

Oncology Nurse Participation in Survivorship Care

Marcia Grant, RN, DNSc, FAAN, Denice Economou, RN, MN, AOCN®,
and Betty Rolling Ferrell, RN, PhD, FAAN

Oncology nurses play an important role in the provision of survivorship care. Using report recommendations from the Institute of Medicine, nurses provide quality cancer care based on the specific characteristics of individual healthcare settings and the populations they serve. As part of the planning process, the evaluation of a setting's resources and goals for desired survivorship activities can make the difference between success and failure. Collaborating with local and national resources for cancer survivors can help expand a setting's services in an efficient and cost-effective manner. Models of care vary, and resources and communication differ among settings; as a result, survivorship care changes across models. Nurses are critical to implementing survivorship activities and facilitating communication among healthcare providers, patients, and caregivers. In addition, nurses significantly contribute to the dissemination and coordination of information between patients and healthcare providers.

The American Cancer Society ([ACS], 2009) predicted that the population of cancer survivors in the United States will be 20 million by 2020. Cancer survivors' healthcare needs are unique and involve specific cancer prevention and detection activities, individual surveillance recommendations, interventions for the consequences of cancer and cancer treatment, and coordination of care. Planning and coordinating those needs involve communication between patients and healthcare providers based on individualized treatment summaries and survivorship care plans.

Oncology nurses have been instrumental in developing and integrating cancer survivorship care into current healthcare settings (Ferrell & Winn, 2006). One hundred and two oncology nurses participated in the National Cancer Institute (NCI)-supported Survivorship Education for Quality Cancer Care program (Grant, Economou, Ferrell, & Bhatia, 2007). This article reports examples of oncology nurses who attended the program and have implemented cancer survivorship care in their settings. The article also briefly defines recommendations for survivorship care, describes the content of the Survivorship Education for Quality Cancer Care project, and provides examples of how nurses are implementing survivorship care in their specific cancer settings. The authors

At a Glance

- ◆ The concept of cancer survivorship is multifaceted and interdisciplinary.
- ◆ Oncology nurses will continue to educate and coordinate multidisciplinary teams on cancer survivorship care.
- ◆ Activities for meeting the needs of cancer survivors vary depending on the institution and available resources.

conclude with recommendations for survivorship care activities for all oncology nurses. The goal of this content is to inspire oncology nurses to join in providing quality survivorship care for all patients with cancer.

Background

The cancer survivorship movement began with the establishment of the National Coalition for Cancer Survivorship (NCCS) in 1986 and the recognition of cancer survivors as a unique

Marcia Grant, RN, DNSc, FAAN, is a director and professor and Denice Economou, RN, MN, AOCN®, is a senior research specialist and project director of survivorship education for quality cancer care, both in Nursing Research and Education; and Betty Rolling Ferrell, RN, PhD, FAAN, is a research scientist and professor in the Cancer Center, all at the City of Hope National Medical Center in Duarte, CA. The authors take full responsibility for the content of the article. The authors did not receive honoraria for this work. The content of this article has been reviewed by independent peer reviewers to ensure that it is balanced, objective, and free from commercial bias. No financial relationships relevant to the content of this article have been disclosed by the authors, planners, independent peer reviewers, or editorial staff. (First submission February 2010. Revision submitted June 2010. Accepted for publication June 26, 2010.)

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population. Efforts to improve survivorship care proceeded steadily and included advocacy at the national level, development of patient educational materials, and the establishment of the Office of Cancer Survivorship at NCI in 1996 (Office of Cancer Survivorship, 2006) (see Table 1). Survivorship activities in cancer settings began to increase in response to the publication of the Institute of Medicine (IOM) report *From Cancer Patient to Cancer Survivor—Lost in Transition* in 2006 (Hewitt, Greenfield, & Stovall). The push for the establishment of cancer survivorship care continued, as reflected in the priority for survivorship programs endorsed by the Association of Community Cancer Centers (Lamkin, Rosiak, Buerhaus, Mallory, & Williams, 2002).

