

Health-Related Quality of Life Among Long-Term Rectal Cancer Survivors With an Ostomy: Manifestations by Sex

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ABSTRACT

Purpose

Intestinal stomas can pose significant challenges for long-term (≥ 5 years) rectal cancer (RC) survivors. Specifying common challenges and sociodemographic or clinical differences will further the development of tailored interventions to improve health-related quality of life (HRQOL).

Patients and Methods

This was a matched cross-sectional study of long-term RC survivors conducted in three Kaiser Permanente regions. The mailed questionnaire included the modified City of Hope Quality of Life-Ostomy (mCOH-QOL-Ostomy) and Medical Outcomes Study 36-Item Short-Form Health Survey, version 2 (SF-36v2). Groups surveyed were permanent ostomates (cases) and those who did not require an ostomy (controls). RC survivors were matched on sex, age, and time since diagnosis. Comparisons between groups used regression analysis with adjustment for age, comorbidity score, history of radiation therapy, income, and work status.

Results

Response rate was 54% (491 of 909). Cases and controls had similar demographic characteristics. On the basis of the mCOH-QOL-Ostomy, both male and female cases had significantly worse social well-being compared with controls, while only female cases reported significantly worse overall HRQOL and psychological well-being. For younger females (< 75 years), ostomy had a greater impact on physical well-being compared with older females. Based on the SF-36v2, statistically significant and meaningful differences between female cases and controls were observed for seven of the eight scales and on the physical and mental component summary scores.

Conclusion

Men and women report a different profile of challenges, suggesting the need for targeted or sex-specific interventions to improve HRQOL in this population. This may include focus on physical HRQOL for female ostomy survivors younger than age 75.

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INTRODUCTION

In 2009, nearly 50,000 people will be diagnosed with rectal cancer (RC) in the United States¹ and will join the country's growing population of long-term RC survivors. As RC survival rates improve,² a growing number of patients are living with the long-term effects of treatment. Many of these survivors will receive intestinal stomas as part of their treatment. Health-related quality of life (HRQOL) outcomes may vary based on sex, as differences for rectal cancer survivors have previously been noted.³

An intestinal stoma, or ostomy, is the surgical exteriorization of the bowel to the anterior abdominal wall. This may include the small (ileostomy) or large (colostomy) bowel. An ostomy may be placed on a permanent or temporary basis. Permanent os-

tomy for RC is most commonly a colostomy. Occasionally, a temporary ostomy becomes permanent as a result of such factors as poor result of surgery (eg, stricture or nonhealing leak), medical intolerance of an invasive procedure, or metastatic disease. While fewer permanent ostomies are being performed today than in the past, the number of new rectal cancers diagnosed annually indicates that a significant number of patients will have a permanent ostomy created.

While we assume that living with an ostomy leads to a lower HRQOL for RC patients, and that an anastomosis is a preferable outcome, this evidence is not definitive. Some studies have shown that persons with ostomies have worse HRQOL than their counterparts with anastomosis⁴⁻⁷; other studies show similar or mixed HRQOL across

these two populations.⁸⁻²¹ In at least one study, patients with stomas have reported better social functioning, self-esteem, and anxiety than those with anastomoses.²⁰ The many HRQOL issues for people with an ostomy include problems with travel, intimacy, and satisfaction with appearance.²² Several studies documented additional problem areas, including sexuality²³⁻³⁰; psychological well-being^{2,31-35}; interference with work, recreational, and sporting activities^{22,29,34,36}; and spiritual HRQOL.³⁷

