

■ Article

# Navigating the Seasons of Survivorship in Community Oncology

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Nurses have an important role in the development, implementation, and evaluation of cancer survivorship programs. Growing numbers of cancer survivors challenge community oncology practices to incorporate survivorship care according to new standards and guidelines. In response, one community-based oncology clinic created an advanced practice nurse (APN)-led survivorship program using the concept of Seasons of Survival as a guide. Survivorship care, when based on a more expansive definition of survivorship as beginning at the time of diagnosis, encompasses holistic nursing and multidisciplinary care. The APN assesses each patient's concerns and quality of life using a validated measure to tailor survivorship and supportive care. This article reviews the foundation and structure of the program in detail, describes program implementation using case studies, and outlines the program evaluation process and results.

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The number of cancer survivors is growing steadily in response to a variety of factors, including earlier diagnosis, improvements in therapy, and the aging population. The number of cancer survivors is projected to reach 18 million by 2020 (Mariotto, Yabroff, Shao, Feuer, & Brown, 2011) based on the broadest definition of cancer survivor as an individual affected with cancer from the time of diagnosis through the remainder of his or her life (National Coalition for Cancer Survivorship, n.d.). Mullen (1985) and Miller (2009) have described the seasons of survivorship as progressing through a series of phases: acute, consisting of initial diagnosis and treatment; transitional, immediately following completion of initial treatment; extended, which includes watchful waiting; and permanent survivorship, which occurs when patients are considered cancer-free but suffer from late or long-term effects of treatment. Together, these phases provide a framework that can be used to organize a comprehensive program of survivorship care that includes care coordination, prevention, identification, and management of acute, long-term, chronic, and late effects

of treatment, including psychosocial consequences and surveillance for recurrence as a part of comprehensive follow-up care (Grant, Economou, & Ferrell, 2010).

The authors of the current article describe a survivorship program developed to comprehensively address survivorship care, using a longitudinal approach, with Mullen's (1985) Seasons of Survival as an organizing framework. The community-based program uses the unique expertise of the advanced practice nurse (APN) as the program facilitator, and is characterized by a philosophy that survivorship care must begin at the time of diagnosis and initiation of treatment. The APN works collaboratively with multiple specialties to coordinate personalized, patient-centered care, to ensure that cancer survivors receive the quality care necessary to meet their unique needs and concerns.

## Program Development

Minnesota Oncology, a community-based oncology practice, serves a large Midwestern area with 10 clinics and several

outreach sites that span urban, suburban, and rural populations. The clinical team includes 46 oncologists, 2 thoracic surgeons, 4 gynecologic oncologists, 5 radiation oncologists, 16 APNs, 8 physician assistants, 1 genetic counselor with four outreach genetics counselors at five additional locations, and 3 dietitians.

The national focus on survivorship provided the impetus to develop resources and a comprehensive approach to survivorship care within the practice for individuals affected by cancer. The authors determined that a need existed to develop a survivorship program, and they felt that this initiative should be led by an APN in close collaboration with the oncology healthcare team. A number of factors influenced this choice. APNs have been shown to improve patient outcomes by providing focused and cost-effective follow-up care (Grant et al., 2010). The APN role provides the knowledge required to work collaboratively with multiple specialties to ensure that cancer survivors receive the quality care necessary to meet their myriad needs. APNs improve patient outcomes by providing focused and cost-effective follow-up care, including assessment and education to prevent, educate, and reduce the intensity of late effects (Grant et al., 2010).

### Establishing a Work Group

Prior to the implementation of a formal survivorship program, a working team was established to lead program planning and development, implementation, and evaluation. Team members were intentionally selected to ensure multidisciplinary as well as both a clinical and administrative representation. This team began its work by conducting a needs assessment to evaluate program needs and available resources. The team also was responsible for defining the scope of the program (e.g., target patient population, estimated patient volume), determining the educational needs of practitioners, patients, and caregivers, and defining both operational aspects of the program (e.g., strategies for reimbursement to offset cost of personnel) and strategies for program expansion to other affiliated practice sites. A business plan was developed to address stakeholder concerns and to ensure financial sustainability.

