e-mail <u>pubpermissions@ons.org</u>.

Patient Preferences Concerning Treatment Plans, Survivorship Care Plans, Education, and Support Services

Tiffany J. Marbach, MSN, RN, and Julie Griffie, MSN, RN, AOCN®, ACNS-BC

ore than 1.5 million people in the United States were estimated to be diagnosed with some form of cancer in 2010, and about 11.4 million Americans are considered cancer survivors as a result of advanced clinical research and new technologies (American Cancer Society [ACS], 2010). The five-year survival rate (1999–2005) of 68% shows a significant upward trend as compared to 50% from 1975–1977 (ACS, 2010). More than 25 needs experienced by survivors, such as fatigue, fear of recurrence, and sleep disturbances, have been identified (Schlairet, Heddon, & Griffis, 2010). That the issues and concerns of survivors are addressed systematically and empathetically is critical to improving quality of life and delivery of cancer care for the growing number of cancer survivors.

The impact of the cancer diagnosis and subsequent treatment needs on each patient's quality of life is extremely complicated (Hewitt, Greenfield, & Stovall, 2006). Patients undergoing diagnosis and treatment for cancer are immersed in a complex medical world of sophisticated treatments. The diagnostic and treatment phases provide unique opportunities for providers to positively impact the patient experience. Providing individualized care to patients and caregivers, communicating clear expectations of treatment plans, and providing support and education are goals of the multidisciplinary and interdisciplinary team members caring for patients with cancer. As more people are surviving, educational tools focusing on survivorship must be developed and tested. Development of new educational information should be sensitive to the preferences and perceived needs of survivors. Creating the tools and delivering the information at the most appropriate times have been understudied from a patient point of view.

Issues of education during treatment, including treatment modality and post-treatment survivorship plans for patients with cancer, have been an area of focus. Organizations such as the National Comprehensive Cancer

Purpose/Objectives: To examine patient preferences for content and methods of delivering treatment plans, educational information, and survivorship care plans.

Research Approach: Thematic analysis of four tape-recorded focus groups of cancer survivors.

Setting: An outpatient clinical cancer center in an academic medical center in the midwestern United States.

Participants: 40 cancer survivors who had completed initial treatment. Participants were grouped by disease site: (a) prostate, genitourinary, and skin; (b) breast and gynecologic; (c) gastrointestinal, sarcoma, and head and neck; and (d) brain, pancreas, and lung.

Methodologic Approach: An exploratory, descriptive approach with in-depth focus group thematic and comparative analysis methodology. The data are grouped into four major, interconnected themes.

Main Research Variables: Survivors' personal experiences with receiving cancer treatment.

Findings: Four categories were agreed on using thematic analysis: educational information, treatment plan, survivorship care plan, and patient support. Themes were identified within each category.

Conclusions: The number of cancer survivors continues to grow each year. Approaching each survivor with individualized educational information, an initial treatment plan, a survivorship care plan, and emotional support is imperative. Oncology nurses must assess cancer survivors for their unique needs and intervene accordingly.

Interpretation: Because oncology nurses assess and recognize the learning needs of each patient, they are best positioned to develop teaching content, strategies, and timing of interventions. The importance of written educational materials cannot be negated. Oncology nurses also are well positioned to provide a proactive role in the development and delivery of treatment and survivorship plans of care.

Network (NCCN), the American Society of Clinical Oncology (ASCO), and the Institute of Medicine (IOM) have developed recommendations related to treatment and survivorship education. Each organization stresses

the importance of enhancing survivorship care, including patient education related to long-term side effects of treatment and surveillance. Although standards have been established, a gap exists in the literature for identifying the best methods of format, timing, style of education, and who will provide and deliver the information to the patient.

The long-term side effects of treatment, monitoring, and follow-up are critical but neglected areas of patient education in adult oncology. Looking beyond treatment and into survivorship for the patients with cancer requires a paradigm shift for the cancer treatment team (Jacobs et al., 2009; Shulman et al., 2009). Survivorship care plans are a means of creating a dialogue about what treatment has taken place, what long-term side effects may occur, the resources available to the patient, and who would best provide future care (Earle, 2006). Additional research is needed to identify the essential components of information delivery. Individual approaches may need different methodologies at various points in the disease and treatment continuum. Little literature exists to support methodology, timing, meaningfulness, and long-term effectiveness of any one method. A qualitative research study using focus groups was designed to address those issues.

