

Patient and Provider Preferences for Survivorship Care Plans

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Abstract

Purpose: Survivorship care plans (SCPs) are tools used to assist in the transition from treatment to surveillance cancer care. However, few studies have investigated survivor and provider preferences regarding SCPs. Our purpose was to explore survivor and primary care provider preferences regarding content, format, and delivery of SCPs.

Methods: Focus groups and provider interviews were performed in 2010. Five different templates were presented to study participants for their feedback. Each SCP included a treatment summary, surveillance schedule, and care plan for the same fictitious patient. Sessions were transcribed, and field notes taken.

Results: Four focus groups (n = 29 survivors) and five primary care providers participated. No cancer survivors had ever received a written SCP. We found clear preferences for the Journey Forward format (with some modifications) and face-to-face delivery (print or electronic) to the survivor by his or her oncologist just before or soon after completion of treatment. Primary care providers preferred an abbreviated version.

Conclusion: Written SCPs were endorsed by all patients and primary care providers as helpful communication tools. However, if used alone, the SCP would be insufficient to ease the transition to follow-up care. Improved communication and care coordination were identified as important for survivorship care that went beyond what this document might provide.

Introduction

The number of individuals living with a cancer diagnosis in the United States has increased from 3 million in 1971 to nearly 12 million today. In the 2005 Institute of Medicine report *Lost In Transition: From Cancer Patient to Cancer Survivor*, survivorship care was identified as a distinct phase of the cancer care trajectory. Its four components are: one, prevention and detection of new cancers; two, surveillance for cancer recurrence or new cancers and interventions for consequences of cancer and its treatment; three, psychologic distress management; and four, coordination between specialists and primary care providers (PCPs) to ensure that survivors' health needs are met.¹ To address these components of care, a survivorship care plan (SCP) was recommended by the Institute of Medicine as a document to be used by the patient and PCP; it typically includes a diagnosis and treatment summary and follow-up care plan and guidelines.²

There have been many challenges to implementing the recommendations in the 6 years since this landmark report was released;³ in response, recommendations regarding development and delivery of SCPs are now included in a number of quality cancer initiatives. For example, the American Society of Clinical Oncology (ASCO) Quality Oncology Practice Initiative identifies the development and delivery of a chemotherapy treatment summary within 3 months of completing chemotherapy as a core indicator; the American College of Surgeons Commission on Cancer (Standard 3.3) requires "a process to disseminate a comprehensive care summary and follow-up plan to patients with cancer who are completing cancer treatment"^{4p60} for 2015; and the National Cancer Institute

Community Cancer Programs are being required to create and standardize survivorship programs.

A number of surveys have been conducted querying PCPs, oncologists, and patients about the use of SCPs.⁵⁻⁹ Although all endorse the concept of an SCP,^{9,10} there is less consensus as to who should prepare and deliver it and when it should be delivered along the cancer continuum.¹⁰⁻¹³ Time, reimbursement, and informatics issues (eg, importing the SCP into the electronic health record) have been identified as barriers.^{3,5} The optimal timing of SCP delivery from survivor and provider perspectives has yet to be determined. Because knowledge regarding the development, implementation, and outcomes regarding SCPs is nascent, better understanding of patient and provider preferences is needed to assist in the implementation of SCPs in survivorship care and programs.¹⁴

There is a range of available SCP templates available; however, evaluation is lacking for most of them.¹⁵ Thus, it is not clear which components are most useful to the intended recipients (survivor and PCP). Therefore, the overall aim of this pilot study was to explore survivor and PCP preferences regarding the content, format, timing, and mode of delivery to provide practical guidance on the development and implementation of SCPs.

Methods

Five different SCP templates were used in the focus groups and provider interviews. Each SCP was developed for the same fictitious patient: a 63-year-old man with stage III colon cancer who underwent surgery and received chemotherapy. This was

selected as a cancer that was not sex specific and included at least two treatment modalities. Treatment summaries, surveillance schedules, and care plans were included in each of the five SCPs:

- Journey Forward (<http://journeyforward.org/>).
- Livestrong (<http://www.livestrongcareplan.org/>).
- South Atlantic Division of American Cancer Society SCP (<http://www.southatlantic-cancer.org/survivortool/ACS-SurvTool-Print.pdf>).
- ASCO colon cancer template (<http://www.asco.org/ASCOv2/Practice+%26+Guidelines/Quality+Care/Quality+Measurement+%26+Improvement/Chemotherapy+Treatment+Plan+and+Summary/Colon+Cancer+Treatment+Plan+and+Summary+Resources>).
- Modified Journey Forward plan (ie, local and disease-specific resources).

