



PROVISION OF SURVIVORSHIP CARE PLANS IN NEVADA

BACKGROUND

The concept of a “survivorship care plan” (SCP) was first introduced in the Institute of Medicine’s (IOM) 2005 report “From Cancer Patient to Cancer Survivor: Lost in Translation” after identifying a wide variation in post-cancer treatment care for the nation’s more than 10 million cancer survivors. The SCP was suggested as a way to summarize information critical to a cancer survivor’s long-term care, such as diagnosis, treatment, and potential consequences or late-effects; recommended timing and content of follow-up visits; tips on maintaining a healthy lifestyle and preventing recurrent or new cancers; legal rights affecting employment and insurance; and the availability of psychological and support services.ⁱ

Memorial Sloan Kettering Cancer Center builds upon the IOM’s concept, adding that the plan should define responsibilities of cancer-related, non-cancer-related, and psychosocial providers. This clear designation for responsibility of care can optimize care coordination, avoid unnecessary use of resources, and ensure care of a survivor does not fall through the cracks.

In addition to containing the above-mentioned information, the IOM’s recommendation for provision of Survivorship Care Plans indicates that plans should be written by the principal provider(s) who coordinated oncology treatment and provided to primary care doctors (or to patients) after completion of primary treatment. SCPs are not provided to metastatic cancer patients.

GUIDELINES AND RESOURCES

Commission on Cancer (CoC) Accreditation, through American College of Surgeons, covers SCPs in standard 3.3. Guidance provided in 2014 outlined the core set of data elements and follow-up care plan content required within the plans, following American Society of Clinical Oncology (ASCO) guidelines. Implementation of SCPs was to be implemented across 10 percent of eligible patients in 2015, followed by increasing percentages of patients and types of cancer through 2019 when CoC-accredited facilities should be providing SCPs to all eligible patients.ⁱⁱ

The National Accreditation Program for Breast Centers (NAPBC) standard 2.20 establishes an expectation that 100 percent of eligible (breast cancer) survivors receive a SCP. Implementation of the standard is being phased in throughout 2015, and by January 2016 100 percent of eligible patients should be receiving SCPs. Through December 2015 compliance is achieved if 50 percent of eligible patients receive a SCP.ⁱⁱⁱ

There are a number of SCP resources and guidelines available online for download and free use.

American Society of Clinical Oncology

ASCO promotes the use of written treatment plans and summary care plans to ensure appropriate coordination among the members of the extended care team. As such, ASCO and partners have developed templates and resources designed to support effective communication of a survivor's health status and long-term care needs. Resources include a general SCP template, as well as templates for specific cancers including: breast, colorectal, and prostate cancers, non-small cell lung cancer, small cell lung cancer, and diffuse large B-cell lymphoma. Additional tools are available to help patients create their own record of treatment.^{iv}

Access tools: <http://www.asco.org/practice-research/survivorship-care-clinical-tools-and-resources>

Journey Forward: Guiding Survivors as They Move Ahead

The Journey Forward program helps survivors transition to life after cancer through the use of treatment summaries and follow-up care plans that include steps for follow-up care and monitoring. Journey Forward's custom-made Survivorship Care Plan Builder is available to any oncologist and is in sync with CoC's SCP standard. The electronic Medical History Builder allows patients to easily record their own health history. An additional tool available for patients is My Care Plan, which allows them to initiate their SCPs for completion with their clinical providers.

Access tools: <http://www.journeyforward.org/>

Livestrong Care Plan

The Livestrong Care Plan is designed for adult survivors and is developed online by the patient using treatment summary information secured from their oncology team. The customized plan includes a basic treatment summary, a list of potential late-effects and side-effects, recommended screenings or follow up tests and evaluations, and tips on healthy living as a survivor. A number of survivorship resources are also provided, covering issues such as fertility, lymphedema, and ostomy; follow-up care and cancer screenings; general health maintenance including smoking cessation, diet, exercise, and weight management; legal and financial assistance; support groups; and recurrence.

