

Rectal Cancer Survivors' Participation in Productive Activities

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ABSTRACT

Context: Rectal cancer and its treatment impair survivors' productivity.

Objective: To assess determinants of market and nonmarket employment, job search, volunteering, and homemaking among survivors five years or longer after diagnosis.

Design: We mailed questionnaires to 1063 survivors who were members of Kaiser Permanente (Northern California, Northwest) during 2010 and 2011.

Main Outcome Measures: Productive activities, functional health status, and bowel management at the time of the survey.

Results: Response rate was 60.5% (577/953). Higher comorbidity burdens were associated with lower productivity for men and women rectal cancer survivors. Productive survivors were younger and had lower disease stage and age at diagnosis, higher household income and educational attainment, and fewer comorbidity burdens and workplace adjustments than did nonproductive survivors ($p < 0.05$ each; 2-sided). Productive rectal cancer survivors were evenly split by sex.

Conclusion: Staying productive is associated with better mental health for rectal cancer survivors. Rectal cancer survivors with multiple chronic conditions, higher disease stage, lower productive activities, and older age need better access to medical care and closer monitoring of the quality of their care, including self-care. To capture the full extent of the involvement of survivors in all types of productive activities, research should routinely include measures of employment, searching for employment, homemaking, and volunteering. Counting market and nonmarket productive activities is innovative and recognizes the continuum of contributions survivors make to families and society. Health care systems should routinely monitor rectal cancer survivors' medical care access, comorbidities, health-related quality of life, and productive activities.

INTRODUCTION

Cancer imposes substantial productivity losses caused by morbidity and the intangible burden of illness, even among those who have survived well beyond 5 years after diagnosis.¹ Survivors of cancer have an elevated disability rate compared with cancer-free patients after adjustment for age, sex, and other factors.² In addition, cancer significantly reduces labor force participation by female survivors compared with women without cancer,³ and both male and female survivors have lower employment rates and work fewer hours

than similarly aged adults do.^{4,5} For male survivors, annual labor-market earnings drop by almost 40% within 2 years after diagnosis and remain low; total family income declines by 20%, although it recovers within 4 years after the diagnosis.⁶

The per capita mean annual incremental lost productivity from all patients with cancer (compared with cancer-free patients of similar age and sex) in the US was recently estimated at \$1459 in 2011 dollars.⁷ The sources of loss were employment disability, missed workdays among employed persons, and lost household

productivity. In a meta-analysis of 26 articles, cancer survivors—particularly gastrointestinal cancer survivors—were more likely to be unemployed than healthy control participants were.⁸

More specifically, compared with an age- and sex-matched cancer-free population, colorectal cancer survivors experience significantly more fatigue and report more problems with thinking clearly, even up to 10 years after diagnosis.⁹ Survivors with ostomies face prominent physical and psychosocial concerns regarding daily activities, work ability, and employment that are also distressing, although less well understood.¹⁰⁻¹² They report persistent deficits in health-related quality of life (HRQOL), including pain, insomnia, and psychological distress.¹³⁻³⁹ The ability of patients and survivors with rectal cancer to resume paid and unpaid labor is in the interest of both the individual and society. A study published in 2005 of rectal cancer survivorship found adverse effects on paid and unpaid labor continuing through 2 years of follow-up.⁴⁰ To update and extend the findings from that study, we examined the composition and correlates of productive status—employment (paid work), volunteering (unpaid work), and homemaking (household production)—among patients with rectal cancer who had survived for 5 or more years after their diagnosis.

METHODS

Participants

Long-term rectal cancer survivors (≥ 5 years after diagnosis) who were members of the Kaiser Permanente Northern

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California (KPNC) and Kaiser Permanente Northwest (KPNW) Regions with permanent ostomy (N = 183) or sphincter-sparing (anastomosis) surgery (N = 394) completed the survey during 2010 and 2011 (60.5% response rate). The study was coordinated at the University of Arizona Cancer Center, Tucson, AZ, and was approved by the institutional review boards at all sites. Details of the study design are available from a methods article by Wendel and colleagues.⁴¹

Surveys

Mailed surveys included the City of Hope Quality of Life Colorectal Cancer tool, which assesses HRQOL in the physical, psychological, social, and spiritual domains.⁴²⁻⁴⁵ The tool consists of 47 forced-choices and open-ended items as well as 43 HRQOL items evaluated using 11-point scales and multiple items related to physical and behavioral adjustments. Validity analysis was conducted using content, construct, discriminant, and criterion-related approaches.⁴²

Our survey also applied the Memorial Sloan Kettering Cancer Center Bowel Function Index⁴³ to assess the bowel function of patients with rectal cancer undergoing surgery. The 18-item questionnaire contains 3 subscales (frequency, dietary, and soilage) with published test-retest reliability of 0.74, 0.62, and 0.87, respectively, and 0.84 for the overall instrument.⁴³ The Bowel Function Index demonstrated discriminant validity among survivors with preoperative radiation therapy, postoperative radiation therapy, or no radiation therapy; among local excision, low anterior resection, and coloanal anastomosis; and between hand-sewn and stapled anastomosis. It further demonstrated consistency with all 4 of the Fecal Incontinence Quality of Life subscales and 9 of the 17 European Organization for Research and Treatment of Cancer (EORTC) subscales.⁴³ The Bowel Function Index had previously been adapted and validated by our team for use by patients with rectal cancer and intestinal ostomies.⁴¹

Our survey instruments contained three employment-related items from the American Cancer Society Studies of Cancer Survivors⁴⁴: 1) "What do you

consider your current employment?" (possible responses were full time, part time, retired and not working another job, homemaker, temporarily laid off, unemployed and looking for work, unemployed and not looking for work, on disability, or other); 2) "Do you volunteer on a regular basis?"; and if the answer was "yes," 3) "About how many hours per week did you spend on volunteer activities in the past four weeks?"^{44,45}

We mailed questionnaires to 1063 rectal cancer survivors (≥ 5 years after diagnosis). Eligible patients were identified in tumor registries in September 2009. Study enrollment dates ranged from January 2010 to December 2011. The CONSORT (Consolidated Standards of Reporting Trials) diagram of our recruitment is available in a previous publication.⁴¹ Survey packets included scannable forms programmed with TeleForms 10.3 (Digital Vision, Highland Park, IL) and developed at the University of Arizona Cancer Center, which were sent to potential participants by their respective Kaiser Permanente sites (KPNC, KPNW). Two weeks after a survey packet was mailed, a potential subject who had not yet returned the study questionnaire was contacted by phone (up to 10 attempts). Individuals interested in participating were asked to complete the questionnaire and return it in the postage-paid envelope, or they could answer the questionnaire items by phone.

