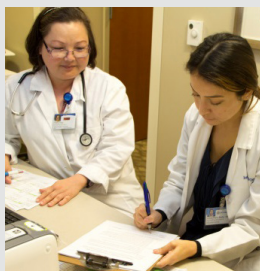


■ Article

# Development of a Survivorship Program

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The number of cancer survivors has steadily climbed to more than 10 million since the 1980s secondary to advances in detection and treatment modalities. This reality, combined with an aging population, has drawn the attention of the medical community to meet the needs of this population. Therefore, cancer care providers are being called to develop survivorship programs for patients with curable disease. Some of the prominent organizations supporting this movement for focused survivorship care include the Institute of Medicine, the National Comprehensive Cancer Network, the American Society of Clinical Oncology, LiveStrong™, and the Oncology Nursing Society. This article provides the necessary steps for the development and implementation of an institution-specific survivorship program to fulfill the new standards for survivorship care.

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Cancer survivors are a rapidly growing population with individualized needs who require attention. In 2005, the Institute of Medicine (IOM) released its report, *From Cancer Patient to Cancer Survivor: Lost in Transition*, delineating the current shortcomings in survivorship care and outlining new recommendations for survivorship care in the future. In 2003, cancer survivor Lance Armstrong decided to enter the ongoing conversation by creating LiveStrong™ and inviting fellow survivors to feel empowered enough to open a dialogue with healthcare providers about their specific needs. In 2007, the IOM released *Cancer Care for the Whole Patient: Meeting Psychosocial Health Needs* to augment the latest research surrounding survivors' unique needs (Adler & Page, 2008).

Both the American Society of Clinical Oncology (ASCO) and the National Comprehensive Cancer Network (NCCN) have developed survivorship guidelines to help guide the growing numbers of healthcare professionals struggling to create survivorship programs (SPs) for their patients. Although the authors'

institution already had some programmatic essentials in place, it was time to design and implement the Center for Breast Cancer Survivors, a comprehensive, evidence-based SP to serve the individualized needs of patients.

## Development

One of the motivating forces to develop an SP was participation in the ONS Foundation-supported Breast Cancer Survivorship (BCS) Quality Measures Set pilot study. Although the authors were aware of national deficits in survivorship care, this project helped identify the programmatic strengths and weaknesses in their initial SP. Although symptom assessment and collaboration of care in follow-up were excelling, documentation supporting the other efforts in survivorship care were lacking. Documented interventions for psychosocial distress, sleep, bone health, fatigue, lymphedema, menopausal symptoms, and neuropathy were all at less than 32% compliance. Survivorship education on community resources, diet, exercise, lymphedema,

and recurrence was documented in less than 34% of the cases. Goal setting and goal attainment was documented in less than 44% of cases. Fatigue and distress reassessment was documented in less than 13% of cases. The results from the BCS Measures pilot study provided the data needed to motivate institutional change in survivorship care.

Development of a breast cancer SP requires the dedication of an interdisciplinary team. Administrative support is vital to the success of any SP. Acknowledgement of the unique needs of the patient and the impact on patient outcomes from the administrative level drives support in program funding. Once funding is established, a dedicated interdisciplinary team is formed to determine the scope of the SP based on available resources to meet the needs of the population. Potential committee members should include representation from advanced practice RNs (APRNs), social workers, nurse navigators, and a survivorship coordinator or designated administrative support, as well as surgical, medical, and radiation oncologists. Meetings should occur frequently enough to keep the members engaged in the discussion while also allowing time for completion of the designated tasks for the SP development. The IOM (2005) report on cancer survivorship, *From Cancer Patient to Cancer Survivor: Lost in Transition*, should be reviewed and used as the basis for SP development and for the components of a survivorship care plan (SCP).

## Survivorship Models of Care

The committee members should determine the best survivorship model to fit patient needs paired with institutional resources. In an integrative model, the SCP is completed by the

- History and physical every 4–6 months for five years, then yearly; assess and address survivorship concerns such as anxiety and depression, cognitive function, fatigue, pain, sexual function, sexual disorder, physical activity, and immunizations and infections.
- Annual mammography
- Annual gynecologic assessment for women on tamoxifen with an intact uterus; monitor bone health with bone mineral density determination at baseline and periodically thereafter for women on aromatase inhibitor or for women who experience ovarian failure while on treatment.
- Assess and encourage adherence to adjuvant endocrine therapy.
- Evidence suggests that active lifestyle and achieving and maintaining an ideal body weight may lead to optimal breast cancer outcomes.

