was examined by means of Structural Equation Modeling.¹⁶ An annotated path diagram of the factor model is given in Figure 2. To account for the dyadic data structure, there are different links (i.e., factor and residual correlations) between the patient- and partner-side of the model. For each domain, a stepwise procedure was followed that used nested factor models to examine the viability of restricting specific model parameters to be equal across time points and between dyad members (see Table 1 and Figure 2 and for an overview, see Millsap, 2011).^{17,18} In the first step, a baseline model was established to check whether the theoretical domain specific factor structure holds across time points and between both dyad members (i.e., configural invariance). If this step does not hold, the same unidimensional factor structure, for the specific domain, is not applicable across time points and between patients and partners. This implies a form of reconceptualization of the specific QoL domain. In the second step, metric invariance (i.e., equal factor loadings) was assessed to verify whether the strength of relationship between each item and the underlying domain construct remains the same across time points and dyad members. If this step does not hold, a form of reprioritization is implied, with for instance one or more items becoming more relevant for the construct domain at a given time point. In the third step, scalar invariance (i.e., equal loadings and intercepts) was assessed to verify, whether specific items show a differential score pattern compared to the general trend across time and between dyad members. If this step does not hold, it implies that certain items get recalibrated across time points and/or are being scored higher/lower by patients or partners. In order to evaluate which items are the likely candidates for a specific response shift phenomenon, specific items that do not fit the common general pattern of results across time points and between dyad members (i.e., appear inconsistent with the imposed invariance restrictions) need to be located.

To evaluate a configural invariance baseline model, we used the chi-square test of absolute fit; (ii) the Root Mean Square Error of Approximation to assess close fit (RMSEA; $<.08$ = acceptable; $<.05$ = good fit), and (iii) the Comparative Fit Index to assess deviations from the null model (CFI; $.90-.95$ = acceptable; $\geq.95$ = good fit). To allow for a clear interpretation of the

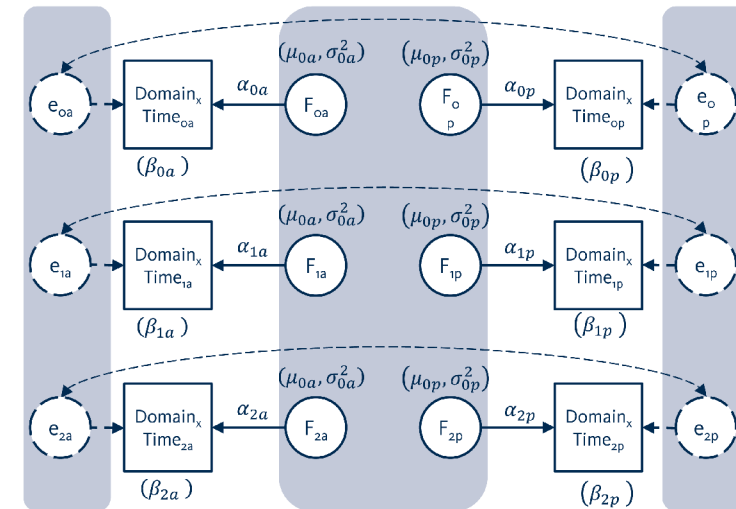
CFI we also fitted the null model (i.e., a model which restricts all correlations between items to be zero). If this null model already shows a reasonable goodness-of-fit (as shown in a relatively small RMSEA), this implies that the average correlation in the data is fairly low and that it will be unlikely to see very large CFI values for other models (as it is hard to greatly improve upon the null model). For the nested model comparisons between the different steps, we relied on chi-square difference tests and differences in the comparative fit index (ΔCFI : a non-reduced CFI or a reduction smaller than or equal to .01 indicates that the null hypothesis of invariance should not be rejected)¹⁹, as well as relative model comparisons based on the sample-size-adjusted Bayesian Information Criterion (saBIC; a lower value indicates a better trade-off between fit and complexity).²⁰ When invariance restrictions did not hold, modification indices were used to locate the items showing potential response shift and, (if possible) partial invariance was established by relaxing the invariance restrictions for these items.²¹ All data-analyses were done in the open-source statistical software R using the lavaan package for Structural Equation Modeling.²²

Table 1 Stepwise procedure using nested factor models to examine the viability of restricting specific model parameters to be equal across time points and between patients and partners (see Figure 2 for the model used)

Invariance	Restrictions
Configural	means and variances for all factors are fixed, $\mu = 0$ & $\sigma^2 = 1$
Metric	all α 's of the same item are equal (i.e., across time points and dyad) variances of all factors are no longer fixed except for the reference factor F_{0a}
Scalar	all α 's of the same item are equal (i.e., across time points and dyad) all β 's of the same item are equal (i.e., across time points and dyad) means of all factors are no longer fixed except for the reference factor F_{0a} variances of all factors are no longer fixed except for the reference factor F_{0a}

Note: α : factorloading, β : item intercept, μ : factor mean, σ^2 : factor variance.

Figure 2 Factorial measurement invariance across time and between patients and partners



Note: Circles are latent variables, with the F's representing common domain factors and the e's unique residuals. Squares are observable variables representing the WHOQOL items. For reasons of clarity only one indicator per factor is shown, yet it represents the whole set of items for the domain. Numerical subscripts indicate the time point, subscript a/p are for patients (actors) and partners (partners), respectively. Variables within a gray box are allowed to intercorrelate. α : factorloading, β : item intercept, μ : factor mean, σ^2 : factor variance.

Results

Participants

In total, 672 eligible patients agreed to be contacted by a member of the research group, who informed them about the study. In total, 313 (47%) patients agreed to participate. Of these patients, 279 (89%) had a partner of which 205 (74%) participated. Due to the dyadic nature of the analyses, only these couples were included ($n=205$). An overview of the number of participants at each time point is presented in **Table 2**. To make use of all available data and account for missing data, the CFA approach was carried out using full information maximum likelihood under the missing at random assumption. Sociodemographic and clinical characteristics of patients and partners (if applicable) are presented in **Table 3**. Skewness and Kurtosis of the WHOQOL-Bref items did not pose problems for the use of normal maximum likelihood estimation procedures and was in line with recommendations for Structural Equation Modeling.²³ For patients, skewness of the WHOQOL-Bref items ranged between -1.35 to .21, while excess Kurtosis ranged from -1.15 to 3.51. For partners, these ranges were -1.42 to .28 and -1.30 to 6.01, respectively. No differences were seen in the mean QoL domains scores between colon and rectal cancer patients/partners ($p>.05$).

Table 2 Number of participants at each assessment point

	Time-0		Time-1		Time-2	
	patients	partners	patients	partners	patients	partners
Completed	164	166	148	141	123	114
Participated from Time-1 onwards	42	40	-	-	-	-
Missing	-	-	10	10	14	14
Drop-out at Time-1	-	-	23	28	23	28
Drop-out at Time-2	-	-	-	-	35	35
Not yet completed the questionnaire*	-	-	25	27	35	35

Note: *Due to the ongoing nature of the study not all participants had already completed all time points.

Table 3 Demographic and clinical characteristics of patients and their partners

	Patients (n=205)	Partners (n=205)
	Mean±SD	Mean±SD
Age at time of survey	62.0±8.6	6.6±9.9
Relationship in years	35.9±16.3	35.9±16.3
	N (%)	N (%)
Male gender	146 (71.2%)	59 (28.4%)
Educational level		
Low	13 (6%)	10 (5%)
Medium	125 (61%)	142 (68%)
High	56 (27%)	47 (23%)
Missing	11 (6%)	9 (4%)
Type of cancer		
Colon	125 (61%)	-
Rectum	80 (39%)	-
Type of surgery		
Low anterior resection	84 (41%)	-
Abdominoperineal resection	35 (17%)	-
Hemicolectomy/ileocecal resection	29 (14%)	-
Sigmoid resection	27 (13%)	-
Other	27 (13%)	-
Unknown type of surgery	3 (2%)	-
Type of radiotherapy (RT)		
No RT	135 (66%)	-
Preoperative RT	42 (21%)	-
Intra-Operative RT	19 (9%)	-
Other RT	5 (3%)	-
Unknown	4 (1%)	-

	Patients (n=205)	Partners (n=205)
	N (%)	N(%)
Chemoradiation		
No	125 (61%)	-
Yes	74 (36%)	-
Unknown	5 (3%)	-
Type of chemotherapy (CT)		
No CT	145 (71%)	-
Postoperative CT	50 (24%)	-
Other CT	7 (3%)	-
Unknown	3 (2%)	-
Stoma		
Yes	122 (60%)	-
No	79 (38%)	-
Unknown	4 (2%)	-
Comorbidity		
Cardiovascular disease	21 (11%)	17 (9%)
Lung disease	8 (4%)	19 (10%)
Diabetes mellitus	11 (6%)	17 (9%)
Artrose	27 (14%)	44 (24%)
Back pain	28 (15%)	37 (20%)

Note: Low = up to ten years of education, middle = 10-14 years of education, high = more than 14 years of education.

Table 4 Factorial invariance for patient-partner dyads and across time points and between dyad members

Invariance Model	χ^2	df	p	CFI	RMSEA	saBIC	$\Delta \chi^2$	Δdf	p	ΔCFI
Physical Health										
Null	4186	931	<.001	.000	.130	15690				
Configural	1034	729	<.001	.900	.045	12974				
Metric	1072	759	<.001	.897	.045	12947	37.67	30	.1583	.003
Scalar	1160	789	<.001	.878	.048	12971	88.45	30	<.001	.019
*Scalar	1115	885	<.001	.892	.045	12934	42.908	26	.0198	.005
Psychological Health										
Null	3144	690	<.001	.000	.131	11716				
Configural	793	510	<.001	.880	.052	9754				
Metric	831	535	<.001	.874	.052	9737	37.35	25	.0534	.006
Scalar	882	560	<.001	.863	.053	9735	51.74	25	.0014	.011
*Scalar	865	558	<.001	.870	.052	9722	34.23	23	.0618	.004
Social Relationships										
Null	968	183	<.001	.000	.144	5971				
Configural	140	93	.001	.933	.050	5337				
Metric	154	103	.001	.927	.049	5330	13.96	10	.1748	.006
Scalar	177	113	<.001	.909	.053	5331	23.00	10	.0108	.018
*Scalar	164	111	.001	.924	.048	5323	1.4	8	.238	.003
Environment										
Null	3712	931	<.001	.000	.120	13965				
Configural	1123	705	<.001	.843	.054	11863				
Metric	1160	735	<.001	.840	.053	11836	37.46	30	.1642	.003
Scalar	1235	765	<.001	.824	.055	11845	73.97	30	<.001	.016
*Scalar	1185	760	<.001	.841	.052	11806	24.169	25	.5096	.001

Note: * Scalar indicates partial invariance: freeing the intercepts of recalibrated items.

