

Establishing survivorship care in a community-based center

When should survivorship care begin? The definition of a cancer survivor and strategies for educating and engaging survivors in their care are explored.



Cancer survivor Anyone living with a history of cancer—from the moment of diagnosis through the remainder of life

DEB ROSS, BSN, RN, OCN

The American Cancer Society (ACS) published some astonishing numbers in its report, *Cancer Treatment and Survivorship Facts and Figures 2012-2013*. An estimated 13.7 million people in America are cancer survivors, and 59% of them are 65 years or older.¹ This increasing population is in need of quality, evidence-based survivorship care. How to best serve this population with the resources available is challenging. When should survivorship care begin? This article explores the definition of cancer survivor and strategies for both informing patients and engaging them in their care.

DEFINING SURVIVORSHIP

The first Sunday in June is designated as National Cancer Survivors Day. Mercy Cancer Centers, in Toledo, Ohio, has hosted a Cancer Survivor Celebration for the past 9 years. To promote the event, we post and hand out flyers to our patients. After handing a flyer to one patient, he replied, “I don’t know that I am a survivor yet.” When does a patient with cancer become a survivor?

A major controversy in oncology is how to define a cancer survivor. The National Cancer Survivors Day (NCS) Foundation defines a *cancer survivor* as “anyone living with a history of cancer—from the moment of diagnosis through the remainder of life.”² Understanding that survivorship is not the end of treatment or being disease-free for a designated period of time is crucial to developing a survivorship program.

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TABLE 1. Key elements of treatment plan and summary³

| Treatment plan |
|--|
| Diagnosis, including histology stage at original diagnosis |
| Disease status |
| Symptoms |
| Physical manifestations |
| Radiologic evidence |
| Tumor markers |
| Treatment purpose |
| Treatment regimen |
| Drugs, route, frequency, toxicity |
| Re-evaluation strategy |
| Timing |
| Modality |
| Summary |
| How was the treatment tolerated? |
| Hospitalization for toxicity |
| Grade 3-4 toxicity |
| Dose reductions |
| Agents discontinued/stopped early |
| What was the response to treatment? |
| Disease-related symptoms |
| Physical manifestations |
| Radiologic evidence |
| Tumor markers |
| Reasons for treatment discontinuation |
| Long-term sequelae of treatment |
| Planned next steps |

WHERE TO BEGIN

Some larger institutions have late-effects clinics and other services that are tailored for patients who have completed therapy; however, community-based programs have limited resources. Cancer survival is divided into three separate phases.¹

The first phase is from diagnosis to the end of initial treatment. Oncology nurses are most familiar with this phase. They educate patients about potential treatment-related morbidities and work with physicians to provide early identification and interventions. For example, recognizing the early signs of ototoxicity or neuropathy in a patient, then working with

the health care team to ensure that the risk of long-term disability is minimized. Oncology nurses are on the front lines of survivorship for patients undergoing cancer treatment.

The second and third phases, the transition from treatment to extended survival and long-term survival, are where most survivorship programs begin. Data from the treatment phase provide information for individualized patient management. “When treatment ends, you move into what has been called the neutral zone, which is characterized by feelings of chaos, loss, and confusion.”³ A *separate survivorship visit* is the ideal opportunity to provide useful information for maintaining health and identifying both the physical and emotional consequences of cancer and its treatment.

COMPONENTS OF A SURVIVORSHIP VISIT

The Institute of Medicine (IOM) provides guidelines for Survivorship Care Plans⁴ (Table 1). These guidelines are a good starting point when deciding how your survivorship program will look.

A **detailed treatment summary** that chronicles the initial diagnosis, staging, and types of treatment is the first component. Completing this portion can be tedious, but selecting a format for data collection makes the process smoother. The summary is also the place to document ongoing treatment-related toxicities, supportive services provided, and contact information for the treatment team. Different treatment summaries are available online; the American Society of Clinical Oncology (ASCO) offers a treatment summary on its Web site, www.asco.org. The ASCO summary can be completed online and printed, or printed first and completed by hand. Another summary that can be completed online is available from Journey Forward (www.journeyforward.org). This online tool needs to be downloaded to your computer, but it is another way to capture the necessary data.

Some institutions prefer to create their own treatment summary. As long as the summary can be transferred into the medical record either by scanning or direct interface and captures the required elements, the origin is not important.

A **follow-up care plan** is also required with the treatment summary. The care plan goes beyond just a schedule of follow-up appointments. The treatment summaries discussed adequately capture most of the information needed; however, they lacked a more in-depth look at long-term side effects and recommendations for healthy behaviors. LiveStrong Care Plans can be utilized to capture the remaining elements. The care plan is easy to access via the LiveStrong Web site (www.livestrong.org) and is a way to engage the patient in the survivorship visit. The care plan program asks a variety of questions related to the diagnosis and treatment, then uses

the data to compile a patient-specific care plan. The care plan can be printed in full or a health care provider summary can be printed and scanned for the medical record. The survivorship visit can generate referrals to resources within your facility and through community agencies. For example, a patient with lung cancer may be referred to your facility’s physical therapy program for ongoing issues with fatigue and also to a community-based cancer support group.

