

The Integration of Survivorship Care Planning at a Comprehensive Cancer Center

ELIZABETH B. McGRATH, DNP, APRN, AGACNP-BC, AOCNP®, ACHPN,
ANNA SCHAAL, MSN, APRN, and CLAIRE PACE, MSN, APRN

From Dartmouth-Hitchcock Medical Center and Geisel School of Medicine, Lebanon, New Hampshire

Authors' disclosures of conflicts of interest are found at the end of this article.

Correspondence to: Elizabeth B. McGrath, DNP, APRN, AGACNP-BC, AOCNP®, ACHPN, 1 Medical Center Drive, Lebanon, NH 03756.

E-mail: elizabeth.b.mcgrath@hitchcock.org

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Abstract

Research has demonstrated that cancer survivors who receive a survivorship care plan (SCP) have better coordinated follow-up care, higher overall satisfaction, and report significantly fewer posttreatment emotional concerns. The Commission on Cancer, a program of the American College of Surgeons, has developed a standard of care in which 100% of eligible patients are to receive an SCP by the end of 2019. Nurse practitioners at a National Cancer Institute (NCI)-designated academic medical center worked to develop a standardized process to deliver SCPs to all eligible patients. The primary objective of the project was to standardize how SCPs were completed and embed them into the electronic medical record (EMR) using a templated note created for the EMR. Through an interdisciplinary steering committee, survivorship priorities were established and aligned with **LIVESTRONG** and American Society of Clinical Oncology guidelines. In addition, survivorship care planning was identified as an essential service to be provided by all cancer disease management groups (DMG) at the cancer center. A cancer SCP subcommittee was formed to explore methods to expand the delivery of SCPs and standardize the SCP process. Prior to this project, SCPs were being done by less than 10% of the providers and only for a few diagnoses, and no standardized method of documentation existed prior to this quality improvement initiative. The standardization of the SCP has increased both participation of other DMGs as well as increased the rate of completion to 34%. We believe that continuous reassessment and process improvement will help us reach the Commission on Cancer goal of providing SCPs to all eligible patients.

The number of patients surviving a cancer diagnosis continues to increase. Cancer survivorship reached nearly 15.5 million people in 2014, and this is projected to increase to over 20 million by 2026 (National Cancer Institute, 2016). Al-

though improved survival is an exciting and much desired outcome of advancing science, cancer survivors are faced with numerous challenges, many of which are unaddressed by the professional health-care community. These challenges include an abrupt transition from active treatment to survivorship care.

Complying with established survivorship guidelines and coordinating this care across multiple health-care providers and systems is challenging. Patients and primary care providers are often unsure of what long-term follow-up will consist of and who will perform it. Often a gap remains between primary care and cancer specialists regarding follow-up care (Hede, 2011). A lack of communication between oncology and primary care has been identified, as well as primary care knowledge deficit of survivorship issues with the rapidly changing landscape of oncology treatments (Yann et al., 2018). Barriers have also been identified, which help to explain why cancer survivors are not receiving this care at primary care offices. These include an absence of cancer survivorship as a recognized clinical category, a lack of primary care recommendations, and a lack of current primary care infrastructure to support cancer survivorship care (Rubinstein et al., 2017).

In spite of national oncology guidelines for survivorship care, recommendations for monitoring for recurrent disease and managing treatment-related side effects are often ambiguous and inconsistently carried out. There is often confusion as to which provider or specialty will ensure follow-up and monitor for recurrence and late effects of treatment (Dulko et al., 2013; Virgo, Lerro, Klabunde, Earle, & Ganz, 2013). There is limited research on survivorship concerns, and many are not currently addressed by current cancer care systems (Alfano et al., 2014). This can all contribute to significant distress in cancer survivors.

