Original Contribution

Colorectal Cancer Survivors' Needs and Preferences for Survivorship Information

By Talya Salz, PhD, Shrujal S. Baxi, MD, MPH, Victoria S. Blinder, MD, MSc, Elena B. Elkin, PhD, Margaret M. Kemeny, MD, Mary S. McCabe, Chaya S. Moskowitz, PhD, Erin E. Onstad, MPH, Leonard B. Saltz, MD, Larissa K.F. Temple, MD, FRCS(C), and Kevin C. Oeffinger, MD

Memorial Sloan-Kettering Cancer Center; Queens Cancer Center of Queens Hospital, New York, NY; and Harvard School of Public Health, Boston, MA

Abstract

Purpose: Before developing a survivorship care plan (SCP) that colorectal cancer (CRC) survivors will value, understanding the informational needs of CRC survivors is critical.

Methods: We surveyed survivors treated for nonmetastatic CRC at two hospitals in New York about their needs and preferences for survivorship information. Participants completed treatment 6 to 24 months before the interview and had not received an SCP. We evaluated whether survivors knew their treatment history (10 topics), whether they understood ongoing risks (four topics), and their preferences for receiving 16 topics of survivorship information.

Results: One hundred seventy-five survivors completed the survey. Most survivors remembered information about past treatment (98% to 99% for each treatment). Fewer survivors knew their risks of local recurrence, distant recurrence, or developing a new CRC (69%, 77%, and 40%, respectively). Most participants reported receiving information about their cancer history and ongoing oncology visits (77% to 86% across topics). Across all topics, 93% to 99% of those who reported receiving information found the information useful. A minority of survivors reported they received information about symptoms to report to doctors, returning to work, or financial or legal issues (5% to 48% across topics), but those who did found the information useful (89% to 100% across topics).

Conclusions: In the absence of an SCP, CRC survivors still generally understood their cancer history. However, many lacked knowledge of ongoing risks and prevention. Most survivors stated that they found the survivorship information they received useful. SCPs for CRC survivors should focus less on past care and more on helping survivors understand their risks and plan for the future.

Introduction

For the 1.2 million colorectal cancer (CRC) survivors in the United States, the challenges of cancer extend beyond treatment completion.[1] CRC survivors frequently do not undergo routine surveillance as recommended.[2-10] They also experience psychological distress (including depression and fear of recurrence)[11-13] and issues with health-related quality of life.[14-17] Further, CRC survivors are less likely to receive necessary general medical care, including management of chronic conditions and preventive care, than people who have never had CRC.[18,19]

Visiting both a cancer specialist and primary care physician is associated with better care for CRC survivors than visiting only one type of provider.[20,21] To improve the coordination of specialty and primary care for cancer survivors, the Institute of Medicine (IOM) proposed the use of survivorship care plans (SCPs). An SCP contains a personalized cancer treatment summary and recommendations for ongoing care to be provided by the cancer specialist, the primary care provider, or other providers.[22] Ideally, survivors share their SCPs with their primary care providers, in order to promote optimal post-treatment care. Although researchers have endorsed SCPs and suggested methods of implementation in clinical settings,[23-31] many aspects of SCPs have not been evaluated, particularly for CRC survivors.[32]

SCPs are intended to help survivors seek out appropriate ongoing care, communicate their cancer history to a primary care provider, recognize important symptoms and late effects of their cancer, and find support resources. If CRC survivors are already aware of this information, SCPs may do little to improve the quality of their ongoing care. It is particularly important to understand whether survivors know enough about their cancer to seek out primary care and communicate information about their medical history and follow-up care needs to a primary care provider.

Although CRC survivors have expressed enthusiasm for SCPs,[33,34] their preferences for the content and use of these plans have not been evaluated. Targeting SCPs to survivors' needs and preferences can help maximize survivors' benefit from SCPs. A plan that appeals to survivors has the potential to both enhance their understanding of survivorship issues and increase the likelihood that the survivor will share the information with a primary care provider.

Our study was designed to better understand whether CRC survivors who do not receive SCPs are equipped to communicate relevant information to primary care providers and manage their own care. We also aimed to assess preferences for the content, format, and delivery of SCPs.