After obtaining institutional review board approval from the University of North Carolina, we conducted 90-minute in-person focus groups (n = 4) with cancer survivors and 60-minute in-depth interviews with PCPs (n = 5) until data saturation was reached by consensus among the coinvestigators. Adults (age > 21 years) who could read and speak English and whose cancer diagnosis had occurred \geq 1 year ago were eligible to participate. PCPs were required to have cancer survivors in their patient panels.

Focus Groups

Invitations to participate in the focus groups were made through announcements in print newsletters and online listservs, which cover the local cancer survivorship community. To ensure adequate participation of minority groups, an invitation was issued at a predominantly African American church. Respondents to the invitation were mailed a consent form and directions; on arrival at the focus group, the purpose and process were described and signatures collected on the consent form. Next, participants were given samples of the five SCP templates, with 10 minutes to review each one individually, and then again to review collectively. Questions were then posed about each of the SCP formats, which were then compared with one another. Next, questions regarding method of delivery (print or electronic; oncologist, nurse, or other provider) and timing (before, during, or after treatment; Appendix [online only] lists questions) were asked. Parking was free, and a light meal and small honorarium were provided. The focus groups were facilitated by the principal investigator (D.K.M.) and were tape recorded and transcribed; the coinvestigators also attended and took observational notes at each session.

PCPs

Participants were recruited through a family practitioner listserv and by word of mouth. Interviews were conducted by the principal investigator in a face-to-face or telephone meeting and recorded and subsequently transcribed. PCPs were given an information sheet that included consent language and copies of the five SCP templates, which were reviewed individually and collectively. Similar to the focus group format, questions were posed about each SCP format, method of delivery, and timing,

and participants were asked for additional comments. A small honorarium was provided for participation.

Analysis

Following the steps outlined by Krueger,^{16,17} all coinvestigators read and reread the transcripts and field notes to become familiar with the data. Next, we met as a group to review the study purpose and questions, analyze and compare our findings, identify common preferences, and identify examples from participants' quotes. Differences were discussed until agreement was reached.

Results

Findings are organized by group (survivor or provider) and include a description of current experiences and preferences of SCP format and delivery. None of the participants had ever received a written SCP.

Survivor Focus Groups

Four focus groups (n = 29 survivors) were conducted. The mean age was 55.6 years (range, 20 to 82 years); 79.3% (23 of 29) were women, and 72.4% (21 of 29) were white. The survivors' cancers included breast (65.5%; 19 of 29), gynecologic (20%; six of 29), prostate (10%; three of 29), non-Hodgkin's lymphoma (7%; two of 29), and thyroid (3%; one of 29); two of the survivors had metastatic disease; three participants had two different primaries, and two participants had metastatic cancer. All had been diagnosed \geq 1 year before participation, with a median of 5 years (range, 1 to 35 years) since diagnosis. The treatments received were distributed across modalities, with 31% (n = 9) receiving either surgery, radiation, or systemic therapy (chemotherapy and/or hormonal therapy) and 38% (n = 11) receiving two of the three treatment modalities; 31% (n = 9) received all three.

Current experiences. Communication between survivor and provider and between providers was an important topic among the survivors (Table 1). Most reported receiving information about their cancers verbally but had trouble understanding and remembering the details of their diagnoses and treatment plans. However, being given written materials early in the process was also not perceived as helpful by some. Although all stated that they had received a plan of care, these were found to be merely verbal instructions (including tests) about the next planned visit. No one had received a written SCP. In addition, survivors expressed confusion about whom to call for specific problems when treatment ended. They described how they came up with their own rules of whether to call someone on their oncology team (and which member of the team) or their PCP.