Equivalence of the QoL domains at different time points and between patients and partners

The null model showed a reasonable goodness-of-fit as can be seen from the relatively small RMSEA (see Table 4, page 211). The nested model comparisons showed that for each of the four QoL domains no support for reconceptualization and reprioritization was found. Hence, the QoL domains demonstrated configural and metric invariance as can be seen from the decreasing saBIC across subsequent models, negligible Δ CFI differences, and RMSEA's of $\leq .05$ (Table 4, page 211).

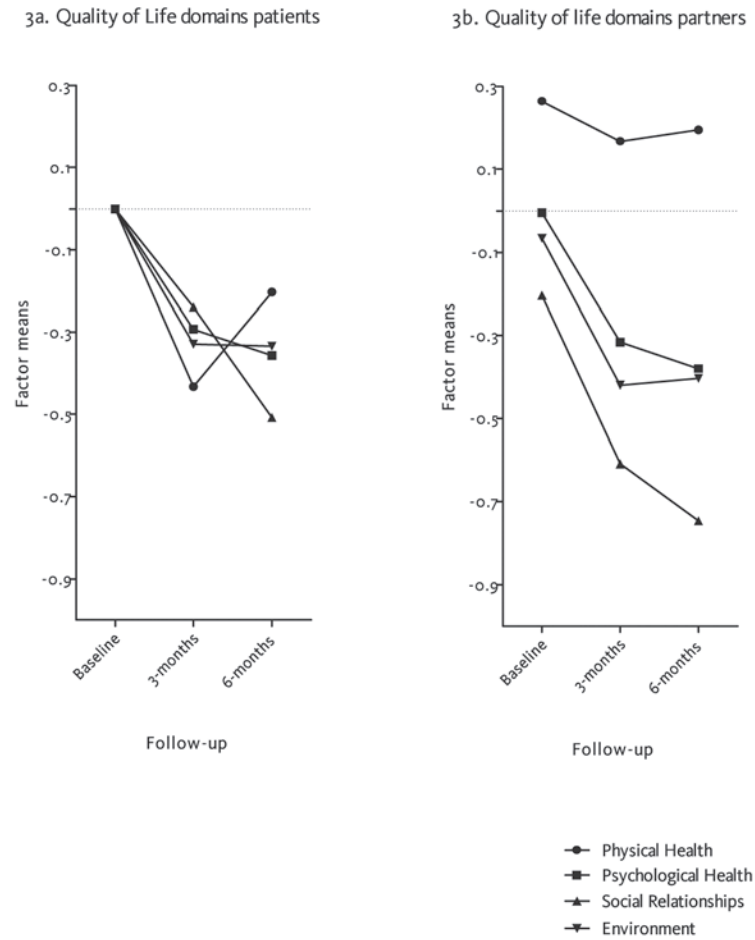
Even though absolute fit indices for scalar invariance were still acceptable, relative comparisons pointed at some minor non-invariance issues at the item intercept level for the QoL domains (i.e., recalibration). Thus, for some items a higher or lower score at specific time points was reported than would be expected based upon the general trend at the domain level. For the Physical Health domain, item 10 “*Do you have enough energy for everyday life*” had a slightly higher intercept at Time-0 ($\Delta=.28$) while item 3 “*To what extent do you feel that physical pain prevents you from doing what you need to do?*” and item 4 “*How much do you need any medical treatment to function in your daily life?*” had slightly lower intercepts at Time-0 ($\Delta=-.15$ and $\Delta=-.48$, respectively). Thus, for item 10 surgery has a higher impact compared to the general trend. Surgery also had a substantial impact on item 3 and 4 resulting in lower preoperative scores on these items compared with the general trend. For partners, item 15 “*How well are you able to get around*” had a slightly lower intercept at Time-0 compared with the patients ($\Delta=-.19$), which indicates that the difference between patients and partners on this item was smaller before surgery. For the Psychological Health domain item 6 “*To what extent do you feel your life to be meaningful?*” had a slightly higher intercept at Time-1 ($\Delta=.12$), compared to Time-0 and Time-2 for the patients. Thus, at the first assessment after surgery patients experienced a general decrease on the Psychological Health domain. However, patients showed less decrease on the extent to which they felt their life to be meaningful. For patients, item 7 “*How well are you able to concentrate?*” had a slightly higher intercept at baseline ($\Delta=.21$). Thus, surgery and adjuvant treatment (if applicable) have substantial impact on the patients’ concentration. For the Social Relationships domain, both patients and partners had a slightly higher intercept at Time-0 for item 20 “*How satisfied are you with your personal relationships?*” compared with Time-1 and Time-2 ($\Delta=-.20$ and $\Delta=-.29$, respectively). This implies that, after surgery, the decrease in satisfaction with personal relations is even stronger than the general decreasing trend in the social relationships domain. Finally, the Environmental domain item 9 “*How healthy is your physical environment?*” had slightly lower intercept for partners than for patients ($\Delta=-.43$), which might be linked to the intrinsically worse physical condition of patients. The occurrence of recalibration indicates that the comparison of individual QoL domain scores may be biased. In total, 8 of the 24 items were affected to some extent by recalibration, yet the intercept

deviations were relatively small and the majority of items for each separate domain could still be considered scalar invariant, hereby providing a broad enough base to warrant comparison of the domains at the factor level.²⁰ Therefore, the results of the QoL domains over time and between dyad-members, based on group-level statistics of the partial scalar invariant factor model, are described below.

QoL domain trajectories

The established partial scalar measurement invariance for the factor structure of the QoL domains allowed comparison of patients and partner over time and between both members of the dyad on these domains at the factor level. For patients and partners the results of these analyses are presented in Figure 3^a and 3^b. For patients, an initial decrease in the Physical Health domain occurred at Time-1 compared with Time-0 ($p<.001$), after which partial recovery to baseline was observed at Time-2 ($p=.055$). For partners, factor means in the Physical Health domain remained constant over time ($p=.189$, $p=.679$) and were at each time point higher than the patients’ factor means ($p=.007$, $p<.001$, and $p=.001$, respectively). Patients’ and partners’ factor means on the Psychological Health domain significantly decreased at Time-1 ($p=.002$ and $p<.001$) after which stabilization occurred at Time-2 ($p=.471$ and $p=.362$). Patients and partners factor means were at each time comparable ($p=.844$, $p=.835$, and $p=.838$, respectively). Patients’ and partners’ factor means on the Social Relationships domain significantly decreased at Time-1 ($p=.018$ and $p<.001$), which decreased further on for patients ($p=.011$), but stabilized for partners ($p=.214$). Partners factor means were significantly lower than patients factor means at Time-1, but not at the other time points ($p=.088$, $p<.001$, $p=.098$, respectively). For the Environmental Domain a decrease in factor means was noted for both patients and partners at Time-1 ($p<.001$ and $p<.001$), after which stabilization occurred at Time-2 ($p=.952$ and $p=.830$). For this domain, patients and partners factor means were at each time comparable ($p=.459$, $p=.346$, and $p=.484$, respectively). For each domain, significant correlations in the QoL construct domains were found across time points, for both groups (see Table 5). These relatively high over-time correlations indicate that the relative position of patients and partners stayed stable over time, however, their actual QoL-scores might still have changed. Between patients and partners, the QoL domain constructs correlated significantly at each time point (see Table 5). For the Social Relationship and Environmental domains between dyad-member correlations were relatively homogenous. However, for the Physical and Psychological Health domains an auto-regressive correlation structure was noted: correlations reduced over time. In addition, at each time point, the correlations between patients and partners for the Physical Health domain were low. Finally, the partners’ lower variances for the Physical Health and Psychological Health domains might indicate that, for these domains, the partners are a more homogeneous group than the patients.

Figure 3 Factor means across time for the QoL domains for patients and partners



Note: The factor mean at baseline for patients is set as reference (i.e., dashed line) and fixed at zero to identify the longitudinal Structural Equation Model.

Table 5 Correlations at different time points and between patients and partners and variances for patients and partners at each time point for the four QoL domain factors

		Patients			Partners		
		Time-0	Time-1	Time-2	Time-0	Time-1	Time-2
Physical Health							
Patients	Time-0	1.000					
	Time-2	.496*	.940				
	Time-3	.420*	.692*	1.052			
Partners	Time-0	.281**	.141**	.152***	.882		
	Time-2	.366*	.123**	.321**	.681*	.702	
	Time-3	.111	-.037	.100	.398*	.706*	.692
Psychological Health							
Patients	Time-0	1.000					
	Time-2	.729*	1.252				
	Time-3	.668*	.721*	.939			
Partners	Time-0	.416*	.282**	.269***	.848		
	Time-2	.329**	.340**	.309**	.269***	.888	
	Time-3	.093	.181	.215	.309**	.760*	.715
Social Relationships							
Patients	Time-0	1.000					
	Time-2	.863*	.847				
	Time-3	.890*	.736*	1.059			
Partners	Time-0	.462*	.435**	.241	1.310		
	Time-2	.493**	.410***	.426**	.681*	.816	
	Time-3	.507**	.353***	.300***	.398*	.808*	1.077
Environment							
Patients	Time-0	1.000					
	Time-2	.765*	1.074				
	Time-3	.856*	.738*	.861			
Partners	Time-0	.496*	.487*	.501*	.973		
	Time-2	.524*	.596*	.592*	.789*	1.041	
	Time-3	.336**	.376**	.548*	.661*	.850*	.998

Note: * $p < .001$, ** $p < .01$, and *** $p < .05$; Variances on the diagonal and correlations on the off-diagonal.

