

# A History of Cancer Survivorship Plans



**A** generation ago cancer care consisted of diagnosis, active treatment, and resigned palliation. Today, advances in cancer care have increased the number of people surviving a cancer diagnosis leading to a new dimension of care—cancer survivorship. The health, psychological, and social needs of cancer survivors are still in the process of being thoroughly understood by the cancer care community. A tool offered up as a means to facilitate survivorship care is the survivorship care plan (SCP). In this *Oncology Issues* we offer a history of SCP development and outline the current state of SCPs in the cancer care community. In part two of our article, we describe our process for developing and using a survivorship care plan, concluding with how this effort fits within the larger context of SCPs throughout the cancer care community and where we intend to focus future efforts. (Editor's Note: Oncology Specialists, SC, Park Ridge, Ill., received a 2014 ACCC Innovator Award for its "EMR-Driven Approach to Survivorship Care Plans." Read more about these efforts starting on page 52.)

Cancer detection, treatment, and management of cancer-related complications have improved greatly in the past 40 years. Accordingly, both the rates of five-year and longer-term survival have also improved. The National Cancer Institute's 2011/2012 Cancer Trends Progress Report, which covered data collected for the year of 2009, found that there were more than 12.6 million cancer survivors in the U.S.<sup>1</sup> The majority of these were prostate, female breast, and colorectal cancer survivors; with five-year survival rates for prostate cancer and female breast cancer being the most robust, standing at 99 percent and 89 percent respectively as of 2003.<sup>1</sup> Across all cancers, the five-year survival rate was estimated at 67 percent in 2003.<sup>1</sup> The number of longer-term survivors, alive at least 20 years after diagnosis, was estimated to be more than 2 million in 2009.<sup>1</sup>

Of these millions of cancer survivors, each has his or her own associated medical, personal, psychosocial, and economic challenges related to individual disease status that must be accounted for in ongoing care. Faced with this evolving and largely overlooked dimension of care, various organizations have issued mandates

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2005 IOM REPORT

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and statements addressing the cancer care community's collective responsibility to these cancer survivors. Most notably, in 2005, the Institute of Medicine (IOM) released its report, “From Cancer Patient to Cancer Survivor: Lost in Transition.”<sup>2</sup> The report notes that cancer survivors “move from an orderly system of care to a non-system in which there are few guidelines to assist them through the next stage of their life or help them overcome the medical and psychosocial problems that may arise.”<sup>2</sup>



### The Role of SCPs

As part of this effort, the IOM recommended the use of survivorship care plans as a step towards standardization of survivorship care and provided a general outline of the requirements of such a plan. In general terms, an SCP is a document to be provided to a cancer survivor, which summarizes his or her diagnosis, treatment, associated short- and long-term toxicities, expected course of recovery, signs of late effects or recurrence, follow-up plan, and information to support the survivor through potential complications.<sup>3</sup>

The IOM's recommendation divides SCPs into two sections: record of care and standards of care. Aimed at ensuring that cancer survivors have an accurate understanding of the

events they have undergone in that “orderly environment” of active cancer care, the record of care includes at a minimum the following:<sup>2</sup>

- Diagnostic tests performed and results
- Tumor characteristics
- Dates of treatment initiation and completion
- Therapies provided (surgery, chemotherapy, radiotherapy, transplant, hormonal therapy, gene therapy, clinical trial, or any other therapies) along with indicators of treatment response and toxicities experienced
- Psychosocial, nutritional, and other supportive services provided
- Full contact information on treating institutions and key individual providers
- Identification of a key point of contact and coordinator of continuing care.