Participants were also aware of when their oncology team and PCP were or were not communicating. "In terms of hand-offs, there were none. Physician to physician, it was me. It was all up to me to carry the information forward." "Providers need to talk to each other so we don't hear different things from different providers." Some PCPs asked the survivors about what was happening or what their test results had indicated. As one

Table 1. Representative Survivor Quotes on Current Experiences

Survivor Quote
"In the beginning you just don't know. Lightning has hit you. You don't want to think about this [survivorship issues] until you've gone through some of the treatments."
"The words we are hearing for the first time are part of your vernacular but not ours. Be patient and make sure we understand what you are telling us."
"I got a lot of information as I was going through treatment but I didn't feel like reading it. I felt like I was living it. You don't want to read something."
"After the radiation, that was it. You're just sort of on your own . . . You're kind of scared. You barely want to talk to anybody."
"I'm confused if I have a question about some part of my health. Do I see my regular doctor? Do I see one of them [oncologists]? If so which one? The hematology oncologist, the radiation oncologist, or the surgeon? Who? So, I call my favorite nurses."

survivor said, "That was the first thing mine [PCP] asked when I went back to him. He said I didn't hear anything from him [oncologist]. I said, 'Well, I gave him your name and number.' That's all I can do. But they never talked to each other." Others stated that their PCPs were helpful, informed, and involved throughout their treatment. "I think my doctor is and was very involved even during the time I was going through treatment. He would still have me come in like maybe once every couple of months just to kind of check in to see how things were going. And he kept up with everything that was going on. And he still corresponds with my oncologist because I do follow-up with him every 3 months since I stopped treatment. He was more there for support or if I had any questions or if I felt like I wasn't getting the answers that I needed then he was kind of there just to run interference."

What survivors want in an SCP. First, Journey Forward was the preferred template of all four focus groups. They preferred the clean and clear layout with sections for major categories of information (ie, general information, care team, background information about cancer, treatment summary, follow-up care recommendations, surveillance guidelines, symptoms to watch for, potential late effects of cancer treatment). Suggested improvements included identifying which provider to call/e-mail for which type of problem and a symptom watch list. Features of other templates were identified as being useful, including questions to ask your provider, local resources, information on nutrition and health promotion, and providing information for family members, especially about genetic counseling (Table 2). As one participant said, "I wish I had something like this. This is very helpful, very helpful. I mean there is just so much about your keeping your own self because when you go through this you know to come back and it will tell you different things but you truly have the date right in your hands. Dates that you don't remember."

Second, the survivors stated that although receiving an SCP was good, it was almost too little, too late. Third, they suggested that the written information about their diagnoses and treatment plans along with local resources be delivered upfront at the start of treatment, including the list of whom to call for specific needs. Fourth, they preferred to receive an updated SCP including a surveillance schedule and health promotion information after completing treatment. Fifth, they requested a description of what a recurrence might look like to help differentiate symptoms to report versus ones not to worry about or to talk to their PCP about.

How survivors want an SCP delivered. Most survivors preferred receiving this document either just before or soon after treatment ended but not on the last day of treatment. All survivors wanted to receive a print version of the SCP in a face-to-face meeting with the provider who was most familiar to them; many were also open to receiving an electronic version that could be shared with family members. "I don't want it to be just this article that we get. I want someone that touches me, you know, that can talk to me."

When asked what they would do with an SCP if they received one, survivors stated they would use it in discussions with their physician or health care provider and with their family and friends. They also said they would use it to change lifestyle and health habits. Others said, "I would just put it in the file with all my other medical reports and all the other stuff and I'm not sure what I would do with it." Even so, they stated they would feel better having it.

Provider Interviews

Participating PCPs included five physicians who practiced in public health (one of five), community (two of five), and academic (two of five) settings; four were women; their average age was 49.5 years (range, 36 to 66 years); and they had been practicing for an average of 18.7 years (range, 7 to 32 years). All had cancer survivors in their panels.

Current experiences. PCPs reported a range of communication frequencies with patients' oncologists, ranging from none to receiving regular updates. This was dependent on the status of their relationship and if they were practicing within the same health care system. If the latter was true, the PCP generally had access to the patient's electronic records or received updates from the oncology team via letters or being copied on clinic notes. When communication was lacking, the PCP had to depend on the patient for updates. All PCPs expected to receive the SCP from the oncologist of record and would not be prepared to complete it themselves.

Continuity of care varied with the extent of the relationship between the PCP and survivor and whether there were nononcology medical issues that needed to be addressed. Some reported not seeing the patient until treatment was over, whereas others had contact (telephone or in person) with the patient during treatment.

