Challenges, Strengths and Opportunities Related to Implementing Comprehensive Evidence-Based Guidelines on Breast Cancer Survivorship Care by Primary Care Physicians and Nurse Practitioners in Southeastern Ontario

by

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A thesis submitted to the Graduate Program in Rehabilitation Science in conformity with the requirements for the Degree of Doctor of Philosophy

Queen’s University
Kingston, Ontario, Canada
July, 2016

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ABSTRACT

Background

Many breast cancer survivors continue to have a broad range of physical and psychosocial problems after breast cancer treatment. As cancer centres move forward with earlier discharge of stable breast cancer survivors to primary care follow-up it is important that comprehensive evidence-based breast cancer survivorship care is implemented to effectively address these needs. Research suggests primary care providers are willing to provide breast cancer survivorship care but many lack the knowledge and confidence to provide evidence-based care.

Purpose

The overall purpose of this thesis was to determine the challenges, strengths and opportunities related to implementing comprehensive evidence-based breast cancer survivorship guidelines by primary care physicians and nurse practitioners in southeastern Ontario.

Methods

This mixed-methods research was conducted in three phases: (1) synthesis and appraisal of clinical practice guidelines relevant to provision of breast cancer survivorship care within the primary care practice setting; (2) a brief quantitative survey of primary care providers to determine actual practices related to provision of evidence-based breast cancer survivorship care; and (3) individual interviews with primary care providers about the challenges, strengths and opportunities related to provision of comprehensive evidence-based breast cancer survivorship care.

Results and Conclusions

In the first phase, a comprehensive clinical practice framework was created to guide provision of breast cancer survivorship care and consisted of a one-page checklist outlining breast cancer survivorship issues relevant to primary care, a three-page summary of key recommendations, and
a one-page list of guideline sources. The second phase identified several knowledge and practice

gaps, and it was determined that guideline implementation rates were higher for

recommendations related to prevention and surveillance aspects of survivorship care and lowest

related to screening for and management of long-term effects. The third phase identified three

major challenges to providing breast cancer survivorship care: inconsistent educational

preparation, provider anxieties, and primary care burden; and three major strengths or

opportunities to facilitate implementation of survivorship care guidelines: tools and technology,

empowering survivors, and optimizing nursing roles. A better understanding of these challenges,

strengths and opportunities will inform development of targeted knowledge translation

interventions to provide support and education to primary care providers.
Co-Authorship

The following manuscripts are published or in review and can be cited as follows:

Manuscript #1 (Chapter 3)

Manuscript #2 (Chapter 4)

Manuscript #3 (Chapter 5)
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<th>Abbreviation</th>
<th>Full Form</th>
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<tbody>
<tr>
<td>ASCP</td>
<td>American Society of Clinical Oncology</td>
</tr>
<tr>
<td>CCO</td>
<td>Cancer Care Ontario</td>
</tr>
<tr>
<td>CHC</td>
<td>Community Health Centre</td>
</tr>
<tr>
<td>CME</td>
<td>Continuing Medical Education</td>
</tr>
<tr>
<td>CPAC</td>
<td>Canadian Partnership Against Cancer</td>
</tr>
<tr>
<td>CPD</td>
<td>Continuing Professional Development</td>
</tr>
<tr>
<td>CPG</td>
<td>Clinical Practice Guideline</td>
</tr>
<tr>
<td>EMR</td>
<td>Electronic Medical Record</td>
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<tr>
<td>FHG</td>
<td>Family Health Group</td>
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<tr>
<td>FHN</td>
<td>Family Health Network</td>
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<tr>
<td>FHO</td>
<td>Family Health Organization</td>
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<td>FHT</td>
<td>Family Health Team</td>
</tr>
<tr>
<td>FP</td>
<td>Family Physician</td>
</tr>
<tr>
<td>IOM</td>
<td>Institute of Medicine</td>
</tr>
<tr>
<td>IP</td>
<td>Interprofessional</td>
</tr>
<tr>
<td>KT</td>
<td>Knowledge Translation</td>
</tr>
<tr>
<td>KTA</td>
<td>Knowledge-to-Action</td>
</tr>
<tr>
<td>LHIN</td>
<td>Local Health Integration Network</td>
</tr>
<tr>
<td>MD</td>
<td>Medical Doctor</td>
</tr>
<tr>
<td>NP</td>
<td>Nurse Practitioner</td>
</tr>
<tr>
<td>NPLC</td>
<td>Nurse Practitioner-Led Clinic</td>
</tr>
<tr>
<td>OT</td>
<td>Occupational Therapist</td>
</tr>
<tr>
<td>PCP</td>
<td>Primary Care Provider</td>
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</tbody>
</table>
PHCNP  Primary Health Care Nurse Practitioner
PT  Physiotherapist
RN  Registered Nurse
RPN  Registered Practical Nurse
SERCP  South East Regional Cancer Program
TEKT  Technology-Enabled Knowledge Translation
CHAPTER ONE

General Introduction

The issue

Breast cancer is the most common cancer affecting Canadian women with approximately 25,000 new cases expected to have been diagnosed in 2015, representing 26% of all new female cancer cases (Canadian Cancer Society's Advisory Committee on Cancer Statistics, 2015). With aging of the population and improved long-term survival the number of breast cancer survivors is increasing, and many continue to see oncology specialists for follow-up care, even years after they finish active treatment. Primary care involvement in post-treatment follow-up is evolving as increasing health care costs, increasing patient numbers and limited supply of oncologists are impacting the availability and accessibility to follow-up care (Erikson, Salsberg, Forte, Bruinooge, & Goldstein, 2007; Campbell, MacLeod, & Weller, 2002; Madarnas et al., 2011; Lichtenfeld, 2009; Kirkwood, 2015; Trent, 2014). Guidelines from a recent report published by the Program in Evidence-Based Care (PEBC) of Cancer Care Ontario (CCO) recommend that breast cancer survivors without ongoing treatment issues may be discharged from specialist-led care to community based family physician-led care (Sussman et al., 2012). However, survivors often describe feeling “abandoned” as they transition from intensive specialist cancer care to primary care follow-up (Huffman, 2007) and often report their health care needs are not being sufficiently met (Burg et al., 2015; Griffith, McGuire, & Russo, 2010; Siu, Catton, Jones, & Jadad, 2013). Many of these women have multiple, complex and unique health care needs and may experience numerous debilitating physical and psychosocial consequences such as pain, fatigue, anxiety, depression, and lymphedema (Aaronsen et al., 2014; Binkley et al., 2012; Harrington, Hansen, Moskowitz, Todd, & Feuerstein, 2010). This is a significant problem that
impacts the lives of breast cancer survivors and their families. The long term health and quality of life of breast cancer survivors is thus dependent upon the ability of primary care medical doctors (MDs) and nurse practitioners (NPs) to recognize and promptly treat long-term and late effects.

