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Primary care providers' needs and preferences for information about colorectal cancer survivorship care

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Abstract

Background—The Institute of Medicine (IOM) proposed that cancer survivors and their primary care providers (PCPs) should receive survivorship care plans to inform ongoing care. We aimed to determine PCPs' preferences for the content of survivorship care plans for colorectal cancer (CRC) survivors.

Methods—PCPs in three practice-based research networks completed a survey regarding 45 topics of CRC information based on the IOM's survivorship care plan framework.

Results—156 PCPscompleted the survey. For 35 topics (78%), at least half of respondents felt the topic was very important. Most PCPs reported receiving too little information about problems with chemotherapy (68%) or radiation (60%), and whether the oncologist intended to monitor for other cancers (71%). PCPs widely agreed that they do not have enough information about increased risk of second CRCs, other cancers, and other diseases (78%); long-term effects of chemotherapy (73%) and radiation (67%); and genetic counseling (83%).

Conclusions—PCPs endorse the IOM's survivorship care plan framework as relevant and often report needing more information. Survivorship care plans may provide important information to PCPs by communicating patients' cancer histories and making recommendations regarding which aspects of care should be provided by the oncologist or the PCP.

Keywords

Colorectal neoplasms; Colorectal cancer; Colon cancer; Rectal cancer; Survivors; Practice-based research networks; Primary Health Care

Introduction

Primary care providers (PCPs) are critical to cancer survivors' health, delivering general and preventive care and managing multiple conditions that may be unrelated to the cancer. However, PCPs may not feel confident in their ability to care for cancer survivors. They may lack relevant information about their patients' cancer treatment, the intended coordination of care with the oncologist, or general survivorship issues. Survivorship care plans are an intervention that can inform PCPs about the recommended care of cancer survivors. Proposed by the Institute of Medicine (IOM) in their report on cancer survivorship, From Cancer Patient to Cancer Survivor: Lost in Transition, survivorship care

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plans are documents that summarize a survivor's treatment history and recommended ongoing care.[1] The authors of the IOM report recommend that oncologists give patients a survivorship care plan that they can then share with their PCPs. The use of survivorship care plans may benefit PCPs by promoting personalized and coordinated cancer survivorship care.

The IOM report enumerates detailed information to include in a survivorship care plan. The information generally falls into the following categories: a summary of the survivor's diagnosis and treatment, recommendations for ongoing care, and a listing of practical survivorship-related resources (such as support groups). As recipients of survivorship care plans, PCPs may or may not value all of this information. Also, PCPs may wish to receive additional information that is not suggested for inclusion in survivorship care plans. In order to maximize the usefulness of survivorship care plans for cancer survivors, we must better understand the perspectives of PCPs and refine the IOM framework for a survivorship care plan accordingly.

Survivorship care plans must ultimately be tailored to a specific cancer, because not all categories of information in the IOM framework (such as descriptions of hormone receptor status, gene therapy, and familial risk) apply to all cancers. Further, PCPs' needs and preferences for information may vary by disease site. Therefore, we focused our study on a single cancer: colorectal cancer (CRC). The involvement of PCPs is particularly important for CRC survivors, who comprise a large group with documented primary care needs. Over a million people are alive in the United States with a diagnosis of CRC, and with improved early detection and treatment, most live beyond the period of active cancer treatment.[2-3] Although CRC survivors typically do not experience severe consequences of their cancer and therapy after treatment completion (distinguishing them from survivors of many other cancers), they do face ongoing medical and psychological challenges that may be addressed by a PCP.[4-7] CRC survivors also receive poorer quality non-cancer care, including less frequent receipt of general preventive health care, compared to individuals who do not have cancer.[8] CRC survivors who visit a PCP receive more preventive care, compared to survivors who do not visit a PCP.[9-10] Preventive care is especially important in this population, because the lifestyle risk factors for CRC (such as obesity) may also contribute to cardiovascular disease and other serious health problems unrelated to the cancer.

In order to inform the refinement of the IOM framework for CRC, , we conducted a survey of PCPs who have cared for CRC survivors to identify their informational needs and preferences for the content and delivery of CRC survivorship care plans.

