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

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**BACKGROUND:** With improving survival from colorectal cancer, there is a growing population of patients undergoing 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:** The aim of this study is to understand the breadth of unmet needs among survivors of colorectal cancer.

**DESIGN:** This is a cross-sectional survey of patients undergoing surveillance after curative-intent therapy for colorectal cancer.

**SETTING:** This study was conducted June 2017 to January 2018 at an academic cancer center.

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**PATIENTS:** There were 99 patients (58 with colon cancer, 41 with rectal cancer).

MAIN OUTCOME MEASURES: We measured patientreported unmet needs by 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:** The mean (±SD) age was 58 (±12), and the time from diagnosis was 34 (±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%) patients with colon cancer and 37 (90%) patients with rectal cancer reported at least one ongoing problem (p = 0.002). Thirty-five (82%) patients with rectal cancer reported an unmet treatment-related need in comparison with 23 (40%) patients with colon cancer (p < 0.001). The median (interquartile range) number of ongoing needs were 1 (0–5) in patients with colon cancer and 4 (2–8) in patients with rectal cancer (p = 0.007).

**LIMITATIONS:** This study was limited by its 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. Patients with rectal cancer 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/A885.

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CME I

*KEY WORDS:* Colorectal cancer; Surveillance; Symptoms; Survivorship; Unmet needs.

urvival after colorectal cancer (CRC) is improving, with a 65% 5-year survival for patients with nonmetastatic disease.<sup>1</sup> 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, and treatment-specific burdens, such as fears about recurrence, postsurgical symptoms, or caring for an ostomy, have all been documented among CRC survivors.<sup>2-5</sup> 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.<sup>6-8</sup> Formal survivorship care is now included in the accreditation standards of the 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.<sup>12,13</sup> 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 patients with CRC in survivorship will be useful to prioritize resource delivery where it is most needed.

In this context, the present study was conducted with 2 goals: 1) to characterize the prevalence of unmet needs among patients with CRC in survivorship, and 2) to determine clinical risk factors for unmet needs. We conducted a cross-sectional survey of survivorship needs of patients who have CRC across 6 domains: emotional, relationship, financial, logistical, treatment-related, and surveillance-related. We hypothesized that the majority of patients would have at least 1 unmet need across those domains. We also hypothesized that patients with rectal cancer would have a greater prevalence of unmet needs than patients with colon cancer.

#### **MATERIALS AND METHODS**

#### **Overview**

This study was a survey of patients with CRC seen in a Multidisciplinary CRC Clinic and a Colorectal Surgery Clinic at a tertiary care hospital. These clinics provide surveillance and symptom management of patients with CRC 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 that includes 27 questions pertaining to 6 domains of survivorship needs.<sup>14</sup> 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 patientreported 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  $\alpha$  was calculated to quantify the interitem reliability of the need domain sum scores. We compared the number of patients with colon and rectal cancer with unmet needs in each domain using the Pearson  $\chi^2$  test. We separately

	No Need		Expe issu nee	rienced ue but ds met	Minor Problem	Moderate Problem	Major Problem
C1. Testing for cancer recurrence (such as CT scans, CEA blood tests, colonoscopy, etc.)	$\Box_1$			$\square_2$	$\Box_3$	$\square_4$	$\square_5$
a. Would you have liked more help with this is	sue?	⊐ <sub>1</sub>	Yes	$\square_2$ No			
C2. Risk of cancer recurrence	□ <sub>1</sub>			$\square_2$	$\Box_3$	$\Box_4$	$\Box_5$
a. Would you have liked more help with this is	sue?	⊐ <sub>1</sub>	Yes	$\square_2$ No			
C3. Neuropathy	□ <sub>1</sub>			$\square_2$	$\Box_3$	$\Box_4$	$\Box_5$
a. Would you have liked more help with this is	sue?	⊐ <sub>1</sub>	Yes	$\square_2$ No			
C4. Bowel functioning (this could include stool frequency, diarrhea, incontinence, or othe issues.)	□ <sub>1</sub>			$\square_2$	$\Box_3$	$\Box_4$	$\Box_5$
a. Would you have liked more help with this is	sue?	⊐ <sub>1</sub>	Yes	$\square_2$ No			
C5. Urinary problems (this could include urinary frequency, incontinence, or othe issues)					$\Box_3$	$\Box_4$	□₅
a. Would you have liked more help with this is	sue?	⊐ <sub>1</sub>	Yes	$\square_2$ No			
C6. Colostomy or ileostomy care or problems		1		$\square_2$	$\square_3$	$\Box_4$	$\Box_5$
l did <u>NOT</u> have a colostomy or an ileostomy, a	ind ther	efo	re th	is questior	n is not app	plicable to m	е.
a. Would you have liked more help with this is	sue? I	⊐ <sub>1</sub>	Yes	$\square_2$ No			
C7. Sexual functioning or sexual relationship issues	. □ <sub>1</sub>			$\square_2$	$\Box_3$	□₄	□5
a. Would you have liked more help with this iss	ue? I	⊐ <sub>1</sub>	Yes	$\square_2$ No			
C8. Prevention of future polyps or cancer recurrence	□ <sub>1</sub>				$\Box_3$	$\Box_4$	□5
a. Would you have liked more help with this iss	ue? I	⊐ <sub>1</sub>	Yes	$\square_2$ No			
C9. Management of stress	$\Box_1$			$\Box_2$	$\Box_3$	$\Box_4$	$\Box_5$
a. Would you have liked more help with this iss	ue? I	⊐ <sub>1</sub>	Yes	$\square_2$ No			
C10. Healthy living: Diet and Exercise	□1			$\square_2$	$\Box_3$	$\square_4$	$\Box_5$
a. Would you have liked more help with this iss	ue? I	⊐ <sub>1</sub>	Yes	$\square_2$ No			
C11. Other issues (please explain)							

