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Ongoing Ostomy Self-Care Challenges of Long-Term Rectal Cancer Survivors

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Abstract

PURPOSE—Surgical treatment for rectal cancer (RC) can result in an intestinal ostomy that requires lifelong adaptation and investment of physical, cognitive, and financial resources. However, little is known about the extent of ongoing challenges related to ostomy self-care among long-term RC survivors. We analyzed the prevalence of self-reported ostomy self-care challenges and the physical and environmental factors that can support or undermine ostomy self-care.

METHODS—We mailed surveys to long-term (≥ 5 years post-diagnosis) RC survivors, including 177 adults with ostomies who were members of integrated health systems in northern California, Oregon, and Washington State. Potential participants were identified through tumor registries. Data were also extracted from electronic health records.

RESULTS—The response rate was 66%. The majority of respondents were male (67%) and the mean age was 75 years. Sixty-three percent of respondents reported at least one ostomy self-care

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COMPLIANCE WITH ETHICAL STANDARDS

Ethical Approval

All procedures performed in studies involving human participants were in accordance with the ethical standards of the institutional and/or national research committee and with the 1964 Helsinki declaration and its later amendments or comparable ethical standards. The Institutional Review Boards at the University of Arizona and in both Kaiser Permanente regions reviewed and approved the study protocol and survey instruments. The survey cover letter contained all elements of informed consent and the requirement for signed consent forms was waived by all the IRBs. This article does not contain any studies with animals performed by any of the authors.

Disclaimer

The contents of this work are solely the responsibility of the authors and do not necessarily represent the official views of the National Cancer Institute, the National Institutes of Health, or Kaiser Permanente.

Conflicts of Interest

We, and our immediate family members, including spouses or partners, have no financial relationships relevant to the content of this manuscript. The Corresponding Author has full control of the primary data and will allow the journal to review the deidentified data if requested.

challenge. The most common challenges were leakage or skin problems around the ostomy and needing to change the pouching system too frequently. Twenty-two percent reported difficulty caring for their ostomy. Younger age and higher BMI were consistently related to ostomy self-care challenges.

CONCLUSIONS—The majority of RC survivors reported ostomy-related self-care challenges and 31% experienced problems across multiple domains of ostomy self-care. In addition, most survivors reported significant physical challenges that could lead to ostomy-related disability. Although the participants surveyed had access to ostomy care nurses, the care gaps we found suggest additional work is needed to understand barriers to ostomy care, reduce unmet needs, and improve well-being among this group.

Keywords

rectal cancer; oncology; ostomy self-care; survivorship; QOL

BACKGROUND

Rectal cancer (RC) affects approximately 40,000 new patients in the United States annually, with 68% of patients surviving 5 years or longer [1]. Surgical treatment results in a permanent intestinal ostomy for approximately 30% of these patients [2]. An ostomy is created surgically to allow feces to be eliminated by bringing the opening of the intestine (large or small) to the abdomen. Most patients will utilize a bag that adheres to the body to capture fecal contents.

Having an intestinal ostomy results in a physical impairment that requires lifelong adaptation and management. However, impairment does not always result in disability, which the World Health Organization defines as restricted participation in meaningful activities. [3–5]. Physical, personal, and environmental factors, use of adaptive equipment (such as ostomy supplies), and, perhaps most importantly, self-care behaviors all play a role in determining whether having an ostomy leads to disability. When the ostomy and ostomy equipment are functioning well, many patients experience little disability as a result of their ostomies. However, when they are not functioning well, a host of interrelated and well-documented problems can occur, including: excessive time committed to ostomy care [6], fecal leakage with associated skin problems [7], clothing damage, stigma, and social embarrassment [8–12], and limited participation in inter-personal and social activities [13–20]. Challenges in self-care provide an important signal of high levels of physical impairment or low levels of adaptive resources which, in turn, can lead to disability and restriction of usual activities.