The standards of care portion stipulates that on discharge from cancer treatment, every patient and his or her primary healthcare provider should receive a written follow-up care plan incorporating available evidence-based standards of care and should include at a minimum:<sup>2</sup>

- The likely course of recovery from treatment toxicities, as well as a need for ongoing health maintenance and adjuvant therapy.
- A description of recommended cancer screening and other periodic testing and examinations, and the schedule on which these should be performed (and who should provide them).
- Information on possible late and long-term effects of treatments and symptoms of such effects.
- Information on possible signs of recurrence and second tumors.
- Information on the possible effects of cancer on marital and partner relationship, sexual functioning, work, and parenting, and the potential future need for psychosocial support.
- Information on the potential insurance, employment, and financial consequences of cancer and, as necessary, referral to counseling, legal aid, and financial assistance.
- Specific recommendations for healthy behaviors. When appropriate, recommendations that first-degree relatives be informed about their increased risk and the need for cancer screening.
- As appropriate, information on genetic counseling and testing to identify high-risk individuals who could benefit from more comprehensive cancer surveillance, chemoprevention, or risk-reducing surgery.
- As appropriate, information on known effective chemoprevention strategies for secondary prevention.

- Referrals to specific follow-up care providers, support groups, and/or the patient’s primary care provider.
- A listing of cancer-related resources and information.

According to the IOM, even though this proposal of SCP use was not preceded by validating studies or evidence, the potential benefits and minimal harm justified its introduction to clinical practice.<sup>3,4</sup> As a result, interest in and support for SCP use began to develop among key oncology organization, notably ASCO, ACS, and the LIVESTRONG Foundation.

In 2012 the Commission on Cancer (CoC) updated its Cancer Program Standards (S3.3), requiring accredited cancer centers to include a comprehensive SCP and treatment summary for each patient by 2015. (Approximately 30 percent of U.S. hospitals have achieved CoC accreditation, a widely-recognized seal of quality. These hospitals treat nearly 80 percent of newly-diagnosed cancer patients each year.<sup>5</sup>) However, in September 2014, the CoC revised and amended 3.3, in response to its findings that accredited cancer centers were showing significant lack in readiness for the new standard. The CoC revision now calls for a phased-in approach over five years for adjuvant patients only, allowing for special recognition to cancer centers that attain the standard requirement sooner.



### The Current State of SCPs

Overall, the oncology community has made tangible progress in fulfilling a legitimate need for survivorship care plans. However, various studies have illustrated the need for a standardized method of survivorship care. Salz et al. published a two-part study in July 2013 consisting of a comprehensive review of literature investigating the content and use of SCPs from the perspective of patients and providers and a quantitative survey to 53 NCI-designated cancer centers on SCPs in breast and colorectal cancer survivors up to July 2009.<sup>3</sup>

**Patient needs.** From the patient perspective, there are problems with survivors being both under- and over-informed. Several studies reported patients who were “unsure of their diagnosis and treatment, particularly the less salient details such as presence of metastasis and which diagnostic tests were used.”<sup>3,6-11</sup> On the opposite end of the spectrum, other studies reported that [patients] “received too much information when they could not focus on it properly.”<sup>3,12,13</sup> Related to the issue of level of detail in SCPs, breast cancer survivors surveyed on the ASCO treatment summary and care plan “felt the language was too technical and preferred more detail about managing their own care.”<sup>3,7,12</sup>

These findings bring to light the special nature of information delivery in oncology care. Clearly a record of information is a basic patient need. Simple transmittal of the information is not enough, however, as the psychological stress from cancer diagnosis and treatment can have varying effects on the patient’s already

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difficult task of interpreting complex medical information. An effective survivorship care program has an SCP that can succinctly simplify medical jargon for the patient and then has a delivery method nuanced enough to verify whether a patient has indeed understood the information.

In the review by Salz et al., other significant conclusions from the patient perspective were that patients rated highly a desire to be “alerted to and informed about potential psychological issues” related to survivorship.<sup>3,7,12,14,15</sup> Patients also “valued the SCP for its role in involving their PCP in their survivorship journey.”<sup>3,6-8,16-18</sup> Finally, not all patients believed that receiving the SCP at the end of treatment was the most beneficial strategy, with preferences for timing of receipt ranging from at the start of treatment to after the end of treatment.<sup>3,8,19</sup>