In a nonrandomized study, 337 cancer survivors were asked to identify their extreme concerns.⁵ **Table 2** lists the most frequently identified extreme concerns of the respondents. During the survivorship visit, the patient and family should be given the opportunity to ask questions and voice concerns. Identifying needs and connecting patients to services is part of care coordination in survivorship.

STEP ONE: THE IDEAL TIME

The published literature provides little direction in regard to the timing of the survivorship visit. Many programs choose a time after the acute effects of treatment have subsided. Depending on the therapy, 2 to 3 months allows for adequate recovery from the short-term side effects of treatment and identification of ongoing toxicities. However, a survivor who is even 6 months or 6 years posttreatment can still benefit from this service! It is never too late to review the current issues a patient is facing and provide a treatment summary. Furthermore, new strategies for managing long-term and late effects of treatment seem to emerge daily. Providing both information and support can give patients a sense of security at the end of treatment, when the frequency of visits declines quickly. A mechanism for scheduling survivorship visits for patients completing treatment helps assure that patients are not missed.

STEP TWO: THE RIGHT PERSON FOR THE ROLE

Larger cancer centers may have a multidisciplinary survivorship team, but smaller centers may need to identify the appropriate personnel for the survivorship visit. Community centers usually have lower patient volumes and less access to patient resources within their facility. Unlike larger centers, they are not likely to have specialty clinics; every diagnosis is treated in the same center. Oncology nurses are well equipped to take the helm of the survivorship visit.⁶ They understand the sequelae of both the disease process and the treatment for cancer; however, both registered nurses and advanced practice nurses can fulfill the role with the right tools. Survivorship care may become a primary role or can be assigned along with other responsibilities. Two or more nurses may share the role. In our center, breast cancer is a large percentage of our patient population. Due to the multifaceted treatment they receive

TABLE 2. Extreme concerns of cancer survivors⁴

| Concerns | Percent of respondents with the concern |
|---|---|
| Fear of recurrence | 17% |
| • Fatigue • Financial concerns | 12% |
| • Concerns about long-term effects of treatment • Peripheral neuropathy • Sexual issues | 11% |
| • Debt from medical bills • Hot flashes • Osteoporosis and bone health | 10% |
| • Living with uncertainty • Loss of strength • Health insurance • Hair and skin issues | 9% |

and their protracted course of therapy, survivorship is a key component of their care.⁷ Our nurse navigator provides the survivorship visits for this group, and the nurse who provides chemotherapy education sees the remaining patients.

STEP THREE: COLLECT THE TOOLS NECESSARY

IOM developed a condensed fact sheet, *Cancer Survivorship Care Planning*, that defines the essential components of the care summary and follow-up plan.⁸ The fact sheet summarizes the information in their book and can be used as a checklist when selecting documentation tools. For those programs accredited by the American College of Surgeons using the Commission on Cancer (COC) Standard, the IOM Fact Sheet can be used to determine compliance with Standard 3.3: Survivorship Care Plan.⁹ The treatment summary from either ASCO or Journey Forward captures the majority of the information regarding treatment and follow-up necessary to meet the IOM Standards of Care. Elements such as long-term and late effects are not captured; however, incorporating a second care plan, such as the LiveStrong plan, can bridge the gaps. For example, two potential late effects for a patient who received radiation therapy to the mediastinum for Hodgkin lymphoma are breast cancer or skin cancer in the radiated field. Making sure the patient is receiving comprehensive and evidence-based information is important. The COC Standard does not stop at providing patient information. The COC wants to see that the program is monitored, evaluated, and presented to the Commission. Giving patients an evaluation form to complete at the end of the survivorship visit can provide valuable feedback and be used in the overall evaluation process.

STEP FOUR: CONDUCTING THE SURVIVORSHIP VISIT

Approximately 1 hour should be allotted for each survivorship visit. This allows for adequate time to review the information and answer questions. The survivorship visit should be conducted in an area that ensures privacy. Computer access may be necessary depending on the tools that are utilized.

The treatment summary should be completed prior to the visit because it requires researching the patient record. The summary often generates questions about tumor markers and staging. Many teaching opportunities arise from survivorship visits. Often, questions arise that are better answered by the patient's primary care provider or another specialist. A form for listing these questions can be helpful, and the patient has a written record to take to future appointments.

If an interactive electronic care plan such as LiveStrong is used, the patient answers the questions on a computer screen (sometimes with nurse assistance), and a care plan individualized to the patient's disease site and treatment type is generated including the following information.

- Side effects related to therapy
- Potential late effects of treatment
- Healthy lifestyle information
- Follow-up care
- Ongoing cancer screening

Referrals to community agencies or supportive services are frequently given at the survivorship visit. The Cancer Legal Resource Center can help address questions regarding employment and/or insurance. The Center has a website (www.cancerlegalresourcecenter.org) and a toll free phone number (1-866-843-2572).

