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Implementing Survivorship Care Plans for Colon Cancer Survivors

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Abstract

Purpose/Objectives—To evaluate the feasibility, usability, and satisfaction of a survivorship care plan (SCP) and identify the optimum time for its delivery during the first 12 months after diagnosis.

Design—Prospective, descriptive, single-arm study.

Setting—A National Cancer Institute–designated cancer center in the southeastern United States.

Sample—28 nonmetastatic colon cancer survivors within the first year of diagnosis and their primary care physicians (PCPs).

Methods—Regular screening identified potential participants who were followed until treatment ended. An oncology certified nurse developed the JourneyForward™ SCP, which then was delivered to the patient by the oncology nurse practitioner (NP) during a routine follow-up visit and mailed to the PCP.

Main Research Variables—Time to complete, time to deliver, usability, and satisfaction with the SCP.

Findings—During one year, 75 patients were screened for eligibility, 34 SCPs were delivered, and 28 survivors and 15 PCPs participated in the study. It took an average of 49 minutes to complete a surgery SCP and 90 minutes to complete a surgery plus chemotherapy SCP. Most survivors identified that before treatment ended or within the first three months was the preferred time to receive an SCP.

Conclusions—The SCPs were well received by the survivors and their PCPs, but were too time and labor intensive to track and complete.

Implications for Nursing—More work needs to be done to streamline processes that identify eligible patients and to develop and implement SCPs. Measuring outcomes will be needed to demonstrate whether SCPs are useful or not.

Keywords

survivorship care plans; colon cancer; communication; transitions; survivorship

Cancer survivorship care represents a distinct phase of the cancer care trajectory and includes four components of care (Hewitt, Bamundo, Day, & Harvey, 2007). The 2007 Institute of Medicine (IOM) report *Implementing Cancer Survivorship Care Planning* (Hewitt & Ganz, 2007) recommended providing cancer survivors and their primary care provider (PCP) with a treatment summary and a care plan as a component of survivorship care. More recently, the American Society of Clinical Oncology (ASCO) identified survivorship care plans (SCPs) as part of high-quality cancer survivorship care, enhancing communication and coordination of care between providers and the patient (McCabe & Jacobs, 2008). Since the IOM recommendations were issued, clinicians have struggled to develop and implement SCPs because of time constraints, lack of development reimbursement, and challenges in health information systems (Jacobs et al., 2009; Schrag, 2006). Because knowledge about SCP development, implementation, and outcomes is nascent, evaluation of system- and patient-level processes and outcomes are needed (Earle, 2007).

Individuals diagnosed with colon cancer comprise the third largest group of male and female cancer survivors in the United States, with over one million survivors (National Cancer Institute, 2014); therefore, treatment and ongoing surveillance are critical for this high-risk population (Figueredo et al., 2003). To improve outcomes, survivors need to learn about surveillance, health maintenance, and health-promotion recommendations to decrease the risk of recurrence and to facilitate early detection (Desch et al., 2005; Hewitt et al., 2007; Hewitt, Greenfield, & Stovall, 2005).

Stage I, II, or III colon cancer is treated with surgery. Adjuvant chemotherapy generally is recommended for stage III and some high-risk stage II colon cancers (i.e., those with obstruction or tumor adherence to adjacent structures) to prevent or delay recurrence and improve survival (Benson et al., 2011). Following recommended surveillance after the completion of treatment has been shown to decrease mortality; however, adherence to this evidence-based schedule is low (Desch et al., 2005; Faul et al., 2012; Faul, Shibata, Townsend, & Jacobsen, 2010; Snyder, Earle, Herbert, Neville, Blackford, & Frick, 2008a,

2008b). Cancer and its treatment can cause permanent body changes (e.g., surgical scarring) and symptoms that may last for years or be permanent (e.g., peripheral neuropathies, diarrhea or frequent bowel movements), along with other physical and psychosocial sequelae that also may need to be addressed (Edwards et al., 2002; Hewitt & Rowland, 2002; Schlairet, Heddon, & Griffis, 2010). To monitor for the recurrence or occurrence of new colon cancers in patients with stage II or III disease, ASCO guidelines recommend routine surveillance with a history and physical examination, a carcinoembryonic antigen blood test, an annual chest and abdominal computed tomography scan, and a colonoscopy within the first three years after diagnosis and then every five years for those at normal risk or as directed by the results (Desch et al., 2005).

