Implementing the Commission on Cancer Standards for Survivorship Care Plans

Carrie Tompkins Stricker, PhD, RN, AOCN®, and Michele O’Brien, RN, MSN, ACNS-BC, BA

The number of adult cancer survivors in the United States has exceeded 13 million and continues to rise, yet care for these survivors continues to be poorly coordinated and their needs remain inadequately addressed. As one solution to this growing problem, the Institute of Medicine in 2006 recommended the delivery of a survivorship care plan (SCP) to each patient completing active treatment. The American College of Surgeons Commission on Cancer subsequently published its Program Standard 3.3, requiring accredited programs to implement treatment summaries and SCPs by 2015, to help improve communication, quality, and coordination of care for cancer survivors. As practices and cancer centers around the country have undertaken SCP implementation efforts, myriad barriers to their preparation and delivery have emerged, with time and human resource burden top among these, in addition to a lack of proven outcomes. Fortunately, a growing number of publications document practical and feasible delivery models, and an increasingly robust body of research on stakeholder preferences is available to focus SCP implementation efforts.

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About 13 million cancer survivors are living in the United States, and more than 28 million are alive globally (Siegel, Naishadham, & Jemal, 2013). The psychosocial and physical issues, risks, and care needs of cancer survivors are complex and widely variable, contributing to the myriad challenges to quality care for this burgeoning population. In a landmark report (Hewitt, Greenfield, & Stovall, 2006), the Institute of Medicine (IOM) defined survivorship care as the phase of care following completion of primary treatment, and recommended that it address four essential components.

• Prevention of recurrent and new cancers and of other late effects
• Surveillance for cancer spread, recurrence, and secondary cancers; assessment of medical and psychosocial late effects
• Intervention for consequences of cancer and its treatment
• Coordination between primary and specialty care

The report concluded that survivorship care falls far short of this ideal, and described the care of cancer survivors in the United States as being characterized by poor communication and coordination, fragmentation of care and inappropriate use of services, underemphasis on preventive care, and inadequate attention to long-term and late effects of cancer treatment (Hewitt et al., 2006). The growing number of survivors is surpassing the capacity of cancer care systems, and those systems are unable to keep pace with demand, which places greater demand on primary care providers (PCPs). PCPs often lack sufficient knowledge about the individualized needs, risks, and surveillance plans for survivors (Hudson et al., 2012; Nekhlyudov, Aziz, Lerro, & Virgo, 2012) and for what they as PCPs are responsible for. This often is caused by poor interprofessional communication patterns and care coordination (Cheung, Neville, Cameron, Cook, & Earle, 2009; Earle, Burstein, Winer, & Weeks, 2003; Earle & Neville, 2004; Nissen et al., 2007; Snyder et al., 2008a, 2008b).

As a result, a carefully coordinated transition from active treatment to cancer survivorship care is a reality for very few (Earle et al., 2003; Earle & Neville, 2004; Mao, Torradas, Xie, Scott, & Jacobs, 2010; Snyder et al., 2008a, 2008b). Researchers have highlighted the need for strategies to help define expectations and ownership for the content and coordination of survivorship care.

The IOM proposed 10 key solutions for improving the quality of survivorship care in its seminal report (Hewitt et al., 2006).
A top recommendation was that all patients completing active treatment should receive a cancer treatment summary and follow-up care plan, collectively called a survivorship care plan (SCP). The goal of an SCP is to guide the content and coordination of care following acute treatment, facilitate care transitions, and foster greater self-management of health by cancer survivors. Other research efforts have further expanded this recommendation to incorporate treatment planning from the time of diagnosis (Balogh et al., 2011). Many organizations have joined the call for universal implementation of SCPs, including the American College of Surgeons Commission on Cancer (CoC) and the American Society of Clinical Oncology (ASCO).

