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Patient-Reported Unmet Needs in Colorectal Cancer Survivors After Treatment for Curative-Intent

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Abstract

Background: With improving survival from colorectal cancer there is a growing population of patients in surveillance. National accreditation organizations have increasingly endorsed formal survivorship care planning. To effectively design patient-centered survivorship programs, an understanding of the prevalence of unmet psychosocial and symptomatic needs is required.

Objective: To understand the breadth of unmet needs among colorectal cancer survivors.

Design: Cross-sectional survey of patients undergoing surveillance after curative-intent therapy for colorectal cancer.

Setting: June 2017 to January 2018 at an academic cancer center.

Patients: 99 patients (58 colon cancer, 41 rectal cancer).

Main Outcome Measures: We measured patient-reported unmet needs using a modification of the Cancer Survivor Unmet Needs instrument, within domains of emotional (stress, concerns about recurrence), relationship (fertility, interpersonal), logistical (need for accessible parking, case management), financial, treatment-related (neuropathy, bowel function), and surveillance-related needs.

Results: Mean ($\pm$ SD) age was 58 ($\pm$ 12) and time from diagnosis was 34 ($\pm$ 18) months. Overall, 74% of patients reported at least one unmet need, 49% reported emotional needs, 24% relationship needs, 24% financial needs, 25% logistical needs, and 33% surveillance needs. Thirty-six (62%) of colon cancer patients and 37 (90%) of rectal cancer patients reported at least one ongoing problem

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Dr. Vu contributed to the analysis and interpretation of data, drafted and revised the work, approved the version to be published, and agrees to be accountable for all aspects of the work. Ms. Matusko contributed to the analysis of data, revised the work, approved the version to be published, and agrees to be accountable for all aspects of the work. Drs. Regenbogen and Hendren made contributions to the interpretation of the data, revised the work, approved the version to be published, and agree to be accountable for all aspects of the work. Dr. Hardiman conceived and designed the work and interpreted the data, drafted and revised the work, approved the version to be published, and agrees to be accountable for all aspects of the work.

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($p=0.002$). Thirty-five (82%) of rectal cancer patients reported an unmet treatment-related need compared to 23 (40%) of colon cancer patients ($p<0.001$). Median (IQR) number of ongoing needs were 1 (0–5) in colon cancer patients and 4 (2–8) in rectal cancer patients ($p=0.007$).

Limitations: Small sample size and lack of generalizability, given the tertiary care setting.

Conclusions: The majority of colorectal cancer survivors reported unmet needs years after completion of curative-intent therapy. Rectal cancer patients were significantly more likely to have unmet needs and may benefit from additional care during survivorship. Colorectal cancer survivorship programs should incorporate psychosocial and symptomatic care in addition to cancer surveillance. See **Video Abstract** at <http://links.lww.com/DCR/Axxx>.

Keywords

Colorectal cancer; Surveillance; Symptoms; Survivorship; Unmet needs

INTRODUCTION

Survival after colorectal cancer (CRC) is improving, with a 65% five-year survival for patients with non-metastatic disease.¹ The growing population of CRC survivors remains at risk for late and long-term effects of cancer and treatment. Emotional, financial, health-related quality of life (HRQOL), and treatment-specific burdens, such as fears about recurrence, post-surgical symptoms, or caring for an ostomy, have all been documented among CRC survivors.^{2–5} There is increased national focus on survivorship in cancer care, with imperatives to incorporate surveillance, symptomatic and psychosocial support, health maintenance, and multidisciplinary care coordination.^{6–8} Formal survivorship care is now included in the accreditation standards of American College of Surgeons Commission, and guidelines have been published to promote holistic survivorship care that goes beyond cancer surveillance.^{9–11}

Despite these efforts, the extent to which survivorship care is meeting patients' needs is not well understood. Qualitative studies have defined the domains of unmet needs, which range from physical to financial to existential, but the prevalence of various needs has not been characterized.^{12,13} Furthermore, research to define which patients are most at risk for unmet needs is required if we are to design programs to better serve CRC survivors. Identifying the most common problems for CRC patients in survivorship will be useful to prioritize resource delivery where it is most needed.