After experiencing cancer and cancer treatment, survivors return to their former lives as different people with long-lasting symptoms and risks to their future health (Doyle, 2008). NCCS (2010) defines a cancer survivor as someone who has been diagnosed with cancer; however, this article uses the perspective of the IOM report and others by focusing on care following completion of treatment (Ganz, Casillas, & Hahn, 2008; Hewitt et al., 2006).

Survivorship Care Defined

A range of activities is included in survivorship care and has been organized within the IOM report into four major components (see Figure 1). Prevention and detection are defined as the promotion of healthy living behaviors and screening for the early detection of cancer. Healthy living behaviors include eating a diet low in saturated fats, regular physical activity several times a week, tobacco cessation or avoidance, and protection from ultraviolet sun rays. Surveillance focuses on medical follow-up care related to specific cancers or cancer treatments. Surveillance includes colonoscopy and skin examinations as well as gender-specific procedures such as mammography, pap smears, prostate-specific antigen testing, and prostate examinations. Interventions focus on symptom management or education for long-term effects of cancer and cancer treatments. They can be organized in relation to the

four domains of quality of life: physical, psychological, social, and spiritual (Ferrell, Hassey Dow, & Grant, 1995). Physical interventions include management of symptoms such as pain or lymphedema. Psychological support includes depression and stress management or support groups. Social interventions include managing work-related issues, changes in family structure, disability, or discrimination issues. Finally, spiritual interventions include supporting specific spiritual activities and helping patients connect with spiritual counselors or chaplains, contacting specific religious organizations to provide spiritual guidance, or special interventions requested by patients. Patients or families may request a priest or rabbi to work through issues or other spiritual counselors as requested (Aziz, 2007; Miller, 2008).

Coordination of care relates to communication among patients, oncologists, and primary care physicians or other healthcare providers. None of the previously defined activities can occur without considering the type of cancer present and the specific treatment the patient received. The primary tools used to provide this coordination are treatment summaries and survivorship care plans. A treatment summary records the specific cancer treatment an individual patient has received and provides the information needed to develop a personalized survivorship care plan. The treatment summary describes surgical procedures performed; documents the type, dose, and number of courses of chemotherapy received; and identifies the amount of radiation received and specific fields involved. Any important events that occur during treatment also are recorded on the treatment summary.

A survivorship care plan is based on the treatment summary and specifies exactly what individual patients should do in relation to prevention and detection, surveillance, and interventions. The document should include when follow-up should occur, as well as individualized recommendations. For example, a survivorship care plan should include dates for follow-up tests, expected or potential effects such as lymphedema and how they should be treated, and when late effects such as cardiac toxicity may occur and how they should be evaluated. Because the treatment summaries and survivorship care plans are complex

Table 1. Reports for Survivorship Care Recommendations

AGENCY	REPORT	WEB SITE
American Cancer Society	<i>National Action Plan for Childhood Cancer</i>	www.cancer.org/acs/groups/content/@nho/documents/document/childhoodcanceractionplanpdf.pdf
American Society of Clinical Oncology	<i>Clinical Practice Guidelines</i>	www.asco.org/ascov2/Practice+&+Guidelines/Guidelines/Clinical+Practice+Guidelines
Association of Community Cancer Centers	<i>Living in the Future: Cancer Survivorship Program</i>	http://accc-cancer.org/education/pdf/edu_CoSS_rosenberg.pdf
Centers for Disease Control and Prevention	<i>National Action Plan for Cancer Survivorship</i>	www.cdc.gov/cancer/survivorship/what_cdc_is_doing/action_plan.htm
National Cancer Institute	<i>Coping With Cancer: Survivorship—Living With and Beyond Cancer</i>	www.cancer.gov/cancertopics/coping/survivorship
Office of Cancer Survivorship	<i>Cancer Survivorship: Moving the Science and Art of Research and Care Beyond Cure</i>	http://legislative.cancer.gov/files/testimony-2003-03-31.pdf