Patients refusing participation were no longer contacted.

Comprehensive information on demographic characteristics and medical history were obtained via the patient survey and the extraction of electronic medical record data. Both KPNC and KPNW maintain a decentralized, standardized virtual data warehouse for research uses.⁴⁶ A variety of definitions have been developed for a wide range of variables from major health plan informatics systems, such as electronic medical record data, enrollment data, hospital discharge abstract systems, medication dispensing systems, outside claims, and referral systems. The Virtual Data Warehouse enabled us to concatenate data from the 2 participating health systems. Multiple demographic parameters were collected: Age, sex, race, Hispanic ethnicity, number of survival years, household income, educational attainment, marital status, and smoking status. Medical history items included weight, height, type of cancer surgery, length of time since cancer surgery; Surveillance, Epidemiology, and End Results general summary stage; and comorbidities, including the Charlson-Deyo comorbidity index for the 12 months before the survivor survey.⁴⁷

Our primary dichotomous outcome measure was whether rectal cancer survivors were engaged in productive activities at the time of the survey.

Table 1. Productivity status of study participants, by sex

Productivity status	Men, no. (%) (n = 330) ^a	Women, no. (%) (n = 233) ^a	Total, no. (%) (N = 563)
Productive			
Total employed: full time + part time + unemployed and looking for work + homemaker	94 (48.7)	99 (51.3)	193 (34.3)
Volunteer, but not employed or homemaker	39 (52.0)	36 (48.0)	75 (13.3)
Total productive: employed and/or homemaker and/or volunteer	133 (49.6)	135 (50.4)	268 (47.6)
Nonproductive			
Retired + not employed + not looking for work + not volunteering + not homemaking	174 (67.7)	83 (32.3)	257 (45.7)
On disability + not employed + not volunteering + not homemaking	7 (63.6)	4 (36.4)	11 (2.0)
Unemployed and not looking for work	2 (40.0)	3 (60.0)	5 (0.9)
Other nonproductive	14 (63.6)	8 (36.4)	22 (3.9)
Total nonproductive	197 (66.8)	98 (33.2)	295 (52.4)

^a Percentages for Men and Women columns are by row. Percentages may not total to 100 because of rounding.

Statistical Analysis

From our previous research, we learned that male and female survivors report different profiles of challenges because of rectal cancer.²³ Therefore, in the current study we analyzed HRQOL outcomes and productive activity patterns for men and women separately. We compared demographic and clinical characteristics between male and female productive and nonproductive rectal cancer survivors by using the 2-sided

Student *t*-test for statistically significant differences in continuous measures and the 2-sided χ^2 test for significance of differences in categorical measures at $p < 0.05$. We analyzed engagement in productive activities (yes/no) using multiple logistic regression models. Statistical significance of regression coefficients was set at $p < 0.05$. All analyses were performed with the SAS statistical package Version 9.4 (SAS Institute Inc, Cary, NC).

RESULTS

Productive Status of Respondents

Our sample contained more male survivors (59%). About 50% of both male and female rectal cancer survivors were engaged in productive activities (Table 1). Approximately two-thirds of nonproductive respondents were men. Of the *nonproductive* respondents, 88% of men and 85% of women were fully retired (ie, not employed, not looking for work, not volunteering, not homemaking, and not

Table 2. Characteristics of study participants, by sex and productivity^a

Characteristics	Men (n = 330)			Women (n = 233)		
	Productive (n = 133)	Nonproductive (n = 197)	p value	Productive (n = 135)	Nonproductive (n = 98)	p value
Demographic characteristics						
Age (y), mean	68.20	76.07	< 0.05	68.67	77.57	< 0.05
Number of survival y, mean	11.78	13.58	< 0.05	12.42	13.03	0.49
Married or partnered, %	81.15	78.79	0.76	45.93	37.89	0.23
Hispanic ethnicity, %	3.79	9.60	< 0.05	5.88	6.19	0.92
Nonwhite race, %	15.27	12.69	0.51	15.44	18.75	0.51
Household income \geq \$30,000, %	61.42	40.98	< 0.05	44.35	22.09	< 0.05
Some college education or higher, %	76.67	66.67	0.06	77.34	56.32	< 0.05
Rectal cancer treatments, %						
Surgery: anastomosis	59.09	46.46	< 0.05	66.18	55.67	0.10
Surgery: temporary ostomy	12.88	12.12	0.84	8.82	13.40	0.27
Surgery: permanent ostomy	25.00	38.38	< 0.05	22.79	27.84	0.38
Radiotherapy for rectal cancer	49.24	43.43	0.30	33.82	25.77	0.19
Chemotherapy for rectal cancer	57.58	51.01	0.24	50.00	43.30	0.31
Health status at time of survey						
Overweight/obese (body mass index \geq 25 kg/m ²), mean	23.85	21.43	0.61	31.34	29.47	0.76
Charlson-Deyo comorbidity score, mean	0.59	1.04	< 0.05	0.45	1.20	< 0.05
Any other pelvic cancer, %	12.88	17.17	0.29	9.56	6.19	0.35
COH physical well-being (0 = low; 10 = high), mean	7.77	7.42	0.10	7.44	7.16	0.28
COH social well-being (0 = low; 10 = high), mean	7.45	7.19	0.31	7.98	7.72	0.36
COH psychological well-being (0 = low; 10 = high), mean	7.95	7.50	< 0.05	7.76	7.28	< 0.05
COH spiritual well-being (0 = low; 10 = high), mean	7.37	7.09	0.22	7.43	7.27	0.55
Is support from family and friends sufficient to meet your needs? (0 = not at all; 10 = extremely), mean	8.74	8.07	< 0.05	8.53	7.59	< 0.05
Current smoker, %	40.00	27.69	< 0.05	58.21	52.63	0.40
Bowel function at time of survey						
How often had soilage in undergarments during the day in past 4 wk (1 = never, 5 = always), mean	2.13	2.21	0.52	1.95	2.03	0.56
How often had loose stool in past 4 wk (1 = never, 5 = always), mean	2.65	2.84	0.11	2.58	2.47	0.45
How often altered activities because of bowel function in past 4 wk (1 = never, 5 = always), mean	2.08	2.19	0.35	2.04	2.03	0.98
Highest number of bowel movements or bag emptying per d in past 4 wk, mean	5.79	6.39	0.45	6.37	4.55	< 0.05
Lowest number of bowel movements or bag emptying per d in last 4 wk, mean	1.58	2.09	0.19	1.80	1.28	\leq 0.05