The Health-Related Quality of Life in Long-Term Colorectal Cancer Survivors Study was undertaken to elucidate experiences and correlates of HRQOL among long-term colorectal cancer survivors with intestinal ostomy.³⁸ This study's results provide the basis for developing and evaluating clinical interventions aimed at mitigating ostomy-related HRQOL deficits for these patients.³⁹ This article reports the main study findings regarding the self-reported HRQOL of RC survivors who had a procedure that resulted in an intestinal stoma compared with patients who experienced similar procedures for which an ostomy was not required. We hypothesized that permanent ostomy would be associated with lower HRQOL at the domain score level (physical, psychological, social, and spiritual), as well as at the item level (satisfaction with appearance, anxiety, ability to travel, and the ability to be intimate). In addition, we hypothesized that there would be differences between the sexes in the HRQOL of long-term RC survivors with ostomies because of differences in the way men and women view body image and appearance and perceive acceptance as persons with disfigured and dysfunctional bodies. Our findings have the potential to guide development of targeted interventions to improve HRQOL for persons with an ostomy.

PATIENTS AND METHODS

We conducted a matched cross-sectional survey of colorectal cancer survivors living at least 5 years after their cancer diagnosis. Patients included RC survivors with permanent ostomies (termed "cases") and those who had similar RC treatment-related procedures but who had an anastomosis (termed "controls"). Presurvey matching was conducted by site of tumor (colon *v* rectum), age (within 5 years), sex, and time interval since diagnosis (5-year intervals). Only RC survivors are reported in this analysis. Patients who had their ostomy reversed were excluded from this study. All patients received care as members of one of three Kaiser-Permanente regions: Northern California, Northwest, and Hawaii. The study protocol and survey instruments were reviewed and approved by the institutional review boards at the University of Arizona, Kaiser-Permanente-Northern California, Kaiser-Permanente-Northwest, and Kaiser-Permanente-Hawaii. Cover letters clearly discussed the study and potential risks, and completion of the survey was considered an implied consent. This study's methods have been reported extensively elsewhere.³⁸

We administered the modified City of Hope Quality of Life Ostomy-specific (mCOH-QOL-Ostomy) questionnaire⁴⁰ and the Medical Outcomes Study 36-Item Short-Form Health Survey, version 2 (SF-36v2, the updated version⁴¹ of the widely used Medical Outcomes Study SF-36⁴²) by mail. The SF-36v2 retains the original SF-36 measurement model, which includes eight multi-item scales (physical function, role limitations due to physical problems, bodily pain, general health perceptions, vitality, social functioning, role limitations due to emotional problems, and mental health) along with physical component summary (PCS) and mental component summary (MCS) scores. The scales and component summary scores have a possible range of 0 to 100, with higher scores reflecting better functioning and/or well-being. Scales were scored and missing data were handled according to the instrument developers'

scoring algorithms. The SF-36v2 scale scores were coded as missing for a respondent if more than half the responses for the scale's items were missing. The mCOH-QOL-Ostomy has demographic, nonscaled, and scaled items (on a scale from 0 = "poor" to 10 = "excellent"). The nonscaled items assess marital status, work, household income, health insurance, sexual activity, psychological support, and diet. The scaled items are mapped onto one of four HRQOL domains (physical, psychological, social, and spiritual well-being) on the basis of psychometric analysis.⁴³

Medical history items were obtained from Kaiser-Permanente clinical and administrative databases (tumor registry, hospital discharge abstracts, ambulatory encounter abstracts, electronic medical records, and outside professional and facility claims), including type of stoma, length of time since diagnosis and surgery, site of tumor, Surveillance, Epidemiology, and End Results (SEER) staging, and pre- and postoperative treatment. We constructed the Charlson-Deyo comorbidity index⁴⁴ from International Classification of Diseases, 9th Revision, Clinical Modification (ICD-9-CM) codes using automated inpatient and outpatient databases during the year before the survey.

