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Long-term Experience of Rectal Cancer Survivors

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Abstract

Purpose—This descriptive, hypothesis-generating study sought to obtain input from rectal cancer survivors regarding key features of their long-term experience.

Methods—We administered a 12-question internet-based survey to self-identified rectal cancer survivors to assess 1) how neuropathy, fatigue, trouble with ostomy/bowel movements, and trouble with sexual function affect daily life; and 2) whether knowing about these symptoms *a priori* would have changed their treatment decision. Responses are presented descriptively. Qualitative analysis assessed themes reported in response to an open-ended question.

Results—Responses from 116 rectal cancer survivors, 55 of whom provided open-ended responses, were obtained. Respondents were predominantly young (62% <50 years at diagnosis) and several years from treatment (53% ≥ 2 years). They reported their lives were affected “A lot” by bowel/ostomy trouble (49%), trouble with sexual function (45%), fatigue (34%), and nerve toxicity (24%). Between 24-50% of survivors reporting a symptom affected their life “A lot” would have changed their treatment decisions with *a priori* knowledge of these lasting effects. Key qualitative themes were the lack of information about and support for negative effects.

Conclusions—Rectal cancer survivors report substantial symptom burden, decisional regret, and inadequate support. Interventions should target patients with high distress during their survivorship transition.

Keywords

Rectal cancer; cancer survivor; symptom burden; informational needs

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Conflict of Interest

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Introduction

Colorectal cancer is second only to lung cancer in annual incidence in the United States, affecting 1 in 20 Americans at some point in their life. ("American Cancer Society. *Cancer Facts & Figures 2014*. Atlanta: American Cancer Society; 2014.,") Cure rates for colorectal cancer continue to rise, (Edwards et al., 2010) and colorectal cancer survivors now comprise 8-9% of the estimated 14.5 million cancer survivors living in the US. (DeSantis et al., 2014) Unfortunately, the treatments used to cure colorectal cancer, including surgery, chemotherapy, and radiotherapy, carry substantial risk of long-term sequelae.

Colorectal cancer treatment undoubtedly results in lasting effects on health-related quality of life and symptom burden among survivors. Colorectal cancer survivors have been reported to have lower health-related quality of life up to 10 years out from their treatment, (Jansen, Herrmann, et al., 2011; Jansen, Hoffmeister, et al., 2011) although other studies have reported that only a minority of patients have a lasting detrimental effect of their treatment. (Ramsey, Berry, Moinpour, Giedzinska, & Andersen, 2002; Rauch, Miny, Conroy, Neyton, & Guillemín, 2004; Sapp et al., 2003; Zucca, Boyes, Linden, & Girgis, 2012) When present, these detrimental effects include disease-specific issues such as difficulty with ostomy and bowel function, and sexual dysfunction, but also encompass nonspecific adverse sequelae common to all cancer survivors such as fatigue. (Di Fabio, Koller, Nascimbeni, Talarico, & Salerni, 2008; Jansen, Herrmann, et al., 2011; Ramsey et al., 2002; Thong et al., 2013) Rectal cancer patients face a unique set of issues related to the more challenging surgical procedure needed to eradicate cancer from the pelvis, and the radiation and chemotherapy given to prevent pelvic and extrapelvic recurrence. Likely because of the greater intensity of therapy and the anatomic constraints of the pelvis, long term detriments in health-related quality of life appear to be more common in this population of colorectal cancer survivors. (Krouse et al., 2009; Mols, Lemmens, Bosscha, van den Broek, & Thong, 2014)

Thus while some, if not most, colorectal cancer survivors have an excellent long-term outcome, there are patients for whom colorectal cancer treatment causes life-altering adverse sequelae. Rectal cancer patients seem at greatest risk for these sequelae. However, just as it is notoriously difficult to predict the likelihood a cancer will respond to treatment resulting in cure, predicting which individuals will have a markedly negative response to the physical changes that follow rectal cancer surgery, chemotherapy, and radiation is exceptionally hard. Gaining a better understanding of these patients who do have lasting suffering by examining their experience and the support they perceive they would benefit from might help ameliorate suffering for those patients whose lives are irrevocably altered by rectal cancer and the long-term sequelae of treatments.

We wanted to obtain input from rectal cancer survivors regarding key features of their long-term experience, and factors they feel would have helped them make more informed decisions about their treatment. To do so we advertised and conducted through social media a web-based survey designed to identify key areas in need of future study in rectal cancer survivors. Here we describe the results of this exploratory, hypothesis-generating study.

Materials and Methods

The objectives of this study were to 1) determine the feasibility of using social media to gather information regarding the patient experience, 2) explore the importance of specific adverse outcomes from rectal cancer on the lives of survivors, and 3) examine whether rectal cancer survivors felt knowing about these lasting effects *a priori* would have changed their treatment decisions. We designed a 12-question survey using the free, online tool available at www.fluidsurveys.com (available from the authors upon request). The survey was distributed through social media by advertising links through the websites and Facebook pages of the Lineberger Comprehensive Cancer Center and the Fight Colorectal Cancer advocacy group.