**FIGURE 1.** Questions added to the CaSUN measure. \**p* < 0.05. We added 10 treatment-related and surveillance-related needs to the instrument. CaSUN = Cancer Survivors' Unmet Needs.

analyzed the number of cancer treatment-related and surveillance needs for patients with colon and rectal cancer, as well as the number of patients who reported needing more help for each of these problems.

Because the outcome 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  $\beta$ -coefficients, which measure how strongly a predictor is related to an outcome. For example, if the outcome were total unmet needs, a  $\beta$ -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  $p \le 0.05$  for all analyses. All analyses were performed using StataSE version 14 (College Station, TX).

#### RESULTS

#### **Patient Characteristics**

One hundred sixteen patients were approached and 102 responded (88% response rate). We excluded 1 patient with rectal cancer who had locally recurrent disease and 2 patients with rectal cancer who had metastatic disease. In total, we included in the analysis 99 patients (58 with colon cancer, 41 with rectal cancer).

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

In the survey, all domain constructs had moderate to excellent reliability with the exception of logistical needs,

TABLE 1. Characteristics of the cohort					
	Color	Colon		ıl	
Characteristics	n	%	n	%	p value
Patients	58		41		
Sex					
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, mo	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	29	50	28	68	0.070
chemotherapy					
Received radiation	2	3	25	61	<0.001
Received surgery	57	98	39	95	0.367

with Cronbach  $\alpha$  ranging from 0.66 (treatment-related, recurrence-related needs) to 0.80 (emotional needs). For logistical needs, the reliability between the 2 items (need for accessible parking and need for an ongoing case manager) was 0.29.

#### Unmet Needs by Domain

Of 58 patients with colon cancer, 36 (62%) reported at least 1 unmet need, whereas 37 (90%) of 41 patients with rectal cancer reported at least 1 unmet need (p = 0.002) (Fig. 2). Of these patients, patients with colon cancer reported a median (interquartile range) of 1 (0-5) unmet need, whereas patients with rectal cancer reported a median of 4 (2–8) (p = 0.007). Patients with rectal cancer were significantly more likely than patients with colon cancer 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**

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

#### Patients Who Reported Needing More Help

A subset of patients answered affirmatively to needing more help with each of the above treatment-related or surveillance needs, and there were no differences between patients who have colon and rectal cancer 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, whereas radiation therapy was predictive



Percentage of Patients With Unmet Needs by Need Domain

**FIGURE 2.** Prevalence of unmet needs. \*p < 0.05. The percentage of patients with colon and rectal cancer reporting at least 1 unmet need is shown, both for total needs and separated into need domains.

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 with 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 3 years after diagnosis, almost two-thirds of colon cancer survivors and 90% of rectal cancer survivors report at least 1 unmet need. Patients with rectal cancer reported higher



Patients with Unmet Treatment and Surveillance-Related Needs

**FIGURE 3.** Prevalence of unmet treatment- and surveillance-related needs. \*p < 0.05. The percentage of patients with colon and rectal cancer reporting specific treatment-related and surveillance-related needs is shown.