At the end of the visit, patients receive a folder containing copies of their documents. In addition to the evaluation form,

patients also receive a copy of the National Cancer Institute (NCI) booklet, *Facing Forward, Life After Cancer Treatment*. Patients are encouraged to review the table of contents and read the sections that apply to them. They are also encouraged to write down any questions that come to mind while reviewing the information. A separate form is provided on which to record their questions.

THE IMPORTANCE OF REHABILITATION

Cancer patients often report changes in their physical and functional ability during and after treatment. Instead of simply expecting patients to accept a new normal, incorporate available speech, occupational, and physical therapies to help them maintain and improve their function. Early identification of patient needs is important to minimize long-term disability. For example, a therapist may not be able to eliminate chemotherapy-induced neuropathy but can instruct the patient on adaptive techniques and equipment that help maintain normal activities.

Educating the health care team about the benefits of rehabilitation can be accomplished through a variety of means. The Survivorship Training and Rehab (STAR) Certification Program (www.oncologyrehabpartners.com) is an avenue for educating both staff members and therapists. The staff receives information about which patients are appropriate for rehabilitation, and therapists receive instruction on the latest therapies. A physician with cancer who realized gaps in her care kept her from maintaining optimal function developed the program. A cost is associated with becoming a STAR Certified Program, but improved patient outcomes justify the cost. Beverly, who had a brain tumor, experienced difficulty with gait and balance toward the end of her treatment. She



Jen Discher, Director of Pastoral Care (left), and Beverly Vasko, a survivor of brain cancer



The author Deb Ross, Blackie Scott, and her daughter, Suzanne Holley (left to right)

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was one of the first patients referred to the STAR program at our center. With physical therapy, she was able to improve her function and maintain an active lifestyle.

ENGAGE PATIENTS IN THEIR CARE

The concept of survivorship is difficult to grasp not only for health care providers. Finding creative ways to educate patients about survivorship can be equally challenging. We held an annual Cancer Survivor Celebration for 6 years before a survivorship program existed. The Celebration is open to anyone with a cancer diagnosis regardless of when or where they were treated. Survivors are encouraged to bring a support person as their guest. The Celebration features a keynote speaker and local survivors who share their stories. Local agencies whose services support cancer survivors are invited to display at the event and provide information for attendees.

Evaluations from the event identify educational needs of survivors and provide direction for future programs. Examples of these include “chemo brain,” fear of recurrence, sexuality, and nutrition/exercise. An evaluation of our 2012 program requested a speaker who survived ovarian cancer. In response, we featured Blackie Scott, a nationally known speaker and author, at this year’s Celebration. Scott is also a survivor of breast cancer and ovarian cancer. Messages of hope from those who shared their cancer experience are powerful and encouraging. They remind patients that they are not alone.

CONCLUSION

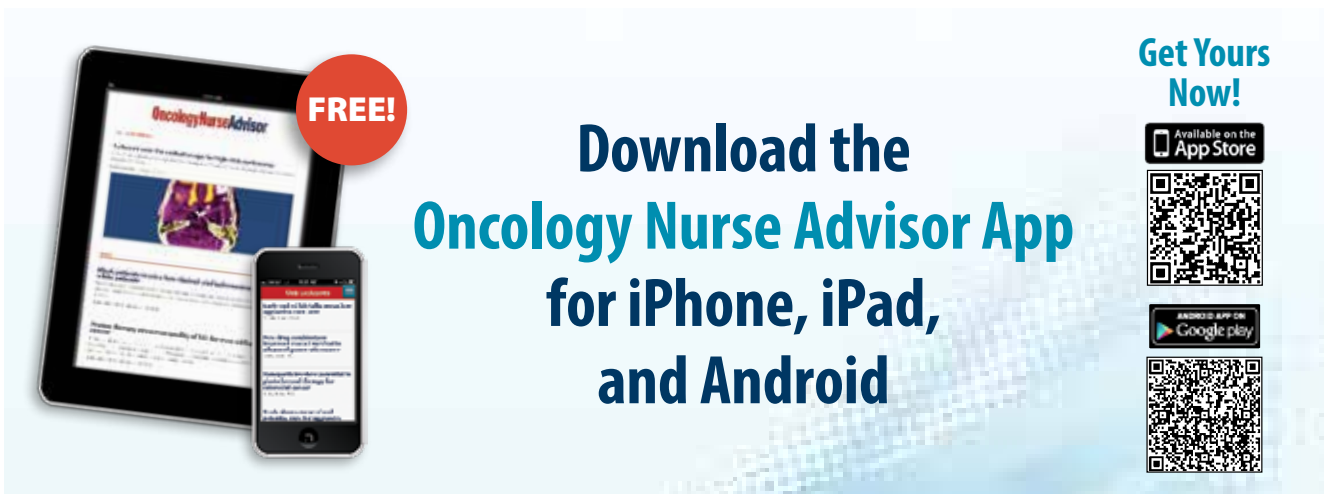
Survivorship is an important component of cancer care. Recognizing the impact of the disease and its treatment

are keys to developing effective, individualized survivorship plans. Oncology nurses, with the right tools, are well equipped to provide survivorship care for their patients. ■

Deb Ross is the education coordinator at Mercy Cancer Centers in Toledo, Ohio.

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