Unfortunately primary care providers, by their own admission, lack knowledge about consequences of cancer treatment and optimal care for cancer survivors (Fitch, 2012; Nissen et al., 2007). In a typical primary care caseload of 1000 to 1500 patients, there may be only one to two patients per year returning to their primary care provider for ongoing survivorship care. Thus keeping up to date with survivorship care recommendations can be challenging in the context of competing demands from other patient populations.

Although clinical practice guidelines exist for follow-up surveillance and certain aspects of survivorship care, there is no single comprehensive guideline that covers all of the significant breast cancer survivorship issues encountered in primary care. It is unclear what specific strategies would be most effective to expedite uptake of best practices related to breast cancer survivorship care within the Canadian health care context and specifically within the province of Ontario where the population of Primary Health Care NPs is growing and where many primary care providers are practicing in interprofessional (IP) teams. The CCO report Models of Care for Cancer Survivorship also includes a recommendation that breast cancer survivors with no ongoing treatment issues may be discharged from specialist-led care to nurse-led care within an institutional setting (Sussman et al., 2012). However, the report included no recommendations related to nursing models of survivorship care within community settings, as no studies could be found to include in the review.
Primary Care Models in Ontario

Primary health care services include all services that contribute to health such as income, housing and education; whereas primary care is an element within primary health care that focusses on delivery of health care including health promotion, and prevention, diagnosis and treatment of illness and injury (Government of Canada, 2012). Efforts to control rising healthcare costs while improving access and quality of primary care have resulted in a number of reforms to the delivery of primary care in Ontario including promotion of IP health care teams and alternate models of remuneration (Kralj & Kantarevic, 2012). Current primary care models in Ontario include: solo primary care physicians/Comprehensive Care Model, Family Health Groups (FGOs), Family Health Networks (FHNs), Family Health Organizations (FHOs), Family Health Teams (FHTs), Community Health Centres (CHCs) and Nurse Practitioner-Led Clinics (NPLCs) (Health Force Ontario, 2013; Ontario Ministry of Health and Long-Term Care, 2015). Remuneration ranges from the traditional fee-for-service (solo physician/comprehensive care models), blended fee-for-service (FHGs), blended capitation (FHNs and FHOs), to salaried models (CHCs and NPLCs); the FHT is an IP team model in which physicians are paid through a blended capitation or blended salary model (Glazier, Zagorski & Rayner, 2012). Capitation and team models are looking after relatively advantaged groups, whereas CHCs and NPLCs serve populations with lower socioeconomic status and higher physical, mental and chronic health conditions (Glazier et al., 2012; Koren, Mian & Rukholm, 2010).

Interdisciplinary team models have the potential to provide comprehensive chronic disease management (Rosser, Colwill, Kasperski & Wilson, 2011), which could enhance survivorship care in the primary care setting. FHTs and CHCs are primary health care organizations that include a team of MDs, NPs, Registered Nurses (RNs), social workers,
dietitians and other professionals working together to provide primary health care (Ontario Ministry of Health and Long-Term Care, 2014, 2016). However, across Ontario only 16% of residents were receiving primary care in FHTs, and 1% in CHCs as of 2010 (Glazier et al., 2012). Some FHTs and CHCs have integrated or collaborate with physiotherapists (PTs) and occupational therapists (OTs) who are first contact, primary health care professionals that participate in health promotion, rehabilitation and chronic disease management activities (Canadian Physiotherapy Association, 2012; Ontario Society of Occupational Therapists, 2013). These services align well with the needs of many breast cancer survivors.

**Regional focus: The South East LHIN**

In Ontario, the South East Local Health Integration Network (LHIN) extends from Brighton in the west to Prescott and Cardinal in the east, north to Perth and Smiths Falls and back to Bancroft in the northwest. The South East LHIN is home to close to 500,000 people (Local Health Integration Network, 2012). It has a sizeable rural population with 44% of its residents living in communities of fewer than 10,000 people and approximately 25% of the population residing in the city of Kingston.

The South East LHIN also has the largest proportion of people over the age of 65 in the province (Bains et al., 2012). As the incidence of cancer in general and breast cancer specifically increases with age, it is expected that the LHIN would also have a relatively high proportion of breast cancer survivors. Although the city of Kingston hosts a regional cancer center and academic health sciences centre, its smaller size has precluded the existence of a comprehensive cancer survivorship/rehabilitation centre. Unfortunately, cancer survivors treated in Kingston do not have access to the wide array of cancer survivorship/rehabilitation services offered in larger urban centres such as Ottawa, Toronto and Montreal, just a few hours away (Luctkar-Flude,
Thus breast cancer survivors living in the South East LHIN are particularly dependent on the survivorship services provided by primary care providers.

As elsewhere in Ontario, the South East Regional Cancer Program (SERCP) is moving forward with earlier discharge of stable, healthy early-stage breast cancer survivors from oncology follow-up to primary care follow-up in the community within two years of their cancer diagnosis and following completion of primary treatment (Langley, 2013). The SERCP Regional Cancer Plan 2011-2014 describes their aim to reduce three-year follow-up appointments for adjuvant breast cancer patients by specialists by 50% by transferring this care to primary care providers (South East Regional Cancer Program, 2011). As each primary care provider may only be seeing one to two newly discharged breast cancer survivors per year (Canadian Medical Association, 2015; Cancer Quality council of Ontario, 2016), it may prove challenging for these providers to remain up to date about the best practices in breast cancer survivorship care (Langley, 2013). It is unclear what the experience of providing this survivorship care is like for primary care MDs and NPs practicing in both the urban and rural communities across the region. It is also unclear what specific resources, education and support these providers feel they need to be able to provide excellent evidence-based care to their patients who are breast cancer survivors. Although PTs and OTs are also first contact, primary health care professionals, who contribute to the provision of comprehensive survivorship care, responsibility for cancer survivorship follow-up care and coordination is directly transferred from the oncology setting to primary care MDs and NPs, thus this thesis will focus on the knowledge, practices and needs of primary care MDs and NPs.

