

**Post-Treatment Physical and Psychosocial
Side/Late Effects and Program and Service Needs of
Breast Cancer Survivors**

Executive Summary

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Background

Medical advances in treatment, earlier detection, better supportive care and ongoing rehabilitation and surveillance have all contributed to an increase in cancer survivorship (Grunfield, 2006; Rowland, 2008). The relative survival of women with breast cancer is 86% at five years post-diagnosis (Mols et al., 2005). There is an abundance of research regarding the need for medical and psychosocial services for cancer survivors following active treatment in areas such as the management of side effects, fertility, employment and healthy lifestyle choices (Canadian Breast Cancer Foundation, 2007; Grunfeld, 2006; Cancer Care Ontario, 2004, Garcia Vivar & McQueen, 2005; Gray et al., 1998; Lyne et al., 2002; Raupach & Hiller, 2002). However, a recent report released by the Institute of Medicine in the United States indicated that coordinated, long-term care of cancer survivors to address the late and long-term effects of a cancer diagnosis and treatment is currently the exception rather than the norm (Hewitt et al., 2006).

This executive summary provides an overview of a project exploring the post-treatment physical and psychosocial side/late effects and program and service needs of breast cancer survivors. There were two main phases of this project. The first phase was a review of the post-treatment breast cancer survivorship literature to identify key health care issues experienced by breast cancer survivors during post-active treatment and existing interventions and models of care. The second phase of the project was an environmental scan and key informant interviews to explore existing post-treatment resources and to identify gaps in service and programming for breast cancer survivors¹ in the Toronto Central Local Health Integration Network (LHIN). This executive summary includes an overview of the findings from both phases of this project. Full reports are available at http://www.womensresearch.ca/programs/survivorship_report.php

Methods

Literature Review

A review of the academic and grey survivorship literature was undertaken between July 2007 and June 2008. One hundred and sixty articles published between 1998 and 2008 were selected for review. Articles were included if they focused on post-treatment physical and psychosocial side and late effects/issues for breast cancer survivors, the management of these issues and/or discussed models for/research about survivorship care.

¹ There is currently no consensus on how 'survivorship' is defined. Respondents in a recent environmental scan by Ristovski-Slijepcevic (2008) defined survivorship in three main ways: from the point of diagnosis to end-of-life; the period immediately following acute treatment to recurrence or end-of-life; and, a specific number of years after treatment. Ganz (2005, p5458) defined survivorship as "a focused period of time in the cancer trajectory at which patients treated with curative intent have completed their initial cancer therapy and are now post-treatment and in follow-up". For the purposes of this project, we defined survivorship as one year beyond the end of active treatment.

Environmental Scan and Key Informant Interviews

An environmental scan was conducted based on publicly available information to identify examples of hospital- and community-based programs and services in the Toronto Central LHIN that address survivorship needs of individuals with breast cancer. Based on this information, semi-structured telephone interviews were conducted with 25 key informants between August, 2008 and February, 2009. Key informants represented a broad range of programs/services including those that focused on breast cancer survivors specifically; programs/services for cancer patients in general; and, specialty programs or services that did not have a cancer focus per se but that addressed some of the late and long-term effects that breast cancer survivors might experience (e.g. bone loss, fertility).

Findings

Literature Review

The articles reviewed were categorized into three thematic areas: 1) Post-treatment physical and psychosocial side and late effects; 2) Interventions to manage physical and psychosocial side and late effects; and, 3) Survivorship care: issues and models. Each area is briefly summarized below.

Post-treatment Physical and Psychosocial Side and Late Effects

The prevalent physical issues identified in the literature included fatigue, insomnia, lymphedema, loss of bone density, reproductive and sexual health issues, pain, obesity, cardiovascular disease and recurrence. The psychosocial side and late effects most often reported include anxiety, depression, cognitive dysfunction, information and communication needs, relationship concerns and work/employment concerns. Findings regarding the quality of life of breast cancer patients are contradictory, with some studies finding little difference in quality of life between breast cancer survivors and the general population, and other studies finding deficits in quality of life in breast cancer survivors.

Interventions to Manage Physical and Psychosocial Side and Late Effects

Evidence-based interventions to manage physical side and late effects include exercise to reduce fatigue; Tamoxifen to stimulate bone formation and aromatase inhibitors to prevent bone loss in postmenopausal women; opioids, heat and cold therapy, massage for lymphedema pain, acupuncture, and relaxation therapy to help manage pain; and, low-fat diets to protect against recurrence particularly for women with estrogen receptor-negative disease.

Interventions to manage psychosocial side and late effects include education, cognitive-behavioural therapy (CBT), support groups, individual psychotherapy, coping skills training, and relaxation training. Meta-analyses about psychosocial interventions have found robust effects on anxiety and less so on depression, decreases in pain and no effect on survival. Particularly useful interventions to manage psychosocial issues include: exercise, cognitive behavioural therapy, peer assistance, and relaxation training.

