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Sexual Function and Health-Related Quality of Life in Long-Term Rectal Cancer Survivors

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Abstract

Introduction—Sexual dysfunction is a treatment sequela in rectal cancer (RC) survivors. Differences in health-related quality of life (HRQOL) may occur based on ostomy status (permanent ostomy versus anastomosis).

Aim—To describe alterations in sexual function and HRQOL based on ostomy status in long-term (≥ 5 years) RC survivors.

Methods—RC survivors with an ostomy (N=181) or anastomosis (N=394) were surveyed using validated HRQOL and functional status tools. We compared sexuality outcomes between the ostomy and anastomosis group, and reported differences adjusted for clinical and demographic characteristics. Qualitative data from one open-ended question on survivors' greatest challenges since their surgery were analyzed to explore sexuality, symptoms, and relationships.

Main Outcome Measures—Whether sexually active, satisfaction with sexual activity, and select sexual dysfunction items from the Modified City of Hope Quality of Life-Ostomy (mCOH-QOL-O).

Results—Survivors with a permanent ostomy were more likely to have been sexually inactive after surgery if it occurred before year 2000, and experience dissatisfaction with appearance, interference with personal relationships and intimacy, and lower overall HRQOL. Female RC survivors with an ostomy were more likely to have problems with vaginal strictures and vaginal pain after surgery that persisted at the time of survey (5+ years later). Radiation treatment, tumor stage, soilage of garments in bed, and higher Charlson-Deyo co-morbidity scores were negatively

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associated with outcomes. Six qualitative themes emerged: loss of and decreased sexual activity; psychological issues with sexual activity, physical issues with sexual activity; partner rejection; ostomy interference with sexual activity; and positive experiences with sexuality.

Conclusions—Sexual dysfunction is a common long-term sequela of RC treatment, with more problems observed in survivors with a permanent ostomy. This warrants widespread implementation of targeted interventions to manage sexual dysfunction and improve HRQOL for these survivors.

Introduction

In 2016, an estimated 40,000 cases of rectal cancer (RC) will occur in the United States.¹ RC treatment involves multimodal approaches, including surgery, chemotherapy, and radiation therapy. For localized RC, the treatment decision-making process is complex, and involves careful considerations on functional outcomes of maintaining or restoring bowel continence. Surgical treatment involving an abdominoperineal resection (APR) with a permanent ostomy was the standard of care.² Surgical techniques that aim to preserve anal sphincter function through low anterior resection (LAR) are thought to be associated with a better health-related quality of life (HRQOL), since no permanent pouch is needed. A recent Cochrane Review has challenged this view, and concluded that no firm conclusions were apparent on whether HRQOL is superior for most survivors without a permanent ostomy.²

One area where differences in the two groups may occur is sexual dysfunction, which is a well-documented long-term effect of RC treatment.^{3–5} Estimates of the incidence of sexual dysfunction in RC survivors varies from 23%–69% in men and 19%–62% in women.⁶ In a population-based study (N=21,802), 25.1% of RC survivors reported sexual dysfunction, and 13.9% reported difficulties with appearance and body image.⁷ RC survivors with a permanent ostomy reported more difficulties with body image (20.9%) and sexual function (27.2%) compared to survivors with no stoma (6.6% and 10.8%, respectively).⁷ Our previous research suggests that permanent ostomies are associated with body image disturbance, sexual dysfunction, and relationship problems, resulting in poor overall HRQOL.^{8–15}

The purpose of this analysis is to further describe sexual function and HRQOL in long-term (> 5 years) RC survivors by ostomy status (permanent ostomy versus anastomosis). Such information may assist clinicians and survivors in RC shared decision-making. Findings may also provide directions for counseling on sexual function for RC survivors post-treatment and through long-term survivorship.