Background

Despite the wide acceptance that SCPs are a necessary component of quality survivorship care, evidence for their effectiveness is limited. Face validity and stakeholder endorsement are most often used to provide support for their implementation (Belansky & Mahon, 2012; Hewitt et al., 2006; Salz, Oeffinger, McCabe, Layne, & Bach, 2012; Sprague et al., 2013). Few large randomized, controlled trials (RCTs) have examined the efficacy of SCPs, and results to date have been disappointing. A large RCT in Canada (Grunfeld et al., 2011) compared a standard oncologist discharge visit prior to transition to PCP with the same standard visit plus a nurse-delivered SCP in a sample of 408 breast cancer survivors a median of 3.5 years since diagnosis. No difference between arms was observed in the primary outcome of cancer-specific distress. In addition, the study was criticized for its design and selection of outcome measures, and the relevance to cancer survivors in the United States was questioned (Jefford, Schofield, & Emery, 2012; Stricker, Jacobs, & Palmer, 2012). In an RCT study by van de Poll-Franse et al. (2011), written SCPs were provided to Dutch gynecologic cancer survivors. Preliminary results were mixed in terms of patient outcomes, and in a subsequently published longitudinal evaluation of provider perceptions of the automated care plan (Nicolaije et al., 2013), providers were satisfied with the care plan and motivated to continue using it, but found that time was a major barrier to use. Brothers, Easley, Salani, and Andersen (2012) examined 121 gynecologic cancer survivors and showed that both those who did and did not receive SCPs rated their care highly, with no difference between arms. In addition, an RCT by Hershman et al. (2013) showed no improvement in distress or concerns in 126 breast cancer survivors who received care plans compared to those who did not, although SCP receipt was associated with decreased cancer worry at three months but not six months.

Nonrandomized studies provide some support for the efficacy of SCPs. A single-arm pre/post-test study (Nissen, Tsai, Blaes, Swenson, & Koering, 2013) of 344 breast and colorectal cancer survivors found improved (but still low) knowledge about disease and treatment details following the mailing of written SCPs to each individual after a median of 79 years from diagnosis. A smaller study by Oeffinger, Hudson, Mertens, and Robinson (2010) mailed a brief SCP focused on guidelines for cardiac and breast cancer surveillance to 72 Hodgkin disease survivors and their PCPs, and found improved adherence to recommended echocardiograms and mammograms. Several small, single-arm pilot studies have explored the feasibility and outcomes of end-of-treatment visits that include the delivery of various types of SCPs and found high rates of patient satisfaction (Jagielski et al., 2010; Jefford et al., 2011; Sprague et al., 2013), reduced patient concerns and unmet needs (Jagielski et al., 2010; Jefford et al., 2011; Stricker et al., 2013), and patient preparedness to manage health care (Jagielski et al., 2010). Although the evidence for SCPs is, at present, very limited, many have argued that SCPs have high face validity for improving a myriad of problematic outcomes in cancer survivors (Ganz & Hahn, 2008; Jefford et al., 2012; Sprague et al., 2013; Stricker et al., 2011).

Implementation of Survivorship Care Plans

Standards and Preferences for Content

The American College of Surgeons CoC adopted the IOM recommendation for SCPs (Hewitt et al., 2006) as one of its standards for implementation by 2015; and ASCO, the National Accreditation Program for Breast Centers (NAPBC), and other accrediting bodies have each incorporated delivery of an SCP into their quality metrics required for accreditation or certification (American College of Surgeons, 2012; ASCO, 2013a). Specifically, CoC program standard 3.3 mandates that a SCP should be prepared by the principal oncology provider and delivered to patients at completion of treatment. ASCO and NAPBC (2011) standards focus on delivery of a comprehensive treatment summary as well as recommendations for follow-up surveillance, health promotion, and risk reduction.

The IOM (Hewitt et al., 2006) explicitly states that SCPs should be congruent with the four goals of survivorship care discussed earlier in this article. Broadly speaking, SCPs should provide

- A summary of an individual’s cancer diagnosis and treatment information (the treatment summary)
- An overview of both physical and psychosocial effects of diagnosis and treatment
- A detailed follow-up plan that outlines surveillance for recurrence and potential late effects as well as recommendations for health-promotion strategies
- Referrals and resources for physical, psychosocial, and practical needs.

