

Coordination of Care in Breast Cancer Survivors: An Overview

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Abstract

The number of breast cancer survivors in the United States is increasing. With longer survival, there has been an increase in the complexity and duration of posttreatment care. Multidisciplinary care teams are needed to participate across the broad spectrum of issues that breast cancer survivors face. In this setting, the need for well-established patterns of communication between care providers is increasingly apparent. We have created a multidisciplinary approach to the management of breast cancer survivors to improve communication and education between providers and patients. This approach could be extended to the care and management of survivors of other types of cancer.

Case

A 65-year-old woman with stage II breast cancer, mild hypertension, and obesity recently completed treatment for her estrogen/progesterone receptor-positive, HER 2-negative breast cancer. She was treated with lumpectomy, radiation therapy, and adjuvant chemotherapy with doxorubicin and cyclophosphamide followed by paclitaxel. She remains on an aromatase inhibitor and is experiencing arthralgias, numbness in her extremities, fatigue, and apprehension about cancer recurrence. She has not seen her primary care physician since the start of her cancer treatment but is concerned that her "heart" and bones may be affected by her therapy.

Scope of the Challenge

As of January 2007, the National Cancer Institute estimated that there are 11.7 million cancer survivors in the United States, which represents approximately 4% of the population. Breast cancer survivors comprise the largest proportion

at 22% of all survivors; and with the aging of the general population, the majority of breast cancer survivors are currently 65 years of age or older.¹ As these numbers expected to grow in the next decade, attention has turned toward the care of this group of patients. These patients, many having completed local and adjuvant cancer treatment with no evidence of recurrent cancer, present a unique set of health-care issues.² Often, they are faced with long-term and/or late-onset physical and psychosocial effects from their cancer and its treatment. They may also suffer from chronic comorbid conditions, such as hypertension or diabetes, that are not actively addressed during their acute cancer treatment. The path which leads the patient to the next step of their medical journey, transitioning from active cancer treatment to posttreatment care, is not always clear to the patient or the practitioners involved.

In 2006, the Institute of Medicine's (IOM) report *From Patient to Cancer Survivor: Lost in Transition* acknowledged and outlined the gaps in comprehensive and coordinated care for these patients as well as the complexity of their care.³ In addition to increasing the awareness of the consequences of cancer and its treatment, the report identified several areas that were considered "essential components" of survivorship care. These include prevention and surveillance for new or recurrent cancers, treatment of long-term

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Table 1**Components of Care for Cancer Survivors³**

1. Surveillance for recurrence of cancer
2. Surveillance and treatment of long-term and late effects of cancer treatment
3. Screening and prevention for second cancers
4. Assessment of psychosocial issues
5. Care of comorbid conditions
6. Preventative health including immunizations, diet, and exercise
7. Coordination between care providers

and late effects of cancer treatment, and coordination of care between oncology care providers and primary care providers (Table 1). The importance of patient and provider education and communication was highlighted as a means to enhance the transition phase from acute cancer treatment to long-term health. However, many hurdles exist in the present health-care structure, often making the delivery of optimal care for these patients difficult.

For a variety of reasons, the care of the breast cancer survivor no longer singularly can fall into the hands of the oncologist. With the aging population and increase in cancer survivors, the demand for oncologists will continue to increase at a much higher pace than the number of oncologists available.⁴ In order to continue to evaluate newly diagnosed cancer patients, oncologists must partner with other health-care providers to manage the cancer survivor. Surveillance, Epidemiology, and End Results (SEER)–Medicare analyses on patterns of preventive care among breast cancer survivors have shown that breast cancer survivors observed by both a primary care practitioner and oncology specialist are more likely to receive appropriate care,^{5,6} supporting the integration of practitioners for improving outcomes. The patient-centered medical home model has been proposed as an approach to improve the quality and cost of health care by enhancing communication. In this primary care physician (PCP)–led initiative, there is to be coordinated, evidence-based care between health-care professionals, with patient involvement.^{7,8} Breast cancer survivorship care could be enhanced if this type of model is effective; however, improved coordination will require clarification of each practitioner's role in care provision.