It has been over a decade since the Institute of Medicine (IOM) first proposed that “all patients should be given a comprehensive summary and a clear explanation of the details of their cancer therapy as well as recommendations for necessary follow-up” (Institute of Medicine and National Research Council, 2006). This seemingly simple task has proved difficult to deliver in many cancer care settings (Arnett, Henry, & Fankell, 2014; Bar-

ton, 2014; Belansky & Mahon, 2012; Birken, Mayer, & Weiner, 2013; Blanch-Hartigan et al., 2014). No superior model of survivorship or survivorship care planning has emerged. However, research indicates that nurse-led programs may be more successful (Hebdon, Abrahamson, McComb, & Sands, 2014; Keesing, McNamara, & Rosenwax, 2015).

Research also indicates that cancer survivors receiving a survivorship care plan (SCP) have better coordinated follow-up care, including cancer screening, surveillance, and management of late and long-term effects (Jabson, 2015). Patients also have a higher overall satisfaction with survivorship care (Palmer et al., 2015; Rocque et al., 2014) and report significantly fewer posttreatment emotional concerns (Rechis, Beckjord, & Nutt, 2014; Sprague et al., 2013) and cancer treatment distress (Majhail et al., 2017).

A recent systematic review suggests that providing SCPs alone is not effective in improving health outcomes, such as following health recommendations and surveillance testing (Jacobsen et al., 2018). One study found that less than half of childhood cancer survivors followed the surveillance guidelines outlined in the SCP (Yan et al., 2018). However, when care planning was paired with a visit to a cancer survivor specialist or clinic, these rates improved significantly. It has been shown that when SCPs are tailored to individuals and their known side effect profile, patients feel confident that they would be able to follow the recommendations (Salz et al., 2017). This suggests that adherence to SCP recommendations requires more than providing patients with a simple document. Counselling and care coordination as a part of an SCP visit seem imperative for successful survivorship care outcomes.

A number of barriers to delivering SCPs have been identified. These include the time-consuming process of developing the SCP, lack of reimbursement for the development of the SCP document, limited staff resources for delivery of the SCP, and confusion regarding who should be creating and reviewing the SCP with the patient (e.g., nurse practitioners [NPs], physicians, or nurses). Other hurdles include a communication gap between primary care providers and cancer specialists as well as a lack of electronic medical record (EMR) integration (Mayer, 2014). Despite

these obstacles, it is vital that cancer centers continue to work toward providing SCPs for all eligible patients. The purpose of this article is to describe the steps taken at one National Cancer Institute–designated cancer center to integrate the SCP into the EMR and into routine cancer care.

STUDY AIMS

The Cancer Survivorship Committee was charged with standardizing a process that would optimize our current electronic medical record (Epic) in order to facilitate the completion of care plans. The work began by the formation of a subcommittee of the Cancer Center Survivorship Committee. The team included NPs, a medical oncologist, oncology nurses, team schedulers, Epic staff, and an informatics expert.

We defined our aims as the following:

1. Define the elements of a comprehensive SCP.
2. Explore how our EMR could facilitate the development of SCPs for cancer patients treated with curative intent.
3. Develop a procedure to identify cancer survivors who are treated with curative intent to ensure they are scheduled within 3 to 6 months of completion of therapy for survivorship visits.
4. Develop disease site–specific care plans that meet American Society of Clinical Oncology (ASCO) standards.
5. Pilot the implementation of SCPs utilizing EMR functions.
6. Evaluate the process and make appropriate modifications.

CONCEPTUAL FRAMEWORK

Dorothea E. Orem developed the Self-Care Nursing Theory that incorporates the assumption that patients should be self-reliant and assume responsibility for their own health care (Orem, 1991). This theory recognizes that nursing has a role in providing patients with knowledge in regard to their illness and potential health problems so that they can assume responsibility for their own health care. Orem’s holistic theory includes physical, psychological, social, and spiritual aspects of health. Survivorship care plans embody this quality of life model and are designed to provide patients with comprehensive information about their cancer and treatment, guide them in the management of late effects of treatments, identify physical, psychological, social, and spiritual concerns, as well as create a plan to promote wellness through shared decision-making.

PROCEDURES

Initially, meetings were dedicated to defining the elements of a comprehensive SCP. In order to achieve this aim, a literature review was completed, and we explored available tools such as Journey Forward and ASCO templates to construct customized template SCPs. Many cancer centers have been challenged to include all of the IOM’s recommendations (Table 1) into the SCP (Salz, Oeffinger, McCabe, Layne, & Bach, 2012).