### Determining Scope

The authors completed a landscape survey and focused review of the literature to identify survivorship care models and essential elements of survivorship care, looking purposefully for standards and programmatic approaches that focused on supporting patients and caregivers throughout their cancer journey, not just at the completion of active treatments. The authors found references to integrated models of survivorship care, but no specific articles outlining an integrated approach to survivorship care. The authors used a number of published standards, guidelines, and recommendations relevant to supportive and survivorship care as well as the Institute of Medicine's (IOM's) recommendation for shared decision making (Hewitt, Greenfield, & Stovall, 2005). As the program evolved, the American College of Surgeons (2012) Commission on Cancer (CoC) standards for patient-centered treatment were included, as was the LIVESTRONG® Essential Elements of Care document (Livestrong Foundation, 2012). The authors chose to focus on the CoC standards, including patient navigation, distress screening, and the provision of treatment summaries and survivorship

care plans at completion of active cancer therapy (American College of Surgeons, 2012). These three core standards, which need to be met by 2015 within CoC-accredited centers, provide a core platform to help ensure the comprehensive identification and management of patient needs across the cancer continuum. Based on the chosen program focus, available resources, and the literature on effective program development, the authors chose to adopt an integrated model of care delivery. An integrated survivorship model allows a survivor to work with a survivorship provider alongside the treatment team. The visits are guided by the phases of survivorship across the care continuum (Miller, 2009; Mullen, 1985) and driven by APN providers (Oeffinger & McCabe, 2006).

As recommended by the IOM's recommendation for shared decision making (Hewitt et al., 2005) and the American College of Surgeons (2012) CoC standards, the authors identified the need to select a validated questionnaire to meet the distress screening standard and identify patient needs, concerns, and symptoms, and to inform personalized intervention, navigation, and survivorship care planning. After a literature review of distress screening and QOL assessment tools, the Minnesota Survivorship Program selected the Functional Assessment of Cancer Therapy (FACT) as its quality-of-life (QOL) assessment and distress screening tool after considering key elements from Hewitt et al. (2005). A pilot feasibility project was conducted with 100 patients to determine how to incorporate the use of the FACT tool in clinical practice using a company that specializes in electronic patient interviews. Using an electronic tool provided the ability to use trended individual patient data that could be computed, summarized, and reported to the APN before the start of the patient visit. Programmatically, it allowed management to evaluate patient data and satisfaction. The authors found that the FACT tool, coupled with a list of concerns, created a better understanding of the physical, functional, emotional and spiritual, and social distress concerns of patients with cancer. The program goal was to use a tool that would assist in a patient-focused comprehensive evaluation. From the feasibility project, the authors decided to use a detailed assessment rather than a screening tool.

### Program Description

Consistent with the guiding framework of Mullen's (1985) Seasons of Survival and the authors' operational definition of survivorship starting at the time of cancer diagnosis, the authors decided to initiate survivorship care as soon as possible after diagnosis. At the time of entry to the clinic, each patient is offered a coordinated series of three planned visits with an APN. This longitudinal series of visits allows for a proactive approach to identify and manage distress, and to assist with patient navigation. By introducing survivorship care early on in the care trajectory, the authors' goal is to improve patient and family ability to cope with cancer and maintain optimal QOL.

The initial visit with the survivorship APN was scheduled after the patient met with the primary cancer care team to determine a treatment plan. The APN met with the patient as soon as possible, with the goal being to meet prior to the initiation of therapy. The patient was then directed to complete a 10-minute questionnaire on an electronic tablet or computer to assess QOL and concerns.

