Development of the Cancer Survivorship Care Plan: What’s Next? Life After Cancer Treatment

Jody M. Jackson, RN, BSN, Kathy Scheid, BS, RD, and Sharon J. Rolnick, PhD, MPH

Post-treatment issues have become increasingly important as more people are living well past their initial cancer diagnosis because of advances in early detection and therapeutic technologies. According to the National Cancer Institute (NCI), about 4% of the U.S. population (14 million individuals) are cancer survivors (Howlader et al., 2011). Sixty-seven percent of adults diagnosed with cancer will be alive five years postdiagnosis, and more than 75% of childhood cancer survivors will be alive after 10 years. For many patients, that survivorship period extends beyond the traditional five-year benchmark; according to the NCI, 15% of all cancer survivors were diagnosed 20 or more years ago (Howlader et al., 2011). For many, cancer is becoming another aspect of life rather than a threat to it. Living with cancer often means living with a complex chronic condition (Phillips & Currow, 2010). In a survey of survivors conducted by Miedema, MacDonald, and Tatemichi (2005), 36% of respondents were unsure which physician was in charge of their cancer care. In addition, in a survey of primary care providers (PCPs) conducted by Nissen et al. (2007), more than 84% reported uncertainty regarding the type, frequency, and duration of surveillance tests for their patients with histories of breast or colorectal cancer. Cheung, Neville, Cameron, Cook, and Earle (2009) surveyed patients and providers and found that (a) patients believe that their oncologists should be more involved in follow-up care than oncologists think they should be; (b) PCPs believe they should be more involved in follow-up care than their patients believe; and (c) oncologists and PCPs disagree about who is responsible for surveillance, other cancer screenings, and preventive health care for patients with cancer. With the increasing number of survivors and length of survival, as well as the discrepancies among key players regarding follow-up care, providing patients with information about their long-term survival has become more important.

Cancer survivorship care plans (SCPs) have been proposed by leaders in the cancer care community to help address uncertainty during the survivorship period. An SCP has two components, a treatment summary and a care plan that act as a record and a guide, respectively. The care plan summarizes details of diagnosis and treatment, as well as provides information...
on future issues such as follow-up care, long-term side effects, and resources for addressing potential psychosocial and practical issues. The use of SCPs gained momentum when the 2005 Institute of Medicine (IOM) report, From cancer patient to cancer survivor: Lost in transition, recommended that all cancer survivors completing primary treatment receive an SCP that includes, at minimum, the following: (a) information on cancer type; (b) treatments received and their potential long-term effects; (c) recommended follow-up, preventive practices, and maintenance of health and well-being; and (d) information on legal protections, employment, access to health insurance, and psychosocial services in the community (Hewitt, Greenfield, & Stovall, 2005).

To help address the post-treatment information needs of cancer survivors and optimize continuity of care, the Minnesota Cancer Alliance (MCA) created the SCP, “What’s Next? Life After Cancer Treatment.” This 25-page booklet is a patient-focused care plan to assist cancer survivors who have finished treatment. The current article discusses why and how the MCA created the care plan, the benefits of care plans cited in the literature, and the relevance to oncology nurses, who are emerging as the most suitable and preferred provider to disseminate SCPs.

Methods

The MCA is a consortium of more than 100 healthcare organizations, community groups, and individuals joined to create and implement the state’s comprehensive cancer control plan. Although the original plan had many objectives, initial efforts focused on four priority areas: tobacco cessation, increasing colorectal cancer screening, reducing disparities in cancer screening and treatment, and quality of life for patients with cancer, specifically, improving access to information and addressing issues of continuity of care.

In 2007, the MCA charged the Quality of Life Task Force with investigating the needs of Minnesota cancer survivors and their care providers. That group surveyed the leadership of the 20 largest hospitals and healthcare systems in Minnesota to determine if they were using an SCP, and examined the content of tools available locally and nationally. The task force identified 24 SCPs including online tools, SCPs from local healthcare organizations, and those created by other states’ comprehensive cancer control plans (e.g., Michigan, West Virginia).