What PCPs want in an SCP. All PCPs desired a scaled-down version of the preferred Journey Forward template (ie, short and

Table 2. Features Identified by Survivors As Helpful Regardless of Survivorship Care Plan Template

Feature
Easy to read format, font, and language
Front page to include contact information of providers, including whom to call for what problems
Diagnosis, including stage of disease
Treatment plan in understandable language, including purpose of treatment (cure, control, palliation) at time of treatment, even if enrolled onto clinical trial* (summary to be updated regarding treatment actually delivered)
Listing of local resources, including transportation, social work, financial aid, community resources*
Documenting of disease status (in remission, evidence of disease) at end of treatment
Listing of complications or unresolved problems
Suggested questions to ask your provider
Information about health promotion, not just disease surveillance, especially nutrition and physical activity
Area to write "I have concerns about . . ."
Description of what a recurrence looks like to know what to report and what not to worry about

* Survivors want this information at the time of diagnosis and treatment planning and again when treatment is over.

Table 3. Features Identified by Primary Care Providers As Helpful Regardless of Survivorship Care Plan Template

Feature
Easy to read format; no more than two to three pages
Front page to include contact information of oncology providers
Diagnosis, including stage of disease
Treatment delivered in understandable language (but not a lot of detail)
Surveillance plan and who will be responsible for each component (primary care provider or oncologist)
List complications or unresolved problems
Potential long-term/late effects
Relevant references, if possible (nice but not necessary)

sweet), which would include diagnosis, an overview of treatment (no acronyms), symptoms to look for regarding recurrence or late effects, surveillance needed, and responsible clinician. This would be inserted into the survivor's medical record for future visits. They did not want the health promotion information and resources section included in the PCP version (Table 3).

How PCPs want an SCP delivered. Providers preferred a print or electronic version to be placed in the patient's medical record and used with each visit. PCPs wanted to receive the SCPs at the same time their patients did, and they welcomed additional resources or references specific to the survivors' situations as citations, links, or PDFs.

Discussion

Cancer survivors endorsed the utility of SCPs, with a clear preference for the Journey Forward format (print or electronic) delivered by their oncologist in person. In addition, PCPs preferred a streamlined version of each patient's SCP, delivered just before or soon after completion of treatment. Although SCPs were endorsed by survivors and PCPs as helpful communication tools, their use alone would be insufficient to ease the transition to follow-up care.¹² Participants stated that they would appreciate receiving a written SCP; however, it became apparent that improved communication and care coordination

that went beyond what this document might provide were needed. This finding was similar to that of a study of breast cancer survivors, in which only 28% felt their oncologists and PCPs communicated well.¹⁸ To address this issue, SCPs could be used at multiple time points across the cancer continuum instead of just at the end of active treatment. Furthermore, SCP core elements were endorsed in an Australian study, but there was a lack of consensus as to who should prepare them.¹⁰

Similar to Sada et al,¹⁹ we found that when providers shared an electronic health record system, the frequency and quality of communication between providers improved. This is particularly important because the projected growth in number of cancer survivors and the impending shortage of oncologists will most likely shift follow-up care back to PCPs. Despite their interest in receiving an SCP, few patients reported receiving survivorship information in recent studies.^{6,7} In addition, most patients reported receiving follow-up care from only their oncologists (53%), from only their PCPs (13%), and from both providers (32%) in a recent online analysis.²⁰ There were differences in expectations as to who should deliver follow-up care between cancer specialists and PCPs and between providers and patients in a study of 992 survivors and 607 physicians.⁵ In a large survey of 1,072 PCPs and 1,130 medical oncologists, there were significant discrepancies in perceived knowledge, attitudes, and practices in caring for breast cancer survivors regarding detecting recurrences and late effects of treatment.²¹

These discrepancies were mirrored in a number of other studies comparing oncologists and PCPs regarding follow-up care.^{12,21,22} Another study of 175 PCPs reflected uncertainty regarding type, duration, and frequency of surveillance.⁸ More than half of the PCPs reported problems with transfer of care from oncologists and wanted more communication from them during this process.