Purpose

The current study's purpose was to obtain patients' recommendations for the amount, type, and methods used to deliver treatment planning information, educational information, and survivorship care planning. In addition, patients' perceptions of the need for and method of enhancing support services were discussed.

Using an exploratory, descriptive approach, focus groups were conducted to investigate the survivors' experiences and understanding of their perspectives of initial treatment plans, educational information, survivorship care plans, and support services during their cancer journey.

Methods

The study was conducted at a large academic medical center in the midwestern region of the United States, where about 4,000 patients were diagnosed and treated in 2009. The center provides care for a variety of cancer diagnoses every year, including breast, lung, colorectal, prostate, sarcoma, and other neoplastic diseases. The center is in the early development of a cancer survivorship program based on recommendations set forth by IOM (Hewitt et al., 2006). The program is supported by center administrators, physicians, nurses, and staff and is a strategic priority. In preparation for implementation of the survivorship program, identifying cancer survi-

vors' perceptions and preferences was deemed necessary. A team of nurse coordinators and administrators assumed responsibility for refining and implementing a survivorship program. Data from the current study will guide the program's development within the cancer center.

During the time the study participants received their treatment, the institution relocated all oncology services into a new, free-standing clinical cancer center designed to facilitate communication and enhance interdisciplinary care. Some of the participants in the focus groups had the benefit of receiving care and treatment in the new facility, and others did not. The focus group sessions were conducted in an easily accessible conference room located within the new cancer center.

Participants

Participants were recruited for four focus groups. Past experience with focus groups showed 200 invitation letters were needed to recruit a total sample size of 60. Group composition was based on the following patient cancer diagnoses: (a) prostate, genitourinary, and skin; (b) breast and gynecologic; (c) gastrointestinal, sarcoma, and head and neck; and (d) brain, pancreatic, and lung. Although the cancer center has a strong bone marrow transplantation program, patients in that program chose not to participate. Groups were chosen by considering common side effects of treatment and prognosis. Six to 12 participants were needed for each group. The names of 200 patients treated from 2007–2008 were drawn from a sequential time-of-diagnosis list of patients who had completed surgery, radiation therapy, and/or chemotherapy for one of the predetermined disease types. Invitation letters were mailed to the homes of patients who completed initial treatment, had a functional status allowing participation, and resided within a two-hour driving distance of the cancer center. Consideration was taken by the researchers to exclude patients with dual cancer diagnoses or psychiatric diagnoses, as well as fragile older adults or patients traveling long distances. More volunteers responded than were needed. Approximately 60 people agreed to participate in groups; however, only 40 were able to attend (see Table 1). Among all four groups, 13 men and 27 women attended.

Procedure

An invitation letter explaining the focus group session and a request to take part in the research was mailed to 200 potential participants. Patients were asked to complete and return a form giving permission for a member of the research team to provide them with further information. Those volunteers without healthcare affiliations were first accepted into the study. Healthcare affiliation was defined by an

Table 1. Participant Characteristics

<u> </u>			
		Gender	
Group and Cancer Type	n	Male	Female
Prostate, genitourinary, and skin	11	6	5
Breast and gynecologic	12	-	12
Gastrointestinal, head and neck, and sarcoma	6	1	5
Brain, pancreatic, and lung	11	6	5
N = 40			

affirmative response to either of the following questions: "Do you or does anyone in your household work in a hospital? Are you or is a member of your household currently a medical professional (doctor, nurse, etc.)?" By accepting volunteers without medical affiliations first, group discussions would theoretically represent a broader view of the patient experience. All participants signed written documentation of their consent of participation, as required by the institutional review board for the hospital. Snacks and free parking were provided. An incentive of a \$25 gift card for a local health-resource store was provided to each participant at the end of the focus group sessions.

One facilitator and one observer were present for each focus group. The groups were tape recorded and transcribed to facilitate information processing. The facilitator, whose background includes a master's degree in business administration, manages a private company that conducts focus groups for the business industry. The observer was a hospital staff member who assists with focus group meetings on a regular basis, including management of the audio and written transcription of sessions.

Questions for Focus Groups Participants

Questions were developed to match the four objectives for the focus groups (see Figure 1). The questions concerned the initial care and treatment plan; educational needs, including delivery methods; end-of-treatment survivorship plans of care; and the need for and desired types of support.