Physical, personal, and environmental factors influence ostomy self-care. Physical factors include the ostomy shape and location [21], having an ileostomy versus a colostomy, having additional abdominal surgeries, having a high BMI, or having had a major change in BMI since surgery [22]. Health conditions unrelated to the ostomy or body habitus, such as an individual's current physical health or comorbidity burden, may also impact ostomy self-care [23]. Personal and environmental factors that can influence ostomy self-care include financial resources, social support, and access to optimal ostomy services and equipment [6,

12, 24]. Having a spouse or partner who can help with ostomy care is also beneficial [7, 17]. Caregivers (most often spouses or partners) can also assist as “healthcare managers” who help to marshal environmental and health system resources to facilitate successful ostomy management. They are often involved in ordering supplies, coordinating medical care, and other similar tasks [12, 25].

The aim of this analysis is to describe the prevalence of long-term ostomy self-care challenges in a population-based sample of rectal cancer survivors. Drawing upon the World Health Organization’s framework for describing functioning and disability, we consider self-care problems as an indicator of impairment that can lead to disability, and we explore physical, personal, and environmental factors that could contribute to such impairment [3].

METHODS

This is a secondary analysis of a large cross-sectional study of the health-related quality of life of long-term survivors of rectal cancer (RC); a detailed description of the overall study methodology is presented elsewhere [26]. The study was conducted with Kaiser Permanente integrated health system members in the Northern California and Northwest (Oregon and southwest Washington State) regions. The University of Arizona Cancer Center coordinated the study. The Institutional Review Boards at the University of Arizona and in both Kaiser Permanente regions reviewed and approved the study protocol and survey instruments. The survey cover letter contained all elements of informed consent and the requirement for signed consent forms was waived by all the IRBs. Return of the survey with responses was the criterion for enrollment in the study.

Study Participants

In 2010-2011, we mailed questionnaires to 313 long-term (≥ 5 years post-diagnosis) RC survivors with ostomies. All eligible survivors (health plan members who were 18 years or older at the time of ostomy surgery) were identified through tumor registry and electronic health records (EHR) at each site.

Measures

Two survey instruments—the City of Hope Quality of Life Colorectal Cancer questionnaire (COH-QOL-CRC) [27], and the Short-Form Health Survey, version 2 (SF-12v2) [28]—were used to collect participant self-reports of ostomy self-care problems, and physical and functional health status. Additional clinical variables were abstracted from the EHR.

Ostomy self-care problems—Five ostomy self-care problem indicators were assessed. Participants reported the frequency with which they changed the pouching system as well as the amount of time they spent each day performing ostomy care on the COH-QOL-CRC. Ostomy self-care problems were defined as changing the pouching system more frequently than every third day and ostomy care that required ≥ 30 minutes per day.

Three questions from the physical domain subscale of the COH-QOL-CRC were also analyzed. Participants responded on an 11-point scale from “no problem” to “severe problem” about whether “leaking from pouch (or around appliance)” and “skin surrounding

the ostomy” was a current problem for them; and on an 11-point scale from “not at all” to “extremely difficult” to the question: “How difficult is it for you to care for your ostomy?” Each variable was recoded as a dichotomous variable; responses of 4 or above were considered to represent moderate to severe ostomy self-care problems as established by Given, et al [29].

We computed an overall ostomy self-care problems score by counting the number of problems reported by each person (0-5 possible).

Physical factors that can influence ostomy self-care—Several variables measuring physical factors were assessed. The type of ostomy (ileostomy or colostomy) was self-reported on the COH-QOL-CRC. Participants also reported their height, current weight, and their approximate weight at the time of surgery. From this information we calculated three BMI measures: BMI at time of survey (continuous), BMI increase from surgery to survey of 1.5 (yes / no), and BMI decrease from surgery to survey of 1.5 (yes / no) [22].

For a global measure of physical health, we calculated the normed physical component score (PCS) from the SF-12v2. The normed PCS for the general population is 49.63; however, for the age groups represented in this study, the normed score varied from 46.9 (participants aged 55-64) to 39.75 (participants over age 75) [30].

EHR diagnosis and treatment data were used to calculate the Charlson-Deyo Co-morbidity Index [31]. EHR data were also used to determine whether the participant had a hernia between the time of rectal cancer diagnosis and the survey. Hernias are a common long-term surgical complication of major abdominal surgery.