Methods

Sample and Data Collection

We conducted a telephone-administered survey of CRC survivors from two hospitals in the New York metropolitan area: Memorial Sloan-Kettering Cancer Center (MSKCC), a private tertiary not-for profit comprehensive cancer center, and Queens Cancer Center (QCC), a comprehensive cancer center at Queens Hospital, a public hospital. We identified patients at both sites through hospital databases and medical record review. Participants were eligible if they were 18 years or older at diagnosis of stages I-III CRC, had completed all nonsurgical treatment for CRC at MSKCC or QCC between 6 and 24 months before the survey, had no evidence of disease at time of survey, and spoke English. We included survivors who received surgery at another hospital but received the remainder of their treatment (chemotherapy, radiation therapy, or both) at MSKCC or QCC. Participants were ineligible if they were diagnosed with metachronous CRC, had metastatic disease, had a history of another cancer other than nonmelanoma skin cancer, received no treatment for their CRC, or received an SCP. At the time of the study, QCC patients and MSKCC patients who had completed treatment within the past 2 years were not offered SCPs. Each patient's last-seen physician was provided an opportunity to exclude the patient from the study. Remaining eligible participants were mailed an invitation and called. Surveys were completed over the phone using a Computer-Assisted Telephone Interview system. All study participants gave verbal consent over the phone. We abstracted diagnosis and treatment data from the medical record. For patients with colon cancer, we used pathological staging. We used clinical stage for patients with rectal cancer when available; otherwise, we used pathological stage. The study was approved by the institutional review boards at both hospitals.

Questionnaire

We designed the survey to evaluate the information survivors may need and want from a survivorship care plan, as described in the IOM framework. Our goal in assessing knowledge of diagnosis and treatment was to understand whether patients with CRC had the minimum amount of information necessary to communicate their diagnosis and treatment history to a primary care provider. The questionnaire elicited 10 basic diagnosis and treatment details: when diagnosis occurred; the site and stage of disease; and whether and when the participant had surgery, chemotherapy, or radiation therapy. We evaluated knowledge of ongoing risks and recommended testing by presenting four statements about risks of local recurrence, risk of distant recurrence, risk of second primary CRCs, and need for ongoing surveillance. For each statement, the response options were a 5-point Likert scale ranging from "strongly agree" to "strongly disagree." We also assessed comparative perceived risk by asking how likely the participant was to have a new CRC compared with someone without a history of cancer, with response options on a 5-point Likert scale ranging from "much less likely" to "much more likely." We assessed receipt of and preferences for survivorship information by asking whether the participant recalled receiving information (in a verbal or written manner) about each of 16 broad topics (adapted from the IOM framework) after treatment completion. If participants reported receiving the information, we assessed whether the patient believed that it was useful. We also elicited preferences for timing of receipt of information and format of delivery.

Analysis

Survey responses were compared with medical record data to assess participant knowledge of their cancer history. Self-reported dates of diagnosis and treatment were considered accurate if they were within ± 30 days of the date in the medical record. Participants' knowledge was considered to be accurate if responses to true statements were "strongly agree" or "agree." For the items that compared CRC risk to that of the general population, "much more likely" and "somewhat more likely" were considered to be accurate responses. All other responses were considered to be inaccurate. Receipt of information and preferences for information were described using means and percentages. Binomial exact tests were used to determine 95% CIs. When there were small numbers and 100% in one group, one-sided 97.5% CIs were calculated. Stata/SE version 11.0 (StataCorp LP, College Station, TX) was used for all analyses.

Results

Sample

Of the 333 eligible participants identified via medical record, 202 (61%) agreed to participate. After confirmation of eligibility by phone, 175 participants (87%) completed the survey. There were no differences between those who refused and participants in terms of sex, tumor site, stage, receipt of surgery, and receipt of chemotherapy or radiation therapy. Study participants were diagnosed between December 2007 and November 2010 and were interviewed between July 2010 and November 2011. As a result of the small number of patients with CRC seen at QCC, nearly all participants (97%) came from MSKCC. The mean age was 59 years, and the mean time since treatment completion was approximately16 months (standard deviation = 5 months; Table 1).