Statistical Analysis

We compared demographic and clinical characteristics between cases and controls using the *t* test for continuous measures (or the Mann-Whitney test if parametric assumptions were not met), a one *df* χ^2 test for trend for income, education, tumor site, or other ordinal variables, and a multiple *df* χ^2 test for heterogeneity (or Fisher's exact test) for race, stage, or other nominal variables. In the event of a significant χ^2 for a categorical variable, each category was compared by χ^2 test with a reference category for ordinal variables (with unknown category compared to all others) or with all other categories for nominal variables. Differences between the two surgery groups on items from the mCOH-QOL-Ostomy and SF-36v2 were determined with multiple regression, adjusting for age, Charlson-Deyo comorbidity score, household income, work status, and history of radiation therapy. These variables were hypothesized *a priori* as potential confounders on the basis of clinical literature and experience. Other variables assessed in multivariate models for potential confounding between ostomy status and HRQOL outcomes included chemotherapy, time since surgery, married/partnered status, race/ethnicity, ostomy type (ileostomy versus colostomy), education, and distance from home to the nearest medical center.

Comparisons of individual scaled items within the mCOH-QOL-Ostomy were explored to generate hypotheses for future research. These tests were limited to scaled items within domains for which we observed significant case-control differences and were subjected to Bonferroni adjustment for multiple comparisons. We used the empirical rule effect size method to judge minimally important differences (MIDs) in outcome measures,⁴⁵ where an MID is defined as equivalent to 8% of the HRQOL tool's theoretical range, which for the mCOH-QOL-Ostomy is 0.88 and for the SF-36v2 is eight points for each of the eight primary scales. The MCS and PCS of the SF-36v2 are scored using a method that transforms the scores to a standardized scale (T-scores) with a norm of 50 and a standard deviation of 10 in the general US population. Based on the work of Kosinski et al,⁴⁶ a two-point or greater difference on the PCS and MCS scores is considered the MID.

RESULTS

The overall response rate of RC survivors was 54% (491 of 909). While cases and controls were sociodemographically similar (Table 1), the two groups differed on several clinical characteristics (Table 2). Proportions of cases and controls who had ever been treated with chemotherapy were comparable (37.8% *v* 40.0%; *P* = .95). Among those receiving chemotherapy, cases were significantly more likely to have received neoadjuvant chemotherapy compared with controls (31.2% *v* 12.2%; *P* = .001). Cases were also significantly more likely to have received radiotherapy (40.7% *v* 29.4%; *P* = .002). Among those receiving radiotherapy, cases were significantly more likely to have received neoadjuvant radiotherapy, compared with controls (32.0% *v* 15.3%; *P* = .01). Of those receiving chemotherapy or radiotherapy,

Table 1. Sociodemographic Characteristics of Respondents

Sociodemographic Characteristic	Cases (n = 246)		Controls (n = 245)		P
	No.	%	No.	%	
Age, years					
Mean	72.4		71.1		.17
SD	10.3		10.1		
Median	73.7		72.0		NA
Male	147	59.8	157	64.1	.32
Race/ethnicity					.13*
White, non-Hispanic	182	74.0	191	78.0	
Black, non-Hispanic	8	3.3	4	1.6	
Hispanic/Latino	20	8.1	8	3.3	
Asian	23	9.4	26	10.6	
Other/unknown	13	5.3	16	6.5	
Education					.12†
Not a high school graduate	29	11.8	23	9.47	
High school graduate	65	26.4	54	22.0	
Vocational degree or some college	69	28.1	73	29.8	
College graduate or graduate school	83	33.7	95	38.8	
Annual household income, \$.11†
≤ 30,000	90	36.6	70	28.63	
30,001 to 50,000	63	25.6	66	26.9	
50,001 to 75,000	36	14.6	42	17.1	
> 75,000	36	14.6	41	16.7	
Unknown/no answer	21	8.5	26	10.6	
Married/partnered prior to surgery	185	75.5	188	77.4	.63
Married/partnered currently	153	63.0	157	64.6	.71
Employment					.63
Full-time	30	12.2	34	13.9	
Part-time	20	8.1	21	8.6	
Retired	185	75.2	184	75.1	
Unemployed/unknown	11	4.5	6	2.5	

Abbreviations: SD, standard deviation; NA, not applicable.

*Fisher's exact test.