Access tools: <http://www.livestrongcareplan.org/>

Equicare

Equicare is a software package for cancer facilities that combines navigation, survivorship care planning, and patient engagement tools as well as a patient portal. The program can interface with some radiation equipment to import radiation treatment details directly into the SCP, and patients can access their SCP through the patient portal. SCP templates within the program are based on those developed by the National Comprehensive Cancer Network (NCCN) and also include follow-up care plans. SCPs can be printed, automatically faxed to physicians, or delivered to a primary care provider online. Patients can also use the SCP through the portal to set email or text reminders for recommended follow-ups.

Access information: <http://www.equicarehealth.com/products/equicare-cs/>

The Children's Oncology Group Long-Term Follow-Up Guidelines for Survivors of Childhood, Adolescent, and Young Adult Cancers (COG LTFU Guidelines)

The COG LTFU guidelines are a resource for healthcare professionals and provide recommendations for screening and management of late-effects in survivors of pediatric malignancies. A complementary set of patient education materials, known as "Health Links," accompany the guidelines in order to enhance patient follow-up visits and broaden the application of the guidelines. Additional materials include templates for cancer treatment summary forms, a radiation reference guide, and a tool to assist in identifying guideline applicability for individual patients based on the therapeutic exposures.

Access tools: <http://www.survivorshipguidelines.org/>

SURVIVORSHIP CARE PLAN SURVEY

Nevada Cancer Coalition identified key cancer treatment providers that impact the greatest number of patients in Nevada. Each facility was approached informally (via email or phone call) to discuss current practices in survivorship care planning and provision of survivorship care plans to patients recently completing treatment.

Providers invited to participate include both CoC or NAPBC accredited and non-accredited hospitals and stand-alone oncology and radiation oncology facilities throughout the state that treat or serve cancer patients. Of the 10 facilities included in the survey, five are accredited as a CoC and/or NAPBC facility, and one additional center is working towards accreditation.

Survey Questions

- Do you currently provide cancer survivorship care plans?
- Which cancers are currently included for provision of survivorship care plans?
- About what percentage of patients are getting survivorship care plans?
- Do you use Journey Forward, ASCO materials, or some other system or templates to create the plans?
- Are your electronic health records tied in to the process?
- How long after a patient completes treatment do they receive their personalized survivorship care plan?
- How is the plan delivered to the patient? Is a copy sent to the primary care provider?
- Please note any barriers or challenges to providing survivorship care plans.

RESPONSE

While provision of SCPs is happening at numerous cancer treatment facilities within Nevada, as a state we are far from having all cancer survivors complete treatment with a SCP in hand. As would be suspected, facilities working to meet standards to either retain or earn accreditation have made more progress in provision of SCPs than those that are not. However, the remaining facilities offering cancer treatment do acknowledge the importance of survivorship care regardless of whether they are creating and providing SCPs for patients.

Creation of Survivorship Care Plans

While some survey respondents have only recently (in 2015) begun to provide SCPs to survivors, other facilities have been provisioning them for as long as 3 – 5 years. Yet others are still in the planning stages of how they will roll out SCPs and provide them to patients.

In facilities working towards NAPBC accreditation, breast cancer patients are the recipients of SCPs because of the specific breadth of the accreditation. Otherwise, provision of SCPs to survivors has been rolled out at the discretion of the facility and with varying strategies. Several facilities began with breast cancer, increasing the percentage of patients receiving those plans, and then moving on to other top cancers including lung and colorectal/GI cancers. Other facilities focus on the types of cancers most-treated in their facilities, such as leukemia and lymphoma. Yet others have covered all cancers, but started with a small percentage of patients and are gradually increasing that percentage until they reach 100 percent. Of those provisioning SCPs, the range of total oncology patients receiving SCPs is anywhere from 10 percent to 100 percent.

In most cases, creation of SCPs is done by nurse navigators using one of the resources such as those provided by Journey Forward, Livestrong, and ASCO, tools included within EHR or other integrated system, or any combination of these. In some cases, oncologists are involved in the creation of the plans or assist patients in managing their own plan using patient-accessible tools and resources. One partner noted that creation of plans may shift from oncology nurse navigators to mid-level nurses or providers as a billable service.