The first objective focused on the initial treatment plan information. Group participants were shown copies of proposed treatment plan formats used in the cancer center and were asked specific questions about the content of the initial treatment plan. The plan was intended to outline the patient's expected course of treatment and included information related to the stage of the disease, the patient's diagnosis date, pathology, histology, and date and type of surgery (if any), as well as details of the patient's proposed chemotherapy regimen and

radiation therapy course (if applicable) (see Figure 2). The treatment plan contains the names and contact information of care team members and recommended or requested multidisciplinary referrals (e.g., dietitians, social workers, financial counselors, genetic counselors, psychological oncology services), as well as information related to whether the patient is participating in a clinical trial. During the focus group, participants were asked their opinion regarding the treatment plan, whether or not receiving a treatment summary would have been helpful, and what aspects of care needed to be added to the proposed treatment plan. Participants also were asked in which format they would prefer to receive the treatment summary (electronic versus paper hard copy) and who would best deliver the plan (physician versus nurse).

The second objective of the current study was to review the education binder the cancer center gave to patients at their diagnosis or initiation of primary treatment. Traditionally, the binder contained basic information about the cancer center and additional information was added based on the disease and individual plan of care. Participants were asked specific questions about content areas, including identifying helpful and unhelpful information and areas needing improvement or expansion. Additional questions included the identification of missing content and the evaluation of the overall effectiveness and usefulness of the materials in the binder. Finally, participants were asked to provide additional ideas for alternative delivery methods (including use of the hospital's Web site).

Initial Care and Treatment Plan

- What types of information were received from staff at the time of initial diagnosis?
- What was helpful and what was missing?
- What types of information would be needed in the initial treatment plan?
- What is the best presentation method (electronic versus paper hard copy) for this type of plan?

Patient Education

- What was useful and what was not useful in the educational binder given to patients at time of diagnosis?
- Was anything missing that should be included?
- What was the overall effectiveness and usefulness of materials?

End-of-Treatment (Survivorship) Plan of Care

- What types of information did patients receive at completion of treatment?
- Was this information complete and how was the information used? What was missing?
- What type of information is needed in a survivorship plan of care?
- In what time frame would they like to receive the information?
- Who is the appropriate person to communicate the plan with the patient?
- In what type of format would the survivor prefer the information?

Figure 1. Questions Asked During Focus Group Discussions

- · Cancer staging information, including site, stage, and histology
- · Contact names and numbers of the patient's care team
- Options for multidisciplinary referrals
- Dates and information regarding treatment, including surgery, radiation therapy, and/or chemotherapy
- Follow-up testing needed, including laboratory tests and imaging
- Clinical trial information (if applicable)

Figure 2. Treatment Plan Components

The third objective was to receive participants' feedback on a draft of the newly developed survivorship care plan, which provides each patient with information on the types of treatment he or she received, the potential late effects of treatment, and a follow-up appointment schedule. Questions focused on identifying types of information participants had received on completion of their treatment and their evaluation of the helpfulness and completeness of the information. The delivery method of the survivorship care plan (electronic versus paper) and preferences for who shared the content of the plan with them (physician versus nurse) also were questioned.

The fourth objective was to identify potentially helpful support resources while undergoing cancer treatment. Services currently available include a quality-oflife center where patients are provided with resources for nutritional counseling, financial counseling, social services, genetic counseling, chaplaincy, and psychosocial therapy. Examples of additional services that might be included were yoga, exercise, massage therapy, and art therapy. Participants were questioned about their use, awareness, and interest in these types of services.

Data Analysis

All focus groups were tape recorded and transcribed. The observer also took field notes. Transcripts were thoroughly read and reviewed by each researcher and then discussed in detail by the researchers. Qualitative analyses of the focus group transcripts were conducted using thematic analysis, in which patterns were recognized within the data that formed the categories for analysis (Fereday & Muir-Cochrane, 2006). Themes represented a pattern of response among the group participants and allowed for exploration of underlying ideas that shaped the content of the data described. The nurse researchers sought to identify recurrent patterns from survivor comments to illuminate the meaning behind the transcripts and understand interconnected themes within the data (Polit & Beck, 2003). In the current qualitative research study, data saturation was reached during analysis of the focus groups' transcripts. When sufficient data saturation was reached, categories and themes became repetitive until no new information was gleaned (Polit & Beck, 2003). The four goals of the study form the major categories reflecting educational information, treatment plan, survivorship care planning, and patient support. Themes were identified within each category. The responses were grouped and the content of these categories were validated without discrepancy with a doctorally prepared nurse research consultant.