This study will contribute to a better understanding of the unique experiences of primary care MDs and NPs and the factors that affect their ability to provide high quality, evidence-based
care to women following primary treatment for breast cancer. A better understanding of these experiences and these factors, and identification of specific knowledge gaps related to existing best practice guidelines will contribute to the development of targeted knowledge translation interventions to provide support and education that can improve primary care provider knowledge, attitudes and practices related to providing breast cancer survivorship care and translate into enhanced long-term health and quality of life outcomes.

**Purpose of the study**

The overall purpose of this multi-phased, mixed methods study was to apply the Knowledge to Action (KTA) Framework (Graham et al., 2006) to determine the challenges, strengths and opportunities related to implementing evidence-based guidelines on breast cancer survivorship care by primary care MDs and NPs in the South East LHIN of Ontario.

Specific research objectives and research questions of the study are the following:

**Objective 1:** To describe evidence-based comprehensive breast cancer survivorship care for primary care practice

*Research Question 1a:* What are the primary health care needs of breast cancer survivors following completion of primary treatment for breast cancer?

*Research Question 1b:* What evidence-based clinical practice guidelines (CPGs) are available for post-treatment breast cancer survivorship care that are relevant to the primary care setting?

**Objective 2:** To determine to what extent the key best practice guideline recommendations for post-treatment breast cancer survivorship care are being implemented by primary care MDs and NPs within the South East LHIN and to describe the gaps in knowledge and care
**Research Question 2a:** Which post-treatment breast cancer survivorship care guideline recommendations are currently being implemented by primary care MDs and NPs?

**Research Question 2b:** What are the knowledge gaps?

**Research Question 2c:** Are there any differences between MD and NP knowledge and practice gaps?

**Objective 3:** To determine the challenges (barriers), strengths (facilitators) and opportunities (recommendations) related to provision of comprehensive evidence-based breast cancer survivorship care by primary care providers within the South East LHIN.

**Research Question 3a:** What are primary care providers’ perceptions of the existing challenges related to the provision of comprehensive evidence-based post-treatment breast cancer survivorship care within the primary care practice setting?

**Research Question 3b:** What are primary care providers’ perceptions of the existing strengths and potential opportunities to enhance the provision of comprehensive evidence-based post-treatment breast cancer survivorship care within the primary care practice setting?

**Significance of the study**

In the short term, this research will contribute to a better understanding of the experiences of primary care MDs and NPs and the factors that affect their ability to provide high quality, evidence-based care to women following primary treatment for breast cancer. In the long term, a better understanding of these challenges, strengths and opportunities will contribute to the development of targeted knowledge translation interventions to provide support and education that can improve primary care provider knowledge, attitudes and practices related to providing breast cancer survivorship care. This study will contribute to a developing program of research
with the overall goal to improve health and quality of life outcomes in the growing population of breast cancer survivors.

**Theoretical Framework and Overview of Methods**

This study was conducted within a pragmatic research paradigm that provides a very practical and applied underlying philosophical framework for mixed methods research and supports the use of both qualitative and quantitative research methods within the same study and within multistage research programs (Tashakkori & Teddlie, 1998, 2003). This approach blends positivist and constructivist paradigms by allowing that there may be a single real world but recognizing that individuals all have their own interpretation of that world. Thus the researcher is not constrained by a single method, but free to choose the method or combination of methods, whether quantitative or qualitative, most appropriate for studying the phenomenon of interest and answering the research questions.

As the long-term goal of this research is to contribute to the development of knowledge translation (KT) interventions for primary care, this thesis was guided by the Knowledge to Action (KTA) Framework (see Figure 1). The Canadian Institutes of Health Research (CIHR) defines KT as a “dynamic and iterative process that includes synthesis, dissemination, exchange and ethically-sound application of knowledge to improve the health of Canadians, provide more effective health services and products and strengthen the health care system” (Straus, Tetroe, & Graham, 2009, p. 4). Knowledge translation addresses the gap between research and practice through the knowledge-to-action (KTA) process as described in the conceptual framework developed by Graham and colleagues (Graham et al., 2006). This framework has been adopted by the Canadian Institutes for Health Research (CIHR) as the accepted model for promoting the application of research (Straus, Tetroe, & Graham, 2009). This framework provides a guiding
and organizing framework to influence the uptake of research and evidence-based practice guidelines into practice and subsequently incite clinical change (Petzold, Korner-Bitensky, & Menon, 2010; Canadian Dementia Knowledge Translation Network, 2013; Campbell, 2010). This thesis was conducted in three phases, each of which incorporated various steps of the KTA framework. Each of the research objectives and research questions have been mapped to the steps of the KTA cycle and the research methods that would best address each question (see Table 1).

The first phase of the thesis, the review of the literature and selection, synthesis and appraisal of relevant clinical practice guidelines fell within the knowledge creation funnel of the KTA Framework, specifically within the knowledge synthesis and knowledge tools/products levels. For effective knowledge translation to occur, knowledge needs to be relevant, appropriate, applicable, timely and reasonable (Campbell, 2010). The steps of the KTA Framework guided the selection and adaptation of knowledge that was relevant to the primary care practice setting. Following the identification, evaluation and synthesis of existing guidelines pertaining to breast cancer survivorship care, the focus of this research became the action cycle of the KTA Framework, the process by which knowledge is implemented (Straus, 2009).