The committee reviewed the various existing templates and defined the elements that met current guidelines. From that, what was defined as a “basic survivor care plan” was built. The ASCO guidelines were utilized to guide the tem-

Table 1. Institute of Medicine Survivorship Care Plan Recommendations

Upon discharge from cancer treatment, including treatment of recurrences, every patient should be given a record of all care received and important disease characteristics. This should include, at a minimum:

- Diagnostic tests performed and results
- Tumor characteristics (e.g., site(s), stage and grade, hormonal status, marker information)
- Dates of treatment initiation and completion
- Surgery, chemotherapy, radiotherapy, transplant, hormonal therapy, gene or other therapies provided, including agents used, treatment regimen, total dosage, identifying number and title of clinical trials (if any), indicators of treatment response, and toxicities experienced during treatment
- 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

Note. Information from Institute of Medicine and National Research Council (2006).

plate formation. The physician member and NPs of the subcommittee then met with the cancer center’s providers to educate them regarding the

goals of the subcommittee and to obtain support for and input on the specific SCP elements. It was determined that the advanced practice registered nurses (APRNs) embedded within each disease management group (DMG) would be best situated to generate and deliver the SCP. Research suggests that NP-led survivorship clinics have been successful in providing quality survivorship care in accordance with the IOM recommendations and demonstrate improvement in patient satisfaction, quality of life, and process efficiency (Spears, Craft, & White, 2017).

Guidelines for identifying patients appropriate for an SCP within the defined timeline were created. These included all patients being treated with chemotherapy or radiation therapy with curative intent. The timing of the delivery of the SCP was targeted between 3 to 6 months after completion of therapy to comply with Commission on Cancer standards. We then explored the components in the EMR that could be utilized to aid in the development of a comprehensive SCP. Integration into the EMR (Epic) was imperative, as this would have the potential to overcome the many barriers associated with successful SCP programs (Hill-Kayser et al., 2016).

Developing each individual SCP is a time-consuming process, and every effort was made to minimize the amount of data entry and chart reviews needed for each SCP. To best accomplish this goal, a novel approach was used by integrating the cancer problem list and treatment flow sheets. When the EMR was implemented, the various oncology DMGs created flow sheets that included information about cancer presentation, pathology details, specific treatments, and treatment toxicities. These flowsheets are live documents and are housed in the problem list under the cancer diagnosis. The cancer flow sheets serve as a basis in the development of the SCP, starting at diagnosis and including the disease- and treatment-specific clinical data required for a comprehensive SCP (Table 2).

A pilot was completed using the cancer flow sheets within two patient populations: prostate and breast cancer survivors. The NP would input data to the flow sheet, and this information was then easily uploaded to the templated SCP document. The data elements could be enhanced to add

Table 2. Sample Cancer Flow Sheet

Date care plan initiated	7/14/2015
Date of presentation	8/1/2014
Age at presentation	62 years old
PSA at presentation	8.31
Presence of symptoms at presentation	Positive
Ethnicity	White
Result of DRE	Normal
Date of TRUS and biopsy	8/14/2014
Volume in cc	40
Gleason grade/score a + b = c	-
Total cores	13
Positive cores	13
Bone scan at presentation	4 + 5 = 9
Date of bone scan	9/30/2014
Prostate confined	-
ECE	+
SV	+
Regular nodes	(no data)
Distant mets	-
Date of MRI	9/30/2014
Urinary continence at presentation	N
Primary therapy	EBRT
EBRT date began	12/29/2014
EBRT total dose (Gy)	79.2
Treatment fractions	44
Elapsed date	3/4/2015
Concurrent ADT	+
Histologic type	Adenocarcinoma
Post primary therapy: nadir date	6/4/2015
Post primary therapy: nadir PSA	< 0.03
Adjuvant therapy	LHRH agonist
ADT duration in months	28

Note. PSA = prostate-specific antigen; DRE = digital rectal exam; TRUS = transrectal ultrasound; ECE = extracapsular extension; SV = seminal vesicles; EBRT = external beam radiotherapy; ADT = androgen deprivation therapy; LHRH = luteinizing hormone-releasing hormone.

details in language that patients could understand and add unique patient-specific information (i.e., care team, contact information, etc.).