**Provider needs.** Compared to oncology providers, primary care providers (PCPs) identified different needs. Various physician surveys showed that only roughly half of surveyed PCPs have confidence in their ability to provide ongoing cancer survivorship care to breast and colorectal cancer patients. This finding was especially true when asked about their confidence in being responsible for cancer recurrence, with 84 percent unsure about type, frequency, or duration of surveillance tests for breast and colorectal cancer.<sup>3,20-21</sup> Because of their varying other clinical responsibilities, it is not unreasonable that PCPs are not intimately familiar with cancer survivorship guidelines and recommendations. In fact, one survey found that over 90 percent of PCPs did not know of the 2005 IOM report regarding SCPs and the needs of cancer survivors. When asked about receiving SCPs from oncology providers, PCPs favored this as tool as a means to improve care for cancer survivorship through written guidelines.<sup>3,12,16,20,22</sup>

Oncology providers are the key stakeholder in the process of implementing SCPs. Evidence seems to suggest that most oncology providers have “bought into” the idea of SCPs and recognize their utility; however, logistical concerns about resources and time remain. Barriers highlighted by oncology providers include choosing an optimal format; allocating time, resources, and personnel to the production of an SCP for each patient; and lack of an adequate reimbursement process for the SCP production and delivery appointment.<sup>3,12,23,24</sup>

A pilot study reviewed by Salz et al. found that it takes 60 to 90 minutes for a research assistant to complete an SCP for a colorectal cancer survivor, which then needs to be reviewed by a nurse. The patient appointment dedicated to SCP delivery took an average of one hour.<sup>3,16,25</sup> Meanwhile, oncology providers surveyed felt that a reasonable amount of time to devote to SCP production was about 20 minutes.<sup>3,12</sup> Of note, two studies found that an EMR-driven tool that allows for automated completion could reduce the oncology provider’s workload.<sup>3,23,24</sup>

Lastly, a lingering question remains regarding the effectiveness of SCPs on influencing tangible outcomes. Most of the literature on survivorship care to date is qualitative rather than quantitative. Whether SCPs actually improve either patient-related endpoints (improved compliance with follow-up, earlier detection of secondary toxicities, etc.) or provider-related outcomes (better adherence to standardized surveillance guidelines, among others), remains to be seen. While qualitative studies paint a picture of the needs an SCP may meet, quantitative studies are needed to evaluate if this is indeed being accomplished.



### SCPs at NCI-Designated Cancer Centers

The second part of the study by Salz et al. discusses a quantitative survey of 53 NCI-designated cancer centers. The survey focused on SCPs for breast and colorectal cancer survivors, evaluating how often these were being used, their content, degree of adherence to the IOM framework, and time and method of SCP delivery, up to July 2009. The survey found that only 43 percent of centers reported using SCPs for breast cancer survivors, colorectal cancer survivors, or both. Somewhat encouragingly, of the centers that reported not using SCPs, 50 percent said SCPs were in planning or development.

Content evaluation revealed very inconsistent adherence to IOM guidelines. Only 1 of the 23 SCPs that were evaluated included information on psychosocial services received by the patient, and none included history of other supportive services used.<sup>3</sup>

The SCPs evaluated did only slightly better on follow-up plans, with breast cancer SCPs generally better developed than those for colorectal cancer. In both instances, more than half of the SCPs included basic recommendations for ongoing care, but less than 20 percent explained which provider would perform follow-up testing. While 40 percent of breast and 17 percent of colorectal cancer SCPs described potential late effects associated with therapy, very few (20 percent breast, 0 percent colorectal) provided descriptions of other non-therapy related medical and psychological issues that may arise. Signs of recurrence or secondary malignancy were included in 65 percent of breast cancer SCPs, but none of the colorectal cancer SCPs included this information. The potential need for psychosocial support was noted in almost half of all SCPs (50 percent breast cancer, 40 percent colorectal cancer), in

keeping with the qualitative data from part one of the study by Salz et al. in which patients expressed desire for more psychosocial support. However delineation of the psychosocial burden of cancer survivorship was not well addressed, with concerns such as impact on marital issues, sexual dysfunction, parenting difficulties, insurance, employment, legal, and financial assistance details being low (0 to 33 percent, depending on disease and type of psychosocial issue).<sup>3</sup>

