

**Ascertaining the Post-Treatment Program, Service and  
Network Formulation Needs of Breast Cancer Survivorship  
Providers in the Toronto Central LHIN**

***Phase 2 – Environmental Scan and Key Informant Interviews***

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**Funded by the Canadian Institutes for Health Research**

**February 28, 2009**



## 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). Breast cancer survivors account for approximately 41% of all cancer survivors (Ganz et al., 2002). 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 making healthy lifestyle choices (Canadian Breast Cancer Foundation, 2007; Cancer Care Ontario, 2004, Garcia Vivar & McQueen, 2005; Gray et al., 1998; Lyne et al., 2002; Raupach & Hiller, 2002). However, a 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).

The first phase of this project was a review of the post-treatment breast cancer survivorship literature to identify key and emerging issues. This review identified a number of physical (e.g. fatigue, insomnia, lymphedema, loss of bone density, reproductive and sexual health, pain, obesity, cardiovascular disease, recurrence) and psychosocial needs (e.g. anxiety, depression, cognitive dysfunction, information and communication needs, relationship concerns and work concerns) of breast cancer survivors. A complete overview of this review is reported separately. The second phase of this 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 survivors<sup>1</sup> in the Toronto Central Local Health Integration Network (LHIN). This report presents the findings from these interviews.

## Methods

An environmental scan was conducted based on publicly available information on the internet to identify examples of hospital-based and community-based programs and services in the Toronto Central LHIN that address survivorship needs of individuals with breast cancer. The list of resources was not exhaustive and was used primarily to identify potential key informants. Snowball sampling was also utilized.

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<sup>1</sup> 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. One of the key informants in the current project indicated that survivorship should be defined as individuals in follow-up care. For the purposes of this project, we defined survivorship as one year beyond the end of active treatment.

Potential key informants were contacted in advance by telephone or e-mail and if they were interested in participating, they were sent an information package and consent form by e-mail. Semi-structured interviews were conducted by telephone and ranged in length from 20 to 45 minutes. Verbal consent was obtained by audiotape at the beginning of each interview and a summary of the interview notes was transcribed. Descriptive and content analysis for themes was used to analyze the feedback from the key informant interviews.

## **Findings**

Twenty-five key informant interviews were conducted between August 1, 2008 and February 3, 2009. Key informants represented a broad range of programs/services including those that focused on breast cancer survivors specifically (e.g. lymphedema program); programs/services for cancer patients in general (e.g. community-based cancer organizations, cancer centre resources such as social work); and, specialty programs or services that did not have a cancer focus per se but that address some of the late and long-term effects that breast cancer survivors might experience (e.g. bone loss, fertility). Key informants were asked to describe the relevant programs/services that their organization offered their awareness of and/or referrals to other organizations within the Toronto Central LHIN, perceived gaps in survivorship care, opportunities for partnerships or linkages between organizations and recommendations to address survivorship needs.

### Overview of Programs and Services

Key informants represented a number of hospital and community-based organizations that provided a range of services and support to individuals in the Toronto Central LHIN. As outlined in Table 1, the organizations provided a broad range of support to cancer patients or the general public, through a variety of mechanisms. Some of the services provided individualized and tailored information and support while others provided group-based or broader information and support. The degree of focus on, or level of programming for, post-treatment survivorship needs, varied considerably between organizations and some 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. Obtaining a referral for the programs or services that required one did not seem to be a barrier. With the exception of a cognitive dysfunction program, respondents indicated that there were no waitlists. It is not clear if this reflects meeting current needs or a lack of awareness of available programs and services. A few respondents expressed concern that if there was more awareness of their service they may not be able to meet the demand with existing resources.

**Table 1 – Overview of Program and Service Delivery Mechanisms and Issues**

<p><b>Types of Services/Support</b></p>	<ul style="list-style-type: none"> <li>• Education</li> <li>• Awareness</li> <li>• Information</li> <li>• Support (group, one-on-one, peer)</li> <li>• Counselling</li> <li>• Access to health reports</li> </ul>
<p><b>Mechanisms of Delivery</b></p>	<ul style="list-style-type: none"> <li>• In-person</li> <li>• Group based</li> <li>• One-on-one</li> <li>• Online</li> <li>• E-mail</li> <li>• Telephone</li> <li>• Videoconference</li> <li>• Workshops and lectures</li> <li>• Written (e.g. brochures, booklets, newsletters)</li> </ul>
<p><b>Issues Covered</b></p>	<ul style="list-style-type: none"> <li>• Fertility</li> <li>• Mental health</li> <li>• Lymphedema</li> <li>• Cognitive dysfunction</li> <li>• Spiritual care</li> <li>• Osteoporosis</li> <li>• Breast reconstruction</li> <li>• Pain</li> <li>• Meditation</li> <li>• Sleep problems</li> <li>• Body image and sexuality</li> <li>• Exercise</li> <li>• Return to work</li> <li>• Finances</li> <li>• Supportive care (e.g. psychologists and psychiatrists, social workers, dieticians, physiotherapists and occupational therapists)</li> </ul>