Methods

The methods of these studies have been published elsewhere.¹⁶ In brief, we surveyed RC survivors from two Kaiser Permanente (KP) Regions, Northern California and Northwest. Study protocol and procedures were approved by both KP regions and the University of Arizona (coordinating site). Using KP's computerized tumor registry, we identified potentially eligible survivors using the following criteria: 1) > 5 years post-diagnosis; 2) tissue-verified RC diagnoses; 3) undergone a major intra-abdominal surgery that resulted in

an ostomy or anastomosis; and 4) age 18 years or older. All identified survivors received via mail a cover letter containing informed consent and a survey. Informed consent was implied by completing and returning the survey. Up to ten reminders were attempted for all survivors who had not returned the survey two weeks after mailings. Survivors were given the option of completing the survey via postage-paid return envelopes or answering questions over the phone. Medical history items were extracted from the KP electronic medical record, including time since surgery, tumor stage (surveillance, epidemiology, and end results [SEER] general summary stage)¹⁷, radiation, chemotherapy, and the Charlson-Deyo comorbidity index.¹⁸

The survey included the Modified City of Hope Quality of Life-Colorectal (mCOH-QOL-CRC). This tool assesses HRQOL in the physical, psychological, social, and spiritual well-being domains.¹⁹ Two items assessed self-reported depression after surgery (Y/N) and at time of survey (0 – 10 ordinal scale, where 10 was least depressed). All scale items (11-point ordinal) and subscales (continuous) range from 0–10. Within the tool are 10 dichotomous or 4-point items related to sexual activity, satisfaction, and sexual dysfunction symptoms (Table 1). Confirmation of construct validity has been previously reported, with reliability ranging from 0.77 to 0.90.^{16,19,20} The survey also included the Duke–UNC Functional Social Support Questionnaire (FSSQ)²¹ and the Bowel Function Index (BFI).^{16,22} The FSSQ contains an item “I get love and affection” with responses on a five-point scale, which we dichotomized to 0 “As much as I would like” versus 1 = “Almost as much as I would like” indicating less support. The BFI includes an item on frequency of soilage (leakage of stool) of garments at bedtime with responses on a five-point scale, which we dichotomized to 1 = “Always” or “Most of the time” versus 0 = “Sometimes,” “Rarely,” or “Never.” An open-ended question that asked survivors to provide written comments on their greatest challenges since surgery was included.

Statistical Analysis

Quantitative Analysis—Demographic and clinical characteristics were compared between ostomy and anastomosis groups with Student’s t-tests for continuous measures and chi-square (or Fisher’s exact) for categorical measures. Adjusted and unadjusted odds ratios (OR) with 95% confidence intervals were produced with logistic regression using ostomy versus anastomosis as the independent variable and sexual activity, satisfaction, HRQOL items and functional problems as outcomes. Outcomes were coded such that the model produced the OR for having an ostomy associated with sexual inactivity, dissatisfaction, presence of fear, lower HRQOL, and presence of functional problems. Fear of resuming sexual activity was evaluated only in those that reported being sexually inactive at time of survey. Undressing in front of a partner was scored a problem if subject responded “a little,” “somewhat,” or “very much.” HRQOL items (0–10 point scale) were coded as low if the score was less than 7.^{23,24} Prior to constructing adjusted models, we evaluated potential effect modification (interaction with ostomy status) by sex, married/partner status, and year of surgery (before or after January 1, 2000, the approximate median date of surgery). Covariates included in adjusted models differed according to the outcome time period in relation to surgery (Table 2). Candidate covariates were identified as biologically and temporally plausible factors and were judged for retention in final models by a change in the

coefficient for ostomy greater than 10% due to covariate. Self-reported depression was evaluated as a covariate as a secondary analysis due to the potential that depression is an intermediate step in the pathway to sexual activity and functional outcomes. We restricted the analysis of functional problems since surgery and at time of survey to participants who did not report the same problem prior to surgery, because the counts of having prior problem were very small in certain strata.

Qualitative Analysis—The qualitative analysis procedures are described elsewhere.²⁵ Briefly, free-text survey responses were transcribed into a spreadsheet. All survey responses were reviewed, and a list of unique topics was created using qualitative, grounded theory approach.²⁶ Codes were created from the topics and grouped into higher level categories. A separate secondary analysis of all coded content was undertaken to explore sexuality, symptoms, and relationships. Two investigators (VS and MG) experienced in content analysis re-reviewed all coded data. Key concepts and coding were evaluated and categorized into themes, and the themes were reviewed and agreed upon by the two investigators. Data that were discordantly coded were discussed with all investigators for refinement and consensus.

Results

Our combined sample consisted of 575 long-term RC survivors, with 181 survivors with permanent ostomy and 394 with anastomosis (Table 3). More than half of survivors were male, with a significantly higher proportion in the ostomy group. Age ranged from 36.2 to 100.3 for the combined sample and was significantly greater in the ostomy group. The majority of survivors were married or partnered before their index surgery and at the time of survey, but marital status did not differ significantly between surgery groups. The ostomy group was significantly more likely to have received preoperative chemoradiation, but not have a regional or distant tumor stage. The ostomy group was more likely to report depression after surgery but not at the time of survey.

