UNDERSTANDING THE PRIMARY HEALTH CARE NEEDS AND CURRENT CARE GUIDELINES FOR WOMEN FOLLOWING BREAST CANCER TREATMENT: A SCOPING REVIEW AND VALIDATION STUDY

By

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ABSTRACT

Purpose: The purpose of this thesis was to perform a scoping review of the current literature and available clinical practice guidelines to generate an understanding of the primary health care needs of women following treatment for breast cancer.

Methods: Based on an extensive scoping review of the literature, research findings regarding the complications of breast cancer treatments and corresponding primary care interventions were synthesized. Additionally, validation of the findings of the scoping review was performed through semi-structured interviews with two primary care physicians and three post-treatment breast cancer patients.

Results: Eleven broad categories related to the primary health care needs of women after undergoing treatments for breast cancer were identified. These included concerns related to: surgical complications, lymphedema, gynecologic and menopausal symptoms, psychosocial issues, additional primary cancers, cardiovascular implications, osteoporosis, lifestyle changes, fatigue, cognitive dysfunction, and pregnancy. Additionally, it was determined that the majority of existing clinical practice guidelines for breast cancer were outdated, and related to cancer detection and treatment as opposed to survivorship care.
Summary: Findings from the scoping review and interviews demonstrate the vast range of primary care needs of women after undergoing treatment for breast cancer. Additionally, these results highlight the critical need for the development of a comprehensive set of current clinical practice guidelines which target primary care physicians and are specifically focused on the survivorship needs of women following breast cancer treatment.
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CHAPTER 1: INTRODUCTION

1.1 The Rapidly Expanding Population of Breast Cancer Survivors

Breast cancer is the most common cancer affecting Canadian women (Canadian Cancer Society, 2011). According to the Canadian Cancer Society (2011), one in nine (11%) Canadian women is expected to develop breast cancer during her lifetime, and in 2011 alone, over 23,000 women will be diagnosed with breast cancer. With continuous advances in diagnostic capabilities and targeted cancer therapies, there is a rapidly expanding population of survivors. The Canadian Breast Cancer Foundation (2011) indicates that the five-year relative survival rate for women with a breast cancer diagnosis is 87% after undergoing various treatments, with approximately two thirds of women diagnosed surviving long-term. This means that from the group of women diagnosed with breast cancer in 2011 alone, nearly 20,000 will survive treatments. With these improvements in cancer medicine and corresponding increase in the number of survivors, there is a need to understand the unique needs that exist post-treatment in order to inform primary health care providers who will facilitate the rehabilitative process experienced by women during the survivorship phase of breast cancer (Rowland & Bellizzi, 2008).

1.2 Focus on Survivorship

Over the past two decades, much of cancer care has focused on cancer screening, surveillance and caring for patients throughout the duration of cancer
treatments. However, the effects of cancer and its treatments in terms of health, functioning, and wellbeing has received significantly less recognition (Silver, 2007). The nature of many breast cancer treatments as well as cancer itself introduces a potential broad range of devastating immediate and long-term health effects for women which will impact primary health care needs (Hewitt, Greenfield, & Stovall, 2006).

During the primary treatment phase, women with breast cancer are cared for by a team of health care professionals that may include a general surgeon, medical oncologist, radiation oncologist, oncology nurse, physiotherapist, occupational therapist, dietician, plastic surgeon, as well as their primary care physician. However, upon completion of treatments, women are often left alone to navigate the lingering effects of cancer and its treatments and return to a sense of normalcy in their lives (McKinley, 2000). A first-hand patient account effectively frames this issue:

“After my very last radiation treatment for breast cancer, I lay on a cold steel table, hairless, half dressed and astonished by the tears streaming down my face. I thought I would feel happy about finally reaching the end of treatment, but instead I was sobbing. I think I cried because this body had so bravely made it through 18 months of surgery, chemotherapy and radiation. Ironically, I also cried because I would not be coming back to that familiar table where I had been comforted and encouraged. Instead of joyous, I felt lonely, abandoned, and terrified. This was the rocky beginning of cancer survivorship for me” (McKinley, 2000, p.479).
1.3 An Attitude Shift

The survivorship stage of cancer care is now receiving attention (Grunfeld, et al., 2006). Survivorship, defined as “the period following first diagnosis and treatment and before the development of a recurrence of cancer or death,” (Hewitt, et al., 2006) is recognized as an important stage of the cancer continuum. Recognizing survivorship signals an important change in attitude as research and clinical care move beyond the diagnosis and treatment of cancer for the consideration of broader healthcare needs. Additionally, focus on survivorship provides the opportunity to address rehabilitative needs through collaboration between a variety of health care professionals in order to optimize the long-term well-being of cancer survivors (Grunfeld, 2009).

A number of landmark initiatives to address the issues of cancer survivorship have taken place in the last few years. In 2006, the Institute of Medicine published a report entitled From Cancer Patient to Cancer Survivor: Lost in Transition, which contained several important recommendations in regard to the long-term health care needs of cancer survivors. Emphasis was placed upon the need for recognition of survivorship as a distinct phase of treatment, as well as the creation of survivorship care plans to ease the transition from specialty to primary care, and the development of clinical practice guidelines for survivorship care. Additionally, in 2008 the Canadian Partnership Against Cancer (CPAC), a federally funded organization that works to implement Canada’s Cancer Control Strategy, held the National Invitational Workshop: Towards an agenda for cancer survivorship, the first ever Canadian workshop to focus on the needs of cancer
survivors. Key recommendations from the workshop included establishing national standards and guidelines, identifying models of care to potentially assemble an interprofessional approach to cancer rehabilitation, developing and implementing survivorship care plans, promoting survivorship research, survivorship advocacy and awareness, and ensuring effective translation of novel research findings to overcome knowledge gaps between the research setting and clinical practice. Clearly, the findings from these survivorship initiatives confirm the need to ensure that sufficient research and clinical efforts are devoted towards the survivorship phase of the cancer trajectory.

1.4 The Primary Care Physician and Barriers to Optimal Care Delivery

As patients transition from active treatment to survivorship, the focus of care shifts from specialty to primary care. In the clinical setting, the primary care physician is the first line of contact to manage health care issues associated with post-treatment sequelae of breast cancer and its treatments (Grunfeld, 2008). As providers of comprehensive, long-term care with an intimate knowledge of the patient’s health and social context, primary care physicians are ideally placed to provide survivorship care (Brennan and Jefford, 2009). Moreover, the survivorship report published by the Institute of Medicine stipulates that the role of the primary care physician is to ensure that all of the physical and emotional health needs of the patient are addressed and to assume responsibility for aspects of care of the chronic disease (Hewitt, et al., 2006). Other research has shown that
follow-up care by a primary care physician leads to the same health outcomes in terms of diagnosing recurring cancer, health-related quality of life, and the number of recurrence-related serious clinical events as specialist follow-up with good patient satisfaction (Grunfeld, et al., 2006; Khatcheressian and Smith, 2006). Furthermore, a recently reported Canadian study found that primary care physicians were very willing to assume exclusive responsibility for the follow-up of survivors (Del Giudice, Grunfeld, & Harvey, 2009), and that other health care professionals such as oncologists and nurses generally believe that primary care physicians can and should have a major role in post-treatment follow-up (Brennan and Jefford, 2009).

However, despite the growing population of breast cancer survivors, primary care physicians are often not particularly familiar with the consequences of cancer treatments (Nissen, Beran, Lee, Mehta, Pine, & Swenson, 2007), seldom receive specific guidelines or information from oncologists (Kantsiper, McDonald, Geller, Shockney, Snyder, & Wolff, 2009) and therefore commonly feel ill-equipped to address the survivorship needs of their patients (Nissen, et al., 2007). Furthermore, the lack of clear survivorship standards of care, such as clinical practice guidelines, for what constitutes best practices in caring for patients with a history of cancer contributes to wide variation in care (Hewitt, et al., 2006). Additionally, cancer care is often poorly coordinated as it is delivered over extended periods of time, by multiple providers, and through multiple phases of illness, and patients pass through the care of different clinicians without any formal means of communication between professionals (Brennan and Jefford,
Finally, current knowledge translation strategies have shown limited success in their ability to help primary care physicians incorporate current research findings into their daily practice, such as clinical practice guidelines for the care of breast cancer survivors (Grunfeld, 2007; Latosinsky, Fradette, Lix, Hildebrand, & Turner, 2007).

1.5 Purpose

The purposes of this thesis were:

a) to synthesize the current literature that addresses the primary health care needs of post-treatment breast cancer patients in a scoping review, as well as

b) to summarize any clinical practice guidelines relevant to the primary care of post-treatment breast cancer patients, and

c) to determine if the perspectives of post-treatment breast cancer patients and primary care physicians are in concordance with the findings of the scoping review.

Chapter 2 of this thesis provides a comprehensive review of literature relating to survivorship care delivery and breast cancer treatments. The following chapters represent the two different sources of data used in this study. Chapter 3 describes the methodological framework and findings regarding the primary care needs of post-treatment breast cancer patients from the scoping review, while
Chapter 4 presents the methodology and findings from the interviews with post-treatment breast cancer patients and primary care physicians. Chapter 5 provides a comprehensive discussion of the results from the scoping review and interviews, including limitations of this study and future directions for research.
CHAPTER 2: BACKGROUND

2.1 Introduction

This chapter provides an overview of the major initiatives in the field of cancer survivorship in the United States and Canada over the last few years. Additionally, the role of primary care physicians in follow-up care of cancer survivors as well as barriers to optimal survivorship care delivery are discussed. Finally, this chapter provides an outline of the breast cancer treatments women may undergo upon diagnosis of breast cancer.

2.2 Major Cancer Survivorship Initiatives

With recognition of the growing cancer survivorship population and citing shortfalls in the current delivery of care provided to survivors, several landmark initiatives focused on cancer survivorship have been undertaken in the United States and Canada over the last several years. The following sections outline each initiative.

2.2.1 Institute of Medicine

In 2006, the American Institute of Medicine released a comprehensive report entitled From Cancer Patient to Cancer Survivor, Lost in Transition. This report defined and described survivorship to be a distinct phase of the cancer journey. Additionally, it provided recommendations for long term care after...
treatment for cancer with the aim of encouraging a comprehensive and
coordinated approach to care that meets the long term health needs of survivors.
The cited goals of the report included raising awareness of the medical,
functional, and psychosocial consequences of cancer and its treatment, defining
quality health care for cancer survivors and identifying strategies to achieve it,
and improving the quality of life of cancer survivors through policies which
ensure access to psychosocial services, fair employment practices, and health
insurance (Hewitt, et al., 2006). Additionally, the three key recommendations
outlined in the report were, as follows:

1. Health care providers, patient advocates, and other stakeholders should
   work to raise awareness of the needs of cancer survivors, establish cancer
   survivorship as a distinct phase of treatment, and act to ensure the delivery
   of appropriate survivorship care.

2. Patients completing primary treatment 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 other screening
   instruments to help identify and manage late effects of cancer and its
   treatment. Existing guidelines should be refined and new evidence-based
   guidelines should be developed (Hewitt, et al., 2006).
Elements of survivorship care

The four essential components of survivorship care are prevention, surveillance, intervention, and coordination (Brennan and Jefford, 2009). Preventative measures focus on decreasing recurrent and new cancers as well as managing the late effects of treatments. As a means of prevention, surveillance is conducted for cancer spread, recurrence, or second cancers, as well as the assessment of medical and psychosocial effects of treatments. Interventions are needed to manage the consequences of treatments, including medical and psychosocial issues of survivors, as well as psychosocial concerns of caregivers. Finally, coordination of care between specialty and primary care is essential to ensure that the survivor’s health needs are met (Hewitt, et al., 2006).

Recipients of survivorship care

With the evolution of attitudes recognizing survivorship care as a distinct phase of treatment, the definition of survivorship has also progressed. The Institute of Medicine (2006) now recognizes survivorship as a phase beginning after primary treatment which extends until recurrence, presence of a second cancer, or death. Additionally, individuals who experience recurrence or a second cancer may re-enter the acute treatment phase, and upon completion, again require survivorship care. The need for specific follow-up services will vary between individuals due to the heterogeneity of the survivorship population. Survivors of early-stage cancer whose treatment may have only included surgery may require limited follow-up care, while other women who undergo surgery, chemotherapy,
radiation and hormone therapies commonly need long-term follow up care and rehabilitation. Additionally, women who undergo prophylactic treatments resulting from a hereditary predisposition to breast cancer may also benefit from survivorship care to manage the complications of the prophylactic intervention (Hewitt, et al., 2006).

 Providers of survivorship care

Survivorship care may be provided by specialists and primary care physicians, nurses, psychologists and social workers, although upon completion of treatment and presumed cessation of specialty care, it is the responsibility of the primary care physician to provide and coordinate survivorship care (Brennan and Jefford, 2009; Grunfeld, et al., 2006; Khatcheressian and Smith, 2006).

 Providing a care plan for survivorship

While it is an integral step in the process of achieving optimal post-treatment cancer care, recognition of the importance of cancer survivorship is not enough (Hewitt, et al., 2006). Instead, a strategy is needed for the ongoing clinical care of cancer survivors. There are many interventions and prevention strategies that exist to ameliorate the complications of cancer and its treatments; however care for cancer survivors often becomes fragmented during the transition from specialty to primary care and opportunities to intervene are overlooked or neglected (Hewitt, et al., 2006). Patients will often complete treatments unaware of the potential medical risks facing them, and thus opportunities for follow-up
care of medical and psychosocial needs are missed (Rowland, Hewitt, & Ganz, 2006).

As soon as patients complete their primary treatment, they should be provided with an organized and comprehensive care summary and follow-up plan that is clearly and effectively explained (Hewitt, et al., 2006). This “survivorship care plan” should be written by the principle provider who coordinated the oncological treatment, and directed towards the primary care physician who will assume responsibility for follow-up care as well as certain recommendations for the patient (Hewitt, et al., 2006). The care plan would summarize the critical information needed for a survivor’s long term care, such as details of the cancer type, treatments received, their potential consequences, and recommendations for preventative practices. Additionally, specific information regarding the timing of follow-up care as well as the availability of psychosocial support services in the community should be included (Ganz, Casillas, & Hahn, 2008). The content of the care plan could be reviewed with the patient before they are formally discharged from specialty care, providing the opportunity for survivors to clarify any questions they may have. This may also prompt them to raise questions with their primary care physician later on, which would help facilitate appropriate care delivery and ensure follow-up recommendations are adhered to (Hewitt, et al., 2006).

At the time that the Institute of Medicine’s report was published there was little formal evaluation of the effectiveness of survivorship care plans, although it
was concluded that this type of tool intuitively made sense and could be reasonably assumed to improve care until contrary evidence accumulates. It was also recommended that further research should be done to determine the impact and costs associated with survivorship care plans, as well as evaluating their acceptance by clinicians and cancer survivors (Hewitt, et al., 2006).

**Clinical practice guidelines**

In order to help facilitate appropriate follow-up care through informing primary care physicians about complications of treatments as well as symptoms of and interventions for late effects of treatments, an organized set of clinical practice guidelines based on the available evidence is needed (Hewitt, et al., 2006). Some guidelines are available, although most cancer-related guidelines focus on detection, treatment, and surveillance, with little emphasis on survivorship care (Rowland, et al., 2006). It is also recommended that existing guidelines should be updated with new evidence at least every two to three years (Hewitt, et al., 2006). Additionally, successful implementation of information from clinical practice guidelines will require effective knowledge dissemination and translation strategies (Grunfeld, 2007).

### 2.2.2 Canadian Partnership Against Cancer

The Canadian Partnership Against Cancer is an independent federally funded organization that works with cancer specialists, charitable organizations,
governments, cancer agencies, national health organizations, patients, and survivors to implement Canada’s cancer control strategy (CPAC, 2011).

Recognition that survivorship is an important, yet under-developed and under-researched aspect of the cancer trajectory prompted the 2008 National Invitational Workshop: Towards an agenda for cancer survivorship, the first ever Canadian survivorship conference. The cited objective of the workshop was to develop a Canadian survivorship agenda and various stakeholders including interprofessional health care providers and cancer survivors were in attendance from Canada, the United States, and Australia. The key recommendations from the workshop were: establishing national standards and guidelines for survivorship care, identifying models of care, developing and implementing survivorship care plans, promoting survivorship research, increasing survivorship advocacy and awareness, and ensuring effective knowledge synthesis and translation (CPAC, 2008). Additionally, four survivorship pilot programs designed to help patients make the transition from active treatment to post-treatment care have been implemented as a result of the workshop. The following sections outline some of the workshop recommendations in more detail.

Establishing National Standards and Guidelines

Practice standards and guidelines are needed at a national level to support all phases of survivorship care, provide consistency in quality of care delivery and establish minimum levels of care. Such standards and guidelines would represent
a statement of consensus from a panel of experts, based on both evidence where data exists and the collective experience of experts (CPAC, 2008).

Identifying Models of Care

Models of care should be profiled that identify important elements and frameworks for cancer patients and different health professionals to work together to eliminate fragmentation of care and improve outcomes. Models may vary according to individual circumstances, such as resources available in rural and urban settings, or cultural issues. All stakeholders including survivors, health care professionals, researchers, agencies and government should be involved in the design, development and implementation of care models (CPAC, 2008).

Developing and Implementing Survivorship Care Plans

While the nature of care plans was debated, it was agreed that survivors need an initial tool that will summarize their important personal information, treatments, and medical and psychosocial resources available to enable them to feel empowered to continue managing their own care as well as facilitating easier transition between clinicians. Templates of survivorship care plans are being tested both in Canada and in the United States, such as the Pediatric Oncology Group of Ontario’s Passport to Health, and could be used as a base. Other details need to be outlined including formatting, responsibilities for completing care plans, as well as gathering research data to evaluate the effectiveness of care plans (CPAC, 2008).
Promoting Survivorship Research

Research into survivorship issues is still in its infancy and there are significant gaps that need to be addressed. Survivorship research will provide an evidence base which will legitimize survivorship issues, facilitate improved health and quality of care, and support economic decisions. An active and well-funded research agenda across disciplines could lead to organized follow-up care, improved quality of care and quality of life (CPAC, 2008).

Ensuring Effective Knowledge Translation and Synthesis

Creation of new knowledge does not always lead to implementation in practice. The need for novel knowledge translation strategies was recommended to disseminate knowledge into widespread practice in Canada. It was suggested that further action could involve implementing a knowledge translation training program and using innovative technological schemes to develop web-based systems where survivors, clinicians, and researchers can share information. Collaboration with other chronic disease groups who have already achieved success with such programs, including the Heart and Stroke Foundation and Canadian Diabetes Association, was also recommended.

2.3 The Role of the Primary Care Physician

With the rapidly expanding breast cancer survivorship population as a result of early detection and advances in cancer medicine, the recent shift in
attention to the value of survivorship care, as well as the demanding nature of oncology practices, primary care physicians are becoming increasingly involved in the care of breast cancer survivors (Brennan, Butow, Spillane, & Boyle, 2008; Grunfeld, 2009; Miedema, MacDonald, & Tatemichi, 2003).

Survivorship now refers to life following the diagnosis and treatment of breast cancer, extending until recurrence or death. Thus, becoming a cancer survivor means adjusting to a new sense of ‘normal’ and adapting to the long term effects of cancer and its treatment, while maximizing health and wellbeing (Brennan, et al., 2008). To address these issues, clinicians are recognizing the need to do more than monitor for recurrence, including devoting attention to other areas such as psychosocial care and the management of long term effects of cancer and its treatment (Brennan, et al., 2008).

Primary care physicians are highly experienced and skilled in providing continuity of care for chronic conditions in a holistic manner. They develop long-term relationships with their patients and have an intimate understanding of the context of the cancer diagnosis in the patient’s life. Thus, they are ideally placed to provide survivorship care to post-treatment breast cancer patients (Brennan, et al., 2008; Brennan and Jefford, 2009; Del Giudice, Bondy, Chen & Maaten, 2006; Stuart, Brennan, French, Houssami, & Boyages, 2006). Moreover, attending to the psychosocial needs of breast cancer survivors is critically important (Murie & Wall, 2006; Oktay, 1998), and busy oncology practices are not the ideal setting for the treatment of symptoms including anxiety, depression, menopausal
symptoms, sexual dysfunction, and infertility (Ganz et al., 2008), whereas the nature of primary care allows physicians the capacity to manage these patient concerns on a regular basis (Oktay, 1998).

There is good evidence that primary care physicians are capable of detecting recurrent cancer and providing follow-up care with a high level of patient satisfaction (Brennan, et al., 2008; Khatcheressian and Smith, 2006). The literature shows that breast cancer survivors are more satisfied by follow-up from a primary care physician, and see follow-up with a primary care physician as an acceptable alternative to specialist follow-up (Grunfeld, Fitzpatrick, et al., 1999).