The second phase of the thesis consisted of the identification of gaps between best practices and actual practices, or knowledge-to-action gaps (step 1 of the action cycle), (Straus & Leung, 2011) related to provision of evidence-based breast cancer survivorship care in primary care. Knowledge-to-action gaps were identified through surveys of primary care practitioners about their current practices and comparing these to the best practices outlined in the first phase of the study.
The third phase consisted of further assessment of the practice context and needs from the perspective of primary care providers which is required in order to understand how to best address the identified knowledge-to-action gaps. This will facilitate adapting knowledge to the local context (step 2 of the action cycle) to ensure it is relevant to the intended users and feasible within the intended practice setting e.g. customizing a clinical practice guideline to a particular user group may help improve acceptance and adherence. Knowledge translation interventions are more likely to be successful if the choices of KT strategies are informed by an assessment of likely barriers and facilitators (Grimshaw, Eccles, Lavis, Hill, & Squires, 2012). Thus, this research will also involve assessing the barriers and facilitators to knowledge use (step 3 of the action cycle) which is appropriately achieved through qualitative approaches such as individual interviews. Barriers and facilitators may be related to the knowledge to be adopted, the potential adopters themselves, and the context in which the knowledge will be used (Canadian Dementia Knowledge Translation Network, 2013). Identification of barriers and facilitators (e.g. awareness/lack of awareness, or current habitual practices) will facilitate the selection, tailoring and implementation of interventions (step 4 of the action cycle) which is beyond the scope of the current study; however, recommendations for future development of KT implementation strategies and evaluation research to enhance provision of evidence-based breast cancer survivorship care in the primary care setting were made.

The importance of context to the success of KT strategies implies the need for involvement of end-users in the research process. Integrated KT refers to collaboration of researchers and knowledge users throughout the entire research cycle including research design and interpretation and dissemination of findings (Canadian Dementia Knowledge Translation Network, 2013). Informal consultation with an oncologist, two primary care physicians, three
primary care nurse practitioners and the manager for the Queen’s University Office of Continuing Professional Development informed the design of the research methods for the proposed study, including recruitment strategies. Formal consultation with a panel of oncology and primary care experts, and breast cancer survivors validated the clinical practice framework for breast cancer survivorship care, as well as the subsequent survey and interview questions. Quantitative feedback was sought from a larger group of primary care MDs and NPs from across the South East LHIN, and qualitative feedback was obtained from a subgroup of survey participants.

In terms of a clinical framework for provision of survivorship care, the seminal report from the Institute of Medicine (IOM) *From Cancer Patient to Cancer Survivor: Lost in Transition* (Hewitt, Greenfield, & Stovall, 2006), is the most frequently reported in the literature providing guidance to breast cancer survivorship care and research (Grunfeld & Earle, 2010; Del Giudice, Grunfeld, Harvey, Piliotis, & Verma, 2009; Salz, Oeffinger, McCabe, Layne, & Bach, 2012; Grunfeld, Earle, & Stovall, 2011). Several of the consensus report recommendations have recently been adapted by the Cancer Journey Survivorship Expert Panel in a pan-Canadian guideline for the organization and structure of cancer survivorship services (Howell et al., 2011). The IOM report synthesizes what is known about cancer survivorship and establishes the survivorship period as an important new focus for care that extends beyond long-term surveillance to include many previously unaddressed medical and psychosocial needs of survivors (Grunfeld et al., 2011). The IOM report specifically outlines four essential components of survivorship care: (1) prevention of recurrent and new cancers, and of other late effects; (2) surveillance for cancer spread, recurrence, second cancers, and medical and psychosocial late effects; (3) intervention for consequences of cancer and its treatment; and (4) coordination
between specialists and primary care providers to ensure that all of the survivor’s health needs are met (Hewitt et al., 2006).

This thesis identified breast cancer survivorship issues and relevant clinical practice guidelines and mapped them to the four domains (essential components) of the IOM report to create a comprehensive clinical practice framework to guide the provision of breast cancer survivorship care in primary care settings. The framework was validated by a panel of experts prior to seeking feedback from a sample of primary care MDs and NPs to determine actual practices as well as the challenges and opportunities related to use of the evidence-based guideline recommendations within the South East LHIN.

**Thesis organization**

This thesis was organized according to the Manuscript Thesis Format as specified by the Queen’s University School of Graduate Studies. Chapter one provides a general introduction to the thesis topic including the statement of issue, the purpose and significance of the study, and the theoretical framework and overview of methods. Chapter two provides a review of the current scientific literature related to evidence-based breast cancer survivorship care and knowledge translation in primary care. Chapter three aligns with research objective #1 and describes the development and expert panel validation of a comprehensive clinical practice framework for provision of post-treatment breast cancer survivorship care within the primary care setting. Chapter four aligns with research objective #2 and describes the results of a brief quantitative survey to determine actual practices related to provision of evidence-based post-treatment breast cancer survivorship care by primary care MDs and NPs within the South East LHIN. Chapter five aligns with research objective #3 and describes the results of individual interviews with a subset of primary care MDs and NPs about the challenges, strengths and
opportunities related to the provision of comprehensive evidence-based post-treatment breast cancer survivorship care within the South East LHIN. Chapter six provides an overall discussion and conclusions from the thesis work including limitations and implications for future research.
References


https://www.osot.on.ca/iMIS15/OSOT/Practice_Resources_Pages/Sector_Resource_Pages/Primary_Health_Care.aspx


Figure 1. The Knowledge to Action Framework

### Table 1

**Summary of Thesis Methods Guided by the Knowledge to Action Framework**

<table>
<thead>
<tr>
<th>Knowledge to Action Steps</th>
<th>Research Objective</th>
<th>Research Question</th>
<th>Research Method</th>
</tr>
</thead>
<tbody>
<tr>
<td>Knowledge Creation:</td>
<td>1. To describe evidence-based comprehensive breast cancer survivorship care for primary care practice</td>
<td>1a. What are the primary health care needs of breast cancer survivors following completion of primary treatment for breast cancer?</td>
<td>Review of literature to identify breast cancer survivorship issues relevant to primary care</td>
</tr>
<tr>
<td>- Knowledge Inquiry</td>
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<td></td>
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<tr>
<td>- Knowledge Synthesis</td>
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</tr>
<tr>
<td>Knowledge Creation:</td>
<td>1. To describe evidence-based comprehensive breast cancer survivorship care for primary care practice</td>
<td>1a. What are the primary health care needs of breast cancer survivors following completion of primary treatment for breast cancer?</td>
<td>Creation &amp; validation of conceptual framework outlining essential domains &amp; specific components of comprehensive breast cancer survivorship care</td>
</tr>
<tr>
<td>- Knowledge Tools/Products</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>- Identify, Review, Select Knowledge</td>
<td></td>
<td></td>
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<tr>
<td>Action Cycle:</td>
<td>2. To determine to what extent the key best practice guideline recommendations for post-treatment breast cancer survivorship care are being implemented by primary care MDs and NPs within the South East LHIN and to describe the gaps in knowledge and care</td>
<td>2a. Which post-treatment breast cancer survivorship care guideline recommendations are currently being implemented by primary care MDs and NPs?</td>
<td>Quantitative survey of primary care MDs and NPs from the South East LHIN comparing best practices (key primary care recommendations) to actual practices</td>
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**Summary of Thesis Methods Guided by the Knowledge to Action Framework**