Methods

Design and sample

We implemented a cross-sectional survey of PCPs (physicians, physician assistants, and nurse practitioners) from a sample of three practice-based research networks (PBRNs) chosen to provide geographic and practice-setting diversity – one each in Minnesota, Pennsylvania, and New Mexico. PBRNs are networks of clinical practices that involve academic and community clinicians engaged in research on primary care. The Minnesota Academy of Family Physicians (MAFP) Research Network includes providers in all counties of Minnesota among 110 practices, 12% of which are academic practices. The Penn State Ambulatory Research Network (PSARN) encompasses 20 practices in both community and academic settings (86% academic) in Central Pennsylvania. None are private practice. Research Involving Outpatient Settings Network (RIOS Net) includes providers in community health centers, Indian Health Services, and academic settings in 70 practices throughout New Mexico. Approximately one third are academic practices.

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All non-pediatrician PCPs at each network were invited to participate in an anonymous online survey. Invitations to participate were sent via email between July 2010 and April 2011.The invitations explained the study topic, that participation and responses were anonymous, and that the survey was deemed exempt from IRB review at their affiliated institution. Additional emailed invitations were sent to all participants between 3 and 6 times over a period of 2 to 6 months. We attempted to balance the proportion of respondents at each site and therefore extended the enrollment time and increased the number of invitations for sites that recruited more slowly. Interested PCPs could take the survey using log-in codes included in the emailed invitation. The survey began with questions screening for eligibility; PCPs who reported that they provided primary care and cared for at least one CRC survivor in their practice over the past year were deemed eligible to participate and automatically continued on to the survey itself.

Instrument

We designed a self-administered internet-based questionnaire assessing PCPs’ opinions and informational needs for survivorship care plans. (Appendix) Using the IOM's framework for a survivorship care plan, we created 45 topics that were potentially relevant to CRC survivors. These topics fall into the categories of 1) patient-specific information about diagnosis, treatment, coordination of care, and medical reports, and 2) general CRC survivorship knowledge. The questionnaire asked providers to consider the care of patients who completed active curative treatment for CRC and had no evidence of disease. The questionnaire elicited providers’ opinions on 1) the importance of each topic, 2) whether the provider typically had enough information about this topic, and 3) preferences for the format and delivery of this information. For the items assessing importance, response options were “not important”, “somewhat important”, “very important”, and “undecided.” For the items regarding having enough information, the response options were “not enough”, “just the right amount”, “too much”, and “it varies too much to say.” The questionnaire assessed past receipt of categories of information in the IOM framework (summary of diagnosis, summary of treatment, recommendations of ongoing care from PCP, and information on what aspects of care PCP and oncology provider are responsible for). For those who received this information, we asked how useful it was; for those who did not, we asked how useful it would be. The questionnaire included open-ended items pertaining to information that providers needed and questions about provider and practice characteristics. The Web Survey Core at Memorial Sloan-Kettering Cancer Center (MSKCC, http://www.mskcc.org/mskcc/html/90103.cfm) implemented the online questionnaire via a secure and private platform. All data from the survey were anonymously received by MSKCC for analysis.

Analyses

We used descriptive analyses to report preferences and information needs. Participants with missing data were excluded on a question-by-question basis, and those participants missing more than 50% of all responses were excluded from all analyses. For brevity, we presented only the percentage of respondents who reported each topic was very important to know and the percentage of respondents who felt they typically do not have enough information about the topic. We categorized physician specialty based on reported board certification. Physicians who reported multiple specialties were conservatively categorized as belonging to the more common specialty. Responses to open-ended items were grouped into categories and reported descriptively.

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Results

Sample

Of the 409 PCPs who were invited to participate, 191 logged into the survey (47%). Seventeen participants were subsequently found to be ineligible, and 18 participants were excluded because they completed less than 50% of the survey, resulting in 156 participants in the analytic sample. (Table 1) One hundred thirty-seven participants (88%) were physicians; 73% of physicians were family physicians. Because of the high proportion of family physicians, we compared their characteristics to those of the remaining respondents as a group. Family physicians were more likely to be male, were older, and completed training earlier than the remainder of the sample. (Data not shown) The distribution of provider types in our sample was not statistically different from that of the three networks, and we were unable to compare other demographic characteristics in our sample to the three networks. The mean reported number of CRC patients and survivors (i.e., those who completed treatment) seen by respondents in the past year was 2.8 (standard deviation (s.d)=4.40) and 5.5 (s.d.=8.89), respectively.