Additionally, there is a solid body of evidence which suggests that breast cancer survivors cared for by their primary care physician following treatments have the same outcomes in terms of survival and quality of life as those cared for by specialists (Khatcheressian and Smith, 2006; Rojas, Telaro, Moschetti, Coe, Fossati, Palli, 2009). A randomized controlled trial in England involving two-hundred and ninety-six women comparing follow-up care between primary care physicians and specialists showed that there was no difference in breast cancer recurrence or anxiety levels (Grunfeld, et al., 1996). Women participating in the trial reported greater satisfaction with primary care physicians in all areas assessed including service delivery, the consultation itself, and continuity of care. They felt that primary care physicians were more likely to explain things, they felt comfortable talking to the primary care physicians about problems of a psychosocial nature, and they felt less rushed when compared with women with
specialist follow-up (Grunfeld, et al., 1996). In a subsequent study conducted in England, it was demonstrated that follow-up by a primary care physician also incurs less cost to the patient and the health care system than hospital based follow-up (Grunfeld, Gray, Mant, & Yudkin, 1999). This finding was the result of lost wages during long hospital visits, as well as the higher cost of specialist outpatient care when compared to primary care. Additionally, follow-up by a primary care physician is deemed to be much more generally accessible to patients than specialist care (Brennan and Jefford, 2009). Furthermore, a landmark Canadian study with similar methodology involving nine-hundred and sixty-eight women also showed no difference in recurrence, serious clinical events, health-related quality of life, or death between the two groups (Grunfeld, et al., 2006).

There is also evidence to suggest that other health care professionals such as oncologists and nurses generally believe that primary care physicians should have a major role in post-treatment care (Brennan, et al., 2008). A recently reported Canadian study found that primary care physicians were very willing to assume exclusive responsibility for the follow-up of survivors (Del Giudice, et al., 2009), although other work suggests that primary care physicians feel comfortable in assuming responsibility for post-treatment breast cancer patients provided that ongoing training or tools such as a written survivorship care plan and a way to stay connected to the oncologist were available (Kantsiper, et al., 2009).

The Institute of Medicine stipulates that the role of the primary care provider is to ensure that all of the physical and emotional health needs of the patient are addressed and to assume responsibility for aspects of care of the patient.
chronic disease (Hewitt, et al., 2006). Thus, there remains a considerable research agenda which may be devoted to findings ways to harmonize the involvement of specialists and primary care physicians in the care of breast cancer survivors in order to meet the long-term health needs of these patients (Allgar & Neal, 2005).

2.4 Barriers to Optimal Survivorship Care Delivery

There are several significant obstacles to the delivery of optimal survivorship care to cancer survivors. Notably, the fragmentation of care between specialty and primary care as a result of the lack of designated responsibility and ineffective communication between care providers (Hewitt, et al., 2006; Mao, et al., 2009). Overcoming these barriers would require a health care system with improved integration between specialty and primary care. Making use of novel information technology systems would likely ameliorate some communication issues and it has been shown in European models of shared care for cancer survivors that the use of web-based systems have promising implications for coordination of care (Hewitt, et al., 2006). However, until such innovations are implemented universally, the burden of managing the fragmentation of patient care remains with primary care physicians and oncologists. Current tools include office reminder systems, standing orders for certain surveillance tests, and standardized letters for primary care physicians (Hewitt, et al., 2006), although there is a substantial body of literature which suggests the use of formalized survivorship care plans as a means of communicating between specialists and
primary care physicians may improve the fragmentation of care for cancer survivors (Ganz and Hahn, 2008; Kantsiper, et al., 2009).

Another obstacle faced by primary care physicians which may prevent optimal care delivery to breast cancer survivors is a lack of education and training regarding the primary care interventions necessary to address the consequences of cancer and its treatments (Hewitt, et al., 2006), an issue which is exacerbated by the lack of survivorship standards of care such as clinical practice guidelines and survivorship care plans (Hewitt, et al., 2006; Hollowell, et al., 2010). In a large investigation of the views of primary care providers on the follow-up care of cancer patients, it was reported that many primary care physicians lacked the necessary information to enable them to feel confident regarding survivorship care (Nissen, et al., 2007). Other work suggests that primary care physicians do feel comfortable assuming responsibility for breast cancer survivors, assuming that they have access to information from the oncologist and ongoing training or tools such as clinical practice guidelines or formalized survivorship care plans (Hollowell, et al., 2010; Kantsiper, et al., 2009).

Providing a breast cancer treatment summary in a formalized survivorship care plan is being recognized as a key component of improving the coordination of care between oncologists and primary care physicians (Ganz, et al., 2008; Miller, 2008). It involves compiling an account of a patient’s course of treatment in conjunction with recommendations for subsequent cancer surveillance, management of late effects of treatments, and strategies for health promotion, and
has been presented as an important solution to improve the delivery of high quality care to cancer survivors (Brennan, Butow, Spillane, & Boyle, 2010; Hewitt, et al., 2006). The use of survivorship care plans was a key recommendation in both the Institute of Medicine’s report *From Cancer Patient to Cancer Survivor: Lost in Transition* as well as by the Canadian Partnership Against Cancer’s *National Invitational Workshop: Towards an agenda for cancer survivorship* as a means of overcoming obstacles in the delivery of optimal cancer care. Additionally, the survivorship care plan can also empower the breast cancer survivor and primary care physician to take charge of future care, with consultation back to the oncologist as necessary (Ganz, et al., 2008). A challenge in providing this type of summary is how to assemble the necessary information which is often incomplete and scattered amongst multiple health care settings (Masood, 2008). However, the growing body of evidence which supports the use of these care plans has stimulated research into the effectiveness of certain models and thus it is likely that effective protocols will emerge in the near future (Ganz, et al., 2008).

Finally, a nagging obstacle is the reality that existing clinical practice guidelines are not always being incorporated into clinical practice (Graham, et al., 2006; Grunfeld, 2007; Latosinsky, et al., 2007). Thus, it is critical that further research into novel knowledge translation initiatives be undertaken to help reduce the gap between research and practice.
2.5 Breast Cancer and Its Treatments

Breast cancer is the most common cause of cancer amongst Canadian women and primary care providers are vital in preserving the overall physical and emotional health and well-being of breast cancer patients as they recover from treatments (Masood, 2008). They must also provide patients with updated information to help them make informed decisions. However, the diversity of breast cancer types and subsequent therapeutic regimens make the treatment of breast cancer a complex process (Holcomb, 2006). The range of individualized therapies has generated a heterogeneous population of cancer survivors with different health care needs that primary care physicians need to be aware of (Holcomb, 2006). In order to recognize primary care needs of post-treatment breast cancer patients, it is important to understand the variety of surgical, radiation, and chemotherapeutic and hormonal interventions used to treat breast cancer. The following section outlines different types of breast cancer and standard respective courses of treatment.

2.5.1 Types of breast cancer

The two types of breast tissues primarily affected by breast cancer are ductal and lobular cells (American Cancer Society [ACS] 2006). Ductal cancers are the most common and comprise approximately 90% of breast cancers. Invasive ductal cancer is the most common subtype of ductal cancer, and comprises approximately 70% to 80% of all diagnoses. Lobular breast cancer
encompasses less than 10% of breast cancer diagnoses and rarely occurs alone. Traditionally it has a stronger response to hormones and is often found in younger premenopausal women (ACS, 2006).

Many breast cancers respond to stimulation by the reproductive hormones estrogen and progesterone. Breast cancers can be estrogen receptor-positive or negative as well as progesterone receptor-positive or negative. While most breast cancers are sensitive to hormones, some cancers do not respond to hormones and these types of breast cancers tend to be more aggressive (Holcomb, 2006).

Approximately 30% of breast cancers display oncogenic amplification of the human epidermal growth factor receptor 2 (HER2) gene or overexpression of its transmembrane receptor protein product. These breast cancers are referred to as HER2-positive, and grow more aggressively than other HER2-negative cancers (Holcomb, 2006).

Between 5% and 10% of breast cancers are considered hereditary and contain certain genetic mutations, specifically in the BRCA1 or BRCA2 genes. Women with mutations in these genes are at a substantially increased risk of developing breast and ovarian cancers, approximately 60% to 80%. Thus, women with strong family histories of breast cancer often undergo genetic counselling for the purpose of undergoing prophylactic treatment such as preventative chemotherapy and mastectomy or oophorectomy to minimize their risk of developing one of these cancers (Holcomb, 2006).
2.5.2 Stages of breast cancer

Breast cancer is staged numerically on a scale of 0-IV according to several characteristics, including the size of the cancer, whether cancer is in the lymph nodes, and whether the cancer has metastasized to other parts of the body. Stage 0 describes non-invasive breast cancers, such as ductal carcinoma in situ, where there is no evidence of abnormal cells which have invaded surrounding tissue. Stage I refers to invasive cancer cells in which the tumour measures up to two centimetres in diameter and there is no lymph node involvement. Stage II is divided into two subcategories, IIA and IIB. Stage IIA refers to invasive cancer in which no tumour can be found in the breast, but cancer cells are found in the axillary lymph nodes, or the tumour measures two centimetres or less and has spread to the axillary lymph nodes, or the tumour is greater than two centimetres but less than five centimetres, and has not spread to the axillary lymph nodes. Stage IIB describes invasive cancer where the tumour is greater than two centimetres but less than five centimetres and has spread to the axillary lymph nodes, or the tumour is larger than five centimetres but has not spread to the axillary lymph nodes. Stage III breast cancer is divided into subcategories IIIA, IIB, and IIC. Stage IIIA refers to invasive cancer in which either no tumour is found, but cancer is found in axillary lymph nodes, or cancer may have spread to lymph nodes near the breastbone, or the cancer is any size and has spread to axillary lymph nodes. Stage IIIB describes invasive cancer in which the cancer may be any size and has spread to the chest wall or skin of the breast and may have spread to axillary lymph nodes or lymph nodes near the breast bone. Stage
IIC refers to invasive cancer where there may be no sign of cancer in the breast, or if there is a tumour, it may be any size and may have spread to the chest wall or the skin of the breast and the cancer has spread to axillary lymph nodes, lymph nodes near the breast bone, or lymph nodes above or below the collarbone. Stage IV describes invasive cancer that has spread beyond the breast and nearby lymph nodes to other organs of the body, such as the lungs, distant lymph nodes, skin, bones, liver, or brain. Corresponding treatment regimens will depend on the type of cancer, the stage of cancer, whether or not the cancer is sensitive to hormones, and the HER2 status (Holcomb, 2006).

2.5.3 Surgical treatment of breast cancer

Surgical treatment options include lumpectomy, unilateral mastectomy, or bilateral mastectomy, and potential reconstruction. Additionally, a sentinel lymph node biopsy to determine possible spread to the lymph nodes will be conducted at the time of surgery. Depending on the degree of metastasis, an axillary lymph node dissection whereby ten to twenty lymph nodes are removed from the affected side may be undertaken (Strozza, 1998).

In the majority of cases, women have options in terms of choosing a type of surgery. The most common option is the breast conserving treatment known as lumpectomy in which the tumour and surrounding tissues are excised. Criteria have been established that exclude a woman from breast conserving surgery and automatically make her a candidate for mastectomy. Such criteria include diffuse
microcalcifications, gross multifocal disease, masses greater than five centimetres in diameter, or previous radiation to the area (Apantaku, 2002; Holcomb, 2006). If mastectomy is chosen as the treatment either by patient preference or characteristics of the cancer, discussion of reconstruction should also take place. Often during mastectomy skin sparing procedures are performed to aid in reconstruction if the patient desires (Holcomb, 2006; Strozzo, 1998).

Reconstructive processes may sometimes be initiated by the plastic surgeon at the same time as the mastectomy, although this requires efficient coordination of care between facilities and thus may not always be an option. Also, depending on the type of reconstruction it may be necessary to wait until radiation therapy has been completed as it can cause damage to the edges of the breast tissue and making the reconstructive process more difficult. Typical reconstructive procedures include the transverse rectus abdominis musculocutaneous flap, latissimus dorsi flap, and the submuscular implant (Holcomb, 2006; Rowland, Desmond, Meyerowitz, Belin, Wyatt, & Ganz, 2000).

Sentinel lymph node biopsy is performed by marking the first three to four nodes which drain the affected breast through the use of nuclear medicine and observing them for uptake of isotope. If the sentinel nodes appear cancer free through the pathology report during surgery then additional lymph node removal is usually avoided. Removal of many lymph nodes increases the patient’s risk of developing lymphedema and thus is avoided where possible (Apantaku, 2002; Cheville, 2010).
2.5.4 Chemotherapy

Following surgery, additional therapies may be initiated depending on the stage of the cancer. Clinical trials have demonstrated that chemotherapy and radiation therapy substantially reduce the risk of cancer recurrence and mortality (Shapiro and Recht, 2001). If the patient is to receive both chemotherapy and radiation therapy, there is no decisive rule as to which treatment should be given first, and sometimes they may be given concurrently. Chemotherapy is generally recommended for patients with positive lymph nodes, evidence of metastatic disease, and for tumour sizes greater than one centimetre in diameter (Abramowicz, 2005). There are numerous chemotherapy courses available for breast cancer, although a standard regimen includes four to six cycles which typically occur every two to three weeks, depending on the relative depletion of the immune system as measured by white blood cell counts (Abramowicz, 2005). Novel therapies have been implemented which stimulate immune function, allowing more frequent chemotherapy cycles. However, these are typically costly, and without extended health insurance may be inaccessible (Abramowicz, 2005).

2.5.5 Radiation therapy

Radiation therapy begins following surgery and possibly chemotherapy. If radiation therapy is to occur before chemotherapy, it usually begins in a shorter time frame following a lumpectomy and longer time frame following mastectomy (Abramowicz, 2005). The longer wait time following mastectomy allows the skin
to heal as radiation therapy can be damaging to the skin, including delaying healing of incision cites and thus causing the patients to be more susceptible to infection (Abramowicz, 2005). Generally, full breast radiation is still the standard regimen with special attention localized to the tumour area (Holcomb, 2006). The effectiveness of partial breast radiation is under study but is not recommended at this time (Holcomb, 2006). Radiation therapy has proven to increase survival rates in women with more advanced or aggressive cancers under circumstances where there are four or more positive nodes, when the tumour has invaded the chest wall, if the tumour was greater than five centimetres in diameter and when negative surgical margins could not be obtained (Abramowicz, 2005; Holcomb, 2006).

2.5.6 Adjuvant therapies for hormone sensitive and HER2-positive breast cancers

Treatment recommendations are also based on the hormone and HER2 status of the cancer and menopausal status of the woman. Premenopausal women with estrogen receptor-positive cancers might consider undergoing a prophylactic bilateral oophorectomy as part of their treatment as these cancers in younger women are more likely to be associated with BRCA mutations (Holcomb, 2006).

Additionally, for postmenopausal women with tumours that are hormone receptor-positive, which includes about 70% of patients, the use of endocrine therapies have been found to reduce recurrence rates by nearly 50% and death
rates by more than 25% (Mrozek and Shapiro, 2005). There are two standards of pharmacological therapies which are often used when patient’s have hormone receptor-positive cancers: aromatase inhibitors and tamoxifen therapy (Mrozek and Shapiro, 2005). Aromatase inhibitors work by inhibiting aromatase, the enzyme responsible for estrogen production, thereby reducing the amount of circulating estrogen in the body with the goal of preventing any remaining tumour cells from being stimulated. Tamoxifen therapy has a similar goal, but functions by competitively inhibiting the estrogen receptor on cells so that estrogen may not bind to and stimulate the receptor. The course of these therapies is typically five years after completion of surgery, chemotherapy and radiation (Mrozek and Shapiro, 2005). When women have cancers that are HER2-positive, they are notoriously more aggressive (Holcomb, 2006). The gold standard of treatment for these patients includes the use of the drug trastuzumab, commercially known as Herceptin. Trastuzumab’s mechanism of action is similar to that of tamoxifen as it competitively inhibits the HER2 receptor, blocking the human epidermal growth factor from binding and stimulating the cell, significantly increasing the survival rate of women with this type of cancer. Typically, a course of treatment extends for one year (Abramowicz, 2005; Holcomb, 2006).

For the purpose of this thesis, the term “post-treatment breast cancer patient” implies a woman who has completed primary surgical excision of the cancer, sentinel node biopsy or axillary node dissection, chemotherapy, and radiation therapy. However, she may still be undergoing reconstructive processes and adjuvant hormone or trastuzumab therapy.
CHAPTER 3: THE SCOPING REVIEW

This chapter provides explanation for why this type of literature review is ideally suited for this investigation and describes the methodology behind the scoping review. Additionally, the findings from the scoping review are presented.
3.1 Methodology: A Scoping Review on the Primary Health Care Needs and Current Guidelines for Women Following Breast Cancer Treatment

3.1.1 Purpose

The summary in Chapter 2 highlights the issue of cancer survivorship, the role of the family physician in managing survivorship issues, and the barriers faced by family physicians in providing optimal follow-up care for their patients. It also emphasizes the toxicities of breast cancer treatments which give rise to the sequelae of short and long term side effects experienced by many women. Given the magnitude these issues, the purpose of this study was to perform a scoping review to:

a) synthesize an understanding from the current literature of the primary health care needs of post-treatment breast cancer patients following breast cancer treatments, as well as

b) identify any clinical practice guidelines targeted towards primary care to aid family physicians in providing optimal care to post-treatment breast cancer patients.

3.1.2 Background

With the steady shift towards evidence-based practice, there is an increasing volume of literature reviews reporting on the effectiveness of certain interventions and procedures. In particular, the scoping review is a useful strategy
which aims to rapidly map the key concepts supporting a research area (Arksey and O'Malley, 2005), and can be undertaken as a distinct project, especially if the area of interest is complex or has not been previously reviewed in a comprehensive manner (Mays, Roberts, & Popay, 2001).

In contrast with systematic reviews which are typically governed under a highly-focused research question that facilitates the return of studies with particular designs, scoping reviews tend to address broader topics and are guided by a requirement to identify all relevant literature regardless of study design (Arksey and O'Malley, 2005).

Additionally, a systematic review aims to present literature from a relatively narrow range of quality controlled studies, while a scoping review operates under a broader inquiry which consequently does not provide assessment of the quality of included studies (Arksey and O'Malley, 2005).

While the characteristics of a scoping review demonstrate the importance of covering the breadth of the literature in a comprehensive fashion, there may be varying degrees in the depth of coverage depending on the original purpose of the review, particularly in the amount of information extracted from each study.

Accordingly, scoping reviews provide a useful mechanism for several objectives, including examining the extent, range and nature of research activity in a particular area, determining the value of undertaking a full systematic review through mapping the literature, identifying existing gaps in the literature (Arksey and O'Malley, 2005), as well as summarizing and disseminating research findings.
to practitioners who might otherwise lack the time or resources to undertake such work themselves (Antman, Kupeinick, Mosteller, & Chalmers, 1992). Therefore, the scoping review is an appropriate tool to address the barriers which impede the ability of family physicians to meet the survivorship needs of breast cancer survivors, as it facilitates investigation into the substance and extent of research in this field, identifies gaps in the literature, and ultimately may be used to address knowledge translation issues.

**3.1.3 Methodology**

The protocol for this scoping review follows the methodological framework presented by Arksey and O’Mally (2005) and comprises five stages:

1) Identify the research question

2) Identify all relevant studies

3) Select studies for analysis

4) Organize Findings

5) Summarize Findings

This protocol stipulates that the process be documented in sufficient detail to enable replication of the study by other researchers, thereby increasing the reliability of the findings and ensuring methodological rigour (Arksey and
O’Mally, 2005; Mays et. al., 2001). As such, the following section outlines the steps taken during each stage of the review.

1) Identifying the research questions

This review was guided by the following research questions:

- What are the primary health care needs of post-treatment breast cancer patients following treatment for breast cancer?
- What are the current clinical practice guidelines in primary care that family physicians need to know in order to provide optimal, evidence-based care to post-treatment breast cancer patients?

2) Sources used to identify relevant studies:

- Electronic search of databases Medline, EMBASE, Cochrane Collection, Pubmed, CINAHL, and HealthStar
- Hand searching of journals: Canadian Family Physician and Canadian Medical Association Journal
- Hand searching of grey literature through online databases of the National Guideline Clearinghouse, Canadian Medical Association, Cancer Care Ontario, Canadian Cancer Society, Canadian Breast Cancer Foundation, Canadian Partnership Against Cancer, National Comprehensive Cancer Network and the Institute for Clinical and Evaluative Sciences
- Hand searching of reference lists of key articles
Cited reference searching of ‘key articles’ to identify other potentially relevant articles which may have cited the ‘key articles’ as references.

Sets of systematically combined keywords were used to identify relevant studies. They are:

1. Breast neoplasms
2. Aftercare; continuity of patient care; primary health care; primary care physician; family practice; family physician; general practice
3. Practice guidelines

It should be noted that the original sets of keywords were:

1. Post-treatment breast cancer; breast cancer; cancer care; cancer rehabilitation; breast cancer survivor; cancer survivorship; health care needs; lumpectomy; mastectomy; breast reconstruction; chemotherapy; axial lymph node dissection; lymphedema; radiation therapy
2. Primary care; primary health care; family physician; medical care; family practice; care gaps; health promotion; disease prevention; long term care; quality of care
3. Practice guidelines

However, search results with this selection of keywords continuously retrieved large numbers of irrelevant studies. Through an iterative process of indexing key articles and examining the nature of the retrieval, it was noted that the original search terms which included terms for breast cancer treatments were returning literature related to current and novel therapies, as opposed to the side effects of
therapies experienced by patients that would be addressed in the primary care setting. Thus, after removal of such terms and revision of the list through indexing key articles, a more reasonable retrieval was obtained. Employment of all of the various search mechanisms generated a retrieval of 2470 articles.

3) Selecting studies for analysis

While initial exclusion criteria are set, it is acknowledged that the process of study selection in a scoping review is iterative, and as familiarity with the literature increases, researchers will likely choose to redefine search terms (Arksey and O’Mally, 2005). Therefore, initially there are often not strict limitations on search terms, identification of relevant studies, and study selection (Arksey and O’Mally, 2005).