We observed a significant interaction ($p=.009$) between year of surgery (before or after 01/01/2000) and ostomy status for the outcome sexually active since surgery, suggesting a stronger effect of ostomy in the earlier period, which persisted when adjusted for model covariates. The same effect modification was not observed for current sexual inactivity. When stratified by year of surgery, before 2000 the proportion inactive since surgery was 51% ostomy versus 29% anastomosis ($p<.001$) [adjusted OR 2.68 (95% CI 1.46, 4.94)] whereas 2000 or later it was 69% ostomy versus 58% anastomosis ($p=0.09$) [1.22 (95% CI 0.62, 2.47)]. Thus, sexual inactivity in the period after surgery was generally less common in the earlier cohort (surgery before 2000), but the gap between surgery groups was wider. There were 67 anastomosis subjects who had had a temporary ostomy after surgery, and the effect modification remained if they were grouped with the permanent ostomy subjects [adjusted OR 2.36 (95% CI 1.28, 4.36) before 2000; adjusted OR 1.17 (95% CI 0.61, 2.25) for 2000 or later]. The effect modification by year of surgery may be partially explained by practice changes in frequency of radiation treatment, which was received by 37% ostomy versus 28% anastomosis ($p=.13$) before 2000 compared to 65% ostomy versus 41%

anastomosis ($p < 0.001$) in 2000 or later. No other significant interaction was observed for year of surgery, gender, or married/partner status.

For HRQOL items (Table 4), we found that RC survivors with an ostomy were more likely to be fearful of resuming sexual activity, have problems with undressing in front of a partner, or have poor scores (< 7 on scale 0 to 10) for interference with personal relationships, ability to be intimate, and satisfaction with appearance after adjusting for confounding factors. RC survivors with an ostomy were also more likely to report lower overall HRQOL. There were no differences by ostomy status for currently sexually inactive, dissatisfaction with sexual activity, and perception that subject get love and attention.

Self-reported depression was an independent predictor for all sexual activity HRQOL outcomes in Table 4. However, among the significant associations between ostomy status and these outcomes observed (including for sexual inactivity since surgery if surgery was before year 2000), only fear of resuming sexual activity changed estimated OR by more than 10% or became non-significant when adjusted for self-reported depression (OR 1.92, 95% CI .98, 3.79).

Multiple other covariates were associated with sexual outcomes in adjusted models. Radiation treatment significantly associated with being sexually inactive since surgery (OR 2.0, $p = .001$), sexually inactive currently (OR 2.0, $p = .002$), and worse QOL outcomes (ORs 1.6 to 1.9, $p = .01$ or less) except satisfaction with appearance. Chemotherapy, tumor stage (in situ/localized vs. regional/distant), and time since surgery were not significantly associated with outcomes. A higher Charlson-Deyo comorbidity score was associated with being sexually inactive after surgery (OR 1.3, $p = .002$) and sexually inactive currently (1.6, $p < .001$). Older age at survey was associated with a higher risk of sexually inactive currently (30% increased risk per 5 years), but lower risk of fear of resuming activity, problem undressing in front of partner, getting love and affection, and the four QOL measures (approximately 15% decreased risk per 5 years). Soilage of garments in bed was associated with worse total QOL (OR 2.7, $p < .001$), interference with personal relationships (OR 2.7, $p < .001$), and interference with intimacy (OR 3.8, $p < .001$). Although not associated with surgery type (thus not important covariates), we observed that older age at diagnosis was associated with higher odds of being sexually inactive before and after surgery, and that being married/partnered was associated with lower odds of being sexually inactive at all time periods.

For sexual-dysfunction related symptoms (Table 5), female RC survivors with an ostomy were more likely to have problems with vaginal strictures and vaginal pain after surgery; the increased likelihood persisted for both symptoms at the time of survey. Men with an ostomy were significantly more likely to report a problem getting an erection and maintaining an erection after surgery, but the increased likelihood did not persist at the time of survey. No other associations were observed for male functional problems (erectile dysfunction, maintaining erection) by ostomy status.