The same questionnaire was administered prior to each scheduled survivorship visit. The questionnaire includes the FACT-General (FACT-G) tool, a self-report of concerns, and a patient satisfaction survey (O'Brien, Ness, Anderson, Sborov, & Foster, 2013). The FACT-G tool assesses physical, social, emotional, and functional well-being domains (Webster, Cella, & Yost, 2003). Two reports are generated from the results; one for the APN and one for the patient. The FACT-G results are reported for each domain of well-being as standardized scores from 0–100, where higher scores reflect higher QOL (Webster et al., 2003). The APN uses clinical evaluation and results from the questionnaire (FACT-G scores and patient concerns) to develop a personalized survivorship care plan at each visit and to ensure interventions correspond with patient-identified needs.

The initial visit with the survivorship APN is dedicated to reviewing the treatment plan, discussing patient-identified concerns and QOL, and creating a plan for maintaining QOL throughout treatment. Required actions from the initial survivorship visits are implemented by the healthcare team with assignment of responsibility based on the type of action required, based on concerns and QOL. The report allowed the APN to implement, promote, educate, and assist in navigating patients. The integration of the nurse, dietitian, social worker, genetics counselor, psychologist, or rehabilitative specialist for successful implementation is dependent on the needs of the individual patient.

Follow-up survivorship visits are scheduled at treatment completion, during remission, at time of recurrence, and as needed. At each visit, the APN assesses distress and creates a care plan. The APN delegates to the RN, who implements and evaluates the plan. Together, the APN and RN complete a treatment summary, as appropriate. The frequency and focus of each visit is at specific time points, but also can be determined by the patient on an as-needed basis.

## Status

The success of the program has allowed it to be active at five of the clinics. Education was an integral aspect of the program, including education for both the healthcare team and patients. Survivorship planning is optimally patient centered, and the clinical lead provided education tools for the patients, family, and caregivers. In addition, the clinical lead offered education for physicians and staff throughout the implementation process. Staff education included information about survivorship and the program model. The clinical lead was a resource for the clinic during the implementation process. The APN shadowed practitioners at survivorship visits prior to doing the visit independently. Dictation templates were created for the specific survivorship visits (e.g., the initial survivorship visit, post-treatment visit or recurrence visit, at the 3–6 month follow-up visit) to ensure continuity throughout the practice locations.

Several limitations and barriers were identified with the timing and tumor-specific program model. The authors broadened the scope of the program, evolving it into a supportive program that blends navigation and survivorship and is accessible to all cancer survivors from the time of diagnosis.

APNs offer one-hour survivorship visits for any patient at any point in their cancer journey. The program redefines survivorship care as a broad service incorporating patient-specific

## Implications for Practice

- ▶ Improve patients' quality of life through proactive survivorship care and by working to the full extent of nurse and advanced practice nurse licenses.
- ▶ Collaborate with community service providers so patients experience seamless referrals.
- ▶ Anticipate psychosocial needs, education opportunities, quality-of-life assessment, distress management, and other key factors for advanced care planning.

concerns, anticipated psychosocial needs, QOL assessment, patient education, cancer prevention, distress management, nutrition therapy, counseling, spiritual assessment, navigation, rehabilitation, and advanced care planning.

## Case Studies

**Patient 1:** P.A. is a 75-year-old male with history of stage II colon cancer who has developed a second primary colon cancer with liver metastasis. The patient underwent a laparotomy surgery with diverting loop ileostomy.

P.A. and his wife met with an APN for his survivorship visit shortly after he met with the medical oncologist, who identified his treatment plan. He completed a questionnaire to assess QOL on the FACT-C (colon-specific subscale of FACT-G) and to identify any issues or concerns. The FACT-G (including the FACT-C) standardized scores are rated on a scale of 0–100, with 0 indicating a poor QOL and 100 indicating a high QOL. The patient's overall QOL was determined at the initial visit to be 60. The QOL scores for each subscale were physical, 82; social, 64; emotional, 67; and functional, 62.

