ORIGINAL ARTICLE

Gastrointestinal ostomies and sexual outcomes: a comparison of colorectal cancer patients by ostomy status

J. B. Reese · P. H. Finan · J. A. Haythornthwaite · M. Kadan · K. R. Regan · J. M. Herman · J. Efron · L. A. Diaz Jr. · N. S. Azad

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Abstract

Purpose Research examining effects of ostomy use on sexual outcomes is limited. Patients with colorectal cancer were compared on sexual outcomes and body image based on ostomy status (never, past, and current ostomy). Differences in depression were also examined.

Methods Patients were prospectively recruited during clinic visits and by tumor registry mailings. Patients with colorectal cancer (N=141; 18 past ostomy; 25 current ostomy; and 98 no ostomy history) completed surveys assessing sexual outcomes (medical impact on sexual function, Female Sexual Function Index, International Index of Erectile Function), body image distress (Body Image Scale), and depressive symptoms (Center for Epidemiologic Studies Depression Scale—Short Form). Clinical information was obtained through patient validated self-report measures and medical records.

J. B. Reese (
) 'P. H. Finan 'J. A. Haythornthwaite 'K. R. Regan Department of Psychiatry and Behavioral Sciences, Johns Hopkins University School of Medicine, 5510 Nathan Shock Dr. Suite 100, Baltimore, MD 21224, USA e-mail: jreese13@jhmi.edu

M. Kadan · L. A. Diaz Jr. · N. S. Azad Department of Oncology, Johns Hopkins Sidney Kimmel Comprehensive Cancer Center, Baltimore, MD, USA

M. Kadan · L. A. Diaz Jr.

The Swim Across America Laboratory and The Ludwig Center for Cancer Genetics and Therapeutics at Johns Hopkins, Baltimore, MD, USA

I M Herman

Department of Radiation Oncology, Johns Hopkins Hospital, Baltimore, MD, USA

I Efron

Department of Surgery, Johns Hopkins University School of Medicine, Baltimore, MD, USA

Results Most participants reported sexual function in the dysfunctional range using established cut-off scores. In analyses adjusting for demographic and medical covariates and depression, significant group differences were found for ostomy status on impact on sexual function (p < .001), female sexual function (p = .01), and body image (p < .001). The current and past ostomy groups reported worse impact on sexual function than those who never had an ostomy (p < .001); similar differences were found for female sexual function. The current ostomy group reported worse body image distress than those who never had an ostomy (p < .001). No differences were found across the groups for depressive symptoms (p = .33) or male sexual or erectile function (p < .001).

Conclusions Colorectal cancer treatment puts patients at risk for sexual difficulties and some difficulties may be more pronounced for patients with ostomies as part of their treatment. Clinical information and support should be offered.

Keywords Colorectal cancer \cdot Oncology \cdot Gastrointestinal ostomies \cdot Sexual function \cdot Body image

Introduction

Following breast and prostate cancers, colorectal cancers have the highest likelihood of long-term survival [1]. As cancer survivors live longer, it becomes increasingly important to understand the factors affecting their quality of life (QoL) including their sexual function and related outcomes [2]. Sexual difficulties are common for men and women with colorectal cancer [3], affecting as many as many as 88 % of men [4] and around half of women [3]. These difficulties have been shown to persist for as long as 10 years after treatment completion [5] and are associated with worse overall QoL and disease impact [6, 7]. A potential contributor to sexual difficulties for colorectal cancer patients is the presence of a



gastrointestinal ostomy [3, 8]. Ostomy surgery can lead to sexual dysfunctions for men and women such as erectile dysfunction and dyspareunia (pain during sexual intercourse), respectively [9, 10]. Furthermore, patients with ostomies report disturbances in body image [11, 12] and logistical obstacles to sexual activity such as unpleasant odors during sex [13], among other issues.

Despite the strong evidence showing ostomy-related sexual difficulties, little is known about whether sexual difficulties persist after ostomies are reversed [14, 15]. Establishing whether the effects of ostomy on sexual outcomes and body image endure after an ostomy is reversed is important given that temporary stomas are increasingly being performed for patients with rectal cancer [16]. This information would also lead to developing appropriate interventions for these at-risk groups. In addition, prior research has focused on physiological sexual dysfunctions rather than psychosocial outcomes (e.g., perceived adjustment to sexual changes, body image distress, and depression)—constituting a critical gap in this literature. In particular, few studies have considered the potential contribution of demographic and treatment-related confounding factors in examining sexual outcomes in ostomy patients [14, 17] and none have considered depressive symptoms as a potential confounding factor—which is important as depressive symptoms may be related to both body image distress and sexual dysfunction in ostomy patients [18, 19]. While the evidence for worse depression for colorectal cancer patients with vs. without ostomies is mixed [8, 11, 20, 21], depression appears to be a risk factor for worse sexual function for colorectal cancer patients [22]. Moreover, body image was shown to predict depression [18] and contribute to sexual problems such as low sexual interest [19] for ostomy patients. Finally, most research studies examining sexual function in colorectal cancer patients have examined sexual function as a secondary outcome, leading to inclusion of brief or unstandardized measures of sexual outcomes [3]. Including a range of comprehensive, standardized measures would represent a methodological improvement by providing a more complete understanding of the sexuality of those with ostomies.