After testing the site-specific flow sheets and the SCP template, work was needed to ensure that all DMGs had disease-specific flow sheets and templates that addressed possible late and long-term effects and management, symptoms of disease recurrence, ongoing surveillance needs, and lifestyle and wellness recommendations, which are all recommended by the IOM (Table 3). The providers (primary care provider or oncology care team) who are expected to order and monitor ongoing surveillance and long-term follow-up for possible complications are clearly documented in each SCP.

In order to ensure a standardized SCP process, the NP group responsible for delivering the care plans met several times to reach a consensus regarding the “smart text” used in the template for the patient education portion of the SCP. A half-day retreat was dedicated to finalizing the patient education information and ensuring it would be uniform and available in all SCP templates, regardless of diagnosis. National

guidelines were used, including National Comprehensive Cancer Network (NCCN) and ASCO guidelines. All patient education was developed into “smart text” that could be uploaded into a patient’s SCP and easily modified for individual patients. Using the disease-specific flow sheet and the templated SCP document, including patient education “smart text,” it was validated that completing a care plan took less than 15 minutes for the majority of patients.

Finalizing disease-specific flow sheets and templates was a collaborative effort. Informatics experts helped to update existing flow sheets and to build new flow sheets into the EMR. In fall 2015, all NPs piloted the site-specific flow sheets and templates. Questions and concerns were addressed at regularly scheduled APRN meetings. The workup to this point was then presented to the physician provider group at a faculty meeting to both educate as well as recruit assistance in identifying patients eligible for a SCP.

We launched our program in January 2016 with the plan to perform an audit every 3 to 6 months to determine the number of eligible patients who had a survivorship visit and care plans.

Table 3. Institute of Medicine–Recommended Standards of Care

Upon discharge from cancer treatment, every patient and their primary health care provider should receive a written follow-up care plan incorporating available evidence-based standards of care. This should include, at a minimum:

- The likely course of recovery from treatment toxicities, as well as need for ongoing health maintenance/adjuvant therapy
- A description of recommended cancer screening and other periodic testing and examinations, and the schedule on which they should be performed (and who should provide them)
- Information on possible late and long-term effects of treatment and symptoms of such effects; Information on possible signs of recurrence and second tumors
- Information on the possible effects of cancer on marital/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 (e.g., diet, exercise, healthy weight, sunscreen use, virus protection, smoking cessation, osteoporosis prevention)
- When appropriate, recommendations that first-degree relatives be informed about their increased risk and the need for cancer screening (e.g., breast cancer, colorectal cancer, prostate cancer)
- 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 (e.g., tamoxifen in women at high risk for breast cancer; aspirin for colorectal cancer 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 (internet-based sources and telephone listings for major cancer support organizations)

Note. Information from Institute of Medicine and National Research Council (2006).

The audit was done by chart review using an Epic/Beacon-generated list that utilizes “curative intent” and completion of a Beacon plan to create an eligible patient list. This list is then reviewed by the NP group to assess the number of eligible patients who have completed SCPs.

RESULTS

A random chart review of 50 patients who completed curative intent therapy was performed prior to initiation of the new SCP templates. Of those 50 charts, only 6% had completed SCPs. Three months after the initiation of standardized SCPs, a second 50-chart review was completed that reflected an increase to 10%. The results of each audit were discussed at monthly APRN meetings. Barriers were identified, and we found many patients did have SCP visits scheduled in the system, but they had yet to be completed in the original 3-month time frame. An additional chart review was done 3 months later with 16% of eligible patients having completed an SCP in the EMR.