In many cases, treatment of a survivor is not done in just one facility or by one provider. Chemotherapy and surgery may take place in one facility, and radiation or stem cell therapy in another. Nurses creating the SCPs gather information from a variety of sources including their own electronic medical records as well as outreach to the survivor's other providers.

Delivery of Survivorship Care Plans

In most cases, a nurse navigator is responsible for providing the final SCP to patients and the goal is to present the SCP, review it with the survivor, and answer any questions they may have. Respondents noted the best-case scenario for delivery of the SCP is at a survivor's final appointment and most facilities strive for this as it may be the last chance to effectively connect with the survivor. If the SCP cannot be delivered at that appointment, a follow-up appointment

is the next best option as nurses prefer to provide the plan in-person to review and discuss it with the survivor. One respondent noted that in some instances geography and distance from the treatment facility creates a barrier to receiving the SCP in person if it is not available at the final appointment. In that case the SCP is mailed to the patient and a nurse navigator places a call to the survivor to review the document and answer any questions.

In all cases the patient is advised to provide a copy of their SCP to their primary care provider for use in their post-treatment care.

Barriers and Challenges with Survivorship Care Plans

There are many resources available to identify the key needs of cancer survivors and assist practitioners and survivors to create SCPs, but many facilities noted there are numerous barriers to using those resources effectively and efficiently.

Electronic health records are in use at all cancer treatment facilities contacted, yet only two have any sort of interface between their EHR systems and their SCP programs and templates, and in those instances it is only partial. Manual entry of treatment details is time consuming and subject to human error. It ties up manpower, often that of the nurse navigator, in departments that are already stretched thin.

Another barrier to use is patient and provider compliance. In some facilities the doctor is involved with assisting in creation of the plan or delivering the plan to patients yet they are not complying, thus halting the process altogether. In nearly all cases the patient is responsible for delivering a copy of the final SCP to their primary care provider, yet anecdotally respondents felt that may not be happening.

Cancer treatment in Nevada is often fragmented, with patients receiving portions of treatment in one facility and other portions in another facility. For example, a patient may receive surgery and chemotherapy services in a hospital, but must receive radiation treatment from an outside provider. In instances where surgery, chemotherapy, and radiation are all offered within one facility it is easier for navigators to compile complete treatment summaries; however, oftentimes once a patient leaves the facility there is limited ability to track treatment without extensive legwork.

Pediatric and Adolescent Survivorship Care Plans: Children's Specialty Center /Cure 4 The Kids, Las Vegas Pediatric Oncology Practice

Children's Specialty Center provides SCPs to 100 percent of oncology patients, using the Children's Oncology Group template for creating the treatment summary. At the onset of treatment, patients are provided with a binder of their initial records, and they bring that binder to every visit. The treatment summary document is filled in throughout the treatment process and the patient's primary care provider is copied on all chart notes throughout the process. At the end of treatment, during a patient's "no more chemo celebration," a summary is provided

to the patient. After maintenance with the primary oncologist is completed care transitions to the center's survivorship clinic where, again, all chart notes are copied to the patient's primary care provider. The center's Long-Term Follow-Up Care clinic offers patient care post-treatment, focused on survivorship activities and late-effects monitoring.

More information: <http://cure4thekids.org/services/long-term-follow-up>

In this case of pediatric and adolescent survivorship, survivorship care is more streamlined, thanks in part to a dedicated long-term follow-up care clinic. Young cancer survivors benefit from this system by having primary care providers focused on care specific to their post-treatment needs and well-versed in late-effects of pediatric cancer treatment, rather than the generalized treatment adult primary care providers can offer. Additionally, the wide breadth of Children's Oncology Group and the research they have compiled into best practices and tools creates a definitive roadmap for practitioners to follow in caring for young cancer survivors.

ⁱ <http://iom.nationalacademies.org/Reports/2005/From-Cancer-Patient-to-Cancer-Survivor-Lost-in-Transition.aspx>

ⁱⁱ <https://www.facs.org/publications/newsletters/coc-source/special-source/standard33>

ⁱⁱⁱ <https://www.facs.org/quality%20programs/napbc/standards/changes>

^{iv} <http://www.asco.org/practice-research/survivorship-care-clinical-tools-and-resources>