Regarding SCP delivery, most centers (71 percent) indicated varying timing of plan delivery within their institution, usually impacted by when patients were referred (self- or provider-driven) to the survivorship program. They were unable to estimate what percent of actual treating clinicians were part of the SCP production and implementation process, but clearly it was not uniform since many of the survivorship programs within the same institution functioned separately from the treating clinician. Among institutions that were able to provide information on SCP delivery statistics, 52 percent stated that less than half of survivors were receiving SCPs.<sup>3</sup>

Salz et al. conclude that SCP use has general support and potential benefit as evidenced by qualitative reviews. However, uptake of SCP implementation among NCI-designated cancer centers is inconsistent, and even among programs that use SCPs, content and delivery is still largely suboptimal. Highlighted deficiencies include lack of psychosocial support information and lack of a key contact person for patients to refer to. Barriers seem to involve financial resources, time, and lack of institutional commitment. Salz and colleagues also hypothesized that part of the variation in SCPs may be due to the actual IOM guidelines, which are essentially a vague and wide-based framework. Additionally, in attempting to address two different audiences (survivors and PCPs), the SCP may lose its effectiveness and fall short of satisfying the needs of either party.<sup>3</sup>



### More Inconsistent Use of SCPs

Since the work by Salz et al., other studies have been published that echo their results and also highlight a few other key points. Further supporting the still infrequent use of survivorship care plans, in 2014, Blanch-Hartigan et al. published a study using data obtained from a 2009 nationwide poll of over 1,020 PCPs and 1,130 oncologists, the Survey of Physician Attitudes Regarding the Care of Cancer Survivors. They examined four variables:

1. Whether oncologists gave written SCPs to patients
2. Whether oncologists discussed SCPs with patients and delineated a responsible party for follow-up
3. Whether oncologists performed both of the previous two roles
4. Whether PCPs discussed the SCP and provider follow-up responsibilities with survivors.

They found that while 64 percent of oncologists “always or almost always” discussed issues of survivorship, when it came to regulated use of an SCP, the results were considerably worse. Less than 10 percent of oncologists “always or almost always” provided a written SCP; about 30 percent of oncologists discussed both the SCP and provider responsibilities; and less than 5 percent regularly did both tasks. Only 12 to 34 percent of PCPs regularly participated in discussions of survivorship recommendations or delineation of provider responsibilities of cancer care and other medical care, depending on the task. Two notable findings were that oncologists who were trained in long-term effects of cancer were twice as likely to discuss in detail survivorship care, and that PCPs who received treatment summaries and follow-up plans from oncologists were nine times as likely to discuss survivorship care. Time was again cited as a major barrier.<sup>26,27</sup>



### Barriers to SCP Use

The barriers to progress suggested in the study by Salz and colleagues were reiterated by Birken et al. in their 2013 study on SCP prevalence and barriers to use through a 12-point survey sent to 71 member programs of the South Atlantic Division of the American Cancer Society. Their findings regarding prevalence were no better than those of Salz et al., with 76 percent of survey recipients responding that 25 percent or less of their institution members were using SCPs. The majority of reported barriers were the usual suspects: 75 percent reported insufficient organizational resources such as time, staff, money, and training. Other barriers included lack of systems to streamline SCP use, with open-ended responses, including lack of EMR and SCP integration. An interesting finding that speaks to the importance of professional society adoption of SCP use is that 61 percent of respondents reported that their programs began SCP use because of professional society recommendations; 62 percent reported a lack of a professional society accreditation requirement for SCP as a barrier.<sup>28</sup>



### SCPs Outside the U.S.

To assess the state of SCP use outside of the U.S., Daudt et al. reviewed 16 SCPs from Canada, the U.K., New Zealand, and Australia on content, method of delivery, and self-evaluation of results after implementation. Most SCPs were delivered by nurses or nurse practitioners at face-to-face meetings. Regarding content, the findings of Daudt and colleagues were similar to the 2009 findings of Salz et al.; survivorship care plans do not all follow IOM guidelines, especially with regards to psychosocial aspects of survivorship and clear designation of a key clinical contact person for follow-up.