Personal and environmental factors that can influence ostomy self-care—The COH-QOL-CRC included questions about receiving help with ostomy care. Respondents who reported receiving help from any source, including spouse/partner, family member, friend, neighbor, or a paid caregiver were coded as receiving help. Marital/partner status and household income were self-reported elsewhere on the survey.

Demographic and clinical characteristics—Additional variables were extracted from the EHR, manual chart review, and the Tumor Registry files (gender, years since rectal cancer diagnosis, stage at diagnosis; tumor distance from the anal verge; receipt of chemotherapy; receipt of radiation therapy), and the survey (race/ethnicity).

Analysis Strategy

We calculated the frequency of each ostomy self-care problem and report the mean and standard deviation for continuous measures and the number and percent for categorical measures. We then tested for the relation between ostomy self-care problems and physical health and demographic factors. We used the two-sided χ^2 test for significance of differences in categorical measures and the two-sided Student t-test for significance of differences in continuous measures, both at $p < .05$. This analysis was exploratory, and we did not adjust the p-value to account for the multiple comparisons (13 predictors by 6 outcomes); we only report here on variables where a pattern of relations between predictors

and outcomes was found. All analyses were performed with SAS statistical package, version 9.4 (SAS Institute Inc., Cary, NC).

RESULTS

Of the 313 surveys mailed, 42 potential respondents were found to be ineligible (e.g., they were deceased, did not have rectal cancer, did not have intra-abdominal surgery), resulting in an eligible population of 271. Surveys were completed by 177 (65% response rate). Table 1 describes the demographic and clinical characteristics of the participants.

Most participants were male (67%), and non-Hispanic white (84%). The average age at survey was 75 years (SD=10.9) and respondents were an average of 15 years (SD=7.5) from RC diagnosis. Fewer than 1/3 of the participants had a college degree (27.7%). Almost all the participants (98.2%) were originally diagnosed with localized or regional stage tumors. Overall, most participants received chemotherapy (59%), and half received radiotherapy to treat their cancers. Thirteen percent of respondents reported that they irrigated their ostomy daily (instilling 500-1000 cc of warm water through the stoma into the bowel to stimulate emptying at a regular time).

Physical Factors

Physical factors that can impair ostomy self-care were common (Table 2). The average PCS was 42.5 (SD=10.39) and the average Charlson-Deyo comorbidity score was 1.1 (SD=1.52). Approximately 7 out of 10 respondents had a change in BMI of 1.5 kg/m^2 since their surgery, and the average BMI at survey was in the obese range, at 26.9 (SD=5.66). More than a quarter of respondents (27%) had a hernia at some point after their surgery. As would be expected in a rectal cancer population, only 7% of participants had an ileostomy.

Personal and Environmental Factors

Personal and environmental factors that could impact optimal ostomy self-care were also relatively common. An annual income of less than \$30,000 was reported by more than one-third of respondents. One-third (33%) of respondents were not married or partnered at the time of the survey, and only 15.9% of respondents reported receiving help with any aspect of ostomy care.

Ostomy Self-care Problems

Ostomy self-care problems were common (Mean: 1.08, SD=1.16). Respondents reported having problems with leakage from the ostomy (28%), skin problems around the ostomy site (26%), and difficulty with ostomy care (22%). More than a quarter reported needing to change their pouching system frequently (26%), while 14% needed more than 30 minutes for ostomy care each day (Table 3). Sixty-three percent of participants reported having at least one ostomy self-care problem while 31% experienced two or more problems.

We then examined the relation between ostomy management problems and physical functioning (PCS, Charlson-Deyo, Hernia, BMI at survey, BMI increase from surgery to

survey, BMI decrease from surgery to survey, and ostomy type) and demographic factors (age, gender, education, income, race/ethnicity, partnered status).