A systematic comparison of the common elements indicated strengths and weaknesses. Many of the SCPs reviewed were too detailed or clinical, with language geared more toward healthcare providers than survivors. Others were too brief or simplified to convey meaningful information. Although a few hospitals and some comprehensive cancer care centers were creating and piloting their own SCPs, results of the healthcare organization survey indicated that use was sporadic. The smaller hospitals without SCPs recognized the need, but reported barriers in adopting one. Many did not have the professional or financial resources to create their own tool, and some existing tools were the property of a single entity (branded for that organization). In addition, existing tools did not fully meet the unique needs of some Minnesotans (e.g., retirees who travel south in the winter, residents of rural areas, Native Americans) who often receive fragmented care in multiple settings, making access to comprehensive and portable information particularly important. Those healthcare systems requested that the MCA create a single comprehensive and user-friendly SCP.

In addition, a convenience sample of 59 participants (oncologists, primary care providers, nurses, social workers, community health workers) provided input regarding desired components of an SCP during a two-hour working session held as part of an MCA annual conference. Although treatment received, possible side effects, and a follow-up plan were considered necessary, participants reported that they also would want to include information on emotional, spiritual, sexual, and economic issues (e.g., returning to work), as well as a section on family history and genetic counseling and testing.

Development of Survivorship Care Plan

Nurses, physicians, social workers, dietitians, community health workers, cancer survivors, and a lawyer from various organizations formed the survivorship care plan project team to create an SCP representative of diverse organizations, roles, and experiences. The overall group consisted of about 35 individuals, with a core group of 12.

The project team spent about two years developing the care plan, meeting at least every other month. During initial meetings, the group drafted a set of core values to guide the work. The team recognized that the SCP tool could not be everything to everyone and, therefore, identified six essential principles for the tool: (a) support, empower, and inform survivors; (b) help identify universal issues but allow for personalization; (c) facilitate communication; (d) help bridge the gap post-treatment; (e) be non-proprietary; and (f) not duplicate medical charts. Those essential principles, results of the community needs assessment, and recommendations from the IOM report on the minimum elements for SCPs shaped the final product. The care plan was intended for patients and, therefore, needed to be user friendly. The group chose to develop a patient-focused tool rather than a provider-focused one because of variations in clinical survivorship care practices across Minnesota (i.e., some practices had formal SCPs in place, and others did not) and to reach as wide an audience as possible. The SCP needed to be able to be tailored to individual needs; however, it also was intended to be used by survivors of any type of cancer, any survivor, or any healthcare system, be a means of information exchange among survivors and the healthcare team, and address the post-treatment information gap and help answer the question, “I’m done with treatment, now what?” The tool was meant to help survivors document the history of their cancer care experience, manage follow-up medical care, better understand short- and long-term side effects, and become more aware of self-care issues.

Exploration on the Go

The Journey Forward™ Survivorship Care Plan Builder is a free resource cosponsored by the Oncology Nursing Society. To access, open a barcode scanner on your smartphone, take a photo of the code at left, and your phone will link automatically. Or, visit http://journeyforward.org/professionals/survivorship-care-plan-builder.
Pilot Project

Before making the SCP officially available, researchers conducted a pilot to obtain feedback from survivors on usefulness and areas for improvement. Healthcare providers affiliated with six MCA organizations across Minnesota were asked to share the SCP with patients with cancer who were nearing completion of treatment or who had completed their treatment in the prior year. Patients were asked to review the SCP and complete an anonymous survey to provide input on the content and use of the SCP.