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Breast cancer is the most common cancer affecting Canadian women with approximately 25,000 new cases expected to be diagnosed in 2015, representing 26% of all new cancer cases in women (Canadian Cancer Society's Advisory Committee on Cancer Statistics, 2015). Although breast cancer incidence rose steadily from 1980 to the early 1990s, the breast cancer death rate has fallen on average, by at least 2% per year between 1998 and 2007 (Canadian Cancer Society's Steering Committee on Cancer Statistics, 2012) and 89% of women diagnosed between the ages of 40 and 79 will survive five years or longer, as a result of advances in screening and treatment (Canadian Cancer Society, 2011). As more patients enjoy long-term survival, more attention is being given to the quality of life of cancer survivors, and primary care providers are expected to play a more comprehensive role in delivery of post-treatment survivorship care (Westfall, Overholser, Zittleman, & Westfall, 2015).

To provide context for this thesis, current research evidence was reviewed in regard to: (1) breast cancer survivorship care, (2) barriers and facilitators to implementing clinical practice guidelines (CPGs), and (3) knowledge translation (KT) for primary care providers. The results of this literature review highlighted what is known about evidence-based breast cancer survivorship care in primary care and provided foundational knowledge for the study.

Breast cancer survivorship care

The cancer survivorship phase and survivorship care

Cancer Care Ontario has adapted a definition of survivorship from the American Institute of Medicine (IOM) report, From Cancer Patient to Cancer Survivor: Lost in Transition: “the phase of the cancer trajectory following diagnosis and treatment and prior to recurrence of
subsequent cancers or death” (Wilson-Li & Duvalko, 2008, p. 3). This definition focuses on the individual following the acute phase of treatment until treatment is needed again or death occurs. This definition of cancer survivorship was used throughout this study.

As patients transition from primary cancer treatment to this survivorship phase, the focus of care shifts from specialty to primary care. Breast cancer patients may experience difficulties while transitioning to survivorship (Kantsiper et al., 2009). The focus of survivorship care for adult cancer survivors has been on surveillance for cancer recurrence and has not addressed health promotion, cancer prevention or symptom management for long-term and late effects of cancer treatment, as recommended by the IOM report (McCabe et al., 2013). An evidence brief prepared by the McMaster Health Forum in 2011 outlined several problems related to transitioning cancer patients to survivorship care: (i) the burden of cancer is growing, (ii) primary and community care programs intersect only minimally with cancer programs, (iii) gaps in health and social care system arrangements limit supports for cancer survivorship, (iv) existing implementation efforts are focused on earlier stages in the cancer care continuum, and (v) additional equity-related observations (Lavis & Montesanti, 2011). Similarly, in 2012, the Canadian Partnership Against Cancer described cancer survivorship care to be patchy, and overall, not of high quality and suggested that guidelines and care plans are needed, and that promoting survivorship research and ensuring effective KT are key priorities of the Canadian agenda for cancer survivorship (Fitch, 2012). One of the key recommendations of the IOM report was to raise awareness of the needs of cancer survivors to ensure delivery of appropriate survivorship care (Hewitt, Greenfield, & Stovall, 2006).
Physical and psychosocial problems following breast cancer treatment

A scoping review and validation study by Young identified eleven broad categories related to the primary health care needs of women after undergoing treatment for breast cancer: surgical complications, fatigue, lymphedema, gynecologic and menopausal symptoms, psychosocial issues, additional primary cancers, cardiovascular issues, osteoporosis, lifestyle changes, cognitive dysfunction, and pregnancy (Young, 2011). This review included evidence from 70 studies, including five randomized controlled trials (RCTs) and ten systematic reviews (level I evidence), 11 observational studies (level III evidence) and 35 reviews (level IV evidence). In addition, many of the acute physical toxicities that appear during treatment for cancer, including breast cancer, often continue beyond the end of treatment as long-term chronic effects, or emerge following treatment, and will require ongoing monitoring by primary care providers (Ganz, 2006). An abundance of research studies have identified numerous physical symptoms and side effects that may persist for years following breast cancer treatment (Binkley et al., 2012; Gho, Steele, Jones, & Munro, 2013; Hill et al., 2014; Schmitz, Speck, Rye, DiSipio, & Hayes, 2012).

Longitudinal and cross-sectional data from a systematic review have demonstrated that symptoms associated with breast cancer survivorship such as pain and fatigue can be experienced for more than 10 years following a wide variety of treatment types and exposure (Harrington, Hansen, Moskowitz, Todd, & Feuerstein, 2010). Data from the longitudinal studies revealed prevalence rates for fatigue ranging from 20-35% at one to two years post-treatment, 20-56% at two to five years post-treatment, and at a rate of 34% at points more than five years post-treatment; rates of sleep disturbance of 59% were reported at one to two years post-treatment, and 14% at two to five years post-treatment (Harrington et al., 2010). Prevalence rates
for pain and functional limitations were reported to range from 21-41% at one to two years post-treatment, and 19-41% at two to five years post-treatment (Harrington et al., 2010).