Accordingly, initial exclusion consisted of removing those articles which were duplicates, not written in English, or published before the year 2000, which allowed for the elimination of 1351 articles. As familiarity with the literature increased, more sensitive exclusion criteria were developed. The remaining 1124 studies were screened based on their abstracts, and excluded if they pertained to cancer prevention, screening, incidence or prevalence, breast health, and genetics, as these topics were outside the scope of the main research questions. Additionally, if the relevance of the study was unclear from the abstract, the full article was obtained. After applying these exclusion criteria to each citation, 248 articles were reviewed in full. Of the 248 articles examined in full, 176 were excluded because they did not pertain to practice guidelines or interventions to
address the primary health care needs of women following breast cancer treatment. The remaining 72 articles were selected for inclusion and reviewed.

4) Organizing findings

Research findings were grouped according to key concepts through use of the “Smart Groups” feature on EndNote® reference software. The key findings were concentrated in the following groups which are listed in descending order with those groups containing the broadest body of evidence at the top:

- Surgical Complications
- Lymphedema
- Gynecologic and Reproductive Implications
- Psychosocial Issues
- Additional Primary Cancers
- Cardiovascular Implications
- Osteoporosis
- Lifestyle Changes
- Fatigue
- Cognitive Dysfunction
- Pregnancy
- Clinical Practice Guidelines

Additionally, this protocol recommends the ‘charting’ of key items. This concept provides a technique for synthesizing and interpreting qualitative data by sorting the material in a narrative way, facilitating the data extraction process for
the researcher as well as other potential stakeholders who may refer to the review in the future (Arksey and O’Mally, 2005). The information obtained in this review is charted according to author, aim of the study, methodology and level of evidence, and key findings, and may be found in Appendix A.

3.2 Summary of Findings

The following section describes the research findings under the headings of the eleven categories identified above, as well as summarizes the clinical practice guidelines for managing the primary care needs of women following breast cancer treatment.

3.2.1 Surgical Complications

Initial treatment for breast cancer patients often involves a localized surgical excision of the malignant cells known as lumpectomy or complete dissection of the breast referred to as mastectomy (Silver, 2007). Women will also undergo a sentinel lymph node biopsy to determine the presence of local metastases and possible axillary lymph node dissection if metastases are present. Finally, if a mastectomy has taken place, women may opt for breast reconstructive surgeries (Silver, 2007).

Secondary complications to surgical interventions experienced by post-treatment breast cancer patients are vast. As with any surgery, the risk of post-
operative infection is of prime concern, and given the number of possible surgeries faced by breast cancer patients including the initial excision as well as potential lymph node dissection and reconstruction, this risk is even greater (Silver, 2007). Furthermore, other treatments such as chemotherapy and radiation therapy may slow healing after surgery and consequently prolong the susceptibility to infection and potential cellulitis (Silver, 2007). Patients should immediately seek the care of a physician if symptoms of infection become present (Apantaku, 2002).

Persistent symptoms following a lumpectomy or mastectomy to treat early-stage breast cancer can include pain and numbness of the chest wall or axilla, tightness, pulling or stretching in the arm or axilla, and fatigue. Persistent pain may be the result of scar formation or fibrosis and symptoms can endure from months to years and result in restriction of arm movement and functionality. Physiotherapy has been shown to be an effective intervention to manage some of these side effects of surgery (Chalasani, Downey, & Stopeck, 2010; Silver, 2007). Major complications of axillary node dissection include lymphedema (see section 3.2.3) and upper extremity morbidities such as chronic pain and loss of strength (Rietman, Geertzen, & Hoekstra, 2006) as well as potential nerve damage. Injury to the long thoracic nerve may denervate the serratus anterior muscle causing a winged scapula, and intercostal brachial nerve damage may cause loss of medial sensation in the upper arm (Apantaku, 2002). These symptoms can occur from two weeks to twelve months after surgery and usually the patient needs reassurance from the primary care physician that they will likely resolve with time.
(Strozzo, 1998). Seromas, excess accumulations of serous fluid, tend to develop with an incidence of 25%-50% after mastectomy and up to 25% after axillary lymph node dissection, and require frequent visits to a physician to have excess fluid drained (Chilson, Chan, & Lonser, 1992).

Finally, psychosocial issues associated with mastectomy and reconstructive procedures have a substantial impact on the emotional well-being and quality of life of these women (Korstjens, Mesters, Gijsen, & Den, 2008). Earlier research has suggested that breast conserving surgery or reconstruction might help mitigate some of the negative effects on a women’s body image and sexual wellbeing (Moyer, 1997), however, recent literature has demonstrated that women undergoing breast reconstruction may experience more distress and sense of disfigurement than previously reported (Rowland, et al., 2000). This may reflect the possibility that a subset of these women likely hoped for lumpectomy but were deemed poor candidates for a breast-conserving approach to their cancer. Additionally, some women have felt that reconstructive procedures did not restore their physical appearance as they had hoped that it would. The psychosocial impact related to surgical procedures for breast cancer are significant and occur largely in areas of body image and feelings of attractiveness, with women receiving lumpectomy experiencing the most positive outcome (Rowland, et al., 2000). Primary care physicians can play a critical role in helping these women cope with the effects of treatments as the nature of practice places family doctors in a unique position to understand the values and concerns of the patient (Strozzo, 1998). Primary care physicians should offer counsel to their patients, as well as
utilize available resources such as a psychologist or social worker when necessary. Additionally, primary care physicians should be aware of the various support groups and networks that exist in the community which may benefit these women as they struggle to manage the psychosocial stresses associated with breast cancer surgeries (Hewitt, et al., 2006; Strozzo, 1998).

3.2.2 Lymphedema

Lymphedema is a relatively common and very serious side effect of surgery and radiation therapy in breast cancer. Axillary lymph node dissection and radiation treatment can disrupt the flow of fluid within the lymphatic system. With impeded drainage, long-term inflammatory changes are observed as excess lymphatic fluid can accumulate in the subcutaneous tissue of the arm, shoulder, and breast area.

Lymphedema often occurs in women who have had lymph nodes removed to determine the extent of cancer spread or to contain cancer. Until the late 1990’s, most women underwent complete axillary lymph node dissection which meant removal of some or all of the lymph nodes around the axilla on the side of the affected breast. In 1994, the sentinel lymph node biopsy procedure was implemented in an effort to decrease the morbidity associated with complete lymph node dissection while still facilitating the diagnostic process of determining the extent of cancer metastases (Posther, Wilke, & Giuliano, 2004). It is estimated that sentinel lymph node biopsy could save 70% of women who
undergo breast cancer treatments from the morbidity associated with complete axillary node dissection. Notably, in a recently published randomized clinical trial, researchers determined that when comparing patients with metastatic breast cancer who were treated with sentinel lymph node biopsy versus axillary lymph node dissection, the use of sentinel lymph node biopsy alone did not result in inferior survival rates (Giuliano, Hunt, Ballman, Beitsch, Whitworth & Blumencranz, 2011), thus potentially shedding light onto the future protocols of breast cancer surgery with the hope of ameliorating the debilitating side effect of lymphedema.

Currently, evidence suggests that between 12-25% of women develop arm edema after breast cancer treatment with varying onset (Chalasani, et al., 2010). For most women it develops within one year of treatment but it may occur up to four years or more following treatment (Badger, Preston, Seers, & Mortimer, 2004). The risk appears to vary with the extent of surgery and radiotherapy involved in the treatment plan, however the impact of combinations of these treatments is not well understood and further research is needed to clarify risk measures (Hewitt, et al., 2006). Currently there are no precise estimates to identify women at greater risk of developing lymphedema (Erickson, Pearson, Ganz, Adams, & Kahn, 2001; Sparaco and Fentiman, 2002). However, apparent risk factors include mastectomy, comprehensive axillary lymph node dissection, radiation therapy, infection, obesity, and older age (Harmer, 2009; Soran, D'Angelo, & Begovic, 2006; Tsai, Dennis, Lynch, Snetselaar, Zamba, & Scott-Cooner, 2009).
Patients with lymphedema may experience significant arm pain, numbness, limited arm function and are susceptible to an increased risk of infection (Chalasani, et al., 2010; Erickson, et al., 2001; Harmer, 2009; Sparaco and Fentiman, 2002). Moreover, patients are faced with the burden of the social stigma associated with arm disfigurement, and accomplishing daily activities involving lifting, gripping, and holding may become difficult, leading to additional emotional distress and diminished quality of life (Fleysher, 2010; Fu, Axelrod, & Haber, 2008).

For primary care providers, emphasis is placed on prevention of lymphedema as treatments are seldom curative (Chalasani, et al., 2010; Fleysher, 2010). Nelson, O’Brien, Ashikaga and Bosompra (2000) suggest that equipping patients with knowledge about lymphedema pathophysiology and the necessary efforts to prevent its onset is crucial to all breast cancer survivors and it makes a positive difference in the overall quality of life. Patients should be educated to avoid trauma to the arm, including vaccinations, blood pressure monitoring, IV administration, constricting sleeves or jewellery, extreme heat, maintain excellent skin and nail care and treat infections or injuries promptly (Chalasani, et al., 2010; Fleysher, 2010; Harmer, 2009; Hurria, Wong, Villaluna, Bhatia, Chung, Mortimer, 2008; Quirion, 2010). Patients should also receive counselling regarding diet and weight management as obesity has been associated with greater lymphedema-related morbidity (Cheifetz, Haley, & Breast Cancer Action, 2010; Soran, et al., 2006). Evidence around exercise is inconclusive although current general recommendations are to avoid strenuous exertion for the susceptible arm
(Chalasani, et al., 2010; McCarthy, 2004). Appropriate exercises include light weight-lifting, walking, swimming, light aerobics, bike-riding, yoga, and pilates (Fleysher, 2010). Notably, an international following of breast cancer survivors have become involved with the sport of dragon-boating. While conclusive evidence is lacking to generate concrete recommendations, the population of breast cancer survivors who partake in this sport continues to grow and personal testaments to the effectiveness of both preventing and managing lymphedema have been very positive (Kent, 2002). Psychosocial concerns of affected individuals should also be monitored regularly by the primary care physician (Mrozek and Shapiro, 2005).

Few well-designed randomized trials exist which test the range of therapies available to manage the occurrence of lymphedema (Badger, et al., 2004). Manual lymphatic drainage through massage and exercise, use of elastic compression garments, and a technique called complex decongestive therapy performed by specialized physiotherapists seem to be effective treatments for lymphedema (Chalasani, et al., 2010; Cheifetz, et al., 2010; Cheville, 2010; Kligman, Wong, Johnston, & Laetsch, 2004; Mrozek and Shapiro, 2005; Quirion, 2010; Torres Lacomba, Yuste Sanchez, Zapico Goni, Prieto Merino, Cerezo Tellez, & Minayo Mogollon, 2010). Additionally, pharmacological interventions such as anticoagulants and diuretics have not been shown to be effective in treating lymphedema (Chalasani, et al., 2010; Loprinzi, 2004; McCarthy, 2004), however certain medications may help alleviate discomfort, infection, or other side effects associated with lymphedema (Erickson, et al., 2001).
3.2.3 Gynecologic and Reproductive Implications

While adjuvant chemotherapy improves prognosis and long term survival in women with breast cancer, there are associated effects on the reproductive system and consequently sexual function. Chemotherapy, prophylactic ovarian removal for women at high risk for hereditary cancer, and women taking aromatase inhibitors to diminish estrogen production are likely to develop premature ovarian failure and consequent amenorrhea. The incidence of premature ovarian failure after common chemotherapies varies depending upon the therapeutic agents used, dosages, and the patients’ age (Burstein and Winer, 2000). More than 70% of women over the age of forty who receive the common chemotherapy cocktail of cyclophosphamide, methotrexate and fluorouracil (known as CMF) will develop permanent ovarian failure while younger women typically experience a phase of transient amenorrhea and then resume menses (Mrozek and Shapiro, 2005). Given that the average age of menopause in North America is fifty-one and roughly one third of patients diagnosed with breast cancer are under age fifty-five, there is a large population of women who will be subject to premature and immediate menopause and the accompanying symptoms. Additionally, tamoxifen therapy may cause dyspareunia and diminished sexual interest and satisfaction and more than half of all women taking tamoxifen experience hot flashes, sweats, and vaginal discharge, itching, or dryness (Ganz, 2001; Ganz, Desmond, Belin, Meyerowitz, & Rowland, 1999; Ganz, Greendale, Petersen, Zibecchi, Kahn, & Belin 2000; Hurria, et al., 2008). However, in most cases symptoms are mild and subside as therapy progresses (Burstein and Winer,
Little evidence exists between the associations of surgery types and sexual functioning; however women who have undergone mastectomy report poorer body image, self-esteem, and sexual desire than women who had breast-conserving surgery (Hayes, 2007; Kirchner, 2005; Rowland, et al., 2000).

The short-term effects of diminished circulating estrogen levels that occur in menopause include: vasomotor symptoms such as hot flushes, sweats, palpitations, vaginal dryness and sexual changes, including pain with intercourse, urinary incontinence, musculoskeletal complications such as joint pain and skin changes, sleep disturbance, and mood changes. Moreover, for women experiencing a normal menopausal transition these changes occur gradually over five to ten years, however because surgery and chemotherapy cause immediate ovarian failure, symptoms for post-treatment breast cancer patients may be more severe and adversely influence quality of life (Burstein and Winer, 2000; Ganz, 2001; Ganz, et al., 2000; Ganz, Kwan, Stanton, Krupnick, Rowland, Meyerowitz, 2004; Hayes, 2007).

Efforts to ameliorate the effect of menopausal symptoms have had suboptimal success. Historically, hormone replacement therapy has been the most effective treatment. However, adjuvant estrogen has been shown to increase the risk of breast cancer recurrence and thus is contraindicated amongst breast cancer survivors (Brennan, Black, French, & Boyages, 2006; Burstein and Winer, 2000; Chalasani, et al., 2010; Chlebowski, Kim, & Cole, 2003; Hayes, 2007). Estrogen vaginal rings such as Estring and Femring appear to be associated with less
systemic absorption of estrogen than topical estrogens, however their safety in breast cancer survivors is not known and thus they should be avoided until further evidence supports their use (Bruno and Feeney, 2006; McCarthy, 2004). There is a great deal of investigation into the effectiveness of alternative therapies and the most promising results are associated with supplemental vitamin E, dietary changes, and exercise (Hurria, et al., 2008; Loprinzi, 2004; Lyon, Roux, & Voll, 2006). However, no conclusive evidence currently exists. Vaginal dryness and dyspareunia can be managed with non-hormonal agents such as vaginal lubricants and moisturizers (McCarthy, 2004). Other non-hormonal therapies have demonstrated their effectiveness in randomized controlled trials in alleviating hot flushes. Such therapies include gabapentin, clonidine and selective serotonin reuptake inhibitors (SSRIs) such as fluoxetine (Bruno and Feeney, 2006; Chalasani, et al., 2010; Chlebowski, et al., 2003; Loprinzi, 2004). However, it is important for primary care providers to be aware that many SSRIs are strong inhibitors of cytochrome P450 2D6, the enzyme responsible for biological activation of tamoxifen. Coadministration of SSRIs and tamoxifen should be avoided as it results in impaired conversion of tamoxifen to its active form, thus decreasing the efficacy of tamoxifen therapy (Chalasani, et al., 2010). There is a lot of interest in other alternative therapies such as soy protein powder, evening primrose oil, and yam creams; efficacy remains to be determined (Chlebowski, et al., 2003; Hewitt, et al., 2006).
3.2.4 Psychosocial Issues

Distress in breast cancer has been defined as an unpleasant emotional experience that may be psychological, social or spiritual in nature (Hewitt, et al., 2006). It covers a range of feelings, including expected feelings of fear, worry, and sadness in coping with cancer and its treatment (Hewitt, et al., 2006). However, these ‘expected’ feelings can extend to more severe or debilitating conditions such as anxiety and depression. Severe distress may be associated with the illness itself, notably the spiritual or existential crisis experienced when faced with something life-threatening, or the complications of cancer treatments and fears of cancer recurrence (Kattlove and Winn, 2003; McKinley, 2000; National Comprehensive Cancer Network, 2004). Additionally, as the breast is an important cultural symbol of femininity, loss or changes in the breast as well as potential hair loss from chemotherapy can have serious implications for body image and sexual functioning (Hurria, et al., 2008; Korstjens, et al., 2008; Oktay, 1998; Partridge, Winer, & Burstein, 2003). Regardless, it has been thoroughly documented that women diagnosed and treated for breast cancer are highly susceptible to experiencing a range of psychosocial sequelae (Collins, Bekker, & Dodwell, 2004; Kattlove and Winn, 2003; Partridge, et al., 2003).

Much of the literature suggests that the majority of women adjust to the diagnosis of breast cancer and manage the associated treatments relatively well, and when cancer related distress does occur, it generally dissipates with time (Burstein and Winer, 2000; Ganz, et al., 2000; Maunsell, Brisson, & Deschenes, 1992; Schag, Ganz, Polinsky, Fred, Hirji, & Petersen, 1993). The highest levels of
distress seem to occur at transition points in treatment, such as the time of
diagnosis, awaiting treatment, upon completion of treatment, follow-up visits,
recurrence, and beginning palliative care (Gaudine, Sturge-Jacobs, & Kennedy,
2003; Hewitt, et al., 2006; Oktay, 1998). Approximately 30% of women exhibit
significant psychosocial concerns at some point during their illness (Hewitt, et al.,
2006). Those women with pre-existing psychosocial stressors, inadequate support
systems, mental health concerns or other serious comorbid conditions, as well as
younger women are at greater risk of experiencing psychosocial distress related to
cancer treatments (Bines and Gradishar, 1997; Burstein and Winer, 2000; Collins,
et al., 2004; Hewitt, et al., 2006; Hurria, et al., 2008; Oktay, 1998; Partridge, et
al., 2003).

Primary care interventions to address distress and other psychosocial
concerns begin with basic education for the patients about the disease and
complications resulting from treatments (Kattlove and Winn, 2003; Partridge, et
al., 2003; Vivar and McQueen, 2005). The clinician should actively monitor the
psychosocial status of the patient by specifically asking questions regarding their
emotional wellbeing (McKinley, 2000). Additionally, they should express
support, encourage patients to voice their fears and concerns, provide information
regarding potential community support systems, utilize resources such as social
work and psychology when necessary, and provide medications to aid in
managing symptoms like insomnia or anxiety and other aspects of cancer such as
pain (Hewitt, et al., 2006; Hurria, et al., 2008; McCarthy, 2004; Rowland, et al.,
Attentive listening and validation of the patient’s emotions can also have powerful therapeutic effects (Hurria, et al., 2008).

Evidence from twenty-one randomized controlled trials, meta-analyses and non-randomized studies of the effectiveness of psychosocial interventions among women with breast cancer supports the inclusion of psychosocial interventions in routine primary care (Hewitt, et al., 2006; Hewitt, Herdman, & Holland, 2004), as these interventions can be expected to reduce psychiatric symptoms and improve quality of life in post-treatment breast cancer patients (Hewitt, et al., 2004).

However, several barriers exist which appear to impede appropriate psychosocial care. Increased complexity of care has minimized the accessibility of clinicians as women see multiple specialists (surgeon, medical oncologist, radiation oncologist, family physician) and care is often not well coordinated (Hewitt, et al., 2006). This fragmentation of care worsens the psychological burden as the patient is not cared for by a single, trusted physician. Having informational needs met and feeling comfortable asking questions or voicing difficult issues are basic needs of breast cancer survivors for addressing psychosocial concerns (Oktay, 1998). However, outpatient offices and clinics can be extremely busy, impersonal, appointments are short and potentially rushed, and the opportunity to discuss psychosocial issues is often lost (Hewitt, et al., 2006). Other barriers to optimal care include the stigma associated with seeking or using mental health services, the reluctance of the patient to discuss concerns with the
clinician combined with the clinician’s failure to ask about distressing psychosocial symptoms, the lack of clinician awareness regarding psychosocial resources in the community and the lack of practice guidelines specifically related to monitoring and addressing psychosocial concerns (Chalasani, et al., 2010; Hewitt, et al., 2006; Oktay, 1998).

3.2.5 Additional Primary Cancers

In addition to the increased risk of breast cancer recurrence, post-treatment breast cancer patients have an increased risk for developing second primary cancers, independent of the first occurrence. This risk is dependent on genetic factors, as well as the treatments used. The underlying risk of developing a second primary cancer in the contralateral breast is 0.5%-1% per year and is greater in women with hereditary breast cancer or women diagnosed at a younger age (Burstein and Winer, 2000; Chalasani, et al., 2010). In the follow-up guidelines published by the American Society for Clinical Oncology in 2006, laboratory and radiological studies such as serum tumour markers, computer tomography scans, or breast magnetic resonance imaging have not been shown to improve recurrence detection or overall survival and therefore are not recommended for routine surveillance. However, primary care providers should ensure that breast cancer survivors undergo annual mammography screening (Burstein and Winer, 2000; Chalasani, et al., 2010; Hayes, 2007; Khatcheressian, Wolff, Smith, Grunfeld, Muss, Vogel, 2006; Partridge, et al., 2003; Rojas, et al., 2009).
Approximately 5%-10% of women carry hereditary genetic mutations in the BRCA genes and these women are at a significantly increased risk of developing a second primary breast cancer and ovarian cancer. Women with BRCA mutations who don’t undergo prophylactic surgery have a risk of breast cancer 45%-84% by age seventy (Ford, Easton, Stratton, Narod, Goldgar, Devilee, 1998). These women may benefit from genetic counselling and other early detection tools including clinical and self-examinations, annual mammography, breast magnetic resonance imaging (Warner, Plews, Hill, Causer, Zubovitis, Jong, 2004), and ovarian detection tools such as transvaginal ultrasound and annual pelvic examination (Isaacs, Peshkin, & Schwartz, 2004). Counselling should be provided regarding prophylactic measures such as mastectomy and tamoxifen use to minimize the risk of breast cancer and oophorectomy to minimize the risk of ovarian cancer (Hewitt, et al., 2006).