Importance of topics in IOM framework

We categorized the 45 topics included in the IOM framework as patient-specific (34) or general (11) as shown in Tables 2 and 3. Across the 34 patient-specific topics, 71% (24) were deemed very important to know by at least 50% of respondents. (Table 2) Cancer characteristics (site, stage, grade, and pathology) were deemed important by the majority of participants (60-92%). Similarly, details about treatment (surgery, chemotherapy, and radiation) were deemed very important by at least 50% of participants, except for the date of completion of chemotherapy, the name and dose of chemotherapy drugs, and the dose of radiation. A substantial minority (37-44%) indicated that information about other treatments provided, such as nutritional and psychosocial services, were very important to know. Ninety-eight percent of respondents felt that knowing whether the oncologist intended to monitor for recurrence and second CRCs was very important, and 90% reported that knowing whether the oncology provider intended to monitor for cancer at other sites (e.g., subsequent breast cancer) was very important. Twenty-four of the 36 patient-specific topics (67%) were deemed important or very important by 95% of respondents or more. Only two topics were considered unimportant by more than 20% of respondents: dose of chemotherapy (48%) and dose of radiation (36%). (Data not shown.)

For the eleven topics that are generalizable to all CRC survivors, at least 64% of respondents endorsed each topic as very important. (Table 3) Ninety-eight percent felt knowing the schedule of recommended CRC surveillance was very important, and 98% felt that knowing increased risks for second CRCs, other cancers, and other diseases was very important. Fewer than 2% of respondents deemed each of the eleven topics unimportant.

For each patient-specific or more generalized topic in which fewer than half of respondents deemed the topic very important, between 50% and 97% of respondents deemed the topic either somewhat important or very important. (Data not shown.)

Need for information about topics in IOM framework

For patient-specific information, a substantial proportion of respondents reported typically not receiving enough information about their patient's diagnosis and treatment across all categories. The most widely endorsed topics for which respondents needed more information were knowing the reason for terminating chemotherapy (60%), whether there were any problems with chemotherapy (67%) or radiation therapy (60%), and whether complementary services were provided during treatment, including psychosocial (66%),

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nutritional (66%), and other supportive services (63%). Seventy percent felt they typically did not have enough information about whether the oncologist intended to monitor the patient for cancers at other sites. A substantial minority of PCPs reported not having enough information about key clinical aspects of a cancer diagnosis, such as stage (40%) and grade (44%). Fewer than 5% of respondents felt they had too much information about each topic, with the exception of dose of chemotherapy and dose of radiation, where 5% and 6% of respondents, respectively, felt they had too much information. (Data not shown)

There was a broader consensus that providers typically do not have enough information about more general issues affecting CRC survivors (i.e., information that does not pertain to individual patients). At least half of all respondents reported needing more information about each general topic. Eighty-three percent typically wanted more information about genetic counseling and testing to identify high-risk individuals, while 78% typically needed more information about increased risks for second CRCs, other cancers, and other diseases. None of the respondents felt they had received too much information about CRC survivorship issues.

Additional topics of importance

For the open-ended items asking respondents to report additional needed information, the most commonly listed topics were the impact of the cancer on the family and psychological status of the patient; each topic was mentioned 17 times. Also commonly reported as lacking were patient-specific information about prognosis (9 comments) and comorbidities (7 comments). Providers also lacked information about patients' practical concerns, including financial, legal, and transportation issues (11 comments). *Preference for format*. Eighty-three percent of respondents reported that a printed survivorship care plan would be acceptable, a higher percentage than those who reported that receiving this information via web site, email, or conversation with the oncology provider would be acceptable. (Table 4) In response to open-ended questions about additional acceptable formats for survivorship care plans, nineteen respondents volunteered that they would prefer the information in an electronic document that would become integrated into the electronic medical record.