A recent, comprehensive review of studies reporting on the late effects of breast cancer treatment described physical problems and rehabilitation needs of breast cancer survivors such as pain, lymphedema, fatigue and sleep disturbances, and concluded that there is a need for screening instruments and guidelines for rehabilitation and interventions for alleviating symptoms in breast cancer survivors (Ewertz & Jensen, 2011). Breast cancer treatments such as radiotherapy, endocrine therapy (tamoxifen and aromatase inhibitors), and chemotherapy (anthracyclines and trastuzumab) may also result in late cardiac toxicity such as cardiomyopathy, coronary ischemia and arrhythmias (Schmitz, Prosnitz, Schwartz, & Carver, 2012; Valachis & Nilsson, 2015), musculoskeletal problems such as arthralgias, osteopenia and osteoporosis (Hill et al., 2014; Menas et al., 2012), or reproductive problems such as infertility, premature menopause and menopausal symptoms (Bruno & Feeney, 2006; King, Wynne, Assersohn, & Jones, 2011; Kenyon, Mayer, & Owens, 2014). Results of an analysis of 122,969 women from the Nurses’ Health Study (NHS) and NHS2 demonstrated that older breast cancer survivors may be particularly vulnerable to physical symptoms due to comorbid conditions that compound the effects of treatment; however, younger women in the study (≤40 years) with breast cancer experienced significant functional declines compared with women without breast cancer, and the largest relative declines as compared with middle-aged and older women (Kroenke et al., 2004). Early identification and management of physical impairments are essential to minimize functional limitations and optimize quality of life of breast cancer survivors (Schmitz, Stout, Andrews, Binkley, & Smith, 2012).
In addition to physical symptoms, breast cancer survivors continue to experience psychological effects and psychosocial and informational needs during long-term survivorship. A breast cancer diagnosis has the potential to result in significant psychological distress and disruption of quality of life, (Stanton, 2006) particularly in women aged 40 years and younger (Kroenke et al., 2004). Adjuvant chemotherapy can result in impaired cognitive function, with residual effects lingering after treatment completion (Brezden, Phillips, Abdolell, Bunston, & Tannock, 2000; Mrozek & Shapiro, 2005). In longitudinal studies, rates of cognitive decline have been reported at 25% at six to twelve months post-treatment (Hurria et al., 2006; Schagen et al., 2006), and 50% at one to two years (Wefel, Lenzi, Theriault, Davis, & Meyers, 2004). Although ongoing physical symptoms may be non-life threatening, they can result in decreased physical functioning which in turn impacts occupational and social functioning, leading to isolation, lack of support and financial strain which are risk factors for development of psychosocial distress (Turner, Hodgkinson, & Boyes, 2010). And physical changes such as lymphedema can also contribute to body image disturbance and psychological distress (Alcorso & Sherman, 2015).

Psychological consequences of cancer or breast cancer diagnosis include depression, anxiety and posttraumatic stress disorder (PTSD) (Andrykowski, Lykins, & Floyd, 2008; Jarrett et al., 2013; Kenyon et al., 2014). There is a wide range in prevalence of both anxiety and depression in long-term cancer survivors. Data from a longitudinal study demonstrated anxiety prevalence rates of 23% at one to two years post cancer treatment and 15% at two to five years post-treatment in women with early breast cancer (Burgess et al., 2005). Data from a recent systematic review demonstrated prevalence of anxiety ranging from 18-33% across four cross-sectional studies with breast cancer survivors who were a mean of 3.9 years post-diagnosis, and
prevalence of severe anxiety ranging from 9-19%; however prevalence and mean anxiety scores were either the same as the general female population (Maass et al., 2015), and in one study were lower (Klein et al., 2011). Prevalence rates for depressive symptoms have been reported as 23% at one to two years post-treatment and 15-32% in survivors two to five years post-treatment in longitudinal studies (Harrington et al., 2010). Results from a recent systematic review demonstrated prevalence of depressive symptoms in breast cancer survivors ranging from 9-66% and severe depressive symptoms ranging from 3-42%, which were higher than the general population and persistent over more than five years after diagnosis (Maass et al., 2015).

Survivor concerns related to sexuality and body image can lead to reduced intimacy and sexual activity, anxiety about resuming or establishing sexual relationships and sexual dysfunction (Turner et al., 2010; Kedde, van de Wiel, WeijmarSchultz, & Wijsen, 2013). One study reported sexual dysfunction rates of 51% at one to two years post-treatment, and 28% at two to five years post-treatment (Mourits et al., 2002). Results of two reviews suggest women with breast cancer continue to experience informational and emotional needs during long-term survivorship, and these needs are often unmet by oncology teams (Vivar & McQueen, 2005; Binkley et al., 2012). Hawkins and colleagues (Hawkins et al., 2008) similarly concluded that many cancer survivors’ lifestyle, social, and financial needs are often addressed inadequately, and that unmet informational needs may contribute to depression and anxiety. Breast cancer survivors often report more unmet needs than other cancer survivors (Burg et al., 2015; Playdon et al., 2016). These needs extend into long-term survivorship, as demonstrated in one study that included 870 breast cancer survivors, nine years post-diagnosis, who reported ongoing information needs related to screening, long-term cancer and treatment effects, and healthy lifestyle behaviors (Playdon et al., 2016).
An additional psychosocial concern commonly reported at completion of breast cancer treatment is fear and anxiety related to cancer recurrence, which has been identified as the highest unmet supportive care need even up to 10 years after diagnosis (Hodgkinson et al., 2007). Women may not identify this concern to their primary care provider in order to conform to a societal expectation of being a brave cancer survivor (Turner et al., 2010). An overview of randomised trials revealed about three-quarters of eventual local recurrence risk occurred during the first five years (Clarke et al., 2005). And in fact, most existing cancer-related practice guidelines focus on detection, treatment and surveillance of cancer (Rowland, Hewitt, & Ganz, 2006).

