



Multidisciplinary Clinical and Research Programs in Cancer Survivorship: Practical Issues

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Living Well after Cancer Program

Abramson Cancer Center at the University of Pennsylvania

Carrie Tompkins Stricker, MSN, CRNP, discusses the practice and consultative care models in the Cancer Survivorship program at the University of Pennsylvania. The following summarizes her presentation.

Cancer Survivorship: A Public Health Issue

- In 2001, the Office of Cancer Survivorship from NCI reported an estimated 9.8 million cancer survivors in the U.S. That number is now believed to have grown to over 10 million.
- 14% of cancer survivors were diagnosed ≥ 20 years ago, and the 5-year survival rate for adult cancers is now 64%. Over 60% of cancer survivors are 65 years and older.
- The 5-year survival rate in children for all cancers is 75%, with impressive rates of 70% at 10 years.
- 25% of deaths in childhood cancer survivors are due to late effects of treatment.

NCI Office of Cancer Survivorship Key Research Questions

- What are the most common late effects of treatment?
- Who is at risk and can they be protected?
- Can treatment-related injury to normal tissue be prevented or reversed?
- What proportion of survivors will experience recurrence of second malignancies?
- Who should be following these survivors to detect disease recurrence?
- What constitutes “optimal surveillance” and what is the cost of such follow-up care?
- Do medical, psychosocial, or behavioral interventions reduce morbidity in these populations?

Living Well after Cancer (LWAC) Program at the Abramson Cancer Center at the University of Pennsylvania

- Established in April of 2001, the Living Well after Cancer (LWAC) Program at the Abramson Cancer Center at the University of Pennsylvania is a specialized center for clinical care, research, and education for adult cancer survivors.

- The program bridges the Childhood Cancer Survivorship program at the Children's Hospital of Philadelphia (CHOP), with the Abramson Cancer Center Survivors program. The program has a full-time NP coordinator, a dedicated cardiologist, and participating medical oncologists.

LWAC Program Goals

The LWAC program has the following goals:

- Build upon the established surveillance guidelines (there are currently no adult cancer survivor surveillance guidelines).
- Establish a standard evaluation approach for cancer survivors, including breast cancer survivors, to identify issues pertinent in these populations, and create individualized risk profiles.
- Develop a dedicated research component to the program.
- Disseminate findings to the providers and patients.
- Advise developing programs nationally (e.g., the Cancer Institute of New Jersey; Dana-Farber Cancer Institute; M.D. Anderson Cancer Center; and Memorial Sloan-Kettering Cancer Center.)

Cancer Survivorship Program Challenges

- Many challenges exist in the provision of care to cancer survivors, including
 - Diverse populations and multiple diagnoses;
 - Multiple care providers;
 - Large patient volumes;
 - Determining when patients migrate to the survivors clinic;
 - Reimbursement and insurance issues;
 - HIPAA guidelines;
 - Funding concerns.

Survivorship Care Models

- Two care models exist: the practice model and the consultative model.
- The practice model is a clinical program that provides direct care to survivors and a forum for clinical research.
- The consultative model is a research program that provide recommendations to survivors/providers; the major focus of this model is research and education

Practice Model

- Initially piloted in breast cancer survivors, the practice model is now used on an ongoing basis in testicular cancer survivors and young adult cancer survivors at least 2 years postdiagnosis.

- The clinical program provides direct care to survivors, with regard to both physical and psychological well-being; long-term effects; and risk of subsequent malignancies.
- Appropriate screening is done on an individualized basis to enhance overall quality of life and well-being.
- An individual risk profile is developed through a thorough clinical assessment that incorporates diagnosis and treatment; complications during treatment; post-treatment complications; family history; current problems and medications; labs and scans to date, etc.
- The practice model calls for the assessment of modifiable risk factors for both primary and secondary prevention. Primary prevention includes diet, exercise, tobacco, alcohol or sunscreen use, etc.
- Secondary prevention occurs through usual and individualized screening as the evidence directs, with colonoscopy, DEXA scan, BSE, etc.
- Clinical management includes recommendations and appropriate referrals. For example, referral back to the APN in the surgical or medical oncology setting if evidence for recurrence is present.
- Referrals may also be back to the PCPs for further management of a detected hypercholesterolemia, osteopenia, or osteoporosis.
- Patients may also be referred to a rehab specialist, nutritionist, psychosocial counselor and other subspecialists within the health system, as needed.

Consultative/Research Model: Prospective Outcomes of Solid Tumors (POST) Study

- All patients seen at the Breast Center at the University of Pennsylvania are entered into a breast cancer database upon their first new-patient visit. At one year post diagnosis they are enrolled in the Prospective Outcomes of Solid Tumors (POST) study, which is evaluating the long-term effects of breast cancer treatment. This is an IRB-approved protocol. HIPAA authorization and consent is obtained prior to patient recruitment.
- Women with stage 0 to III breast cancer are eligible, and links to tumor-specific registries and tissue resources are available.
- Patients complete a core questionnaire that asks about disease status, treatment, comorbidities, etc.
- Symptoms are assessed using the Memorial Symptom Assessment Scale, physical activity through the International Physical Activity Questionnaire (IPAQ), and QOL through the City of Hope, Cancer Survivors, the FACT B and instruments. Questions from the National Health Interview Survey are included so that some comparisons can be made to population-based non-cancer patients.

Consultative Model: LWAC Breast Cancer Research Program

- The LWAC breast cancer research program is driven by clinical evidence collected.
- Patients are identified through the breast cancer database previously described. The physician or an APN is asked for consent to contact their patients. A member of the research staff meets the patient at their next clinic visit or contacts them by phone if no clinic visit is planned. Patients receive the core questionnaire either in clinic or in the mail.
- Specific aims of the program include the following:
 - Decrease the physiological and psychosocial morbidity associated with cancer treatment.
 - Describe the QOL of cancer survivors in the immediate post-treatment period and over time.
 - Describe the physical activity (PA) of breast cancer survivors over time and relate PA to physiologic, psychosocial, and QOL outcomes in this population.
 - Develop interventions that will improve the QOL for all cancer survivors.
- Ongoing research projects at LWAC include:
 - Risk and predictors of major depressive disorder.
 - Genetic determinants of premature menopause and bone loss.
 - Hot flashes and QOL.
 - Randomized clinical trial on acupuncture for hot flashes.
 - Sleep intervention study.
 - Patterns and determinants of physical activity in older and younger breast cancer survivors.

Conclusions

- The optimal follow-up for cancer survivors in terms of provider and venue has not yet been defined.
- The increase in adult cancer survivors necessitates that we have clinical programs addressing specific clinical care needs as well as specific research in areas such as late effects of treatment; second cancers and quality of life.
- Patients are very receptive to this program, whereas providers sometimes are not.
- Research in clinical care requires an integrated and multidisciplinary approach because of the vast and varied needs of the survivors.
- Different cancers require different approaches, e.g., practice model versus consultative model.
- The PhD-prepared APN with a research focus is ideal in this setting.
- Adequate infrastructure and funding is an ongoing necessity.
- Great opportunity exists for a network of centers to collaboratively approach survivorship.