Past receipt and usefulness

While the vast majority of respondents reported having ever received a summary of diagnosis or a summary of treatment for their patients who completed treatment for CRC (86% and 89%, respectively), a minority reported having ever received recommendations for ongoing primary care or information about what aspects of care the PCP and oncology provider are responsible for (30% and 20%, respectively). (Table 5) Across these categories (summary of diagnosis, summary of treatment, recommendations for ongoing primary care, what aspects of care the PCP and oncology provider are responsible for), more than three quarters of those who had ever received information within each category found it useful (77-81%), and almost all respondents who never received this information reported that they would find it useful (96-100%). Nearly all respondents would like to receive a summary of the diagnosis (100%), a summary of treatment (99%), recommendations for ongoing care the patient should receive from the PCP (96%), and information from the patient's cancer care provider about what aspects of post-treatment care the PCP and the cancer care provider are each responsible for (97%).

Discussion

We identified informational needs of PCPs who care for CRC survivors. When presented with 45 topics included in survivorship care plans, PCPs generally found them important but lacking when caring for CRC survivors. More than three quarters of the topics were deemed

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very important by at least half of participants, and few topics were deemed unimportant, suggesting that the IOM framework includes information that is critical to PCPs.

Surveys of PCPs have typically found some discomfort in taking on care of cancer survivors, either in the capacity of shared care with oncology providers or as sole providers of post-treatment care.[11-14] This may result from limited communication with oncology providers about patients' treatment.[13] Our study found that providers rarely had complete information about CRC survivors' diagnosis and treatment, a problem which PCPs have reported in other studies (although sometimes to a lesser degree).[11,15] Further, most providers in our study valued communication regarding which specialty should assume responsibility for specific aspects of treatment, but only one-fifth ever received information on delineating specific aspects of care between the PCP and the oncology provider.

PCPs have previously noted a lack of training on survivorship issues.[11] Providers in our study reported a need for information about multiple facets of CRC follow-up. Although guidelines for CRC survivorship care are put forth by both the American Society of Clinical Oncology (ASCO) and the National Comprehensive Cancer Network (NCCN), they are limited in scope, focusing on monitoring for recurrences and second CRCs and not on addressing medical and psychological late effects.[16-17] They also are not directly disseminated to PCPs, who may not keep abreast of cancer society guidelines. Indeed, previous studies of PCPs have found limited awareness of guidelines and other information to inform follow-up care for cancer survivors.[11,13]

The use of survivorship care plans may ameliorate both poor communication and limited dissemination of survivorship information. Despite the fact that survivorship care plans were proposed in 2006, fewer than a third of study participants ever received written recommendations for ongoing care, and fewer than a quarter ever received information on what aspects of care PCP and cancer care providers are responsible for. These are key elements of survivorship care plans, and our study demonstrates a critical gap between the IOM recommendations and the actual practice of survivorship care. This gap has been described elsewhere, as implementation of survivorship care plans lags behind recommendations.[18]

Respondents who received written recommendations for ongoing care and descriptions of responsibilities of each provider generally found this information useful. Further, explicit coordination of care with regard to monitoring for CRC recurrence was deemed very important by 98% of respondents. Of those who never received information in survivorship care plans, nearly all reported that it would be useful. Previous studies have found that PCPs are receptive to survivorship care plans as tools to improve coordinated care for cancer survivors.[11-12,15,19-21]

Notably, a small proportion of providers in our study reported that the name and dose of chemotherapy drugs and the dose of radiation were very important, although a substantial proportion of respondents (41-46%) felt they did not have enough information about these topics. This discrepancy may be explained by at least half of respondents finding these topics at least somewhat important. (Data not shown.) These treatment details may be the most relevant risk factors predicting the occurrence of important late effects. However, reporting treatment may be the most burdensome part of completing a survivorship care plan. A simplified strategy for presenting information in survivorship care plans would entail limiting the presentation of treatment details (which PCPs find less important than other information) but providing clear guidance about how to prevent, detect, and manage the late effects of treatment.

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Our study had a limited response rate, although it is similar to the response rate (37%) achieved in a similar internet-based survey of providers within PBRNs.[22] In that study, an option of a mailed paper-based survey improved response rates, but we opted to limit our survey to internet-based administration to reduce network and clinician burden. It is possible that those who did not respond to our internet-based survey but would have responded to a paper-based survey have different informational preferences, especially regarding the format of receiving information, than our sample. It is also possible, more generally, that our sample participants were more interested than nonresponders in the challenges of caring for CRC survivors or felt a stronger need for information, potentially biasing our results toward demonstrating greater informational needs. The widespread agreement across issues raised in this study suggests that even if there were a bias, a pattern of strong needs and preferences for information would remain. This study was not powered to identify predictors of preferences for information, which may vary by provider characteristics, such as experience with CRC survivors. This survey relied on providers to recall their experiences and report estimates, and we were unable to verify responses. The three sites chosen for this study may not be generalizable to all PCPs. However, we have no reason to believe that participants were more or less informed about CRC or interested in receiving survivorship information than PCPs elsewhere.

