Implementation of a Breast Cancer Survivorship Program

Heather Lowry MSN, WHNP-BC, Nayana Dekhne MD, Ryan Wood, BCSc-IE, MBA, CSSBB, Angela DeLaere, MBA
Beaumont Health, Royal Oak, MI

Background

As of January, 2014, there were over 14.5 million cancer survivors in the U.S. - of those, over 3 million are breast cancer survivors (1). This number is expected to continue to rise and is estimated to grow to 19 million by the year 2024 (2). According to the American Cancer Society, more and more cancer patients are surviving. In fact, about two-thirds of people with cancer are expected to live at least 5 years after their diagnosis.

There have been many publications and mandates to assure adequate care and follow up for cancer patients. In 2005, the Institute of Medicine [IOM], in collaboration with the National Cancer Institute, released their report “From Cancer Patient to Cancer Survivor: Lost in Transition” (2). According to the IOM, “The transition from active treatment to post-treatment care is critical to long-term health.” To ensure the best possible outcomes for cancer survivors, the IOM report aims to: raise awareness of the medical, functional, and psychosocial consequences of cancer and its treatment, define quality health care for cancer survivors and identify strategies to achieve it and improve the quality of life of cancer survivors through policies to ensure their access to psychosocial services, fair employment practices, and health insurance. “If care is not planned and coordinated, cancer survivors are left without knowledge of their heightened risks and a follow-up plan of action” (Hewitt, Greenfield, & Stovall, 2005).

Additionally, there are many other groups including the American College of Surgeons/National Accreditation Program for Breast Centers [ACoS/NAPBC], The American Society of Clinical Oncology [ASCO], the National Comprehensive Cancer Network [NCCN], the National Consortium of Breast Centers [NCBC] and the Commission on Cancer [CoC] that have recommendations for survivorship care and quality initiatives. Many of these include recommendations of Survivorship Care Plans and treatment summaries. The IOM, however, also has specific recommendations for oncology nurses which include educating health professionals to ensure proper training and education and promoting oncology certification. Specific survivorship recommendations include the following.

1. Raise awareness of cancer survivorship and to establish this as a distinct phase of cancer care.
2. Patients should be provided with a comprehensive care summary and follow-up plan that is clearly and effectively explained.
3. Health care providers should use systematically developed evidence-based clinical practice guidelines, assessment tools, and screening instruments to help identify and manage late effects of cancer and its treatment.

(Hewitt, Greenfield, & Stovall, 2005)
The CoC standards for accredited cancer centers include requirements on survivorship care. CoC “Standard 3.3” *Guidelines on Survivorship Care Plan* specifies that “the cancer committee develops and implements a process to disseminate a comprehensive care summary and follow-up plan to patients with cancer who are completing cancer treatment” (3). “The process is monitored, evaluated, and presented at least annually to the cancer committee and documented in minutes.” The requirement is that this process be phased-in in 2015. The CoC requires “a survivorship care plan to be prepared by the principal provider(s) who coordinated the patient’s oncology treatment... and is given to the patient upon completion of treatment”. Additionally, recommended by the CoC is that “this care plan contains a record of care received, important disease characteristics and a follow-up plan of care...”.

The NCCN also has new guidelines specific to Survivorship which focus on survivors after completion of treatment, and specify general recommendations for survivorship care and the management of long-term and late side effects of cancer treatment and screening for secondary cancers (4).

Survivors are often reported to feel abandoned. They have distinct needs, more ongoing health issues, need documentation of their treatment and want their PCP to be informed (3, 5). Survivors need support so they can resume life and adjust to the new normal (5). In general, survivorship care is necessary to assist patients as they transition to a new life, by providing emotional support, managing long term side effects of treatment, monitoring for new cancers, identifying cancer recurrence, promoting health and wellness, and addressing concerns to meet the needs of the cancer survivor and assure patients are not lost to follow up (4).

In response to the recommendations for cancer survivors and mandates for CoC accredited cancer centers, Beaumont Health, a tertiary care hospital, began an initiative to deliver survivorship care in a systematic fashion.

**Methods**

The cancer survivorship program at Beaumont Health in Royal Oak was developed to provide services and support to all cancer survivors, from the time of diagnosis, through treatment and into post-treatment. The mission of the Cancer Survivorship Program is “To partner with patients, families and their healthcare providers to promote optimized health and healing of the mind, body and spirit. While supporting and empowering patients through integrative practices and education before, during and beyond treatment”. In an effort to provide optimal services to cancer survivors and to meet required mandates, Beaumont formed a survivorship project planning group, in order to develop detailed services, specific to cancer survivors at Beaumont. This group identified 5 major components of survivorship care at Beaumont, as well as outlined program coordination with system services. These components included exercise and wellness, nutrition, psychosocial support, integrative medicine and long term follow-up (as demonstrated in figure 1).
A long term follow up clinic model was also designed to encompass the long term issues related to cancer survivorship, (see Figure 2).
Multidisciplinary subgroups were later developed. As the Beaumont breast program was well established, with a team of multidisciplinary professionals with expertise in caring for breast cancer survivors, a breast program committee was created to spearhead the cancer survivorship initiative. The intent of this team was to initiate cancer survivorship services within this cohort of cancer survivors. In 2013, Beaumont formed a breast cancer specific steering committee (BSC) consisting of a program lead oncology nurse, breast program medical director, business manager, nurse practitioner (NP), management engineer and improvement coordinator and pediatric oncology nurse, from the Beaumont Pediatric Long Term Follow-Up Clinic, to design and implement a breast specific survivorship program at the Beaumont Health, Royal Oak campus. This group met biweekly over the course of a year. A community needs assessment, survey of programs and resources throughout Beaumont was conducted. In addition, our team worked with a survivorship work group from the Michigan Cancer Consortium (MCC), in a joint effort to aid in survivorship care plan creation and implementation for cancer accredited centers. This workgroup compiled a process of decision making and developed best practice documents as well as ascertaining the need for a multidisciplinary process in survivorship program planning (6).