† χ^2 test for trend.**Table 2.** Clinical Characteristics of Study Participants

Clinical Characteristic	Cases (n = 246)		Controls (n = 245)		P
	No.	%	No.	%	
Years since cancer diagnosis					
Mean	12.6		11.0		NA
SD	6.6		4.9		
Median	10.8		10.3		.052*
Years since surgery					
Mean	12.0		10.7		NA
SD	6.9		5.2		
Median	9.8		9.9		.20*
SEER summary stage					.94†
Local	123	50.0	135	55.1	NA
Regional	98	39.8	104	42.5	NA
Distant	2	0.8	4	1.6	NA
Unknown	23	9.4	2	0.8	< .001‡
Chemotherapy					.95§
Preoperative	29	11.8	12	4.9	NA
Postoperative	58	23.6	79	32.2	NA
Timing unknown	6	2.4	7	2.9	NA
None	137	55.7	146	59.6	NA
Unknown	16	6.5	1	0.4	< .001‡
Radiation therapy					.002§
Preoperative	32	13.0	11	4.5	NA
Postoperative	50	20.3	44	18.0	NA
Timing unknown	18	7.3	17	6.9	NA
None	133	54.1	173	70.6	NA
Unknown	13	5.3	0	0.0	< .001‡
Type of stoma					
Colostomy	226	93.4	NA		NA
Ileostomy	10	4.1	NA		NA
Unknown	10	4.1	NA		NA
Charlson-Deyo index, > 2	58	23.6	44	18.0	.13

Abbreviations: NA, not applicable; SD, standard deviation; SEER, Surveillance, Epidemiology, and End Results.

*Mann-Whitney test.

† χ^2 test for trend.

‡Fisher's exact test.

§Any treatment versus no treatment.

there was no significant difference in the proportion of cases and controls that had unknown timing of such therapy. Finally, no significant difference was observed in the Charlson-Deyo comorbidity index between cases and controls ($P = .13$).

Multiple demographic and clinical variables were significantly related to HRQOL in bivariate analyses but were not found to be significant in multivariate analyses. Age ($P < .001$), comorbidity score ($P = .008$), household income ($P = .001$), and work status ($P = .04$) were independent predictors of total HRQOL. History of radiation therapy was not a significant predictor for total HRQOL but was retained as an adjuster in all models on the basis of prior hypotheses and clinical judgment. Despite evidence from previous studies highlighting the importance of having a partner as a positive influence on HRQOL, this was not shown to be an independent predictor in our analysis.

Table 3 compares mCOH-QOL-Ostomy overall HRQOL and domain subscales between male and female cases and controls, respectively. Women without ostomies scored the same or higher than men without ostomies. Women with an ostomy, however, scored the same or lower than men with an ostomy for each domain, suggesting that having an ostomy is associated with poorer HRQOL among female long-term RC survivors. Significant interactions were observed between ostomy status and sex for the psychological domain with trends for the total score and spiritual domain. All subsequent differences

between cases and controls are presented separately by sex. Statistically significant adjusted mean differences between cases with and without ostomies were noted for men in the social domain and women in overall HRQOL, psychological, and social domains. Differences for women in the psychological and social domains exceeded the MID. We observed a significantly greater association between having an ostomy and physical well-being among younger (< 75 years) women (interaction $P < .001$); the adjusted mean score was 0.83 lower among cases compared with controls ($P < .05$). In women age 75 years or older, there was no significant difference (0.34 higher in cases; $P = .44$).