## TABLE 2. Negative binomial regression models for need domains

	β	D	
Unmet needs	Coefficient	value	95% CI
Total unmet needs			
Cancer type (ref: colon)			
Rectal cancer	0.231	0.477	-0.407 to 0.869
Received radiation therapy	0.697	0.082	-0.090 to 1.483
Received chemotherapy	0.345	0.291	-0.296 to 0.985
Underwent surgery	0.406	0.577	-1.021 to 1.832
Age at diagnosis	-0.009	0.406	-0.029 to 0.012
Years from diagnosis	-0.216	0.010	-0.380 to -0.052
Emotional needs			
Cancer type (ref: colon)			
Rectal cancer	0.261	0.486	-0.407 to 0.869
Received radiation therapy	0.736	0.11	-0.090 to 1.483
Received chemotherapy	0.065	0.868	-0.296 to 0.985
Underwent surgery	0.336	0.712	-1.021 to 1.832
Age at diagnosis	-0.016	0.199	-0.029 to 0.012
Years from diagnosis	-0.241	0.021	-0.380 to -0.052
Relationship needs			
Cancer type (ref: colon)			
Rectal cancer	-2.513	0.127	-5.742 to 0.715
Received radiation therapy	3.337	0.051	-0.014 to 6.687
Received chemotherapy	0.678	0.328	-0.680 to 2.037
Underwent surgery	-0.438	0.727	-2.896 to 2.019
Age at diagnosis	-0.031	0.143	-0.073 to 0.011
Years from diagnosis	-0.382	0.054	-0.769 to 0.006
Logistical needs			
Cancer type (ref: colon)			
Rectal cancer	0.023	0.970	-1.174 to 1.220
Received radiation therapy	0.561	0.463	-0.937 to 2.060
Received chemotherapy	-0.078	0.887	-1.147 to 0.992
Underwent surgery	-0.721	0.412	-2.444 to 1.001
Age at diagnosis	0.021	0.231	-0.014 to 0.056
Years from diagnosis	-0.310	0.037	-0.602 to -0.018
Treatment-related needs			
Cancer type (ref: colon)			
Rectal Cancer	0.369	0.245	-0.252 to 0.990
Received radiation therapy	0.822	0.025	0.102 to 1.543
Received chemotherapy	0.304	0.350	-0.334 to 0.943
Underwent surgery	0.239	0.687	-0.922 to 1.400
Age at diagnosis	-0.019	0.063	-0.038 to 0.001
Years from diagnosis	-0.044	0.570	-0.196 to 0.108
Surveillance-related needs			
Cancer type (ref: colon)			
Rectal cancer	0.337	0.459	–0.556 to 1.231
Received radiation therapy	-0.068	0.902	-1.147 to 1.011
Received chemotherapy	0.524	0.229	-0.330 to 1.377
Underwent surgery	0.721	0.549	-1.637 to 3.080
Age at diagnosis	0.004	0.807	-0.025 to 0.032
Years from diagnosis	-0.176	0.125	-0.400 to 0.049

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 patients with rectal cancer may be mediated in part by receiving radiation therapy; alternatively, radiation may be an indicator of receiving more treatment overall as well as more morbid pelvic surgery.<sup>16</sup>

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 patients with colon cancer 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 patients with CRC report neuropathy, 70% of patients report bowel changes, 46% of patients have chronic diarrhea, and 22% of men and 43% of women report sexual changes.<sup>4,17,18</sup> Additionally, Krouse and colleagues<sup>3,19,20</sup> showed that CRC survivors describe negative psychosocial effects, late treatment-related effects, comorbidities, postoperative recovery, and negative experiences with health care as some of their greatest challenges in survivorship, even at 5 years after treatment. Because of its breadth, our study was able to demonstrate that the majority of both patients with colon cancer and with rectal cancer experience a broad range of survivorship needs even years out from the completion of therapy. Colorectal surgeons, medical oncologists, and primary care providers should anticipate that patients with colon cancer are equally susceptible to ongoing emotional stress or surveillance burden, while targeting symptom-related care to patients with rectal cancer. 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.<sup>21,22</sup> 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 trade-off to implementing survivorship care programs, because they may be costly to create and support. However, there may be high personal cost of unaddressed needs for patients; 45% of patients with CRC of working age no longer have their jobs 1 year after diagnosis, and this high rate of financial toxicity may be related to ongoing symptoms.<sup>23,24</sup> In addition, issues such as poor ostomy maintenance may lead to increased health care 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 health care 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 8-month period and were largely white, potentially limiting generalizability to other colorectal cancer practices. Patients with rectal cancer were somewhat overrepresented at 44% of patients (compared with 30% of CRC nationally).<sup>25</sup> 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.<sup>26</sup> 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 that patients had experienced in the past 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 2 of 3 patients with colon cancer and 9 of 10 patients with rectal cancer 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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