Researchers have emphasized that an SCP should assist with coordination of care by outlining which providers (e.g., primary care versus oncology) are responsible for particular aspects of care (Ganz, Casillas, & Hahn, 2008; Sprague et al., 2013; Stricker et al., 2011). Hewitt et al. (2006) also provided the IOM Fact Sheet: Cancer Survivorship Care Planning, which outlined SCP elements with great specificity. Although these components were derived from expert consensus among IOM taskforce members and have yet to be validated by research linking particular elements with desired outcomes (Houlihan, 2009; Palmer et al., in press; Salz et al., 2012; Stricker et al., 2011), the fact sheet is commonly viewed as the reference standard for SCP content. A checklist to evaluate concordance of SCP content with IOM recommendations is available to assist centers (Palmer et al., in press). The checklist has demonstrated excellent inter-rater reliability in breast cancer survivors (Palmer et al., in press). ASCO also is developing standards for the minimal...
A variety of SCP templates are available to help ensure implementation of SCPs that incorporate the IOM recommended content. These include both paper and web-based documents created by professional organizations and advocacy-based groups such as ASCO, LIVESTRONG® (www.livestrongcareplan.org), and Journey Forward (www.journeyforward.org) (see Table 1). Many institutions have developed and are willing to share their own documents, several of which have been published or otherwise made publically available for use (Belansky & Mahon, 2012; Houlihan, 2009).

A variety of factors should guide the specifics of content in practice, including the patient population served and availability of disease-specific survivorship guidelines, local survivorship resources available, and the intended audience for the SCP (e.g., patient or provider). For example, content regarding the risk of late and long-term effects may vary widely depending on the population under consideration, given differential risk across populations of cancer survivors (Hewitt et al., 2006). Because no gold standard for SCPs exists, actual content varies widely in essential SCP content and convened a special taskforce in late 2013 to refine its standards for SCP content (with a planned release in 2014).

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### TABLE 1. Survivorship Care Plan (SCP) Templates

<table>
<thead>
<tr>
<th>Organization</th>
<th>Tool</th>
<th>Overview</th>
<th>Content</th>
<th>Format</th>
<th>Website</th>
</tr>
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<tbody>
<tr>
<td>American Society of Clinical Oncology</td>
<td>Chemotherapy Treatment Plan and Summary</td>
<td>Intended to be a record of the patient’s cancer treatment as well as a brief outline of recommended follow-up care. Templates are available for breast, colorectal, lung, and lymphoma diagnoses. A generic form also is available.</td>
<td>Stage and pathologic details of the cancer; dose of chemotherapy; specific drugs used, number of cycles completed, and surgeries performed; additional treatments, including radiation, targeted therapies, and/or hormonal therapy; recommended follow-up care, including a schedule of office visits as well as surveillance testing, with space to indicate provider responsible for performing each aspect of follow-up care.</td>
<td>The forms can be downloaded from the American Society of Clinical Oncology website and are intended to be filled out by a member of the oncology care team.</td>
<td><a href="http://bit.ly/1ddtP7a">http://bit.ly/1ddtP7a</a></td>
</tr>
<tr>
<td>LIVESTRONG®</td>
<td>The LIVESTRONG Care Plan</td>
<td>Product of a collaborative agreement between the University of Pennsylvania Abramson Cancer Center, OncoLink, and LIVESTRONG. The care plan was developed to allow the patient to create an SCP by inputting information regarding cancer diagnosis, treatment, and current symptoms.</td>
<td>The output from the tool has extensive information about survivorship issues that the patient is at risk for or presently experiencing. The recommendations generated are based on guidelines available, such as those provided by the Institute of Medicine, Children’s Oncology Group, the National Cancer Institute, and American Society of Clinical Oncology.</td>
<td>An electronic document that can be printed or converted to a PDF.</td>
<td><a href="http://www.livestrongcareplan.org">www.livestrongcareplan.org</a></td>
</tr>
<tr>
<td>National Coalition for Cancer Survivorship; the UCLA Cancer Survivorship Center; WellPoint, Inc.; and Genentech</td>
<td>Journey Forward</td>
<td>This site was created through the collaborative efforts of the organizations listed here. Journey Forward’s SCP can be downloaded from the Internet to the user’s desktop.</td>
<td>The SCPs in Journey Forward are based on the American Society of Clinical Oncology’s Chemotherapy Treatment Plan and Summary templates and Surveillance Guidelines. These include detailed summaries of cancer treatments, as well as follow-up care plans that incorporate education regarding late effects, recommendations for cancer surveillance and other healthcare issues, and links to relevant resources for cancer survivors.</td>
<td>Free online program</td>
<td><a href="http://www.journeyforward.org">www.journeyforward.org</a></td>
</tr>
<tr>
<td>--</td>
<td>Prescription for Living (developed by Haylock et al., 2007)</td>
<td>Paper care plan template developed by oncology nurses</td>
<td>Cancer diagnostic, treatment details, follow-up care plan in a checklist format that allows the provider to individualize recommendations for follow-up care and surveillance testing, preventive behaviors, and education regarding potential late effects</td>
<td>Available online</td>
<td><a href="http://bit.ly/L5C6je">http://bit.ly/L5C6je</a></td>
</tr>
</tbody>
</table>
practice, with no cancer centers addressing all content (Salz et al., 2012; Stricker et al., 2011). However, studies of stakeholder preferences provide guidance as to what may be important to include. A growing number of studies have examined both patient and provider perspectives, including those of oncology nurses and physicians as well as PCPs, and are summarized in Figure 1. All of the studies are in agreement that the SCP should be personalized, easy to read and understand, and should clearly outline who is to do what, when, and why. Many survivors and PCPs have voiced the desire for the SCP to be a living document, created at the start of treatment rather than a summary prepared at time of completion of active treatment. PCPs express a particular desire for concise information on treatments received and surveillance recommendations, particularly clear direction about what they are responsible for (Mayer, Gerstel, Leak, & Smith, 2012; Nissen et al., 2007). In contrast, survivors appear to desire more comprehensive information on resources and referrals for symptoms and late effects (Belansky & Mahon, 2012; Mayer et al., 2012). Given these unique needs, different versions of the SCP have been recommended for distribution to PCPs and survivors (Mayer et al., 2012). Additional research is needed to define and evaluate the optimal depth, breadth, and specifics for SCP content; a one-size-fits all approach is unlikely to be viable. Substantial individualization of content will be necessary to serve the needs of diverse survivor populations.