Table 4 displays individual items from the mCOH-QOL-Ostomy that were examined in an exploratory manner. We tested and presented only items from the psychological and social domains separately by sex. People with ostomies reported statistically significant and/or meaningfully worse (ie, exceeded MID) scores than those without ostomies on multiple items across these domains for women and in the social domain for men, including virtually all of the social items for both sexes. Items specific to care or experience of an ostomy are shown in Table 5. Mean scores were comparable between sexes, except for a meaningfully lower mean score for travel privacy among

Table 3. mCOH-QOL-Ostomy Domain Scores* and Adjusted† Mean Differences Between Cases and Controls by Sex

Scale/Domain	Males						Females						Ostomy-Sex Interaction† <i>P</i>
	Cases (n = 147)		Controls (n = 157)		Adjusted Difference†		Cases (n = 99)		Controls n = 88)		Adjusted Difference†		
	Mean	SD	Mean	SD	Mean‡	<i>P</i>	Mean	SD	Mean	SD	Mean‡	<i>P</i>	
Total QOL	7.3	1.5	7.6	1.5	−0.24	.16	7.0	1.7	7.8	1.2	−0.72	< .002§	.09
Physical	7.5	1.7	7.4	1.9	−0.08	.13	7.1	2.0	7.4	1.9	−0.27	.38	.41
Psychological	7.4	1.7	7.7	1.5	−0.23	.22	6.8	1.8	7.8	1.3	−0.93¶	< .001	.02
Social	7.2	2.2	8.2	2.1	−0.88	< .001	7.2	2.2	8.5	1.8	−1.16¶	< .001	.44
Spiritual	6.9	2.3	6.8	2.1	0.12	.65	6.7	2.4	7.4	2.1	−0.47	.19	.07

Abbreviations: mCOH-QOL-Ostomy, City of Hope Quality of Life-Ostomy questionnaire; SD, standard deviation; QOL, quality of life.

*Based on a response scale of 0 to 10, with higher scores reflecting more positive outcomes.

†Adjusted for age, Charlson-Deyo comorbidity score, income, work status, and history of radiation treatment. Although not shown, similar results were obtained when analyses were adjusted for time since surgery in addition to these primary adjusters.

‡Negative adjusted difference indicates lower QOL for cases.

§Statistically significant ($P < .05$) with no Bonferroni adjustment.

¶Exceeds minimally important difference.

||Statistically significant after Bonferroni adjustment (adjusted alpha = .05/4 = .0125).

women. The items reported as most difficult for both sexes were traveling privacy and odor.

We compared the cases and controls on two nonscaled items for this analysis: depression and suicidal ideation following the initial surgery. Compared with cases with anastomoses, those with ostomies were significantly more likely to report depression following their

surgery for both men (40% v 22%; odds ratio [OR], 2.4; 95% CI, 1.4 to 4.0) and women (40% v 22%; OR, 2.3; 95% CI, 1.2 to 4.8). We observed trends suggesting that people with ostomies are significantly more likely to experience suicidal ideation following their surgery for both men (5.5% v 1.3%; OR, 4.5; 95% CI, 0.9 to 44) and women (8.1% v 2.3%; OR, 3.7; 95% CI, 0.7 to 36).

Table 4. mCOH-QOL-Ostomy Scaled Item Scores* and Adjusted† Mean Differences Between Cases and Controls by Sex