Knowledge of Diagnosis and Treatment

Respondents generally had strong basic knowledge of their diagnosis and treatment (Table 2). Eighty-eight percent knew whether their disease was in their colon or rectum, and 99% to 100% accurately reported whether they had surgery, chemotherapy, or radiation therapy. Across the three treatment types, 77% to 94% of respondents reported the last date of treatment accurately. Seventy-nine percent of patients with colon cancer and 47% of patients with rectal cancer correctly reported their stage. Nineteen percent of patients with rectal cancer and 13% of patients with colon cancer stated that they did not remember their stage. Eighty-six percent of patients accurately reported their stage as nonmetastatic. We also investigated whether patients who require more intensive monitoring (stages II and III)

Table 1. Participant Demographic and Clinical Characteristics (N = 175)

Characteristic	No.	%
Hospital		
Memorial Sloan-Kettering Cancer Center	170	97
Queens Cancer Center	5	3
Sex		
Male	90	51
Female	85	49
Race/ethnicity		
White	150	86
Hispanic	5	3
Black	13	7
Asian	6	3
Other/unknown	1	1
Age at diagnosis, years		
Mean	57	
SD	12	
Age at survey, years		
Mean	59	
SD	12	
Time between diagnosis and survey, months		
Mean	23	
SD	6	
Tumor site		
Colon	101	58
Rectum	73	42
Both	1	1
Treatment received		
Surgery	171	98
Chemotherapy	131	75
Radiation	52	30
Colorectal cancer stage		
I	35	20
II	48	27
III	92	53
Clinical trial participation		
Yes	10	6
No	165	94

Abbreviation: SD, standard deviation.

knew their stage; 79% of this higher risk group reported their stage as II or III.

Knowledge of Ongoing Risks and Recommended Testing

Sixty-nine percent and 77%, respectively, correctly agreed that CRC could return at the original site of disease or in another part of the body (Table 2). Forty percent felt they were more likely to have a new CRC than a person who has never had CRC. Almost all participants (95%) agreed that they needed to continue with routine surveillance of their colon and rectum.

Receipt of Information

Reported receipt of the 16 topics of information is shown in Table 3. Seventy-eight percent and 86% reported that they had received information about their diagnosis and treatment history, respectively. There was a wider range of reported receipt of information about future oncologic and nononcologic care. Most respondents reported receiving information about the importance of visiting an oncologist (77%), the need for tests to monitor for recurrence (82%), and information about diet and exercise (66%). Only 38% reported being told of the importance of visiting a primary care provider after treatment completion. Nonmedical information regarding such topics as support groups, return to work, and potential health insurance and legal issues was not commonly reported as having been received, with rates ranging from 5% to 51% of respondents across six categories.

Preferences for Information

For each of the 16 topics, at least two thirds of respondents who received the information reported that they found it useful (Table 3). Summaries of diagnosis and treatment were found useful by 93% and 96%, respectively, of respondents who received that information. For information about the eight topics of ongoing medical needs, between 94% and 100% of those who reported receiving information reported that it was useful. Among those who received information about nonmedical needs, between 68% and 100% (across six topics) reported that the information was useful.

Additional Topics of Importance

When asked whether there were additional topics of information participants would like to have received after treatment completion, there were 62 comments about late effects and challenges to expect, such as the persistence of fatigue and bowel symptoms. Twenty-two comments addressed the need for information about general health, such as guidance about diet. There were 12 comments about knowing more about what follow-up is recommended, including recommended tests and which physicians may be sensitive to the needs of cancer survivors. Twelve comments concerned the need for information about cancer, such as recurrence risk and prognosis. Finally, there were seven comments that fell outside these categories, including finding local options for ongoing care, getting personalized information, and finding reliable sources of information.

Preferences for Timing and Format of Information Delivery

Fifty-nine percent of respondents volunteered that they would have liked to have had survivorship information provided during their treatment. Twenty-one percent preferred to receive information immediately after treatment completion, and 8% preferred to receive information several months after treatment completion. Although not offered as a response option, 11% of respondents volunteered that they would have liked to have

Table 2. Accuracy of Self-Reported Cancer Information and Risk Perception

Item	n	No. Correct	% Correct	95% CI
Cancer information				
Tumor site (colon *v* rectum)	175	154	88	82 to 92
Treatment received				
Surgery	175	174	99	97 to 99
Chemotherapy	175	174	99	97 to 99
Radiation therapy	175	175	100	98 to 100*
Date of treatment (± 30 days)				
Diagnosis	175	156	89	84 to 93
Surgery	171	160	94	89 to 97
Last chemotherapy treatment	131	101	77	69 to 84
Last radiation therapy treatment	52	46	88	77 to 96
Cancer stage	175	114	65	58 to 73
Clinical trial participation	161	151	94	89 to 97
Risk perception				
Risk of recurrence or second CRC†	167	116	69	62 to 76
Risk of metastasis	175	134	77	70 to 83
Need for ongoing surveillance†	167	159	95	90 to 98