Discussion

For both patients with colorectal cancer and their partners no indication for reconceptualization (i.e., no dissimilarity in the conceptual frame of the construct domains across time points) and reprioritization (i.e., similar relative importance of one or more of the items relevant for the construct domain at a given time) was found. Furthermore, conceptualization and prioritization was similar between patients and partners.

The lack of indications for reconceptualization and reprioritization might be surprising, since earlier studies did find these indications in other populations.^{24,30} The questionnaire used to assess response shift may in part explain the outcomes.³¹ Questionnaires routinely used to assess response shift are in fact questionnaires that assess health status (e.g., The Short Form (12/36) Health Survey; SF-12/36).³ The terms QoL, health status, and health-related quality of life are often used interchangeably, however, the distinction between these definitions is important.³² Health status evaluates the impact of disease on functioning.³² Questionnaires evaluating health status, such as the SF-12/36, therefore assess physical possibilities, social activities, and psychological function, but not the participants' feelings concerning this functioning.³² QoL is defined by the World Health Organization Quality of Life Group as "an individual's perception of his/her position in life in the context of the culture and value systems in which he/she lives and in relation to his/her goals, expectations, standards and concerns".³³ This definition implies that QoL is always subjective in nature. Therefore, QoL entails participants' subjective interpretation of their well-being. Thus, health status questionnaires measure the impact of disease on functioning whereas QoL questionnaires measure the extent to which a participant is bothered by these limitations.³² Therefore, questionnaires using the SF12/36 might assess response shift in health status as opposed to response shift in QoL. In addition, our study only examined within-domain reconceptualization. However, in order to detect reconceptualization between the several domains it is also necessary to evaluate the cross-loadings. Unfortunately, we were unable to conduct these multidimensional analyses due to a limited sample size. In addition, in both research and clinical practice the WHOQOL-Bref is only used to evaluate each domain individually (i.e., no total score is computed), therefore, comparing the domains does also not fit within the established fixed framework. Thus, in this study the current within-domain analyses were justified, but future studies in this area are still needed. In line with earlier studies^{5,6}, indications for recalibration were found. That is, some items showed a differential score pattern compared to the general trend over time and between dyad members. It is not surprising that patients preoperatively reported to have more energy (item 10), a better ability to concentrate (item 7), less prevented in their activities by physical pain (item 3), and in less need of medical treatment (item 4) compared with the

general domain trend. Especially since surgery and adjuvant treatments (if applicable) can have a substantial impact on these aspects. It is also not surprising that the preoperatively difference between patients and partners was smaller on their ability to get around (item 15). However, it is noteworthy that the decrease in satisfaction with personal relations is stronger than the general decreasing trend in the Social Relationships domain. Potentially, the social support received after treatment did not live up to patients' and partners' expectations. In addition, even though patients experienced a general decrease on the Psychological Health domain at Time-1, patients showed less decrease on the extent to which they felt their life to be meaningful. In our opinion, this reflects what is in clinical practice often meant with response shift. Finally, for the Environmental domain partners reported their physical environment to be less healthy, which might be linked to the intrinsically worse physical condition of the patients.

While the indications for recalibration prohibited straightforward comparison of individual QoL domain scores, the established (partial) scalar measurement invariance did allow comparison of patients and partners QoL domain factor means over time and between both members of the dyad. For both patients and partners these factor level analyses showed, for the domain Psychological Health and the Environmental domain (consisting of questions such as 'To what extent do you have the opportunity for leisure activities?'), an initial significant decrease at Time-1 compared with Time-0, after which stabilization was observed at Time-2. This makes sense, since patients and partners both need to recover psychologically from the diagnosis and impact of cancer treatment. Patients' and partners' factor means on the Social Relationships domain also decreased at Time-1. However, at Time-2 this dissatisfaction increased for patients, while a partial recovery occurred for partners. As can be expected, partners had higher scores on the Physical Health domain compared with patients and correlations between patients and partners for this domain were low. All in all, these results show that both patients and partners are affected by the patients' illness. Therefore, it is recommended that health care professionals and researchers pay attention to the QoL of both patients and partners.

To our knowledge, this is the first study that examined measurement invariance and QoL over the first six months after colorectal cancer surgery from a dyadic perspective. The results of the factor level QoL domain analyses acknowledge the notion that a couple-based perspective to coping with colorectal cancer is warranted. Using the WHOQOL-Bref was an important advantage, as it assesses the subjective evaluation of functioning instead of functioning alone. However, there are also some limitations that need to be noted. For instance; although the first questionnaire was completed prior to surgery (Time-0) it probably does not reflect the

patients' and partners' actual baseline QoL. The time after diagnosis but prior to surgery can be very distressing for patients, as the consequences and results of cancer treatment are still unknown. Furthermore, the patient population was quite heterogeneous. Within and between patients with colon and rectal cancer a wide variety of treatment schedules and possible consequences of treatment (e.g., a stoma) can occur. This might have influenced our results, even though no differences in QoL were found between patients with colon and rectal cancer. In addition, future studies are needed to evaluate multidimensional reconceptualization and how the QoL trajectories develop in the future. Finally, even though patients' self-report is the most common and straightforward way to obtain QoL information, questionnaires may not completely capture the response shift experienced. In this regard, Rapkin and Schwartz rightly advise to incorporate direct measures of QoL appraisal and interviews in order to account for inter-individual and temporal differences in the meaning attributed to QoL scales.³¹

Conclusion

For patients with colorectal cancer and their partners no reconceptualization and reprioritization occurred within each of the QoL domains, but indications for recalibration of specific items were found. The reported partial scalar factorial invariance implied that straightforward comparison of individual QoL domain scores was not warranted, but that comparisons over time and between patients and partners were feasible if restricted to group-level statistics at the factor level. The QoL domain trajectories showed that both patients and partners are affected by the patient's disease and treatment. Therefore, it is recommended that health care professionals and researchers give attention to the couple as opposed to the patient alone.

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The sexual health care needs
after colorectal cancer:
the view of patients, partners,
and health care professionals



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Abstract

Background

Sexual dysfunction among patients with colorectal cancer is frequently reported. Studies examining patients' sexual health care needs are rare. We examined the sexual health care needs after colorectal cancer treatment according to patients, partners, and health care professionals (HCPs). Factors that impede or facilitate the quality of this care were identified.

Method

Participants were recruited from three Dutch hospitals: St. Elisabeth, TweeSteden, and Catharina hospital. Patients ($n=21$), partners ($n=9$), and 10 HCPs participated in eight focus groups.

Results

It is important to regularly evaluate and manage sexual issues. This does not always occur. Almost all participants reported a lack of knowledge and feelings of embarrassment or inappropriateness as barriers to discuss sexuality. HCPs reported stereotypical assumptions regarding the need for care based on age, sex, and partner status. The HCPs debated on whose responsibility it is that sexuality is discussed with patients. Factors within the organization, such as insufficient re-discussion of sexuality during (long-term) follow-up and unsatisfactory (knowledge of the) referral system impeded sexual health care. The HCPs could facilitate adequate sexual health care by providing patient-tailored information and permission to discuss sex, normalizing sexual issues, and establishing an adequate referral system. It is up to patients and partners to demarcate the extent of sexual health care needed.

Conclusions

Our findings illustrate the need for patient-tailored sexual health care and the complexity of providing/receiving this care. An adequate referral system and training are needed to help HCPs engage in providing satisfactory sexual health care.

Introduction

There is an increasing awareness that patients coping with cancer may have sexual health care needs.¹ Previous studies have shown that patients with breast-, gynecological-, or prostate cancer may need informational support and treatment to optimize the patients' sexual functioning and/or the quality of sexual life.¹ However, these needs may not be adequately met.¹

Although sexual dysfunctions among patients with colorectal cancer are frequently reported², studies examining the sexual health care needs of these patients are rare.^{3,5} One study investigated the informational needs of patients and reported that 55% of them did not remember receiving any information on how cancer or cancer treatment may affect their sexual functioning, while 58% rated this topic as important (*somewhat – very important*).³ In addition, patients' unmet sexual health care needs were positively related to psychological symptom distress, but negatively related to age.⁴ To our knowledge, only one study noted an impact of surgery or a stoma on the sexual relationship.⁵ However, the two latter studies did not provide an in-depth view, since sexual health care needs were examined as a secondary objective. Furthermore, studies examining both patients and partners are lacking, even though coping with cancer is probably a dyadic affair.^{6,7} Finally, there may be a mismatch in expectations between patients and partners and health care professionals (HCPs) with regard to the necessity for sexual health care.^{8,9}

Due to the abovementioned reasons it is important to ascertain the sexual health care needs of patients and partners coping with colorectal cancer and to explore when and by whom these sexual issues could be evaluated and managed.^{10,11} Knowledge of the barriers and facilitators associated with providing or receiving adequate sexual health care may enable patients, partners, and HCPs to overcome these issues. Therefore, the aim of the current focus group study was to examine (i) the sexual health care needs according to patients, partners, and HCPs and (ii) factors that impede or facilitate the sexual health care.