^a Productive = employed (full time, part time, unemployed and looking for work), and/or volunteer, and/or homemaker. COH = City of Hope.

disabled). Fourteen respondents did not provide answers to the productive activities questions.

Descriptive Statistics for Rectal Cancer Respondents

Demographic Characteristics

Average age of the rectal cancer survivor cohort was 73.1 years, and 63% were married or partnered at the time of survey. Sex composition was 59.1% men and 40.9% women. More male than female rectal cancer respondents were likely to be married or partnered (80% vs 42%, $p < 0.05$) or to have an annual household income of \$30,000 or more (50% vs 35%, $p < 0.05$).

Rectal Cancer Treatment

Compared with male rectal cancer survivors, female survivors were more likely to have had anastomoses as surgical treatment (61% vs 52.5%, $p < 0.05$) and less likely to have received radiotherapy (30.6% vs 45.5%, $p < 0.05$).

Health Status at Time of Survey

More female than male rectal cancer survivors were overweight or obese (30% vs 23%, $p < 0.05$), were smokers (55% vs 33%, $p < 0.05$), and had higher social well-being scores (7.9 vs 7.3, $p < 0.05$). Male rectal cancer survivors were nearly twice as likely as female rectal cancer survivors to have experienced another pelvic cancer (primarily prostate cancer among men; 15% vs 8%, $p < 0.05$).

Bowel Function at Time of Survey

For the 4 weeks before completing the survey, male rectal cancer survivors reported substantially higher frequency of soilage in undergarments ($p < 0.05$) and loose stools ($p < 0.05$) than female rectal cancer survivors did.

Characteristics of Productive and Nonproductive Rectal Cancer Survivors, by Sex

Demographic Characteristics of Productive and Nonproductive Rectal Cancer Survivors

For both men and women, productive rectal cancer survivors were significantly younger than nonproductive rectal cancer survivors (men: 8 years, $p < 0.05$; women: 9 years, $p < 0.05$), and were more likely to have an annual household income of \$30,000 or greater (men: 61% vs 41%, $p < 0.05$; women: 44% vs 22%, $p < 0.05$; Table 2). Productive female rectal cancer

survivors had higher educational attainment than nonproductive female survivors (77% vs 56%, $p < 0.05$). Nonproductive male rectal cancer survivors had significantly longer survivorship periods than their male productive counterparts did (by 1.8 years, $p < 0.05$). Productive male rectal cancer survivors were less likely to be Hispanic compared with nonproductive male survivors (3.79% vs 9.60%, $p < 0.05$).

Rectal Cancer Treatments

Among productive male rectal cancer survivors, surgical treatment with an anastomosis was more prevalent compared with nonproductive male survivors (59% vs 46%, $p < 0.05$), and, conversely, treatment with a permanent ostomy was less prevalent (24% vs 38%, $p < 0.05$; Table 2). Types of rectal cancer treatments were not significantly related to productivity status for female survivors. Rates of receipt of radiotherapy and chemotherapy between productive and nonproductive rectal cancer survivors were not significantly different for both men and women survivors.

Health Status at Time of Survey

Both male and female nonproductive rectal cancer survivors had higher comorbidity scores than productive rectal cancer survivors did ($p < 0.05$ for men and women), whereas both productive male and female rectal cancer survivors had higher psychological well-being scores than nonproductive survivors did ($p < 0.05$ for both men and women; Table 2). Both productive male and female survivors reported receiving higher levels of support from family and friends than nonproductive survivors (men: 8.74 vs 8.07, $p < 0.05$; women: 8.53 vs 7.59, $p < 0.05$). Among male rectal cancer survivors, productive men were more likely to smoke than nonproductive men (40% vs 28%, $p < 0.05$).

Bowel Function at Time of Survey

Productive female rectal cancer survivors had a higher average number of bowel movements or colostomy bag emptyings per day than did nonproductive female survivors for both the highest (6.4 vs 4.6 movements or bag emptyings per day, $p < 0.05$) and lowest (1.8 vs 1.3, $p < 0.05$) frequency days (Table 2). No statistically significant differences in bowel function

between productive and nonproductive male rectal cancer survivors were found.

Multiple Logistic Regression

Women

Altogether, the independent variables included in the logistic regression for female rectal cancer survivors explained a statistically significant portion of the variance in the odds of being productive ($p < 0.05$). However, the only individual variable to reach statistical significance was the Charlson-Deyo comorbidity index for the 12 months before the survey; the higher the comorbidity burden, the lower the odds of female rectal cancer survivors participating in productive activities ($p < 0.05$; Table 3).