In this context, the present study was conducted with two goals: (1) to characterize the prevalence of unmet needs amongst CRC patients in survivorship; and (2) to determine clinical risk factors for unmet needs. We conducted a cross-sectional survey of CRC patients' survivorship needs across six domains: emotional, relationship, financial, logistical, treatment-related, and surveillance-related. We hypothesized that the majority of patients would have at least one unmet need across those domains. We also hypothesized that rectal cancer patients would have a greater prevalence of unmet needs compared to colon cancer patients.

MATERIALS AND METHODS

Overview

This study was a survey of CRC patients seen in a Multidisciplinary CRC Clinic and a Colorectal Surgery Clinic at a tertiary care hospital. These clinics provide surveillance and symptom management of CRC patients after treatment at our facility. This study was reviewed and approved by the University of Michigan Institutional Review Board.

Study Population

The study period was June 2017 to January 2018. We screened and approached all patients who had undergone curative intent treatment for CRC coming to Multidisciplinary CRC Clinic and Colorectal Surgery Clinics for surveillance visits during selected weeks within the study period. We included adult patients who had undergone curative-intent therapy (surgery, radiation, and/or chemotherapy) for colon or rectal cancer and had no evidence of disease. We excluded patients who had recurrent or metastatic cancer that had not been resected. Patients were approached for enrollment during their clinic visit and completed the written survey in person.

Survey Instrument

The survey instrument was based on the Cancer Survivors Unmet Needs instrument (CaSUN) which includes 27 questions pertaining to six domains of survivorship needs.¹⁴ Patients were instructed to answer about ongoing needs “in the past month.” Emotional needs included questions about stress, concerns about cancer recurrence, or emotional support. Relationship needs included needing help with fertility, supporting a partner, or developing new relationships. Financial needs included help with life or travel insurance, getting or maintaining employment, or finding financial support. Logistical needs included needing help with accessible parking or finding a case manager. Surveillance-related needs included prevention of future cancer or recurrence and further testing. We added 10 questions about CRC treatment-related needs, including questions about sexual, bowel, and urinary dysfunction, neuropathy, and colostomy or ileostomy care, based on patient-reported symptoms from the literature.^{4,15} For the cancer treatment-related and surveillance needs, each question was accompanied by a yes/no question, “Would you have liked more help with this issue?” The additional questions are included in Figure 1.

Outcome and Explanatory Variables

The primary outcome was the number of total unmet needs reported. Other outcomes of interest were the total number of emotional, relationship, financial, logistical, treatment-related, and surveillance-related needs. Clinical explanatory variables included cancer type (colon versus rectal), radiation therapy, chemotherapy, surgery, age at diagnosis, and time from diagnosis.

Analysis

Descriptive statistics were used to characterize the patterns of unmet needs overall and in each domain. Cronbach’s alpha was calculated to quantify the inter-item reliability of the

need domain sum scores. We compared the number of colon and rectal cancer patients with unmet needs in each domain using Pearson's Chi-square test. We separately analyzed the number of cancer treatment-related and surveillance needs for colon and rectal cancer patients, as well as the number of patients who reported needing more help for each of these problems.

Because the outcomes of interest was the count of unmet needs, negative binomial regression models were used to test for independent associations between patient factors and unmet needs. Outcomes for this analysis were (1) total needs, and (2) each need domain. Effect sizes for negative binomial regression models are presented in β -coefficients, which measure how strongly a predictor is related to an outcome. For example, if the outcome were total unmet needs, a β -coefficient of 1.0 for age at diagnosis would mean that for every unit increase of age, total unmet needs would increase by 1. Two-sided significance tests were used with significance set at $P = 0.05$ for all analyses. All analyses were performed using StataSE version 14 (College Station, Texas).