Our study focused on the use of survivorship care plans as static documents communicating information from the oncologist to the PCP, as described in the IOM report.[1] However, coordination may be enhanced with the use of dynamic survivorship care plans that oncologists update over the course of treatment and follow-up, thereby keeping PCPs informed while the patient is under the oncologist's care.[23-24] At the same time, PCPs may wish to inform the oncologist about changes in the survivor's health status, the provision of testing, or other general preventive measures. Future studies should examine whether a dynamic survivorship care plan would be useful and feasible for PCPs, CRC survivors, and oncologists.

This is the first published study that we are aware of to assess the potential usefulness to PCPs of the IOM framework for survivorship care plans for CRC survivors. Our sample of PCPs, which includes physicians and non-physician providers in academic and community settings in multiple distinct locations, represents a wide array of practitioners. Despite this diversity, there is widespread agreement that providers would appreciate and use the information in the IOM framework. There are deficiencies in communication about survivors’ treatment history and specific gaps in knowledge about CRC survivorship, both of which should be addressed in survivorship care plans created for CRC survivors.

Findings from this study suggest that PCPs want comprehensive CRC survivorship information, but before calling for the development of lengthy CRC survivorship care plans, further research with oncologists must assess whether creating such detailed documents is feasible and deemed an important use of clinical resources. Our study still provides a strong evidence base for the creation of a CRC survivorship care plan that responds to the needs of PCPs. The development of a new CRC survivorship care plan will provide a basis for future research evaluating whether survivorship care plan use resolves deficiencies in care for CRC survivors. Specifically, studies need to address whether survivorship care plans facilitate coordination of care, improve quality of care, and help PCPs feel more comfortable in providing care to CRC survivors.

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Table 1

Demographic and practice characteristics of study sample (N=156)

	N	(%)	Mean	(SD)
Practice-based research network				
Minnesota Academy of Family Practice	43	(28)		
Penn State Ambulatory Research Network	55	(35)		
Research Involving Outpatient Settings Network	58	(37)		
Male Gender	90	(58)		
Profession				
Physician: Family medicine	115	(74)		
Physician: Internal medicine[a]	20	(13)		
Physician: No board certification reported	2	(1)		
Nurse practitioner	13	(8)		
Physician assistant	6	(4)		
Electronic medical records used in practice (%)	134	(86)		
Age in years			50	(9)
Year training completed			1989	(10)
Cancer patients[b] seen in last year			20	(30)
Colorectal cancer patients[b] seen in last year			3	(4)
Survivors[b] of any cancer seen in last year by PCP			44	(67)
Survivors[b] of colorectal cancer survivors seen in last year by PCP			6	(9)

[a] One family physician was also board certified in internal medicine

[b] “Patient” refers to people currently undergoing treatment. “Survivor” refers to those who completed treatment.

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Table 2

PCPs' perspectives regarding information about individual colorectal cancer survivors' diagnosis and treatment characteristics