Methods and Models of Plan Delivery

Perhaps even more important than the content of SCPs is the process by which SCPs are delivered. Parry, Kent, Forsythe, Alfano, and Rowland (2013) reinforced that “we cannot expect a document to do the work of a process” (p. 2651), and urged PCPs to carefully consider the process of survivorship care planning more carefully than the content of an SCP. A number of survivorship care models have previously been described, but few have been studied (Grant, Economou, & Ferrell, 2010; Landier, 2009; McCabe & Jacobs, 2008; Oeffinger & McCabe, 2006). Although approaches vary widely, the delivery of SCPs should be integral to each of these models of care, particularly for shared care models where PCPs and oncology providers are each responsible for distinct components of care. Many different approaches to implementing SCPs have been described in the literature (Dulko et al., 2013; Ganz, 2009; Jackson, Scheid, & Rolnick, 2013); however, best practices have not yet been validated through research. SCPs may be delivered in the context of dedicated survivorship visits and/or clinics, or via integration into routine oncology care processes. Although not well-described in the literature, it appears that most SCPs are delivered within a formalized survivorship care program or clinic rather than distributed by patients’ oncology care providers (Dulko et al., 2013; Landier, 2009; Oeffinger & McCabe, 2006; Salz et al., 2012; Stricker et al., 2011).

Across all models of care, nurses, including advanced practice providers (APPs), are taking an increasingly central role in the implementation of survivorship care and care planning efforts (Grant et al., 2010; Stricker et al., 2011). Nurse-led models are described in a variety of program-implementation articles (Grant et al., 2010; Hewitt et al., 2006; Irwin, Klemp, Glennon, & Frazier, 2011; McCabe & Jacobs, 2008; Patton, 2010; Rosenberg, 2008), and research is underway to evaluate outcomes of these models of care. Novel approaches to survivorship care delivery, including telephone, Internet, mail-based, and peer-led interventions are being explored (Oeffinger et al., 2010). Results from research and clinical endeavors will hold significance for informing the development and dissemination of optimal models of survivorship care planning.