Self-reported depression was an independent predictor for problems getting and maintaining an erection after surgery, but was not associated (neither adjusted nor unadjusted) with

current erectile dysfunction or female functional problems. When adjusted for self-reported depression after surgery, the estimated ORs with ostomy status were reduced and no longer significant for problems with getting an erection (OR 1.69, 95% CI .92, 3.11), and problems with maintaining an erection (OR 1.62, 95% CI .85, 3.07) after surgery. Radiation was associated in adjusted models for symptoms after surgery: vaginal dryness (OR 3.0, $p=.03$), vaginal pain (OR 2.5, $p=.08$), problem getting erection (OR 2.1, $p=.02$), and problem maintaining erection (OR 2.1, $p=.02$). Tumor stage was associated with problem getting erection after surgery (adjusted OR 1.9, $p=.04$) and problem maintaining erection after surgery unadjusted (OR 2.5, $p=.001$) but not in the adjusted model (adjusted OR 1.8, $p=.07$).

Qualitative Findings on Sexuality, Symptoms, and Relationships

Six prominent themes emerged following content analysis of written comments on the “greatest challenges” open-ended question in the survey (see Table 6 for representative comments). Survivors discussed decreased or loss of sexual activity following ostomy formation as one of their greatest challenges. Sexual dysfunction resulted in depression, as one survivor described, “I feel depressed and worthless in this area.” Physical issues included radiation-associated symptoms such as treatment-induced menopause, vaginal dryness and burns, and erectile dysfunction. Pain led to difficulties to engage in sexual activity, “because it hurts so much to have intercourse I really don’t think about having sex... This at times has become an issue and I feel awful.” Survivors also described partner rejection (failed engagements and marriages) because of sexual dysfunction. Ostomy appliances and associated odors, flatulence, and leakage contributed to decreased confidence to engage in sexual intercourse, as one survivor described, “I never felt I could be an adequate sexual partner after my operation.” Despite having a permanent ostomy, some survivors were grateful that their relationships remained intact, as one survivor described, “I have maintained an 11 year relationship with my partner despite my sex problems. Sure I’d like my erection and energy back, but I’m grateful for what I have.”

Discussion

Sexual dysfunction is a common and often persistent sequela after surgical treatment for RC. In this study with long-term (≥ 5 years post treatment) RC survivors, having a permanent ostomy was associated with more problems with appearance, intimacy, and lower overall HRQOL compared to anastomosis. Similar findings were observed in a population-based study, where RC survivors with permanent ostomy reported more problems in body image and sexual function, compared to survivors with no ostomy or temporary ostomy.⁷ These findings suggest that sexual dysfunction should be a focus for targeted interventions that aims to improve HRQOL in long-term RC survivorship, particularly for survivors living with an ostomy.

The majority of survivors, regardless of ostomy status, reported not being sexually active at the time of survey. This has been suggested previously^{4,5}, although the absence of sexual activity may not be an accurate reflection of physiologic functionality or the presence of associated symptoms.⁶ Lack of sexual activity after surgery with a permanent ostomy can likely be psychogenic or be a result of functional disorders such as erectile dysfunction.

Mood disorders such as depression may also contribute to erectile dysfunction. Lack of sexual activity in the ostomy group may also be due to partner's attitudes towards ostomy. In our quantitative data, the majority of RC survivors in our sample did not report dissatisfaction with their sexual activity. This may be a function of time, as our sample included survivors who were 5 or more years from their surgery, so a certain level of adaptation may have occurred. However, survivors with an ostomy were more likely to experience problems with undressing in front of a partner. We also found evidence of this in our qualitative data, where the ostomy appliance was described as "ugly" and "not appealing." Evidence suggests that sexual dysfunction is associated with a range of psychological well-being outcomes, including body image, anxiety, and posttraumatic distress.^{27,28} Survivors with permanent ostomies are also more likely to experience social distress post-treatment.²⁹ Similar to other studies^{4,5}, we found a high prevalence of persistent sexual dysfunction associated symptoms in both female and male survivors regardless of ostomy status. This suggests that problems with the physiologic functionality that impact sexual function are universal for all RC survivors. The management of both physical and psychological impact of sexual dysfunction is critical to improving HRQOL in RC survivors.