Radiation therapy contributes to higher incidence of cancer in areas near the original exposure sight, such as soft-tissue sarcomas of the thorax, shoulder, and pelvis, as well as lung cancers (Matesich and Shapiro, 2003).

High dose adjuvant chemotherapy can increase the risk of acute mylogenous leukemia (AML) and myelodysplastic syndrome (MDS) by three and a half times, facilitating occurrences in less than 1% of women undergoing chemotherapy for breast cancer treatment (Bines and Gradishar, 1997; Cole and Strair, 2010; Fisher, et al., 1999; Hurria, et al., 2008; Matesich and Shapiro, 2003; Mrozek and Shapiro, 2005). Symptoms of MDS, a common predecessor to AML,
typically include fatigue or easy bruising related to anemia, along with thrombocytopenia (Cole and Strair, 2010). Diagnosis of AML or MDS is determined though examining blood and bone marrow, although in many cases a bone marrow biopsy is necessary to confirm the diagnosis. Monitoring of serum tumour markers, ultrasound and computed tomography scanning is not recommended for routine surveillance as these tests haven’t be shown to improve overall survival outcomes, are costly, and often produce false positive results. However, primary care physicians should investigate any blood abnormalities and be vigilant for physical symptoms presenting in breast cancer survivors (Cole and Strair, 2010; Chalasani, et al., 2010).

Tamoxifen is usually administered for five years after completion of primary treatments to women with tumours which are estrogen receptor-positive in nature. While the benefits of tamoxifen therapy are proven, there is a two to four fold increased risk of onset of endometrial cancer, primarily in women over the age of fifty (Chalasani, et al., 2010; Hayes, 2007). Most endometrial cancers that develop are early-stage and low-grade tumours which are often successfully treated (Burstein and Winer, 2000), however, primary care providers need to ensure that patients undergoing tamoxifen therapy receive annual pelvic examination and report any irregular bleeding (Bines and Gradishar, 1997; Burstein and Winer, 2000; Chalasani, et al., 2010; Shapiro and Recht, 2001).
3.2.6 Cardiovascular Implications

Chemotherapy, radiation therapy, and hormone therapy have been associated with increased cardiovascular disease in women treated for breast cancer (Chalasani, et al., 2010).

One of the most life-threatening complications of the standard anthracycline-containing chemotherapy regimen for breast cancer is congestive heart failure, which develops in 0.5%-1% of women (Burstein and Winer, 2000; Hurria, et al., 2008; McCarthy, 2004; Mrozek and Shapiro, 2005). This is particularly devastating since the cardiac dysfunction is potentially irreversible, and capable of appearing years or even decades following therapy (Hewitt, et al., 2006). Although heart failure is the most extreme effect of anthracycline toxicity, a range of complications can occur, including hypertension, myocardial infarction, and venous thromboembolic and cerebrovascular events (Chalasani, et al., 2010; Hurria, et al., 2008; Partridge, et al., 2003). Other chemotherapeutic agents such as taxanes have been associated with arrhythmias, and the drug trastuzumab which is given to patients HER2-positive tumours, has been implicated in myocardial depression and congestive heart failure (McCarthy, 2004; Moore, 2001; Mrozek and Shapiro, 2005; Yeh, Tong, Lenihan, Yusuf, Swafford, Champion, 2004). Additionally, when radiation therapy is administered even in the absence of anthracyclines, cardiac damage may still occur, particularly if the dose of radiation is focused on the left breast (Chalasani, et al., 2010; Theodoulou and Seidman, 2003), as it damages the microvasculature of the
myocardium and coronary arteries, leading to endothelial cell damage and consequent fibrosis (Mrozek and Shapiro, 2005).

Risk factors for developing cardiac damage resulting from treatments include age over fifty years, pre-existing heart disease, higher dose of anthracyclines, and radiation that includes the left breast. Routine screening for cardiac function is not recommended. However, primary care physicians should ensure that patients with suggestive symptoms are evaluated with electrocardiography and echocardiography (Burstein and Winer, 2000).

Tamoxifen therapy has been shown to have beneficial effects on lowering lipid profiles, although the aromatase inhibitors lack the lipid-lowering properties (Love, Wiebe, & Newcomb, 1991) and the effects of aromatase inhibitors on cardiac risk are unclear (Chalasani, et al., 2010). Until a solid body of evidence is assembled and given the increased risk of adverse cardiac events, it is important that primary care providers monitor post-treatment breast cancer patients for general cardiac risk factors such as hypertension and hypercholesterolemia (Chalasani, et al., 2010; Theodoulou and Seidman, 2003).

3.2.7 Osteoporosis

Women with a history of breast cancer may be at increased risk of osteoporosis due to the loss of bone mineral density associated with estrogen depletion. This reduction in circulating estrogen may be caused by premature
ovarian failure from chemotherapy, hormonal therapies such as aromatase inhibitors and estrogen receptor antagonists, or premenopausal women who have undergone prophylactic oophorectomy (Grunfeld, Dhesy-Thind, Levine, & Fossati, 2005).

As a result, the Canadian Steering Committee on Clinical Practice Guidelines for the Care and Treatment of Breast Cancer published guidelines in 2005 which recommend that primary care physicians counsel at-risk patients on lifestyle changes, such as performing weight-bearing exercises, ensuring an adequate intake of calcium (1200mg/day) and vitamin D (400-800IU/day), and cessation of smoking. Additionally, women who are postmenopausal or taking aromatase inhibitors should undergo a bone mineral density test annually and if osteoporosis is present, treatment should include a bisphosphonate (Chalasani, et al., 2010; Grunfeld, et al., 2005; McCarthy, 2004; Mrozek and Shapiro, 2005; Sawka, Ioannidis, Papaioannou, Thabane, Olszynski, Brown, 2005).

It has been shown that tamoxifen preserves bone mineral density in postmenopausal women and may reduce the incidence of osteoporotic fractures (Chalasani, et al., 2010), however in premenopausal women it has been associated with varying degrees of loss of bone mineral density (Burstein and Winer, 2000) and therefore treatment with a bisphosphonate during or just after adjuvant hormone therapy may prevent excessive loss of bone mineral density (Partridge, et al., 2003).
3.2.8 Lifestyle Changes

Weight gain is a common problem associated with adjuvant breast cancer chemotherapy. At least half of women undergoing chemotherapy report a weight gain of 5.5-11 pounds, and more significant weight gain around 22-44 pounds has been reported in 20% of women (Hewitt, et al., 2006). The exact cause is not well understood, although it may be explained in terms of decreased activity levels during therapy, and changes in metabolic rate associated with the transition into menopause (Hewitt, et al., 2006; Hurria, et al., 2008; McCarthy, 2004).

Obesity has serious health implications and should be addressed in this population as some studies have shown obesity to be associated with impaired psychological wellbeing and cancer recurrence (Chlebowski, et al., 2003). Additionally, moderate exercise programs have been shown to lessen fatigue, as well as symptoms of depression and anxiety among survivors and boost self-esteem in breast cancer survivors (Khatcheressian and Smith, 2006). Multidisciplinary efforts including nutritional advice, counselling, and exercise programs can be utilized to help breast cancer survivors lose weight (Burstein and Winer, 2000; Khatcheressian, et al., 2006).

Additionally, the American Society of Clinical Oncology has outlined guidelines on nutrition for cancer prevention which can be regarded as the basis of a healthy diet during all phases of cancer, including survivorship (Khatcheressian, et al., 2006). The guidelines include balancing protein, carbohydrate and fat intake, so that the level of fat in the diet is 20%-35% of energy consumed, with saturated fat intake limited to less than 10% and trans fatty acids limited to less than 3% of...
the total energy intake. Some studies have suggested that omega-3 fatty acids may have specific benefits for cancer survivors, but these findings are not certain, and more research is needed. However, including foods that are rich in omega-3 fatty acids such as fish and walnuts should still be encouraged because it is associated with a lower risk for cardiovascular diseases and a lower overall mortality rate (Khatcheressian, et al., 2006).

Adequate protein intake is critical during all stages of cancer treatment, recovery, and survivorship and an intake of 10%-35% of energy from protein is recommended for adult cancer survivors. Healthy choices to meet protein needs are foods that are also low in saturated fat such as fish, lean meat and poultry, eggs, non-fat and low-fat dairy products, nuts, seeds, and legumes (Khatcheressian, et al., 2006).

Carbohydrates should account for 45%-65% of energy intake and healthy sources include foods that are rich in essential nutrients, phytochemicals, and fibre, such as vegetables, fruit, whole grains, and legumes. These foods should provide the majority of carbohydrate in the diet. Limiting sugar consumption is recommended (Khatcheressian, et al., 2006).

Higher intakes of vegetables and fruits have been specifically associated with a lower incidence of cancer at several sites and cancer survivors should consume at least five servings of a variety of vegetables and fruit each day (Khatcheressian, et al., 2006).
Women who consume one alcoholic drink per day can lower their risk for heart disease, but higher levels do not offer additional benefit and may increase the risk of complications from alcohol overuse as well as cancer. It is important for the primary care provider to provide advice on alcohol consumption to the individual cancer survivor. The cancer type and stage, treatment, risk factors for recurrence or new primary cancers, and comorbid conditions should be considered when making these recommendations (Khatcheressian, et al., 2006).

3.2.9 Fatigue

Fatigue is a common side effect experienced by approximately one third of women who have undergone chemotherapy or radiation therapy for breast cancer. Despite the evidence supporting its occurrence, the underlying mechanism of fatigue in relation to treatments remains unclear as there are no standard criteria for assessing chemotherapy-related fatigue (Mrozek and Shapiro, 2005). Patients at the greatest risk for experiencing severe and persistent fatigue are those with other chronic conditions such as depression and pain. Other factors which potentially contribute to increased fatigue include sleep deprivation, menopausal changes, weight changes, radiation-induced hypothyroidism (Ganz, et al., 2004), anemia, and those lacking a strong social support network (Hewitt, et al., 2006; Mrozek and Shapiro, 2005).

For primary care physicians, the first step to managing fatigue in patients is identifying and addressing the underlying physiological and psychological
causes. Subsequent therapies may then include recommendations for lifestyle modifications regarding nutrition and exercise, counselling and psychological support, and pharmacological interventions such as antidepressants.

3.2.10 Cognitive Dysfunction

A growing body of observational evidence demonstrates that cognitive dysfunction is associated with breast cancer survivors who have been treated with adjuvant chemotherapy (Brezden, Phillips, Abdolell, Bunston, & Tannock, 2000; Ganz, 1998; Mrozek and Shapiro, 2005). The symptoms are colloquially referred to as “chemobrain” and include deficits in memory, concentration, language, and attention (Mrozek and Shapiro, 2005). These symptoms can be persistent and debilitating and can impede attainment of work, education and general quality of life goals (Mrozek and Shapiro, 2005).

The underlying mechanisms of the impaired cognition are unknown and no correlation between subjective complaints of cognitive impairment and objective measures has been observed (Grunfeld, et al., 2005). Thus, there are currently no specific physiological interventions recommended to alleviate these symptoms (Grunfeld, et al., 2005). Primary care providers should ask patients about potential cognitive deficits and provide emotional support when necessary (Grunfeld, et al., 2005).
Due to the limited strength of evidence, the last recommendation from the Canadian Steering Committee on Clinical Practice Guidelines for the Care and Treatment of Breast Cancer stated that it is premature to recommend routine neuropsychological testing or interventions for these women (Grunfeld, et al., 2005). In order to understand the onset and underlying mechanisms of chemotherapy-induced cognitive dysfunction in breast cancer survivors, longitudinal, multicentre studies are needed to determine specifically how chemotherapy affects cognitive function (Grunfeld, et al., 2005; Hurria, et al., 2008; Mrozek and Shapiro, 2005).

3.2.11 Pregnancy

Patients who wish to become pregnant after treatment often seek advice as to whether or not pregnancy increases the risk of cancer recurrence. Currently, the body of evidence suggests that pregnancy after undergoing treatment for breast cancer does not increase the risk of cancer recurrence, and previous treatments have not proven detrimental to the development of a normal pregnancy (Burstein and Winer, 2000; Kirschner, 2005; McCarthy, 2004; Mrozek and Shapiro, 2005; Partridge, et al., 2003).

Due to the teratogenic effects of chemotherapy drugs and the hormone therapy tamoxifen, it is important to advise patients to wait until completion of treatment before trying to become pregnant as significant birth defects in a developing fetus may occur with the use of these therapies (Hurria, et al., 2008;
Additionally, depending on a woman’s age and the treatment regimen used, it is recommended that clinicians suggest that patients wait two to five years after completing treatment before becoming pregnant as the risk of recurrence peaks during the first few years after treatment and then begins to diminish (Burstein and Winer, 2000; Chalasani, et al., 2010; Kirschner, 2005; Mrozek and Shapiro, 2005). As some women enter permanent ovarian failure from chemotherapy treatments, they may need to utilise modern reproductive technologies such as in vitro fertilization in order to pursue conception. However, this body of evidence is incomplete and thus information for these women is limited (Partridge, et al., 2003).

3.2.12 Clinical practice guidelines

Through a comprehensive hand search of the online databases of the National Guideline Clearinghouse, Canadian Medical Association, Cancer Care Ontario, and National Comprehensive Cancer Network for any clinical practice guidelines which pertain to addressing the primary care needs of post-treatment breast cancer patients, several recommendations published by the American Society of Clinical Oncology and Health Canada’s Steering Committee on Clinical Practice Guidelines for the Care and Treatment of Breast Cancer were identified.
American Society of Clinical Oncology

The following table outlines the 2006 update to the recommendations published by the American Society of Clinical Oncology pertaining to surveillance for the onset of additional cancers precipitated by primary breast cancer treatments as well as diet and exercise guidelines. The guidelines were developed by the American Society of Clinical Oncology Expert Panel, who reviewed pertinent information from the literature through March 2006. The panel indicated that more weight was given to studies that tested a hypothesis directly relating testing to one of the primary outcomes in a randomized design (Khatcheressian, et al., 2006).

**Table 1: Summary of the 2006 update of the American Society of Clinical Oncology recommendations for breast cancer follow-up and management**

<table>
<thead>
<tr>
<th>Primary health care issue</th>
<th>Recommendations</th>
</tr>
</thead>
<tbody>
<tr>
<td>History, Physical Examination, and Patient Education Regarding Symptoms of Recurrence</td>
<td>All women should have a history and physical examination every three to six months for the first three years after primary therapy, then every six to twelve months for the next two years, and then annually.</td>
</tr>
<tr>
<td></td>
<td>Physicians should educate patients regarding symptoms of recurrence including lumps, bone pain, chest pain, dyspnea, abdominal pain, or persistent headaches.</td>
</tr>
<tr>
<td></td>
<td>Women at high risk for familial breast cancer should be referred for genetic counselling. High risk patient populations include: Ashkenazi Jewish heritage; history of ovarian cancer at any age in the patient or any first- or second-degree relatives; any first-</td>
</tr>
</tbody>
</table>
degree relative with a history of breast cancer diagnosed before the age of fifty years; two or more first- or second-degree relatives diagnosed with breast cancer at any age; patient or relative with diagnosis of bilateral breast cancer; and history of breast cancer in a male relative (Khatcheressian, et al., 2006).

<table>
<thead>
<tr>
<th>Mammography</th>
<th>Women treated with breast-conserving therapy should have their first post-treatment mammogram six months after completion of radiation therapy. Subsequent mammograms should be obtained every six to twelve months for surveillance of abnormalities (Khatcheressian, et al., 2006).</th>
</tr>
</thead>
<tbody>
<tr>
<td>Coordination of Care</td>
<td>The risk of breast cancer recurrence continues through fifteen years after primary treatment and beyond. Follow-up by a primary care physician is recommended and seems to lead to the same health outcomes as specialist follow-up with good patient satisfaction (Khatcheressian, et al., 2006).</td>
</tr>
<tr>
<td>Gynaecological Care</td>
<td>Regular pelvic examination is recommended for all women. Particularly, women receiving tamoxifen therapy are at increased risk for developing endometrial cancer and should be advised to report any vaginal bleeding to their physicians (Khatcheressian, et al., 2006).</td>
</tr>
<tr>
<td>Laboratory Screening and Imaging</td>
<td>Laboratory surveillance testing and diagnostic imaging for evidence of recurrence of the primary cancer or development of a second cancer is not recommended for routine breast cancer follow-up in an otherwise asymptomatic patient with no specific findings on clinical examination. (Khatcheressian, et al., 2006).</td>
</tr>
</tbody>
</table>

| Diet and Exercise | Nutrition and physical activity recommendations are especially important for breast cancer survivors as there is good evidence to suggest that obesity is associated with breast cancer recurrence.  

Diets should emphasize vegetables and fruits, low amounts of saturated fats, and sufficient dietary fibre.  

If soy foods are consumed, intakes should be kept in moderation, and concentrated sources of isoflavones should be avoided.  

Regular physical activity should be maintained regardless of weight concerns as exercise has been shown to improve cardiovascular fitness, muscle strength, body composition, fatigue, anxiety, depression, self-esteem, happiness, and several components of quality of life (physical, functional, and emotional) in cancer survivors (Khatcheressian, et al., 2006). |
Sixteen Canadian clinical practice guidelines related to breast cancer were originally published in the *Canadian Medical Association Journal* in 1998, with the most recent update in 2005. Of those guidelines, there are three which target primary care and survivorship needs. The following summary made by Health Canada’s Steering Committee on Clinical Practice Guidelines for the Care and Treatment of Breast Cancer addresses survivorship issues related to undergoing breast cancer treatments. The steering committee indicated that the guidelines were developed based on a systematic review of the English-language literature retrieved from 1991-2004. Additionally, a nonsystematic review of the literature and monitoring of major conferences on breast cancer were continued through January 2005 (Grunfeld, et al., 2005).

**Table 2: Summary of the 2005 update of Health Canada’s Steering Committee on Clinical Practice Guidelines for the Care and Treatment of Breast Cancer recommendations for follow-up after treatment for breast cancer**

<table>
<thead>
<tr>
<th>Primary health care issue</th>
<th>Recommendations</th>
</tr>
</thead>
<tbody>
<tr>
<td>History, Physical Examination, Mammography, and Surveillance</td>
<td>All patients with breast cancer should have regular follow-up surveillance with the frequency of visits adjusted according to individual patient’s needs.</td>
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<tr>
<td></td>
<td>Each visit should include a medical history.</td>
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<tr>
<td></td>
<td>For women who are taking tamoxifen, it is important to ask about vaginal bleeding.</td>
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<tr>
<td></td>
<td>Physical examination should include breasts, regional lymph nodes, chest</td>
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wall, lungs and abdomen. The arms should be examined for lymphedema.

Annual visits should include mammographic examination.

Routine laboratory and imaging investigations should not be carried out for the purpose of detecting distant metastases.

Patients should be encouraged to report new, persistent symptoms promptly, without waiting for the next scheduled appointment (Grunfeld et al., 2005).

<table>
<thead>
<tr>
<th>Psychosocial Concerns</th>
<th>Psychosocial support should be encouraged and facilitated (Grunfeld et al., 2005).</th>
</tr>
</thead>
<tbody>
<tr>
<td>Coordination of Care</td>
<td>The responsibility for follow-up should be formally allocated to a single physician. Communication between all members of the team must be ensured to avoid duplication of visits and tests (Grunfeld et al., 2005).</td>
</tr>
<tr>
<td>Cognitive functioning</td>
<td>There may be an effect of chemotherapy on cognitive functioning, which may be sustained. However, there is no correlation between subjective complaints of cognitive impairment and objective measures and thus the steering committee feels that it is premature to recommend routine neuropsychological testing or interventions. Prospective longitudinal controlled studies should be encouraged (Grunfeld et al., 2005).</td>
</tr>
<tr>
<td>Fatigue</td>
<td>Fatigue may affect approximately one-quarter to one-third of breast cancer survivors although the mechanism of fatigue and the relation between fatigue and primary treatment remains unclear. Patients should be asked about symptoms of fatigue and physiologic causes of fatigue such as depression and pain should be investigated and ruled out (Grunfeld et al., 2005).</td>
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<tr>
<td>Weight management</td>
<td>Weight management should be discussed with all breast cancer survivors and overweight patients should be encouraged to participate in evidence-based weight-management programs (Grunfeld et al., 2005).</td>
</tr>
<tr>
<td>Osteoporosis</td>
<td>Patients who are postmenopausal, or are premenopausal with risk factors for osteoporosis, or are taking aromatase inhibitors should undergo bone mineral density screening annually. Patients should be counselled on exercise and on adequate intake of vitamin D. Osteoporosis treatment should include a bisphosphonate (Grunfeld et al., 2005).</td>
</tr>
<tr>
<td>Sexual functioning</td>
<td>Sexual functioning should be discussed with women at follow-up visits (Grunfeld et al., 2005).</td>
</tr>
<tr>
<td>Pregnancy</td>
<td>Women considering pregnancy following a diagnosis of breast cancer should be informed of the limited data on the effect of pregnancy on outcomes such as breast cancer recurrence and survival. There is currently no evidence that subsequent pregnancy adversely affects survival (Grunfeld et al., 2005).</td>
</tr>
</tbody>
</table>
3.3 Summary

The findings from this scoping review have emphasized the multitude of health complications experienced by women following treatment for breast cancer. Synthesis of this information as well as the most recent publications of clinical practice guidelines for follow-up after treatment for breast cancer have also revealed the long term primary care needs of these women as they embark upon the journey of cancer survivorship. Particularly, primary care physicians need to monitor for potential infection, manage issues associated with lymphedema as well as a rapid transition into menopause, provide support for psychosocial sequelae and cognitive dysfunction, monitor for second primary cancers, cardiovascular damage and osteoporosis, make recommendations for diet and exercise modifications, and help to reduce pain and fatigue.
CHAPTER 4: VALIDATION OF THE SCOPING REVIEW

With the goal of enriching and potentially validating the findings of the scoping review, as well as generating a more complete understanding of the primary care needs of women following breast cancer treatment, interviews were conducted with three breast cancer survivors and two family physicians. This chapter will describe the interview process under the headings of objectives, sample, recruitment, data collection and analysis, and findings.
4.1 Interview Methodology

4.1.2. Objectives

The specific objectives of this component of the project were to:

1. Determine if findings from the scoping review are in concordance with the perspectives of:
   a) Breast cancer survivors
   b) Primary care physicians

2. Identify possible gaps between current literature and clinical practice in terms of:
   a) Novel research findings which have not been translated into everyday clinical practice
   b) Significant issues, perspectives, or practices for which a supportive body of evidence is lacking

4.1.2. Sample

Interviews were conducted with three post-treatment breast cancer patients and two family physicians to obtain an opinion of care from the Kingston area. This sample size was chosen out of convenience as these were the number of participants who responded to interview requests.
Inclusion Criteria

1. Criteria for the inclusion of participants for the post-treatment breast cancer patient interviews were;

   a) female, and

   b) have successfully undergone any treatments for breast cancer.