Method

Participants and procedure

Participants were recruited from the St. Elisabeth Hospital (Tilburg, the Netherlands), TweeSteden Hospital (Tilburg and Waalwijk, the Netherlands), or Catharina Hospital (Eindhoven, the Netherlands). First, the patients' medical records were reviewed in order to determine the patients' eligibility. Eligible participants had to be (i) diagnosed with colorectal

cancer between January 2010 and February 2012 *or* be the partner of an eligible patient diagnosed with colorectal cancer within this time frame and (ii) aged between 18 and 75 years. Persons were excluded if they (i) had metastatic colorectal cancer *or* their partner had metastatic colorectal cancer, (ii) were physically not fit enough to attend the focus group, (iii) had a history of mental disease or cognitive problems, or (iv) had insufficient knowledge of the Dutch language. One of the researchers (MJT) contacted the eligible participants to explain the purpose of the study and invited them to participate. In order to ensure a wide variety of experiences to be represented, potential participants were informed that having sexual health care needs and/or being sexually active was not a prerequisite to participate in this study. In addition, patients and partners were selected based on their sex, age, and tumor type (if applicable) in order to attain a fair representation of the colorectal cancer patient population and their partners. To rule out selection bias, the partners were still invited to participate when patients declined participation and *vice versa*. A purposive sampling method was applied. Purposive sampling implies that the recruitment of participants was stopped after the intended number of participants and sufficient diversity between the participants in the focus groups was achieved. The participating HCPs were invited by two members of the research team (JAR and HJTR). JAR and HJTR selected HCPs based on their expertise and experience working with the colorectal cancer patient population. The medical ethical committee approved the study. All participants gave written informed consent. Participation was voluntarily; no financial reward was given.

Focus group meetings

Conducting focus groups is one of the most used methods in qualitative research.¹² Focus groups facilitate the in-depth exploration of a person's perspective through group interaction.¹³ Since sexual health care needs were the topic of the focus groups we thought that participants may share information more easily when not in the presence of their partner, someone of the opposite sex, or their HCP. Therefore, patients, partners, and HCPs were interviewed separately. In addition, the patient and partner groups were sex-specific. Usually, six to eight participants are invited per focus group.¹³ However, given the sensitive topic, we allowed fewer participants per group. After eight sessions data saturation was reached.¹⁴ Each focus group was guided by a focus group moderator (MJT). The moderator was assisted by a student who took notes. The moderator started each focus group by explaining the purpose of the study followed by an introductory round in which each of the participants briefly shared their experiences. During the focus groups two main questions were asked: "Which sexual health care needs did you have during the course of treatment or do you still have?" and "During which

treatment phase did you need/receive this sexual health care?". Follow-up questions were asked to capture the experiences of the participants and their view on how to improve sexual health care (if needed). The focus group structure was the same for each focus group. The focus groups took about 90 minutes and were audio taped with the participants' permission.

Questionnaire

Patients and partners completed questions assessing socio-demographic factors (i.e., age, sex, marital status, and educational level). In addition, they rated on a 10-point scale: (i) the importance of sexuality, (ii) the severity of sexual problems, and (iii) the influence of sexual problems on their quality of life. For the item on the importance of sexuality a higher score indicated a higher importance. For the latter two questions a higher score indicated more severe sexual problems and a bigger influence of these problems on quality of life, respectively.

Data analysis

The focus group meetings were analyzed using a grounded theory approach.^{14,15} Data analysis proceeded stepwise. First, the focus groups were transcribed verbatim. Next, open coding was used in order to identify the needs and determinants for change. Subsequently, the determinants were grouped into barriers and facilitators. Next, these barriers and facilitators, could be grouped according to the model of Wensing *et al.*, (2005)^{17,18} who described factors that impede or facilitate change in the care system: (i) individual factors (e.g., motivational, cognitive, or behavioral), (ii) social factors (e.g., professional teams, professional development, and professional networks), (iii) organizational factors (e.g., organizational processes, structure of the organization and work processes, and available resources), and (iv) societal factors (e.g., financial factors, law and regulations). Two authors (MJT and BLDO) independently reviewed and coded each of the transcripts and ensured data saturation. In addition, these authors discussed the different sets of coding. When coding disagreements arose, the authors discussed the responses and selected the most appropriate code for each response. After this discussion, the transcripts were re-read and re-coded. Analyses were done using color coding in Microsoft Word and Excel.

Results

In total, 21 patients and nine partners participated (see **Figure 1** and **Table 1**). For the patients and partners, the sociodemographic characteristics as well as the scores reflecting the importance of sexuality, the severity of sexual problems, and the influence of sexual problems on their quality of life are presented in **Table 1**. The clinical characteristics of the patients are also reported in **Table 1**. Ten HCPs participated: two surgeons, one gynecologist, one gynecologist/oncologist, an urologist, two sexologists/psychologists, a physician assistant, a nurse practitioner, and a stoma nurse.

The sexual health care needs according to patients, partners, and HCPs

Survival seems to be the main priority for patients and partners, especially during treatment and the first months after treatment. However, sexuality may regain a more prominent position in the couples' life after treatment. Patients and partners especially considered being intimate (e.g., hugging and kissing) and having a good relationship important. Moreover, they often rated intimacy as more important than being able to have sexual intercourse.

Patients and partners both acknowledged the importance of receiving sexual health care. They reported having frank conversations about the possible consequences of colorectal cancer and its treatment on sexual function and/or the quality of sexual life as an important need. Since intimacy was often the main priority, they stated that these conversations should not focus solely on potential sexual dysfunctions, but also on psychosexual changes that may occur. Patients and partners also reported a need for (knowledge of) treatment options if a sexual dysfunction or sexual problem occurs. The HCPs acknowledged that sexual health care should be provided, both on an informational and treatment level. However, all participants also acknowledged a number of barriers to providing sexual health care. They reported similar individual and organizational factors that could impede or facilitate change. Therefore, the results are presented per factor. Within these factors few sex- or role-specific (patient-partner-HCP) themes were reported. If a theme was only applicable for a subgroup of participants, then this is explicitly stated in the text.

Figure 1 Study Flow Chart

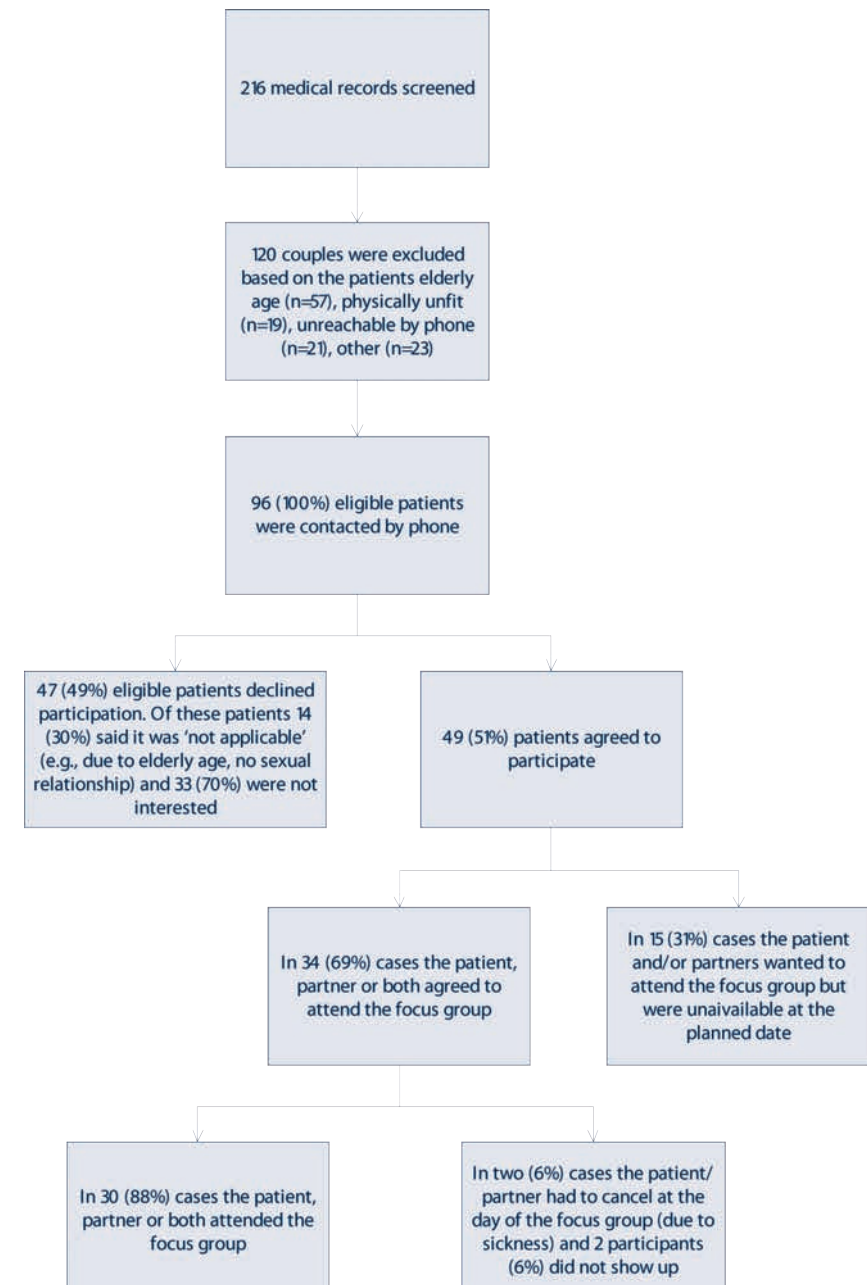


Table 1 Demographic and clinical characteristics of patients and partners

	Male patients (n=12)	Female patients (n=9)	Male partners (n=4)	Female partners (n=5)
	Mean±SD	Mean±SD	Mean±SD	Mean±SD
Age at time of focus group	63.1 ± 8.5 [47-73]	63.4 ± 5.2 [56-73]	70.7 ± 6.7 [63-75]	61.6 ± 8.1 [51-73]
Months since surgery	6.6 ± 2.9 [2-12]	7.6 ± 5.9 [2-20]	-	-
Importance of sexuality	6.6 ± 1.8 [3-8]	6.4 ± 1.4 [5-8]	6.0 ± 1.4 [5-7]	5.3 ± 2.9 [2-7]
Severity of sexual problems	4.8 ± 4.0 [0-10]	5.0 ± 2.3 [2-8]	3.0 ± 0.0 [3-3]	2.3 ± 2.5 [0-5]
Influence of sexual problems on quality of life	3.3 ± 3.0 [0-8]	2.0 ± 3.7 [0-7]	0.0 ± 0.0 [0.0]	1.3 ± 2.5 [0-5]
	N (%)	N (%)	N (%)	N (%)
Educational level				
Low	3 (25%)	0 (0%)	1 (33%)	1 (7%)
Medium	6 (50%)	7 (78%)	1 (33%)	4 (79%)
High	3 (25%)	2 (22%)	1 (33%)	2 (14%)
Marital status				
Partnered	12 (100%)	4 (44%)	-	-
Widowed/no partner	0 (0%)	5 (56%)	-	-
Type of cancer				
Colon	7 (58%)	3 (33%)	-	-
Rectum	5 (42%)	6 (67%)	-	-
Type of stoma				
No stoma	4 (33%)	4 (45%)	-	-
Temporary stoma	4 (33%)	2 (22%)	-	-
Definitive stoma	4 (33%)	3 (33%)	-	-

Note: Low = up to ten years of education, middle = 10-14 years of education, high = more than 14 years of education. *These questions were answered on a 1-10 scale. The demographical information of one male patient is missing.