Men

All the independent variables included in the logistic regression for male rectal cancer survivors explained a statistically significant portion of the variance in the odds of being productive ($p < 0.05$; Table 3). Eight variables predicting participation in productive activities by male rectal cancer survivors were statistically significant. Those male survivors whose rectal cancer was diagnosed at regional or distant stages or had a higher Charlson-Deyo comorbidity index score in the year before the survey had lower odds of participating in productive activities at the time of the survey ($p < 0.05$ for both). Longer rectal cancer survival periods, receipt of chemotherapy, higher current body mass index, current smoker, annual household incomes of \$30,000 or greater, and receipt of positive on-the-job feedback and flexible working conditions after rectal cancer diagnosis or surgery were associated with significantly higher odds of being productive ($p < 0.05$ for each).

DISCUSSION

We sought to understand the determinants of being engaged in productive activities—employment, volunteering, and homemaking—among long-term rectal cancer survivors. Compared with their nonproductive counterparts, productive male and female rectal cancer survivors were on average eight to nine years younger, and had higher educational attainment and incomes. In addition, survivors with anastomoses were

more likely to be productive than those with permanent ostomies. In the logistic regressions, higher comorbidity burden was associated with lower levels of productive activities among *both* men and women. These results reinforce findings from our previous research in veterans with ostomies⁴⁸ as well as other research on the general population of rectal cancer survivors⁴⁹ that high comorbidity burden is significantly associated with lower HRQOL and affects more domains than having an ostomy. Survivors with above-average and/or increasing comorbidity burdens should be regularly evaluated for medical care, care management, and support service needs. Survivorship care plans for patients with rectal cancer should include routine monitoring and evaluation for decreasing engagement in nonmarket productive activities—volunteering and homemaking. Productive rectal cancer survivors should be monitored for increasing difficulties in sustaining

their productive roles and activities; those identified should receive help to resolve barriers to remaining productive at the same level, adjusting productive activities in the workplace and home to transition to fewer and/or easier productive activities. The goal is for these transitions to be perceived as planned, not unexpected. Integrated health care systems with a single electronic medical record system have a structural advantage in implementing coordinated management of multiple comorbidities.

With the total number of cancer survivors increasing and living longer after diagnosis,⁵⁰ understanding the long-term effects of cancer and cancer treatments on patients and their families is imperative for formulating health care delivery reforms and policy initiatives.⁵¹ Previous research has demonstrated that the consequences of anastomosis or colostomy for rectal cancer can manifest for many years, and include psychological problems^{14,52-56}

and interference with work.⁵⁷⁻⁶⁰ Cancer-related fatigue can affect up to one-third of survivors and is associated with much higher levels of disability compared with persons without cancer.³⁶ Having a permanent ostomy appears to inhibit rectal cancer survivors, especially women, from seeking and holding jobs.⁵⁸⁻⁶⁰ Many ostomates report feeling stigmatized by their appliance and being more likely to avoid situations where they must interact with others and use bathrooms in their workplaces and other locations outside their homes.^{19,51} Ostomies are also associated with multiple HRQOL difficulties, including those related to travel, social situations, and appearance.^{14,52,53,61-65} Rectal cancer survivors experiencing challenges could benefit from coordinated support of health and vocational professionals regarding remaining productive, coping, managing self-care, and maintaining social networks and personal relationships.⁵²⁻⁵⁵ Unmet information needs are

Table 3. Multiple logistic regression results: Participation in work and/or volunteer and/or homemaking activities of men and women rectal cancer survivors

Parameter	Men				Women			
	Estimate	Standard error	Wald χ^2	p value	Estimate	Standard error	Wald χ^2	p value
Intercept	-122.60	53.29	4.46	< 0.05	-39.38	67.20	0.34	0.56
Ileostomy for rectal cancer	-0.33	0.82	0.16	0.68	13.35	1262.0	0.0001	0.99
Permanent ostomy for rectal cancer	-0.43	0.35	1.54	0.21	0.45	0.45	1.03	0.31
Rectal cancer regional stage or higher	-0.93	0.38	6.12	< 0.05	-0.05	0.44	0.01	0.91
Years since rectal cancer surgery	0.05	0.03	4.13	< 0.05	0.02	0.03	0.31	0.58
Receipt of radiotherapy for rectal cancer	0.12	0.40	0.09	0.77	0.63	0.49	1.63	0.20
Receipt of chemotherapy for rectal cancer	0.87	0.45	3.69	< 0.05	-0.80	0.54	2.21	0.14
Any other pelvic cancer	0.07	0.40	0.03	0.85	0.59	0.74	0.63	0.43
Prior year Charlson-Deyo comorbidity index	-0.39	0.14	7.76	< 0.05	-0.59	0.19	10.03	< 0.05
Current body mass index (kg/m ²)	0.06	0.03	4.10	< 0.05	0.03	0.03	1.22	0.27
Current smoker	0.87	0.32	7.44	< 0.05	0.25	0.37	0.47	0.49
Physical well-being	0.18	0.11	2.58	0.11	0.07	0.12	0.33	0.56
Social well-being	-0.11	0.10	1.21	0.27	-0.07	0.13	0.26	0.61
Psychological well-being	0.21	0.16	1.66	0.20	0.28	0.21	1.65	0.20
Spiritual well-being	0.00	0.09	0.00	0.98	-0.15	0.13	1.43	0.23
Married or partnered	-0.16	0.38	0.18	0.67	-0.06	0.38	0.03	0.87
Hispanic ethnicity	-1.24	0.67	3.42	0.06	0.75	0.84	0.80	0.37
Nonwhite race	-0.45	0.45	1.01	0.32	0.13	0.53	0.06	0.81
Some college education or higher	0.18	0.34	0.29	0.59	0.60	0.41	2.16	0.14
Household income \geq \$30,000	0.73	0.32	5.27	< 0.05	0.55	0.43	1.65	0.20
Receipt of positive job action because of cancer	1.20	0.39	9.69	< 0.05	0.12	0.55	0.05	0.82
Receipt of negative job action because of cancer	-0.08	0.45	0.03	0.86	-0.12	0.68	0.03	0.86
Model χ^2 (df = 21)			63.84	< 0.05			35.21	< 0.05

prevalent in 36% to 48% of cancer survivors; furthermore, patients who were less satisfied with information received and had more unmet information needs reported more anxiety, more depression, and lower quality of life.⁵⁶