   At the time that the interviews took place, Participant A was age 56 and had completed primary treatments 13 months prior to the interview, Participant B was age 69 and had completed primary treatments two years prior to the interview, and Participant C was age 59 and had completed primary treatments two months prior to the interview. All women were well educated and exercised regularly prior to their cancer diagnosis.

2. Criteria for the inclusion of participants for primary care physician interviews were;

   a) primary care family physicians, and

   b) have encountered post-treatment breast cancer patients during their clinical practice.
4.1.3 Recruitment

Post-Treatment Breast Cancer Patients

Participants for the post-treatment breast cancer patient interviews were recruited from the main breast cancer survivorship support group in Kingston, Ontario, Breast Cancer Action Kingston. The board of Breast Cancer Action Kingston was contacted and the study objectives and letter of information were provided. The board then found several women who were willing to participate and provided them with contact information. They then contacted the researcher to schedule the interviews.

Family Physicians

Participants for the primary care physician interviews were recruited through Queen’s University in Kingston, Ontario. Queen’s Family Medicine and Queen’s Student Health were contacted with the study objectives, and two physicians responded who were willing to participate in the interviews.

4.1.4 Data Collection and Analysis

The findings of the scoping review were evaluated using semi-structured interviews. These two efforts were conducted concurrently with the intention of obtaining uninformed perspectives from consumers and physicians. Interview guides were developed based on general themes encountered during initial searching of the literature. The interviews were open-ended with the general
themes discussed at the beginning of the interview (Appendix B and C). However, if participants wished to discuss any other themes related to the research study or future directions of similar research, this was also recorded. The participants were given a letter of information about the interview and a consent form to sign (Appendix D, E, and F), and approval to conduct these interviews was granted from the Queen’s University Health Sciences and Affiliated Teaching Hospitals Research Ethics Board (Appendix G). Each participant was interviewed by the researcher once, at a location of their choice, and for approximately 30 minutes. The interviews were audio-recorded, transcribed, and analyzed for content by the researcher to identify general themes in the patient and physician comments. The results follow, and are reported using the themes identified in a narrative form including specific quotations.

4.2 Findings

4.2.1 Interviews with post-treatment breast cancer patients

Findings from the three interviews conducted with post-treatment breast cancer patients regarding their health issues and primary care needs were grouped into the following themes: quality of care received, participation in own care, patient needs related to the primary care physician, psychosocial issues resulting from treatments and medical issues resulting from treatments.
Quality of Care Received

Several aspects of clinical care were considered to be important by these women. All three patients emphasized the importance of sustaining an enduring, trustworthy relationship with their physician. They noted that the importance of the personal nature of the relationship and what it meant to them in terms of their comfort level when discussing certain issues as well as feeling supported: “She is very kind and compassionate, she always hugged me and stuff like that, she was always there, and I trusted her.” Conversely, they also commented on the negative aspects of a physician who does not possess a “good bedside manner” and the subsequent implications in their ability to trust and feel comforted by this clinician, who, in this case was an oncologist: “I asked not to have her anymore; you know she doesn’t have a very good bedside manner.” The women also highlighted the importance of time in terms of the timely reception of information regarding their health, as well as the clinician devoting sufficient time to them during their visit. This was emphasized in a comparison drawn between primary and specialty care where regarding seeing her specialist, one patient said:

“The oncologists are very distant. They are frequently not there. And I know how many people they see... but it’s just that idea of come on, hurry up, we’ve got all of these people [to see].”

Fragmentation of care was a major issue highlighted by all three patients. They felt that the health care system was not well coordinated in terms of the
transition between clinicians and they were unclear as to who was responsible for managing their care throughout their transition into survivorship.

“One of the things that chemo causes is heart problems and I was having heart palpitations and my oncologist looked at me and said to me “well you should probably see someone about that.” And I had nothing to say to that, so I just phoned my [family] doctor and I went to see her.”

Participation in Own Care

Comments around the advantages in participating in their own care largely revolved around the importance of taking good care of themselves through a healthy diet, exercise, and getting adequate rest when needed. All three women were involved in regular exercise programs such as yoga, cycling, and dragon boating and cited the importance in terms of their ability to cope with cancer treatments,

“They [white blood cell counts during chemotherapy] didn’t go down enough to be a problem. And I credit a lot of that to being, to the amount of time, to the amount of physical exercise I get. I really do. Because I think my immune system is probably better than most my age simply because I do work out a lot.”

as well as the effect on their wellbeing: “I would like to recommend that women keep active...I saw so many women just sitting around and the more you sit around the worse you feel. Be active.” Additionally, receiving adequate rest and
participating in social engagements only when they felt well enough were
suggested as being important when recovering from treatments:

“In I did have a little bit of a setback because I
overextended myself one day [at a Christmas
party] and I was really tired the next few days so I
took it easy and stayed away from all people.”

All three patients strongly emphasized the value of maintaining a positive outlook
in terms of their ability to cope and persevere throughout treatments and the
transition into survivorship: “I try to think positive. You know, I have what I have.
But I mean to say, why dwell on it, you know?” They also spoke about playing a
role in their own treatment decisions and maintaining some kind of ‘control’ over
their disease and course of treatment. The following statements were made in
regards to the decision to undergo a bilateral mastectomy: “I believe firmly that
every woman should make their own decision, every woman knows her body best
and she knows her life.” Another patient said:

“My thoughts are you can only live each day to its
fullest, you can’t go back and change anything in
the past, you can only go forward... it took over my
life for an entire year. And I wanted to do
everything I possibly could now, and then if it
would recur or metastasize later I wouldn’t be
thinking, “oh maybe if I’d done this...”, and so the
decision to have the bilateral mastectomy was
made on that basis.”

The importance of control as it pertains to emotional wellbeing was also
mentioned: “I’m getting excellent medical treatment, I’m taking good care of
myself. I’m doing everything I can to control how I respond to treatment and
that’s all I really can do.” Finally, they spoke about control in relation to their information needs regarding their disease, treatment options, and future plans:

“I did a lot of research, I read online, I read medical journals, I read, read, read, everything I could... I want to know as much as I can...you try to be in control of the things you can be and how you react to things...I always figured the more you know the better prepared you are because you understand why something is being done, or you understand why you feel a certain way. So to me the more knowledge you have, the more control you have in the sense that you have an understanding of things.”

Patient Needs Related to the Primary Care Physician

In addition to citing the informational needs from the primary care physician, the patients emphasized the meaning of the physician devoting sufficient time to them,

“You know how they [family physicians] always tell you that you can only talk to them about one or two things? She doesn’t, I mean when I went in, she said “just tell me everything that is going on.” So she will sit down and talk to me, so she has been really good,”

as well as the importance of someone to listen:

“[something she has done that has been very helpful] is listening. And when I said god I just feel like I’m complaining she would say ‘no you can tell me.’ So that has been nice.”
Additionally, the patients felt that it was important for the physician to be compassionate and knowledgeable in order to have someone to talk to in a relatable way:

“[As a woman going through breast cancer treatments, I need from my doctor] somebody to talk to. Somebody who has been through the journey, and I think they’re more compassionate, you know...When people ask you how you are, I don’t think they want to really hear how you are. They want to hear I’m okay. So I say I’m Okay. I’m surviving. I don’t think they want to sit down and hear your whole story. But having somebody who knows...they are more apt to listen.”

They also cited the importance of receiving follow-up care after completing their treatments: “[I needed] some sort of follow up, not just to say ‘that’s it, bye, see you.’ Some sort of just ‘are you okay? Do you need anything?’”

Psychosocial Issues Resulting From Treatments

The patients felt that there were several psychosocial challenges associated with treatments, particularly the loss of breasts from mastectomy as well as hair loss during chemotherapy treatments. Additionally, they found it difficult being treated like a ‘sick person’ after finishing their treatments:
“it was also about getting people to stop saying ‘oh you have cancer you poor thing.’ It’s no, I was being treated for cancer, now I am better. Think of it that way, not that I’m sick. That was an emotional thing for me, to stop people from saying ‘oh poor you.’”

Each woman strongly expressed fears of cancer recurrence or death. When asked about the most distressing experience during treatment, one patient responded:

“You know, nobody wants to die.” When asked about the follow up schedule, another woman responded:

“Nope, its ‘bye!’ And I don’t have an appointment again until October. That’s what I say is kind of disconcerting. All of this time you’ve had all of this [treatment] and all of a sudden it’s like ‘well, bye.’ There’s nothing to look at, no blood work to do, it’s just like ‘well, you know, hope you’re better’. And that’s it.”

Finally, the patients discussed the difficulty of transitioning into the survivorship phase and the difficulties associated with adjusting to a new sense of normalcy.

“It’s really interesting because you would expect it [completion of treatment] to be really exciting, instead it isn’t that at all. It’s like oh my god, now what am I going to do? For like a whole year your life has just revolved around appointments and treatments, and there are people looking after you...everyone says oh just go back to normal, but it’s been so abnormal for so long... it’s like what’s normal again?”
Medical Issues Resulting from Treatments

Throughout the course of the interviews the patients discussed a variety of health complications resulting from the breast cancer treatments they had undergone. Particular emphasis was placed on the development of the post-surgical complication cellulitis, the symptoms of cognitive dysfunction referred to as ‘chemobrain,’ as well as fatigue and an overall perceived decrease in energy levels. Radiation therapy-induced burning of the chest skin, peripheral neuropathy, heart palpitations, nausea, vomiting, and corresponding weight loss, and an inflammatory condition of a superficial layer of the eye known as episcleritis, were also noted as complications of treatments.

4.2.2 Interviews with primary care physicians

Findings from the two interviews conducted with primary care physicians regarding the primary care needs of post-treatment breast cancer patients were grouped into the following four themes: role and responsibilities of the family doctor, perceived challenges faced by post-treatment breast cancer patients, challenges to providing optimal care, and means to improve care delivery.

Role and Responsibilities of the Family Doctor

Both physicians discussed some of their responsibilities in caring for post-treatment breast cancer patients. They cited aspects of their perceived role as coordinating care, meeting information needs, interpreting results, advocating for
their patients within the health care system, managing family issues, being the main provider of care: “They sort of graduate from the surgeon or radiation oncologist and then they are back to you, and you then look after them and they become yours and yours alone,” addressing issues in a timely manner, monitoring for cancer recurrence, monitoring for psychosocial concerns and providing psychosocial support, and being someone to take the time and simply listen. One physician stated:

“It's a very junior member of the team that doesn’t have maybe the life experience or clinical experience, but they have the time. Medical students will tell you this all of the time. They’ll say ‘I was the only one for 2 weeks to see Mrs. So-and-so. The staff members weren’t around and the resident was on holiday or they were in emerg seeing consults and this poor person was sitting there and suffering. So all I did was sit there and let the person talk.’ And I would say well that is incredibly therapeutic, thank god you were there.”

Perceived Challenges Faced by Post-treatment Breast Cancer Patients

The doctors discussed their perceptions of some of the main challenges faced by this group of patients. They reviewed aspects of treatment sequelae including lymphedema, concerns about future pregnancies, fatigue, arm pain and weakness, fears of recurrence, family issues and the ability to return to
occupational activities. Additionally, the notion of regaining a sense of normalcy was cited as a major issue:

“[The biggest challenge facing women after undergoing breast cancer treatments is] probably returning to a normal lifestyle, in a psychosocial sense and also trying to get back to their activities and athletics. It’s slow going.”

Furthermore, the physicians discussed the issue of these women not having adequate time devoted to their care in the hospital setting as a key challenge faced by post-treatment breast cancer patients:

“You’d hear that they weren’t given enough time to get their questions answered or really sit and be able to talk about their anxieties, their fears, their worries, their questions, that everybody seemed to be in a hurry and they would say ‘well I understand that but it would be nice to be able to have that feeling of being listened to.’”

**Challenges to Providing Optimal Care**

Both family doctors spoke about a variety of barriers which prevent optimal care delivery. Particularly, they spoke about the issue of some doctors divesting responsibility to other health care professionals:
“Depending on the stage of the disease, or what they’ve been told, if it’s not good news, then you probably have more intensive involvement with them. It’s sometimes up to the comfort level of the family doctor too, and their own experience, their own training. We try to encourage that model of comprehensiveness where you see that as your responsibility. But, we know that not all family doctors are comfortable with that and so they divest that over to some other member of their team. And now that we’re organized into Family Health Teams, you could say that there are more options available to the physician, but you could also phrase it the other way and say that you could dump the patient on another member of the team [such as a psychologist or social worker] if you’re not that comfortable or if they take too much of my time. And, anecdotally I’m getting a sense that that’s starting to happen a bit more than I would like to see, than was the intention of Family Health Teams.”

Another barrier which was highlighted was the availability of resources in different regional settings:

“For things like exercise and strengthening and those post-op recovery questions like lymphedema, pain management, I would really want to turn to a physio or rehab person...but it depends on what resources are available to you. If you’re in a remote setting, you don’t maybe have access to those people close by.”

The lack of available clinical practice guidelines as well as strategies to incorporate new research findings into clinical practice were also emphasized as major obstacles facing optimal primary care delivery:
“There hasn’t been much literature for post-treatment breast cancer patients. Most of the literature is sort of the front end, the diagnostic, the guidelines around screening and prevention, case findings, at that end. That may be true of a lot of things in medicine. Sort of find the problem and fix it and then we’ve done our job. It’s somebody else’s problem now, that’s usually with us, primary care and rehab people. So, ya I haven’t been aware that there’s been much change in that flow of information.”

Communication barriers between specialty and primary care are also cited as creating challenges for the effective coordination of care:

“There is a lag. What I’m finding is that there is a real lag. So, you know, the patient comes in and says I was at the cancer clinic and had you know a, b, and c done, and the last report I have was done three months ago. And you know, they had this done last month. And I’m like well, I don’t have those results, you know? So, there is definitely a time lag and that makes it difficult.”

Finally, the lack of formal framework to improve the effectiveness of the transition between specialty and primary care in combination with a hierarchy of physicians over other health care professionals was discussed as creating a challenge to the delivery of care for post-treatment breast cancer patients:
“it’s [a formal survivorship care plan] certainly a long time coming. If you look at it from way back, the idea of a care plan has a whole dimension and it belongs more in nursing or physio, not in medicine. We’re the weak point. The physicians are the weak link. The sad thing is that is sort of whose running the hospital there. In most cases, no matter what people like to think, it’s still that way. There is this hierarchy, and so to introduce something that is a very logical way of addressing a problem isn’t always easy you know when you’re dealing with physicians.”

Means to Improve Care Delivery

Three methods of improving the delivery of care for post-treatment breast cancer patients were discussed. Notably, the use of a formal transition protocol such as the previously mentioned ‘survivorship care plan’ was deemed to be very important. Both physicians agreed that it would have a lot of value: “Ya, that would be beneficial...that would be awesome.” Additionally, the use of electronic health records was mentioned as advantageous in terms of disabling some communication barriers between specialty and primary care:

“The problem of getting good complete information as to what actually happened is better though, from what I can see its better than it used to be. We’re using sort of electronic records a bit better that way, to convey information more quickly.”

Finally, both physicians strongly emphasized the importance of interprofessional care and making use of specialized resources when they are available to ensure
that the patient is receiving the best treatment. The incorporation of interprofessional education into the curriculum for medical, physiotherapy, occupational therapy, and nursing students, was also discussed with the goal of demonstrating the value of interprofessional care to future health care professionals:

“In terms of making it [the transition between specialty and primary care] better, it seems like having an interprofessional care plan, where the roles are defined and understood by all parties. and that they’ve been arrived at by everyone...that’s really going to benefit everybody, the patient first and foremost, and then the care providers as well. And it should improve communication; it should make it very easy to communicate theoretically, if I know that these people are also involved and we all know that, we’ve all agreed to that, the patient knows that, they’re in the centre of this whole matrix, then, at least in theory that should work...And backing up, going upstream in terms of education, what we’re seeing a lot more of is interprofessional education starting at a real undergraduate level... it seems like a worthwhile exercise, they [students] just don’t always recognize it at the time, but they’ll look back at it and realize they actually did learn something as to what is the role of the other professionals when it comes to actually sitting and being responsible for patients.”
CHAPTER 5: DISCUSSION AND CONCLUSIONS

5.1 Summary of Findings

The purpose of this thesis was to perform a scoping review in order to synthesize an understanding from the current literature of the primary health care needs of post-treatment breast cancer patients following treatment for breast cancer, as well as to identify any clinical practice guidelines for primary care that would aid family physicians in providing optimal, evidence-based care to post-treatment breast cancer patients. Additionally, the scoping review and interviews would also be used to identify current gaps in the literature with the goal of stimulating further research efforts. The main findings derived from this research are:

1. The scoping review identified eleven broad categories related to the primary health care needs of women after undergoing treatments for breast cancer. They were:

   a) surgical complications,

   b) lymphedema,

   c) gynecologic and reproductive implications,

   d) psychosocial issues,

   e) additional primary cancers,

   f) cardiovascular implications,
g) osteoporosis,

h) lifestyle changes,

i) fatigue,

j) cognitive dysfunction, and

k) pregnancy.

Each category potentially contains a multitude of side effects that these women may experience during the survivorship phase of breast cancer. For some categories there is a solid body of evidence which facilitates primary care interventions to address the complications of treatments. However, for the majority of health issues faced by breast cancer survivors, gaps in the literature exist as to how primary care physicians may manage certain treatment complications and care for these women effectively.

2. The scoping review identified clinical practice guidelines applicable to the survivorship needs of post-treatment breast cancer patients from two different sources: the American Society of Clinical Oncology, and the Steering Committee on Clinical Practice Guidelines for the Care and Treatment of Breast Cancer, which was convened by Health Canada. The most recent updates of the guidelines were in 2006 and 2005 respectively.
The American Society of Clinical Oncology made guidelines for two areas of survivorship (Khatcheressian, et al., 2006), including:

a) history, physical examination, patient education regarding symptoms of recurrence, and surveillance which also contains recommendations for mammography, coordination of care, gynecologic care, laboratory screening, and imaging, and

b) diet and exercise recommendations.

The Steering Committee on Clinical Practice Guidelines for the Care and Treatment of Breast Cancer developed guidelines which cover nine areas of survivorship (Grunfeld et al., 2005), including:

a) history, physical examination, mammography, and surveillance,

b) psychosocial concerns,

c) coordination of care,

d) cognitive functioning,

e) fatigue,

f) weight management,

g) osteoporosis,

h) sexual functioning, and

i) pregnancy.
3. Interviews with post-treatment breast cancer patients and primary care physicians validated some of the findings identified by the scoping review in terms of secondary health complications resulting from breast cancer treatments as well as the challenges associated with coordinating the care of breast cancer survivors. Interviews also demonstrated a gap between research findings and clinical practice as physicians were not aware of certain research findings or published guidelines for the care of post-treatment breast cancer patients. Additionally, the importance of certain aspects of care as highlighted by the patients and physicians has not been emphasized in the current body of survivorship literature.

Each of these findings is discussed further in the subsequent sections of this chapter.

5.1.1. Primary Health Care Needs of Post-Treatment Breast Cancer Patients

The findings of this thesis have highlighted the vast range of health complications associated with breast cancer treatments and consequently the primary care needs of these women as they enter the phase of breast cancer survivorship. Of the eleven categories identified by the scoping review as significant health complications that may be addressed by primary care physicians, there are five that are supported by a comprehensive body of evidence which includes a reasonably complete understanding of the underlying mechanism in combination with effective primary care interventions. These
categories are surgical complications, additional primary cancers, cardiovascular implications, osteoporosis, and obesity and nutrition issues. However, the remaining categories highlight significant gaps in our knowledge of either the mechanisms underlying the health complications from certain treatments and subsequently our ability to create effective interventions, or areas in which the pathology is understood yet still require additional research in order to discover effective therapies.