RESULTS

Patient characteristics

116 patients were approached and 102 responded (88% response rate). We excluded one patient with rectal cancer who had locally recurrent disease and two patients with rectal cancer who had metastatic disease. In total, we included in the analysis 99 patients—58 colon cancer, 41 rectal cancer.

Demographic data for respondents are shown in Table 1. Mean ($\pm$ SD) age was 60 ($\pm$ 12) for colon cancer patients and 56 ($\pm$ 11) for rectal cancer patients ($p=0.130$). The mean time from diagnosis to survey was 34 ($\pm$ 19) months. 29 (50%) of colon cancer patients and 28 (68%) of rectal cancer patients received chemotherapy ($p=0.07$). 2 (3%) of colon cancer patients and 25 (61%) of rectal cancer patients received radiation therapy ($p<0.001$).

In the survey, all domain constructs had moderate to excellent reliability with the exception of logistical needs, with Cronbach's alpha ranging from 0.66 (treatment-related, recurrence related-needs) to 0.80 (emotional needs). For logistical needs, the reliability between the two items (need for accessible parking and need for an ongoing case manager) was 0.29.

Unmet needs by domain

Of 58 colon cancer patients, 36 (62%) reported at least one unmet need, while 37 (90%) of the 41 rectal cancer patients reported at least one unmet need ($p=0.002$) (Figure 2). Of these patients, colon cancer patients reported a median (IQR) of 1 (0 – 5) unmet need, while rectal cancer patients reported a median of 4 (2 – 8) ($p=0.007$). Rectal cancer patients were significantly more likely than colon cancer patients to report unmet cancer treatment-related needs (80% vs 40%, $p<0.001$). The proportions of patients reporting emotional, relationship, financial, logistical, or surveillance related needs were similar between colon and rectal cancer. Of all the patients, 51 (42%) reported unmet emotional needs, 24 (24%) had unmet relationship needs, 24 (24%) had unmet financial needs, 24 (24%) had unmet logistical needs, and 34 (34%) had unmet surveillance needs.

Cancer treatment-related needs

Compared to colon cancer patients, rectal cancer patients were significantly more likely to report treatment-related needs, including bowel and bladder dysfunction, problems with a colostomy or ileostomy, and sexual dysfunction (Figure 3). The 29 (50%) colon cancer and 28 (68%) rectal cancer patients who received chemotherapy had similar rates of neuropathy (48% vs. 63%, $p=0.269$). Rectal cancer patients had higher rates of bowel function needs than colon cancer patients (50% vs 16%, $p<0.001$). Colon and rectal cancer patients reported similar rates of unmet needs related to recurrence risk and cancer prevention.

Patients who reported needing more help

A subset of patients answered affirmative to needing more help with each of the above treatment-related or surveillance need, and there were no differences between colon and rectal cancer patients in the likelihood of wanting more help. Patients most commonly reported needing help with neuropathy (21% of patients), bowel dysfunction (18%), and future cancer or recurrence prevention (25%). Additionally, 20% of patients also reported needing help with healthy living or exercise (20%).

Predictors of unmet needs

Negative binomial regression analysis identified that increased time from diagnosis was associated with reporting fewer needs, while radiation therapy was predictive of reporting more needs. Other factors, including cancer type, chemotherapy, surgery, and age at diagnosis, were not associated with need burden (Table 2). For a given patient, each year further from diagnosis would result in an average of 0.2 fewer total needs (95% CI: 0.05 – 0.37, $p=0.010$), 0.2 fewer emotional needs (95% CI: 0.04 – 0.45, $p=0.021$), and 0.3 fewer logistical needs (95% CI: 0.02 – 0.60, $p=0.037$).

For treatment-related needs, having radiation was associated with a greater number of unmet needs. Using the model to predict the adjusted number of unmet needs, patients who had radiation reported an average of 1 additional need compared to patients without radiation (95% CI: 0.1 – 1.5, $p=0.025$).