After a comprehensive review of pre-established care plans in the literature, the decision was made to create a new survivorship care plan document, specific to Beaumont Health, for use system wide. Each cancer specific disease state is able to individualize the general care plan to meet their patient’s specific cancer related needs.
Results:
Upon review of breast cancer (BC) patients treated at Beaumont Health over the last 5 years, 6,293 BC survivors were identified. A program model was developed to incorporate all components and services offered to BC survivors and families (see figure 3). Marketing strategies were created to reach the community and presentations to both the community and physician leads were conducted to relay both, the program vision and the importance of survivorship care. Resources and personnel were designated to the pilot Breast Cancer Survivorship Clinic (BCSC), which opened in September, 2014. The BCSC is a multidisciplinary clinic, designed to incorporate the unique needs of the BC survivor with a focus on wellness and health promotion, as a supplement to regular oncology follow up visits.

The vision of the BCSC was created as a nurse practitioner driven and physician supported clinic, designed to provide patients with a multidisciplinary approach to education, long term follow up and survivorship care. The goal of the BCSC is to provide patients with a survivorship care plan for their continued care, and to offer clinical and supportive services.

Prior to evaluation in the clinic, patients complete a comprehensive health questionnaire. Additionally the team assesses quality of life, to identify areas of concern and to help improve quality of life. Many quality of life tools were evaluated by the BSC in collaboration with social work. The tool found best suited to meet the needs of the breast cancer survivor, was The City of Hope, Quality of Life Questionnaire (7). Additionally, patients complete a 3 day food diary, which is brought to the clinic appointment and later reviewed with the dietitian.

During the survivors’ visits to the BCSC, the multidisciplinary team of specialists discuss each patient and review the patient’s present concerns, health and cancer specific history, self-reported quality of life tool and food diary. Each patient is seen individually by the nurse practitioner, who performs a comprehensive physical exam. In addition, a MSW, physical therapist with special training in cancer survivorship and lymphedema management, a registered dietitian and a representative from the integrative medicine department see the survivor during their visit to the BCSC. The team addresses the immediate, as well as the long term, needs of the cancer survivors. BC survivors can be seen at any time, following completion of treatment, and in special circumstances still receiving treatment. Management of problems, interventions, clarifications and educational materials are provided. Referral to appropriate disciplines and coordination of additional services are also provided as needed. Each survivor is provided with a detailed clinical summary and individualized care plan.
Figure 3, Breast Cancer Survivorship Clinic Program Model.

Survivorship Clinic Provider – Nurse / Nurse Practitioner

- Medical / Administrative Assistant
- Integrative Medicine
- Social Worker
- Physical Therapist

Survivorship Clinic
- Clinical summary & care plan
- Resources
- Information & education

Patient referral to clinic

Patient referral back to physicians for follow up care
Conclusions:
With collaboration from multiple disciplines and administration, implementation of a breast cancer survivorship program can be realized. A detailed review of institutional and community resources are imperative to assure delivery of quality care (5). Partnering with patients to make sure they understand their cancer diagnosis, long term side effects of cancer treatment and the importance of ongoing surveillance, will provide an opportunity for the BC survivor to transition towards a focus on health promotion and improvement in quality of life. Not only are these implementations consistent with survivorship requirements but, have the potential to improve outcomes for patients.

Ongoing challenges found by the MCC were also observed at our institution and included system and provider buy-in, gathering historical information from private medical offices, adequate staffing allotted to survivorship and time constraints for individualized care plan creation(6). There is a need across systems to assess and expand resources available to cancer survivors. A process for identifying who will create the survivorship care plan and clinical summary and how it will be tracked, are important considerations as well as multidisciplinary team involvement, which was found to be imperative for success of this program (6). Following the MCC survivorship work group, new strategies for cancer survivorship implementation were defined as part of the overall goal of improving the quality of life for cancer survivors in Michigan, as a part of the MCC’s Comprehensive Cancer Control Plan for 201 (8). New priorities are expected in 2016. Further research is needed in the area of survivorship specific to breast cancer patients, as well as the feasibility of survivorship care and dedicated survivorship clinics. As health care providers we have many opportunities at varying stages of cancer treatment to
partner with our patients - to advocate for them, while enhancing quality of care and helping to improve the quality of life of cancer survivors(9).

The authors would like to acknowledge the following:

The Breast Cancer Survivorship Clinic Pilot Team; Mary Kalil, Marie Mastracci, Deb Martz, and Elizabeth Hager
Jeanne Parzuchowski, RN, MS, OCN, Oncology Survivorship Program Coordinator, Beaumont Health
Lisa Muma, RN, Pediatric Oncology Nurse, Beaumont Pediatric Long-Term Follow up Clinic
Debbie Webster, Cancer Patient Navigation Consultant, Michigan Cancer Consortium

References:


4.) National Comprehensive Cancer Network Inc., NCCN Clinical Practice Guidelines in Oncology (NCCN Guidelines®), reproduced with permission from NCCN Supportive Care Guidelines (NCCN Guidelines®) for Survivorship, Version I.2015. © 2015 National Comprehensive Cancer Network, Inc. All rights reserved.