P.A.'s responses to the four domains of the FACT-G did not suggest any specific problem, but the FACT-C identified an issue that he was unwilling to discuss. P.A. indicated that he was embarrassed by his ostomy appliance. He also indicated that he "somewhat" liked his body. Based on these patient responses, the APN was able to focus her discussion on his specific concern related to his ostomy appliance. The APN contacted the patient's colorectal surgeon and medical oncologist to see if the ileostomy could be reversed. Unfortunately, this was not an option. The patient was given information concerning patient-support resources, and was encouraged to connect with the local chapter of the United Ostomy Association for one-on-one support from a fellow ostomate. In addition, arrangements were made to have P.A. re-evaluated by a wound ostomy nurse, which resulted in a fitting of the stoma appliance.

This case illustrated that the responses to the QOL questionnaire guided the conversation to focus on the embarrassment about the ileostomy that was causing distress for P.A., which he was unable to articulate on his own. Prior to the assessment, P.A. seemed to be coping with the ileostomy. After the completion of the FACT-C, the APN was able to quantify how much the ileostomy had negatively impacted his QOL.

The QOL assessment provided a window into the patient's distress. Although the APN could not facilitate the ileostomy

take down, she was able to provide the patient with tools to help him cope with having an ileostomy. Here, the APN acted as both counselor and navigator. Including a QOL assessment normalizes conversations about ostomies so the APN can offer guidance and support. A follow-up QOL assessment was not completed because the patient passed away.

**Patient 2:** T.C. was a 42-year-old premenopausal female with a history of stage IA bilateral synchronous primary invasive breast cancer (estrogen and progesterone receptor [ER/PR] positive and human epidermal growth factor receptor 2 [HER2/neu] negative). Her treatment plan consisted of bilateral lumpectomies and adjuvant therapy involving chemotherapy, radiation, and anti-estrogen therapy.

T.C.'s first survivorship visit was after surgery prior to adjuvant chemotherapy. The patient's QOL scores (0-100) were physical, 54; social, 61; emotional, 60; and functional, 56. Her breast cancer raw score was 101 on a scale of 0-144, with 0 indicating a poor QOL and 144 indicating a high QOL. She identified that her concerns were physical, emotional, financial, and nutritional.

T.C. revealed that she was concerned about pain that was not associated from her surgery. She had a preexisting condition that was exacerbated by surgery. Her job required repetitive motions that increased her discomfort, and she had to decrease her hours to part-time. This affected her family because her husband was laid off from work and she needed to work to maintain insurance. They had difficulty paying bills and buying groceries. Using the QOL assessment, the APN identified how her emotional and physical concerns impacted her QOL.

The QOL assessment and T.C. identifying her concerns enabled the APN to have an open discussion with the patient. T.C. was referred to a Survivorship Training and Rehabilitation (STAR) Program<sup>®</sup> physician (Oncology Rehab Partners, 2013) to evaluate the impact the bilateral lumpectomies had on her rare preexisting condition and risk for lymphedema.

The APN educated the patient that some repetitive movements at work could be done with her nondominant arm that was not affected by her preexisting condition. The APN reviewed the patient's diagnosis, treatment, and symptom management plan and provided her with resources to help maintain QOL through treatment. The social worker identified a local grant to help with living expenses. She also met with an oncology dietitian for counseling prior to chemotherapy. The patient expressed that the visit was helpful for her to create her own survivorship plan. This helped her decrease her emotional and physical distress so she could balance treatment with her life. In this scenario, the electronic assessment facilitated discussion and supported the APN, who used critical thinking and counseling skills to plan supportive care. The clinic RN was able to work from a more problem-focused care plan and improved communication with the patient to meet her needs. The patient and clinical staff were better equipped to understand her emotional and functional needs prior to the initiation of chemotherapy.