Individual factors

Patients and partners were not always able to recall if they received information on the potential sexual consequences of treatment. Especially, the potential consequences of (neo) adjuvant therapy were reported as unknown. Knowledge on the available health care for sexual problems was also limited. Patients and partners reported this insufficient knowledge as a barrier to discuss their sexual health care needs with their HCP. Furthermore, the couples mentioned that sexuality is, in their opinion, still a taboo; therefore, they felt embarrassed to discuss their sexual problems. In addition, they considered it as inappropriate to discuss sexuality with their HCPs, since the main goal of treatment is survival. The partners felt that they had to be strong for the patient and that the patient's needs were most important, so they discarded their own sexual needs (Table 2).

The HCPs reported several barriers for providing sexual health care. Most HCPs felt that they are insufficiently equipped to have in-depth discussions about sexuality or felt that it is outside their purview of care. The HCPs also reported several beliefs that made them reluctant to discuss sexuality (i) a feeling of inappropriateness to discuss sexuality, since survival is the primary concern, (ii) a fear to cause discomfort, due to the private nature of the conversation, especially when other family members (e.g., children) are present, and (iii) sexuality was sometimes seen as irrelevant based on the patients' age, gender, or relationship status (Table 2).

The participants reported that discussing sexuality may become more easy if the HCPs (i) initiate and encourage the discussion without making any stereotypical assumptions, (ii) normalize concerns by providing straightforward information on the possible sexual consequences of treatment and treatment options in case sexual problems arise, (iii) give couples explicit permission to raise sexual issues at any time, (iv) possess an open-minded attitude, (v) maintain a personalized approach, (vi) be able to create a safe environment by placing the discussion not only into the context of the patient's disease but also in the context of the couples' lives, and (vii) pay attention to psychosexual changes instead of focusing solely on clinical outcomes. Subsequently, it is up to the couples to demarcate the depth of sexual health care needed. Thus, discussing sexuality was seen as a shared responsibility of all participants (Table 2).

Table 2 Barriers to and facilitators for change – Individual factors

Factors	Themes	Quotes
Consumer level (patients/partners)		
Cognitive factors	• Knowledge of possible sexual dysfunction	! 'I am glad that they discussed it (<i>potential sexual dysfunctions</i>) (...), because otherwise you wouldn't even know that it has to do with the surgery.' <i>Female patient</i>
	• Knowledge of treatment options for sexual problems	! 'Hopefully you don't experience it (<i>a sexual dysfunction</i>). However, if you do then the logical question is whether you were really prepared and if there is anything you can do?' <i>Male patient</i>
Motivational factors	• Need for help	! 'About 3-4 months after treatment, I finally started feeling that I wanted more than cuddling (..) I felt in better physical and emotional shape to do something more... And then, at one point, I realized that it was not working as it should.' <i>Male patient</i>
	• Beliefs	
	→ Taboo	! 'You feel exposed when you say "I do have a problem". A lot of patients are embarrassed.' <i>Male patient</i>
	→ Appropriateness	! 'The doctor said "Then (<i>during chemotherapy</i>) you can not have sex with your husband". I did not know what she was talking about, that was difficult. However, I was doing chemotherapy, so I did not ask any further.' <i>Female patient</i>
	→ Partners' needs	! 'He's sick, my needs recede into the background.' <i>Female partner</i>
Behavioral facilitators*	• Active participant	! 'When the HCPs do not provide any attention to it (<i>sexuality</i>), then the patient will, nine out of 10 times, not initiate the discussion.' <i>Male patient</i>
		√ 'Sexuality should be discussed with everybody. Then everybody can decide for themselves what is applicable to them.' <i>Female partner</i>
Provider level (HCPs)		
Cognitive factors	• Knowledge	! 'I don't do that (<i>discuss sexuality extensively</i>), since my knowledge about it is too limited. However, I do try to mention it.' <i>HCP</i>
	• Competence	! 'They (<i>the couples</i>) may experience premonitory relationship problems (..) Then I think "I am not qualified for this".' <i>HCP</i>

Factors	Themes	Quotes
Provider level (HCPs)		
Motivational factors	• Improving sexual health care	√ 'People often do not know what the possibilities are. I think that also applies to the HCPs.'
	• Beliefs	
	→ Appropriateness	! 'I don't believe sexuality is a subject you discuss in the diagnostic and treatment phase. (..) During that phase patients are mostly concerned with survival. (..) Sexuality is, in my opinion, a quality of life aspect, which is important in the long run, after treatment. If I discuss sexuality a lot with patients who are trying to survive, then the patients will think; "That doctor is crazy, he needs to get his priorities straight".' <i>HCP</i> 'I have to admit that the situation in which the children are present works restraining.' <i>HCP</i>
	→ Gender	! 'I think that with women you don't discuss it (<i>sexuality</i>) that often. I mean, if you're talking about problems, then I think of men instead of women.' <i>HCP</i>
	→ Age	! 'What is the point? A lot of patients, elderly patients, will say: "That is no longer an issue".' <i>HCP</i>
	→ Partner status	! 'An increasing number of elderly people still undergo these kinds of surgeries and then, if there is someone sitting in front of me who is single, then I think oh well...' <i>HCP</i>
		√ 'You might unexpectedly get a partner, you never know. Then you should know which problems you might encounter and how you should deal with them.' <i>Widowed female partner</i>
	→ Need for help	! 'There are physicians who literally said: "My patients don't have those kinds of (<i>sexual</i>) problems".' <i>HCP</i>
Behavioral facilitators*	• Initiate the discussion	√ 'They should at least ask "Would it be helpful to discuss not only the medical but also psychological issues?".' <i>Male patient</i>
	• Attitude	√ 'Often it is normalizing concerns; the surgery, the disease, or permanent changes may alter sexuality. That should be open to discussion. HCP

Factors	Themes	Quotes
Provider level (HCPs)		
	• Personalized approach	√ 'I think it helps if you place a story in the context of a person's life, not only in the context of the disease.' <i>HCP</i>
	• Provide explicit permission	√ He (<i>the HCP</i>) always asks: "Is there anything special"? Well, that not very inviting. However, if he would ask "How are things going sexually? Do you experience problems?" Then you can say yes or not to that.' <i>Male partner</i>
	• Holistic view	√ 'It (<i>the MDT</i>) is mostly a technical club (...) √ However, a sexual problem may not only be technical problem, but may also be a psychological problem' <i>HCP</i> 'Surgeons often try to resolve it (<i>sexual dysfunctions</i>) with medication; however, I wonder if they should do that.' <i>HCP</i>

Note: In order to increase the readability of the table only one quote (either a barrier or facilitator) is provided by one of the participants. However, this does not reflect the total spectrum of quotes reported. * = these behavioral facilitators were reported by the participants (patient, partners, and HCPs) as the prerequisites to provide adequate sexual health care. • = Themes described, ↗ = Beliefs mentioned, ! = Barriers to change, √ = Facilitators for change.

Social factors

Having a professional multidisciplinary team within the hospital may facilitate providing adequate sexual health care, especially when this team adopts a holistic patient approach. Amongst the HCPs, there was debate on whose responsibility it is to discuss sexuality. However, the patients and partners suggested that the HCPs of each discipline could discuss the possible consequences of their treatment modality and evaluate the patients' sexual health during follow-up. In this way, the couples expected to receive patient-tailored information. For instance, sexual issues accompanied with having a stoma only have to be discussed with patients with a stoma. Furthermore, the HCPs acknowledged that they could further improve their professional development by attending courses on how to provide (limited) information and how to evaluate sexual issues. In addition, learning to recognize the boundaries of the HCPs own profession and the possibilities of other HCPs may enable the HCPs to make a timely referral, if more extensive treatment is needed. The HCPs believed that the professional network as a whole could increase the awareness that providing sexual health care is an important aspect of cancer care (Table 3).

Organizational factors

Establishing a primary contact person for the couples was seen as an organizational process that could advance the sexual health care. The structure of the organization could further benefit from sufficient time to discuss sexuality during the existing consults. However, it is important to carefully select the information given during these consults in order to avoid an information overdose. Therefore, a structural re-discussion of sexuality during (long-term) follow-up is essential. Furthermore, improving the (awareness of) available resources might enable HCPs to provide better sexual health care. Personalized information in writing could for instance complement the verbal information. In addition, the sexologists pointed out that the HCPs have to be able to identify existing problems; however, if psychosexual counseling (e.g., by a sexologist) or treatment for dysfunctions (e.g., by a gynecologist or urologist) is needed, then the HCPs should be aware of the possibilities for referral. Finally, patients and partners mentioned a potential role for their general practitioner in the management of their sexual health care needs. The general practitioner could play a key role in observing potential sexual problems and the referral of patients (Table 3).