Daudt and colleagues did uncover a potentially useful point regarding timing of delivery. They noted in qualitative feedback



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that patients wished they had been given information earlier in their disease course. When evaluating the U.K.'s National Cancer Survivorship Initiative (NCSI), the authors found a unique approach to intent of SCP and timing of delivery. Unlike most SCPs, which are delivered at the end of treatment, the NCSI plan encompassed the entire cancer timeline. The NCSI SCP began with continuous nurse assessments based on validated tools: the Distress Thermometer and the Sheffield Assessment Instrument. As treatment approached completion, the care team adopted a "risk stratified pathway," in which they categorized patients into different types of care plans determined by the level of their needs thus far based on the validated assessment tools. At the end of treatment, based on the continuously developing care plan already in place, an SCP was generated and also distributed to the PCP. The NCSI's self-evaluation of this process shows that this broad and dynamic approach to care plans improves patient satisfaction, patient confidence in self-managing their health, and cost effectiveness, and decreases need for acute medical care.<sup>29</sup>




### The Big Picture

An evaluation of the state of survivorship care plans reveals a developing process. IOM and CoC standards have undoubtedly increased SCP use. However, due to the vagueness of these guidelines, interpretative freedom has allowed an organic growth process for SCPs. This has resulted in progress as well as "growing pains." In summary:

- Adoption of SCP implementation remains inconsistent among the oncology care community.
- Where SCP adoption has taken root, there remains a lack of standardization of the components (as identified by the IOM) and in SCP delivery.

- Two IOM SCP features are under-represented in plans: psychosocial aspects of survivorship and a key point of contact for continuing care.
- Barriers to progress thus far are resource related: time, money, and lack of ability to provide dedicated staff time to this effort.

Remaining issues that need further study include whether SCP implementation is truly cost effective and ultimately useful. Intuitively, a plan that facilitates better preventive care during survivorship should theoretically minimize needs for acute care, as seen by the NCSI. Studies to date have not demonstrated cost savings with SCP use.<sup>30</sup> However, these results were obtained on SCPs as they stand currently. As SCPs themselves improve in content and use, future studies may yield different results in terms of cost effectiveness and utility. Validated metrics are also needed to accurately evaluate SCPs, as well as patient satisfaction, as we move forward in their evolution. At this point in their trajectory, SCPs are recognized as a yet unproven but flexible tool with potential to aid in providing holistic and patient-centered care to cancer survivors. 

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### References

1. NCI. Cancer Trends Progress Report-2011/2012 Update. Available online at: <http://progressreport.cancer.gov>. Last accessed Nov. 13, 2014.
2. IOM. Cancer Survivorship Care Planning Fact Sheet; 2005. Available online at: <http://www.iom.edu/~media/Files/Report%20Files/2005/From-Cancer-Patient-to-Cancer-Survivor-Lost-in-Transition/factsheet-careplanning.pdf>. Last accessed Nov. 13, 2014.
3. Salz T, Oeffinger KC, McCabe MS, Layne T, et al. Survivorship care plans in research and practice. *CA Cancer J Clin.* 2012;62(2):101-117.
4. Hewitt M, Greenfield S, Stovall E, eds. From Cancer Patient to Cancer Survivor: Lost in Transition. Institute of Medicine and National Research Council. Washington, D.C.; 2005.
5. CoC. Cancer Program Standards 2012: Ensuring Patient-Centered Care. American College of Surgeons, 2012.
6. Brennan ME, Butow P, Marven M, et al. Survivorship care after breast cancer treatment—experiences- and preferences of Australian women. *Breast.* 2011; 20(3):271-277.
7. Burg MA, Lopez ED, Dailey A, et al. The potential of survivorship care plans in primary care follow-up of minority breast cancer patients. *J Gen Intern Med.* 2009;24(Suppl 2):S467-S471.
8. Marbach TJ, Griffie J. Patient preferences concerning treatment plans, survivorship care plans, education, and support services. *Oncol Nurs Forum.* 2011;38(3):335-42.