Patients and practitioners have concerns about the present communication between providers. In a survivor/physician survey, there were differences in expectations of care delivery between patients and their physicians as well as between PCPs and oncologists,⁹ with PCPs expecting more involvement in survivorship care than patients had perceived. Both PCPs and oncologists felt they should be prominently involved in cancer surveillance and screening as well as preventive health care, making it less clear who was to complete the task. In a cross-sectional survey of breast cancer patients, while survivors' perceived confidence in PCPs' survivorship care increased with the frequency of office visits, most patients felt the communication between PCPs and oncologists was poor.¹⁰ Similarly, many PCPs consider the transfer of care

and information provided from the treating oncologist as fair or poor.^{11–13}

Primary care providers may also have reservations about survivorship care and about their ability to successfully integrate care for an already complex medical patient. In a survey of community- and academically based internal medicine physicians, 47% of respondents lacked formal training in cancer survivorship and felt inadequately prepared. Eighty-two percent felt that primary care guidelines for adult cancer survivors were not well defined.¹³ Despite this uncertainty, there is evidence suggesting that noncancer physicians are able to deliver appropriate long-term care to breast cancer survivors. Studies by Grunfeld et al.¹⁴ comparing PCP follow-up with oncologist follow-up of survivors of early-stage breast cancer in Canada demonstrated no difference in recurrence-related serious clinical events or health-related quality of life. Patient satisfaction was better and health service costs were lower with PCP delivery of long-term follow-up.^{15,16}

A specific recommendation of the IOM report to improve the transition period for the cancer survivor is the completion of a comprehensive care summary and follow-up plan termed a "Survivorship Care Plan."³ The goals of a treatment summary should be to improve communication between care providers as well as to serve as educational material for future care of the breast cancer survivor by all providers. It should involve a written consolidation of the cancer treatment history with specifics on cancer type, surgeries, radiation treatment, chemotherapy, as well as any additional therapy planned. The physicians involved in the patient's care and their contact information should be included to streamline communication. The survivorship care plan would be an individualized assessment of the posttreatment and long-term effects of the cancer treatment.^{17–19} A care-plan template proposed by the American Society of Clinical Oncology includes follow-up care testing recommendations for care provider visit frequency, mammography, breast exam, pelvic examination, and genetic counseling. It also addresses the importance of coordination of care between providers to clarify appropriate follow-up. Available evidence-based clinical practice guidelines should be reviewed and shared with other health-care providers involved in the patient's care. The care plan should delineate responsibilities of all care providers in an effort to facilitate seamless coordination and communication. The timing of the completion of a care summary may be patient-dependent but often occurs at a point when surgery, chemotherapy, and/or radiation are completed. Some have suggested that these discussions occur during a dedicated clinic visit or some other protected time.

In addition to reviewing and documenting the patient's cancer treatment and coordinating health-care providers, this visit or protected time is an opportunity to refocus the patient on other health-care issues. Often, comorbidities are an afterthought to patients and practitioners during cancer treatment, but the implications can be just as serious. Recent studies of postmenopausal breast cancer survivors show higher risks of death from cardiovascular disease than from breast

cancer,^{20,21} especially for those diagnosed with early-stage breast cancer. Obesity and diabetes have also been linked to worse outcomes in breast cancer patients.^{22,23} Other known or newly-identified comorbidities should be discussed to ensure a follow-up care plan is in place and routine preventative health measures such as exercise, diet, immunizations, and cancer screening are reviewed.

Optimizing Care Delivery

In addition to instituting a care plan and treatment summary, the relationship between treating providers should be examined. The most common model that exists in practice is that in which a newly diagnosed cancer patient's care is assumed by an oncologist during the active treatment phase and years thereafter for monitoring of recurrence or long-term side effects of therapy. The role of the PCP is unclear during this time, and the dissemination of treatment information is limited. While oncologists are trained in internal medicine, the noncancer medical issues of the patient may be given lower priority. After acute cancer treatment is completed, the role of the PCP may still be unclear. Patients may feel an intense relationship with their oncologists and express anxiety about leaving their care. PCPs may not receive enough information regarding the cancer patient's treatment course and long-term cancer-related side effects.¹²

A shared-care model of health-care delivery involves a more coordinated effort between practitioners with regard to communication and delineation of responsibilities and has been proposed as a model that may enhance survivorship care for breast cancer patients.²⁴ In this model, the roles of the oncologist and the PCP would be clarified and complement one another. At the time of cancer diagnosis, the primary responsibilities for treatment would be with the oncologist but the management of comorbid illnesses and health maintenance would be handled by the PCP. Primary responsibility for patient care would then shift back to the PCP at a transition point in the patient's cancer care. The oncologist's role would entail short- and mid-term surveillance of cancer, treatment of acute- and short-term complications, and screening for second cancers. The primary care domain would involve preventive services, screening for second cancers, long-term surveillance, and treatment of long-term complications. Implicit in the shared-care model is ongoing exchange of information between care providers with the oncologist available and accessible for consults and dissemination of new surveillance recommendations or information on long-term side effects from treatments.