Accordingly, our objective for this study was to use comprehensive validated measures to compare colorectal cancer patients by ostomy classification group (never, past, and current) with respect to sexual function, perceived impact of their disease and treatment on sexual function, and body image distress. We hypothesized that (1) the study sample overall would report sexual function below established norms and that (2) both ostomy groups (i.e., past and current) would report worse sexual outcomes and body image distress than the group without an ostomy. These hypotheses were influenced by prior research suggesting that psychological and relational factors (e.g., getting "out of the habit" of intimacy) are related to sexual difficulties for those with either temporary or permanent ostomies [13].



Patients

Men and women older than age 21 with a diagnosis of colorectal cancer were eligible for this research. Participants were recruited between December, 2009 and April, 2012 from Johns Hopkins Sidney Kimmel Comprehensive Cancer Center. Both partnered (married or cohabiting) and unpartnered patients completed sexuality items in all study analyses. Individuals with colostomies or ileostomies were included (see Table 1).

Procedure

Participants in the current study were involved in a larger prospective study examining physical and emotional predictors of sexual QoL in colorectal cancer. Baseline data focusing on patients' sexual outcomes and body image distress are presented here. Candidates were recruited directly in the clinic or through mailings to Johns Hopkins tumor registry patients (diagnosed within past 5 years). Two hundred fifty-eight surveys assessing patients' emotional, physical, and sexual health were administered and 143 (55 %) were returned. Two patients who completed the survey were excluded because they did not have colorectal cancer. The final sample included 141 individuals with colorectal cancer; 57 % were recruited in the clinic (n=80); the rest (n=61) were recruited through mailings. Patients recruited in the clinic were younger and were more likely to have metastatic disease, be receiving treatment, have received chemotherapy, and have a shorter length of time since diagnosis than patients recruited through mailings (p values < .01). Patients recruited in the clinic reported greater depressive symptoms (M=7.5; SD=5.94) than those recruited through mailings (M=5.46; SD=5.79; p=.04); no other differences were found. Institutional Review Board approval was obtained, and patients provided informed consent through completion of the baseline survey. All surveys were returned through the mail, and patients were mailed parking coupons for completing study surveys.

Measures

Medical impact on sexual function The Sexual Function Questionnaire (SFQ) [23] was developed specifically for use in cancer populations [23, 24] while the Medical Impact subscale assesses the impact of a medical condition or treatment on patients' sexual lives and sexual function. The Medical Impact subscale consists of five questions assessing the impact of the patient's medical condition (in this case, "colorectal cancer or its treatment") on aspects of his or her sex life, resulting in a mean score. Items assess the impact on desire, arousal, orgasm, overall impact, and degree of adjustment to



Table 1 Demographic and medical characteristics for the total sample and by ostomy group

Variable	Total (N=141; N (%))	Never had ostomy $(n=98; N (\%))$	Past ostomy $(n=18; N (\%))$	Current ostomy $(n=25; N (\%))$
Age (mean±SD, year)	57.7±13.2	58.4±13.5	61.3±9.3	52.2±13.0
Female gender	59 (41.8)	40 (40.8)	7 (38.9)	12 (48.0)
Education				
Less than a bachelor's degree	46 (32.6)	31 (31.6)	8 (44.4)	7 (28.0)
Bachelor's degree or advanced degree Ethnicity	95 (67.4)	67 (68.4)	10 (55.6)	18 (72.0)
Caucasian	117 (83.0)	81 (82.6)	16 (88.9)	20 (80.0)
African American	11 (7.8)	8 (8.2)	1 (5.6)	2 (8.0)
Asian	9 (6.4)	5 (5.1)	1 (5.6)	3 (12.0)
Other	4 (2.8)	4 (4.1)	0 (0.0)	0 (0.0)
Marital status	4 (2.8)	4 (4.1)	0 (0.0)	0 (0.0)
Married or cohabiting	121 (85.8)	83 (84.7)	17 (94.4)	21 (84.0)
Tumor site	121 (65.6)	03 (04.7)	17 (94.4)	21 (64.0)
Colon	104 (73.8)	85 (86.7)	7 (38.9)	12 (48.0)
Rectum	37 (26.2)	13 (13.3)	11 (61.1)	13 (52.0)
Disease stage at survey	37 (20.2)	13 (13.3)	11 (01.1)	13 (32.0)
I	13 (9.2)	10 (10.2)	2 (11.1)	1 (4.0)
II/IIA	24 (17.0)	19 (19.4)	1 (5.6)	4 (16.0)
IIIA	3 (2.1)	2 (2.0)	1 (5.6)	0 (0.0)
IIIB	22 (15.6)	12 (12.2)	5 (27.8)	5 (20.0)
IIIC	9 (6.4)	6 (6.1)	1 (5.6)	2 (8.0)
IV	70 (49.6)	49 (50.0)	8 (44.4)	13 (52.0)
Currently receiving treatment	56 (39.7)	40 (40.8)	4 (22.2)	12 (48.0)
Length of time since diagnosis (months) Treatment received	31.5±23.0	31.7±24.6	36.3±15.1	27.1±20.8
Surgery	132 (93.6)	89 (90.8)	18 (100.0)	25 (100.0)
Chemotherapy	106 (75.2)	68 (69.4)	16 (88.9)	22 (88.0)
Radiation	45 (31.9)	16 (16.3)	14 (77.8)	15 (60.0)
Colostomy (vs. ileostomy)	13 (9.2)	_	2 (11.1)	11 (44.0)
Pelvic surgery	50 (35.5)	17 (17.3)	15 (83.3)	18 (72.0)
Perforations during surgery	6 (4.3)	3 (3.1)	1 (5.6)	2 (8.0)
Obstruction during surgery	18 (12.8)	11 (11.2)	3 (16.7)	4 (16.0)
Post-operative complications	32 (22.7)	16 (16.3)	6 (33.3)	10 (40.0)
Received Folfox	77 (54.6)	51 (52.0)	9 (50.0)	17 (68.0)
Received Folfiri	22 (15.6)	17 (17.3)	2 (11.1)	3 (12.0)
Received Xelox/Xeloda	20 (14.2)	12 (12.2)	5 (27.8)	3 (12.0)