Participants in the focus groups had a wide breadth of experiences in their cancer treatments. Some participants experienced very complex treatment regimens, difficult procedures, complicated symptom management issues, and major changes in performance status. Others reported treatment regimens that resulted in few side effects, little change in performance status, and minimal interruption in daily activities for long periods of time.

Findings

Four categories of findings were established during analysis: educational information, treatment plan, survivorship care planning, and patient support.

Educational Information

Participants were clear about the utility of the patient education binder. They found it essential to their care and understanding of their disease and treatment. One participant referred to it as "a tool or a way of dealing with the situation or, simply, a method of coping." Participants reported that they sometimes were unable to ask questions because they were overwhelmed during their consultation visits. They were able to obtain the information later from the binder, and it provided them with a way to organize their personal information and begin to plan how they would move forward. Information could be read at the patient's own pace, and read by family members who would, in turn, assist the patient in sorting the personally meaningful details and reinforcing how to obtain other needed information. Participants reported they needed information at all phases of treatment and the binder was one unifying center for it. A strong message came forth that the patient with newly diagnosed cancer must contemplate the information to understand it. The organizational framework of the binder provided a vehicle to support the patient in doing just that.

Within the educational information category were themes of anger and confusion. Confusion arose about treatment information, staff roles, how to reach staff, treatment side effects, and, notably, "Who do I call to ask questions when I can't find the answer?" One response to the personal anger that was heard from a number of patients was, "Just get me a good glossary," so that the translation process could be done at the patient's own pace. If the patient could translate the information, it could be understood and the patient could deal with other issues, such as moving forward with other decision making.

Treatment Plan

Again, emotional themes of anger and confusion were heard, in addition to fear related to the development and communication of a treatment plan. The difficulty in defining and understanding individual medical plans of care was identified as confusing and as the source of anger and other negative emotions (e.g., fear) that challenged team communication. Participants described strategies for dealing with all of these areas; however, they were most enthusiastic about a formalized written document that might be given to them describing their personal plan of care. Participants believed it would provide them with what one called "a starting point for understanding." Included in the document would be a disclaimer of "subject to change by the provider."

Confusion was a defining theme at the start of treatment. Many things were highlighted as "taken for granted," such as use of medical terminology, confusion over order of treatments, and sequencing of treatments. Patients saw multiple physicians during the consultation period. If the physicians did not agree, the patients were aware of that. Participants shared the difficulty in going forward with confidence if, initially, the consensus amongst consultants was not strong. Vocabulary used by the providers and staff strongly played into the patient's understanding of how the plan of care was received and, ultimately, understood. One participant stated,

I went to all the different doctors and they told me what their role would be in my treatment, but I would say if there is any room for improvement in that scenario, I really did not have a good idea of what comes first and what comes second.

Another patient added,

I wanted a real clear game plan laid out for me, in writing as opposed to verbal, so I could take it home to review later . . . to know that there is a game plan for you is simply comforting in itself.

Patients who enrolled in a clinical trial reported strong confidence in knowledge of their treatment plan. The study coordinator provided intricate details and written materials to help the patient and family understand the steps and time frames required for their treatment. Participants desired a guide with timelines to avoid confusion. One patient summed it up by saying,

If details are not written down for me, they simply evaporate. If there are no details in writing, I become increasingly confused. When I am confused, I am frustrated.

Participants reported they would prefer that the initial treatment plan be delivered by the physician, seemingly

because, early on, they had not yet developed a trust in individual nursing staff members.

Survivorship Care Planning

When asked about post-treatment, long-term follow-up care, themes of needing to sort and understand information clearly were described relative to follow-up, testing, and surveillance. The need for the development and delivery of a written survivorship care plan for each patient was evident, as described in the literature and supported by a number of professional organizations such as IOM, NCCN, LIVESTRONGTM, and ASCO (NCCN, 2010). Participants in each focus group were shown an example of a survivorship care plan that would be given to them at completion of treatment (see Figure 3).

First, the participants were asked whether they felt a survivorship care plan was needed. Among all the focus groups, each participant said they would have liked to have received a clear, concise survivorship care plan on completion of treatment (whether it was surgery, radiation therapy, chemotherapy, or a combination). A few participants felt they had received adequate teaching verbally on the long-term side effects of treatment but felt they needed more written information on what to expect next in terms of follow-up and surveillance. One participant in particular said,

To this day, the aftercare is where I get confused . . . the question is who do you start with if you don't know and just lack of continuity of who to call after the fact?