Abbreviation: CRC, colorectal cancer.
* One-sided 97.5% CI.
† Participants who underwent a total colectomy were excluded.

received survivorship information before treatment. Respondents were able to select more than one preferred format for receiving survivorship information. Ninety-three percent stated they would like a conversation with their doctor, and 75% wanted a personalized printed document. Only 61% wanted to receive information from a Web site.

Discussion

Our study found that among survivors who had not received an SCP, knowledge of the most salient aspects of diagnosis and treatment was generally accurate. This confirms prior evidence that CRC survivors know at least basic information about their illness. An Australian study evaluated CRC survivors' recall of

Table 3. Information Given to Survivors After Completion of Cancer Treatment

		Received Information			Found Information Useful		
Topic	n	No.	%	95% CI	No.*	%	95% CI
Type of cancer	174	136	78	71 to 84	127	93	88 to 97
Type of treatment	174	149	86	80 to 90	143	96	91 to 99
Visiting a cancer doctor in the future	175	135	77	70 to 83	131	97	93 to 99
How often to visit a cancer doctor in the future	174	145	83	77 to 89	144	99	96 to 99
Visiting a PCP in the future	172	66	38	31 to 46	63	95	87 to 99
How often to visit a PCP in the future	173	31	31	13 to 24	29	94	79 to 99
Tests to make sure CRC has not come back	175	143	82	75 to 87	141	99	95 to 99
Test to check for other cancers	175	71	41	33 to 48	69	97	90 to 99
Symptoms to tell your doctor about	173	83	48	40 to 56	83	100	96 to 100*
Diet and exercise to keep you healthy	174	115	66	59 to 73	108	94	88 to 98
Support groups for people who have had CRC	175	90	51	44 to 59	61	68	57 to 77
Web sites for people who have had CRC	175	37	21	15 to 28	28	76	59 to 88
People to talk to if feeling sad or anxious	175	89	51	43 to 58	68	76	66 to 85
Going back to work after treatment	173	70	40	33 to 48	63	90	80 to 96
Health insurance or financial assistance issues	174	44	25	19 to 33	39	89	75 to 96
Legal issues related to employment or health insurance coverage	174	9	5	2 to 10	9	100	66 to 100*

Abbreviations: CRC, colorectal cancer; PCP, primary care provider.
* Denominator may not include all those who received information because of missing responses.
† One-sided 97.5% CI.

their own diagnosis and found relatively good recall for broad categories of information (eg, which symptoms prompted diagnosis).[35] A more recent American study found that among CRC survivors in an integrated health care system (mean of 5.8 years from diagnosis), 89% knew the site of their disease; 88% knew the year of diagnosis; and 95% and 96% knew whether they had chemotherapy or radiation, respectively.[36] Although our study included more recently diagnosed CRC survivors (mean 23 months from diagnosis), participants in our study had similarly high accuracy in their recall of disease site, diagnosis year, and receipt of treatment. In both studies, only approximately two thirds of survivors accurately recalled their disease stage. The errors in staging were found primarily among rectal cancer survivors, who typically have a more complicated method of staging. Patients with rectal cancer are staged before treatment (clinical staging) and again after surgery (pathological staging), which may confuse patients. In our study, 79% of higher risk survivors (who need more intensive surveillance) accurately reported having either stage II or stage III disease. If primary care providers rely solely on survivors to report their stage and guide follow-up care, incorrect reporting of stage may result in underuse of surveillance.

Some respondents in our study (23% to 31%) reported that they were not at risk for recurrence and second primary CRCs, suggesting that they were either unaware of their risks or were expressing optimism about remaining cancer free. Although risk perception is often seen as predictive of health behaviors, in our population, 95% of CRC survivors agreed that ongoing surveillance was important. Ideally, a future study would see how closely the intention to receive surveillance is related to actual surveillance.