In practice, careful attention to feasibility and sustainability is crucial, particularly since best practices are not yet known. Grant et al. (2010) proposed a number of questions that should be considered when planning for and implementing survivorship programs, including the delivery of SCPs. Characteristics of the target patient population and the setting for care plan delivery should guide the structure and process of SCP delivery, including a careful assessment of the available resources within a practice. In terms of timing, the best time point for distribution of SCPs is unclear. Intuitively, it seems optimal to distribute SCPs around the time of completion of active treatment.

![FIGURE 1. Patient and Primary Care Provider Preferences for Survivorship Care Plans](image-url)
as recommended in the American College of Surgeons (2012) CoC standard. If SCPs are provided by the patient’s primary oncology provider(s), as the CoC standards advise, distribution at this time point would ensure that the largest number of survivors receive SCPs, particularly because some survivors are lost to follow-up after the completion of active cancer treatment (Hewitt et al., 2006). In addition, much of the information contained in SCPs would be useful to patients at this juncture, since a primary goal of the documents is to provide a framework for follow-up care, including recommended surveillance and preventive strategies (Dulko et al., 2013; Mao, Torradas, Xie, Scott, & Jacobs, 2010; Mayer et al., 2012).

Implementation: Uptake and Reach

Implementation of SCPs into practice has been slow, and concordance with IOM recommendations has been limited. Stricker et al. (2011) examined the content, process, and reach of SCPs within 13 community and academic centers participating in the LIVESTRONG Survivorship Centers of Excellence Network. Delivering SCPs to breast cancer survivors was a participation requirement. At the majority of these institutions, less than 10% of breast cancer survivors received an SCP. For those who did provide SCPs, only about half of the IOM recommendations were addressed within the documents. Content areas particularly lacking included documentation of supportive care referrals, information on psychosocial effects and recommended preventive and health-promotion behaviors, guidance about relatives’ cancer risk and need for surveillance, and content to guide coordination of care (e.g., delineation of responsibility for follow-up care). This could be one reason why studies have failed to show improvements in care coordination as a result of SCP delivery (Brothers et al., 2012; Sprague et al., 2013). Efforts should be made to ensure inclusion of this information, particularly since they align with patient and PCP stated preferences for SCP content.

Salz et al. (2012) examined the delivery of SCPs at more than 50 National Cancer Institute-designated comprehensive cancer centers. Only 43% of the centers provided SCPs to either breast or colorectal cancer survivors. No center’s care plans addressed all of Hewitt et al.’s (2006) recommendations, and most addressed only a small subset. Two surveys have evaluated the reach of SCPs. Merport, Lemon, Nyambos, and Prout (2012) examined 108 oncologists and 400 PCPs in Massachusetts and found that 56% provided treatment summaries to their patients; however, only 14% provided SCPs to their patients’ PCPs. A similar proportion of PCPs reported receiving these documents (Merport et al., 2012). Irwin et al. (2011) surveyed a random sample of 399 Oncology Nursing Society members and found that only 37% reported that SCPs were provided in their work environments. Data taken from centers participating in ASCO’s Quality of Oncology Practice Initiative revealed that only 30% of participating practices were routinely providing treatment summaries to their patients (McCabe et al., 2013). The number of centers providing SCPs does not seem to be increasing with time, prompting an examination of barriers to implementation.

Overcoming Barriers to Implementation

Barriers to the provision of SCPs are many, and include patient, provider, and system variables. Patient barriers include lack of awareness, and provider and system barriers include limited financial, time, and human resources. Barriers appear particularly difficult to overcome in community settings, given limited resources and the demand for high practice volume (Grant et al., 2010; Irwin et al., 2011). Working collaboratively with affiliated hospitals and/or health systems can help community practices to offer a greater variety of resources.

Time often is quoted as the largest barrier to SCP delivery (Dulko et al., 2013; Salz et al., 2012). The preparation of detailed treatment summaries and individualized follow-up care plans often is a time-consuming process, taking an average of 60–90 minutes per patient in one report from 13 centers (Stricker et al., 2011). Beginning the preparation of SCPs at the time of diagnosis and prospectively capturing disease and treatment data over time is another strategy. Harnessing the ability of electronic medical record (EMR) systems and other health information technology solutions is one oft-quoted strategy for improving the efficiency of preparing SCPs (Houlihan, 2009; Jacobs et al., 2009). However, EMRs may fail to provide efficient solutions. Although some have begun to create SCP templates, only limited diagnosis and treatment information can be pulled into EMR SCP templates, which also fail to provide automated customization of follow-up care plans. A LIVESTRONG-funded project is underway to determine the feasibility of generating and providing automated SCPs (LIVESTRONG Foundation, 2013). In addition, a Health Level Seven International standard was published in November 2013 (ASCO, 2013b) to standardize the reporting of breast cancer disease and treatment data in EMRs, which may help to improve efficiency once implemented.