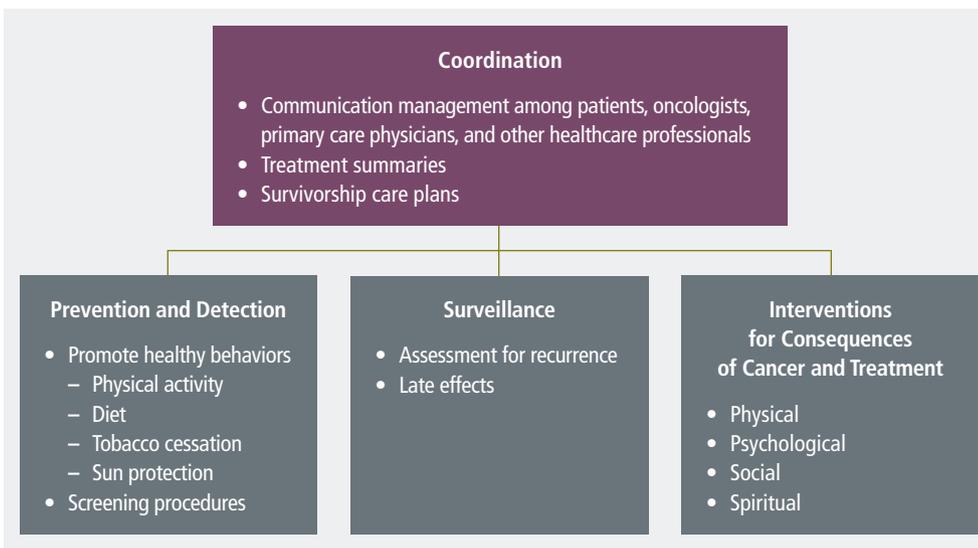


Figure 1. Components of Survivorship Care

Note. Based on information from Aziz & Rowland, 2003; Hewitt et al., 2006.

across the United States (Grant & Economou, 2007). The primary aim of the program was to improve care and quality of life for cancer survivors. The teams were composed of a doctor, an RN, an administrator, or a social worker as one member and another healthcare professional for the second member. Each team developed three goals to implement when they returned to their setting. Follow-up evaluations were done with each individual team and included goal achievement, telephone interviews, an institutional assessment, and an institutional survey at 6, 12, and 18 months after the course. The information gained from the different teams described nursing pro-

documents that require time and effort by educated personnel, templates for developing personalized patient documents have been developed. One of the earliest models for the treatment summary and survivorship care plan was described in the Prescription for Living care plan by Haylock, Mitchell, Cox, Temple, and Curtiss (2007). The Lance Armstrong Foundation combined with OncoLink at the University of Pennsylvania (UPenn) to develop the LIVESTRONG Care Plan (2010), one of two care plan-building sites available electronically to date. The program links through OncoLink and OncoPilot to help keep track of treatments. The care plan-building program is directed toward adult cancer survivors. The Journey Forward (2010) Care Plan Builder was the second program created in collaboration among NCCS; the University of California, Los Angeles (UCLA) Cancer Survivorship Center at the Jonsson Comprehensive Cancer Center; WellPoint, Inc.; and Genentech, Inc. The templates include American Society of Clinical Oncology treatment summary templates and surveillance guidelines. The information in the treatment summaries and survivorship care plans can impact future health for each patient. Providing the treatment summaries and survivorship care plans to all healthcare providers as well as patients ensures personalized survivorship care.

In summary, survivorship care encompasses a broad spectrum of activities, from prevention and surveillance to treatment of specific long-term and late effects. Coordination of survivorship care includes an individualized treatment summary and a care-planning process that addresses future healthcare needs. This area is important for the entire population as well as for cancer survivors and includes many activities already provided within cancer and noncancer health facilities.

Survivorship Education for Quality Cancer Care

The Survivorship Education for Quality Cancer Care program, funded by a grant from NCI, provided three-day survivorship education via four annual workshops held at City of Hope in Duarte, CA, to 204 two-person multidiscipline teams from

motion of survivorship care at many different levels to cancer survivor populations. Examples from each of the cancer settings illustrate how care is integrated into professional standards by oncology nurses practicing in a variety of settings.