Survivorship Care: Issues and Models

Few countries have well developed policies or plans specifically for cancer survivorship. There is variability with respect to who provides follow-up care (e.g. oncologist, family physician) and inconsistency with respect to the frequency and duration of follow-up visits and the routine investigations utilized to monitor physical effects. Only a few models of care for breast cancer survivorship have been tested and reported in the literature. These survivorship models were found to be relevant and helpful in dealing with post-treatment breast cancer issues and one had a positive effect on breast cancer survivors' emotional state, mental well-being, and perception of post-operative pain one year after surgery (Boman et al., 1999).

A survivorship care plan is recommended to provide continuity of care and enhance communication between providers and patients, standardize follow-up care and facilitate the transition from active treatment to survivorship. A survivorship plan should include information about cancer type, treatments received and potential side effects, timing and content of follow-ups and recommendations for monitoring and preventing late effects (Earle, 2006). The care plan should also identify providers responsible for each type of care; inform clients of available resources including psychosocial services in the community; and provide information to address insurance, employment, and financial concerns (Earle, 2006).

Environmental Scan and Key Informant Interviews

Overview of Programs and Services

The key informants did not identify the existence of any survivorship care plans/models in the Toronto Central LHIN. Cancer survivors access a number of hospital and community-based organizations that provide a broad range of services and support to cancer patients in the Toronto Central LHIN. These programs and services included osteoporosis and fertility clinics; psychosocial support through community-based cancer organizations; programs addressing lymphedema, cognitive dysfunction and return to work; pain clinics; and, supportive care professionals (e.g. social workers, dieticians, physiotherapists, occupational therapists). Some of the services provide individualized support and tailored information while others provided group-based programs. The degree of focus on or level of programming for, post-treatment survivorship needs varied considerably between organizations. A number of key informants indicated that they primarily saw individuals early, near the time of diagnosis or during treatment. The majority of programs and services could be accessed through self-referral, were offered without cost to the client (except for services offered by private practitioners) and waitlists were not evident although this may reflect a lack of awareness of existing resources.

There appeared to be good linkages between, and within, hospital- and community-based organizations. However, we did not measure where gaps exist in current referral patterns (i.e. where links do not currently exist). One central directory of resources does not currently exist. Although not exclusively, cancer centres often referred patients to community-based cancer organizations (e.g. Wellspring, Willow, Gilda's Club) for psychosocial support. Community-based organizations refer clients back to cancer centres for any issues that arise outside the scope of their support (e.g. physical concerns).

Themes Related to Gaps and Needs

A number of key informants described the concept of a “void” or “black hole” for patients once treatment ends and that there is currently a lack of transitional support or information provided to breast cancer patients at the end of their treatment. This leads to uncertainty for the individual about who to contact for care and for what issues, and more existential concerns such as “*what am I suppose to do with my life?*”. There is a need to provide resources to facilitate the transition from cancer centre to community-based care so that patients know where and who to go for support.

Key informants validated the post-treatment issues that were identified in the literature review. They also acknowledged a current lack of programs and services in the Toronto Central LHIN that address some specific issues including: sexuality; relationship concerns; body image; cognitive dysfunction; fertility; and, practical issues such as managing finances, return to work and insurance coverage. Overall, there is growing awareness of the need to address the late and long-term effects and many of the organizations are initiating or expanding post-treatment programming and service to address survivorship issues.

A few key informants indicated that there is limited access to patient-centred support that proactively identifies and is responsive to the individual needs of survivors. This support would reflect differing needs, preferences for how support is received and link patients, where possible, to services and programs in their own community rather than based on the location of the cancer centre where they received their treatment. The population within the Toronto Central LHIN is also very multicultural and therefore cultural and language barriers are always a potential reality as organizations have varying levels of resources to access translation services and interpreters.

Conclusions

The literature review, environmental scan and key informant interviews highlighted the need to facilitate the transition from active treatment to follow-up care for breast cancer survivors. One mechanism for facilitating this transition is the development and implementation of standardized survivorship care plans. Earle (2006 p.5112) stated that these plans should identify providers that would be responsible for different aspects of care and “*address the chronic effects of cancer (pain, fatigue, premature menopause, depression/anxiety), monitoring for and preventing late effects like osteoporosis, heart disease, and second malignancies, and promoting healthy lifestyles*”. There is currently no systematic way that people learn about what to expect post-treatment and that it is “*hit and miss*” what and how people learn about resources are available. It is currently up to each doctor and/or care team to determine what information and follow-up plan is provided. Often the patient is the one to self-identify needs and the information and services provided are dependent on which health care professional is asked and where they receive treatment. More coordination and standardization of this information is required. The Institute of Medicine stated that survivorship care plans “*have strong face validity and can reasonably be assumed to improve care unless and until evidence accumulates to the contrary*” (Earle, 2006, p5115). There is also an opportunity to learn from existing survivorship care models; build upon current relationships for cross-referrals; identify opportunities to redistribute resources; and, implement mechanisms to improve coordination of post-treatment care.

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The complete reports are available at www.womensresearch.ca/programs/survivorship_report.php

- 1) *Survivors of Breast Cancer: Exploring Post-Treatment Physical and Psychosocial Side/Late Effects and their Interventions – Phase 1 Surveying the Literature*
- 2) *Ascertaining the Post-treatment Program and Service Needs of Breast Cancer Survivorship Providers in the Toronto Central LHIN – Phase 2 Environmental Scan and Key Informant Interviews*