**Breast cancer survivorship care guidelines**

Differentiating between symptoms related to cancer progression or recurrence, treatment-related issues, and non-cancer-related problems is challenging for primary care providers (Hammond, Levitan, & Williams, 2002). One strategy that could address this challenge is the use of systematically developed evidence-based CPGs, assessment tools, and other screening instruments to identify and manage late effects of cancer treatment, as recommended in the IOM report (Hewitt et al., 2006). Although research in the area of best practices in survivorship care is lacking (Chomik, 2010; Collins, Bekker, & Dodwell, 2004) there are evidence-based guidelines available on follow-up surveillance for detection of recurrent breast cancer (Grunfeld, Dhesy-Thind, & Levine, 2005; Khatcheressian et al., 2006; Rojas et al., 2009). However, optimal cancer survivorship care involves more than surveillance tests (Grunfeld, Earle, & Stovall, 2011). Several reviews are available in the literature to guide general primary care follow-up of complications related to local and systemic treatment for breast cancer, (Burstein & Winer, 2000; Chalasani, Downey, & Stopeck, 2010; Partridge, Winer, & Burstein, 2003) including
psychosocial care (Jacobsen, 2009). The National Comprehensive Cancer Network (NCCN) Clinical Practice Guidelines in Oncology on Breast Cancer devotes only one and a half pages specifically to post-therapy surveillance and follow-up (National Comprehensive Cancer Network, 2012a). There are also guidelines available related to specific survivorship issues such as nutrition, (Toles & Demark-Wahnefried, 2008) physical activity, (Schmitz et al., 2010) and cancer fatigue (National Comprehensive Cancer Network, 2012b).

Available Canadian guidelines have not been updated since 2005 (Grunfeld et al., 2005). These guidelines, published in the *Canadian Medical Association Journal*, provided general recommendations to patients and their medical doctors (MDs) regarding follow-up strategies and topics relevant to follow-up after treatment for breast cancer. These guidelines included general recommendations for surveillance, as well as specific recommendations related to the following health concerns frequently experienced by breast cancer survivors: cognitive functioning, fatigue, weight management, osteoporosis, sexual functioning and pregnancy. Health Canada funding for the Steering Committee responsible for writing these guidelines has ended and thus guideline updates remain unpublished (Grunfeld, 2007). Cancer Care Ontario continues to endorse the recommendations published by the Steering Committee in 1998 and 2005 (Cancer Care Ontario, 2013). Thus primary care practitioners in Canada must rely on breast cancer survivorship care evidence updates from other sources. It is unclear which sources and guidelines are currently being accessed and/or utilized by primary care MDs and nurse practitioners (NPs) in Ontario. Further it is unclear what strategies would be most effective to promote awareness of and use of evidence-based guidelines on breast cancer survivorship by primary care providers.
Barriers and facilitators to implementing clinical practice guidelines

While it is expected that health care professionals use evidence-based practice to provide high-quality, safe and ethical care, the amount of new knowledge produced daily makes it unrealistic to expect each practitioner to conduct literature reviews regularly to update their practice; thus, best practice guidelines or CPGs developed by credible organizations are generally considered one way that clinicians can provide effective, evidence-based care by bringing the best evidence to the point of care to impact clinical practice and patient outcomes (Registered Nurses Association of Ontario, 2012). They can be used by practitioners and patients to assist with clinical decision making and assure quality of health care; however, despite widespread availability, the existence of CPGs is not enough to ensure their implementation by healthcare professionals (Cabana et al., 1999; Field & Lohr, 1992; Koutsavlis, 2001). In addition to practitioner-related factors such as knowledge and attitudes that influence evidence use, there are numerous external contextual or resource barriers and facilitators at the practice and systems levels.

The Clinical Practice Guidelines Framework for Improvement published by Cabana and colleagues (1999) identified and organized barriers to MD adherence to practice guidelines according to MD knowledge, attitudes and behaviours. This seminal framework is one of the more frequently cited conceptual frameworks for assessing barriers to knowledge use in healthcare (Harrison, Legare, Graham, & Fervers, 2010). Knowledge barriers were described related to lack of awareness of guidelines due to the increasing body of research, and lack of familiarity and ability to apply them correctly. Attitudinal barriers were related to lack of agreement with guidelines in general or specific guidelines, and lack of motivation, self-efficacy or outcome expectancy. Behaviours were also influenced by external barriers including patient
factors, guideline factors, and environmental factors such as lack of time or resources (Cabana et al., 1999).

Other researchers have built upon this work, further validating its applicability for assessing both barriers and facilitators to knowledge use. In 2003, Espeland and Baerheim identified additional barriers that were not included in the original framework, however these barriers could be classified as either attitudes (lack of expectancy of desired processes, emotional difficulty following guideline) or external barriers (improper access to health services, pressure from other health care providers or organizations) (Espeland & Baerheim, 2003). In 2004, Larson developed the Attitudes Regarding Clinical Practice Guidelines Tool that assesses attitudes towards CPGs in general, as well as attitudes towards a specific hand hygiene guideline (Larson, 2004). In 2007, Cochrane and colleagues conducted a literature review using the Cabana model as a framework for analysis and categorized barriers similarly as cognitive/behavioural, attitudinal/rational-emotional, professional, guideline/evidence, support/resource and systems/process barriers (Cochrane et al., 2007).

In Canada in 2008, Légaré and colleagues expanded the framework further to include attributes of the Diffusion of Innovation Theory (Rogers, 1995), and identified that most of the factors in the framework could be characterized as both barriers and facilitators (Legare, Ratte, Gravel, & Graham, 2008). This revised version of the Clinical Practice Guidelines Framework for Improvement is frequently tied to the Knowledge-to-Action (KTA) Cycle as assessing barriers to knowledge use is an important step in the action cycle (Harrison et al., 2010). As well, this framework is featured in the Canadian Institutes for Health Research (CIHR) materials related to knowledge translation (Legare, 2010). Thus it was appropriate to use this framework to guide the planning, data collection and data analysis phases of this thesis, beginning with a
review of the literature related to the knowledge, attitudes and external barriers influencing the practices of primary care MDs and NPs related to implementing evidence-based breast cancer survivorship care.

**Primary care MD knowledge, attitudes and practice of survivorship care**

Cancer and survivorship care is under-represented in North American undergraduate and postgraduate training including nursing and family medicine programs (Cheung, Fishman, & Verma, 2009; Ferrell, Virani, Smith, & Juarez, 2003; Ferrell & Winn, 2006). Although primary care MDs provide the bulk of survivorship care, only a small subset report providing multidimensional care that includes management of late effects, mental health and monitoring for cancer recurrence (Bober et al., 2009). Primary care MD knowledge of the late and long-term effects of cancer treatment is limited (Nekhlyudov, Aziz, Lerro, & Virgo, 2014). Inadequate preparation and lack of formal training in cancer survivorship has been cited as a major barrier to providing this care (Bober et al., 2009). Results of interviews with post-treatment breast cancer patients and primary care MDs validated some of these findings in terms of the challenges associated with coordination of care for this patient population, and demonstrated a gap between research findings and clinical practice as MDs were not aware of certain research findings or published guidelines for the care of post-treatment breast cancer patients (Young, 2011).