The participant went on to say,

Once you've had cancer, every little thing that comes up you think is the cancer recurring and you want an opinion about what's happening.

In addition, participants felt it was important to have a survivorship care plan because they would like to be able to monitor the health of their family members in case the cancer they received treatment for had a genetic component. Many participants also felt that the survivorship care plan would be helpful because it could be handed to a new physician if needed in the future, enabling him or her to take better care of the survivor.

- Cancer staging information, including site, stage, and histology
- Contact names and numbers of the patient's care team
- · Multidisciplinary referrals used
- Chemotherapy drugs (route, how tolerated, and start and end dates)
- Radiation therapy (how tolerated, start and end dates, and site)
- Surgery (date and type of procedure)
- · Follow-up testing needed, including laboratory tests and imaging
- Clinical trial information (if applicable)
- Potential late effects of treatment

Figure 3. Survivorship Care Plan Components

Participants shared their desire for a survivorship care plan that stemmed from the array of emotions and psychological distress they experienced post-treatment. For example, a few participants expressed a post-treatment fear of recurrence. One participant stated that the emotional needs of the survivor must be addressed, and a survivorship care plan would be an acceptable way to decrease the fear. In addition, participants stated that they experienced aftercare confusion as to what next steps to take in caring for their health and wellness.

One of the areas on the survivorship care plan that survivors liked outlined the recommended surveillance for late effects of treatment. Many participants noted that even if a year or more had passed since treatment ended, that information would be helpful to monitor for unusual or abnormal side effects. For example, some participants noted that, with completion of radiation therapy, their side effects from treatment worsened over time. One patient was told that recovery would be quick and never anticipated the number of weeks recovery took post-therapy.

Participants indicated the method of delivery of the survivorship care plan also is important. All participants wanted the survivorship care plan in a paper, hard-copy format, although some also wanted it electronically. The participants felt it should be given in person, but did not want to make a separate trip to the cancer care center to receive it. Some thought it would be appropriate to give the plan to the patient at the last radiation therapy appointment or last chemotherapy treatment. No matter when it was given, participants were adamant about the need for it to be provided in writing and reviewed with them personally. Participants reported trust in nursing staff to provide and deliver the survivorship plan of care.

Patient Support

The final category was the need for ongoing patient support during and after active treatment. Many participants stated they had established wonderful relationships with their care team members, but that more emotional, spiritual, and other support services would have been beneficial during their cancer journey.

Participants noted that the initial few weeks following completion of treatment were emotionally taxing. Participants expressed joy in the completion of the treatment, but they felt the initial concern given to them by family, friends, and healthcare providers waned once treatment ended. As one participant described it,

Once you are out and have three months or six months between visits, I found I got into a rut. . . . I looked fairly normal, I was living a normal life, and am back at work, and there was still a great need for support in those three months between visits.

And that week before the visit in the third month, I really needed to say "keep going, keep going;" you are really cut off during that time.

For example, participants who experienced many changes in body image (e.g., head and neck cancer survivors) felt that their emotional support was lacking and they needed continued support from the healthcare team and their family and friends for their emotional needs to be met.

Participants, particularly in the breast cancer focus group, expressed a need for more spiritual support during active treatment and follow-up care. Although chaplains in the cancer center regularly visit patients undergoing chemotherapy and radiation therapy, participants felt additional support from clergy would be helpful. Participants expressed a need for more support because their diagnosis made the possibility of dying a real outcome of their disease. They expressed a desire for the addition of a spiritual group for discussing issues that are encountered by cancer survivors, such as faith, prayer, and spirituality. One participant with breast cancer said,

[I] would have liked to have seen more spiritual support. For me, cancer equaled death and fear. I get a magazine that has uplifting spiritual support stories in it, and a woman wrote a small article that I read that changed my life forever. Cancer equals faith. And what she said in a few sentences was more than I ever got anywhere—including here. I tell you that changed my way of thinking because before that I thought, "Okay, I will just wait here until I die."

Additional support services, such as massage therapy, meditation, yoga, aromatherapy, acupuncture, and exercise classes were identified as desirable by participants. Some felt that although they may not have taken advantage of every support service available, they found it important to know about them and how to access them.