Lymphedema is arguably one of the most debilitating ramifications of breast cancer treatments and affects a significant percentage of breast cancer survivors, and yet preventative measures are the most effective defence as there are still no decisively curative interventions. Published recommendations that exist simply caution physicians to monitor for the occurrence of lymphedema and state that further research is need to determine an effective intervention. Given the devastating nature of its onset, lymphedema represents a critically important research area in need of the discovery of effective treatments, comprehensive evaluation of current treatments, and emphasis on preventative practices through improved patient education.

Some of the gynecologic and reproductive implications such as mood disturbances and vaginal dryness for example may be addressed with pharmacological interventions and vaginal lubricants. The use of SSRIs has also proven successful to ameliorate hot flushes. However, given that many breast cancer survivors experience menopausal symptoms at a much greater intensity
than the average women transitioning into menopause due to the immediate ovarian failure, coupled with the fact that estrogen replacement is contraindicated in this population, and also that a large percentage of breast cancer survivors won’t have the opportunity to benefit from the use of SSRIs due to the adverse interaction with tamoxifen, this is a particularly concerning gap in our current knowledge. The range of side effects is vast and has significant implications for reduced wellbeing and quality of life. As such, particular emphasis must be placed on facilitating new research efforts in this area.

The complex nature of psychosocial issues has been well documented in post-treatment breast cancer patients, and yet a significant body of literature still maintains that this area represents a wide gap in care. Additionally, the only published recommendations suggest that primary care providers inquire about potential concerns, with no concrete evidence regarding effective therapeutic methods or information about other support resources. Due to the nature of family practice in comparison to specialty care, primary care providers are in an ideal position to address these issues by providing support and counselling to these women. Therefore, it is critically important that they are equipped with the proper knowledge and resources to effectively intervene and significantly improve the psychological wellbeing of this patient population.

Fatigue and cognitive dysfunction have both been documented extensively through patient reports and observational studies, however understanding of the pathophysiological mechanisms beneath these issues as they relate to cancer
treatments is lacking, and thus therapies are limited. Most of the literature emphasizes the need for prospective, multi-centred, longitudinal controlled studies to advance our knowledge of these treatment complications.

A growing body of evidence suggests that women who wish to become pregnant after undergoing breast cancer treatments are not at an increased risk of cancer recurrence. However, specific recommendations for primary care physicians in terms of advising a patient on how long she should wait after completion of treatments before getting pregnant are unclear. Additionally, there is very limited information surrounding fertility issues and assisted reproductive options for these women, highlighting an area which needs continued exploration.

5.1.2. Clinical Practice Guidelines

When considering the available guidelines for the follow-up care of breast cancer survivors, there are some which provide useful information for primary care physicians in terms of specific, evidence-based recommendations with effective interventions. Such guidelines include those for history, physical examination and surveillance, diet and exercise, sexual functioning, pregnancy, and osteoporosis. However, while the very existence of the remaining guidelines highlights the presence of certain health issues, they are generally lacking in complete recommendations or therapeutic implications. For example, the guidelines to address psychosocial concerns state that “psychosocial support should be encouraged and facilitated.” However, the supporting evidence lacks
specification of successful interventions and patients who would be at increased risk of developing these issues, and fails to make mention of other psychosocial support resources that may be of benefit to patients.

Similarly, the guidelines to address cognitive dysfunction and fatigue may have minimal impact. The corresponding body of supporting evidence is lacking in terms of our understanding of the underlying mechanisms and thus recommendations are limited.

Finally, the available clinical practice guidelines fail to address some of the important health complications experienced by breast cancer survivors as a result of treatments. Such issues include surgical complications, lymphedema, additional primary cancers, and cardiovascular implications.

While numerous clinical practice guidelines for breast cancer have been published, it was found that the majority corresponded to breast cancer treatments, such as novel surgical or chemotherapeutic recommendations, as opposed to focusing on survivorship care. As a result, the majority of guidelines are directed towards cancer specialists as opposed to primary care physicians. Additionally, while there are a few guidelines published by the Canadian Medical Association and American Society of Clinical Oncology which involve survivorship issues, they were only most recently updated in 2005 and 2006 respectively before federal funding was removed. The Institute of Medicine stipulates that clinical practice guidelines require an update every two to three years at minimum.
(Hewitt, et al., 2006; Rowland, et al., 2006) and this is especially important when considering cancer care given the rapidly evolving nature of cancer treatments.

Taken together, the scoping review has highlighted a critical need for the development of a comprehensive set of current clinical practice guidelines which target primary care physicians and are specifically focused on the survivorship needs of post-treatment breast cancer patients.

5.1.3 Patient and Physician Perspectives

The results of this thesis demonstrate that many of the findings of the scoping review are in concordance with the experiences and perspectives of post-treatment breast cancer patients and primary care physicians. Some of the significant physical and psychological sequelae described in the interviews were identified in the review, although there were several medical issues encountered by the breast cancer survivors who participated in the interviews which were not highlighted in the scoping review, such as radiation therapy-induced burning of the chest skin, peripheral neuropathy, nausea, vomiting, and episcleritis. This is likely because many of these symptoms occur acutely while treatments are still taking place, and thus would be addressed in the cancer clinic with the specialist as opposed to the primary care setting. Additionally, both patients and physicians highlighted barriers to optimal care delivery such as the suboptimal coordination of care and inefficient transitions between specialty and primary care, key issues that were also identified in the literature. The primary care physicians also
discussed their perceived role in the care of post-treatment breast cancer patients and agree with the current body of survivorship literature which emphasizes that they become responsible for the care of women after completion of breast cancer treatments. Furthermore, the physicians supported the findings identified by the scoping review that a gap exists between research findings and clinical practice as they were not aware of certain research findings or published guidelines for the care of post-treatment breast cancer patients. Finally, the interviews comment on areas of the survivorship literature which could undergo further exploration. Patients discussed the importance of certain aspects of care that have not been previously emphasized, such as some of the ideas around participation in their own care as well as the quality and type of care that they could ideally receive.

5.2 Limitations

There are some limitations to consider with the results of this thesis. While a key strength of the scoping review is its ability to rigorously and rapidly map a particular area of research, it has inherent limitations. First of all, scoping reviews do not evaluate the quality of evidence gathered in the primary research. Thus, the amount of data generated can be considerable, which can lead to difficult decisions about the extent to which broad coverage is more important than detailed coverage (Arksey and O'Malley, 2005). Additionally, scoping reviews do not address the issue of ‘synthesis,’ which is the relative weight of the evidence in favour of the effectiveness of any particular intervention (Arksey and O'Malley, 2005). Consequently, scoping reviews provide a descriptive account of the literature. For these reasons, scoping reviews are excellent tools to map the
literature in order to find areas to pursue a systematic review, as they do require appraisal of study quality. However, it should be noted that it would be inaccurate to view the scoping review method as a simple option because it avoids difficulties around evaluating the quality of studies. Indeed, Arksey and O’Malley (2005) stipulate that conducting a scoping review requires a high degree of analytic skill in order to process and describe a large volume of research.

A second limitation of this study is that it is possible that the scoping review did not identify all relevant research, such as those articles which focus on psychosocial issues highlighted in the interviews with breast cancer survivors. This is likely a result of the keywords and databases used in the electronic search. In order to address this issue, it might be useful to conduct an additional search in interprofessional health care databases, including those related to nursing, physiotherapy, occupational therapy, psychology, and social work, and through the indexing of key articles, identify additional search terms which may ultimately lead to a more comprehensive account of the literature related to breast cancer survivorship.

A third limitation of this study is that the two family physicians who were interviewed did not have a great amount of current experience to draw upon based on the number of post-treatment breast cancer patients in their practice. It would be interesting to learn the perspectives of other family doctors who have contact with numerous breast cancer survivors.
A fourth limitation of this study is the limited number of post-treatment breast cancer patients who were interviewed. Due to the heterogeneous nature of breast cancer and its treatments, there are many different treatment protocols and therefore many different complications of treatments. Thus, interviewing a greater number of patients would theoretically allow for a more generalizable narrative of the primary care needs of post-treatment breast cancer patients.

A fifth limitation of this study is that all of the women who were interviewed came from reasonably similar socioeconomic backgrounds, led fairly healthy lifestyles prior to their cancer diagnoses, and underwent treatment for breast cancer in the same health care setting. It would be interesting to hear from women with different socioeconomic and health backgrounds to understand whether these factors contribute to different survivorship experiences. Additionally, it would also be valuable to gain the perspectives of women who have received treatments in different care settings and regions to learn about potential differences in care delivery as well as implications of the availability of certain resources.

5.3 Future Directions

The future directions arising from this thesis will be discussed in three categories as they apply to new research implications.
5.3.1 **Filling Current Literature Gaps**

It is clear from the findings of the scoping review that there are certain knowledge gaps regarding the long-term toxicities of breast cancer treatments, and effective primary care interventions to help patients cope with the complications of treatment. For example, there is a need to develop and evaluate treatments for lymphedema, and to determine the modifiable mechanisms underlying cognitive dysfunction and extreme fatigue following chemotherapy, to develop therapies to minimize the associated symptoms.

Moreover, research should focus on finding effective treatments to diminish the side effects of the rapid menopausal transition encountered by a large proportion of breast cancer survivors, as well as obtaining a better understanding of the fertility issues experienced by younger women who wish to become pregnant following treatments. Finally, significant gains can be made to facilitate effective intervention for psychosocial concerns of post-treatment breast cancer patients. Specifically, improving methods of care coordination by eliminating the fragmented nature of the transition from specialty to primary care may significantly ease the psychological burden experienced by many women as they enter the phase of cancer survivorship.

5.3.2 **Development of Current Clinical Practice Guidelines**

With rapid advances in cancer medicine there is a growing population of cancer survivors, and upon completion of cancer treatments many of these
individuals develop potentially devastating treatment-related health consequences. As a result, the Institute of Medicine and Canadian Partnership Against Cancer have recently emphasized the need to view cancer survivorship as a distinct phase of cancer treatment. As part of their respective recommendations, the need to generate clinical practice guidelines has been highlighted as an important tool to aid primary care physicians in managing the survivorship needs of this population. Additionally, the rapid evolution of cancer medicine, both in cancer treatments themselves as well as novel therapies to ameliorate side effects of cancer treatments implies that new knowledge will be generated regularly regarding the side effects of advancing treatments and corresponding primary care interventions. Thus, it is critically important in this field that clinical practice guidelines are frequently updated. In fact, the Institute of Medicine recommends that an update take place at least every two to three years (Hewitt, et. al., 2006).

The findings from this thesis have demonstrated three important conclusions for the clinical practice guidelines related to primary care for post-treatment breast cancer patients. First, only a few breast cancer guidelines which specifically focus on survivorship even exist. Second, some of the existing guidelines lack recommendations for primary care interventions which is likely related to knowledge gaps. Finally, the most recent update of Canadian clinical practice guidelines took place in 2005. Thus, they are out of date and may not facilitate delivery of optimal care. Taken together, the development and regular update of a novel set of comprehensive clinical practice guidelines, which will aid primary care physicians in their ability to care for post-treatment breast cancer
patients, is an important area of future research as this population continues to rapidly grow and evolve.

5.3.3 Knowledge Translation

In 2007, an evaluation of the effectiveness of the Canadian clinical practice guidelines for breast cancer was undertaken (Latosinsky, et al., 2007). It was concluded that the guidelines were not meeting their stated objective, citing the need for new methods of knowledge translation. It was later proposed that the guidelines were ‘as effective as possible under the circumstances’ (Grunfeld, 2007) due to the complex nature of disseminating guidelines, and that to expect clinical practice to change following the simple publication of guidelines, without appreciating the complex factors that facilitate their uptake, is unrealistic (Grunfeld, 2007).

In the clinical setting, it is the responsibility of the primary care physician to address the follow-up care needs of patients who have undergone breast cancer treatment (Grunfeld, 2008). However, due to the current nature of family practice, many physicians lack the time and resources necessary to maintain current knowledge of best practices in every health area (Boissel, Amsallem, Cucherat, Nony, & Haugh, 2004), leading to a gap in the quality of primary care delivery. A key issue that has been identified to exacerbate the knowledge gap between research and clinical practice is the rapid accumulation of evidence and the ability of practitioners to keep up with new information in all health areas (Armstrong,
Waters, Crockett, & Keleher, 2007). Additionally, it has been suggested that primary care physicians face significant constraints with the amount of time that they can dedicate to searching for new research evidence compared with the time required to cognitively interpret and translate the information to practice (Boissel, et al., 2004). Moreover, with the rapid advancements in healthcare research today, the amount of novel evidence and growing complexity of the evidence is well beyond the human capacity for synthesizing knowledge, and physicians simply cannot manage such expanding volumes of evidence concurrently with the ongoing demands of family practice (Sim & Rennels, 1997). Accordingly, in order to address this issue it may become pertinent to identify alternative models of care which facilitate an increasingly interprofessional approach to rehabilitation in cancer survivors.

Boissel (2004) maintains that for optimal patient care, primary care physicians need to be able to estimate the benefits and risks for clinical guidelines based on the specific needs of each individual patient. Therefore, primary care physicians need access to a vast amount of information which must be reliable and immediately available for use. Thus, a major challenge to delivering optimal care has been identifying a strategy whereby primary care physicians receive current evidence-based research outlining novel best practice guidelines in a manner that is easily understandable and readily translatable to their everyday practice.
Currently, there is limited research demonstrating efficient and effective translation of new clinical knowledge to primary care practitioners. However, it has been demonstrated that new evidence-based practice guidelines are unlikely to initiate change in the clinical setting unless they are linked to a knowledge management process that includes practitioner engagement (Armstrong, et al., 2007), highlighting a major barrier to the uptake of new research information as time pressure for practitioners. They also found that practitioners were less likely to make use of resources which were too long, too general and too difficult to navigate and revealed practitioner concerns about the need for quick and easy access to the evidence-based literature. Furthermore, it has been demonstrated that primary care physicians are able to incorporate new practices of follow-up care for breast cancer survivors as long as regularly updated practice guidelines are made available to them in a manner that may be easily understood and incorporated into daily practice (Grunfeld, et al., 2006).

The growing awareness that research findings are not being translated into clinical practice in an efficient manner, coupled with current emphasis on evidence-based healthcare practice has highlighted the need to find ways to minimize barriers in translating knowledge to action (Graham et. al., 2006) with the outcomes of improving primary care delivery to patients. It is clear that new methods of knowledge translation to aid family physicians in bridging the gap between research and practice need to be developed. Accordingly, the findings of this thesis will ideally be incorporated into an innovative knowledge translation strategy that is underway at Queen’s University in Kingston, Ontario, called
“Actionable Nuggets”™ (Aiken & McColl, 2009). This technique employs the use of focused packages of evidence-based information outlining the primary care needs of post-treatment breast cancer patients, which may be disseminated to family physicians and rapidly translated into clinical action.

5.4 Conclusions

Although treatment of the malignancy is essential for a desirable long-term prognosis, it is clear that many breast cancer patients have fewer health issues before commencing treatment than upon treatment completion. The multitude of secondary health complications associated with breast cancer treatment highlights the long-term primary care needs of these patients. Notably, monitoring for potential infection and cellulitis, managing issues associated with rapid menopausal transition and lymphedema, providing support for psychosocial sequelae and cognitive dysfunction, monitoring for second primary cancers, cardiovascular damage and osteoporosis, making recommendations for lifestyle modifications, helping to reduce pain and fatigue, and meeting informational needs.

With this extensive list of rehabilitative needs, it is not surprising that the Institute of Medicine’s landmark survivorship report emphasized the notion that: “the focus on physical and emotional healing is key during the survivorship phase and primary care professionals can do much to intervene in a positive manner.” However, in order for this to be possible there are challenges which must be overcome. Such challenges include improving interprofessional collaboration and
communication, creating a formal protocol to ease the transition of patients into the survivorship phase, as well as generating new knowledge about effective therapies accompanied by successful methods of translating such knowledge into clinical practice.

When equipped with the proper knowledge and resources, the enduring relationships formed between primary care physicians and post-treatment breast cancer patients can be invaluable for improving quality of life and potentially affecting long-term survival as these women embark upon and tackle the challenges associated with breast cancer survivorship.
Reference List


## Appendix A

### Charting of Articles Included in the Scoping Review

<table>
<thead>
<tr>
<th>Reference</th>
<th>Aim of the Study</th>
<th>Summary of Methodology and Level of Evidence</th>
<th>Key Findings</th>
</tr>
</thead>
<tbody>
<tr>
<td>Apantaku (2002)</td>
<td>Overview of surgical treatments for breast cancer. Presents breast-conserving methods.</td>
<td>Nonsystematic review of literature (level IV)</td>
<td>Needle biopsies may be used to minimize scarring. Preferred method of treatment for women diagnosed with early breast cancer is lumpectomy plus radiation. Sentinel node biopsy is being investigated as an alternative to axillary node dissection, hopefully reducing morbidity by minimizing onset of lymphedema. Reconstruction after mastectomy is now routinely formed. History, physical, mammography are the most effective means of follow-up.</td>
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<tr>
<td>Badger, Preston, Seers, &amp; Mortimer (2004)</td>
<td>To assess the effect of physiotherapy on volume, shape, condition and long-term control of lymphedema.</td>
<td>Cochrane Review (level I)</td>
<td>Only three studies involving 150 randomised patients were included. One crossover study of manual lymph drainage (MLD) followed by self-administered massage versus no treatment, concluded that improvements seen in both groups were attributable to the use of compression sleeves and that MLD provided no extra</td>
</tr>
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</table>
benefit at any point during the trial.

Another trial looked at hosiery versus no treatment and had a very high dropout rate. The authors concluded that wearing a compression sleeve is beneficial.

The bandage plus hosiery versus hosiery alone trial, concluded that in this mixed group of participants bandage plus hosiery resulted in a greater reduction in excess limb volume than hosiery alone and this difference in reduction was maintained long-term.

All three trials have their limitations and have yet to be replicated, so their results must be viewed with caution. There is a clear need for well-designed, randomised trials of the whole range of physical therapies to determine the best approach to managing lymphedema.

<table>
<thead>
<tr>
<th>Author(s)</th>
<th>Title</th>
<th>Study Type</th>
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<tbody>
<tr>
<td>Bines &amp; Gradishar (1997)</td>
<td>Overview of primary care concerns for the breast cancer survivor.</td>
<td>Nonsystematic review of literature (level IV)</td>
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</tbody>
</table>

Discussion of primary care and quality-of-life issues for the breast cancer survivor particularly pertaining to psychosocial concerns and second primary cancers (AML, MDS, endometrial).