T.C. had a second survivorship visit at completion of her chemotherapy. This visit focused on recovering from chemotherapy and preparing for radiation and anti-estrogen therapy. Her QOL scores were physical, 50; social, 59; emotional, 89; and functional, 61. Her breast cancer raw scale score was 108.

Her physical score decreased because she was struggling with hot flashes, vaginal dryness, fatigue, and cognitive changes. Throughout her treatment, T.C. continued to meet with a physical therapist from the STAR program. She was given exercises and a compression garment for lymphedema. After chemotherapy completion, she met with a STAR occupational therapist for cognitive changes.

The APN counseled T.C. on interventions for hot flashes and vaginal dryness. The conversation allowed the patient to talk freely about how her body image changed and how it had affected her intimacy with her husband. She stated, "I haven't been able to talk to him about all of the changes my body has gone through. Hasn't he had to put up with enough?" Her emotional score improved because they were both back to work and were communicating better. She was surprised that her social score did not improve. Her perception was that it had because she felt better equipped to deal with concerns because of her previous survivorship visit. She asked several questions about what to expect in the next phase of care. The RN made a follow-up phone call several weeks after the visit to evaluate whether the APN's suggestions were successful and to offer support.

Several months later, T.C. had her third survivorship visit. She was excited to move into the recovery phase. Her QOL scores were physical, 60; social, 77; emotional, 79; and functional, 64. Her breast cancer raw scale score was 119. T.C. identified physical, functional, and fatigue concerns. She completed her visits with the STAR cancer rehabilitation specialists and had resolution in her pain from her preexisting condition. Her body image concerns improved because her hair had started to grow. Her intimate relationship with her husband had improved. Her emotional score decreased because she was experiencing fear of recurrence. Several resources were identified to help with her psychological distress and she was referred to a counselor and support group. Those were resources she declined earlier.

TABLE 1. Patient-Reported Concerns by Stage at Diagnosis

Concern	Stages I, II, III (N = 255)		Stage IV (N = 89)	
	n	%	n	%
Physical, functional	158	62	56	63
Fatigue	140	55	61	69
Emotional	107	42	41	46
Food, nutritional	87	34	40	45
Body image	66	26	–	–
Financial	54	21	23	26
Mind, body, spirit	54	21	26	29
Employment, disability	43	17	–	–
Healthcare directive	–	–	23	26
Social, community support	–	–	21	24

in her treatment plan. She was given a written treatment summary developed by the APN/RN team based off of the patient's identified and QOL evaluation. The RN promoted healthy behaviors and coordinated the surveillance schedule with the patient and primary care physician to ensure that the patient was not lost to follow up.

## Program Evaluation

### Methods and Approach

A program evaluation plan was designed and institutional review board approval to share the results was obtained. The authors prospectively collected patient characteristics, reported concerns, FACT-G average raw scores by survivorship visits, and patient satisfaction. They retrospectively collected data on referrals generated from survivorship visits for a one-month period through a chart audit. The authors also collected data from 344 patients in 421 visits from January 1 to December 31, 2012, which were analyzed to assess program implementation and patient satisfaction.

### Results

The organization defined success as monthly increase in visits and confirmed patient satisfaction. Each visit is billable by time spent counseling and coordinating care, which supports program financial viability. Retrospective visit tracking showed growth in the number of survivorship visits and was evaluated from two clinic locations. The average number of monthly visits grew throughout 2012, from a low of 16 in February to a high of 25.8 in December. A large documented potential for growth existed because only 39% of newly diagnosed patients with cancer had a survivorship visit in 2012. This discrepancy challenged the practice on ways to increase volumes.

Patient satisfaction was measured with pre- and post-visit questionnaires that included collecting qualitative and quantitative data. The response rate for pre-visit questionnaires was 99% and 53% for post-visit questionnaires. With each questionnaire, patients were asked about involvement in healthcare decisions and whether QOL was important to their healthcare team. An increase occurred in agreement with the statement for both questions from pre- to post-visit. Patients were asked if they valued the survivorship visit, and 92% of respondents did. Patient comments described the visit as "a human touch" to oncology care. Several patients wrote that they "appreciated the visit," but wished it could have been sooner or later in their journey.