DISCUSSION

In this study of patient-reported survivorship needs in CRC, we identified a high prevalence of unmet needs across multiple domains in CRC survivors that persists years after treatment is complete. At a mean of almost three years after diagnosis, almost two-thirds of colon cancer survivors and ninety percent of rectal cancer survivors report at least one unmet need. Rectal cancer patients reported higher rates of treatment-related problems, and multivariable analysis found that radiation was associated with higher numbers of treatment-related needs. The higher need burden in rectal cancer patients may be partly mediated by receiving radiation therapy; alternatively, radiation may be an indicator of receiving more treatment overall as well as more morbid pelvic surgery.¹⁶

It may be unsurprising that rectal cancer survivors report more unmet needs after treatment. More concerning is how frequent and diverse CRC survivorship needs are regardless of

cancer location. We have shown that, even colon cancer patients have substantial long-term side effects, despite the preconceived idea that they should have relatively good long-term outcomes. Existing studies focus only on specific domains of survivorship need, or are limited to certain patient populations, such as patients with ostomies, whereas our study assessed needs across a broad range of needs, both treatment specific and more general. Previous survey studies have shown that up to 65% of CRC patients report neuropathy, 70% of patients report bowel changes, 46% of patients have chronic diarrhea, and 22% of males and 43% of females report sexual changes.^{4,17,18} Additionally, Krouse et al. showed that CRC survivors describe negative psychosocial effects, late treatment-related effects, comorbidities, postoperative recovery, and negative experiences with healthcare as some of their greatest challenges in survivorship, even at five years after treatment.^{3,19,20} Because of its breadth, our study was able to demonstrate that the majority of both colon and rectal cancer patients experience a broad range of survivorship needs even years out from completion of therapy. Colorectal surgeons, medical oncologists, and primary care providers should anticipate colon cancer patients to be equally susceptible to ongoing emotional stress or surveillance burden, while targeting symptom-related care to rectal cancer patients. Additionally, increased awareness of the prevalence of unmet needs can help providers set patient expectations about recovery and long-term quality of life in survivorship.

For providers, the first step should be screening for unmet needs and asking whether patients desire assistance. This may lead to meaningful help for patients who otherwise would not know about available treatments or support. For example, for patients with neuropathy, providers can offer options including medications or alternative therapies such as exercise.^{21,22} Patients experiencing anxiety about surveillance and recurrence risk may benefit from reassurance and counseling about risk reduction. Survivorship clinics or care pathways can be established to address commonly reported issues that may require involvement of other providers, such as bowel or sexual dysfunction, issues with an ileostomy or colostomy, or financial needs. There is certainly a tradeoff to implementing survivorship care programs, as they may be costly to create and support. However, there may be high personal cost of unaddressed needs for patients; 45% of CRC patients of working age no longer have their jobs one year after diagnosis, and this high rate of financial toxicity may be related to ongoing symptoms.^{23,24} In addition, issues such as poor ostomy maintenance may lead to increased healthcare utilization in the form of Emergency Department visits. Survivorship care programs should be established in a prudent and efficient way, but centralized care coordination for CRC survivors may be able to reduce healthcare costs.

Our study does have important limitations. The sample size is limited, which could limit power to detect some important differences. Patients were derived from a single academic referral institution over an eight month period and were largely caucasian, potentially limiting generalizability to other colorectal cancer practices. Rectal cancer patients were somewhat overrepresented at 44% of patients (compared to 30% of CRC nationally).²⁵ However, the distribution of stage at presentation was comparable to national rates, and we separated patients by disease site to ensure that we did not overestimate the prevalence of unmet needs overall.²⁶ The reproducibility of the findings is bolstered further by the very high response rate, which we achieved by administering surveys in person during clinic visits. Also, as with all survey studies, our results may be subject to recall bias. However, we

mitigated this risk by focusing on ongoing needs patients had experienced in the last month. Finally, we did not have comparison data from patients undergoing a different disease process, such as trauma or diagnosis of chronic disease. These data would help elucidate which of the ongoing needs reported are specific to CRC and which may be characteristic of a life-changing health event in general, but this would be a worthwhile focus of future studies.