Topic (adapted from Institute of Medicine Report)	Very important to know		Not enough information	
	n	(%)	n	(%)
Diagnosis				
The stage of the patient's disease	143	(92)	63	(40)
The grade of the patient's disease	122	(78)	68	(44)
The site of the patient's disease (colon or rectum)	113	(73)	34	(22)
The relevant pathology of the patient's disease	104	(67)	64	(42)
Where the patient received treatment	93	(60)	38	(24)
The method of diagnosis	76	(49)	36	(23)
Surgery				
If the patient had surgery	144	(92)	15	(10)
Any lingering effects of surgery	140	(90)	84	(55)
What the patient's anatomy is post-surgery	126	(81)	97	(63)
If there were surgical complications	108	(69)	87	(56)
The date of the patient's surgery	89	(57)	32	(21)
Chemotherapy				
If the patient had chemotherapy	147	(94)	28	(18)
The reason for terminating chemotherapy	123	(79)	93	(60)
Whether there were problems with chemotherapy	120	(77)	104	(68)
The contact information for the doctor who administered chemotherapy	96	(62)	66	(42)
The name of each chemotherapy drug administered	56	(36)	67	(43)
The dates each regimen of chemotherapy was completed	43	(28)	73	(47)
The dose of each chemotherapy drug administered	8	(5)	71	(46)
Radiation				
If the patient had radiation therapy	146	(94)	26	(17)
Whether there were problems with radiation therapy	128	(82)	93	(60)
The reason for terminating radiation therapy	111	(72)	87	(56)
The location where radiation was administered	97	(62)	69	(45)
The contact information for the doctor who administered radiation therapy	86	(55)	62	(40)
The date radiation therapy was completed	85	(54)	61	(39)
The dose of radiation	25	(16)	64	(41)
Other aspects of treatment				
If the patient was hospitalized for complications during treatment	109	(70)	76	(49)
Whether psychosocial services were provided during treatment	69	(44)	103	(66)
Whether the patient was in a clinical trial	63	(40)	87	(56)
Whether other supportive services were provided during treatment	59	(38)	99	(63)
Whether nutritional services were provided during treatment	58	(37)	103	(66)

Topic (adapted from Institute of Medicine Report)	**Very important to know**		**Not enough information**	
	n	**(%)**	**n**	**(%)**
Coordination of care				
Whether the cancer care provider(s) intend(s) to monitor the patient for recurrences and second primaries	153	(98)	90	(58)
Whether the cancer care provider(s) intend(s) to monitor the patient for cancers at other sites	141	(90)	109	(71)
Medical reports				
The pathology report	106	(68)	71	(46)
The operative report	73	(47)	62	(40)

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Table 3

PCPs' perspectives regarding colorectal cancer survivorship issues

	Very important to know		**Not enough information**	
Topic	**n**	**(%)**	**n**	**%**
Any increased risks for second colorectal cancers, other cancers, and other diseases	153	(98)	122	(78)
The schedule of recommended colorectal cancer surveillance	153	(98)	79	(51)
Possible signs of recurrence and second tumors	145	(93)	93	(60)
The schedule of recommended screenings for non-colorectal cancers	139	(89)	85	(54)
Chemoprevention strategies for secondary prevention (e.g., tamoxifen in women at high risk for breast cancer)	135	(87)	112	(72)
The possible long-term risks and complications from radiation therapy	135	(87)	104	(67)
The possible long-term risks and complications from chemotherapy	131	(85)	114	(73)
Other types of follow-up care providers that may be needed (e.g., rehabilitation, fertility, psychology)	124	(79)	111	(71)
Genetic counseling and testing to identify high-risk individuals who could benefit from more comprehensive cancer surveillance	122	(78)	129	(83)
Possible effects of cancer on marital/partner relationship, sexual functioning, work, parenting, and future needs for psychosocial support	117	(75)	99	(63)
Support groups and other resources for colorectal cancer survivors	100	(64)	105	(67)

Total number of respondents does not always equal 156 due to missing data.

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Table 4

Preferences for format and delivery of survivorship care plan.

	Number (%) who would like this
Format	
Printed document	129 (83)
Website	39 (25)
Email	44 (28)
Conversation with cancer care provider	50 (32)
Delivery	
From the patient at an office visit	32 (21)
Directly from the cancer care providers office	153 (98)

Note: Percentages do not add to 100 because respondents could select multiple formats or styles of delivery.

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Table 5

PCPs' perspectives regarding receipt and usefulness of information about colorectal cancer survivors.

		Ever received component		If ever received component, was it:			
				Extremely useful		Somewhat useful	
Component of survivorship care plan	**N**	**Yes**	**%**	**N**	**(%)**	**N**	**(%)**
Summary of diagnosis	156	130	(86)	99	(76)	30	(23)
Summary of treatment	155	133	(86)	102	(77)	30	(23)
Recommendations for ongoing primary care	156	45	(29)	36	(80)	9	(20)
Information on what aspects of care PCP and cancer care providers are responsible for	156	31	(20)	25	(81)	6	(19)