Table 3 Barriers to and facilitators for change – Social, organizational, and societal factors

Factors	Themes	Quotes
Social level		
Professional teams	• Multidisciplinary team (MDT)	✓ 'Sometimes it (<i>sexual intercourse</i>) is physically possible, but there may be a lack of arousal, lack of desire, or relationship problems. That is at least as interesting from a sexuological point of view.' <i>HCP</i>
		✓ 'Patients mostly have issues concerning intimacy, these issues are often not even that erotically charged. Even if 'it' doesn't work anymore, then you can still address that.' <i>HCP</i>
	• Responsibility	✓ 'I believe it is an 'and and' approach (...) During treatment patients should feel that they can ask that question.' <i>HCP</i>
Professional development	• Boundaries of own profession	✓ 'I believe that it only takes one question: "Are there any sexual problems?" If that is the case we have a sexologist and it is very common that patients talk to him/her.' <i>HCP</i>
	• Training	✓ 'If needed we can train them.' <i>Sexologist</i>
Organizational level		
Organizational processes	• Primary contact person	✓ 'When I go to the bank, I have a person who handles all my affairs: a case manager. I really miss this in healthcare.' <i>Male patient</i>
Structure of the organization and work processes	• Time during consult	! 'I occasionally thought about discussing it (<i>sexual problems</i>) (...). However, 10 minutes later you are outside again (<i>after an consult</i>). While I walked through the corridor I thought I should have asked this and this.' <i>Male partner</i>
	• Amount of information in one consult	✓ 'It is always difficult; during the consult I have to do a physical exam, take a history, give education about the surgery. Some people I see don't even know that they are getting a stoma. Then you have to discuss the complications that can occur postoperatively. And then I still have to tell them that there is also a possibility that (<i>referring to potential sexual dysfunction</i>). I mention it, but you can hear the couples think; "oh not that as well".' <i>HCP</i>
	• Follow up	! 'But that is the problem; once it is needed (<i>sexual health care</i>) then I think they are often no longer under follow-up within the hospital, which is a shame.' <i>HCP</i>

Factors	Themes	Quotes
Organizational level		
Available resources	• Psycho/sexual referral	✓ 'I am no advocate of referring all patients with colorectal cancer to a sexologist, I am really not. Some aspects are part of the regular course of treatment. However, if they deviate from what is perceived as normal and this concentrates around sexuality, then they are welcome.' <i>Sexologist</i>
	• Biomedical referral	! 'I see patients with prostate cancer, but patients with colorectal cancer? That may only have happened once. So that is only seldom.' <i>Urologist</i>
		✓ 'Every sexually active female patient who has had radiation on the pelvic area followed by surgery should be quickly referred to a gynecologist. (...) The first year after treatment patients barely have sexual needs. (...) However, later when the disease is well under control, then they start to believe and have an increasing sexual desire, however, then the vagina may be totally obstructed by tissue reaction due to radiation.' <i>HCP</i>
	• General practitioner	✓ 'What about your general practitioner? He is there as well. I mean, in case you really want to discuss stuff.' <i>Female patient</i>
	• Information booklets	✓ 'But you do read it (<i>the information booklets</i>) and then, if you experience side-effects in the future, then you can at least think "Oh yes, I read about this somewhere".' <i>Female patient</i>
Societal level		
Law's and regulations	• Patient centered care	! 'That (<i>providing separate care to the partners</i>) is not possible according to the law. You have a relationship with the patient, not with the partner. However, you can easily address that in a conversation. Just say, it has been a rough period for you as a partner or as a family.' <i>HCP</i>
		! 'Just prescribe the lubricants. (...) You get a lot of medications (<i>at the pharmacy</i>), if that includes them, well yes I would find that quite logical.' <i>Female patient</i>
Financial factors	• Health care insurance	✓ 'For a lot of patient are the financial costs an argument. The advantage of a hospital is that the insurance is covered.' <i>HCP</i>

Note: In order to increase the readability of the table only one quote (either a barrier or facilitator) is provided by one of the participants. However, this does not reflect the total spectrum of quotes reported. • = Themes described, → = Beliefs mentioned, ! = Barriers to change, ✓ = Facilitators for change.

Societal factors

Societal factors were sporadically mentioned. For instance, one of the HCPs stated that the psychosexual care is largely covered by the health care insurance. However, another HCP mentioned that they can only provide limited care to the partner (i.e., Medical Treatment Agreements Act). Finally, some patients said that they could benefit from sexual aids (e.g., lubricants); however, buying these aids was considered difficult and embarrassing. Therefore, they wondered if the HCPs could prescribe sexual aids in order to increase the accessibility (Table 3).

Discussion

Patients and partners coping with colorectal cancer have sexual health care needs that are not always adequately met. While all patients and partners stated that it was important to have their sexual health care needs evaluated and managed, some HCPs wrongfully assumed that elderly, widowed, or female patients might have a lower need for sexual health care. Therefore, there was a mismatch between patients, partners, and HCPs with regard to the importance of providing/receiving adequate sexual health care in these specific patient populations. Several barriers to and facilitators for change were identified. Almost all participants reported a lack of knowledge and unsatisfactory communication skills as important barriers, while the HCPs (except for the psychologist/sexologist) additionally reported a lack of knowledge with regard to the referral possibilities. In addition, as stated above, some beliefs made the HCPs decide that discussing sexuality was not important which impeded the probability that sexual issues were discussed. Finally, resources, such as a good referral and consultation system and training are needed to help the HCPs engage in providing satisfactory sexual health care.

Even though we did not explicitly ask participants about factors that might impede or facilitate change, we were able to apply the theoretical framework of Wensing *et al.* (2005)¹⁸. Logically, the patients and partners were more concerned with the dynamics between the patient/couple and the HCP, while the HCPs were also more concerned with organizational and social, issues. Societal factors were only sporadically mentioned. Therefore, future studies should investigate these societal factors more explicitly.

Our findings corroborate previous studies among other types of cancer.⁸ For instance, the need for sexual health care has been found quite consistently in studies evaluating the sexual health care needs of primarily breast, gynecological, or prostate cancer patients (for an overview we refer to Park, Norris, and Bober; 2009⁸). These studies also reported several aspects, such

as insufficient knowledge about the potential sexual consequences of cancer treatment and beliefs about sexuality, as barriers to satisfactory sexual health communication.⁸ Furthermore, sufficient time during consults and adequate recourses (such as a good referral system) also are previously reported facilitators.⁸ These results suggest that the majority of sexual health care needs are applicable across cancer types and across (Western) countries. However, each cancer type may have additional disease-specific aspects that need to be taken into account. For instance, the participants in our study reported a need for information on how to have an intimate relationship while having a stoma (if applicable). In addition, individual barriers that may arise in the colorectal cancer patient population, such as assumptions based on age, sex, and partner status, were identified.

Overall, the patients and partners stated that it is important that they are adequately informed and that their sexual health care needs are carefully evaluated and managed; however, they also said that it is up to them to determine the extent of health care wanted. It is important to keep in mind that there may not always be a need for help. Based on the need for tailored sexual health care, the adoption of a stepped care program, such as the Extended PLISSIT (Ex-PLISSIT) model may improve the sexual health care.¹⁹ The traditional PLISSIT model developed by Annon (1976) follows a stepwise approach in which various levels of discussion or treatment are used.²⁰ If a lower order level is insufficient, than a higher order level can be deployed (for examples see Katz, 2005²¹). Although this model is widely used, the applicability for patients with colorectal cancer has only recently received attention.^{22,23} For instance, a recent intervention study reported that patients with a stoma who received more psycho-education with regard to sexuality had better sexual satisfaction.²² The acronym PLISSIT signifies the four levels of intervention: Permission (P), Limited Information (LI), Specific Suggestions (SS), and Intensive Therapy (IT). The Ex-PLISSIT model extends the original model by emphasizing the role that Permission-giving plays at all stages by postulating that each stage is underpinned by Permission-giving.¹⁹ In addition, Intensive Therapy may be used at any stage. If the HCP is challenged with something they feel unable to deal with, it is important that they refer the patient/couple to a colleague who is better qualified, regardless of stage. Finally, the Ex-PLISSIT model enables practitioners to use reflection and review to develop their own practice. In current practice, the different levels of this model can be divided amongst several HCPs. In this way, providing sexual health care becomes a shared responsibility, which is also time effective. If needed, psychosexual counseling can be combined with medical treatment (e.g., phosphodiesterase type 5 inhibitor - PDE5-Is, vacuum erection devices, lubricants). Although the PLISSIT model provides a framework for discussing sexual issues, it does not provide the clinical knowledge and communication skills to exploit this dialogue in an effective

manner.²³ Thus, providing training to HCPs could be beneficial, especially since the HCPs in our study stated that they could additionally benefit from education focused on improving their communication skills with regard to these domains (if needed).

This study contributed to the current literature since it assessed an important, but still under evaluated, field of research namely the sexual health care needs of patients with colorectal cancer and their partners. Especially since we not only examined the patients' perspective, but also that of the partners and HCPs. In addition, this study not only included partnered participants, regardless of their level of sexual activity, but also single and widowed patients. Another important strength lies in the study design: The semi-structured qualitative design of this study facilitated an in-depth exploration of the sexual health care needs. We noticed that participants felt free to share their experience, which facilitated frank in-depth conversations. We conducted the focus groups in a standardized manner in order to keep information gathered and style of questioning consistent (e.g., used the same moderators). Furthermore, our study strengthens the general belief that the majority of the sexual health care needs are applicable across cancer types and across (Western) countries. Hopefully, our study challenges HCP's to begin to evaluate their own needs for information, education, and skill-training, along with affirmation from the patients and partners that sexuality is an important area of a quality of life that should be discussed during and after treatment. Finally, the results of this study allowed us to provide clear recommendations for both research and clinical practice (e.g., the use of the Ex-PLISSIT model) and questions for future research (e.g., the need to include ethnic minorities, see below).