### FIGURE 1. NCCN Guidelines® for Breast Cancer and Survivorship: Surveillance/Follow-Up

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patient's existing breast cancer team, with each provider completing their component as treatment is given. Another model is a stand-alone or consultative visit performed at a designated appointment after completion of all cancer treatment. That survivorship model can occur as a one-time appointment or spread over a few follow-up visits. Patient transition to a survivorship clinic with a designated survivorship provider is another option once treatment is completed. In the model chosen by the authors, the SCP is completed in the first survivorship clinic visit. The length of time that these patients will be followed by the survivorship team should be discussed and patient preference needs to be taken into consideration. Coordination of survivorship follow-up with primary care should be integrative and communication of care should be shared after completion of the SCP and after each subsequent visit. Determination of ongoing SP follow-up is individualized by practice. Some models stop after one visit, whereas others share care over years. The anticipated patient population and SP resources should be considered when determining length of specialized care.

## Survivorship Care Plan

### Establishing a Plan

The survivorship appointment timing and feasibility is the next factor. Who will conduct the initial survivorship visit where the SCP is assembled and presented to the patient? How much time should be allotted for these visits? When is the SCP best received by patients transitioning to survivorship care? Is an interdisciplinary approach plausible for these visits or will one provider complete the visit and summarize all of the cancer care? The Quality Oncology Practice Initiative (QOPI) (ASCO, 2014) and the Commission on Cancer ([COC], 2012) suggested that the optimal timing for SCP delivery is as close as possible to the end of cancer treatment. The QOPI recommends that the SCP be given within three months of chemotherapy completion (ASCO, 2014).

The components of the SCP should be determined next. The length, format, reading level, and ability to personalize the SCP all need to be considered and consensus reached by the SP team. The COC national standard for the contents of an SCP includes a record of care received, important disease characteristics, a written plan incorporating patient goals, and evidence-based standards (COC, 2012). Ongoing collaboration of care for the survivorship population cannot be understated. Patients often feel lost after cancer treatment. A planned schedule of visits alternating among their providers ensures that they are followed every three months for the first three years, while also ensuring that their providers are communicating and collaborating to deliver best care (Khatcheressian et al., 2012). Emphasis of ongoing primary care follow-up should be stressed. Healthy lifestyle habits that can optimize outcomes and minimize additional cancer risks should be addressed in the SCP. Exercise recommendations, smoking cessation, bone health guidelines, dietary changes, and any other evidence-based recommendations for survivorship care can be included in the initial review of the SCP. Having patients identify specific goals for their well-being are strongly encouraged as part of the initial SCP discussion and documented for future assessment at follow-up visits.

Additional educational resources can be included in the SCP packet for patient reference, such as brochures or booklets from prominent organizations, SP supplements specific to the institution, as well as any community resources for patients with cancer that may be appropriate.

## Implementing a Plan

The type of SP chosen by the current authors was an APRN-led survivorship clinic, which met the needs of the robust academic breast cancer program. This model allowed physicians to concentrate on the newly diagnosed, active treatment, and metastatic populations. The APRN team is able to take the extra time necessary to address the unique needs of the institution's breast cancer survivorship population. The treating medical oncologist and APRN make the decision when the patient is ready for referral to the survivorship clinic. Only patients who are treated with curative intent are referred to the survivorship clinic (Khatcheressian et al., 2012).

The first appointment is scheduled for one hour and includes a thorough physical examination. Individual cancer features and the patient's entire treatment course is reviewed. Residual treatment symptom burden is assessed and documented along with potential long-term and late side effects of treatment, including menopausal symptoms, lymphedema, fatigue, cognitive function, energy recovery, sleep pattern, and residual pain. The patient is instructed on symptoms of recurrence, a collaborative follow-up plan, and when to call for concerns. Educational pamphlets and community resources for survivorship support are provided. The patient completes a psychosocial distress survey and referrals for appropriate hospital and community-based follow-up are then made, including social work, spiritual care, sexual counseling, nutritional services, financial counseling, and palliative care for pain management (NCCN, 2014).

At the end of treatment visit, the patient is also invited to an Orientation to Survivorship class. This is an educational offering for patients at any point in their survivorship journey. The purpose of this class is to discuss common psychosocial concerns of transitioning to a breast cancer survivor, as well as discussing NCCN guidelines for survivorship care (see Figure 1). This two-hour class is led by a licensed social worker, nurse, and/or APRN.