SCPs provide a communication tool for providers and patients. A number of surveys have been conducted asking PCPs, oncologists, and patients about the use of SCP. Although they all endorse the concept of an SCP (Baravelli et al., 2009; Watson, Sugden, & Rose, 2010), less consensus exists as to who should prepare and deliver it, and when that delivery should occur within the cancer continuum. The optimal timing of SCP delivery from survivors' or providers' perspectives has not yet been determined.

Given the discordant views of who should administer certain aspects of care to survivors (Cheung, Neville, Cameron, Cook, & Earle, 2009; Cheung, Neville, & Earle, 2010), delivering a copy of the SCP to both the patient and the PCP may foster communication among the oncologist, survivors, and the PCP as well as promoting shared care, adherence to screening, and health promotion. As the projected growth in cancer survivors and shortage of oncologists will most likely shift care back to the PCPs, this becomes increasingly important. In recent analyses of an online SCP, 53% percent of participants reported follow-up care from only their oncologist, 13% from only their PCP, and 32% from both; few participants (12%) received survivorship information (Hill-Kayser, Vachani, Hampshire, Jacobs, & Metz, 2009). Evaluating the process of delivering SCP to the survivor and PCP is needed.

JourneyForward™ provides free web-based SCP templates created in collaboration with the National Coalition for Cancer Survivorship; University of California, Los Angeles Cancer Survivorship Center; Oncology Nursing Society; WellPoint, Inc; and Genentech (www.journeyforward.org). JourneyForward SCPs have templates for treatment summaries and surveillance, with a version specifically adapted for colon cancer survivors. Therefore, this pilot study developed, implemented, and evaluated the feasibility, acceptability and satisfaction of the JourneyForward SCP for stage I–III colon cancer survivors from both the survivor and provider perspectives.

Methods

This was a descriptive study of colon cancer survivors treated at a National Cancer Institute (NCI)–designated comprehensive cancer center in the southeastern United States and their PCPs conducted over one calendar year.

Patients with stage I, II, or III colon cancer who had completed treatment and were within the first year of diagnosis were eligible. Participants also had to be older than 21 years and able to read and speak English.

Institutional review board approval was received, and potentially eligible patients were identified at the weekly gastrointestinal (GI) tumor board meeting where all patients newly diagnosed with colon cancer are presented. Their electronic medical records were screened for eligibility and then followed on a weekly basis for appointments. To recruit other potentially eligible colon cancer survivors, the study program manager reviewed weekly schedules of the 11 GI oncology providers. Once a potentially eligible patient was identified, an SCP was developed using the JourneyForward template by an oncology certified nurse (OCN[®]) trained in its use. Any discrepancies or questions were reviewed by the medical oncologist on the team. The OCN kept a log of how long it took to complete each SCP and any issues that arose in preparing it. The nurse practitioner (NP) for the surgical or medical oncology team was notified the week the patient was scheduled for a follow-up appointment and was given the patient's SCP. The SCP draft was reviewed and finalized by the NP and then reviewed with the patient.

After completing the SCP review with the patient, the NP briefly described the study and requested permission for a follow-up contact by study personnel; study personnel then obtained informed consent when first contacting the patient. SCPs were delivered 6–12 weeks after completion of the patient's treatment or at any scheduled return visit from 3–12 months after diagnosis. The SCP visit was billed using length of time at a level four or five evaluation and management code with appropriate documentation for Centers for Medicare and Medicaid Services reimbursement (Schrag, 2006). The NP kept a log of the visits, including length of time to deliver the SCP verbally and in print, as well as any issues regarding the tool or visit. The study personnel then contacted the patient at home and completed the study measures by phone two weeks after the visit; patients were sent a \$20 gift card and a copy of NCI's *Facing Forward: Life After Cancer Treatment*.