We considered homemaking as a productive activity—unpaid nonmarket production of household services, which, if not performed by a household member, would have to be purchased on the market. We found that female rectal cancer survivors were engaged in all types of productive activities at a higher rate than male survivors were (59% vs 42%). Overall, women were more likely to be employed, volunteering, and/or homemaking; men were more likely to report being retired. One consideration is that male survivors may underreport their homemaking activities. Some husbands may have gradually taken on more homemaking activities but did not perceive or report themselves as homemakers, especially if their spouses were also performing homemaking tasks. Also, female spouses or partners tend to take on caregiving responsibilities for their partners (60% of caregivers who care for someone aged 50 years or older are female, and most provide care for a relative).⁵²

Compared with nonproductive female rectal cancer survivors, productive female rectal cancer survivors had significantly more daily bowel movements per day than did nonproductive women. We do not interpret this association to mean that more bowel movements generate more productivity; rather, women survivors who face the demands of balancing employment, volunteering, and/or housekeeping may be more focused on their bowel function. Working female rectal cancer survivors often find their employment situations demotivating and emotionally stressful.^{58-60,64,65} Survivors who continue to expose themselves to productive activities and the associated physical and social environments (employment and volunteering can reduce access to bathrooms and greater involvement in social groups) may find that any amount of bowel dysfunction is disruptive and socially embarrassing. This may reduce their tolerance of bowel problems and increase their propensity to report

bowel problems. Moreover, survivors who need the income from employment to meet their daily needs may be more likely to continue working despite poor bowel function.

The major strengths of our study are as follows: 1) having the data to treat volunteering and homemaking as productive activities equivalent to employment, 2) combining social survey and electronic medical record data, and 3) having a defined Health Plan population with continuing enrollment patterns. We were able to define and identify our study population before we administered our survey. By using a target population of cancer survivors enrolled in an integrated managed care system with sophisticated informatics resources, we captured nearly all medical care use of our survey respondents during their cancer treatment and survivorship. We also measured comorbidity burden, health insurance coverage, and cancer status and achieved a good response rate to our lengthy mailed survey, in part because of our considerable experience of more than 50 years in conducting research in our managed care system. However, except for use of medical care, our cross-sectional design was restricted to participant recall for historical self-reported data, which are subject to reinterpretation in light of subsequent events.

CONCLUSION

Counting both *market and nonmarket* activities as productive is innovative and recognizes the continuum of contributions survivors make to their families and communities. We have confirmed our previous finding that comorbidity burden reduces the ability of male rectal cancer survivors to sustain productive activities, and we now know that it similarly affects female rectal cancer survivors.⁴⁸ Our findings also suggest that physicians caring for rectal cancer survivors should be monitoring for manifestations of multiple interacting diseases, including the physical, social, emotional, and cognitive components of HRQOL. Rectal cancer survivors with multiple chronic conditions may benefit from periodic social surveys of HRQOL to identify self-reported functional impairments that

may not be visible during routine office visits. Time plots of HRQOL scores could reveal erosion of functional status as comorbidities progress and additional diseases emerge.

Cancer reduces the economic well-being of affected adults and their families. Male rectal cancer survivors with advanced disease are more likely to be restricted from participating in both market and nonmarket productive activities during their survivorship periods than those with less advanced disease. Future research should examine whether this subgroup of survivors could benefit from additional health coaching and environmental support to cope with their changes in bowel function and external appearance, thereby facilitating their productive activities.

Finally, we found evidence that supportive work environments can sustain productive activities among male rectal cancer survivors in particular. This assistance could include emotional support from supervisors, co-workers, and family members. It could also include environmental modifications, such as reducing business travel and modifying workplace bathrooms to make it more convenient for ostomates to empty, clean, or change their ostomy bags. ❖

Disclosure Statement

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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 Declaration of Helsinki and its later amendments or comparable ethical standards.

This study was approved by the University of Arizona Institutional Review Board (IRB) and the IRBs at both Kaiser Permanente sites in accordance with assurances filed with and approved by the US Department of Health and Human Services. Informed consent was considered to be received by return of the completed survey.