Survivorship Care Settings

Models for delivering survivorship programs are evolving and are related to the type of setting, staffing resources, and survivor populations served (Haylock & Curtiss, 2007; Oeffinger & McCabe, 2006). The size of the institution, number of patients served, types of cancer treated, and availability of institutional and community resources all influence the services that can be provided. This article divides healthcare settings into four categories (see Table 2).

National Cancer Institute–Designated Cancer Centers Within Academic Institutions

These large, multidisciplinary medical centers include academic training for healthcare professionals, adult and pediatric programs, and multiple outpatient clinics, services, and research programs. The settings generally address all diseases, as well as conduct basic and clinical research. They provide multiple medical, surgical, and oncology disease-specific clinics and may have nurse-led follow-up clinics and supportive care programs. Integrating separate survivorship follow-up clinics may fit within this multiple disease-specific clinic setup. The accessibility of multiple disciplines and expanded medical records provide the information needed for treatment summaries and survivorship care plans. Examples of academic settings whose teams attended Survivorship Education for Quality Cancer Care include the University of Michigan, UCLA, UPenn, and the Norris Cotton Cancer Center at Dartmouth-Hitchcock Medical Center.

The University of Michigan Comprehensive Cancer Center team included an administrator, an RN, a doctor of philosophy,

Table 2. Models for Delivering Survivorship Care by Setting

VARIABLE	NCI-DESIGNATED CANCER CENTER OR ACADEMIC INSTITUTION	FREESTANDING NCI-DESIGNATED CANCER CENTER	COMMUNITY CANCER PROGRAM	AMBULATORY CARE SETTING
Population served	Adult and pediatric	Adult and pediatric	Adult and pediatric	Adults only
Disciplines	Large, multidisciplinary medical centers	Multidisciplinary support services available	Limited support services (psychosocial, dietitian, physical therapy)	Limited support services (psychosocial, dietitian, physical therapy)
Settings	Inpatient and outpatient	Inpatient and outpatient cancer treatment only	Inpatient and outpatient	Outpatient only
Academic training	Yes	Yes; outreach site for academic residency programs	No; may be outreach site for academic residency programs	No
Depends on community resources	Sometimes	Sometimes	Yes	Yes
Grant-funded research	Yes	Yes	Sometimes	Sometimes
Innovation	Research-focused multidisciplinary programs	Oncology focus only	Community resources; limited disciplines	Community resources; limited disciplines
Leadership	Doctors share care; nurses lead follow-up programs.	Doctors share care; nurses lead follow-up programs.	Staff share responsibilities; refer to community resources as needed.	Nurse-led activities, coordinated with local community resources

NCI—National Cancer Institute

and a nurse practitioner, all of whom were codirectors of the Center for Cancer Survivorship. Following the City of Hope course, the team held focus groups to identify cancer survivors' needs. They also developed a research infrastructure within the program to support areas of research in cancer survivorship. Their initial focus was on populations of patients with pediatric, prostate, and breast cancer. Focus groups were held to identify cancer survivors' needs and resulted in a course entitled *Preparing for Life as a New Survivor*.

UCLA's team included a physician and nurse practitioner from the UCLA LIVESTRONG Survivorship Center of Excellence Program. Following the City of Hope course, the UCLA team developed templates for their childhood cancer survivorship program that would transition pediatric survivors to adulthood by using the Children's Oncology Group survivorship guidelines. The guidelines then were used to educate providers and adult childhood cancer survivors regarding treatment history and risk of late effects. In addition, the team established a follow-up symptom-management clinic for survivors, led by the nurse practitioner. The UCLA team also was instrumental in the development of the Journey Forward Survivorship Care Plan template.