Domain/Item	Males						Females					
	Cases (n = 147)		Controls (n = 157)		Adjusted Difference†		Cases (n = 99)		Controls (n = 88)		Adjusted Difference†	
	Mean	SD	Mean	SD		P†	Mean	SD	Mean	SD		P†
Psychological												
Useful	6.8	3.0	7.4	2.6	−0.43	.19	6.6	3.2	7.1	2.7	−0.14	.73
Enjoyment	7.1	2.8	7.7	2.4	−0.36	.24	6.8	2.8	8.0	2.0	−0.99‡	.01
Remembering	7.2	2.4	7.1	2.2	0.20	.45	6.5	2.6	7.1	2.2	−0.58	.13
Control	7.4	2.8	7.5	2.3	0.03	.91	6.7	3.0	8.1	1.9	−1.19‡	.003
Appearance	6.9	2.5	7.1	2.3	−0.19	.49	5.4	3.1	6.8	2.3	−1.46‡	.001§
Anxiety	7.4	2.7	7.0	2.7	0.48	.14	6.6	2.8	7.7	2.3	−1.22‡	.002§
Depression	7.9	2.6	7.9	2.5	0.05	.87	7.0	2.9	8.3	2.3	−1.24‡	.003
Fear of recurrence	7.0	3.3	7.6	2.6	−0.59	.08	7.1	3.3	7.2	2.9	−0.12	.81
Difficulty meeting new people	8.2	2.7	8.6	2.1	−0.36	.19	8.0	3.0	8.7	2.0	−0.73	.07
Support	7.9	3.1	8.2	2.6	−0.35	.30	7.2	3.4	8.2	2.7	−0.94‡	.06
Privacy	9.1	2.1	8.7	2.5	0.47	.09	8.9	2.3	9.1	2.2	−0.21	.56
Uncertainty	6.8	3.5	7.7	2.8	−0.74	.04	6.2	3.3	7.5	3.0	−1.30‡	.01
Social												
Financial burden	7.4	3.2	8.6	2.2	−1.12‡	< .001§	8.3	2.6	8.9	2.0	−0.48	.19
Family distress	7.0	3.1	7.4	2.6	−0.35	.30	6.8	3.1	7.3	2.7	−0.52	.25
Travel challenges	6.8	3.2	8.2	2.9	−1.28‡	< .001§	6.3	3.6	8.0	3.0	−1.41‡	.008
Personal relationships	7.2	3.4	8.7	2.5	−1.28‡	< .001§	7.8	3.3	9.2	1.8	−1.53‡	< .001§
Isolation	8.2	2.8	9.0	2.2	−0.72	.02	7.8	2.9	9.2	1.8	−1.34‡	.001§
Recreational activities	6.0	3.7	7.6	3.2	−1.44‡	.001§	6.2	3.6	8.1	2.8	−1.79‡	.001§
Social activities	6.9	3.3	8.3	2.6	−1.27‡	< .001§	6.9	3.4	8.8	2.3	−1.63‡	.001§
Intimacy	4.7	3.9	7.6	3.3	−2.59‡	< .001§	5.9	3.9	8.5	2.8	−2.53‡	< .001§

Abbreviation: SD, standard deviation.

*Items tested only from domains that showed a significant difference between cases and controls in either sex. Based on a response scale of 0 to 10, with higher scores reflecting more positive outcomes.

†Adjusted for age, Charlson-Deyo comorbidity score, income, work status, and history of radiation treatment. Although not shown, similar results were obtained when analyses were adjusted for time since surgery in addition to these primary adjusters.

‡Exceeds minimally important difference.

§Statistically significant after Bonferroni adjustment (adjusted alpha = .05/20 = .0025).

Table 5. mCOH-QOL-Ostomy Scaled Items Used for Cases Only

Domain/Item	Males (n = 147)		Females (n = 99)	
	Mean	SD	Mean	SD
Physical well-being				
Skin problems	7.6	2.5	7.4	2.9
Odor	6.6	3.0	6.7	3.3
Leaking	7.6	3.1	7.3	2.7
Psychological well-being				
Travel privacy	6.7	3.1	5.8	3.5
Social well-being				
Adjustment difficulty	7.2	2.8	6.9	2.7
Embarrassment	7.2	3.0	7.0	3.3
Difficulty looking	8.7	2.3	8.7	2.5
Ostomy care	8.4	2.2	8.3	2.4

Abbreviations: mCOH-QOL-Ostomy, modified City of Hope Quality of Life-Ostomy questionnaire; SD, standard deviation.

Comparing adjusted means revealed multiple differences on the SF-36v2 scale scores between cases and controls (Table 6). Significant ostomy–sex interactions were observed for physical function, general health, and role-emotional scales. The patterns of findings between sexes, however, were markedly different. Among women, statistically significant MIDs were observed for adjusted mean scores on seven of the eight scales as well as the PCS scale and the MCS scale.