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References

- Yabroff KR, Guy GP Jr, Ekwueme DU, et al. Annual patient time costs associated with medical care among cancer survivors in the United States. *Med Care* 2014 Jul;52(7):594-601. DOI: <https://doi.org/10.1097/mlr.0000000000000151>.
- Short PF, Vasey JJ, Belue R. Work disability associated with cancer survivorship and other chronic conditions. *Psychooncology* 2008 Jan;17(1):91-7. DOI: <https://doi.org/10.1002/pon.1194>.
- Moran JR, Short PF. Does cancer reduce labor market entry? Evidence for prime-age females. *Med Care Res Rev* 2014 Jun;71(3):224-42. DOI: <https://doi.org/10.1177/1077558713510359>.
- Farley Short P, Vasey JJ, Moran JR. Long-term effects of cancer survivorship on the employment of older workers. *Health Serv Res* 2008 Feb;43(1 Pt 1):193-210. DOI: <https://doi.org/10.1111/j.1475-6773.2007.00752.x>.
- Moran JR, Short PF, Hollenbeak CS. Long-term employment effects of surviving cancer. *J Health Econ* 2011 May;30(3):505-14. DOI: <https://doi.org/10.1016/j.jhealeco.2011.02.001>.
- Zajacova A, Dowd JB, Schoeni RF, Wallace RB. Employment and income losses among cancer survivors: Estimates from a national longitudinal survey of American families. *Cancer* 2015 Dec 15;121(24):4425-32. DOI: <https://doi.org/10.1002/ncr.29510>.
- Ekwueme DU, Yabroff KR, Guy GP Jr, et al; Centers for Disease Control and Prevention (CDC). Medical costs and productivity losses of cancer survivors—United States, 2008-2011. *MMWR Morb Mortal Wkly Rep* 2014 Jun 13;63(23):505-10.
- de Boer AG, Frings-Dresen MH. Employment and the common cancers: Return to work of cancer survivors. *Occup Med (Lond)* 2009 Sep;59(6):378-80. DOI: <https://doi.org/10.1093/occmed/kqp087>.
- Thong MS, Mols F, Wang XS, Lemmens VE, Smilde TJ, van de Poll-Franse LV. Quantifying fatigue in (long-term) colorectal cancer survivors: A study from the population-based patient reported outcomes following initial treatment and long term evaluation of survivorship registry. *Eur J Cancer* 2013 May;49(8):1957-66. DOI: <https://doi.org/10.1016/j.ejca.2013.01.012>.
- Mehnert A. Employment and work-related issues in cancer survivors. *Crit Rev Oncol Hematol* 2011 Feb;77(2):109-30. DOI: <https://doi.org/10.1016/j.critrevonc.2010.01.004>.
- Mehnert A, de Boer A, Feuerstein M. Employment challenges for cancer survivors. *Cancer* 2013 Jun 1;119 Suppl 11:2151-9. DOI: <https://doi.org/10.1002/ncr.28067>.
- Aaronson NK, Mattioli V, Minton O, et al. Beyond treatment—psychosocial and behavioural issues in cancer survivorship research and practice. *EJC Suppl* 2014 Jun;12(1):54-64. DOI: <https://doi.org/10.1016/j.ejcsup.2014.03.005>.
- Schmidt CE, Bestmann B, Küchler T, Longo WE, Kremer B. Prospective evaluation of quality of life of patients receiving either abdominoperineal resection or sphincter-preserving procedure for rectal cancer. *Ann Surg Oncol* 2005 Feb;12(2):117-23. DOI: <https://doi.org/10.1245/aso.2005.12.036>.
- McKenzie F, White CA, Kendall S, Finlayson A, Urquhart M, Williams I. Psychological impact of colostomy pouch change and disposal. *Br J Nurs* 2006 Mar 23-Apr 12;15(6):308-16. DOI: <https://doi.org/10.12968/bjon.2006.15.6.20678>.
- Vironen JH, Kairaluoma M, Aalto AM, Kellokumpu IH. Impact of functional results on quality of life after rectal cancer surgery. *Dis Colon Rectum* 2006 May;49(5):568-78. DOI: <https://doi.org/10.1007/s10350-006-0513-6>.
- Krouse R, Grant M, Ferrell B, Dean G, Nelson R, Chu D. Quality of life outcomes in 599 cancer and non-cancer patients with colostomies. *J Surg Res* 2007 Mar;138(1):79-87. DOI: <https://doi.org/10.1016/j.jss.2006.04.033>.
- Mao JJ, Armstrong K, Bowman MA, Xie SX, Kadakia R, Farrar JT. Symptom burden among cancer survivors: Impact of age and comorbidity. *J Am Board Fam Med* 2007 Sep-Oct;20(5):434-43. DOI: <https://doi.org/10.3122/jabfm.2007.05.060225>.
- Mitchell KA, Rawl SM, Schmidt CM, et al. Demographic, clinical, and quality of life variables related to embarrassment in veterans living with an intestinal stoma. *J Wound Ostomy Continence Nurs* 2007 Sep-Oct;34(5):524-32. DOI: <https://doi.org/10.1097/01.won.0000290732.15947.9e>.