sexual difficulties. Mean scores were calculated when ≥ 80 % of items (4/5) were completed. Higher scores indicate greater impact.

Female sexual function The Female Sexual Function Index (FSFI) [25] is a 19-item questionnaire that assesses female sexual function and has been used in many cancer studies [26–28]. The scale provides scores on six domains: desire, arousal, lubrication, orgasm, satisfaction, pain, and a total score

which we report on in the current study to allow for comparisons with established cut-off scores. Respondents report on the past 30 days. Higher scores indicate better function.

Male sexual function The International Index of Erectile Function (IIEF) [29] is a 15-item widely used multidimensional scale assessing sexual functioning in men [28, 30, 31]. The IIEF consists of five domains: erectile function, orgasmic function, sexual desire, intercourse satisfaction, overall satisfaction,



and a total sexual function score. In the current study, we report on both total sexual function score to provide data on overall sexual function across a range of domains and on the erectile function domain score to allow for comparisons with established clinical cut-off scores on this domain. Respondents report on the past 30 days. Higher scores indicate better function.

Body image distress Body image distress was assessed using the Body Image Scale (BIS) [32], a ten-item scale developed for use in cancer patients that assesses body image changes and distress due to cancer and its treatment. Higher scores indicate greater symptoms or distress.

Depressive symptoms The Center for Epidemiologic Studies Depression Scale—Short Form is a ten-item, self-report scale designed to measure symptoms of depression in the general population [33]. Given the potential importance of depression as impacting sexual function and body image distress, as well as inconsistent prior findings pertaining to differences in depressive symptoms for those with and without ostomies [11, 12, 20, 34], we examined group differences in this outcome and considered depressive symptoms as a potential covariate in comparisons on other sexual outcomes. We did not hypothesize as to which groups would differ significantly on this outcome.

Medical information Information on medical characteristics including on tumor site (colon/rectum), disease stage, treatment status (on treatment or completed treatment), types of treatments and surgery, ostomy status and type, and length of time since diagnosis were obtained through self-report and/or medical chart review.

Statistical methods

Ostomy groups (current, past, and none) were compared on demographic and health status variables, including depressive symptoms, using Chi-square or Fisher's exact tests for categorical variables and general linear models for continuous or semi-continuous variables. Next, descriptive analyses were conducted on female and male sexual function to facilitate comparisons with established cut-off scores. General linear models were used to test for ostomy group differences in the following outcomes in unadjusted models: medical impact on sexual function, female and male sexual function, and body image distress. Then, the following covariates were included in initial adjusted models: age, gender, pelvic surgery, metastatic disease, chemotherapy, radiation therapy, and depressive symptoms. Our selection of covariates was motivated by both sample characteristics and associations reported in prior literature [8, 11, 14, 28, 35]. Nonsignificant covariates (p > .10)were removed from the final models (see Table 2). Surgery was classified as either pelvic (lower anterior resection and abdominoperineal resection/proctectomy) or nonpelvic (colectomy or hemicolectomy). Patients who received other surgeries (transanal excision, n=3; exploratory laparotomy, n=1; sigmoidectomy, n=1), those who had not received surgery at the time of the baseline survey (n=5), and those who had missing data for type of surgery (n=7) were not included in analyses adjusting for pelvic surgery. Considering the high number of comparisons, pair-wise differences were examined and multiple comparisons corrected by the Bonferroni procedure within each analysis. To maximize the use of available data, means of existing items were imputed for missing items when the majority of items on a scale were completed. Total FSFI and IIEF scores were calculated when all domain scores were available from which to calculate a total score. When too few items were completed to calculate a score (e.g., a complete scale was left blank) for a participant, those data were excluded. Analyses were performed using SPSS Version 20 (SPSS, Chicago, IL). All tests were twotailed, and p values below .05 were considered statistically significant.