9. Hawkins NA, Pollack LA, Leadbetter S, et al. Informational needs of patients and perceived adequacy of information available before and after treatment of cancer. *J Psychosocial Oncol*. 2008;26(2):1–16.
10. Lynch BM, Youlden D, Fritschi L, et al. Self-reported information on the diagnosis of colorectal cancer was reliable but not necessarily valid. *J Clin Epidemiol*. 2008;61(5):498–504.
11. Phillips KA, Milne RL, Buys S, et al. Agreement between self-reported breast cancer treatment and medical records in a population-based Breast Cancer Family Registry. *J Clin Oncol*. 2005; 23(21):4679–86.
12. Hewitt ME, Bamundo A, Day R, et al. Perspectives on post-treatment cancer care: qualitative research with survivors, nurses, and physicians. *J Clin Oncol*. 2007;25(16):2270–3.
13. Royak-Schaler R, Passmore SR, Gadalla S, et al. Exploring patient-physician communication in breast cancer care for African American women following primary treatment. *Oncol Nurs Forum*. 2008; 35(5):836–843.
14. Beckjord EB, Arora NK, McLaughlin W, et al. Health-related information needs in a large and diverse sample of adult cancer survivors: Implications for cancer care. *J Cancer Surviv*. 2008; 2(3):179–189. [PubMed: 18792791]
15. Baravelli C, Krishnasamy M, Pezaro C, et al. The views of bowel cancer survivors and health care professionals regarding survivorship care plans and post treatment follow up. *J Cancer Surviv*. 2009; 3(2):99–108.
16. Miller R. Implementing a survivorship care plan for patients with breast cancer. *Clin J Oncol Nurs*. 2008; 12(3):479–87.
17. Kantsiper M, McDonald EL, Geller G, et al. Transitioning to breast cancer survivorship: perspectives of patients, cancer specialists, and primary care providers. *J Gen Intern Med*. 2009;24(SUPPL. 2):S459–S466.
18. Blinder V, Norris V, Peacock N, et al. Patient perspectives on a breast cancer treatment plan/summary program in community oncology care: an ASCO pilot program. Under review.
19. Smith S, Singh-Carlson S, Downie L, et al. Survivors of breast cancer: patient perspectives on survivorship care planning. *J Cancer Surviv*. 2011:1–8.
20. Del Giudice ME, Grunfeld E, Harvey BJ, et al. Primary care physicians' views of routine follow up care of cancer survivors. *J Clin Oncol*. 2009; 27(20):3338–45.
21. Nissen MJ, Beran MS, Lee MW, et al. Views of primary care providers on follow-up care of cancer patients. *Fam Med*. 2007; 39(7):477–482.
22. Bober SL, Recklitis CJ, Campbell EG, et al. Caring for cancer survivors: A survey of primary care physicians. *Cancer*. 2009; 115(SUPPL. 18):4409–4418. [PubMed: 19731354]
23. Horning SJ. Follow-up of adult cancer survivors: new paradigms for survivorship care planning. *Hematol Oncol Clin North Am*. 2008; 22(2):201–10. v. [PubMed: 18395145]
24. Earle CC. Long term care planning for cancer survivors: a health services research agenda. *J Cancer Surviv*. 2007; 1(1):64–74.
25. Jefford M, Lotfi-Jam K, Baravelli C, et al. Development and pilot testing of a nurse-led posttreatment support package for bowel cancer survivors. *Cancer Nurs*. 2011;34(3):E1–E10.
26. Barton MK. Oncologists and primary care physicians infrequently provide survivorship care plans. *CA Cancer J Clin*. 2014 Sep 10;64(5):291–2.
27. Blanch-Hartigan D, Forsythe LP, Alfano CM, Smith T, Nekhlyudov L, Ganz PA, Rowland JH. Provision and discussion of survivorship care plans among cancer survivors: results of a nationally representative survey of oncologist and primary care physicians. *J Clin Oncol*. 2014 May 20; 32(15):1578–1585.
28. Birken SA, Mayer DK, Weiner BJ. Survivorship care plans: prevalence and barriers to use. *J Cancer Educ*. 2013 June;28(2):290–6.
29. Daudt HM, Mossel C, Dennis DL, Leitz L, Watson HC, Tanliao JJ. Survivorship care plans: a work in progress. *Curr Oncol*. 2014 June;21(3):e466–79.
30. Coyle D, Grunfeld E, Coyle K, Pond G, et al. Cost effectiveness of a survivorship care plan for breast cancer survivors. *J Oncol Pract*. 2014 Mar;10(2):86–92.