A paper copy of the SCP was sent by mail to the PCP on record along with a cover letter and a review article (Ganz, 2009) on the care of adult cancer survivors (Mayer, Gerstel, Leak, & Smith, 2012). Follow-up by the program manager with the PCPs was conducted within two weeks of SCP delivery with a mailed followup survey. A reminder was sent two weeks later if the survey had not been returned. Return of the survey reflected consent from the PCP.

Measures

Demographic and medical information were collected from the participant and his or her medical record. Logs were completed to track the process of developing and implementing SCPs.

A modified **System Usability Scale (SUS)** (Brooke, 1996) was used to evaluate the SCP tool from the PCPs' and survivors' perspectives (Sauro, 2011). The measure consists of six items with a five-point Likert-type scale ranging from 1 (strongly disagree) to 5 (strongly agree). Comments were solicited about each section of the SCP and usability of the SCP overall.

An adapted version of the Agency for Healthcare Research and Quality's Consumer Assessment of Healthcare Providers and Systems Adult Specialty Care Clinician Questionnaire (Hargraves, Hays, & Cleary, 2003) was used, including eight items regarding care received from NPs, including provider communication, health promotion and education, help with problems or concerns, and demographics (Cronbach alpha > 0.75). A six-point Likert-type scale ranging from 1 (not at all) to 6 (all the time) was used. Participants also were asked to add any comments about the SCP.

Descriptive statistics were computed for all variables for each participant. Continuous variables were summarized using means, standard deviations, medians, minima, and maxima. Categorical variables were summarized with frequencies and percentages. Reliability coefficients were computed for all scales.

Results

Seventy-five patients were screened, 49 patients were eligible and had an SCP developed, and 34 SCPs were delivered; a total of 28 survivors and 15 PCPs participated in this study (see Figure 1). Fifteen patients were considered lost to follow-up as they did not receive their SCP; 28 of those who received their SCP agreed to participate in the study. Of the 28 survivors, 11 had surgery only and 17 had surgery and chemotherapy (see Table 1). Surgery-only survivors were predominantly female, older, Caucasian, married, and had a high school education. Survivors who received surgery and chemotherapy were more likely to be male, younger, and college educated. PCPs were female, physicians, younger than 50 years, and in practice an average of 23 years (see Table 2).

It took the OCN an average of 49 minutes (SD = 27, range = 30–90) to complete a surgery SCP and 90 minutes (SD = 48, range = 45–210) to complete a surgery and chemotherapy SCP. Although the authors' institution uses electronic health records, chemotherapy was documented in separate electronic and paper records, which meant accessing multiple physical and electronic sites to complete the SCP. In addition, clinic notes did not consistently or clearly document side effects and changes in chemotherapy drugs or dosing, which needed to be included in the SCP, accounting for the increased preparation time compared to the surgeryonly participants.

A total of 34 SCPs were delivered to patients; 6 were not delivered because of missed appointments or extremely busy clinics on the day they were to be delivered. Delivery took an average of 16 minutes (SD = 2, range = 15–20) for the surgery SCP, and 26 minutes (SD = 2.2, range = 25–30) for the surgery and chemotherapy SCP during a regularly scheduled surveillance visit. At the end of the study, the NPs did not feel an SCP added time to the regular visit, but provided more structure when reviewing the information contained within the SCP.

Almost all survivor participants found the SCP easy to use and understand (see Table 3). Although some thought they would need help using it, the SCP received high satisfaction (\bar{X} = 5, SD = 0.56) and usability (\bar{X} = 4, SD = 0.38) ratings from survivors. PCPs rated the usability of the SCP highly (\bar{X} = 4, SD = 0.5) but commented that it was too long for their

use (see Table 4). Written comments from patients and PCPs were reviewed by the study team; all were positive and related to the reassurance the written plan provided.