Completion and utilization of a cancer treatment summary and survivorship care plan could be a pivotal accessory for the physical and psychological transfer of care responsibilities between practitioners. However, the timing and completion of the document may be more complex. A risk-stratified approach for the timing of transition has been implemented for the care of pediatric cancer survivors and involves an individualized assessment for risk of recurrence or late effects as well as patient preferences.²⁵ A similar model for breast

cancer survivors could be employed with those having the lowest risk of cancer-related health problems transitioning at the completion of active treatment and patients with a higher risk of side effects or recurrence remaining closely linked with their cancer care provider but having continued involvement of their PCP.²⁴

Models of Care

The mechanism to complete survivorship care plans and optimize the shared-care model for cancer survivors may depend on the resources available. At large academic centers there often exist many resources for cancer survivors, but coordinating their efforts may be difficult. The use of electronic health records can improve communication between providers within an institution and may help facilitate the transfer of information beyond a single care setting.

Models of survivorship care are evolving within programs designed to utilize the expertise of multidisciplinary teams to deliver or coordinate long-term care for the cancer survivor.²⁴ The first model of long-term cancer survivorship care originates from the pediatric cancer survivor population. These programs typically follow the pediatric cancer survivor longitudinally and are comprised of a team of practitioners, including an oncologist, and often coordinated by an oncology nurse practitioner. They may also utilize pediatric and adult medicine specialists, social workers, and psychologists.²⁶ Annual visits include surveillance for recurrence, evaluation of long-term side effects, counseling for symptom management, and patient education.

From this paradigm, some cancer centers are developing programs that involve the survivorship care of multiple cancer groups and are more diverse than the pediatric survivorship population. The unifying goal is to bring physicians, nurses, social workers, mental health-care providers, and other relevant experts in cancer survivorship together to maximize the available services for the cancer survivor. Within these programs, various care-delivery patterns exist, such as that of a one-time consultative visit with a practitioner with survivorship expertise in which the cancer treatment summary and care plan are completed.

Another type of care is a survivorship clinic led by a nurse practitioner. Here, cancer patients who have completed acute treatment are followed for a period of time by the nurse practitioner with cancer expertise and then transitioned back to their PCP, with the nurse practitioner acting as the liaison in the shared-care model to maximize support of long-term care.

A third type of care delivery for comprehensive survivorship programs is similar to the pediatric long-term follow-up clinic and entails a multidisciplinary team of care providers involved in the assessment of the patient's needs, including oncology nurse experts, mental health-care providers, social workers, physical therapists, oncologists, and consultants. Physicians, sometimes nononcologists, who are not involved in active treatment assume the role of survivorship care and long-term follow-up.

Other centers have chosen to focus efforts on disease-specific survivorship programs, coordinating efforts of disciplines relevant to treatment issues and side effects of an individual cancer such as breast cancer. These often serve as the springboard to coordinate larger survivorship initiatives within an institution.

How We Do It

At our institution, the evolution of the care delivery for breast cancer survivors has involved a multidisciplinary team identifying distinct areas of need for improvement in implementing survivorship care. We established a collaborative relationship across the schools of nursing, medicine, and public health and received funding from Susan G. Komen of Maryland to develop a multifaceted program. Our working group consists of a breast oncologist, general internists, advanced-practice oncology nurses, social worker, breast cancer survivors, and researchers with expertise in nursing and health-care outcomes. Goals for improving the transition of care for breast cancer survivors included implementing a multidisciplinary approach to survivorship care planning and education of survivors and care providers.

The development of risk-adjusted individualized care strategies was paramount to coordination of care between oncology providers including medical oncologists, surgeons, and radiation oncologists, as well as identifying the appropriate time to initiate a transition of care. This approach was developed to avoid overlap of care services between oncology providers and to offer a guide for practitioners and patients on care expectations. Development of these strategies was complicated by varying expectations from the oncology practitioners and their desire for continued follow-up for even low-risk patients. Provider expectations and concerns regarding survivorship care delivery were clarified through focus groups conducted with patients, oncologists, and PCPs.¹² The limitations of the use of established survivorship care plan templates were identified and led to modifications that would be piloted.