More attention to ongoing written communication was identified as important, beginning at the time of diagnosis and treatment planning, not just once at the end of treatment. Additionally, survivors expressed concern about knowing what a recurrence would look like to help manage anxiety and facilitate their own surveillance. This finding was similar to those of other studies that identified survivor concerns about recurrence and learning more about managing effects of the disease and treatment.²³⁻²⁶ Attention to the delivery and coordination of survivorship care beyond the SCP will be important in addressing many of these issues.²⁷

There were several limitations in this study. Although this was a small convenience sample from the southeastern part of the United States, our findings are similar to those of other studies. For example, Marbach et al²⁶ identified the need for information at all phases of treatment and the desire for written information about follow-up, testing, and surveillance as part of the SCP in focus groups with 40 cancer survivors. In addition, the presence of social pressure could have influenced the individual responses within the focus groups. However, great effort was expended by the principal investigator to minimize this effect.

Given that survivors identified a variety of preferences for content (even within the same format), more than one approach will be needed. The needs of PCPs are different from the needs of survivors; therefore, an adapted approach in SCP con-

tent and delivery is required to improve communication. Future large-scale efforts should focus on the evaluation of SCP effects on patient outcomes. However, identification of expected outcomes associated with the use of SCPs will first be needed for this to occur.¹⁵ Demonstrating the impact of SCPs may enhance adoption of this new standard for quality cancer care.

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Appendix

Focus Group Questions

General Questions for Primary Care Providers

Thinking back to patients who have had cancer in your practice:

- How involved are you with the patient during the diagnostic process? During the treatment process? When active treatment ends?
- What type of communication occurs between yourself and the oncologists? How satisfied are you with that? What could be done to make it better?

Care Plan–Specific Questions

- An Institute of Medicine report suggested that patients and their primary care providers receive a treatment summary and care plan when treatment was finished. What do you think of the idea?
- Have you heard of survivor care plans? What do you know about them? Have you ever received one?

We are showing you examples of treatment summaries and care plans

- What is your initial reaction to this?
- How would you use it?
- Is it easy to understand? (readable? simple? etc)
- Is the information presented in a format that would help people understand it better?

Let's go through each section (get feedback on what is/is not included).

- Would you find something like this helpful for your patients? For yourself? (If not, probe reasons why. If yes, probe what do they like about it.)
- Would you want to create and deliver a print report like this?
- Who would you think should review this with your patient (doctor, nurse, someone else)?
- When do you think it would be best to deliver this? (Before treatment ends? If so, how long before treatment ends? Last day of treatment, first follow-up appointment after treatment, some other time?)
- Who do you think should get a copy?
- Final thoughts/comments?

General Questions for Survivor Focus Groups

- When your treatment was ending, what were you most worried about?

- Where you able to talk with your doctor or nurse about what you were worried about? If yes, was that helpful? If not, why not?
- When your treatment was ending, did your doctor or nurse talk with you about what was next regarding your cancer care? If yes, who was it? When and where did they talk with you? What did they talk about? Did they give you any instructions or materials to take home?
- If you were going through this again, what would you have found to be helpful?

Care Plan–Specific Questions

- An Institute of Medicine report suggested that patients and their primary care providers should receive a treatment summary and care plan when treatment was finished. What do you think of the idea?
- Have you heard of survivor care plans? What do you know about them? Have you ever received one?

We are showing you examples of treatment summaries and care plans (either hand out to each person or project overhead).

- What is your initial reaction to this?
- How would you use it?
- Is it easy to understand? (readable? simple? etc)
- Is the information presented in a format that would help people understand it better?

Let's go through each section (get feedback on what is/is not included).

- Would you find something like this helpful? (If not, probe reasons why. If yes, probe what do they like about it.)
- Who would you think should review this with you (your cancer doctor, your cancer nurse, your primary care provider or someone else)?
- When do you think it would be best to receive this? (Before treatment ends? If so, how long before treatment ends? Last day of treatment, first follow-up appointment after treatment, some other time?)
- Who do you think should get a copy?
- What if this were online?

Thinking back to the care you received during and after your cancer treatment:

- How involved was your primary care provider during your diagnosis? During your treatment process? When your active treatment ended?
- What type of communication occurred between yourself, your primary care provider, and the oncologists? How satisfied are you with that? What could be done to make it better?
- Final thoughts/comments?