UPenn's team included a nurse with a doctorate in philosophy who was the director of survivorship research for the LIVESTRONG Survivorship Center of Excellence at the Abramson Cancer Center, as well as an NP who was the survivorship project manager. Following the City of Hope course, the UPenn team (a) integrated cancer treatment summaries into breast cancer clinical practices, (b) developed an educational initiative for clinicians to raise awareness and knowledge of survivorship issues, and (c) developed an infrastructure and

resources to organize the UPenn cancer network hospitals for community-based outreach survivorship programs. Treatment summaries for patients with breast cancer were created with the OncoLink template, which later transitioned into www.livestrongcareplan.org with the collaboration of the Lance Armstrong Foundation. As a team, they provided education to nurse practitioners in the network hospitals on survivorship care and use of electronic care plans. The UPenn team also developed an educational program to provide primary care physicians with survivorship education. As part of the LIVESTRONG Center of Excellence requirements, UPenn also supports outreach programs in the community. UPenn assisted its affiliate hospital in conducting breast cancer survivor needs assessments and, subsequently, in providing an educational program to its cancer survivors. In partnership with the Lance Armstrong Foundation, UPenn piloted the LIVESTRONG Care Plan and assisted two outreach hospital programs in integrating the treatment summaries and survivorship care plans into their breast cancer practices.

The team from Norris Cotton Cancer Center at Dartmouth-Hitchcock Medical Center consisted of two nurse practitioners. The team completed a patient-survivor needs assessment and compiled the results for presentation to the Cancer Steering Committee for administrative support and implementation. Using that approach, the team gained administrative support and defined the infrastructure needed for the planned advanced practice nurse-led clinic. Next, they identified available resources and submitted three grant applications for support of the nurse practitioner-run clinics. A future plan involves applying for philanthropic grant money to help support Norris Cotton Cancer Center's nurse practitioner clinics.

Freestanding National Cancer Institute–Designated Cancer Settings

These settings focus on clinical cancer trials and generally have both inpatient and ambulatory patient services. Resources for patients with cancer, including support groups, educational materials, and multidisciplinary support, are provided broadly. Within freestanding cancer centers, disease-specific clinics for cancer survivors are developing and often are run by nurse practitioners. A component less frequently found in these settings is medical expertise for noncancer complications, such as cardiac complications related to chemotherapy toxicity. An example of a freestanding cancer center is Memorial Sloan Kettering Cancer Center (MSKCC).

One of the three teams from MSKCC included a nurse practitioner and a program coordinator, who worked together as part of the survivorship services provided by MSKCC. Survivorship activities included providing a treatment summary to patients in the survivorship program and mailing the same information to community physicians to facilitate coordination of care across settings. In addition, the MSKCC team adapted the children's oncology group guidelines to transition those pediatric patients to the adult clinic. A unique aspect of the MSKCC survivorship program is the survivor newsletter. With the support of a volunteer survivor with editorial experience, the survivor program coordinator produces a newsletter entitled *Bridges—Connecting Cancer Survivors*. The newsletter, which is mailed to all survivors, serves as a sounding board for survivors to discuss their experiences and has been an important asset for patients and families. To gather information, MSKCC asks survivors to visit www.mskcc.org/bridges and submit their personal cancer stories.

Community Cancer Programs

Community cancer programs are found in large and small community hospitals. They provide inpatient and outpatient care and may include a designated oncology center or unit. Survivorship care in these hospitals usually is provided in the outpatient or rehabilitation departments. The institutions frequently do not provide academic training or multiple in-house specialty services and may or may not include a pediatric department. Community programs may have limited psychosocial, rehabilitation, and dietary resources. Their specific services generally are related to the expertise of their staff. They may provide or coordinate specific supportive services such as support groups and cancer rehabilitation. Providing treatment summaries or survivorship care plans is more difficult in community settings. Smaller community cancer programs have low patient volumes and limited financial support to build specific survivorship programs and provide resources. One approach is to collaborate with local or national community resources in an effort to provide supportive services to cancer survivors. In community cancer programs, oncologists and primary care physicians both care for cancer survivors. Private foundations such as the Lance Armstrong Foundation, ACS, and CancerCare can provide survivorship services and resources to settings and families and can be particularly valuable in smaller community and rural settings. Nurses can refer patients to online and tele-

phone support groups and educational sessions. Resources for education on prevention and detection as well as health promotion programs are available for patients, caregivers, and families (see Figure 2).