Eighteen participants thought the SCP should be delivered either before the end or within the first three months of completing treatment. In addition, survivors were highly satisfied (5.4/6) with their SCP visit. Twenty-seven survivor participants felt enough time was spent on their visit, and that they had things explained to them, and 26 felt that were encouraged to ask questions.

Discussion

Many patients with cancer find the transition from acute treatment to extended survival difficult (Hewitt et al., 2005). Survivors may not know the significance of surveillance, in particular, what tests need to be done, who to see, or how often to go for follow-up visits once treatment is over. Many do not receive the recommended follow-up care for colon cancer (Cooper & Doug Kou, 2008; Davies et al., 2012; Earle & Neville, 2004).

This study was conducted for one type of cancer in a single institution. Attrition at each step of the process demonstrates the difficulty in conducting studies mirroring clinical practice (for example, one of the two NPs had maternity leave during the study and patients were missed during this time). Because the study was limited to one year, researchers were not able to follow the patients and providers over time to measure outcomes such as adherence to the surveillance guidelines. Although these issues limit generalizability, the study did provide an in-depth look at the logistics behind the development and implementation of an SCP. The greatest barriers in the development and implementation of SCPs were identifying the patients and delivering the SCP during busy clinical practices. If electronic health records could be developed and programmed to populate the SCP and alert the provider when a patient might be due for an SCP, much of the development time could be reduced, making this a more feasible intervention.

A number of studies have been conducted on patients' and PCPs' preferences and experiences (Kantsiper et al., 2009; Lawler, Spathonis, Masters, Adams, & Eakin, 2011; Lewis et al., 2009; Nissen et al., 2007; O'Malley & Cunningham, 2009; Rowland, 2008; Skolarus et al., 2011). Faul et al. (2012) conducted in-depth interviews with seven colon cancer survivors who had received an SCP and their respective oncology providers from one setting (Faul et al., 2012). The survivors found the printed SCP versions very helpful and used them as a guide for care, many sharing with others and bringing them to appointments. Survivors also saw value in the SCP as a tool to help reduce duplication of testing, addressing their fear of recurrence and providing peace of mind. Oncology providers generally were supportive but did raise concerns about the logistics of their development, sustainability, and impact on outcomes (Potosky et al., 2011). PCPs may not feel they have the information they need to provide survivorship care to colorectal cancer survivors (Salz, Oeffinger, Lewis, et al., 2012; Salz, Oeffinger, McCabe, Layne, & Bach, 2012); the SCP could be one means to deliver that information.

Although still nascent, a growing number of studies are evaluating the outcomes of SCP delivery (Grunfeld et al., 2011; Hershman et al., 2013; Nissen, Tsai, Blaes, Swenson, & Koering, 2013). Grunfeld et al. (2011) conducted a randomized, controlled trial of 408 Canadian women with breast cancer at a mean of 35 months after diagnosis. The women either acted as controls and received a discharge visit prior to returning to their PCP, or they were in the intervention group and received an SCP (Grunfeld et al., 2011). The only significant differences between the two groups were found in knowledge of follow-up care. Those who received the SCP significantly identified that their PCP was responsible. The researchers did not describe the process or time needed to complete the SC, but they were delivered by a nurse during a 30-minute session during the discharge visit. Hershman et al. (2013) randomized women with breast cancer to receive the NCI's *Facing Forward: Life After Cancer Treatment* booklet with or without meeting an NP and nutritionist who delivered an SCP six weeks after completing treatment. Women in the intervention group had less worry at three, but not six, months afterward. Again, the researchers did not describe the process or content of SCP development. Nissen et al. (2013) sent treatment summaries by mail to colorectal and breast cancer survivors who were eight years post-diagnosis, and then surveyed them 17 months later. Although knowledge about diagnosis did increase, it was still very low. Again, no details were given about SCP development.