Age was related to skin problems, leakage, and the number of ostomy self-care problems reported. Participants reporting skin problems were approximately 4-5 years younger ($M=71.8$ years, $SD=10.6$) than those without skin problems ($M=76.1$ years, $SD=10.9$; $p=.021$) as were participants reporting leakage ($M=71.2$ years, $SD=11.4$; compared to those without leakage problems $M=76.4$, $SD=10.5$; $p=.0041$). Respondents reporting 2 or more ostomy self-care problems were also younger ($M=72.5$, $SD=10.3$) than respondents with 0 or 1 ostomy self-care problem ($M=76.1$, $SD=11.1$, $p=.045$).

BMI at survey was related to skin problems, leakage, self-reported difficulty with ostomy care, and the number of ostomy function problems. Participants reporting skin problems had a significantly higher BMI ($M=29.6$, $SD=6.6$) than those without skin problems ($M=26.0$, $SD=5.1$, $p=.0002$); as did respondents reporting problems with leakage (BMI $M=29.2$, $SD=7.8$; compared to $M=26.0$, $SD=4.5$ for those without leakage problems, $p=.0006$). Participants who reported that ostomy care was difficult had a higher BMI at survey ($M=29.1$, $SD=6.7$) compared to participants without ostomy care difficulties ($M=26.3$, $SD=5.2$; $p=.0054$) as did those reporting two or more ostomy function problems (BMI $M=29.8$, $SD=6.9$) compared to respondents with zero or one ostomy function problem (BMI $M=25.7$, $SD=4.5$, $p<.0001$).

Leakage was also related to BMI increase and BMI decrease from surgery to survey. Survivors with an increase in BMI ≥ 1.5 were more likely to report leakage problems (36.9%) compared to those whose BMI did not increase (21.0%; $p=.025$). Survivors with a decrease in BMI of >1.5 were less likely to report leakage problems (14.3%) compared to those without a BMI decrease (32.8%; $p=.015$).

No statistically significant relations were found between any of the ostomy self-care problems and gender, income, race/ethnicity, being married/partnered, ostomy type, hernia, or the Charlson-Deyo comorbidity score.

DISCUSSION

Ostomy self-care problems were common in this population of long-term rectal cancer survivors with ostomies. The majority of survivors reported having at least one problem and almost a third experienced multiple problems. In one previous population-based survey of colorectal cancer survivors, Burg, et al. [32] found that 35% reported unmet physical needs. An earlier systematic review of unmet needs in cancer patients found that unmet physical needs ranged in prevalence from 26–52% during the post treatment, follow-up and survivorship phase, however it did not report the rate specific to colorectal or rectal cancer or to the survivorship period only [33]. Ostomy self-care problems are a portion of physical problems that colon and rectal cancer patients can experience, but the higher prevalence of such problems in our survey, 63%, suggests that rectal cancer survivors with ostomies may carry a higher burden of physical challenges than the general colorectal cancer survivor population [34].

The most common problems, reported by approximately one out of four people, were leakage and skin problems around the ostomy and the need to change the pouching system frequently. These ostomy self-care problems have been identified in previous research and are known by ostomy and wound care specialists [6, 17, 21]. As members of an integrated health care system, the RC survivors in this study had access to Wound and Ostomy Care Nurses (WOCNs) who could help with ostomy management. Even so, survivors reported that ostomy management problems were common. This discrepancy reveals unmet needs of ostomy patients and a care gap that merits further research. Areas of research should include institutional and patient barriers to accessing WOCN resources on an outpatient basis, patient expectations regarding ostomy function, and reasons that patients do or do not reach out to medical providers [35].

In addition, the majority of survivors reported significant physical challenges that could lead to ostomy-related disability, both in terms of overall measures of physical health and specific measures such as BMI. Survivors with skin problems, leakage problems, and those who reported more difficulty with ostomy care had higher BMI than survivors without these ostomy self-care problems. Those with higher BMI also had a larger number of problems. Having higher BMI can make it harder to reach or see the ostomy, and additional skin folds may make it more difficult to get the pouch adhesive to adhere well. Leakage was more commonly reported by survivors with an increase in BMI from surgery to survey, while survivors who lost weight in the years after their surgery were less likely to report leakage problems. Continuing efforts to support patients with ostomies to maintain their BMI in the normal range is important. In addition, research is needed to identify improved methods of managing ostomies for higher BMI patients; along with ostomy product development aimed at these patients [36].