Participants expressed a desire for additional support groups and mentorship. Some participants felt that support groups needed to exist for every cancer type, and that they wished they would have had a mentor or someone to call who had experienced their treatment. One patient stated,

It is a very hard thing to go through, so if you could just have someone to talk to. Even for your own husband, it is hard for him to understand, so if you could have someone who understands what you are going through [that would be helpful].

Another patient added,

It would be an excellent idea to have a group of volunteers who went through the same procedure so, if you wanted to talk to someone, a volunteer would talk to you, explain what they went through, and how they handled it.

Participants identified a desire to become familiar with all of the support service resources available to them early in the diagnostic and treatment process. Although some patients had many different services offered to them during their cancer journey, others felt support services had not been sufficiently offered.

Limitations

The sample was a small group of self-selected participants, so generalizability among all cancer centers and cancer survivors is limited. Because patients who underwent bone marrow transplantations self-chose not to participate; their needs were not expressed. Patients who undergo bone marrow transplantations may require a different methodologic approach than focus group participation to determine their needs for education, treatment, and survivorship planning. The extent to which the participants represent the population of people diagnosed and treated in the cancer center is not known. Confirmation of the information learned from the current study's group of participants needs to occur among a larger group of population.

Conclusions

The information obtained from the current study is invaluable to future program development. Use of the research ultimately will provide a starting point for the cancer center to move forward in the ongoing development of the cancer survivorship program. Although the nursing leaders in the cancer center are very experienced in caring for and understanding patient issues and concerns, they found the focus group provided them with an opportunity to listen to the needs and preferences of patients. The participants freely shared the personal meaning of treatment plans, survivorship plans, educational issues, and emotional support. After qualitative review of the focus groups, the following conclusions were drawn.

- Taking time to clearly hear the voice of patients is critical for guidance in individual program development.
- Patients expect written personal treatment plans and survivorship plans.
- Treatment plans, along with educational tools, assist in addressing the overwhelming anger and confusion of patients and family members.
- Nurses play a primary role in the development, delivery, and clarification of plans of care, along with other multidisciplinary team members. Patients expect nursing involvement.

Nursing Implications

Oncology nurses play a critical role in the development, implementation, and evaluation of a successful survivorship program, as well as in the patient's education related to the treatment plan, survivorship care plan, and support services available. Many times, the oncology nurse coordinates all of the care disciplines to ensure that patients have the support they need for questions or concerns that arise during the cancer journey (Jersild, 2007).

In addition to the areas of survivorship care described, oncology nurses are influential in teaching patients about how to adjust to their new normal life (Walsh-Burke & Marcusen, 1999). Oncology nurses often are the healthcare team members responsible for providing a supportive and unhurried environment that allows patients and families to express their distress and share their psychosocial concerns (Kaplan, 2008). As strong members of the care team, they are poised to implement, with other care providers, the treatment plan and survivorship education (Haylock, Mitchell, Cox, Temple, & Curtiss, 2007; Morgan, 2009). Because of the future predicted constraints on oncologists, the need to transition patients who have completed treatment to their primary care physician will become more and more critical. Just as patients educate themselves to be part of their team at the time of diagnosis, empowering them to take charge of their survivorship care is a critical role of all cancer care team members (Ganz & Hahn, 2008).

As evidenced by the results of the four focus groups, the oncology nurse plays a critical role in survivorship care coordination. Providing patient care information, developing and delivering treatment plans and survivorship care plans, and providing additional support service referrals places oncology nurses at the forefront of quality oncology care. Recognizing that these standards are vital to patient outcomes and are what patients measure their care by is a critical first step. High-level education and survivorship care cannot be ignored in any cancer care setting.

Future Research

The number of cancer survivors is continuing to increase as a result of earlier diagnosis and evolving treatment options. Oncology programs must develop and implement sustainable, effective survivorship programs to meet the unique needs of this population. Listening to the voice of the cancer survivor is the first step in creating these programs. Oncology nurses are an integral part of sustaining a survivorship program. Future research is needed to determine whether learning needs exist for survivorship education for oncology nurses working in clinical settings. Is it realistic to expect that the current oncology nursing workforce possesses the knowledge needed to provide survivorship education? Further research should be directed to address that question.