The current researchers’ SCP was shared with 117 survivors from six organizations. Because of the minimal budget and anonymity of the survey, the researchers were not able to track surveys or perform follow-up with nonresponders (contact the corresponding author to request a copy of the evaluation survey). About 25% (n = 27) of patients who were given booklets provided feedback. At least two-thirds of respondents agreed or strongly agreed on each dimension assessed, including ease of use (n = 21, 78%), and that the SCP would help identify health concerns (n = 18, 67%), manage post-treatment health information (n = 24, 89%), and improve understanding of post-treatment care (n = 20, 74%) and communication with healthcare providers (n = 20, 74%). Seventy-four percent reported they would continue to use the SCP to manage their care. All respondents said that the SCP should be offered to patients with cancer in the future. Although the booklet was geared toward survivors in the post-treatment phase, 67% reported that the SCP should be given at diagnosis or the beginning of treatment.

Based on suggestions for improvement, the developers provided more space for individuals to record information, worked with a health literacy editor on the language to replace or clarify much of the medical jargon, and reiterated in the introduction that each survivor’s experience is unique and that all content may not apply to everyone.

Dissemination of the Survivorship Care Plan

The SCP was made public the first week of June 2010, to coincide with National Cancer Survivors Day. With 2,000 copies distributed on request to Minnesota healthcare providers in 2010, and another 3,000 in 2011, the SCP has been received well locally.

I have shared your booklets with the radiation therapy and chemotherapy departments, and everyone loves them! We see this booklet as a great tool for our patients!

The topic of living well post-treatment is a frequent one [in the adult support group]. So many of our participants feel that they don’t know how to organize the next part of their healing. I saw the original version at the conference last fall and loved it. I think it would help our participants greatly.

The tool has also received national attention, including inquiries from Wisconsin, Michigan, Washington, and California, and it is listed as one of the first resources on the American Cancer Society’s Web page on SCPs.

Discussion

The MCA’s SCP was developed to help cancer survivors prepare for the next phase of their cancer journey. The booklet was designed to help survivors document the history of their cancer care experience and support them in becoming active participants in their post-treatment care. A breast cancer survivor who participated on the project team said, “A survivor care plan is for the future—an empowering reminder that you still have control of your life,” summing up the team’s definition of an SCP.

A strength of the current SCP is its user-friendliness, as it was designed specifically for the public. It was created by a coalition of individuals representing many organizations, skills, and experiences and benefited from strong survivor input throughout its development. The SCP could be used by large healthcare organizations in combination with existing care plan resources, or serve as a single care plan document for small organizations that may not have the skills or budget to create their own tool.

Several other publicly available SCPs exist, including the American Society of Clinical Oncology’s templates for breast and colorectal cancer, the Cancer Survivor’s Prescription for Living (Haylock, Mitchell, Cox, Temple, & Curtiss, 2007), and Internet-based tools, such as Journey Forward® Survivorship Care Plan Builder and the LIVESTRONG® Care Plan, powered by Penn Medicine’s Oncolink (Hill-Kayser, Vachani, Hampshire, Jacobs, & Metz, 2009a, 2009b; Hill-Kayser, Vachani, Hampshire, & Metz, 2012; Vachani, Di Lullo, Hampshire, Hill-Kayser, & Metz, 2011). Those SCPs vary in their length, complexity, and patient friendliness.

The body of literature on the benefits of SCPs is growing. However, many articles describe the postulated benefits of SCPs (Earle, 2006; Ganz, Casillas, & Hahn, 2008; Ganz & Hahn, 2008; Grunfeld & Earle, 2010; Haylock et al., 2007; Hede, 2006; Horning, 2008; Houlihan, 2009; Printz, 2009). Few examinations have been conducted regarding SCPs. Those that have involve the development and delivery of SCPs (Hahn & Ganz, 2011; Miller, 2008), and patient (Burg, Lopez, Dailey, Keller, & Prendergast, 2009; Marbach & Griffie, 2011), and provider (Brennan, Butow, Spillane, & Boyle, 2010) perspectives related to care plans.