Examples of community cancer programs implementing survivorship activities are Pearlman Cancer Center at South Georgia Medical Center in Valdosta and the Sanford Cancer Center Oncology Clinic in Sioux Falls, SD. The team at Pearlman Cancer Center involved two nurses. They began by creating a timeline for implementation of a comprehensive survivorship program at their institution; they also were part of a larger state collaboration with the NCI Community Cancer Centers Program. As a result, part of their activities included helping to coordinate survivorship programs from a state-wide perspective. That collaboration led to the development of a survivorship care plan template for patients with breast cancer and refinement of a cancer survivors' needs assessment tool that had been developed by the cancer education program at the Mayo Clinic Cancer Center. The needs assessment tool helped the team identify and develop the survivorship components of care they would provide at Pearlman Cancer Center. The needs assessment can be obtained through the City of Hope Pain and Palliative Care Resource Center Web site (<http://prc.coh.org>).

The team at Sanford Cancer Center Oncology Clinic consisted of a nurse practitioner and an administrator. Their survivorship activities included educational and psychosocial programs for the survivor population in their community. The team developed an educational program called Journey to Cancer Wellness that directed survivors to local psychosocial support services. Next, they developed a series of educational sessions: Cancer Corrections focuses on healthy lifestyle changes and exercise, and Cancer Kickers Support Group helps patients and families cope with daily issues surrounding their cancer diagnosis. Exercise and yoga classes already available were expanded to support the needs of survivors and reduce stress. Future plans include a follow-up clinic and the hiring of additional staff to support the program.

American Cancer Society (www.cancer.org): educational resources for healthcare professionals, patients, caregivers, and families

CancerCare (www.cancercare.org): survivorship support groups and educational resources

Cancer Care for the Whole Patient: Meeting Psychosocial Health Needs (http://books.nap.edu/openbook.php?record_id=11993): survivorship education and resources for psychosocial support of cancer survivors

City of Hope Pain and Palliative Care Resource Center (<http://prc.coh.org>): educational resources and evaluation tools

Journey Forward Care Plan (www.journeyforward.org): survivorship education and resources and care plan template

Lance Armstrong Foundation LIVESTRONG Program (www.livestrong.org and www.livestrongcareplan.org): survivorship education and resources and care plan template

National Coalition for Cancer Survivorship (www.canceradvocacy.org): survivorship education for patients, healthcare professionals, and caregivers, including the Cancer Survival Toolbox®

Figure 2. Survivorship Resources

Ambulatory Care Settings

Ambulatory care settings include large and small freestanding physician office practices that may provide infusion and radiation services but have limited supportive services for psychosocial care, physical therapy, or dietary support. Staffing for survivorship clinics for follow-up care usually is nonexistent, and collaboration with local and national resources often is used to provide psychosocial support. Providing treatment summaries or survivorship care plans in ambulatory care settings is challenging and requires considerable staff and physician support. Acute clinical treatment takes priority; therefore, resources from the community must be used. An example of an ambulatory care setting is Dayton Physicians, LLC, Hematology and Oncology in Ohio. The nurse practitioner and RN clinical educator team from this setting focused on finalizing a template for treatment summaries and survivorship care plan documentation. They began by using the Lance Armstrong Foundation survivorship handouts (e.g., patient notebooks) and a locally developed patient resource guide that they provided to all patients at the completion of treatment to introduce the concept of survivorship. The team then focused on educating their staff about survivorship issues to build an awareness of survivorship care, and they presented inservices on survivorship needs and issues to the medical and radiation oncology office staff. The team also reached out to the greater community by providing education on survivorship care at their local Oncology Nursing Society chapter meetings. In addition, they were asked to participate with a local hospital-based task force on survivorship care. The team plans to collaborate with the hospital for breast cancer survivor-specific programs. The team's biggest barrier continues to be physician support when time is taken away from acute patient care. In an effort to start exploring how treatment summaries and survivorship care plans can be developed, the team is evaluating existing templates from LIVESTRONG and Journey Forward online tools.