The resource burden of reviewing the SCP with survivors is also substantial, often taking up to an hour per patient and often performed by highly skilled APPs (Salz et al., 2012; Stricker et al., 2011). An APP can bill and be reimbursed for delivering an SCP in the context of a clinical visit, but no specific code is active that specifically reimburses for the extensive time spent in preparing and/or delivering the SCP (Grant et al., 2010). Novel strategies such as group-based survivorship care planning visits and mailed SCPs may improve efficiency and decrease resource intensity of survivorship care planning (Nissen et al., 2013; Oeffinger et al., 2010; Trotter, 2011).

Other barriers to SCP delivery include patient factors, such as the desire to stay with a specific oncology provider rather than

Implications for Practice

- Comply with the Commission on Cancer standard by delivering survivorship care plans (SCPs) at the conclusion of active treatment.
- Provide clear and concise guidance to patients and primary care providers on what to expect following active cancer treatment.
- Pay attention to feasibility and integration into the clinical workflow when designing and implementing an SCP.
receive SCPs within a survivorship clinic. Integrated models of survivorship care address this concern (Landier, 2009; McCabe & Jacobs, 2008). The shortage of research to guide evidence-based guidelines for survivorship care is a major barrier to providing specific care recommendations within SCPs (McCabe et al., 2013); however, a variety of consensus-based guidelines (National Comprehensive Cancer Network) and guidance statements (ASCO, American Cancer Society) are becoming available to guide care while the evidence base grows (Cowens-Alvarado et al., 2013; McCabe et al., 2013). Another factor influencing the time and resource burden is the wide scope of content that SCPs are designed to address. IOM recommendations for content are comprehensive and detailed (Palmer et al., in press). Research clearly is needed to define the most important elements of SCPs and link particular elements to outcomes of interest. This will allow evidence-based refinement of content standards and has the potential to improve the feasibility and effectiveness of survivorship care planning efforts (Parry et al., 2013; Stricker et al., 2011). Others, such as the Minnesota Oncology group, whose approach is presented elsewhere in this supplement (O’Brien et al., 2014), have improved the efficiency and sustainability of SCP implementation by preparing and delivering the SCP during not just one, but rather a prospective series of office visits starting at treatment initiation and culminating after active treatment is complete.

Conclusion

After the 2006 IOM report proposed their implementation as a solution for improving coordination and quality of care, SCPs rapidly gained national and international attention. Accrediting bodies such as the CoC quickly adopted as a standard the delivery of SCPs to all patients completing active treatment, despite little available evidence to support their anticipated effects. Although ongoing research continues to examine outcomes of SCP delivery and seeks to link content and processes of SCP delivery to desired outcomes, oncology practices and cancer centers struggle to overcome plentiful barriers to their implementation. Time and resource burden inherent in SCP preparation and delivery remain highest among these barriers, as does a lack of clarity about who is responsible for their preparation and delivery.

Fortunately, a growing number of templates, information technology-facilitated solutions, and novel care models are continuously being developed and tested with the intent of improving the efficiency, effectiveness, and reach of SCPs, and oncology nurses are the healthcare providers who have largely embraced SCP implementation. However, for SCPs to be feasible and sustainable, their delivery must be integrated into existing care-delivery processes and their content streamlined and focused to meet the needs of their intended recipients without becoming overly burdensome to prepare and deliver. Evolving delivery models include both integrated and group-based SCP delivery, and research has made it increasingly clear that content for patients and PCPs alike should focus on providing guidance on what to expect following treatment, what cancer and late-effect surveillance should be done and by whom, and who to contact and/or what resources to access should problems or concerns arise. Keeping these principles in mind should help to streamline and focus SCP implementation efforts while awaiting the results of ongoing research and demonstration projects to help more clearly elucidate the use of SCPs and best practices for their delivery.

References