The majority of programs and services were available without cost to the client. The main exceptions are services provided by private therapists, some lymphedema therapy and fertility treatments although in this later situation at least one program offered reduced prices for individuals with cancer.

## Linkages

The key informants identified a number of organizations, programs and services they were aware of in the Toronto Central LHIN that provide support to address late and long term effects of a breast cancer diagnosis and treatment (see Table 2). 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).

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).

A challenge for both cancer centres and community organizations is to remain up to date on what programs and services are currently available. This information is used both as a resource for themselves, other health care professionals and for their patients and clients to access. There is currently no one central resource that is maintained and utilized but rather each organization has compiled their own lists.

## Themes Related to Gaps and Needs

### *Transition Gap*

A number of key informants described the concept of a “void” or “black hole” for patients once treatment ends. As one key informant stated, “*you just get dropped*” at the end of treatment and patients are “*left to their own devices*”. As well, patients often feel supported while receiving treatment at the cancer centre and there is a mixture of “*relief and/or anxiety about not being followed anymore*”. One key informant indicated that she tries to normalize this experience for patients and encourages them to let them know if they have problems so that they can be linked to resources to meet their needs.

The key informants indicated 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 about who to contact for care (e.g. family physician or oncologist) 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. One key informant said that ideally patients would be able to continue using cancer centre services however recognized that in reality cancer centres have limited capacities to provide ongoing care for patients post-treatment.

**Table 2 - Examples of Organizations, Programs and Services within Toronto Central LHIN<sup>2</sup>**

- Rehabilitation program for breast cancer survivors (St. John's)
- Breast Cancer Survivorship Program, pain clinic, lymphedema clinic, Healing Journey (PMH)
- Supportive care teams through cancer centres (e.g. psychologists, social work, psychiatry, dieticians, spiritual care, occupational therapy, physical therapy)
- Canadian Breast Cancer Foundation
- Casting for Recovery Canada (fly fishing retreats for women with breast cancer)
- PYNK program at Sunnybrook (program for young women with breast cancer)
- Fertility programs (Mt. Sinai, PMH, Women's College/Sunnybrook)
- Community Care Access Centres (CCAC)
- Cancer Drug Assistance Program, CCO
- Cottage Dreams
- Table of Plenty (Mt. Sinai)
- Wellspring (e.g. return to work program, coping skills, support groups)
- Willow (e.g. information service, peer support)
- Gilda's Club (e.g. Thriving and Surviving)
- Olive Branch of Hope (support organization for women with breast cancer with a focus on women of colour and immigrant women)
- Lymphovenous Association of Ontario and Canada
- Camp Renewal
- Look Good Feel Better
- Assistive Devices Program (ADP)
- Mindfulness Wellness (St. Joseph's)
- Ontario Disability Support Program
- Interlink (community oncology nursing program)
- Canadian Cancer Society
- On-line directory of programs and services  
<http://info.cancer.ca/csd/searchcon.aspx?lang=E&id=354>
- CCS encyclopaedia <http://info.cancer.ca/e/cce/cceexplorer.asp?tocid=10>
- Ontario Breast Cancer Information and Exchange
- Multidisciplinary Osteoporosis Program (Women's College)
- Breast reconstruction workshops (Women's College)

*Gaps in Programs or Services Addressing Specific Late and Long-Term Effects*

Key informants validated the post-treatment issues that were identified in the literature review (see Table 3). There was a strong awareness among key informants of the need to address these late and long-term effects and a sense that there is currently a lack of programs and services addressing these concerns. One respondent stated that “*there is less support exactly when clients*

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<sup>2</sup> This is not an exhaustive list of all organizations, programs and services in the Toronto Central LHIN that might be relevant to breast cancer survivors but rather an example of some organizations, programs and services that key informants mentioned during the interviews.