We observed an association between radiation therapy and negative sexual outcomes. Multimodal treatment approaches, including surgery and radiation, may cause direct damage to the autonomic nervous system, resulting in a variety of symptoms that are associated with sexual dysfunction. Many studies report poor sexual function for both men and women following pre-operative radiation.^{30–32} Sexual activity declined significantly in 72% of irradiated females, and irradiated patients had poorer erectile function, orgasmic function, and intercourse satisfaction.^{33,34}

There are limitations to this study that warrant further discussion. The analysis was unable to fully explain the effect modification by year of surgery, which may have been related to neoadjuvant/adjuvant treatments received. We did not obtain data on treatment for sexual dysfunction/erectogenic medications, particularly for male survivors. We did not include a validated measure in our survey to assess for functional disorders such as erectile dysfunction. The ostomy group was more likely to have received chemoradiation and reported more comorbidities compared to the anastomosis group; these significant differences may have influenced our findings. We did not ask survivors to provide the reasons for being sexually inactive; therefore, we were unable to include a definition of sexual inactivity. Some survey questions asked patients to recall their sexual function experience and issues; as a result, recall bias is a potential. Many survivors who participated in the study were 12–14 years post-surgery at the time of survey. In addition, the average age of our sample was 70; this may have influenced our findings since sexual dysfunction and cessation of sexual activity may occur regardless.

Conclusions

Sexual dysfunction is a common and persistent problem for long-term RC survivors. The magnitude of associated physical and psychological problems supports the development and widespread implementation of targeted interventions for RC survivors. This is particularly

important given that there is an increasing trend in prevalence of RC in younger populations (< 50 years).³⁵ Interventions should include management and counseling that facilitate discussions of sexual dysfunction between providers, patients, and families that begins in the preoperative setting to enhance informed shared decision-making.

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Table 1

Sexual Function and Issues Items from Study Survey

Were you sexually active before having your operation?
Have you been sexually active since having your operation?
Are you currently sexually active?
If NO, are you fearful of resuming sexual activity?
Is your sexual activity satisfying?
Since your operation, is undressing in front of your partner a problem?
I get love and affection
Has your operation interfered with your personal relationship?
Has your operation interfered with your ability to be intimate?
How satisfied are you with your appearance?

Table 2

Odds Ratios and Adjuster Variables

Odds Ratio	Adjuster Variables
Sexually inactive before surgery	Gender
Sexually inactive since surgery	Gender, Radiation treatment (Y/N), Charlson-Deyo comorbidity score, Sexually inactive before surgery (Y/N), self-reported depression *
Sexually inactive currently and Sexual activity not satisfying	Gender, Age at survey, Radiation treatment (Y/N), Charlson-Deyo comorbidity score, self-reported depression *
Fear of resuming sexual activity, I get love and affection, and Undressing in front of partner a problem	Same variables as Sexually inactive currently plus years since surgery
Remaining activity and QOL outcomes	Same variables as Sexually inactive currently plus years since surgery and Garment soilage in bed (Y/N)
Functional problems before surgery	Age at diagnosis
Functional problems since surgery	Radiation treatment (Y/N), Charlson-Deyo comorbidity score, tumor stage (In situ/Localized vs Regional/Distant), self-reported depression *
Functional problems currently	Age at survey, Radiation treatment (Y/N), Charlson-Deyo comorbidity score, years since surgery, tumor stage (In situ/Localized vs Regional/Distant), self-reported depression *

* Self-reported depression, if associated with outcome, in secondary analysis only

Table 3

Demographic and Clinical Characteristics by Ostomy Status

Characteristic	Ostomy (N=181)	Anastomosis (N=394)	P-value
Age (yr), mean (SD) [range]	74.9 (11.0) [43.5–100.3]	72.4 (10.7) [36.2–96.5]	.01
Male, n (%)	119 (65.8)	221 (56.1)	.03
Marital status pre-surgery, n (%)			
Single	12 (6.6)	31 (7.9)	.93
Married/partnered	136 (75.1)	288 (73.1)	
Divorced/separated	(8.3)	28 (7.1)	
Widowed	(8.8)	42 (10.7)	
Missing	2 (1.1)	5 (1.3)	
Marital status at survey, n (%)			
Single	14 (7.7)	31 (7.9)	.95
Married/partnered	117 (64.6)	249 (63.2)	
Divorced/separated	14 (7.7)	28 (7.1)	
Widowed	33 (18.2)	81 (20.6)	
Missing	3 (1.7)	5 (1.3)	
Stage ^I			
In situ/Localized	83 (45.9)	201 (51.0)	.16
Regional/Distant	89 (49.2)	184 (46.7)	
Unknown	9 (5.0)	9 (2.3)	
Received radiation treatment, n (%)	89 (49.2)	138 (35.0)	.001
Received chemotherapy, n (%)	105 (58.0)	189 (48.0)	.03
Charlson-Deyo comorbidity score mean (SD) - one year before surgery	1.09 (1.50)	0.69 (1.16)	<.001
Years since surgery, mean (SD)	14.8 (7.6)	12.4 (5.5)	<.001
Age at diagnosis (yr), mean (SD)	59.4 (11.7)	59.3 (10.6)	.95
Self-reported depression after surgery, n (%)			
Missing	9 (5.0)	5 (1.3)	<.001
Self-reported depression at survey, mean (SD)	7.6 (2.6)	8.1 (2.3)	