However, there are also some limitations and still remaining questions that need to be addressed. With a response rate of 51% the possibility of response bias has to be recognized. Even after emphasizing that having sexual health care needs and/or being sexually active was not a prerequisite to participate, the majority of patients and/or partners that declined participation said that they were not interested in discussing sexual health care needs. It might be that these patients and partners felt embarrassed to talk about sexuality. In addition, our study population unfortunately consisted solely of Caucasian participants. The inclusion of ethnic minorities was impeded by the fact that sufficient knowledge of the Dutch language was an inclusion criterion. Therefore, future studies are needed to examine the sexual health care needs and the determinants for change of participants with other ethnic backgrounds. Finally, the primary aim of the focus groups was to address sexual health care needs in general as opposed to participants' own private needs/functioning; therefore we obtained only limited quantitative information (i.e., the importance of sexuality, the severity of sexual problems, and the influence of sexual problems on their quality of life). Future research

should evaluate the sexual functioning and quality of sexual life of this patient group more in-depth. In the future, it could be beneficial if sexual health is included as a theme in the national guidelines on (colorectal) cancer. Nowadays, sexuality is only represented in the Dutch Nursing guidelines.²⁴ In that way, quality indicators can be developed which can be used to evaluate the quality of care at a national level. These quality indicators can be used to highlight potential quality concerns, while information on barriers and facilitators can guide the selection of implementation strategies to improve sexual health care.^{17,18}

Conclusion

Our findings illustrate the need for patient-tailored sexual health care and the complexity of providing or receiving this care. An adequate referral and consultation system and training are needed to help HCPs engage in providing satisfactory sexual health care.

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General discussion



In the 1950's Bernstein and Long stated: "It is the feeling of the authors that the incidence of sexual dysfunction following operations for cancer of the rectum and sigmoid colon is a reliable index of the amount of lymphatic-bearing tissue which has been removed during the procedure."¹ This statement indicates that sexual dysfunction after (colo)rectal cancer surgery was considered unavoidable. While the current surgical procedures challenge the inevitable damage to the pelvic nerves necessary for an adequate physiological sexual response,² prospective research focusing on Sexual Function (SF) and colorectal cancer is limited.^{3,4} Furthermore, patients' subjective evaluation of the consequences of a colorectal cancer diagnosis and treatment on his/her sexual life (i.e., the quality of sexual life - QoSL) has not yet been evaluated in depth. Moreover, research incorporating the partner's perspective and couple dynamics is, especially in the colorectal cancer population, scarce.^{5,6} Therefore, three major topics were examined in this dissertation. First, biopsychosocial consequences of colorectal cancer on SF and QoSL were identified (**Chapter 2-5**). Next, a dyadic-perspective was taken into account conceptually and methodologically (**Chapter 6-8**). Finally, patients' and partners' sexual health care needs were evaluated (**Chapter 9**). Based on these chapters, future research directions and implications for clinical practice are provided.

SF and QoSL

The literature on SF and QoSL in patients with colorectal cancer was systematically reviewed in **chapter 2**. In the literature, erectile or ejaculatory dysfunction was reported for men, while women experienced dyspareunia and lubrication problems. Factors associated with sexual dysfunction were a higher age, neoadjuvant radio(chemo)therapy, a stoma, complications during or after surgery, having rectal cancer, having had an abdominoperineal resection (compared with an anterior resection), and a lower tumor location. Most studies ($n=66$, 81%) evaluated treatment-related sexual dysfunction in patients with rectal cancer.⁷⁻⁷² While this interest is not surprising, due to the potential nerve damage, psychosocial factors may still be missed. In addition, few studies focused on female sexual (dys)function^{38,52,54,68,73-75} and patients with colon cancer^{76,77} ($n=7$, 9% and $n=2$, 2%, respectively). Moreover, there was insufficient research into factors associated with QoSL to form clear conclusions. Broadening the scope to evaluate (i) women and patients with colon cancer and (ii) biopsychosocial predictors for both SF and QoSL was therefore warranted.

A higher age has been identified as a strong predictor of sexual dysfunction (see **chapter 2**). However, there has been a debate if sexual dysfunction in a higher age is not only normal,

but also not problematic.^{78,79} In order to address this issue, **chapter 3** compared colorectal cancer survivors with an age-matched normative population. Compared with the normative population, male rectal cancer survivors reported lower erectile function and female colorectal cancer survivors reported more lubrication problems and pain during intercourse. Furthermore, sexual enjoyment for men was similar across groups, while women with colorectal cancer scored lower than the normative population. A higher age, being a woman, not having a partner, a low educational level, rectal cancer, depressive symptoms, and fatigue were negatively associated with SF, while a higher age, being a woman, depressive symptoms, and cardiovascular disease were negatively associated with sexual enjoyment. This study therefore shows that not all sexual dysfunction reported after surgery can be attributed to age. In addition, it raises awareness for sexual dysfunction also being a relevant topic in patients with colon cancer and women. Finally, this chapter showed a potential role for psychological variables.

Chapter 2 also noted that preoperative SF and QoSL scores were often lacking. However, preoperative information on SF and QoSL is needed in order to determine the effects of treatment. In addition, at the time the review was conducted, only one study⁸⁰ focused on the consequences of colorectal cancer for the family. Therefore, data obtained after diagnosis but prior to surgery were analyzed for patients and partners in **chapter 4**. Patients with colon and rectal cancer had comparable scores on SF and the QoSL. However, compared with normative data derived from the manuals of the questionnaires⁸¹⁻⁸⁴, patients with colorectal cancer and partners reported a lower preoperative SF and QoSL. A partial explanation for the lower scores may be that neoadjuvant treatment may have already started for some patients with rectal cancer. Moreover, psychological factors may also contribute as high levels of psychological distress have been reported in patients awaiting a possible cancer diagnosis⁸⁵⁻⁸⁸ and recently diagnosed cancer patients^{86,87,89-91}. Thus, surgery may not be the sole cause of sexual dysfunction as low levels of SF and QoSL are already reported preoperatively.

Psychological factors (e.g., mood⁹², body image⁹³) have been previously related to SF. In addition, **chapter 2, 3, and 4** suggest that psychological factors may contribute to the levels of SF and QoSL. Therefore, **chapter 5** evaluated biopsychosocial predictors for both constructs with a one-year prospective study. Across time, correlations between SF and QoSL ranged from small to high, which indicates that SF and QoSL are distinctive but related constructs. This distinctiveness was further supported by the fact that SF did not change significantly over time, while QoSL decreased during the first year after surgery. Furthermore, different biopsychosocial predictors were identified for SF (i.e., a higher age, more fatigue, not being sexually active, and having a stoma) and QoSL (i.e., having rectal cancer, more depressive

symptoms, lower SF, and more relationship maladjustment). Moreover, partners' SF and QoSL contributed to patients' SF and QoSL, respectively. Interdependence between patients and partners has been reported before⁹⁴ and may also be true in this chapter. Finally, a significant interaction effect between time and gender showed that SF and QoSL trajectories differ for men and women. All in all, this chapter showed that SF and QoSL are related but distinctive constructs and that attention for both SF and QoSL, from a biopsychosocial perspective, is needed.

Towards a dyadic approach

The importance of viewing cancer as a we-disease⁹⁵ is increasing rapidly.^{6,94,96,97} While **chapter 4 and 5** already incorporated the partners, the importance of adopting a couple-based perspective was highlighted in the systematic review on dyadic coping and relationship function (**chapter 6**). Dyadic coping entails that both partners are mutually involved in the stress coping process, providing and receiving support from each other and engaging in joint problem-solving activities and shared emotion regulation.^{98,99} This definition illustrates that couples may react as a unit rather than as individuals while coping with cancer.^{94,96,100} The review showed that stress communication is an important aspect of dyadic coping. Expressing worries, feelings, and needs regarding cancer-related issues or the relationship itself was associated with better relationship function, while demand-withdraw communication (i.e., one partner pressuring the other partner to discuss concerns while the other partner withdraws from the conversation) was related with lower relationship function. Furthermore, the review revealed that having a spouse that is generally responsive to the individual's needs (i.e., supportive behaviors) is beneficial for relationship function, while unsupportive behaviors such as protective buffering (i.e., hiding concerns, denying worries, and avoiding discussion) and overprotection are not constructive. Finally, adequate dyadic coping (e.g., joint information seeking and problem solving, sharing of feelings, mutual commitment, and relaxing together) was found to be related to the maintenance or even enhancement of relationship function. Therefore, this review established the importance taking couple dynamics into account.

Chapter 7 evaluated the bidirectional influence of sexual, marital, and general life (mal) adjustment on each other (i.e., stress-spillover) prospectively from a dyadic perspective. Compared with available norm data⁸⁴, patients and partners reported longitudinal sexual maladjustment. The analyses, based on the Actor-Partner Interdependence Model (APIM; **Figure 4, chapter 1**)¹⁰¹, showed significant Actor- and Partner effects for the longitudinal

change in the partners' sexual (mal)adjustment. This result suggests interdependence between patients and partners. Sexual (mal)adjustment did not influence marital and general life (mal)adjustment. These results are in line with **chapter 4** which showed that SF was lower in patients with colorectal cancer than in a norm population, while relationship function was comparable. Moreover, the reversed direction could be true since maladjustment in the more broad general life domain did spill over to the smaller marital and sexual domains. Therefore, in line with the literature^{102,103}, this study shows that awareness for patients' and partners' Quality of Life (QoL) remains important.

Based on the notion that QoL should be taken into consideration (**Chapter 7**), the goal of **chapter 8** was to evaluate patients' and partners' QoL longitudinally. However, it is known that QoL standards may change over the course of the disease trajectory (i.e., response shift).¹⁰⁴⁻¹⁰⁶ If participants complete a questionnaire longitudinally, but with changing QoL standards, then the assessments cannot be adequately compared.¹⁰⁷ Therefore, response shift was assessed first. For patients and partners no reconceptualization (i.e., a redefinition of QoL) and reprioritization (i.e., a change in the relative importance of the domains constituting QoL) occurred within each of the QoL domains. However, indications for the recalibration (i.e., a change in the respondent's internal standards) of specific items were found. Therefore, comparisons over time and between patients and partners were only feasible if restricted to group-level statistics at the factor level. The QoL analyses showed that patients' and partners' Psychological Health and scores on the Environmental domain decreased at three months postoperative, with stabilization at six months postoperative. For both domains, patients and partners factor means were comparable across time. Patients' and partners' Social Relationship factor means both decreased a three months follow-up, which decreased further for patients but stabilized for partners. Partners' factor means were only lower than patients' factor means at three months follow-up. Finally, partners had relatively stable scores for the Physical Health domain which were, at each time point, higher than patients' scores. The QoL trajectories reflect that both patients and partners are affected by the patient's disease and treatment.