Ongoing audits have successfully identified additional barriers that prevent the completion and delivery of SCPs and have allowed for improvements to the process. The chief barrier the APRN group identified was that many DMGs were having a difficult time identifying patients who completed therapy and were eligible for SCPs because of incomplete Beacon plans (intention of treatment not completed) or electronic completion of Beacon plan by providers not done, leaving unidentified patients eligible for SCP. Another common finding among the DMGs was that the patient follow-up was being scheduled with a physician and not necessarily the NP who was responsible for the SCP. Some of these patients were able to be captured at a later date but not within the expected goal of 3 to 6 months. In addition, patients being followed by both radiation oncology and medical oncology were difficult to capture as it was not clear which specialty was responsible for the SCP.

The standard operating procedure (SOP) now identifies medical oncology as the provider responsible for all combined modality patients. Radiation oncology is responsible for patients receiving definitive radiation therapy only. In

collaboration with the EMR informatics support, we were able to run a master list of patients who have completed chemotherapy and radiation treatment with curative intent. This list is given to secretaries who then schedule the SCP appointment with the appropriate NP. The list is generated monthly to ensure scheduling of these appointments. The initial chart review following initial implementation showed an increase to a 29% completion rate and more recently is up to 34%. As we move forward, more eligible patients are being scheduled per the new SOP. We anticipate continued improvement to reach our capture rate closer to the goal of 70% completed SCPs.

DISCUSSION

Despite this comprehensive SOP, challenges remain. Patients who are treated on clinical trials are followed closely by a research nurse but do not have electronic chemotherapy plans nor do they always have an NP following their care. Another challenge is how to integrate the satellite and outreach clinics. Our goal is for all cancer care sites to follow the SOP for SCPs. Unfortunately, not all sites are staffed with NPs or use the same EMR. A further challenge is the allogeneic transplant population, as the timing of the SCP is difficult in this cohort since they often are still under active therapy for up to 1 to 2 years after treatment. Long-term survival is impacted by late relapses, late complications, and late non-relapse mortality, thus making the timing of the SCP in this group difficult to standardize (Majhail & Rizzo, 2013).

The APRN group has found that counselling and care coordination is a major component of delivering the SCP. The SCP visit is used as a springboard for referrals for late side effects as well as time to explore a patient’s emotional response to therapy and future plans. As recommendations such as exercise, diet, and smoking cessation are reviewed, the APRNs capitalize on the opportunity to educate as well as identify community resources with the patients. Follow-up visits regarding these issues are scheduled as necessary. The feedback from patients regarding the SCP visit is consistent with the research in that patients express a high degree of satisfaction and appreciation for the recommendations.

CONCLUSION

Continuous process improvement has allowed an academic medical center continued success at meeting the Commission on Cancer Standard for providing patients with an SCP at the completion of curative treatment. Going forward, the quality improvement plan includes continued chart reviews until the minimal goal of 70% SCPs completed is met. To help reach this goal, the completion of SCPs is included as a metric in the advanced practice nurse biannual peer review. The intention is to continue to identify barriers and adjust the SOP in order to capture all eligible patients.

Once we have reached our goal in providing cancer patients who have been treated with curative therapy with SCPs, we would also like to expand to patients who receive treatment for control of the disease. Future research regarding specific patient outcomes will also be considered. Through the Shared Governance Ambulatory Care Council, we hope it will possible to expand the care planning process to other disease groups for use as a communication and education tool.

Developing a successful SCP SOP has been a rewarding experience. It began as a multidisciplinary task force that evolved into an APRN-led program. The complexities of cancer treatment, EMRs, and multimodality therapy have proved challenging. Continued process improvement with frequent audits and discussions with the APRN group as a whole has been imperative to improve outcomes and getting closer to reaching the goal of 100% of eligible patients receiving SCPs. Infomatic expert consultation proved invaluable in order to decrease the amount of time required to prepare each SCP, as well as assisting with reports to run audits. The delivery of the SCP is a worthwhile experience for all. Patients have provided us with excellent feedback regarding value and overall satisfaction with the office visit. APRNs also appreciate the usefulness of the visits, and the level of engagement with patients is seen as rewarding.

The task of developing and implementing SCPs is difficult at best. It is hoped that other institutions who are in the process of developing a SCP program may find our experience helpful. ●

Disclosure

The authors have no conflicts of interest to disclose.

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