- McMullen CK, Hornbrook MC, Grant M, et al. The greatest challenges reported by long-term colorectal cancer survivors with stomas. *J Support Oncol* 2008 Apr;6(4):175-82.
- Baldwin CM, Grant M, Wendel C, et al. Influence of intestinal stoma on spiritual quality of life of US veterans. *J Holist Nurs* 2008 Sep;26(3):185-94. DOI: <https://doi.org/10.1177/0898010108315185>.
- Altschuler A, Ramirez M, Grant M, et al. The influence of husbands' or male partners' support on women's psychosocial adjustment to having an ostomy resulting from colorectal cancer. *J Wound Ostomy Continence Nurs* 2009 May-Jun;36(3):299-305. DOI: <https://doi.org/10.1097/won.0b013e3181a1a1dc>.
- Baldwin CM, Grant M, Wendel C, et al. Gender differences in sleep disruption and fatigue on quality of life among persons with stomas. *J Clin Sleep Med* 2009 Aug 15;5(4):335-43.
- Krouse RS, Herrinton LJ, Grant M, et al. Health-related quality of life among long-term rectal cancer survivors with an ostomy: Manifestations by sex. *J Clin Oncol* 2009 Oct 1;27(28):4664-70. DOI: <https://doi.org/10.1200/jco.2008.20.9502>.
- Liu L, Herrinton LJ, Hornbrook MC, Wendel CS, Grant M, Krouse RS. Early and late complications among long-term colorectal cancer survivors with ostomy or anastomosis. *Dis Colon Rectum* 2010 Feb;53(2):200-12. DOI: <https://doi.org/10.1007/dcr.0b013e3181bdc408>.
- Popek S, Grant M, Gemmill R, et al. Overcoming challenges: Life with an ostomy. *Am J Surg* 2010 Nov;200(5):640-5. DOI: <https://doi.org/10.1016/j.amjsurg.2010.07.009>.
- Grant M, McMullen CK, Altschuler A, et al. Gender differences in quality of life among long-term colorectal cancer survivors with stomas. *Oncol Nurs Forum* 2011 Sep;38(5):587-96. DOI: <https://doi.org/10.1188/11.onf.587-596>.
- Hornbrook MC, Wendel CS, Coons SJ, et al. Complications among colorectal cancer survivors: SF-6D preference-weighted quality of life scores. *Med Care* 2011 Mar;49(3):321-6. DOI: <https://doi.org/10.1097/mlr.0b013e31820194c8>.
- McMullen CK, Wasseman J, Altschuler A, et al. Untreated peristomal skin complications among long-term colorectal cancer survivors with stomas. *Clin J Oncol Nurs* 2011 Dec;15(6):644-50. DOI: <https://doi.org/10.1188/11.cjon.644-650>.
- Grant M, McMullen CK, Altschuler A, et al. Irrigation practices in long-term survivors of colorectal cancer with colostomies. *Clin J Oncol Nurs* 2012 Oct;16(5):514-9. DOI: <https://doi.org/10.1188/12.cjon.514-519>.
- Bulkley J, McMullen CK, Hornbrook MC, et al. Spiritual well-being in long-term colorectal cancer survivors with stomas. *Psychooncology* 2013 Nov;22(11):2513-21. DOI: <https://doi.org/10.1002/pon.3318>.
- Skeps R, McMullen CK, Wendel CS, et al. Changes in body mass index and stoma related problems in the elderly. *J Geriatr Oncol* 2013 Jan;4(1):84-9. DOI: <https://doi.org/10.1016/j.jgo.2012.10.172>.
- Sun V, Grant M, McMullen CK, et al. Surviving colorectal cancer: Long-term, persistent ostomy-specific concerns and adaptations. *J Wound Ostomy Continence Nurs* 2013 Jan-Feb;40(1):61-72. DOI: <https://doi.org/10.1097/won.0b013e3182750143>.
- McMullen CK, Schneider J, Altschuler A, et al. Caregivers as healthcare managers: Health management activities, needs, and caregiving relationships for colorectal cancer survivors with stomas. *Support Care Cancer* 2014 Sep;22(9):2401-8. DOI: <https://doi.org/10.1007/s00520-014-2194-3>.
- Sun V, Grant M, McMullen CK, et al. From diagnosis through survivorship: Health-care experiences of colorectal cancer survivors with stomas. *Support Care Cancer* 2014 Jun;22(6):1563-70. DOI: <https://doi.org/10.1007/s00520-014-2118-2>.
- Sun V, Grant M, Wendel CS, et al. Dietary and behavioral adjustments to manage bowel dysfunction after surgery in long-term colorectal cancer survivors. *Ann Surg Oncol* 2015 Dec;22(13):4317-24. DOI: <https://doi.org/10.1245/s10434-015-4731-9>.
- Jones JM, Olson K, Catton P, et al. Cancer-related fatigue and associated disability in post-treatment cancer survivors. *J Cancer Surviv* 2016 Feb;10(1):51-61. DOI: <https://doi.org/10.1007/s11764-015-0450-2>.
- Jansen L, Koch L, Brenner H, Arndt V. Quality of life among long-term (≥ 5 years) colorectal cancer survivors—systematic review. *Eur J Cancer* 2010