Difficulties faced by the FP such as breaking bad news, finding a treatment team, managing the side effects of treatment, and providing information and support for the patient and her family are discussed.
<table>
<thead>
<tr>
<th>Brezden, Phillips, Abdolell, Bunston, &amp; Tannock (2000)</th>
<th>Assess whether there are differences in cognitive function between breast cancer patients treated with standard dose adjuvant chemotherapy compared with healthy controls.</th>
<th>Case-control questionnaire of 31 women currently undergoing treatment, 40 women who had completed treatment, and 36 healthy controls (level III).</th>
<th>Cognitive differences were observed in breast cancer patients receiving adjuvant chemotherapy compared with healthy controls.</th>
</tr>
</thead>
<tbody>
<tr>
<td>Bruno and Feeney (2006)</td>
<td>Discussion of the evidence for the use of alternative therapies for menopausal symptoms in breast cancer survivors.</td>
<td>Nonsystematic review of literature (level IV)</td>
<td>The use of antidepressants (fluoxetine, clonidine, gabapentin) is recommended but not if the woman is taking tamoxifen. Recommend use of vaginal moisturizer as needed. Avoid use of high estradiol rings because of the risk of recurrent cancer. Lack of safety data for the efficacy of topical estrogen.</td>
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<tr>
<td>Chalasani, Downey, &amp; Stopeck (2010)</td>
<td>Review of the primary care needs of the breast cancer survivor.</td>
<td>Nonsystematic review of literature (level IV)</td>
<td>Complications of treatment for breast cancer, including lymphedema, osteoporosis, cardiovascular disease, and vasomotor symptoms are discussed as well as strategies for screening, monitoring, and treating</td>
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<td>Study</td>
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<tr>
<td>Cheifetz, Haley, &amp; Breast Cancer Action (2010)</td>
<td>Review of the management of lymphedema following breast cancer treatment.</td>
<td>Evidence suggests that there are several safe and beneficial treatments, including complex decongestive therapy, physiotherapy, and exercise. Resistive exercises have been found to be both beneficial and safe with careful progression and monitoring.</td>
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<tr>
<td>Cheville (2010)</td>
<td>Assess the impact of early physiotherapy after axillary node dissection in reducing the onset of lymphedema in breast cancer survivors.</td>
<td>Evidence supports the usefulness of physiotherapy after surgical clearance of the axillary lymph nodes to control pain, enhance shoulder functionality and range of motion, and reduce a woman’s risk of developing lymphedema. Future research is needed to assess the efficacy of specific treatment modalities such as education and manual lymphatic draining.</td>
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<tr>
<td>Chilson, Chan, &amp; Lonser (1992)</td>
<td>Assess the impact of the flap tacking surgical procedure on reducing the number of women who develop a seromas following mastectomy and thus reducing the amount of necessary office visits in the first two months after the operation.</td>
<td>The most common mastectomy-associated complication is seroma formation and can be associated with other more serious complications such as skin flap necrosis, delayed wound healing, infection, and lymphedema. Women who developed a seroma, compared to those who did not, averaged nearly twice as any office visits in the first two months after the operation.</td>
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<tr>
<td>Author(s)</td>
<td>Title</td>
<td>Study Design</td>
<td>Summary</td>
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<tr>
<td>Chlebowski, Kim, &amp; Cole (2003)</td>
<td>Review of the management of symptoms of estrogen deficiency in breast cancer survivors.</td>
<td>Nonsystematic review of literature (level IV)</td>
<td>Given the potential for adverse influence of menopausal hormones on breast cancer recurrence risk, menopausal hormones should not be used for chronic disease risk reduction in breast cancer survivors. The SSRIs and Gabapentin represent a reasonable first choice for vasomotor symptoms management in breast cancer survivors. Most other proposed pharmacological and herbal interventions when vigorously tested have been found to have modest to no efficacy and/or limiting toxicity.</td>
</tr>
<tr>
<td>Cole and Strair, (2010)</td>
<td>To bring to the attention of family physicians the unintended consequence of leukemia secondary to aggressively treated breast cancer.</td>
<td>Systematic review of the literature and medical records of several patients from Robert Wood Johnson University Hospital, with previously treated breast cancer admitted for therapy for AML or Chemotherapy and radiation therapy administered for breast cancer predispose patients to the development of MDS or AML. The authors hypothesize that the breast cancer (BRCA) gene mutations might add to the risk and that primary care physicians must be aware of the long-term risks of cytotoxic therapy, including the development of MDS or</td>
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<tr>
<td>Author(s)</td>
<td>Research Objective</td>
<td>Methodology</td>
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<tr>
<td>Collins, Bekker, &amp; Dodwell (2004)</td>
<td>To identify and integrate primary research on the effectiveness of follow-up services for breast cancer patients.</td>
<td>Systematic review of the literature (level I).</td>
<td>Patient survival and quality of life were not affected by intensity of follow-up or location of care. Patients held positive attitudes towards follow-up but psychological distress was consistently high regardless of location of services.</td>
</tr>
<tr>
<td>Erickson, Pearson, Ganz, Adams, &amp; Kahn (2001)</td>
<td>To summarize the research literature related to the management of lymphedema in women with breast cancer.</td>
<td>Systematic review of published breast cancer guidelines and literature (level I)</td>
<td>Arm edema is a common complication of breast cancer therapy that can result in substantial functional impairment and psychological morbidity. The risk of arm edema increases when axillary dissection and axillary radiation therapy are used. Recommendations for preventive measures, such as avoidance of trauma, are available, but these measures have not been well studied. Nonpharmacologic treatments, such as massage and exercise, have been shown to be effective therapies for lymphedema, but the effect of pharmacologic interventions remains uncertain.</td>
</tr>
<tr>
<td>Fleysher (2010)</td>
<td>To provide health professionals with specific educational tools with regard to the prevention,</td>
<td>Narrative review of recommendations for health professionals (level IV).</td>
<td>There is no cure for lymphedema once it has developed, thus prevention is essential. Therefore, patient education regarding risk reducing behaviours (avoiding trauma to the affected side, exercise,</td>
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<td>Study</td>
<td>Methodology</td>
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<td>Recommendations</td>
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<tr>
<td>Ford, Easton, Stratton, Narod, Goldgar, Devilee (1998)</td>
<td>Assess the contribution of BRCA1 and BRCA2 mutations to inherited breast cancer. Linkage and mutation analysis in 237 families, each with at least 4 cases of breast cancer (level III).</td>
<td>Overall, disease was linked to BRCA1 in an estimated 52% of families, to BRCA2 in 32% of families, and to neither gene in 16%, suggesting other predisposition genes. The estimated cumulative risk of breast cancer reached 28% by age 50 years and 84% by age 70 years. The corresponding ovarian cancer risks were 0.4% by age 50 years and 27% by age 70 years.</td>
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<tr>
<td>Fu, Axelrod, &amp; Haber (2008)</td>
<td>To explore the effect of providing lymphedema information on breast cancer survivors’ symptoms and practice of risk-reduction behaviors. Cross-sectional design was used to obtain data from 136 breast-cancer survivors in New York City from August 2006 to May 2007 through an interview tool, the Lymphedema and Breast Cancer Questionnaire, and Lymphedema Risk-Reduction Behavior Checklist (level III).</td>
<td>Providing lymphedema information has an effect on symptom reduction and more risk-reduction behaviours being practiced among breast cancer survivors.</td>
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<tr>
<td>Ganz (1998)</td>
<td>Narrative review of literature (level IV)</td>
<td>Emphasis is placed upon providing patients with information of the potential chemotherapy-associated cognitive dysfunction which</td>
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<td>Source</td>
<td>Methodology</td>
<td>Findings/Results</td>
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<tr>
<td>Ganz (2001)</td>
<td>Review the symptoms and everyday problems associated with tamoxifen adjuvant therapy and their impact on patients’ quality of life.</td>
<td>Purported toxic effects of tamoxifen therapy include premature menopause, weight gain, and depression. Ultimately, the decision to receive tamoxifen therapy is a personal choice for each woman to make on the basis of the evidence of tamoxifen therapy’s benefits and risks, along with her own motivation to receive therapy.</td>
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<tr>
<td>Ganz, Desmond, Belin, Meyerowitz, &amp; Rowland (1999)</td>
<td>To identify variables that might be predictive of sexual health (interest, dysfunction, and satisfaction) in a large sample of breast cancer survivors.</td>
<td>The common predictors of sexual health were vaginal dryness, emotional wellbeing, body image, the quality of the partnered relationship, and sexual problems in the partner, offering potential avenues for future interventions to address the sexual health and well-being of breast cancer survivors.</td>
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</tr>
<tr>
<td>Ganz, Desmond, Leedham, Rowland, Meyerowitz, &amp; Belin (2002)</td>
<td>Obtain information regarding the long-term quality of life of breast cancer survivors.</td>
<td>Survey of 914 women who were between 5 and 10 years after their initial cancer diagnosis (level III). Long-term, disease-free breast cancer survivors reported high levels of functioning and quality of life many years after primary treatment. Past systemic adjuvant adjuvant therapy.</td>
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<tr>
<td>Reference</td>
<td>Study Objective</td>
<td>Study Design</td>
<td>Conclusion</td>
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<tr>
<td>Ganz, Greendale, Petersen, Zibecchi, Kahn, &amp; Belin (2000)</td>
<td>To test the efficacy of a comprehensive menopausal assessment (CMA) intervention program in achieving relief of symptoms, the improvement in quality of life, and sexual functioning in breast cancer survivors.</td>
<td>Randomized controlled trial (level I).</td>
<td>A clinical assessment and intervention program for menopausal symptom management in breast cancer survivors is feasible and acceptable to patients, leading to reduction in symptoms and improvement in sexual functioning. Measurable improvement in a general quality of life measure was not demonstrated.</td>
</tr>
<tr>
<td>Ganz, Kwan, Stanton, Krupnick, Rowland, Meyerowitz (2004)</td>
<td>Investigate the baseline psychosocial status of women enrolled in a randomized trial testing two psychosocial interventions for at the end of primary breast cancer treatment.</td>
<td>Randomized controlled trial (level I).</td>
<td>Women in all report good emotional functioning but report decreased physical functioning, particularly among women who have a mastectomy or receive chemotherapy. Clinical interventions to address common symptoms associated with treatment should be considered to improve physical and emotional functioning at the end of primary treatment for breast cancer.</td>
</tr>
<tr>
<td>Gaudine, Sturge-Jacobs, &amp; Kennedy (2003)</td>
<td>To understand the experience of waiting and of follow-up from the perspective of</td>
<td>Phenomenological study, approach, using semi-structured interviews to capture the</td>
<td>The women’s experiences were captured in four themes: life-changing; a sense of belonging; uncertainty; needing to know.</td>
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<td>Authors</td>
<td>Study Objective</td>
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<tr>
<td>Giuliano, Hunt, Ballman, Beitsch, Whitworth, &amp; Blumencranz (2011)</td>
<td>To determine the effects of complete axillary lymph node dissection on survival of patients with sentinel lymph node metastasis of breast cancer.</td>
<td>Among patients with limited SLN metastatic breast cancer treated with breast conservation and systemic therapy, the use of SLND alone compared with ALND did not result in inferior survival.</td>
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<tr>
<td>Grunfeld, Dhesy-Thind, Levine, &amp; Fossati (2005)</td>
<td>To provide information and recommendations to patients and their physicians regarding follow-up strategies and topics relevant to follow-up after treatment for breast cancer.</td>
<td>All patients with breast cancer should have regular follow-up surveillance. All visits should include a medical history. For women who are taking tamoxifen, it is important to ask about vaginal bleeding. Physical examination should include breasts, regional lymph nodes, chest wall, lungs and abdomen. The arms should be examined for lymphedema. Annual visits should include mammographic examination. Routine laboratory and radiographic investigations should not be carried out for the purpose of detecting</td>
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distant metastases.

Psychosocial support should be encouraged and facilitated.

Fatigue may affect approximately one-quarter to one-third of breast cancer survivors. Patients should be asked about symptoms of fatigue and physiologic causes of fatigue such as depression and pain should be investigated and treated.

Weight management should be discussed with all breast cancer survivors. Overweight patients should be encouraged to participate in evidence-based weight-management programs.

Patients who are postmenopausal, or are premenopausal with risk factors for osteoporosis, or are taking aromatase inhibitors should undergo a screening bone mineral density test, and be counselled on exercise and on adequate intake of calcium and vitamin D. Osteoporosis treatment should include a bisphosphonate.

Women considering pregnancy following a diagnosis of breast cancer should be informed of the limited data on the effect of pregnancy on outcomes such as breast cancer recurrence.
and survival. There is currently no evidence that subsequent pregnancy adversely affects survival.

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<tr>
<td>Hayes (2007)</td>
<td>Provide a review of current literature for clinicians regarding health care issues faced by the breast cancer survivor along with subsequent interventions.</td>
<td>Nonsystematic review of literature (level IV).</td>
<td>Annual mammographic screening and physical examination are warranted to screen for new primary breast cancers, but no specific screening is recommended for occult metastatic disease or rare treatment-related cancers in asymptomatic patients.</td>
<td>The consequences of premature menopause, antiestrogen therapy, and other adjuvant therapies should be recognized and treated if indicated, and estrogen therapy avoided. Medications, including SSRIs, SSNRIIs, and gabapentin, may be effective in treating hot flashes.</td>
<td>Sexual dysfunction can be addressed through sexual counselling and treatment of vaginal dryness with nonhormonal preparations or with cautious use of estrogen ring preparations, with the</td>
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recognition that there is the potential for slight systemic absorption.

Bone mineral density should be assessed, adequate intake of calcium and vitamin D and regular weight-bearing exercise encouraged, and bisphosphonate treatment initiated, if indicated.

<table>
<thead>
<tr>
<th>Author(s)</th>
<th>Description of Cancer Survivorship</th>
<th>Evidence Type</th>
<th>Summary</th>
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</thead>
<tbody>
<tr>
<td>Hewitt, Greenfield &amp; Stoval (2006)</td>
<td>Address and describe cancer survivorship, barriers to optimal care, methods to improve care deliver, and health issues faced by certain patient populations.</td>
<td>Nonsystematic review of the literature (level IV).</td>
<td>Survivorship needs to be recognized as a distinct phase of cancer treatment. Emphasis on the need for clinical practice guidelines and survivorship care plans to help physicians meet the survivorship needs of patients as they transition into survivorship.</td>
</tr>
<tr>
<td>Hurria, Wong, Villaluna, Bhatia, Chung &amp; Mortimer (2008)</td>
<td>Discuss the principles of follow-up care of the breast cancer survivor.</td>
<td>Nonsystematic review of literature (level IV).</td>
<td>An emphasis is placed on detection of recurrent disease in the breast or a second primary tumour. An understanding of the side effects of loco-regional and systemic treatment (psychological, weight gain, menopausal side effects,</td>
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<tr>
<td>Author(s)</td>
<td>Description</td>
<td>Expert Opinion (level V)</td>
<td>Explanation</td>
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<tr>
<td>Kattlove and Winn (2003)</td>
<td>Describe aftercare issues for the most common cancers to alert physicians to be aware of and help survivors to deal with these issues.</td>
<td></td>
<td>Emphasis on follow-up to specifically address psychosocial issues, especially discussion of fears of recurrence.</td>
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<tr>
<td>Kent (2002)</td>
<td>Discussing the dragon boat involvement of many breast cancer survivors.</td>
<td></td>
<td>While evidence is still uncertain, many women around the world are now taking part and the effect has been so profound and positive on their emotions.</td>
</tr>
<tr>
<td>Khatcheresian and Smith (2006)</td>
<td>Discuss the impact of the RCT done by Grunfeld et al., 2006 regarding family physician vs. specialist follow-up.</td>
<td></td>
<td>The evidence from multiple randomized clinical trials suggests that the American Society of Clinical Oncology should begin partnering with primary care colleagues to better improve the follow-up process.</td>
</tr>
<tr>
<td>Khatcheresian, Wolff, Smith, Grunfeld, Muss, Vogel (2006)</td>
<td>To update the 1999 American Society of Clinical Oncology (ASCO) guideline on breast cancer follow-up and management in the adjuvant setting.</td>
<td>An ASCO Expert Panel reviewed pertinent information from the literature through March 2006. More weight was given to studies that tested a hypothesis directly relating testing to one of the primary</td>
<td>All patients should have a careful history and physical examination. Examinations should be performed every 3 to 6 months for the first 3 years, every 6 to 12 months for years 4 and 5, and annually thereafter. For those who have undergone breast-conserving surgery, a post-treatment mammogram should be obtained 1 year after the initial mammogram and at least 6 months after</td>
</tr>
<tr>
<td>Kirschner (2005)</td>
<td>Discuss follow-up issues related to the young breast cancer survivor.</td>
<td>Nonsystematic review of literature (level IV).</td>
<td>Young women have complex healthcare needs following breast cancer treatment, specifically around reproductive concerns and sexual functioning. There is a need for interprofessional collaboration from social workers, sex therapists, gynecologists and primary care physicians to manage the follow-up care of young women with breast cancer.</td>
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<tr>
<td>Kligman, Wong, Johnston, &amp; Laetsch (2004)</td>
<td>Provide an evidence summary report on the question: What</td>
<td>Systematic review of literature (level I).</td>
<td>There is some evidence to suggest that compression therapy and manual lymphatic drainage may improve established outcomes in a randomized design (level II).</td>
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<tr>
<td>Study</td>
<td>Research Question</td>
<td>Methodology</td>
<td>Findings</td>
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<tr>
<td>Korstjens, Mesters, Gijsen, &amp; Den (2008)</td>
<td>Explore patients’ perspectives on how and to what extent the rehabilitation program had met their needs in order to optimize the program.</td>
<td>An existing 12-week cancer rehabilitation group program, combining physical training and psychosocial sessions, was recently tested in a longitudinal cohort study ($n = 658$). This study employed interviews and focus groups with patients to evaluate the program.</td>
<td>Participants valued the group-based multi-modal cancer rehabilitation program and recommendations mainly concerned the psychosocial component, suggesting that it should focus more on developing skills to cope with cancer.</td>
</tr>
<tr>
<td>Love, Wiebe, &amp; Newcomb (1991)</td>
<td>Determine the effects of tamoxifen on cardiovascular risk factors in postmenopausal women</td>
<td>Double blind randomized controlled trial,</td>
<td>During 2 years of treatment, tamoxifen showed generally beneficial effects on the lipid and lipoprotein profiles in postmenopausal women which may partially explain...</td>
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<td>Source</td>
<td>Description</td>
<td>Methodology</td>
<td>Conclusion</td>
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<tr>
<td>Lyon, Roux, &amp; Voll (2006)</td>
<td>Review the current knowledge regarding survivorship issues in women with early-stage, estrogen receptor–positive breast cancer, focusing on advances in hormonal therapies for reducing the risk of recurrence.</td>
<td>Nonsystematic review of literature (level IV).</td>
<td>Innovations in antiestrogenic and estrogen modulator therapies are an important aspect of ongoing care after primary breast cancer treatment.                                                                                                    Primary care providers may play an important role in monitoring potential complications of antiestrogenic treatment.</td>
</tr>
<tr>
<td>Matesich and Shapiro (2003)</td>
<td>Overview of second cancers after breast cancer treatment.</td>
<td>Nonsystematic review of literature (level IV).</td>
<td>Breast irradiation, adjuvant chemotherapy, and tamoxifen are associated with an increased risk of second cancers such as sarcomas, leukemias, and endometrial cancers, that may manifest decades after treatment.                                                                                     The benefits of adjuvant therapy outweigh the risks of developing second cancers. Additional studies are needed to more precisely identify patients who are or are not likely to benefit from adjuvant therapy, and individual factors that influence the development of second cancer.</td>
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<tr>
<th>Author</th>
<th>Text</th>
<th>Methodology</th>
<th>Conclusion</th>
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<tbody>
<tr>
<td>Maunsell, Brisson, &amp; Deschenes (1992)</td>
<td>Evaluate risk for psychosocial distress following breast cancer treatment.</td>
<td>Potential risk factors for psychological distress were assessed among 205 patients by home interview 3 and 18 months after surgery.</td>
<td>The number of stressful life events before diagnosis and history of depression appear to be strong indicators of the risk of psychological distress and may be useful for identifying patients with breast cancer in need of more intense psychosocial support.</td>
</tr>
<tr>
<td>McCarthy (2004)</td>
<td>Review of health issues faced by the breast cancer survivor.</td>
<td>Nonsystematic review of literature (level IV)</td>
<td>Health issues such as menopause, lymphedema, pregnancy, and cardiac toxicity are discussed.</td>
</tr>
<tr>
<td>McKinley (2000)</td>
<td>The author is a family physician and breast cancer survivor who uses her experiences to call attention to things a family doctor can do to help support women in the survivorship phase.</td>
<td>Expert opinion (level V)</td>
<td>The primary care physician will be seeing an increasing number of survivors and must focus on how their survivors are faring, both emotionally and physically. Emphasis on the importance of simply talking to survivors about their fears and the changes cancer has brought to their lives.</td>
</tr>
<tr>
<td>Moore (2001)</td>
<td>Discuss the diagnosis, management, and follow-up of chemotherapy-induced congestive heart failure (CHF) in breast cancer survivors.</td>
<td>Expert opinion and review of case study (level V).</td>
<td>Chemotherapy-induced CHF may occur years following completion of breast cancer treatments. Recognition of risk factors and symptoms of CHF is essential to minimize the morbidity and mortality that accompanies cardiac failure. It is imperative that family physicians are aware of the risks of this disorder amongst breast cancer survivors under their care.</td>
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<tr>
<td>Moyer</td>
<td>Compare the</td>
<td>Meta-analytic</td>
<td>Modest advantages for</td>
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<td>Year</td>
<td>Study Title</td>
<td>Methodology</td>
<td>Findings</td>
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<tr>
<td>1997</td>
<td>Psychosocial outcomes of breast-conserving surgery versus mastectomy on breast cancer survivors.</td>
<td>Review of literature (level I).</td>
<td>Breast-conserving surgery were identified for psychological, marital-sexual, and social adjustment; body/self-image; and cancer-related fears and concerns.</td>
</tr>
<tr>
<td>2005</td>
<td>Mrozek and Shapiro</td>
<td>Nonsystematic review of the literature (level IV).</td>
<td>Breast cancer survivors face many potential complications of treatments, including cardiac toxicity, osteoporosis, additional cancers, and premature ovarian failure. Research efforts to ameliorate treatment-related side effects must be expanded given the increasing number of breast cancer survivors.</td>
</tr>
<tr>
<td>2000</td>
<td>Nelson, O’Brien, Ashikaga &amp; Bosompra</td>
<td>Interviews with breast cancer survivors (level III).</td>
<td>Providing information to patients around lymphedema is critical to reduce its onset and providers need to be motivated to provide information to their patients at every opportunity. Higher levels of awareness and practice of lymphedema reducing behaviours were associated with citing a primary care physician as an information source.</td>
</tr>
<tr>
<td>1998</td>
<td>Oktay</td>
<td>Nonsystematic review of literature (level IV).</td>
<td>Common psychological reactions during and after treatment include anxiety, denial, anger, and depression. Self-image, family issues and social support are also factors.</td>
</tr>
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</table>
in a woman’s ability to cope with breast cancer.

Primary care providers have an important role in improving psychosocial concerns associated with breast cancer, and by being aware of the common psychological and social problems faced by breast cancer survivors, they can be prepared to contribute to a successful outcome for their patients.