Nurses across settings, from large academic NCI-designated comprehensive cancer settings to small ambulatory clinics, are able to initiate and implement many survivorship care activities. The most common activities appear to be related to providing interventions for long-term effects of cancer and cancer treatment, such as symptom management and psychosocial support. The most challenging activities across all settings are the development and distribution of individualized treatment summaries and survivorship care plans. Staffing and treatment priorities are the biggest barriers to overcome in developing the documents and distributing them to patients, oncologists, and primary care physicians. The least frequent activities in this article's examples were prevention and surveillance, which are not traditionally found in cancer settings. Providing the many components of survivorship care to the ever-increasing population of cancer survivors will continue to be a challenge.

Implementation for Oncology Nurses

Nurses integrating survivorship care into their current position and practice must first assess the setting and the populations of patients with cancer served. One approach would be

to identify resources for survivorship care already available at the institution. This could be organized under the four components of care.

- **Prevention:** Do patients have access to screening procedures and, if not, where are they referred? Can anyone in the setting address healthy living recommendations, either in written material or educational groups?
- **Surveillance:** Are patients referred for routine follow-up evaluations specific to their cancer? For example, is magnetic resonance imaging required for specific diseases, and who does this scheduling? Are patients taught what to look for and when to contact their primary care provider or oncologist?
- **Interventions:** A range of activities are relevant. Do support groups exist, and could they provide time for an educational session on survivorship issues? Do clinics exist that can take care of long-term effects, such as pain management and lymphedema? Can the National Coalition for Cancer Survivorship's Cancer Survivor Toolbox[®] be provided to every patient who completes treatment? Do activities to which survivors can be referred occur in the community? Providing a Cancer-Care calendar of programs and other outside resources can be an efficient way to expand a setting's services.
- **Coordination and communication:** What system is currently used for recording patient data? Is an electronic medical record used? Can a treatment summary begin to be filled for all new patients? Is a group of interested professional staff available that could examine the current templates for treatment summaries and survivorship care plans and evaluate whether one or the other might fit best within their setting? Resources are available to help with the initial questions (see Figure 3). A survey for patients with cancer can be used to identify the needs of specific populations (e.g., breast cancer survivors). Once this information is gathered, initial activities can focus on resources currently available that can be adapted or expanded to include survivors, as well as educational materials already available that can be distributed as patients complete treatment. Additional development may depend on resources to provide staffing and identification of priorities within an institution. With this information, oncology nurses can provide valuable support in building a survivorship program or incorporating survivorship-focused activities within their institution or setting.

- Is your staff informed about survivorship issues related to cancer care?
- Are champions of care available who will support and participate in survivorship services in your setting?
- What are the five largest disease populations you see in your setting?
- What are the needs or deficits in your patients' care?
- What services does your setting currently offer for patient support during treatment?
- Who in your setting provides patient support services?
- What community resources are available to meet survivors' needs?
- Do you have any relationships with the community resources?
- Examine the services offered in your setting and expand them to include the components of survivorship care (prevention, detection, surveillance, interventions, and coordination).

Figure 3. Questions to Ask When Assessing a Setting for Survivorship Care

Conclusion

The growing population of cancer survivors needs care beyond the end of treatment. Survivorship care falls within four major areas: prevention, surveillance, interventions, and coordination. The Survivorship Education for Quality Cancer Care course provided information on how nurses from various settings have begun to integrate survivorship activities into their individual settings. Nurses can play a significant role in helping to disseminate and coordinate information, connect with community resources, spearhead survivorship activities within their own settings, and provide public and professional education on survivorship care. The role of the oncology nurse traditionally has been to coordinate care during treatment; that role needs to expand to include a focus beyond treatment to the needs of cancer survivors.

Author Contact: Marcia Grant, RN, DNSc, FAAN, can be reached at mgrant@coh.org, with copy to editor at CJONEditor@ons.org.

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