The survey asked the extent to which the following common lasting adverse outcomes affect the life of respondents: neuropathy, fatigue, trouble with bowel movements or ostomy, and trouble with sexual function. These domains were chosen based on the clinical experience of the research team, literature review, and through discussion with rectal cancer patients. Responses were scored on a three-point Likert scale of how much the respondent's life was affected: "A lot", "A little", "Not at all". An option of "Not applicable" was provided for each question. These response options were selected to allow exploration of the severity of effect on decisional regret. For each adverse outcome, respondents were asked whether they would have changed their choice regarding treatment if they had known beforehand of that outcome. Respondents were asked to provide open-ended comments on any additional potential benefits or harms of rectal cancer treatment they believe to be important when considering treatment options. Self-reported age at diagnosis, sex, and length of time since the end of the initial course of treatment were also collected. Because no identifying information was collected, we cannot confirm that each response is from a unique individual. In addition, although the survey was entitled, "Rectal Cancer Patient Experience Survey" we cannot confirm all respondents had rectal cancer.

Because a large proportion of respondents provided a lengthy response to the open-ended question, we undertook an exploratory qualitative data analysis to better categorize the key themes reported by rectal cancer survivors. Qualitative data analysis of the 55 responses was conducted by three members of the study team (WLM, ALM, SW). A list of coding variables was created to encompass the themes reported by respondents. Two coders independently read through all of the responses and recorded the presence or absence of each coding variable. When the coders' ratings were not in agreement, a third coder broke the tie. Inter-coder reliability was excellent for the majority of coded variables, Cronbach's alpha was >0.8 in 36/45 variables and >0.7 in 42/45 variables. Variables which were deemed to report a similar higher order concept as judged by the study team were combined into higher-order variables and analyzed together. For example, sexual side effects and neuropathy were both included with many other adverse negative outcomes in the higher-order variable called side effects.

Given the exploratory nature of this survey and the lack of generalizability in the sampling scheme, survey responses are presented descriptively. No significance testing was performed.

This voluntary survey collecting de-identified data was deemed exempt from review by the Office of Human Research Ethics at the University of North Carolina (13-1390).

Results

A total of 116 surveys were completed over the course of 31 days, with 90 (78%) responding within 48 hours. The respondents were overwhelmingly female (87, 75%), Table 1. Seventy-two (63%) were less than 50 years of age when diagnosed with rectal cancer, 39 (34%) aged 50-64. Only three reported being 65-69 years old when diagnosed, and one between the ages of 70-74 years.

The majority of rectal cancer survivors reported having at least “A little” trouble with each of the symptom domains questioned, Table 2. Survivors commonly reported their lives were affected “A lot” by bowel or ostomy trouble (49%), trouble with sexual function (45%), fatigue (34%), and nerve toxicity (24%). Symptom severity was greater among patients over 50 years, with older patients reporting having “A lot” of difficulty in each domain more frequently than younger patients, Figure 1A. For all symptoms except sexual function, those within the first year of treatment completion reported having “A lot” of difficulty more frequently than those 3 or more years from treatment completion, Figure 1B.

Between 24-50% of survivors reporting symptoms affect their lives “A lot” said they would have changed their treatment decisions if they had known beforehand about the lasting effects of treatment on these domains, Figure 2.

These symptoms and decisional regret were further explored in the qualitative data analysis of open-ended comments. The key higher-order themes reported focused on the presence of negative side effects (38%) and lack of information about and support for addressing these negative effects (35%), Table 3. As would be expected in rectal cancer survivors, 27% reported upon lasting effects on continence and bowel/digestive function.

Discussion

Although colorectal cancer survivors, including those with permanent ostomies, can have excellent long-term health-related quality of life across a broad variety of domains, we found that a large proportion of rectal cancer survivors responding to this internet-based survey reported a major effect of fatigue, bowel/ostomy trouble, sexual trouble, and neuropathy on their daily life. Further, many of these survivors reported that, had they known about the durable nature of these moderate to severe symptoms at the time of treatment decision-making, they would not have made the same decision about treatment. Because of the limited nature of the survey, we have no information with regard to which decisions the survivors would change nor whether this sentiment is a lasting one or might change over time.

The sampling scheme for this survey—a purely internet-based survey geared towards people looking at cancer and colorectal cancer websites and Facebook pages—is inherently biased towards a unique subset of younger, predominantly female rectal cancer survivors. It is also reasonable to assume that the sample is enriched with survivors with lasting sequelae who

would be more likely to be engaged in websites related to colorectal cancer. Thus, while these results are limited and cannot in any way be interpreted to represent the prevalence of symptoms in the general population of rectal cancer survivors, they do highlight that a subset of rectal cancer patients have lasting adverse effects.