CONCLUSION

In summary, this cross-sectional survey study found that almost two out of three colon cancer patients and nine out of 10 of rectal cancer patients have unmet needs, years after curative intent treatment. These findings suggest that screening for ongoing survivorship needs and designing therapeutic interventions for their management must be critical components of high-quality survivorship care. This study highlights the need for more in-depth investigation of predictors of ongoing long-term difficulties and can inform the design of targeted interventions for patients at highest risk for unmet survivorship needs. In addition, these findings may help patients and providers have realistic expectations for recovery and quality of life after curative treatment.

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	No Need	Experienced issue but needs met	Minor Problem	Moderate Problem	Major Problem
C1. Testing for cancer recurrence (such as CT scans, CEA blood tests, colonoscopy, etc.)	☐ 1	☐ 2	☐ 3	☐ 4	☐ 5
a. Would you have liked more help with this issue?	☐ 1 Yes	☐ 2 No			
C2. Risk of cancer recurrence	☐ 1	☐ 2	☐ 3	☐ 4	☐ 5
a. Would you have liked more help with this issue?	☐ 1 Yes	☐ 2 No			
C3. Neuropathy	☐ 1	☐ 2	☐ 3	☐ 4	☐ 5
a. Would you have liked more help with this issue?	☐ 1 Yes	☐ 2 No			
C4. Bowel functioning (this could include stool frequency, diarrhea, incontinence, or other issues)	☐ 1	☐ 2	☐ 3	☐ 4	☐ 5
a. Would you have liked more help with this issue?	☐ 1 Yes	☐ 2 No			
C5. Urinary problems (this could include urinary frequency, incontinence, or other issues)	☐ 1	☐ 2	☐ 3	☐ 4	☐ 5
a. Would you have liked more help with this issue?	☐ 1 Yes	☐ 2 No			
C6. Colostomy or ileostomy care or problems	☐ 1	☐ 2	☐ 3	☐ 4	☐ 5
☐ I did NOT have a colostomy or an ileostomy, and therefore this question is not applicable to me.					
a. Would you have liked more help with this issue?	☐ 1 Yes	☐ 2 No			
C7. Sexual functioning or sexual relationship issues	☐ 1	☐ 2	☐ 3	☐ 4	☐ 5
a. Would you have liked more help with this issue?	☐ 1 Yes	☐ 2 No			
C8. Prevention of future polyps or cancer recurrence	☐ 1	☐ 2	☐ 3	☐ 4	☐ 5
a. Would you have liked more help with this issue?	☐ 1 Yes	☐ 2 No			
C9. Management of stress	☐ 1	☐ 2	☐ 3	☐ 4	☐ 5
a. Would you have liked more help with this issue?	☐ 1 Yes	☐ 2 No			
C10. Healthy living: Diet and Exercise	☐ 1	☐ 2	☐ 3	☐ 4	☐ 5
a. Would you have liked more help with this issue?	☐ 1 Yes	☐ 2 No			
C11. Other issues (please explain)	<input type="text"/> <input type="text"/> <input type="text"/> <input type="text"/>				

Figure 1. Questions added to the CaSUN measure.

*, $p < 0.05$. CaSUN, Cancer Survivors' Unmet Needs. We added 10 treatment-related and surveillance-related needs to the instrument.

Figure 2. Prevalence of unmet needs.

*, $p < 0.05$. The percentage of colon and rectal cancer patients reporting at least one unmet need is shown, both for total needs and separated into need domains.

Patients with Unmet Treatment and Surveillance-Related Needs

Figure 3. Prevalence of unmet treatment- and surveillance-related needs.

*, $p < 0.05$. The percentage of colon and rectal cancer patients reporting specific treatment-related and surveillance-related needs is shown.

Table 1.