Sexual health care needs

Besides obtaining knowledge on the sexual consequences of colorectal cancer it is important to evaluate the sexual health care needs of patients and partners.^{108,109} The qualitative study described in **chapter 9** showed that these needs are not always adequately met. All patients and partners stated that having their sexual health care needs evaluated and managed

was important. However, health care professionals sometimes wrongfully assumed that elderly, widowed, or female patients had a lower need for sexual health care. Therefore, a mismatch existed between patients, partners, and health care professionals with regard to the importance of providing/receiving sexual health care. Furthermore, almost all participants reported a lack of knowledge, feelings of embarrassment or inappropriateness, and unsatisfactory communication skills as important barriers. The health care professionals (except for the psychologist/sexologist) additionally reported a lack of knowledge regarding the referral possibilities. Factors within the organization, such as debate on who is responsible to discuss sexuality, insufficient re-discussion of sexuality during (long-term) follow-up, and unsatisfactory (knowledge of the) referral system also impeded providing sexual health care. Health care professionals could facilitate sexual health care by providing patient-tailored information, normalizing sexual issues, and establishing/using an adequate referral system. However, it is up to the patients and partners to demarcate the extent of sexual health care needed; there may not always be a need for help. Based on the established need for tailored sexual health care, the adoption of a stepped care program, such as the Extended PLISSIT (Ex-PLISSIT)^{110,111} model may be helpful (see **Chapter 9**).

Methodological considerations of the dissertation

Prospectively evaluating SF and QoSL from a biopsychosocial perspective allowed us to address the gaps in knowledge formulated in **chapter 1**. However, since all eligible patients with colon and rectal cancer were included in our study, a wide variety of treatment schedules are represented. Unfortunately, the combined treatment modalities, in combination with the observational nature of this study, prohibit the possibility to determine the unique contribution of a specific treatment modality on SF or QoSL. Furthermore, it would have been beneficial if a true baseline assessment was obtained. In our study, the preoperative assessment should not be mistaken for a baseline measurement as the time between diagnosis and surgical treatment can already be psychologically burdensome for patients and partners. In addition, some of the patients with rectal cancer may already started with neoadjuvant therapy. Moreover, **chapter 3, 4, 5, 7, and 8**, relied on self-report questionnaires. While the importance of validated and reliable questionnaires is acknowledged, the current questionnaires may not capture SF and QoSL completely. Furthermore, in line with current best practice, statistical models were used that enable analyzing the couple as a unit (**chapter 7 and 8**). Moreover, analyses most suited to deal with missing data, such as linear mixed-effects models (**chapter 5**) and structural equation

modeling (**chapter 7 and 8**) were deployed. Nonetheless, a substantial number of drop-outs and/or participants who had not yet completed all assessments should be noted. Finally, the results should be generalized with caution because: (i) the included sample predominantly consisted of male, heterosexual, Caucasian participants, (ii) our study did not recruit elderly patients (>75 years), and (iii) a response rate of approximately 45% was achieved. In this regard, it especially needs to be acknowledged that some patients and partners felt reluctant to participate in a study that evaluates SF and QoSL, which may further limit the generalizability.

Future research directions

The field of research into patients' and partners' QoSL is still in its infancy; therefore further validation of the results is needed. Future research could, for instance, explore biopsychosocial mediators or moderators of QoSL. Furthermore, in **chapter 3** patient's SF, sexual enjoyment, and male/female sexual problems was compared with a recent age-matched normative population. This chapter is quite unique. For **chapter 4, 7, and 8** normative data presented in the manuals of the questionnaires had to be used. However, this data was, unfortunately, very limited and perhaps even outdated. Currently, some normative data is available on SF in general.^{112,113} However, in order to adequately compare the same constructs/domains, it is desirable that (Dutch) normative data for the sexuality questionnaires is collected. In addition, the development of clear cutoff scores can allow stratification of scores in terms of severity. Finally, as stated above, the current questionnaires may not capture SF and QoSL completely. Therefore, we encourage the development of questionnaires that are applicable for both men and women and that incorporate not only important aspects of SF but also of the QoSL.

Furthermore, this dissertation showed that a couple-based perspective to coping with cancer is needed. However, no studies have specifically evaluated dyadic challenges associated with QoSL for couples coping with colorectal cancer. Moreover, **chapter 6** showed that adequate dyadic coping is required in order to maintain or improve relationship function in general. It can be hypothesized that dyadic coping is also beneficial in maintaining or improving QoSL. In order to address this issue, it would be helpful if future research specifically explores (i) which dyadic challenges couples coping with colorectal cancer face with regard to their QoSL, (ii) to what extent and in which form dyadic coping is needed in order to maintain or retain a satisfactory QoSL. However, in order to achieve this, a more uniformly conceptualized perspective is needed on what dyadic coping is and how dyadic coping differs from individual spousal support, and (iii) ways to expand dyadic coping. Currently, there are already some

pilot studies that report promising results for couple-based interventions to improve QoSL.¹¹⁴⁻¹¹⁷ However, future research is needed to evaluate this potential further and to determine specific benefits for defined types of couples, individuals, and types of cancer.

With regard to the sexual health care needs this dissertation addressed several barriers and facilitators for change. However, societal factors were only sporadically mentioned. Currently, this topic may be especially relevant since the Dutch health care insurance now only covers sexual health care by a sexologist if the sexual problem is accompanied by a psychological disorder, psychotropic medication, or sexual abuse or if patients have an additional insurance policy. A substantial number of patients with colorectal cancer will not meet these criteria. However, if patients have to pay for counseling themselves they may become more reluctant to seek adequate care. Future research on the influence of societal changes is therefore needed.

Implications for clinical practice

The perspective on sexual (dys)function after colorectal cancer surgery has changed since the 1950's from being considered unavoidable into maximizing the possibilities to perform nerve sparing surgery. However, the levels of sexual dysfunction still postulate the need to further develop strategies that may enable (i) minimizing sexual dysfunction caused by the multidisciplinary treatment (e.g., laparoscopic surgery¹¹⁸) and (ii) providing adequate psychosexual care to patients and partners. Moreover, the future research directions show that no definitive clear-cut conclusions can be formed as to which patients/couples may benefit from psychosexual interventions. However, some implications for clinical practice can be made. This results from this dissertation may play a role in (i) increasing awareness for SF and QoSL as relevant topics during and after treatment, (ii) showing that psychosocial variables may also play a role in SF and QoSL, (iii) creating alertness for cancer as a 'we-disease', (iv) inspiring health care professionals to include QoSL into their conversations with patients/couples, (v) encouraging health care professionals to optimize their knowledge of and collaboration with other health care professionals in order to lower the threshold for referral, and (vi) challenging health care professionals to evaluate their own needs for information, education, and skill-training. In order to achieve these goals we suggest incorporating QoSL as a theme in the national guidelines on (colorectal) cancer.

In addition, **chapter 9** described how providing sexual health care (ranging from information provision to intensive therapy) is important. In our opinion, providing sufficient

evidence-based information is a basic premise. While this may seem like a small step, to date information on the potential sexual consequences of colorectal cancer may still not be adequately provided during and after treatment.^{108,109,119,120} The need for additional sexual health care is a collaborative decision between health care professional and the patient/couple (i.e., shared decision-making¹²¹). We do not suggest that each patient needs to be referred for sexual health care, but rather draw upon the flexibility of the current health care system to provide sexual health care to those who need it. However, since sexual (mal)adjustment did not seem to influence relationship function (**chapter 4 and 7**) and QoL (**chapter 7**), there may not always be a need for sexual health care. Providing sexual health care may be best considered as a multidisciplinary effort, demanding close collaboration between several health care professionals (e.g., surgeon, radiotherapist, oncologist, and psychologist/sexologist). The referral needed is largely based on the nature of the sexual problem. A biological problem, for instance, can be referred to an urologist/gynecologist, while a psychosexual problem can be referred to a psychologist/sexologist. A stepped care program, in which a higher order level of care is only deployed if a lower order level is insufficient, is recommended (see the Ex-PLISSIT model^{110,111,122}, also described in **chapter 9**).

If (intensive) therapy by a psychologist/sexologist is indicated, then adequate psychosexual diagnostics are important to determine which therapy may fit best. There are several evidence-based treatments that can be deployed. For instance, Cognitive Behavioral Therapy (CBT)¹²³ addresses dysfunctional cognitions (e.g., 'having sexual intercourse will hurt') that lead to dysfunctional behaviors (e.g., avoidance of sexual intercourse). CBT is proven beneficial in treating psychosexual issues in patients with cancer.¹²⁴⁻¹²⁶ However, if dysfunctional relational dynamics are the main issue (e.g., if patient and partner have different expectations and feelings about their sexual life) then Emotionally-Focused Therapy (EFT)¹²⁷ may be a suitable option. EFT enables couples to create synchrony of emotional responsiveness needed to build and maintain secure emotional bonds.^{128,129} Hereby, EFT focuses on intrapersonal processes (i.e., how both partners process their emotional experiences) but also takes dyadic, interpersonal processes (i.e., how partners organize their interactions into patterns) into account.¹²⁷ EFT is a well-established marital therapy.¹²⁸ The potential for EFT to address sexual problems in couples coping with cancer will be evaluated in the near future.¹³⁰

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List of publications



List of publications

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Traa MJ, De Vries J, Roukema JA, Rutten HJT, Den Oudsten BL. The sexual health care needs after colorectal cancer: the view of patients, partners, and health care professionals. *Support Care Cancer* 2014;22(3):763-772.

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Traa MJ, De Vries J, Roukema JA, Rutten HJT, Den Oudsten BL. The sexual health care needs after colorectal cancer: the view of patients, partners, and health care professionals [Een focusgroep studie naar de professionele ondersteuning voor de seksuele gevolgen na dikkedarmkanker: de perceptie van patiënten, partners en zorgverleners]. [Revision submitted]

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