Educational endeavors for stakeholders involved in optimizing breast cancer survivorship care were developed. A Web site was created for patients as well as practitioners, addressing issues such as symptom management, follow-up care, survivorship care planning, side effects of therapy, reducing risk of recurrence, fertility issues, and genetic counseling. Videos of breast cancer survivors discussing their experiences are accessible on the site, and further patient specific-materials were developed to complement the summary care plan.²⁷ Within the school of nursing, an oncology student interest group was established with a focus on lectures promoting cancer survivorship issues. Several nursing initiatives to increase the exposure of students to breast cancer survivor issues were implemented, including clinical placements in oncology settings. To increase the awareness of PCPs and oncology providers to the unique needs of breast cancer survivors, a wide range of educational seminars were given at the local and national levels. These included multidisciplinary panel presentations involving advanced nurse

specialists, internists, oncologists, gynecologists, and a health services researcher.

The timing, content, and method of a transition experience from acute oncology treatment to long-term follow-up care and coordination with primary care was determined by several factors at our institution. Practitioner availability, location, and reimbursement parameters factored into the development of our care model. Many of our clinical resources are not physically or operationally centralized, and simplifying this for patients was a consideration. The model in existence had breast cancer survivors maintaining a long-term relationship with either their oncologist or an oncology nurse practitioner with little coordination of care between nononcology providers for long-term survivorship issues or general medical health care. There existed no formalized mechanism to institute a transition visit or complete a survivorship care plan.

Initially, and during the piloting phase of the cancer survivorship care plan template, we envisioned the transition visit would be best handled between the oncology physician and patient. The presumed benefits would be the familiarity of the relationship and the physician's knowledge of cancer treatment. The appropriate timing would be determined based on the individual's risk of recurrence and comfort with transition. Practitioners, while supportive of the concept of the visit and coordination of care, found it difficult to utilize the oncology appointment solely for this purpose and found the completion of the care summary time-consuming.

We tested a model for referral of patients who were completing the active treatment phase to an internal medicine provider with experience in breast cancer survivorship care for a consultative one-time evaluation. The physician was linked with oncology providers by an electronic medical record facilitating the review of prior cancer treatment but was in a separate clinical care area. Benefits of this approach were the psychological and physical shift of focus from acute cancer treatment to survivorship care issues. Attention to comorbid illnesses and health prevention was emphasized in addition to identification of side effects from treatment. This approach had several limitations, including practitioner availability, as many patients then wished to continue their long-term primary care with this care provider after the completion of the visit. Most important, we wanted to maintain the established relationships many patients may have had with their PCPs prior to their cancer treatment and had concerns this model might undermine those relationships. Additionally, the treatment care summaries were not being completed by a cancer care provider and the perspective of an oncology care provider was being lost. The financial feasibility of the model was also of concern as insurance reimbursements for a consultative survivorship visit delivered by a PCP were variable.

To maintain the relationship of the patient with the oncology center yet coordinate transition of long-term care to the PCP, we then considered utilizing the expertise of the oncology advanced-practice nurses (nurse practitioners and a clinical nurse specialist) embedded in the cancer center. These providers had already established relationships with

many of the breast cancer patients during their active treatment phase and were intimate with the nuances of the oncology care and symptom management. Their nursing backgrounds also included a focus on health promotion and supportive care. Our multidisciplinary group met to outline and clarify the expectations, goals, and best practices of a survivorship care transition visit for these clinicians. Integral to the mission was patient and staff education, patient self-care guidance, resource identification to address the unique physical and psychosocial referral needs of the survivors, and the development and communication of treatment summaries and survivorship care plans for PCP follow-up.

Patients are identified for the transition visit by either their breast cancer physician or oncology nurse practitioner based on an individualized risk-adjusted stratification, as well as by patient interest. A distinct appointment is made for this coordination of care visit, establishing it as a unique counseling appointment. After completion of the visit, a treatment summary and care plan are provided for the patient and her care providers. Patient-directed educational resources are also made available.