Results

Sample characteristics

Sample characteristics for the total sample and by ostomy group are presented in Table 1; 12.7 % of the sample currently had an ostomy (n=18), 17.7 % previously had an ostomy (n=25), and 69.5 % had no history of an ostomy (n=98). Most participants (73.8 %) had colon cancer and half the sample (49.6 %) had Stage IV disease. Almost all patients had undergone surgery; most had also undergone chemotherapy and/or radiation therapy.

Comparisons among ostomy groups on demographic, medical variables, and depressive symptoms

The ostomy groups did not differ significantly on gender, race, marital status, ¹ highest educational degree obtained, currently receiving treatment, or metastatic disease (*p* values ≥ .23). The



¹ To examine the role of partnered status in influencing sexual outcomes in the current sample, we compared partnered vs. unpartnered participants on sexual outcomes using general linear models. Most partnered women completed the SFQ (40/46) and the FSFI (38/46). Most partnered men completed the SFQ (69/75) and the IIEF (72/75). A few unpartnered women (1/13) and men (3/7) completed the SFQ, the FSFI (4/13), and the IIEF (4/7). On the SFQ, partnered patients reported higher impact on sexual function (M=2.54; SD=1.06) than unpartnered patients (M=1.49; SD=.35; p=.05). Partnered and unpartnered participants did not differ on body image, depression, or male sexual function or erectile function (p values≥.12). On the FSFI, partnered patients reported marginally higher sexual function (M=16.63; SD=10.94) than unpartnered patients (M=6.68; SD=9.09; p=.09).

Table 2 Differences (means and confidence intervals) on sexual outcomes and body image distress by ostomy group

Measure and possible range	GLM	Never had ostomy (<i>N</i> =98)	Past ostomy (<i>N</i> =18)	Current ostomy (<i>N</i> =25)	F value	Partial η^2	P value
Medical impact on sexual function (.2–6)	Unadjusted	2.15 (1.94, 2.35) ^a	3.19 (2.71, 3.66) ^b	3.38 (2.97, 3.79) ^b	19.06	.26	<.001
	Adjusted ^a	2.00 (1.79, 2.21) ^a	2.97 (2.51, 3.43) ^b	3.04 (2.63, 3.45) ^b	18.79	.24	<.001
Body image distress (0-30)	Unadjusted	6.09 (4.71, 7.48) ^a	7.22 (3.99, 10.46) ^a	13.26 (10.51, 16.00) ^b	10.62	.13	<.001
	Adjusted ^b	6.48 (5.42, 7.54) ^a	8.67 (6.20, 11.13)	12.26 (10.10, 14.43) ^b	11.68	.15	<.001
Female sexual function (2–36)	Unadjusted	18.14 (14.07, 22.20) ^a	$10.77 (5.03, 16.52)^{b}$		4.47	.10	.04
	Adjusted ^c	18.63 (15.08, 22.17) ^a	10.39 (5.16, 15.63) ^b		6.87	.16	.01
Male sexual function (5–75)	Unadjusted	41.38 (34.67, 48.08)	33.73 (19.01, 48.45)	36.83 (22.74, 50.93)	0.53	.01	.59
	Adjusted ^d	35.60 (28.26, 42.94)	39.60 (26.27, 52.93)	35.77 (23.55, 47.98)	.12	.00	.88
Erectile function (1–30)	Unadjusted	16.64 (13.29, 20.00)	13.55 (6.18, 20.91)	13.92 (6.87, 20.97)	0.45	.01	.64
	Adjusted ^e	13.87 (10.27, 17.46)	17.28 (10.69, 23.87)	12.34 (6.33, 18.35)	.61	.02	.54

Note: medical impact on sexual function=SFQ medical impact subscale score; body image distress=BIS; female sexual function=FSFI total score; male sexual function=IIEF total score; erectile function=IIEF erectile dysfunction domain. Possible ranges are presented for each outcome measure. Means are presented followed by confidence intervals in parentheses. F values, partial η^2 and p values are presented for the variable "ostomy type" in each model. Groups that were significantly different from one another in post hoc tests are shown with differing superscripts. The female sexual function comparison included past and current ostomy patients in one group

groups differed marginally on age (p=.05); the past ostomy group was slightly older than the current ostomy group (p=.08). The group with no ostomy history was more likely to have colon cancer than the other groups (χ^2 =28.40, p<.001). Both ostomy groups were significantly more likely to receive pelvic surgery (χ^2 =44.75, p<.001), radiation therapy (Fisher's exact=36.13, p<.001), and post-operative complications (χ^2 =6.38, p=.04), and marginally more likely to receive systemic chemotherapy (Fisher's exact=5.46, p=.06) than those with no ostomy history. On depressive symptoms, no differences were found among those with a past ostomy (M=5.39; SD=3.36), current ostomy (M=8.08; SD=6.10), or no ostomy history (M=6.49; SD=6.25, p=.33).