Taken together, survivors in our study generally recalled basic information about their diagnosis and treatment, although they recalled less information about their stage and ongoing risks. Also, respondents more frequently reported receiving medical information about their cancer or its follow-up than about nonmedical issues, such as support groups, counseling, and financial and insurance issues. The lack of communication about nonmedical issues, ranging from psychosocial support to practical problems, highlights the need for multidisciplinary support for cancer survivors. Many of these topics fall beyond the reasonable purview of oncology providers and suggest that oncology care must at least be supplemented with nonclinical support. SCPs document available supportive resources for CRC survivors and may facilitate the use of these important services.

A troubling finding in our study was that only 38% of respondents recalled being told about the importance of primary care. If oncology providers are not providing this information to survivors, it may, in part, indicate a confidence on the part of the oncologist that survivors are already being seen by a primary care provider. Nevertheless, coordinated post-treatment care depends on active participation of both oncology and primary care providers to ensure comprehensive, nonduplicative care.[22] The SCP has two roles in the coordination of care. First, it informs or reminds the survivor of the importance of visiting a primary care provider. Second, if the primary care provider receives a copy of the SCP (from either the survivor or directly from the oncology provider), the primary care provider gets a concise summary of the survivor's treatment history, information about late effects and ongoing risks that may help guide ongoing primary care, and information about how the oncology provider intends to share post-treatment care.

SCPs serve not only as communication between providers, but also as a way for patients to know what to expect and how to manage their own health. Although not explicitly asked whether they would like to have received an SCP, survivors in our study broadly found the information they received to be useful, and many reported wishing they had received even more information, such as their specific risks for recurrence, changes to their body, recovery time, and symptoms to expect. Survivors also favored receiving this information early: the majority wanted to receive information during treatment. Creating a document that includes a plan of care at the start of treatment could be used as the basis for a summary of treatment to be delivered after treatment completion. Whether patients and survivors would appreciate having an ongoing dynamic document remains untested.

This study was limited in that almost all patients were from one cancer center that is likely not representative of all CRC survivors. However, the similarity of our findings to those in a CRC survivor cohort from an integrated health care system in the Midwest suggests that our findings are externally valid.[36] The study was not sufficiently powered to determine differences by cancer center or other patient characteristics. Future studies should focus on CRC survivors in other hospital settings (including public hospitals), in order to explore such variation. By design, we only asked basic information about cancer diagnosis and treatment, reasoning that this was the minimum amount a primary care provider would need to provide optimal post-treatment care. However, it is possible that CRC survivors would be unable to recall more detailed treatment information, such as specific chemotherapy agents and toxicity information that could be useful to a primary care provider. Also, patients may not have been able to recall accurately whether they received survivorship information when completing treatment. Although receipt of information is likely underreported in this study, limited recall underscores the need for information to be presented in a format that can be reviewed or remembered more than 6 months after treatment completion, when survivorship needs are still salient. Finally, respondents with no evidence of disease may, with the benefit of hindsight, prefer knowing more information than they may have wanted when they initially completed treatment. Survivorship information, particularly about ongoing risks, may be more overwhelming to receive at the time of treatment completion, when the future may feel uncertain. Preference assessment may be useful at various times during the survivorship period.

In summary, although CRC survivors may not need an SCP to communicate basic treatment history with their primary care providers, they prefer to be given this information. CRC survivors reported that the receipt of survivorship information was useful, even in the first 2 years after treatment completion. The primary benefit of SCPs for CRC survivors may be less in recording past care and more in helping them understand their risks and plan for the future.

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Author Contributions

Conception and design: Talya Salz, Victoria Blinder, Elena B. Elkin, Margaret Kemeny, Mary McCabe, Chaya S. Moskowitz, Leonard B. Saltz, Larissa K.F. Temple, Kevin C. Oeffinger

Financial support: Talya Salz

Administrative support: Talya Salz

Collection and assembly of data: Talya Salz, Erin E. Onstad

Data analysis and interpretation: Talya Salz, Shrujal S. Baxi, Chaya S. Moskowitz, Erin E. Onstad

Manuscript writing: All authors

Final approval of manuscript: All authors

Corresponding author: Talya Salz, PhD, Memorial Sloan-Kettering Cancer Center, 307 E 63rd St, 2nd floor, New York, NY 10065; e-mail: salzt@mskcc.org.

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