Ongoing success of a program includes being responsive to real-time patient concerns (Ness et al., 2013). An evaluation of patient concerns shows that, regardless of cancer stage, patients are most concerned about physical and functional well-being and fatigue (see Table 1). It also shows that patients with stage I, II, and III disease are concerned more about body image, whereas patients with stage IV disease are concerned more about healthcare directives. As a result, the authors' clinic is developing referral lines that reflect these concerns. Table 2 shows a snapshot from July 2012 of the most common referrals initiated at a survivorship visit. Cancer rehabilitation is a growing referral trend as a result of the physical and functional concerns.

TABLE 2. Referrals Generated From Survivorship Visits in One Month (N = 34)

Staff or Department	n	%
Community services	16	47
Dietitian	13	38
Rehabilitation	10	29
Social worker	8	24
Mental health professional	8	24
Financial	3	9
Drug therapy management	3	9

## Conclusions and Implications for Nursing Practice

Survivorship care is essential to the health and wellness of patients with cancer and is continually being refined. As oncology care evolves to meet the survivorship needs of patients, a nursing model is feasible and provides quality supportive survivorship care. Successful oncology care incorporates the knowledge and experience of a multidisciplinary team of healthcare providers.

### Primary Implications

The national guidelines and recommendations to include survivorship care in oncology practice resonate with the core of nursing practice. Holistic, patient-focused survivorship care in a broad sense *is* nursing care. Nurses must be involved in how survivorship care is defined, implemented, and measured. In addition, survivorship tools assist nurses in providing care, but cannot replace patient-nurse interactions. As more organizations collect data on the quality of cancer care, the quality of patient-nurse interactions must not be overlooked. The QOL tool and assessment are important to enriching the nurse-patient interaction, as is delivering the survivorship care plan. Finally, much still remains to be learned about survivorship care and ample room exists for ongoing nursing-based survivorship research.

Challenges to incorporating survivorship visits, QOL assessments, and survivorship care plans into the clinical care continuum are ongoing. Minnesota Oncology continues to define how and when a patient is scheduled for survivorship visits. A limitation to the program was that the appointment was optional for patients. In addition, the authors presented the survivorship program to all patients who attended chemotherapy class. Not all of the patients attended this class, so this may have limited the population to those initiating chemotherapy being offered survivorship. Limitations for a successful community-based program include communicating the purpose of the survivorship visit to patients, lack of guidelines on late effects in adult patients with cancer, and proving value to payers. Barriers exist

to scheduling a survivorship visit prior to initiation of therapy. Many patients do not understand the purpose or benefit of such visits, nor do some consider themselves survivors before starting treatment.

The lack of published screening guidelines for late effects in adult patients with cancer limits the ability of the APN to counsel and screen for late effects. In addition, while everyone recognizes the need for high-quality care in oncology, defining and measuring the indicators of quality care continues to be a challenge. A future direction for the integrated survivorship program is to incorporate the FACT-G short form as a screening tool that could offer an evaluation between formal survivorship visits. The authors' goal is to continue to work collaboratively with community resources and hospital networks to improve cancer outcomes with a proactive approach.

The nursing profession is uniquely qualified to offer supportive care under a series of survivorship visits as directed by patient needs. The community-based oncology survivorship program uses technology to report subjective patient QOL that personalizes the care provided. Early survivorship care simplifies program delivery while allowing personalized care. A successful survivorship program builds on the skill of the multidisciplinary healthcare team. The APN and RN are the foundation for survivorship care that includes QOL assessment, palliative care, advanced care planning, delivery of treatment summaries and care plans, review and management of late effects, and patient navigation.

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