DISCUSSION

Our study highlights the HRQOL differences between men and women RC survivors by ostomy versus anastomosis. These data are consistent with sex differences observed in adaptation to chronic illness. Previous studies found that approximately one quarter of pa-

tients with an ostomy experience significant, clinically meaningful psychological symptoms.⁴⁷ In our study, the ratio of women to men stating that they felt depressed postoperatively was about 2:1, similar to known sex differences for depression.⁴⁸ Increased suicide rates have been observed among all people with cancer,⁴⁹ and rates for suicidal ideation for women in our study parallel the 7.2% reported for patients with bowel cancer in a recent study of patients from an outpatient clinic in a regional cancer center in Edinburgh.⁵⁰ We also found a trend for worse current feelings of depression (scaled item) among men with ostomies ($P = .08$), with a significant difference for women with ostomies ($P = .007$). While prior research has shown depression in this population,^{51,52} our findings are novel in describing postoperative states, including risk of suicide, which must be addressed in the perioperative setting. In addition, both men and women report greater anxiety, with only women exceeding the MID. Our findings underscore the need for primary care providers to evaluate psychological pathology among persons with ostomies postoperatively and among long-term survivors.

Fundamental sex differences have been found in coping and adaptation to disease and chronic illness.⁵³ Women engage in more coping behaviors and seek more social support than men, including emotional and spiritual activities, and this trend appears to hold true for RC survivors. Of note, differences may be due in part to worsening perceptions of HRQOL, especially in the physical domain, for younger (< age 75 years) females with stomas.

As with our study of veterans, the major HRQOL differences between persons with and without ostomies were related to social well-being.²² The social implications of an ostomy were reported more than 50 years ago in some detail,^{2,54,55} and more recent reports have also described these deficiencies.^{12,28,29,32,34,36,51,52,56–59} Our study further illustrates that intimacy was the most affected item for both male and female ostomates. While this may be a difficult issue for patients to address, intimacy takes on different forms beyond sexuality⁶⁰ and is potentially treatable for some patients. Other

Table 6. SF-36v2 Scale Scores and Adjusted Mean Differences Between Cases and Controls by Sex

Scale	Males						Females						Ostomy-Sex Interaction* <i>P</i>
	Ostomy (n = 147)		Control (n = 157)		Adjusted Difference*		Ostomy (n = 99)		Control (n = 88)		Adjusted Difference*		
	Mean	SD	Mean	SD	Mean	<i>P</i>	Mean	SD	Mean	SD	Mean	<i>P</i>	
Physical function	67.5	27.0	70.2	29.4	−1.1	.72	48.9	31.3	64.9	29.1	−10.2†	.02	.03
Role physical	67.5	29.5	74.5	25.3	−6.0	.05	58.5	31.7	75.9	25.7	−13.8†	.001‡	.12
Bodily pain	65.0	27.3	70.2	25.7	−4.1	.20	61.6	27.7	71.4	25.4	−7.8	.07	.46
General health	62.1	25.1	68.2	20.5	−5.2	.05	55.7	23.3	71.1	18.6	−14.0†	< .001‡	.04
Vitality	59.4	23.9	63.3	22.2	−3.0	.27	51.7	25.1	62.9	20.1	−9.5†	.009	.13
Social function	76.2	27.6	83.1	22.6	−5.6	.05	67.7	33.0	83.4	21.9	−13.7†	.002‡	.09
Role-emotional	79.4	27.7	84.6	21.5	−4.1	.16	70.4	31.1	87.2	19.2	−15.9†	< .001‡	.03
Mental health	76.1	21.5	81.8	16.6	−5.1	.02	70.4	23.7	81.8	14.6	−11.6†	< .001‡	.11
PCS§	44.1	10.9	45.6	10.6	−1.0	.46	39.6	10.7	44.9	10.9	−3.3†	.04¶	.16
MCS	50.4	12.7	53.4	9.8	−2.6†	.05	47.3	14.7	54.3	8.7	−7.4†	< .001¶	.08

Abbreviations: SF-36v2, Medical Outcomes Study 36-Item Short-Form Health Survey, version 2; SD, standard deviation; PCS, physical component summary; MCS, mental component summary.