Other studies have looked at variations within practice, such as the percent of oncology providers or programs reporting developing and delivering SCPs and of PCPs who have received them (Howell et al., 2012; Merport, Lemon, Nyambose, & Prout, 2012; Salz, Oeffinger, McCabe, et al., 2012). Adoption of the 2005 IOM recommendation has been slow (Birken, Mayer, & Weiner, 2013; Chubak et al., 2012; Stricker et al., 2011; Stricker, Jacobs, & Palmer, 2012), which may, in part, be because of barriers to development and lack of significant benefits in patient outcomes (Grunfeld & Earle, 2010; Hershman et al., 2013; Stricker et al., 2011). However, the American College of Surgeon's (2012) Commission on Cancer has adopted a standard that requires that by 2015,

The cancer care committee develops and implements a process to disseminate a comprehensive care summary and follow-up plan to patients with cancer completing cancer treatment. A survivorship care plan is prepared by the principal provider(s) who coordinated the oncology treatment, is given to the patient on completion of treatment, contains a record of care received, important disease characteristics, and a written follow-up plan. (p. 78)

More work needs to be done to improve the development and implementation process of SCPs to increase adoption (Salz, Oeffinger, McCabe, et al., 2012; Wolin, Colditz, & Proctor, 2011). Electronic health records may lessen the development time of SCPs but other process issues still need to be addressed, such as systematically identifying eligible patients, the timing of delivery, and the provider responsible for delivering the SCP to the patient and sharing it with the PCP. Institutional cancer committees may champion or provide support to attend to this process. As SCPs become disseminated more widely, survivor outcomes may be measured. For example, do SCPs increase adherence to surveillance recommendations? Do they reduce redundant testing or promote more evidence-based surveillance? Is it the SCP that makes the difference or the survivorship visit when it is delivered? Lessons learned

about implementation of the SCP from this study also can be used for implementation and evaluation in other settings or with other types of cancer. Given the new Commission on Cancer's standard on SCPs, these issues will need to be addressed.

Knowledge Translation

Survivorship care plans (SCPs) will be required as evidence of quality cancer care in new standards by the American College of Surgeon's Commission on Cancer.

Nurses will serve a key role in addressing those standards in their practices.

Organizations will need to address the time and resources needed to develop SCPs before questions about effectiveness can be addressed.

Limitations

This study was done in a single academic center focusing on one tumor population, which limits generalizability to other types of practice settings and populations. It does, however, identify a process for implementation and evaluation that may be useful in other settings.

Implications for Nursing

Before asking questions about effectiveness, SCPs must be developed and implemented. Long-term studies on the use of SCPs are needed to measure patient and provider outcomes (Haq et al., 2013; Hill-Kayser et al., 2013). As more institutions move to electronic health records, there may be ways to semi-automate the development of SCPs to facilitate completion in a more streamlined manner. However, systems will still need to be in place to identify, track, and evaluate their implementation in cancer programs.

Nurses will be instrumental in addressing the development and implementation of SCPs in cancer practices. Participation in cancer committees also will be necessary to raise system issues to make this practice possible for the majority of patients ending their cancer treatment. Systems that identify eligible patients and how to develop, deliver, and document this activity will be important in meeting this Commission on Cancer standard.

Conclusions

This pilot study developed, implemented, and evaluated the feasibility, usability, and satisfaction of the JourneyForward SCP from both the survivor (n = 34) and provider (n = 15) perspectives. A number of issues prevented all of the developed SCPs from being delivered. For example, it took an average of 49 minutes to complete a surgery SCP and 90 minutes to complete a surgery and chemotherapy SCP. Survivors also preferred receiving the SCP just before treatment ended or within the first three months. The SCPs were well received by the survivors and their PCPs. This process needs to be streamlined to encourage more widespread adoption. Only then will researchers determine whether SCPs help facilitate care coordination and communication to improve the quality of cancer care (Parry, Kent, Forsythe, Alfano, & Rowland, 2013).

