

Creating partnerships for survival

Mark Sborov, MD, and Michele O'Brien, RN, MSN, ACNS-BC, BA

Minnesota Oncology, Edina

The projected increase in the number of cancer survivors will present unprecedented challenges for community-based practices, and the Institute of Medicine¹ and the American College of Surgeons' Commission on Cancer² have made recommendations to meet the needs of this growing patient population. However, most community-based practices do not have the resources to implement the recommendations and will have to work closely with resources outside of the practice to develop financially viable and sustainable programs.

Survivorship care should incorporate prevention, early diagnosis, pretreatment evaluation, treatment, evaluating distress, ensuring good nutrition, counseling, rehabilitation, spiritual care, and advanced care planning. It should be rooted in the concept of shared decision-making during all phases of the cancer trajectory up to and beyond the completion of treatment, with the goal of improving the patient's quality of life (QOL). The definition of survivorship has evolved over time. In its definition of survivorship, the National Coalition for Cancer Survivorship (NCCS)³ emphasizes that a patient becomes a survivor at diagnosis and remains a survivor through treatment and afterward until the end of life. It also stresses that survivorship planning and management should include family members, friends, and caregivers. Few programs focus on survivorship throughout the patient's cancer journey in the way the NCCS recommendations do.

A diagnosis of cancer can unleash substantial physical and psychosocial distress in a patient, which could have a bearing on quality of life and disease outcome. As such, it is important that patients' physical, spiritual, and psychosocial needs are addressed in addition to their receiving

the appropriate anticancer treatment. Patients and caregivers can experience a range of emotions, from anger and depression to fatigue and a sense of extreme loss. There is a growing expectation among survivors that their needs, both during and following their course of treatment, will be met.

At our practice, we are developing a comprehensive model for survivorship that incorporates assessment of a patient's QOL and identifies patient concerns and needs. Unlike most academic organizations, we do not have services such as psychological counselling, rehabilitative care, or complementary medicine options (acupuncture, massage, healing touch, and so on) within the practice, so we have to refer patients to groups such as the American Cancer Society, community wellness programs, disease-specific organizations, wig or prosthetic suppliers, or support groups, for that assistance. Our model is led by advanced practice registered nurses (APRNs), who create a survivorship care plan that is tailored to the patient's physical, emotional, functional, and social concerns. The APRN facilitates care at all phases of the cancer trajectory, from explaining the treatment decisions and symptom management, to ensuring a seamless transition between the phases of care, as well as advocating for the patient to ensure that their care is patient centered. We believe that over time, the empirical data will demonstrate the effectiveness of identifying real-time patient concerns, improvements in QOL, and the extent to which the APRN's interventions make a difference in patient outcomes.

Key to our program, known as Stride for Stride: A Partnership for a New Normal, is that team members work closely with the oncologist to ensure that survivorship care is part of the overall treatment plan focusing on what Mullan⁴ called the "seasons" of survivorship: acute (diagnosis and initial treatment), extended (watchful waiting), transition, and permanent.⁵ The survivorship plan should ideally begin shortly after the oncologist has determined a treatment plan. This is often a difficult and confusing time for the newly diagnosed patient and introducing survivorship care

Correspondence to: Armin D Weinberg, PhD, Life Beyond Cancer Foundation, 21 Waterway Avenue, Suite 300, The Woodlands, Texas 77380; e-mail: armin@lifebeyondcancer.org.

Disclosures: Dr. Sborov and Ms. O'Brien have no conflicts of interest or financial disclosures to declare. Ms. O'Brien participates in speakers' bureaus for Lilly Oncology and Bayer Pharmaceutical.

Commun Oncol 2012;9:108-109
doi:10.1016/j.cmonc.2012.02.007

© 2012 Published by Elsevier Inc.

A survivor speaks

My nurse navigator taught me to be a cancer survivor.

I was very fortunate to have access to a nurse navigator support system, from my diagnosis for lung cancer, through surgery, chemotherapy, and maintenance drug therapy. My nurse navigator taught me to be a cancer survivor.