^I Surveillance, epidemiology, and end results (SEER) general summary stage

Table 4

Sexual Activity Health-Related Quality of Life Measures by Ostomy Status

Characteristic	Ostomy (n = 182) (%)	Anastomosis (n = 394) (%)	Unadjusted		Adjusted	
			OR ¹	95% CI	OR ¹	95% CI
Sexually inactive before surgery ²	19.4	21.7	0.87	0.56, 1.36	1.01	0.63, 1.62
Sexually inactive since surgery ^{2,3}	58.9	44.3	1.80	1.25, 2.59	1.77	1.15, 2.71
Sexually inactive currently ²	74.4	68.2	1.36	0.91, 2.03	1.03	0.65, 1.62
Fearful of resuming sexual activity, if not sexually active ⁴	19.0	13.5	1.50	0.84, 2.71	2.19	1.13, 4.25
Sexual activity not satisfying ⁵	36.8	34.5	1.11	0.63, 1.94	0.97	0.54, 1.76
Undressing in front of partner a problem ⁶	41.2	10.6	5.92	3.56, 9.87	7.62	4.30, 13.50
Social Support: "I get love and affection," ⁷	40.0	35.0	1.24	0.86, 1.78	1.17	0.78, 1.76
Total HRQOL ⁸	44.4	27.4	2.12	1.47, 3.06	2.41	1.60, 3.62
Interference with personal relationships ⁸	41.2	18.9	3.00	2.03, 4.45	3.63	2.32, 5.69
Interference with ability to be intimate ^{8, 9}	54.7	34.3	2.31	1.60, 3.33	2.55	1.68, 3.88
Satisfaction with appearance ⁹	39.1	24.2	2.01	1.37, 2.93	2.38	1.57, 3.61

¹OR associated with having an ostomy²Not stated: before surgery 6 ostomy, 16 anastomosis; since surgery 6 ostomy, 28 anastomosis; currently 5 ostomy, 26 anastomosis³Effect modification by year of surgery (p=0.005): earlier years adjusted OR 2.68 (95% CI 1.46, 4.94); later years adjusted OR 1.22 (95% CI 0.62, 2.47)⁴Percent of those reporting not being currently sexually active (133 ostomy, 251 anastomosis); whether fearful not stated 10 ostomy, 14 anastomosis⁵Not limited to those who reported being sexually active; not included in total are 93 ostomy/177 anastomosis who responded "Not Applicable" and 14 ostomy/40 anastomosis with no response to satisfaction question.⁶34 ostomy and 85 anastomosis answered "Not Applicable;" not stated 11 ostomy, 25 anastomosis⁷Lower support, indicated by responses other than "As much as I would like"

Score < 7 on a scale 0–10 where 10 = best HRQOL
not stated 9 ostomy, 15 anastomosis

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Table 5

Sexual Dysfunction-Associated Symptoms by Ostomy Status

Characteristic	Ostomy (%) (n=62 women)	Anastomosis (%) (n=173 women)	Unadjusted		Adjusted	
			OR /	95% CI	OR /	95% CI
Female functional problems:						
Problem with vaginal dryness Before surgery	22.8	28.3	0.73	0.36, 1.48	0.73	0.36, 1.48
After surgery	35.9	39.0	0.88	0.46, 1.67	1.02	0.40, 2.62
Currently	36.0	42.7	0.73	0.38, 1.42	.78	0.29, 2.08
Problem with vaginal stricture Before surgery	3.8	7.8	0.46	0.10, 2.13	0.45	0.10, 2.10
After surgery	25.5	16.8	1.70	0.79, 3.64	2.71	1.08, 6.75
Currently	27.5	17.4	1.75	0.83, 3.71	3.29	1.20, 9.04
Problem with vaginal pain Before surgery	7.3	7.6	0.95	0.29, 3.07	0.95	0.29, 3.08
After surgery	25.0	14.6	1.95	0.90, 4.24	2.75	1.04, 7.32
Currently	21.6	12.0	1.97	0.86, 4.50	5.53	1.64, 18.63
Male functional problems:	(n=119 men)	(n=221 men)	OR /	95% CI	OR /	95% CI
Problem with getting erection Before surgery	15.8	21.0	0.71	0.38, 1.33	0.68	0.36, 1.30
After surgery	70.1	58.8	1.65	0.98, 2.75	2.02	1.12, 3.63
Currently	73.3	69.2	1.22	0.72, 2.07	1.36	0.73, 2.52
Problem with maintain erection Before surgery	20.6	25.1	0.77	0.43, 1.39	0.76	0.42, 1.37