Changes in lifestyle to provide optimal health outcomes in survivorship are recommended based on each individual's needs. This includes discussion of diet, exercise, tobacco cessation, minimizing alcohol consumption, sun protection, bone health, and any other health needs. Patients are then encouraged to set at least one 12-month health goal. Progress towards goal achievement will be assessed at future follow-up visits. The patient is encouraged to maintain regular visits with their primary care provider (PCP), as many become disconnected with their PCP during the course of their cancer treatment (NCCN, 2014).

The institution's SP adopted the ASCO guidelines for follow-up survivorship care with examinations every three months for the first three years, every 6–12 months for the fourth and fifth years, and annually thereafter (Khatcheressian et al., 2012). The goal of the program was to alternate visits among the breast cancer team specialists (radiation oncology, surgical oncology,

## Implications for Practice

- ▶ Implement a survivorship program to streamline ongoing assessment, intervention, and reassessment of any treatment-related toxicities.
- ▶ Identify and assist with individualized patient goals to help each patient regain more of his or her pretreatment normalcy.
- ▶ Provide education on signs of recurrence, long-term implications related to treatment, and ways to optimize health to help inform and involve each patient in his or her ongoing survivorship.

and survivorship) to fulfill the guidelines set by NCCN and ASCO for coordination of care. The program has been successfully implemented, ensuring survivors that their providers are communicating in their ongoing care.

The SP is routinely evaluated by the breast cancer providers to maintain evidence-based practice. Feedback from patients, PCPs, and other providers regarding this transition process has been valuable. Ongoing evaluation of the institution's SP is important to provide the most current evidence-based recommendations and guidelines for its survivorship population.

## Nursing Implications

Many implications exist for nursing staff in an SP, including evaluation and documentation of distress, coping, fatigue, lymphedema, sleep disturbance, and menopausal symptoms. In addition, reinforcement and encouragement of established patient goals for healthy lifestyle are crucial for change to occur. Education on symptom management, community and hospital-based resources, and referral management generally is the responsibility of the SP nurse. Nurses are also instrumental to the collaboration of care among providers and the documentation of SP care. Nursing commitment is integral to the success of any SP.

## Conclusion

Institutional support, interdisciplinary representation in the development process, and a dedicated committee are essential in the successful formation of an SP. Research supports the ongoing need for specialized and dedicated survivorship care (IOM, 2005). The steps provided within the context of this article can be adapted to any cancer type or SP with minimal modifications. Collaborative care provided in SPs can increase patients' confidence (IOM, 2005). The setting of an SP allows patients to continue their journey of healing beyond the physical treatment.

One of the major lessons learned from participation in the BCS Measures pilot study was the importance of documentation of care. Although proficient survivorship care was assumed, lack of documentation made the authors unable to prove that the institution's efforts were truly successful. Participation in the BCS Measures pilot study allowed for evaluation of the SP and implementation of quality projects to improve survivors' experience and collaboration of care. With a more structured

design and well-documented approach in the SCP, the survivorship care delivered is less fragmented for patients, and the communication among providers has improved significantly, which has been paramount to a successful SP.

## References

Adler, N.E., & Page, A.E.K. (Eds.). (2008). *Cancer care for the whole patient: Meeting psychosocial health needs*. Retrieved from <http://www.ncbi.nlm.nih.gov/books/NBK4015/>

American Society of Clinical Oncology. (2014). *Quality oncology practice initiatives measures summary, Spring 2014*. Retrieved from <http://qopi.asco.org/documents/QOPI-Spring-2014-Measures-Summary.pdf>

Commission on Cancer. (2012). *Cancer program standards 2012: Ensuring patient centered care*. Retrieved from <http://www.facs.org/cancer/coc/programstandards2012.pdf>

Institute of Medicine. (2005) *From cancer patient to cancer survivor: Lost in transition*. Washington, DC: National Academies Press.

Khatcheressian, J.L., Hurley, P., Bantug, E., Esserman, L.J., Grunfeld, E., Halberg, F., . . . Davidson, N.E. (2012). Breast cancer follow-up and management after primary treatment: American Society of Clinical Oncology clinical practice guideline update. *Journal of Clinical Oncology*, 30, 961-965. doi:10.1200/JCO.2012.45.9859

National Comprehensive Cancer Network. (2014). *NCCN Clinical Practice Guidelines in Oncology: Survivorship* [v.1.2014]. Retrieved from [http://www.nccn.org/professionals/physician\\_gls/pdf/survivorship.pdf](http://www.nccn.org/professionals/physician_gls/pdf/survivorship.pdf)