My diagnostic visit was traumatic. The doctor said, "It's cancer and surgery is necessary." But survivorship begins at diagnosis, and Michele, my nurse navigator, was there to help me and my husband through the emotional trauma. She put us on the path to dealing with cancer. We left with surgery scheduled, medication prescribed, and I was told I could call her any time! There was somebody there for me, and it helped me feel more confident about my care. Physicians do not have the time to sit with a patient and deal with the emotional aspects of this horrible disease. It is the nurse navigator who pulls it all together.

My second survivorship visit was right after I had completed chemo, and I was falling apart. I was physically exhausted, wanted my hair back . . . life was a bitch. Michele helped me refocus emotionally—helping me understand that cancer is a journey of the body, mind, and spirit. At that meeting, we also touched on maintenance therapy with erlotinib. At my third visit, a month after chemo and just before I was due to start maintenance therapy, Michele explained how the therapy worked and what side effects to expect. Part of me wanted to be done and I worried about quality of life issues. Again, she guided me through that.

We developed a great relationship through these visits, which improved my quality of life and outcome. When I began my therapy, Michele held my hand through the initial 30-day period. I had a major reaction to erlotinib and an allergic reaction to the antibiotic for side effects, but with her guidance and support, I stayed out of hospital.

I work for a small mental health clinic and understand the importance of mental health in recovery from illness. How one is cared for during one's journey with cancer affects the outcome of the disease. I regained my mental and physical health through treatment, exercise, weight loss, and a very caring supportive team of physicians, my nurse navigator, and other providers. And for that, I am very grateful.

— Sharon Rothgeb

early can help the patient cope with the physical, logistical, and psychological rigors of therapy. Our program includes a series of at least three, one-on-one patient-APRN visits, at diagnosis, treatment completion, and 3-6 months after treatment completion. These are billable

visits that allow financial viability. The focal point of these visits is a QOL assay that allows real-time measurement of distress and issues of concern. At that point, based on the assessment findings, the patient can be referred to the relevant experts and/or programs for support, assistance, and follow-up. The premise is that the earlier the patient's concerns and distress are identified and addressed, the better.

To implement a similar program a practice, one should consider the following:

- Define the starting point for initiating survivorship care. We have found that patients are not reluctant to have the extra office visit, but rather appreciate time to review their concerns before they start therapy.
- Identify reliable, easy-to-use screening tools that can be administered to gauge a patient's distress level, concerns, and QOL.
- Clarify how to administer the tool, establish the score, and interpret the results before you administer it. Multiple QOL tools exist, and no one tool is ideal.
- Assemble a group of physicians, APRNs, social workers, dietitians, and therapists to be part of the team.
- Meet with the patient to discuss concerns relating to the diagnosis and treatment as well as psychosocial, spiritual, and financial matters, before treatment begins.
- Establish who comprises the patient's support system—family members, friends, care givers, and so on—and evaluate their potential influence and impact on the patient's well-being.
- Draw up a list of experts, specialists, programs, and community resources to which patients might be referred once they been assessed.
- Integrate care between the patient, the oncologist, and the primary care provider.

References

1. Hewitt M, Greenfield S, Stovall E, eds. *From cancer patient to cancer survivor: Lost in transition*. Committee on Cancer Survivorship: Improving Care and Quality of Life. Institute of Medicine and National Research Council, Washington, DC: The National Academies Press; 2005.
2. Commission on Cancer. From the American College of Surgeons. Available at: <http://www.facs.org/cancer/coc/cps2012draft.pdf>. Accessed November 15, 2011.
3. Cancer Advocacy: A Cancer Survivor's Handbook. National Coalition for Cancer Survivorship. Available at: <http://www.canceradvocacy.org/assets/documents/self-advocacy-publication.pdf>. Accessed November 15, 2011.
4. Mullan F. Seasons of survival: reflections of a physician with cancer. *N Engl J Med*. 1985;313(4):270-273.
5. Miller KD. Revisiting the Seasons of Survival. *Cure* June 9, 2009. US Oncology. Available at: http://www.usoncology.com/network/Misc/Websites?p_url=www.curetoday.com/. Accessed November 15, 2011.