Characteristics of the Cohort.

	Colon		Rectal		
Characteristics	N	%	N	%	p-value
Patients	58		41		
Gender					
Male	27	47%	23	56%	0.876
Female	31	53%	18	44%	
Race					
White	55	95%	36	88%	0.101
Black	3	5%	1	2%	
Hispanic/Latino	0	0%	3	7%	
Asian	0	0%	1	2%	
Marital Status					0.234
Single	9	15%	2	5%	
Married	41	71%	36	88%	
Divorced	5	9%	2	5%	
Widowed	3	5%	1	2%	
Mean (SD) age at diagnosis	60 (12)		56 (11)		0.130
Mean (SD) time from diagnosis, months	33 (20)		36 (17)		0.332
Stage					0.863
1	16	28%	10	24%	
2	18	31%	14	34%	
3	19	33%	15	36%	
4	5	9%	2	5%	
Received Chemotherapy	29	50%	28	68%	0.070
Received Radiation	2	3%	25	61%	<0.001
Received Surgery	57	98%	39	95%	0.367

Table 2.

Negative Binomial Regression Models for Need Domains.

Unmet Needs	β Coefficient	P-value	95% CI	
Total Unmet Needs				
Cancer type (ref: colon) Rectal cancer				
	0.231	0.477	−0.407	0.869
Received radiation therapy	0.697	0.082	−0.090	1.483
Received chemotherapy	0.345	0.291	−0.296	0.985
Underwent surgery	0.406	0.577	−1.021	1.832
Age at diagnosis	−0.009	0.406	−0.029	0.012
Years from diagnosis	−0.216	0.010*	−0.380	−0.052
Emotional Needs				
Cancer type (ref: colon) Rectal cancer				
	0.261	0.486	−0.407	0.869
Received radiation therapy	0.736	0.11	−0.090	1.483
Received chemotherapy	0.065	0.868	−0.296	0.985
Underwent surgery	0.336	0.712	−1.021	1.832
Age at diagnosis	−0.016	0.199	−0.029	0.012
Years from diagnosis	−0.241	0.021*	−0.380	−0.052
Relationship Needs				
Cancer type (ref: colon) Rectal cancer				
	−2.513	0.127	−5.742	0.715
Received radiation therapy	3.337	0.051	−0.014	6.687
Received chemotherapy	0.678	0.328	−0.680	2.037
Underwent surgery	−0.438	0.727	−2.896	2.019
Age at diagnosis	−0.031	0.143	−0.073	0.011
Years from diagnosis	−0.382	0.054	−0.769	0.006
Logistical Needs				
Cancer type (ref: colon) Rectal cancer				
	0.023	0.970	−1.174	1.220
Received radiation therapy	0.561	0.463	−0.937	2.060
Received chemotherapy	−0.078	0.887	−1.147	0.992
Underwent surgery	−0.721	0.412	−2.444	1.001
Age at diagnosis	0.021	0.231	−0.014	0.056
Years from diagnosis	−0.310	0.037*	−0.602	−0.018
Treatment-Related Needs				
Cancer type (ref: colon) Rectal cancer				
	0.369	0.245	−0.252	0.990
Received radiation therapy	0.822	0.025*	0.102	1.543
Received chemotherapy	0.304	0.350	−0.334	0.943

Underwent surgery	0.239	0.687	−0.922	1.400
Age at diagnosis	−0.019	0.063	−0.038	0.001
Years from diagnosis	−0.044	0.570	−0.196	0.108
Surveillance-Related Needs				
Cancer type (ref: colon)				
Rectal cancer	0.337	0.459	−0.556	1.231
Received radiation therapy	−0.068	0.902	−1.147	1.011
Received chemotherapy	0.524	0.229	−0.330	1.377
Underwent surgery	0.721	0.549	−1.637	3.080
Age at diagnosis	0.004	0.807	−0.025	0.032
Years from diagnosis	−0.176	0.125	−0.400	0.049