- Nov;46(16):2879-88. DOI: <https://doi.org/10.1016/j.ejca.2010.06.010>.
38. Jansen L, Herrmann A, Stegmaier C, Singer S, Brenner H, Arndt V. Health-related quality of life during the 10 years after diagnosis of colorectal cancer: A population-based study. *J Clin Oncol* 2011 Aug 20;29(24):3263-9. DOI: <https://doi.org/10.1200/jco.2010.31.4013>.
 39. Ness S, Kokal J, Fee-Schroeder K, Novotny P, Satele D, Barton D. Concerns across the survivorship trajectory: Results from a survey of cancer survivors. *Oncol Nurs Forum* 2013 Jan;40(1):35-42. DOI: <https://doi.org/10.1188/13.onf.35-42>.
 40. van den Brink M, van den Hout WB, Kievit J, et al. The impact of diagnosis and treatment of rectal cancer on paid and unpaid labor. *Dis Colon Rectum* 2005 Oct;48(10):1875-82. DOI: <https://doi.org/10.1007/s10350-005-0120-y>.
 41. Wendel CS, Grant M, Herrinton L, et al. Reliability and validity of a survey to measure bowel function and quality of life in long-term rectal cancer survivors. *Qual Life Res* 2014 Dec;23(10):2831-40. DOI: <https://doi.org/10.1007/s11136-014-0724-6>.
 42. Grant M, Ferrell B, Dean G, Uman G, Chu D, Krouse R. Revision and psychometric testing of the City of Hope Quality of Life-Ostomy Questionnaire. *Qual Life Res* 2004 Oct;13(8):1445-57. DOI: <https://doi.org/10.1023/b:qure.0000040784.65830.9f>.
 43. Temple LK, Bacik J, Savatta SG, et al. The development of a validated instrument to evaluate bowel function after sphincter-preserving surgery for rectal cancer. *Dis Colon Rectum* 2005 Jul;48(7):1353-65. DOI: <https://doi.org/10.1007/s10350-004-0942-z>.
 44. Smith T, Stein KD, Mehta CC, et al. The rationale, design, and implementation of the American Cancer Society's studies of cancer survivors. *Cancer* 2007 Jan 1;109(1):1-12. DOI: <https://doi.org/10.1002/cncr.22387>.
 45. Lerro CC, Stein KD, Smith T, Virgo KS. A systematic review of large-scale surveys of cancer survivors conducted in North America, 2000-2011. *J Cancer Surviv* 2012 Jun;6(2):115-45. DOI: <https://doi.org/10.1007/s11764-012-0214-1>.
 46. Ross TR, Ng D, Brown JS, et al. The HMO Research Network virtual data warehouse: A public data model to support collaboration. *EGEMS (Wash DC)* 2014 Mar 24;2(1):1049. DOI: <https://doi.org/10.13063/2327-9214.1049>.
 47. Deyo RA, Cherkin DC, Ciol MA. Adapting a clinical comorbidity index for use with ICD-9-CM administrative databases. *J Clin Epidemiol* 1992 Jun;45(6):613-9. DOI: [https://doi.org/10.1016/0895-4356\(92\)90133-8](https://doi.org/10.1016/0895-4356(92)90133-8).
 48. Krouse RS, Grant M, Wendel CS, et al. A mixed-methods evaluation of health-related quality of life for male veterans with and without intestinal stomas. *Dis Colon Rectum* 2007 Dec;50(12):2054-66. DOI: <https://doi.org/10.1007/s10350-007-9004-7>.
 49. Jain S, McGory ML, Ko CY, et al. Comorbidities play a larger role in predicting health-related quality of life compared to having an ostomy. *Am J Surg* 2007 Dec;194(6):774-9. DOI: <https://doi.org/10.1016/j.amjsurg.2007.08.020>.
 50. DeSantis CE, Lin CC, Mariotto AB, et al. Cancer treatment and survivorship statistics, 2014. *CA Cancer J Clin* 2014 Jul-Aug;64(4):252-71. DOI: <https://doi.org/10.3322/caac.21235>.
 51. de Moor JS, Mariotto AB, Parry C, et al. Cancer survivors in the United States: Prevalence across the survivorship trajectory and implications for care. *Cancer Epidemiol Biomarkers Prev* 2013 Apr;22(4):561-70. DOI: <https://doi.org/10.1158/1055-9965.epi-12-1356>.
 52. Weber-Raley L, Smith E, Greenwald & Associates. *Caregiving in the US: 2015 report* [Internet]. Bethesda, MD: National Alliance for Caregiving (NAC); 2015 [cited 2017 Jul 25]. Available from: www.caregiving.org/wp-content/uploads/2015/05/2015_CaregivingintheUS_Final-Report-June-4_WEB.pdf.
 53. Lundy JJ, Coons SJ, Wendel C, et al. Exploring household income as a predictor of psychological well-being among long-term colorectal cancer survivors. *Qual Life Res* 2009 Mar;18(2):157-61. DOI: <https://doi.org/10.1007/s11136-008-9432-4>.
 54. Black PK. Hidden problems of stoma care. *Br J Nurs* 1994 Jul 28-Aug 10;3(14):707-11. DOI: <https://doi.org/10.12968/bjon.1994.3.14.707>.
 55. Aron S, Carrareto R, Prazeres SM, de Cerqueira AP, Santos VL. Self-perceptions about having an ostomy: A postoperative analysis. *Ostomy Wound Manage* 1999 Apr;45(4):46-50, 52-4, 56 passim.
 56. Berndtsson I, Lindholm E, Ekman I. Thirty years of experience living with a continent ileostomy: Bad restrooms—not my reservoir—decide my life. *J Wound Ostomy Continence Nurs* 2005 Sep-Oct;32(5):321-6. DOI: <https://doi.org/10.1097/00152192-200509000-00010>.
 57. Stergiou-Kita M, Grigorovich A, Tseung V, et al. Qualitative meta-synthesis of survivors' work experiences and the development of strategies to facilitate return to work. *J Cancer Surviv* 2014 Dec;8(4):657-70. DOI: <https://doi.org/10.1007/s11764-014-0377-z>.
 58. Bains M, Munir F, Yarker J, Steward W, Thomas A. Return-to-work guidance and support for colorectal cancer patients: A feasibility study. *Cancer Nurs* 2011 Nov-Dec;34(6):E1-12. DOI: <https://doi.org/10.1097/ncc.0b013e31820a4c68>.
 59. Bains M, Munir F, Yarker J, et al. The impact of colorectal cancer and self-efficacy beliefs on work ability and employment status: A longitudinal study. *Eur J Cancer Care (Engl)* 2012 Sep;21(5):634-41. DOI: <https://doi.org/10.1111/j.1365-2354.2012.01335.x>.
 60. Bains M, Yarker J, Amir Z, Wynn P, Munir F. Helping cancer survivors return to work: What providers tell us about the challenges in assisting cancer patients with work questions. *J Occup Rehabil* 2012 Mar;22(1):71-7. DOI: <https://doi.org/10.1007/s10926-011-9330-4>.
 61. Faller H, Koch U, Brähler E, et al. Satisfaction with information and unmet information needs in men and women with cancer. *J Cancer Surviv* 2016 Feb;10(1):62-70. DOI: <https://doi.org/10.1007/s11764-015-0451-1>.
 62. Burch J. Psychological problems and stomas: A rough guide for community nurses. *Br J Community Nurs* 2005 May;10(5):224-7. DOI: <https://doi.org/10.12968/bjcn.2005.10.5.18051>.
 63. Brown H, Randle J. Living with a stoma: A review of the literature. *J Clin Nurs* 2005 Jan;14(1):74-81. DOI: <https://doi.org/10.1111/j.1365-2702.2004.00945.x>.
 64. Downing A, Morris EJ, Richards M, et al. Health-related quality of life after colorectal cancer in England: A patient-reported outcomes study of individuals 12 to 36 months after diagnosis. *J Clin Oncol* 2015 Feb 20;33(6):616-24. DOI: <https://doi.org/10.1200/jco.2014.56.6539>.
 65. Pachler J, Wille-Jørgensen P. Quality of life after rectal resection for cancer, with or without permanent colostomy. *Cochrane Database Syst Rev* 2012 Dec 12;12:CD004323. DOI: <https://doi.org/10.1002/14651858.cd004323.pub4>.

Care and Heal

The physician takes care, nature heals.

— Hippocrates of Kos, 460 BC – 370 BC, Greek physician of the Age of Pericles