Comparisons among ostomy groups on sexual outcomes

Medical impact on sexual function Most participants completed the SFQ (113/141; 80.1 %). Means and 95 % confidence intervals for the three groups from unadjusted and adjusted analyses are shown in Table 2. In adjusted analyses, estimated marginal means are shown. When controlling for

chemotherapy and depressive symptoms, ostomy status distinguished significantly among the groups (p<.001). Both the past and current ostomy groups had worse medical impact on sexual function than those with no ostomy history (p<.001). Age, gender, pelvic surgery, metastatic disease, and radiation therapy were removed from the final model.

Female sexual function Most women (42/59; 71.2 %) completed the FSFI; of them, most (74 %) reported sexual function below the FSFI clinical cut-off (26.55) indicating sexual dysfunction [36]. All women with a current ostomy scored in the dysfunctional range (10/10), compared with 75 % of women with a past ostomy (3/4) and 64 % percent of women with no ostomy history (18/28). Given the small sample sizes in the past and current ostomy groups, we collapsed data across these two groups and compared this new group (past or current ostomy) with those who never had an ostomy. In adjusted analyses, ostomy status differentiated female sexual function when age and depressive symptoms were covaried (p=.01); the past/current ostomy group had lower sexual function than those who never had an ostomy. Pelvic surgery, metastatic disease, chemotherapy, and radiation therapy were removed from the final model. The two groups did not differ on partnered status (χ^2 =.30, p=.58).

Male sexual function Most men in the overall sample (76/82; 92.7 %) completed the IIEF; of them, 65 % scored below the



^a The final model included the covariates chemotherapy and depression

^b The final model included the covariates gender, age, and depression

^c The final model included the covariates age and depression

^d The final model included the covariates age, metastatic disease, radiation therapy, and depression

^e The final model included the covariates age, metastatic disease, and radiation therapy

² Data were analyzed on the following number of patients within the never had ostomy, past ostomy, and current ostomy groups, respectively: medical impact on sexual function—78/98, 15/18, and 20/25; female sexual function—28/40, 4/7, and 10/12; male sexual function and erectile function—53/58, 11/11, and 12/13.

IIEF Erectile Dysfunction clinical cut-off of 25 indicating dysfunction [31]. Mean scores for all three groups fell in the moderate range of erectile dysfunction; 67 % of men with a current ostomy scored in the dysfunctional range for erectile dysfunction (8/12), compared with 82 % of men with a past ostomy (9/11) and 60 % of men with no ostomy history (32/53). There were no group differences by ostomy status on male overall sexual function or erectile function (p values \geq .54). For both overall sexual function and erectile function, age, metastatic disease, and radiation therapy were significant covariates; for overall sexual function, depressive symptoms were also significant.

Body image distress Complete data were available for the BIS. The three groups differed significantly on body image distress when adjusting for age, gender, and depressive symptoms (p<.001). Current ostomy patients had significantly worse body image distress than those with no ostomy history (p<.001). Pelvic surgery, metastatic disease, and radiation therapy were removed from the final model.

Discussion

Sexual disturbances are common and problematic for many colorectal cancer patients. In this study, patients in both the past and current ostomy groups reported greater perceived impact on sexual function than those who never had an ostomy, and this did not differ by gender. Furthermore, women with either a past or current ostomy (combined into one group) reported worse sexual function than women who never had an ostomy. By contrast, the past ostomy group reported similar body image distress to those who never had an ostomy, suggesting that unlike impact on sexual function, body image may improve with ostomy reversal. Thus, sexual difficulties can persist after ostomy reversal and may be attributable to factors other than body image distress (e.g., difficulties making behavioral adjustments and long-term physical dysfunction).

Importantly, sexual dysfunction was common irrespective of ostomy status and gender. All women with a current ostomy reported sexual function mean scores in the dysfunctional range based on established cut-off scores, and most women in the two other groups also fell in the dysfunctional range. Similarly, most men in the overall study sample reported erectile dysfunction in the dysfunctional range. The lack of group differences on male sexual function contrasts somewhat with prior research which found worse sexual function for male patients with ostomies [8]. This may be attributable to characteristics of the study sample, such as a somewhat lower age across all three groups than in other studies [17]. That group differences were found for some measures and not others highlights the importance of assessing multiple dimensions of sexuality. Taken with prior research [13], findings suggest that colorectal cancer and its treatment are associated with sexual difficulties and some difficulties appear more pronounced for those with ostomies as part of their treatment.

