

ONCOLOGY

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 survivors of rectal cancer (RC). Differences in health-related quality of life (HRQOL) can occur based on ostomy status (permanent ostomy vs anastomosis).

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

Methods: Survivors of RC 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 groups 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-Colorectal.

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

Conclusion: 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.

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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 with a permanent ostomy has been the standard of care.² Surgical techniques that aim to preserve anal sphincter function through low anterior resection are believed to be associated with a better health-related quality of life (HRQOL), because no permanent

pouch is needed. A recent Cochrane Review has challenged this view and concluded that no firm conclusions are apparent as to whether HRQOL is superior for most survivors without a permanent ostomy.²

One area in which differences in the two groups can 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 survivors of RC vary from 23% to 69% in men and from 19% to 62% in women.⁶ In a population-based study (N = 21,802), 25.1% of survivors of RC reported sexual dysfunction and 13.9% reported difficulties with appearance and body image.⁷ Survivors of RC with a permanent ostomy reported more difficulties with body image (20.9%) and sexual function (27.2%) compared with survivors with no stoma (6.6% and 10.8%, respectively).⁷ Our previous research suggested 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) survivors of RC by ostomy status (permanent ostomy vs anastomosis). Such information could assist clinicians and survivors of RC in shared decision making. Findings also could provide directions for counseling on sexual function for survivors of RC after treatment and through long-term survivorship.

METHODS

The methods of these studies have been published elsewhere.¹⁶ In brief, we surveyed survivors of RC from two Kaiser Permanente (KP) regions, Northern California and the Northwest. The study protocol and procedures were approved by the two KP regions and the University of Arizona (coordinating site). Using KP's computerized tumor registry, we identified potentially eligible survivors using the following criteria: (i) at least 5 years after diagnosis; (ii) tissue-verified RC diagnoses; (iii) underwent a major intra-abdominal surgery that resulted in an ostomy or anastomosis; and (iv) age at least 18 years. All identified survivors received through the mail a cover letter containing informed consent and a survey. Informed consent was implied by completing and returning the survey. Up to 10 reminders were attempted for all survivors who had not returned the survey 2 weeks after mailings. Survivors were given the option of completing the survey by 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. This tool assesses HRQOL in the physical, psychological, social, and spiritual well-being domains.¹⁹ Two items assessed self-reported depression after surgery (yes vs no) and at the time of the survey (0–10 ordinal scale, where 10 is least depressed). All scale items (11-point ordinal) and subscales

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?

(continuous) range from 0 to 10. Within the tool are 10 dichotomous or four-point items related to sexual activity, satisfaction, and sexual dysfunction symptoms (Table 1). Confirmation of construct validity has been reported, with reliability ranging from 0.77 to 0.90.^{16,19,20} The survey also included the Duke-UNC Functional Social Support Questionnaire²¹ and the Bowel Function Index.^{16,22} The Duke-UNC Functional Social Support Questionnaire 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") vs 1 ("almost as much as I would like"), indicating less support. The Bowel Function Index 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") vs 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 the ostomy and anastomosis groups with the Student t-test for continuous measurements and the χ^2 (or Fisher exact) test for categorical measurements. Adjusted and unadjusted odds ratios (ORs) with 95% CIs were produced with logistic regression using ostomy vs 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 who reported being sexually inactive at the time of the survey. Undressing in front of a partner was scored a problem if the subject responded "a little," "somewhat," or "very much." HRQOL items (0- to 10-point scale) were coded as low if the score was lower than 7.^{23,24} Before constructing adjusted models, we evaluated potential effect modification (interaction with ostomy status) by sex, married or partner status, and year of surgery (before or after January 1, 2000, the approximate median date of surgery). Covariates

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