<table>
<thead>
<tr>
<th>Author(s)</th>
<th>Title</th>
<th>Source</th>
<th>Description</th>
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<tbody>
<tr>
<td>Partridge, Winer, &amp; Burstein</td>
<td>Overview of literature around follow-up of breast cancer survivors.</td>
<td>Review of literature (level IV)</td>
<td>Women with a history of breast cancer should be followed for recurrence or metastatic disease, as well as for the development of a second primary breast cancer in the contralateral breast. Regular follow-up visits can foster an ongoing patient-clinician relationship both to ensure adequate surveillance and so that symptoms of recurrence or complications of therapy will be reported by the patient and addressed promptly. Clinicians can also provide guidance and counselling as well as psychosocial support to patients regarding medical and psychosocial decisions that may be affected by their personal history of breast cancer.</td>
</tr>
<tr>
<td>Posther, Wilke, &amp; Giuliano</td>
<td>Overview of the clinical trials investigating</td>
<td>Review of literature/expert opinion (level IV).</td>
<td>The current national sentinel lymph node clinical trials for breast carcinoma address the prognostic and therapeutic</td>
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<td>Study</td>
<td>Overview</td>
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<td>Findings</td>
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<tr>
<td>Quirion (2010)</td>
<td>Overview of the physiology of lymphedema, incidence, risks, and costs as well as a guide for the primary care provider on how to recognize the symptoms.</td>
<td>Review of literature and expert opinion (level IV).</td>
<td>Lymphedema is the most common complication related to breast cancer treatment and it most commonly occurs within the first 3 years after breast cancer treatment, but can occur after many years. Complete decongestive therapy, compression bandages, and a proper skin care regime are important for good outcomes after the onset of lymphedema.</td>
</tr>
<tr>
<td>Rietman, Geertzen, &amp; Hoekstra (2006)</td>
<td>Assess long-term upper limb morbidity, quality of life, and activities of daily living in women who underwent sentinel lymph node biopsy versus axillary node dissection.</td>
<td>Prospective study of long term upper-limb morbidity, perceived disabilities in activities of daily life and quality of life were assessed before and two years after sentinel lymph node biopsy or axillary lymph node dissections for breast cancer (level III).</td>
<td>Two years after surgery for breast cancer, women show significantly less treatment related upper limb morbidity, perceived disability in activities of daily living and worsening of quality of life after sentinel lymph node biopsy compared with axillary node dissection.</td>
</tr>
<tr>
<td>Rojas, Telaro,</td>
<td>Assess the effectiveness</td>
<td>Cochrane systematic review</td>
<td>Follow-up programs based on regular physical</td>
</tr>
<tr>
<td>Authors</td>
<td>Overview</td>
<td>Methodology</td>
<td>Findings</td>
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<tr>
<td>Moschetti, Coe, Fossati, Palli (2009)</td>
<td>of different policies of follow-up for distant metastases on mortality, morbidity and quality of life in women treated for breast cancer.</td>
<td>All randomised controlled trials assessing the effectiveness of different policies of follow-up after primary treatment were reviewed for inclusion (level I).</td>
<td>examinations and yearly mammography alone are as effective as more intensive approaches based on laboratory tests in terms of timeliness of recurrence detection, overall survival and quality of life. In one RCT, follow-up care performed by trained general practitioners had comparable effectiveness to that delivered by specialists in terms of quality of life and time to detection of distant metastases.</td>
</tr>
<tr>
<td>Rowland, Desmond, Meyerowitz, Belin, Wyatt, &amp; Ganz (2000)</td>
<td>Examine women’s adaptation to breast cancer surgeries in two large cohorts of breast cancer survivors, focusing on psychosocial outcomes of women who underwent lumpectomy, mastectomy alone, or mastectomy with reconstruction.</td>
<td>Cohort study with a total of 1957 breast cancer survivors (1–5 years after diagnosis) were assessed using a self-report questionnaire that included a number of standardized measures of health-related quality of life, body image, and physical and sexual functioning (level II).</td>
<td>The psychosocial impact of type of primary surgery for breast cancer occurs largely in areas of body image and feelings of attractiveness. Women receiving lumpectomy experience the most positive outcomes. Beyond the first year after diagnosis, a woman’s quality of life is more likely influenced by her age or exposure to adjuvant therapy than by her breast surgery.</td>
</tr>
<tr>
<td>Schag, Ganz, Polinsky, Fred, Hirji, &amp; Petersen (1993)</td>
<td>Provide a description of rehabilitation problems of women, considered to be low risk and at risk for</td>
<td>A sample of 227 newly diagnosed breast cancer patients were systematically interviewed by a clinical social worker and</td>
<td>The at-risk women had significantly more problems with greater severity than the low-risk women in all areas (physical, psychosocial, medical interaction, sexual, and marital) and the at risk group had significantly more</td>
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<tr>
<td>Study</td>
<td>Objective</td>
<td>Methodology</td>
<td>Findings</td>
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<tr>
<td>Sawka, Ioannidis, Papaioannou, Thabane, Olszynski, Brown (2005)</td>
<td>Determine whether oral bisphosphonates are more effective than calcium with vitamin D in improving lumbar spine bone mineral density within one year in breast cancer survivors.</td>
<td>Breast cancer survivors with at least one year of clinical follow-up were identified from the Canadian Database of Osteoporosis and Osteopenia and analysis of covariance was used to examine the effects of bisphosphonates on change in lumbar spine bone mineral density compared to calcium and vitamin D (level III).</td>
<td>Treatment with bisphosphonates was associated with significantly greater improvements in lumbar spine bone mineral density within one year in breast cancer survivors compared with calcium or vitamin D.</td>
</tr>
<tr>
<td>Shapiro and Recht (2001)</td>
<td>Overview of adjuvant therapies used for breast cancer treatment.</td>
<td>Review of literature/expert opinion (level IV).</td>
<td>Adjuvant treatment reduces mortality from breast cancer. Most of the side effects of treatment are reversible, thus, the benefit-to-risk ratio favours adjuvant treatment in women with primary invasive breast tumors that</td>
</tr>
<tr>
<td>Silver (2007)</td>
<td>Discuss the need for rehabilitation for breast cancer survivors, including complications of treatments, as well as interventions.</td>
<td>Literature review/expert opinion (level V).</td>
<td>Discussion of treatments on the impact of women’s health, specifically surgical implications, as well as rehabilitation interventions to encourage exercise and lessen pain and fatigue.</td>
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<tr>
<td>Soran, D'Angelo, &amp; Begovic (2006)</td>
<td>Determine the predictive factors of breast cancer-related lymphedema and investigate the impact of predictors on the severity of lymphedema.</td>
<td>Case-control with patients who underwent breast cancer surgery between 1990 and 2000 and had lymphedema. Data were collected on 52 women with lymphedema and logistic regression was utilized to assess the relationship between risk factors and lymphedema. Risk factors considered were occupation/hobby (hand use), TNM stage, number of dissected nodes, number of positive nodes, tumour size, infection, allergy, diabetes mellitus, hypertension, hypothyroidism, chronic obstructive</td>
<td>The risk and severity of lymphedema was statistically related to infection, body mass index, and level of hand use.</td>
</tr>
<tr>
<td>Author(s)</td>
<td>Topic</td>
<td>Methodology</td>
<td>Key Points</td>
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<tr>
<td>Sparaco &amp; Fentiman (2002)</td>
<td>Overview of lymphedema in breast cancer survivors.</td>
<td>Review of literature/expert opinion (level IV).</td>
<td>A wide range of incidence has been reported but the generally accepted rate is around 12%. The exact pathophysiological mechanisms remain unclear.</td>
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<td>The psychosocial importance and management is fundamental in limiting the impact on survivors.</td>
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<td></td>
<td>Investigation into potential tools that may eliminate or reduce the extent of lymph node dissection without compromising prognosis is warranted.</td>
</tr>
<tr>
<td>Strozzo (1998)</td>
<td>Overview of surgical management of early stage breast cancer for the primary care provider.</td>
<td>Review of literature (level IV).</td>
<td>The primary care physician plays an important role in supporting the breast cancer survivor throughout and after treatment and should be fluent with the issues faced by these women, as well as informed regarding other supportive services in the community.</td>
</tr>
<tr>
<td>Theodoulou and Seidman (2003)</td>
<td>Provide an overview of the cardiac effects of adjuvant therapy in the treatment of early breast cancer.</td>
<td>Nonsystematic review of literature (level IV).</td>
<td>The recognition of late cardiac effects from adjuvant therapies is the most important step in prevention and early intervention of these adverse effects.</td>
</tr>
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<td></td>
<td>The identification of risk factors, (including hypertension, pre-existing cardiac disease, advancing age, and prior mediastinal irradiation) in patients who</td>
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are about to embark on potentially cardiotoxic therapy is critically important.

Modern radiation techniques, the development drugs with safer cardiac profiles, the use of cardioprotective drugs, and optimizing screening methods prior, during, and long after the treatment of drug therapy are all important steps in decreasing the morbidity and mortality from potentially curative interventions.

<table>
<thead>
<tr>
<th>Authors</th>
<th>Study Details</th>
<th>Results</th>
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<tbody>
<tr>
<td>Torres Lacomba, Yuste Sanchez, Zapico Goni, Prieto Merino, Cerezo Tellez, &amp; Minayo Mogollon (2010)</td>
<td>Determine the effectiveness of early physiotherapy in reducing the risk of secondary lymphedema after surgery for breast cancer.</td>
<td>Randomised, single blinded, clinical trial. The early physiotherapy group was treated by a physiotherapist with a physiotherapy program including manual lymph drainage, massage of scar tissue, and shoulder exercises. This group also received an educational strategy. The control group received the educational strategy only (level I). Early physiotherapy could be an effective intervention in the prevention of secondary lymphedema in women for at least one year after surgery for breast cancer involving dissection of axillary lymph nodes.</td>
</tr>
<tr>
<td>Tsai,</td>
<td>Understand the Meta-analytic Mastectomy, extent of</td>
<td></td>
</tr>
<tr>
<td>Study Authors</td>
<td>Study Title</td>
<td>Study Design</td>
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<tr>
<td>Dennis, Lynch, Snetselaar, Zamba, &amp; Scott-Cooner (2009)</td>
<td>Treatment and prognostic factors for lymphedema following breast cancer treatment.</td>
<td>Review of literature (level I).</td>
</tr>
<tr>
<td>Vivar and McQueen (2005)</td>
<td>Review of the informational and emotional needs of long-term breast cancer survivors.</td>
<td>Nonsystematic review of literature (level IV).</td>
</tr>
<tr>
<td>Warner, Plews, Hill, Causer, Zubovitis, Jong (2004)</td>
<td>Compare the sensitivity and specificity of 4 methods of breast cancer surveillance (mammography, ultrasound, MRI, and Surveillance study of 236 Canadian women aged 25 to 65 years with BRCA1 or BRCA2 mutations who underwent 1 to 3 annual examinations).</td>
<td>Surveillance study of 236 Canadian women aged 25 to 65 years with BRCA1 or BRCA2 mutations who underwent 1 to 3 annual examinations.</td>
</tr>
<tr>
<td>Clinical breast examination in women with hereditary susceptibility to breast cancer due to a BRCA1 or BRCA2 mutation.</td>
<td>Screening examinations, consisting of MRI, mammography, and ultrasound. On the day of imaging and at 6-month intervals, clinical breast examination was performed (level II).</td>
<td>Regimens that include MRI will reduce mortality from breast cancer in high-risk women requires further investigation.</td>
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<tr>
<td>Yeh, Tong, Lenihan, Yusuf, Swafford, Champion (2004) Overview of cardiac toxicity of chemotherapeutic agents used in cancer treatments.</td>
<td>Review of literature/expert opinion (level IV).</td>
<td>The cardiac toxicity of anticancer agents can lead to significant complications affecting patients. The severity of toxicity depends on many factors such as the molecular site of action, the immediate and cumulative dose, the method of administration, the presence of any underlying cardiac condition, and the demographics of the patient. Cardiotoxic effects can occur immediately during administration of the drug, or they may not manifest themselves until months or years after the patient has been treated. Further research will be required to more accurately predict which patients are at risk for developing cardiac toxicity and strategies to reduce cardiac toxicity, need to be developed.</td>
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Appendix B

Topic Guide for Primary Care Physicians

• At what point would you typically see one of your breast cancer patients for issues resulting from treatments? (during / after treatment)

• If during, explain. (What type of issues? Why did she come to you vs. oncologist?)

• What are the typical primary care needs of women after undergoing treatment for breast cancer?

• What types of interventions would you use to address a,b,c,... (Diet/exercise, lymphedema, fatigue, menopausal symptoms, cognitive)

• There is a large body of literature that says that these women experience many psychosocial issues. Is it routine for you to monitor the psychosocial wellbeing of these women? How do you intervene?

• What role do you play in managing issues related to hormone therapies? (Tamoxifen/Herceptin/Arimidex)

• What would you say is the greatest challenge facing women after undergoing breast cancer treatments?

• Are you aware of any clinical practice guidelines that have been published to care for breast cancer survivors?

• Are you aware of the guidelines for the Care and Treatment of Breast Cancer, published in CMAJ with the last update in 2005?

• Were they published in way that made it readily translatable into your every practice?

• What is your preferred way to keep informed about the issues related to breast cancer treatments and what the best interventions are to help these women?

• What is your preference for literature dissemination?

• Do you feel like the care of these women is well coordinated between specialty and primary care?
• Is there anything you would change about the process of transition from specialty to primary care that would ease

• What do you feel is your role as the primary care provider for these women?

• Based on the guidelines and/or literature that has been made available to you, how confident do you feel in your ability to manage the survivorship needs of this population?

• What is the biggest challenge you face as the primary care physician for meeting and or addressing the health care needs of these women?
Appendix C

Topic Guide for Post-treatment Breast Cancer Patients

• When were you diagnosed?

• How old were you when you were diagnosed? (pre/post-menopausal, amenorrhea, etc)

• When did you complete treatment?

• Can you tell me about the course of treatments that you had following your diagnosis?
  -Hormone Status
  -HER2 status

• Are you taking Tamoxifen? Arimidex? Herceptin?

• Reconstruction?

• Can you tell me about your feelings related to completing your treatments?

• What do you feel are the main health issues you face as a result of [surgery/chemo/radiation/hormone/herceptin] treatments? Physically? Emotionally?

• Of all of these health issues, what has caused you the most distress?

• How have these issues been addressed? (Onc/Nurse/FP/Psych?)

• When you finished treatment, what kind of follow-up information was given to you by your oncologist?
  -Diet/exercise?
  -Lymphedema related? (education/prevention)

• When you finished treatment, what kind of follow-up information was given to you by your family physician?
• Since completion of your treatment, what types of things do you see your family physician for?

• Since completion of your treatment, what has your family physician done for you that was useful?

• Is there anything that you would have liked for him or her to do differently?

• What is the biggest challenge you have experienced during the first year following breast cancer treatments?

• If I was your family physician, what would you tell me about your health care needs as a result of undergoing breast cancer treatments?
Appendix D
Letter of Information

You are invited to participate in a study entitled “A Scoping Review on the Primary Care Needs of Post-Treatment Breast Cancer Patients.” This is a research project being conducted through the School of Rehabilitation Therapy at Queen’s University. The principal investigator is Tessa Young, and this study is her MSc thesis. This study is being conducted to identify the primary health care needs and any existing best practice guidelines in primary care by family physicians for post-treatment breast cancer patients to manage the secondary complications of breast cancer treatments.

You are being asked to participate in an interview, either over the telephone or face-to-face depending on your preference, which will take approximately 30 minutes of your time. The interview will be audio taped, transcribed by the researcher, and then erased. Your interview will be kept strictly confidential, identifiable only by a code. All audio tapes and transcriptions will be kept in a locked filing cabinet and will be available only to the principle investigator and her supervisory committee. Any data collected will be presented as group data only, so your individual responses will not be identifiable. There are no anticipated risks or benefits from your participation in this study.

Your participation in this study is voluntary. You may refuse to answer any questions that you do not feel comfortable answering. You may withdraw from the study at any time. If you have any questions about your participation in this study, or would like to have your data removed from the study you may do so by contacting the principal investigator, Tessa Young, at (613) 766-5801 or 4ty1@queensu.ca, or her supervisor, Dr. Alice Aiken at (613) 533-6710, or her department head, Dr. Elsie Culham at (613) 533-6727. If you have any questions regarding your rights as a research subject, you may contact Dr. Albert Clark, Chair of the Queen's University Health Sciences and Affiliated Teaching Hospitals Research Ethics Board at (613) 533-6081.

If you agree to participate, please sign the attached consent form and return it to the researcher. Please keep this letter so you have all the appropriate contact information and your code number should you wish to have your information removed from the study.

Thank you very much for taking the time to participate in this study.

Sincerely,

Tessa Young
Appendix E
Consent Form (Physicians)

I have agreed to participate in a study entitled “A Scoping Review on the Primary Care Needs of Post-Treatment Breast Cancer Patients.”

I understand that:
1) This is a research project being conducted through the School of Rehabilitation Therapy at Queen’s University. The principal investigator is Tessa Young, and this study is her MSc thesis.
2) This study is being conducted to identify the primary health care needs and any existing best practice guidelines in primary care by family physicians for post-treatment breast cancer patients to manage the secondary complications of breast cancer treatments.
3) I am being asked participate in an interview to supplement the information obtained from the literature review, which will take place either over the telephone or face-to-face depending on my preference, and will last for approximately 30 minutes.
4) There are no anticipated risks or benefits from my participation in this study.
5) My interview will be audiotaped and then transcribed. Once it has been transcribed, the tape will be erased.
6) The transcription of my interview will be kept strictly confidential, identifiable only by a code.
7) All interview data will be kept in a locked filing cabinet and will be available only to the principle investigator and her supervisory committee. Any data collected will be presented as group data only, so my individual responses will not be identifiable.
8) My participation in this study is voluntary. I may refuse to answer any questions that I do not feel comfortable answering and I may withdraw from the study at any time without penalty.
9) If I have any questions about my participation in this study, or would like to have my data removed from the study I may do so by contacting:
   a) the principal investigator, Tessa Young, at (613) 766-5801 or 4ty1@queensu.ca, or
   b) her supervisor, Dr. Alice Aiken at (613) 533-6710, or
   c) if I have any questions regarding my rights as a research subject, I may contact Dr. Albert Clark, Chair of the Queen's University Health Sciences and Affiliated Teaching Hospitals Research Ethics Board at (613) 533-6081.

Signature of Physician ___________________________ Date ___________________________
Appendix F
Consent Form (Patients)

I have agreed to participate in a study entitled “A Scoping Review on the Primary Care Needs of Post-Treatment Breast Cancer Patients.”

I understand that:
1) This is a research project being conducted through the School of Rehabilitation Therapy at Queen’s University. The principal investigator is Tessa Young, and this study is her MSc thesis.
2) This study is being conducted to identify the primary health care needs and any existing best practice guidelines in primary care by family physicians for post-treatment breast cancer patients to manage the secondary complications of breast cancer treatments.
3) I am being asked to participate in an interview to supplement the information obtained from the literature review, which will take place either over the telephone or face-to-face depending on my preference, and will last for approximately 30 minutes.
4) There are no anticipated risks or benefits from my participation in this study.
5) My interview will be audiotaped and then transcribed. Once it has been transcribed, the tape will be erased.
6) The transcription of my interview will be kept strictly confidential, identifiable only by a code.
7) All interview data will be kept in a locked filing cabinet and will be available only to the principle investigator and her supervisory committee. Any data collected will be presented as group data only, so my individual responses will not be identifiable.
8) My participation in this study is voluntary. I may refuse to answer any questions that I do not feel comfortable answering and I may withdraw from the study at any time without penalty.
9) If I have any questions about my participation in this study, or would like to have my data removed from the study I may do so by contacting:
   a) the principal investigator, Tessa Young, at (613) 766-5801 or 4tyl@queensu.ca, or
   b) her supervisor, Dr. Alice Aiken at (613) 533-6710, or
   c) if I have any questions regarding my rights as a research subject, I may contact Dr. Albert Clark, Chair of the Queen’s University Health Sciences and Affiliated Teaching Hospitals Research Ethics Board at (613) 533-6081.

________________________________________  ____________________________
Signature of Patient                                Date
Appendix G
Ethics Approval

QUEEN'S UNIVERSITY HEALTH SCIENCES & AFFILIATED TEACHING HOSPITALS RESEARCH ETHICS BOARD

September 24, 2010

This Ethics Application was subject to:

☐ Full Board Review
☐ Meeting Date:
☒ Expedited Review

Ms. Tessa Young
School of Rehabilitation Therapy
Louise D. Aaron Building
Queen's University

Dear Ms. Young,

Study Title: A Scoping Review on the Primary Care Needs of Post-Caregiver Breast Cancer
Co-Investigators: Dr. Alice Aiken

I am writing to acknowledge receipt of your recent ethics submission. We have examined the protocol and consent form for your project (as stated above) and consider it to be ethically acceptable. This approval is valid for one year from the date of the Chair's signature below. This approval will be reported to the Research Ethics Board. Please attend carefully to the following list of ethics requirements you must fulfill over the course of your study:

➢ Reporting of Amendments: If there are any changes to your study (e.g. consent, protocol, study procedures, etc.), you must submit an amendment to the Research Ethics Board for approval. (see http://www.queensu.ca/irs/reb.html).

➢ Reporting of Serious Adverse Events: Any unexpected serious adverse event occurring locally must be reported within 2 working days or earlier if required by the study sponsor. All other serious adverse events must be reported within 15 days after becoming aware of the information.

➢ Reporting of Complaints: Any complaints made by participants or persons acting on behalf of participants must be reported to the Research Ethics Board within 7 days of becoming aware of the complaint. Note: All documents supplied to participants must have the contact information for the Research Ethics Board.

➢ Annual Renewal: Prior to the expiration of your approval (which is one year from the date of the Chair's signature below), you will be reminded to submit your renewal form along with any new changes or amendments you wish to make to your study. If there have been no major changes to your protocol, your approval may be renewed for another year.

Yours sincerely,

[Signature]

Chair, Research Ethics Board

Date: Sept 27, 2010

Study Code: REH-481-10

➢ Investigators please note that if your trial is registered by the sponsor, you must take responsibility to ensure that the registration information is accurate and complete.