Differences in sexual outcomes by ostomy status could not be attributed to these patients being older, of a particular sociodemographic group, more or less likely to be partnered, or to receiving pelvic (vs. non-pelvic) surgery, chemotherapy, or radiation therapy. Depressive symptoms, which have not been previously analyzed as a covariate in similar studies, contributed variance in final models, but did not significantly differ among ostomy groups. As some current ostomy patients in this study had temporary, rather than permanent ostomies, this may have lowered the potential depression levels of current ostomy patients. It is interesting that the groups in this study differed on body image but not depressive symptoms, even though body image distress and depression have been shown to be associated in prior studies of ostomy patients [18]. Taken with prior research, these findings suggest that ostomy patients with poor body image are at particularly elevated risk for psychological distress.

The current study is strengthened by the inclusion of a range of validated, comprehensive measures and a prospective study design. However, several aspects of the current study limit the ability to generalize findings. First, the data analyzed were cross-sectional and do not support causal interpretations. Future prospective studies examining change in sexual function from pre- to postsurgery are necessary to understand the persistence of poor sexual outcomes and body image distress after ostomy reversal. Second, the two ostomy groups had relatively few subjects. Future studies with larger samples are needed to replicate findings. About a quarter of women did not complete sexual function items, reflecting a challenge in collecting female colorectal cancer patients' sexual function data seen in prior research [17]. In addition, half of the study sample had advanced disease, making it difficult to generalize to patients with early stage disease. While we adjusted for metastatic disease, our sample size limited the ability to adjust for factors such as length of time from treatment, and future studies should do this. Third, we were not able to compare study completers with those who refused to participate on demographic or clinical factors; future studies should conduct such comparisons. As colon and rectal cancer may have different effects on sexual function [22], future studies should be powered to allow for these two related but different cancers to be examined separately. Finally, as the ostomy patients in this sample also underwent pelvic surgery and often radiation, we cannot state with certainty whether poorer sexual outcomes on some measures are due to the ostomy itself or to the consequences of the pelvic surgery or radiation such as scarring of the vaginal wall and injury to pelvic nerves (hypogastric nerves or nervi erigentes). However, prior research strongly suggests that ostomies affect multiple aspects of patients' sexuality, including their sexual identities, intimate relationships, and psychological function [13, 35]. Thus, it is doubtful that the associations found in this study between



ostomy use and worse sexual outcomes are due exclusively to physical changes resulting from surgery or radiation.

Findings of the study have several clinical implications. First, they suggest that use of an ostomy—even when it has been reversed—is associated with difficulties with sexual adjustment for those with colorectal cancer. Therefore, discussions about the potential impact of colorectal cancer treatment on sexuality may be beneficial. Assessments should be conducted to identify patients with concerns or difficulties, and interventions addressing the particular concerns of ostomy patients could be utilized for patients with the greatest difficulties. The PLISSIT model [37] can guide approaches to managing sexual complaints for ostomy patients [38, 39]. In this model, permission to discuss sexual issues is first given by raising the topic of sexuality, followed by limited information on how the ostomy may affect body image and sexuality, then specific suggestions (e.g., using ostomy covers during sexual activity; emptying the ostomy pouch prior to sexual activity), and finally intensive therapy for patients with severe or complex sexual difficulties. In the context of a busy oncology clinic, an effective strategy may be to have one provider on the treatment team trained to offer brief sexual counseling [40]. An increasing number of comprehensive cancer centers maintain experts on staff able to address the sexual health needs of patients who require intensive assessment and treatment (e.g., psychologists and sex therapists), as we do at our site. When on-site specialists are not available, providers should know of off-site resources and make such referrals when appropriate. Continuing to engage in sexual activity, including nonintercourse physical intimacy, and redefining sexual function and activity are particularly promising strategies that could be incorporated into interventions for those with colorectal cancer [19, 41]. Sexuality is a critical domain of QoL that warrants clinical and research attention for those with colorectal cancer.

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References

 Howlader N, Noone AM, Krapcho M, Garshell J, Neyman N, Altekruse SF, Kosary CL, Yu M, Ruhl J, Tatalovich Z, Cho H, Mariotto A, Lewis DR, Chen HS, Feuer EJ, Cronin KA (eds) (2013) SEER Cancer Statistics Review, 1975–2010, National Cancer Institute. Bethesda, MD, based on November 2012 SEER data submission, posted to the SEER Website, April 2013. Available from http://seer.cancer.gov/csr/1975_2010/