*Adjusted for age, Charlson-Deyo comorbidity score, income, work status, and history of radiation treatment. Negative adjusted difference indicates lower quality of life (QOL) for cases. Although not shown, similar results were obtained when analyses were adjusted for time since surgery in addition to these primary adjusters.

†Exceeds minimally important difference.

‡Statistically significant after Bonferroni adjustment (adjusted alpha = .05/8 = .00625).

§Standardized physical component summary score.

¶Statistically significant ($P < .05$) with no Bonferroni adjustment.

||Standardized mental component summary score.

items, such as the perceived greater financial burden for both men and women with an ostomy, should be pursued through additional research. We have previously demonstrated a significant association between difficulty paying for ostomy supplies and overall HRQOL for veterans with intestinal stomas.⁶¹ We found that financial issues remain a concern, even among insured persons with ostomies. Counseling, supportive interventions, and changes in coverage for ostomy supplies could address these concerns and perhaps lead to overall HRQOL improvement.

Women with ostomies reported lower spiritual well-being scores than women without ostomies. The most significant item differences occurred on the questions related to having a sense of inner peace and hopefulness. While these items map to the spirituality domain, they also correlate (> 0.40) with both depression and anxiety from the psychological subscale.⁴³ Although persons with an ostomy did not score low on these items, they were meaningful (ie, exceeded the MID) compared with persons having anastomoses. Concerns about spirituality should be considered as a potential unmet need for female RC survivors with ostomies.

While our case and control groups were similar demographically, there were some clinical differences related to treatments. Although more ostomy patients had neoadjuvant treatments and radiation therapy, these do not seem to impact our HRQOL findings. While radiation therapy is thought to have an impact on function and other HRQOL issues, this could not be shown in our data set.

Our study has several limitations. First, it is a cross-sectional study. Baseline factors, such as preoperative rectal function along with longitudinal data such as post-treatment outcomes and changes in HRQOL over time, could add important information. Next, we were unable to further differentiate tumor location within the rectum. This is difficult when using electronic records, but RC patients do have similar risks no matter the exact location of the tumor. Additionally, while our response rate was only 54%, greater than 50% is considered adequate for a mailed survey study.^{62,63} Finally, while we hoped to attain a greater number of minority respondents, our findings are generalizable for many community cancer survivors.

Recognizing sex-specific trends in HRQOL concerns among long-term RC survivors with ostomies should lead to different approaches to survivorship care. The Primary Care Evaluation of Mental Disorders (PRIME-MD) 1000 study indicated symptom reporting to be generic rather than symptom-specific, with women reporting more medically unexplained symptoms. The effect of sex on symptom reporting was independent of psychiatric comorbidity.⁶⁴ Psychosocial and cultural factors, social roles and responsibilities, and physiologic differences, such as women's greater sensitivity to the external environment, have been posited to account for sex differences in symptom reporting.⁶⁴ These factors should be taken into consideration when men and women with ostomies are seen in the health care setting.

Our data clearly show the multiple HRQOL-related challenges that should be assessed by clinicians who care for RC long-term survivors with intestinal stomas. While fear of recurrence seems to be minimal in our sample, numerous other issues remain problematic.

Importantly, clinicians must recognize that sex plays a large role in the long-term HRQOL for these cancer survivors, and sex must be considered when developing strategies to improve HRQOL for men and women. Interventions should include early psychological evaluation and subsequent follow-up, recognizing that significant numbers of patients will feel depressed or even suicidal. We should also focus on the social well-being of long-term RC survivors with ostomies. Spiritual activities, religious or nonreligious, should be encouraged. Social support is important for both sexes, but women may have more concerns related to isolation and familial distress. Focus on physical problems for females younger than age 75 years must be considered. Fatigue and functional capacity should be explored. Finally, sexuality and intimacy concerns also merit special attention in supporting these patients.

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