The authors gratefully acknowledge the contributions of the cancer survivors who made this research possible, as well as the following colleagues for assisting with recruitment, editing the

article, and helping with participant enrollment: Sue Derus, J. Frank Wilson, MD, Katherine Myers, BSN, RN, Heidi Stark, BSN, RN, OCN®, Lori Jemison, RN, Pam Papenfuss, BSN, RN, Kathleen Sweeney, MSN, RN, AOCNS®, ACNS-BC, Mary Jo Burgoyne, MSN, RN, PMH-CNS-BC, and Polly Ryan, RN, PhD.

Tiffany J. Marbach, MSN, RN, is a clinical nurse specialist in palliative care and Julie Griffie, MSN, RN, AOCN®, ACNS-BC,

is a clinical nurse specialist, both in the Clinical Cancer Center at Froedtert Hospital and the Medical College of Wisconsin in Milwaukee. No financial relationships to disclose. Marbach can be reached at tmarbach@mcw.edu, with copy to editor at ONFEditor@ons.org. (Submitted June 2010. Accepted for publication July 28, 2010.)

Digital Object Identifier: 10.1188/11.ONF.335-342

References

- American Cancer Society. (2010). Cancer facts and figures 2010. Atlanta, GA: Author.
- Earle, C.C. (2006). Failing to plan is planning to fail: Improving the quality of care with survivorship care plans. *Journal of Clinical Oncol*ogy, 24, 5112–5116. doi: 10.1200/JCO.2006.06.5284
- Fereday, J., & Muir-Cochrane, E. (2006). Demonstrating rigor using thematic analysis: A hybrid approach of inductive and deductive coding and theme development. *International Journal of Qualitative Methods*, 5(1), 1–11.
- Ganz, P.A., & Hahn, E.E. (2008). Implementing a survivorship care plan for patients with breast cancer. *Journal of Clinical Oncology*, 26, 759–767. doi: 10.1200/JCO.2007.14.2851
- Haylock, P.J., Mitchell, S.A., Cox, T., Temple, S.V., & Curtiss, C.P. (2007). The cancer survivor's prescription for living: Nurses must take the lead in planning care for survivors. *American Journal of Nursing*, 107(4), 58–70.
- Hewitt, M., Greenfield, S., & Stovall, E. (Eds.) (2006). From cancer patient to cancer survivor: Lost in transition. Washington, DC: National Academies Press.
- Jacobs, L.A., Palmer, S.C., Schwartz, L.A., DeMichele, A., Mao, J.J., Carver, J., . . . Meadows, A.T. (2009). Adult cancer survivorship: Evolution, research, and planning care. CA: A Cancer Journal for Clinicians, 59, 391–410. doi: 10.3322/caac.20040
- Jersild, S. (2007). Programs work toward transitioning survivors to primary care. ONCOLOGY: Nurse Edition, 21(4, Suppl.), 40–43.

- Kaplan, M. (2008). Cancer survivorship: Meeting psychosocial needs. Clinical Journal of Oncology Nursing, 12, 989–992. doi: 10.1188/08 .CJON.989-992
- Morgan, M.A. (2009). Cancer survivorship: History, quality-of-life issues, and the evolving multidisciplinary approach to implementation of cancer survivorship care plans. *Oncology Nursing Forum*, 36, 429–436. doi: 10.1188/09.ONF.429-436
- National Comprehensive Cancer Network. (2010). Life beyond cancer. Retrieved from http://www.nccn.com/Life-Beyond-Cancer/Default.aspx?id=508
- Polit, D.F., & Beck, C.T. (2003). Nursing research: Principles and methods (7th ed.). Philadelphia, PA: Lippincott Williams and Wilkins.
- Schlairet, M., Heddon, M.A., & Griffis, M. (2010). Piloting a needs assessment to guide development of a survivorship program for a community cancer center. *Oncology Nursing Forum*, 37, 501–508. doi: 10.1188/10.ONF.501-508
- Shulman, L.N., Jacobs, L.A., Greenfield, S., Jones, B., McCabe, M.S., Syrjala, K., . . . Ganz, P.A. (2009). Cancer care and cancer survivorship care in the United States: Will we be able to care for these patients in the future? *Journal of Oncology Practice*, *5*, 119–123. doi: 10.1200/JOP.0932001
- Walsh-Burke, K., & Marcusen, C. (1999). Self-advocacy training for cancer survivors: The Cancer Survival Toolbox. Cancer Practice, 7, 297–301. doi: 10.1046/j.1523-5394.1999.76008.x