- Wilson IB, Cleary PD (1995) Linking clinical variables with healthrelated quality of life: a conceptual model of patient outcomes. JAMA 273(1):59–65
- Traa MJ, De Vries J, Roukema JA, Den Oudsten BL (2012) Sexual (dys)function and the quality of sexual life in patients with colorectal cancer: a systematic review. Ann Oncol 23(1):19–27. doi:10.1093/ annonc/mdr133
- Ameda K, Kakizaki H, Koyanagi T, Hirakawa K, Kusumi T, Hosokawa M (2005) The long-term voiding function and sexual function after pelvic nerve-sparing radical surgery for rectal cancer. Int J Urol 12(3):256–263. doi:10.1111/j.1442-2042.2005.01026.x
- Schmidt CE, Bestmann B, Kuchler T, Longo WE, Kremer B (2005) Ten-year historic cohort of quality of life and sexuality in patients with rectal cancer. Dis Colon Rectum 48(3):483–492
- Di Fabio F, Koller M, Nascimbeni R, Talarico C, Salerni B (2008) Long-term outcome after colorectal cancer resection. Patients' self-reported quality of life, sexual dysfunction and surgeons' awareness of patients' needs. Tumori 94(1):30–35
- Reese JB, Shelby RA, Keefe FJ, Porter LS, Abernethy AP (2010) Sexual concerns in cancer patients: a comparison of GI and breast cancer patients. Support Care Cancer 18(9):1179–1189. doi:10.1007/ s00520-009-0738-8
- Sprangers MA, Taal BG, Aaronson NK, te Velde A (1995) Quality of life in colorectal cancer. Stoma vs. nonstoma patients. Dis Colon Rectum 38(4):361–369
- Tekkis PP, Cornish JA, Remzi FH, Tilney HS, Strong SA, Church JM, Lavery IC, Fazio VW (2009) Measuring sexual and urinary outcomes in women after rectal cancer excision. Dis Colon Rectum 52(1):46–54. doi:10.1007/DCR.0b013e318197551e
- Nordstrom GM, Nyman CR (1991) Living with a urostomy. A follow up with special regard to the peristomal-skin complications, psychosocial and sexual life. Scand J Urol Nephrol Suppl 138:247–251
- Ross L, Abild-Nielsen AG, Thomsen BL, Karlsen RV, Boesen EH, Johansen C (2007) Quality of life of Danish colorectal cancer patients with and without a stoma. Support Care Cancer 15(5):505–513. doi: 10.1007/s00520-006-0177-8
- Sideris L, Zenasni F, Vernerey D, Dauchy S, Lasser P, Pignon JP, Elias D, Di Palma M, Pocard M (2005) Quality of life of patients operated on for low rectal cancer: impact of the type of surgery and patients' characteristics. Dis Colon Rectum 48(12):2180–2191. doi: 10.1007/s10350-005-0155-0
- Manderson L (2005) Boundary breaches: the body, sex and sexuality after stoma surgery. Soc Sci Med 61(2):405–415
- 14. Krouse RS, Herrinton LJ, Grant M, Wendel CS, Green SB, Mohler MJ, Baldwin CM, McMullen CK, Rawl SM, Matayoshi E, Coons SJ, Hornbrook MC (2009) Health-related quality of life among long-term rectal cancer survivors with an ostomy: manifestations by sex. J Clin Oncol 27(28):4664–4670
- Kasparek MS, Hassan I, Cima RR, Larson DR, Gullerud RE, Wolff BG (2012) Long-term Quality of Life and Sexual and Urinary Function After Abdominoperineal Resection for Distal Rectal Cancer. Dis Colon Rectum 55 (2):147–154, doi: 110.1097/ DCR.1090b1013e31823d32606
- Montedori A, Cirocchi R, Farinella E, Sciannameo F, Abraha I (2010) Covering ileo- or colostomy in anterior resection for rectal carcinoma. Cochrane Database Syst Rev 5:CD006878. doi:10.1002/14651858.CD006878.pub2
- Milbury K, Cohen L, Jenkins R, Skibber JM, Schover L (2012) The association between psychosocial and medical factors with long-term sexual dysfunction after treatment for colorectal cancer. Support Care Cancer 21(3):1–10. doi:10.1007/s00520-012-1582-9
- Sharpe L, Patel D, Clarke S (2011) The relationship between body image disturbance and distress in colorectal cancer patients with and without stomas. J Psychosom Res 70(5):395–402
- Ramirez M, McMullen C, Grant M, Altschuler A, Hornbrook MC, Krouse RS (2009) Figuring out sex in a reconfigured body:



- experiences of female colorectal cancer survivors with ostomies. Women Health 49(8):608–624. doi:10.1080/03630240903496093
- Bossema ER, Seuntiëns MWM, Marijnen CAM, Baas-Thijssen MCM, van de Velde CJH, Stiggelbout AM (2011) The relation between illness cognitions and quality of life in people with and without a stoma following rectal cancer treatment. Psychooncology 20(4):428–434. doi:10.1002/pon.1758
- Fucini C, Gattai R, Urena C, Bandettini L, Elbetti C (2008) Quality of life among five-year survivors after treatment for very low rectal cancer with or without a permanent abdominal stoma. Ann Surg Oncol 15(4):1099–1106. doi:10.1245/s10434-007-9748-2
- Den Oudsten BL, Traa MJ, Thong MSY, Martijn H, De Hingh IHJT, Bosscha K, van de Poll-Franse LV (2012) Higher prevalence of sexual dysfunction in colon and rectal cancer survivors compared with the normative population: a population-based study. Eur J Cancer 48(17):3161–3170
- Syrjala KL, Schroeder TC, Abrams JR, Atkins TZ, Brown WS, Sanders JE, Schubert MA, Heiman JR (2000) Sexual function measurement and outcomes in cancer survivors and matched controls. J Sex Res 37(3):213–225. doi:10.1080/00224490009552042
- 24. Brotto LA, Heiman JR, Goff B, Greer B, Lentz GM, Swisher E, Tamimi H, Van Blaricom A (2008) A psychoeducational intervention for sexual dysfunction in women with gynecologic cancer. Arch Sex Behav 37(2):317–329
- Rosen R, Brown C, Heiman J, Leiblum S, Meston C, Shabsigh R, Ferguson D, D'Agostino R Jr (2000) The Female Sexual Function Index (FSFI): a multidimensional self-report instrument for the assessment of female sexual function. J Sex Marital Ther 26(2):191–208
- Alder J, Zanetti R, Wight E, Urech C, Fink N, Bitzer J (2008) Sexual dysfunction after premenopausal stage i and ii breast cancer: do androgens play a role? J Sex Med 5(8):1898–1906
- Speer JJ, Hillenberg B, Sugrue DP, Blacker C, Kresge CL, Decker VB, Zakalik D, Decker DA (2005) Study of sexual functioning determinants in breast cancer survivors. Breast J 11(6):440–447. doi:10.1111/j.1075-122X.2005.00131.x
- Hendren SK, O'Connor BI, Liu M, Asano T, Cohen Z, Swallow CJ, Macrae HM, Gryfe R, McLeod RS (2005) Prevalence of male and female sexual dysfunction is high following surgery for rectal cancer. Ann Surg 242(2):212–223
- Rosen RC, Riley A, Wagner G, Osterloh IH, Kirkpatrick J, Mishra A (1997) The international index of erectile function (IIEF): a multidimensional scale for assessment of erectile dysfunction. Urology 49(6):822–830
- Canada AL, Neese LE, Sui D, Schover LR (2005) Pilot intervention to enhance sexual rehabilitation for couples after treatment for

- localized prostate carcinoma. Cancer 104(12):2689–2700. doi:10. 1002/cncr.21537
- Rosen RC, Cappelleri JC, Gendrano N 3rd (2002) The International Index of Erectile Function (IIEF): a state-of-the-science review. Int J Impot Res 14(4):226–244
- 32. Hopwood P, Fletcher I, Lee A, Al Ghazal S (2001) A body image scale for use with cancer patients. Eur J Cancer 37(2):189–197
- Andresen EM, Malmgren JA, Carter WB, Patrick DL (1994) Screening for depression in well older adults: evaluation of a short form of the CES-D. Am J Prev Med 10(2):77–84
- Jess P, Christiansen J, Bech P (2002) Quality of life after anterior resection versus abdominoperineal extirpation for rectal cancer. Scand J Gastroenterol 37(10):1201–1204
- Grant M, McMullen CK, Altschuler A, Mohler MJ, Hornbrook MC, Herrinton LJ, Wendel CS, Baldwin CM, Krouse RS (2011) Gender differences in quality of life among long-term colorectal cancer survivors with ostomies. Oncol Nurs Forum 38(5):587–596
- Wiegel M, Meston C, Rosen R (2005) The female sexual function index (FSFI): cross-validation and development of clinical cutoff scores. J Sex Marital Ther 31(1):1–20
- Annon J (1976) The PLISSIT Model. Journal of Sex Education Therapy 2:1–15
- Ayaz S, Kubilay G (2009) Effectiveness of the PLISSIT model for solving the sexual problems of patients with stoma. J Clin Nurs 18(1): 89–98. doi:10.1111/j.1365-2702.2008.02282.x
- Sprunk E, Alteneder RR (2000) The impact of an ostomy on sexuality. Clin J Oncol Nurs 4(2):85–88
- Schover LR (1999) Counseling cancer patients about changes in sexual function. Oncology (Williston Park) 13(11):1585–1591, discussion 1591–1582, 1595–1586
- Reese JB, Porter LS, Somers TJ, Keefe FJ (2012) Pilot feasibility study of a telephone-based couples intervention for physical intimacy and sexual concerns in colorectal cancer. J Sex Marital Ther 38:402– 417

Relevance to inform research, policies, and/or programs

This study contributes to the research understanding the sexual outcomes and body image distress of colorectal cancer patients by ostomy status (never, current, and past). Identifying which groups are at greatest risk for worse adjustment will inform future intervention studies targeting these at-risk groups. Data from this study can also help guide clinical discussions with patients about sexuality and body image.