Only recently have a few randomized, controlled trials evaluated patient outcomes when SCPs are incorporated into care (Grunfeld et al., 2011; van de Poll-Franse et al., 2011). Some of the cited benefits of SCPs include facilitating the transition of the patient from oncology to primary care, improving communication between those provider groups (Grunfeld & Earle, 2010; Hewitt et al., 2005; Horning, 2008; Houlihan, 2009), and addressing a lack of coordination of care, specifically, who is in charge and for which aspects (Earle, 2006). Because a major function of SCPs is as a record of treatment, they may help patients who receive fragmented care from multiple providers maintain more consistent and comprehensive information in real time. The end of cancer treatment has been described as a teachable moment (Ganz, 2005). Therefore, SCPs may be a preferred method for increasing patient knowledge and awareness. Empowering patients with information about their history and their future, however, may be one of an SCP’s most valuable attributes. Enabling patients to be active participants in the next phase of their cancer journey was one of the foremost goals of the MCA SCP project team. Finally, care plans provide the opportunity to address areas beyond that of the medical dimension, including future lifestyle changes, psychosocial issues, and practical needs (e.g., financial assistance, legal aid) (Hewitt et al., 2005).
Nurses are well-suited to develop and implement SCPs. Nurses educate patients along the entire cancer continuum. They coordinate care among multiple specialties and often are the go-to team member to listen to patients’ psychosocial concerns. In addition, colleagues and patients consider nurses the preferred provider in developing and implementing SCPs. In a study of patient and provider perspectives on SCPs by Baravelli et al. (2009), 50% (n = 15) of doctors and 66% (n = 43) of the nurses said they thought the nurse was the most appropriate person to deliver details of SCPs. In a study conducted by Marbach and Grifﬁe (2011) of survivor preferences for survivorship services, participants reported that they trusted nurses to communicate the SCP.

Since the 2005 IOM report, initiatives related to SCPs have come from the Centers for Disease Control and Prevention and the NCI. However, the landscape regarding SCPs is rapidly changing. Early recommendations and initiatives related to SCPs have now evolved into mandates. The Commission on Cancer® (COC), 2012, which accredits cancer care centers, added a new standard on SCPs. The COC requires that, on completion of the ﬁrst course of treatment, a patient be given an SCP prepared by the providers who coordinated the patient’s oncology treatment, and that the plan should include a record of care received, disease characteristics, and a written follow-up plan by 2015. Nurses will undoubtedly be key in helping their organizations fulﬁll the COC SCP standard. SCPs are particularly relevant in nursing, because nurses play such an integral role in conveying information to patients. SCPs are another tool in the nurse’s kit to empower patients.

Limitations

The MCA’s SCP may not ﬁt every survivor’s diagnostic and treatment experience or follow-up needs; for example, the tool is currently only available in English. In addition, the SCP is a hard-copy document rather than electronic, and patient information cannot be entered or maintained online. However, the fact that the SCP is a hard-copy tool may be appealing to some patients, particularly those who may not be receptive to, or have access to, electronic SCP tools.

Conclusions

Several care plan options are available to support the post-treatment process, one of which is What’s Next? Life After Cancer Treatment, available for download on the MCA Web site at www.mncanceralliance.org. Nurses are encouraged to ﬁnd a care plan that resonates with them, their organization, and the patients they serve. One respondent of the MCA SCP pilot summed up the issues driving the need for SCPs and what the MCA SCP project team hoped to achieve: “The longer we live, the more important side effects become. Tell them to make books of their information and create a space in their bookshelves. Get ready to learn!”

The authors gratefully acknowledge the members of the Minnesota Cancer Alliance survivorship project team, who contributed their time, expertise, and experiences in creating the care plan; the healthcare providers who shared the booklet with patients; and the survivors who provided feedback during the pilot.

References


**Receive Continuing Nursing Education Credits**

Receive free continuing nursing education credit* for reading this article and taking a brief quiz online. To access the test for this and other articles, visit http://evaluationcenter.ons.org/Login.aspx. After entering your Oncology Nursing Society profile username and password, select CNE Tests and Evals from the left-hand menu. Scroll down to *Clinical Journal of Oncology Nursing* and choose the test(s) you would like to take.

* The Oncology Nursing Society is accredited as a provider of continuing nursing education by the American Nurses Credentialing Center’s COA.