*need more support.* Key informants identified a few specific areas where gaps exist including: sexuality; relationship issues; body image; cognitive dysfunction; fertility; and, practical issues such as finances, return to work and insurance. For some of these issues, what is available is being offered within the context of a research or pilot study e.g. body image, sexuality and cognitive dysfunction. This might reflect the current challenge to identify effective strategies and interventions to address these concerns. One key informant described the tension between implementing a program and evaluating it versus identifying something that has been demonstrated to be effective through a trial and obtaining the evidence needed to substantiate claims that it should be part of standard care.

**Table 3 - Post-Treatment Issues Identified in Literature Review**

Physical	Psychosocial
<ul style="list-style-type: none"> <li>• Fatigue</li> <li>• Insomnia</li> <li>• Lymphedema</li> <li>• Loss of bone density</li> <li>• Reproductive/sexual health</li> <li>• Premature menopause</li> <li>• Pain</li> <li>• Obesity and CVD risk</li> <li>• Development of other cancers</li> </ul>	<ul style="list-style-type: none"> <li>• Anxiety/depression</li> <li>• Cognitive dysfunction</li> <li>• Information/communication needs</li> <li>• Relationship concerns</li> <li>• Body image</li> <li>• Work/employment concerns</li> </ul>

Organizations recognize the need to address survivorship issues and are increasingly providing programs and services to meet these needs (e.g. return to work, financial counselling, lymphedema therapy). A few key informants indicated that as the focus on survivorship and post-treatment needs of individuals grows that it is important to prevent duplication between organizations with respect to the mechanisms of delivery (e.g. one-on-one, group based, online etc...) and the issues addressed.

*Barriers to Access*

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 (e.g. online, in person, group based) and link patients, where possible, to services and programs in their own community versus referrals based on the location of the cancer centre they received their treatment. This patient-centred care would also recognize that not everyone wants to be considered a survivor and that some individuals want to get back to their life and “*reclaim who they are*”. 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.

## **Recommendations**

There is a need to facilitate the transition at the end of treatment from hospital to community-based follow-up care and services. 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*”. These plans are currently not being used. There is no systematic way that people learn about what to expect post-treatment (acute vs. chronic issues) 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, 5115).

With respect to specific programs and services focusing on post-treatment needs, key informants recognized the need to address existing gaps but there was no consensus on what or how to do this. Key informants made a broad range of recommendations (see Table 4). Some overarching comments were that programs and services should not cost patients; that the timing is important and support should be as close to the end of treatment as possible; that it is important to not reinvent the wheel by learning from existing survivorship programs (e.g. Lance Armstrong Foundation); and finally, use community resources that currently exist, fill in gaps that need to be met and not duplicate what is already being done with respect to mechanisms of delivery and issues covered.

**Table 4 - Recommendations**

- Implement survivorship care plans
- Revise protocols at first post-treatment follow-up appointment e.g. checklist of physical and psychosocial symptoms
- Develop a survivorship centre with resource coordinators that can be a central resource - “one stop shopping”
- Organize cancer education and awareness forums and workshops that would focus on identified post-treatment needs with presentations by experts
- Provide peer support with post-treatment mentors
- Provide meeting space for groups
- Develop programs and/or services to address current gaps such as sexuality, cognitive dysfunction, breast reconstruction
- Develop a compendium of resources that can be accessed by health care professionals, community organizations and survivors, and develop a mechanism for maintaining and accessing this resource
- Organize a community day/workshop for women post-treatment 2-3 times/year to provide an opportunity to obtain information
- Provide support groups for older women
- Develop a mechanism for high risk screening (e.g. mental health issues)

## **Conclusions**

The post-treatment needs of breast cancer survivors that were discussed by key informants were consistent with those identified in the literature review. There is growing awareness of the need to address these late and long-term effects and indeed many of the hospital and community-based organizations are initiating post-treatment programs and services. There is an opportunity for these organizations to learn from existing survivorship care models; build upon existing relationships for cross-referrals; identify opportunities to redistribute resources; and, implement mechanisms to improve coordination of post-treatment care. The increasing focus on post-treatment needs will ultimately help to provide support during the transition period post-treatment; standardize the information that patients receive; and, improve the likelihood that individualized needs are identified and addressed.

The findings from this study will be shared with the Senior Executive Team at Women’s College Hospital and the Survivorship Program at Princess Margaret Hospital; and, disseminated to the key informants who participated in this project, cancer agencies in Ontario and to the National Survivorship Working Group that has representatives of cancer agencies, patient and professional organizations and the community. The mandate of the Working Group is to review the priorities identified at the 2008 National Survivorship Workshop and develop action plans to accelerate the development and implementation of care maps and models of care.

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