This study also highlights social media as an untapped resource for research. We were able to obtain responses from 90 individuals free of charge within two days of survey posting. Certainly, strategies to overcome the aforementioned limitations imposed by the sampling scheme need to be overcome prior to widespread use of social media as a research recruitment tool.

Of major concern is that in this group of young, internet savvy rectal cancer survivors, over one third of those providing open-ended responses said they were not able to get enough information about treatment and side effects. A patient's perception of how well their informational needs about their cancer, treatment, and side-effects have been fulfilled is strongly associated with key long-term outcomes of health-related quality of life, anxiety, and depression as well as their perception of their illness severity.(Husson, Mols, & van de Poll-Franse, 2011; Husson et al., 2013)

The failure of oncologists to convey realistic expectations with regard to cancer treatments and difficulties in patient-physician communication have been well described.(Ayanian et al., 2005; Weeks et al., 2012) It is clear that no single "one size fits all" strategy will work across all ages, cultures, and levels of education. Studies of the informational needs of patients embarking upon rectal cancer therapy that are large enough to evaluate the effect of sociodemographic characteristics on these needs, as well as how the urgency of treatment affects quality decision-making are clearly needed. Our preliminary data also highlight how we must focus on finding ways to address the ongoing symptom distress and perceived lack of information and support among rectal cancer survivors. Targeted interventions for patients with high perceived illness severity and a high symptom burden might help alleviate the significant distress reported by these rectal cancer survivors.

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Implications for practice

i) Rectal cancer patients even three or more years from the end of treatment may have symptoms that have a substantial negative effect on their daily life; ii) They also report feeling inadequately informed about how to deal with their lasting symptoms. Iii) Careful attention to the symptom burden and level of distress of patients as they make their transition to post-treatment surveillance, with focused symptom management and education for those with high levels of distress, may improve the long term outcomes of those with lasting adverse effects from treatment.

Figure 1. Severity of the Effect of Adverse Outcomes on Daily Life by Age and Time from Initial Course of Treatment. Panel A, Severity by Age, Panel B, Severity by Time from Initial Course of Treatment

Figure 2.
Proportion who would Change Treatment Decision with *A Priori* Knowledge of Current Symptoms

Table 1

Respondent Characteristics

Characteristic	n (%)
Sex	
Male	29 (25%)
Female	87 (75%)
Age Range when Diagnosed	
<50 years	72 (62%)
50-64 years	39 (34%)
65-70 years	3 (3%)
70 years	1 (<1%)
Missing	1 (<1%)
Time from Initial Treatment	
<1 year	29 (25%)
1-<2 years	21 (18%)
2- <3 years	18 (16%)
3 years	44 (39%)
Missing	2 (2%)
Time from Survey Posting to Completion	
1 day	67 (58%)
2 days	23(20%)
3-5 days	4 (3%)
6-31 days	22 (19%)

Table 2

Severity of the Effect of Adverse Outcomes on Daily Life

Symptom	Total responding ^a	A Lot n (%)	A Little n (%)	Not at all n (%)	Not Applicable n (%)
Trouble with Bowel or Ostomy	114	56 (49%)	49 (43%)	8 (7%)	1 (1%)
Trouble with Sexual Function	113	51 (45%)	22 (19%)	24 (21%)	16 (14%)
Fatigue	115	39 (34%)	51 (44%)	25 (22%)	0
Nerve Toxicity	113	27 (24%)	49 (43%)	28 (25%)	9 (8%)

^a Respondents were not required to provide an answer to each question.

Table 3

Qualitative Themes Reported in 10% or more of Open-Ended Responses

Thematic Higher-Order Variable	N (%) Who Commented on this Theme
Negative side effects	36 (65%)
Negative side effects were due to radiation/chemo/other	21 (38%)
Lack of information about treatment options, side effects, and/or support for side effects	19 (35%)
Incontinence/bowel/digestive problems	15 (27%)
Thematic Variable: Treatment	N (%)
Had radiation	27 (49%)
Had surgery	24 (44%)
Had chemotherapy	19 (35%)
Had ostomy/ileostomy/colostomy	15 (27%)
Time since treatment ended	7 (13%)
Wanted to try aggressive treatment	6 (11%)
Thematic Variable: Durable Adverse Outcomes	
Continues to experience negative side effects	19 (35%)
Negative side effects due to radiation	15 (27%)
Negative side effects were worth beating the cancer	12 (22%)
Other bowel/digestive problems	10 (18%)
Sexual side effects	9 (16%)
Nerve problems/Neuropathy	8 (15%)
Negative side effects due to chemo	8 (15%)
Complications from surgical/medical procedure	8 (15%)
Incontinence	6 (11%)
Loss of energy/fatigue	6 (11%)
Thematic Variable: Inadequate Information/Support and Regret	
Lack of information about and/or support for side effects	17 (31%)
Felt negative about choice/would choose differently next time	13 (24%)
Desire for more support dealing with long-term effects including ostomy	10 (18%)
Wasn't told at all or enough about side effects	8 (15%)
Felt positive about choice	6 (11%)