Discussion

With the growing population of breast cancer survivors, the importance of coordinated care to foster improved long-term follow-up for these patients is paramount. The IOM's report on cancer survivorship has identified gaps in care delivery and provider awareness of the issues unique to these patients. As models of care are developed, mechanisms for assessment must follow to continue to refine efforts aimed at improving care delivery and patient outcomes. In the context of our program, short-term feedback from patients completing cancer treatment summaries and survivorship care plans during the transition visit with an advanced nurse practitioner will be obtained with regard to patient expectation, achievement of stated goals, and satisfaction with the process. Educational materials will be developed as areas of further need are clarified. Similar feedback from other clinicians involved in the care of the patient will be incorporated into the process and dissemination of care plans. Our experience in developing a survivorship care model for breast cancer is paving the way for other cancer types, such as prostate and colon, that also continue to have a growing survivor population.

At our institution, the coordination of care for breast cancer survivors has demonstrated the complexities of the multidisciplinary approach to patient care. Identifying, engaging, and organizing the various stakeholders involved in care delivery can be both challenging and rewarding. Physicians' and patients' attitudes toward a shared-care model have been varied, but all agree communication between providers is essential. Patient-specific recommendations from oncologist to PCP can alleviate some of the uncertainties of care,²⁸ and summary information should be adapted to the needs of the care provider so as not to make care plans so complex that they are not practical. Clarifying the timing of a transition visit in the trajectory of breast cancer care must be individ-

ualized, and this is best accomplished by the oncology care providers. The transition of care goals should be patient-centered, with the patient's symptoms and concerns clearly identified and triaged appropriately. The utilization of advanced-practice oncology nurses to meet the multifaceted needs of the breast cancer survivor and coordinate communication between the oncology and primary care settings has been an effective model. Adequate training for these professionals in the area of cancer survivorship should be expanded and refined as more evidence-based guidelines are developed. Identification of referral bases for physical therapy, psychological support, social work, or gynecological care is necessary to expand survivorship resources.

We present our experience from a large tertiary care facility, but there are components that are adaptable to clinical care settings in the community. First, the education of oncology and noncancer practitioners on the importance and specifics of care relevant to the breast cancer survivor can be achieved through continuing medical education, Web-based educational modules, and treatment summaries with evidence-based guidelines. Limited practitioner time and availability may dictate the flexibility for survivorship visits but with the implementation of a cancer treatment summary and survivorship care plan, clinicians may engage their nononcology counterparts in a shared-care model and refocus their efforts on acute care management. Through patient education and information sharing, the cancer survivor may also better navigate the health-care system. Access to Web-based educational material for patients and providers that is developed and curated by reputable organizations, such as cancer.net by the American Society of Clinical Oncology, offers the opportunity to reach out to patients and PCPs whenever convenient.

While some of the medical or psychological implications of cancer treatment are related to the particular cancer type, many of the survivorship issues patients face are similar regardless of their specific cancer. Patients with early-stage cancers that are amenable to treatment with a curative intent and have a favorable prognosis may have few long-term oncologic needs, but appropriate screening and surveillance planning as well as assessment of long-term side effects is warranted. Similarly, patients undergoing cancer treatments that have more debilitating side effects may benefit from the multidisciplinary services identified in a survivorship program, including nutrition, physical therapy, pain management, and psychological support. While the timing or need for a transition visit may be different for other cancers, the concepts of patient education and consolidation of a treatment summary still apply as ways to enhance communication with the patients' primary care provider.

Conclusion

The patient case presented is emblematic of a course for an early-stage breast cancer survivor. She is experiencing side effects from her therapy that are common with treatments that may be managed by her oncologist or her PCP. She has

been disengaged from her PCP during her acute cancer treatment and may be unsure of who should address her physical and psychological concerns including the long-term and latent side effects that may remain. In a model of survivorship care, she could be evaluated by an oncology nurse specialist or care provider with survivorship expertise, who would identify her ongoing symptoms and put them in the context of her cancer treatment. A care plan would be devised to include appropriate follow-up with the clinicians best suited for her needs, including listing contact information of oncology providers and her PCP. Educational information in the form of printed materials and Web-site resources detailing the evaluation and treatment options for her symptoms such as neuropathy and fatigue would be provided, and consideration of referrals for other services such as physical therapy or a mental

health-care provider may be discussed. A printed copy of coordination of clinician visits, screening guidelines, and surveillance of long-term side effects from therapy that is individualized would be provided for the patient and physicians. By engaging the patient as a health advocate and improving lines of communication and education between providers, the care of breast cancer survivors will continue to improve.

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