Survivors who reported leakage and skin problems were younger than those who did not report these problems. One potential explanation for this finding is that younger survivors are more likely to be working and involved in activities outside the home. These settings provide survivors less control over their day which can result in more problems with ostomy self-care [37]. While younger cancer survivors may have fewer comorbidities than older survivors, the impact of having cancer at a younger age may be greater than for having cancer at an older age. Much larger sample sizes are required to enable rigorous comparisons of HRQOL among younger versus older CRC survivors.

An important strength of our study is that we identified subjects through a tumor registry and did not depend on health care use, such as a list of current patients receiving WOCN services. Our study population may more accurately reflect the prevalence of challenges among long-term RC survivors with ostomy than a population recruited through ostomy nurses or utilization records.

In many settings, systems for ongoing outpatient ostomy checkups are absent or inadequate, and patients have limited access to WOCNs [38–40]. Comments by ostomy patients show that even in integrated health systems such as Kaiser Permanente, where patients have access to specialized ostomy nurses, survivors may have difficulty securing adequate support [17, 41]. The level of support should be adjusted to each patient's needs and required time to

become comfortable with ostomy self-care. The optimal timing, dosing, and duration of ostomy care supportive interventions requires further research.

Future Directions

Our findings point to the need for research designed explicitly to understand prevalence and factors influencing disability associated with having an ostomy. Innovative interventions and intervention studies are needed to identify effective methods to reduce unmet needs and improve well-being for RC survivors with ostomies [42]. In addition, more research on service utilization in patients identified as having unmet ostomy care needs is key to improving the supportive care system that works with and for the patients who need it most [35].

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Table 1

Demographic and Clinical Characteristics of Study Participants

Characteristic	Participants (N=177)
Demographics	
Age at survey (years), M (SD)	75.0 (10.9)
Male (yes)	118 (66.7%)
Race (N = 176)	
White or Caucasian	155 (88.1%)
Asian	12 (6.8%)
Other or more than one race	9 (5.1%)
Hispanic (yes)	16 (9%)
Education (N=170)	
High school graduate or less education	63 (37.0%)
Vocational degree and/or some college	60 (35.3%)
College graduate or more education	47 (27.7%)
Income (N=165)	
<\$30K/year	59 (35.8%)
\$30K – \$75K /year	67 (40.6%)
> \$75K/year	39 (23.6%)
Married/partnered (yes) (N=175)	116 (66.3%)
Clinical	
Years since diagnosis, mean (SD) (N=175)	14.9 (7.4)
Stage at diagnosis (N=168)	
Localized	81 (48.2%)
Regional	84 (50.0%)
Distant	3 (1.8%)
Tumor distance from anal verge > 6 cm (N=160)	51 (31.9%)
Received chemotherapy (%)	105 (59.3%)
Received radiation treatment (%)	89 (50.3%)
Reported irrigating daily	23 (13.0%)

Table 2

Physical Factors that Can Impact Ostomy Self-care

	M	SD
Physical Component Score (N=176)	42.48	10.39
Charlson-Deyo comorbidity score	1.10	1.52
BMI at survey (N=176)	26.91	5.66
	N	%
BMI increase of 1.5 from surgery to survey (N=167)	66	39.5%
BMI decrease of 1.5 from surgery to survey (N=167)	50	29.9%
Hernia (yes)	48	27.1%
Ileostomy (vs. Colostomy) (N=167)	12	7.2%

Table 3

Percentage of Participants Reporting Ostomy Self-care Problems

	N	%
Leakage from the ostomy (N=175)	49	28.0%
Frequent pouching system change (N=164)	43	26.2%
Skin problems around the ostomy site (N=176)	45	25.6%
Difficulty with ostomy care (N=176)	39	22.2%
30 minutes needed for ostomy care each day (N=174)	24	13.8%
Number of ostomy self-care problems		
None	65	36.7%
One	58	32.8%
2-5	54	30.5%