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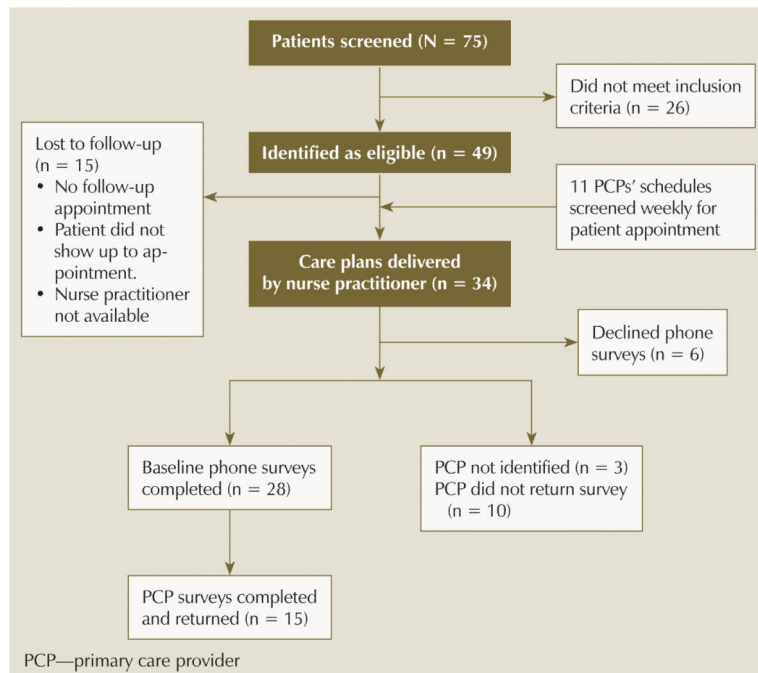


Figure 1. Patient and Provider Survivorship Care Plan Recruitment

Table 1

Sample Characteristics (N = 28)

Characteristic	Total			Surgery (n = 11)			Surgery and Chemotherapy (n = 17)		
	\bar{X}	SD	Range	\bar{X}	SD	Range	\bar{X}	SD	Range
Age (years)	56	13.4	35–87	62	15.8	39–87	52	10.5	35–70
Time since diagnosis (months)	9	3.2	3–13	9	3.2	3–13	10	2.3	6–13
Characteristic	n			n			n		
Gender									
Male	15			5			10		
Female	13			6			7		
Race									
Caucasian	23			10			13		
African American	5			1			4		
Marital status									
Married	18			8			10		
Other	10			3			7		
Education									
High school	11			6			5		
Some college	1			1			–		
College or more	16			4			12		
Insurance type									
Private	15			5			10		
Medicare	7			4			3		
Medicaid	4			1			3		
Missing data	2			1			1		
Stage									
I	7			6			1		
II	9			5			4		
III	12			–			12		

Table 2

Primary Care Providers' Demographics (N = 15)

Characteristic	\bar{X}	Range
Years in practice	23	3–45
Characteristic	n	
Gender		
Female	15	
Age (years)		
Younger than 50	9	
50 and older	6	
Role		
Medical doctor	13	
Other	2	

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Table 3

Patient Evaluation of the Survivorship Care Plan (SCP) (N = 28)

Patient-Centered Communication	Total	Surgery Only (n = 11)	Surgery and Chemotherapy (n = 17)
	Agree or Strongly Agree	Agree or Strongly Agree	Agree or Strongly Agree
Explained things so I can understand	27	11	16
Listened carefully to me	24	11	13
Easy to understand	27	11	16
Showed respect	26	11	15
Checked my understanding	25	11	14
Spent enough time	27	11	16
Encouraged questions	26	11	15
Talked about specific things	26	11	15
SCP Usability	Agree or Strongly Agree	Agree or Strongly Agree	Agree or Strongly Agree
Easy to understand	26	10	16
Simple to use	26	10	16
Good length	24	9	11
Useful	27	11	16
Covered correct topics	27	11	16
Needed help using it	7	4	2
Best time to receive the SCP			
Before treatment ends	8	2	7
3 months post-treatment	10	7	–
6 months post-treatment	8	2	7
9 months post-treatment	2	–	3

Table 4

Provider Evaluation of the Survivorship Care Plan (N = 15)

Survivorship Care Plan Usability	Agree or Strongly Agree
Easy to understand	14
Good length	9
Useful	14
Covered correct topics	14

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