Characteristic	Ostomy (%)	Anastomosis (%)	Unadjusted		Adjusted	
After surgery	71.4	60.5	1.63	0.96, 2.79	1.91	1.03, 3.56
Currently	77.2	74.3	1.17	0.66, 2.09	1.29	0.65, 2.54

I OR associated with having an ostomy

Table 6

Qualitative Findings: Sexuality, Symptoms, and Relationships

Theme	
Loss of or Decreased Sexual Activity	“Loss of sexual function is the greatest challenge.”
	“It has interfered with intimate activities.”
	“No sexual activity after operation. Really bothers me a lot. The right answer is not out there. Tried everything still no sexual activity.”
Psychological Issues with Sexual Activity	“I miss my sex.”
	“I would recommend counseling before this long, confusing road to treatment begins it is so important to understand what is going to happen to your body and any relationships you have.”
	“I am depressed at my sexual dysfunction, which so far I have not had any success with treatments in this area. I feel depressed and worthless in this area (male).”
	“Reluctance to be naked in front of others.”
Physical Issues with Sexual Activity	“Most of the long-term problems are secondary to the perirectal radiation – vaginal burns, dryness, abrupt menopause with ovarian function has effected sexual function severely. This of course has effect on marital relationship.”
	“Apparently due to radiation I have retro emission-no ejaculation. Not a huge problem, but like a loss of masculinity.”
	“Losing the ability for an erection after radiation treatment.”
	“Damaged ability to maintain an erection. Intimacy is difficult when your rectum hurts, also, fear of not being able to maintain an erection makes sex uncomfortable.”
	“Unable to sustain erection affected sex life completely.”
	“The other part was the surgery and scarring it caused internally. It has really made it difficult and painful to have sexual relations.”
	“Another challenge is having sex. Because it hurts so much to have intercourse I really don’t think about having sex. Much to my partner’s regret! This at times has become an issue and I feel awful.”
Partner Rejection	“Getting my wife to have sex with me.”
	“I was 44 years old at the time of surgery and I was engaged to be married. My fiancé decided after that, we would not get married. I think he was scared that the cancer would return or more importantly, that having sex would disappear completely. I’m turning 64 years old and since my treatment and my fiancé left, I have never been with a man and never had sex again.”
	“The disintegration of a 35 year marriage and facing life alone in my 50’s.”
Ostomy Interference with Sexual Activity	“Coming to grips with the loss of my sexuality. Everything revolves around your colostomy. All timing – travel, recreation, eating, sex – everything requires planning.”
	“I have to use a catheter for urinating and wear incontinence pads. This has definitely put a damper on sexual activity.”
	“The other challenge that has affected my entire life and relationship with my husband is having this colostomy with ugly appliances attached to the front of my stomach. It is not very appealing. Our sexual relations are almost non-existent. I do not feel comfortable and I know he is bothered by it as well. This whole episode has put such a strain on me and my marriage.”
	“I was single and didn’t dare to date. The ostomy was noisy, stinky, messy and I couldn’t wait to get rid of it.”
	“I never felt I could be an adequate sexual partner after my operations.”
Positive Experiences with Sexuality and Intimacy	“It has been nearly [years] since my cancer and life is once again fulfilling with no sexual problems at all.”
	“My greatest challenge was immediately after surgery. Would my husband still find me attractive? Luckily the answer to the question was yes. I am now 11 years married to a

Theme	
	wonderful man who had been a friend up until and during the time of surgery and treatments.”
	“I have maintained an 11 year relationship with my partner despite my sex problems. Sure I’d like my erections and my energy back, but I’m grateful for what I have.”

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