In addition to knowledge gaps, the attitudes and practices of primary care MDs are factors that may affect the quality of follow-up care provided following cancer treatment. In one U.S. study, which included 1072 primary care MDs and 1130 oncologists, only 40% of the primary care MDs reported confidence in their knowledge of testing for recurrence, and only 23% reported confidence in their knowledge of caring for late physical effects of cancer (Potosky et al., 2011). In another U.S. study, which included 150 MDS, 13 NPs and 12 physician
assistants, 52% of these primary care providers were comfortable having responsibility for surveillance of cancer recurrence and only 43% were confident they were following standard guidelines (Nissen et al., 2007). In a Canadian study conducted in British Columbia, primary care MDs (n=587) responding to a mailed survey were most confident in screening for recurrence and managing patient anxiety in breast cancer survivors, and least confident in managing lymphedema and providing psychosocial counselling (Smith, Wai, Alexander, & Singh-Carlson, 2011).

From the patient perspective, only 50% of breast cancer survivors surveyed in a U.S. study (n=286) perceived their primary care provider as knowledgeable about cancer follow-up and only 41% perceived them as knowledgeable treating symptoms related to cancer or cancer treatment (Mao et al., 2009). Similarly, in a more recent U.S. study, cancer survivors (n=352) were generally satisfied with their primary care MD survivorship care, but only 43% perceived they were knowledgeable about cancer follow-up, and 45% perceived them as knowledgeable about late and long-term effects of cancer therapy (Nyarko et al., 2015). Although breast cancer survivors (n=1065) in a Canadian study were reasonably confident in the ability of primary care MD to screen for recurrence, many expressed low confidence in their MD’s ability to provide psychosocial care such as counseling about fear of recurrence (23%), sex and body image (35%) and family counseling (33%) (Smith, Murchison, Singh-Carlson, Alexander, & Wai, 2015).

Consequences of lack of knowledge of guidelines and recommendations may be reflected in primary care provider attitudes towards survivorship care. For example, primary care MDs in a U.K. study (n=352) were less likely than specialists to strongly agree that the purpose of follow-up was to detect late effects of treatment (18% vs. 33%) and to provide psychological support for patients and carers (27% vs. 39%) (Frew et al., 2010). This is concerning as these are
two of the key areas identified as foci for survivorship follow-up, and attitudes may influence provider willingness to provide this care. It is also concerning that clinicians valued clinical reasons (mean score 3.8/5) for follow-up more highly than supportive reasons (mean score 3.5/5) (p<0.001) in another U.K. study that included 421 cancer experts and 54 primary care MDs (Greenfield et al., 2009). Physician experience is another factor that may influence attitudes. For example, in a recent Canadian study (n=587), primary care MDs who followed more breast cancer survivors in their practice reported higher confidence in managing their follow-up (Smith et al., 2011).

Although primary care MDs in Canada report a willingness to provide follow-up survivorship care, they report a need for resources and indicate that the most useful modalities to assist them in providing follow-up cancer care are patient-specific letters from the specialist, printed guidelines, expedited routes of referral, and expedited access to investigations for suspected recurrence (Del Giudice, Grunfeld, Harvey, Piliotis, & Verma, 2009). These results suggest that with appropriate information and support in place, primary care providers are willing to assume responsibility for cancer survivorship care.

Both attitudes and lack of knowledge may influence the practices of primary care MDs in providing breast cancer survivorship care. Although patients with breast cancer in a randomized controlled trial were more satisfied with follow-up in general practice than in hospital outpatient departments, a large proportion of patients in both groups indicated it was difficult to discuss their concerns with the MD and that the MD should tell them more about their problem and treatment (Grunfeld et al., 1999). There is also evidence that follow-up care differs in different practice settings. For example, in one study, it was reported that primary care MDs were more likely than oncologists to endorse routine use of non-recommended blood and imaging tests for
detecting cancer recurrence, with both groups departing substantially from guideline recommendations (Potosky et al., 2011). Patients followed only by primary care MDs were more likely to receive preventive interventions for non-cancer conditions, whereas those followed by oncologists were more likely to receive cancer surveillance interventions, (Grunfeld & Earle, 2010) and compliance with surveillance guidelines were met more consistently by cancer specialists than primary care MDs (Hollowell et al., 2010). Although primary care led follow-up for breast cancer is generally as effective as oncology follow-up, primary care providers require clear guidance to provide this care (Emery et al., 2014). Gaps in practice could be addressed in a knowledge translation intervention for primary care MDs.

**Nurse practitioner knowledge, attitudes and practice of survivorship care**

The number of NPs in primary care is increasing in Ontario and across Canada (Koren, Mian, & Rukholm, 2010; Martin-Misener, 2010). Emerging research supports an NP role in survivorship care. Evidence provided by three systematic reviews suggests that the quality and effectiveness of care provided by primary care NPs is similar or better than that provided by MDs (Horrocks, Anderson, & Salisbury, 2002; Stanik-Hutt et al., 2013; Martinez-Gonzalez et al., 2014). Survivorship care provided by NPs has similarly been found analogous to care provided by MDs, as they manage comorbid conditions and long-term sequelae of cancer treatment and provide referrals to speciality care providers (Cooper, Loeb, & Smith, 2010). Several studies have described the various roles that NPs play in providing survivorship care (Cureton, Pritham, Royce, & Zahn, 2009; McKenney, 2005; van Hezewijk M. et al., 2011). Data from one U.S. study indicated that secondary cancer screening rates among breast cancer survivors were comparable between NPs and MDs, and that although NPs were more likely to
discuss lifestyle modification, self-reported improvements in nutrition and exercise did not differ by provider type (Kenison, Silverman, Sustin, & Thompson, 2015).

Some studies have described NP knowledge, attitudes and practices of cancer risk assessment which is one component of follow-up care for cancer survivors. Several studies have found NP knowledge of breast cancer risk assessment and screening approaches were low. Over a third of NPs in a U.S. study (n=147) did not respond correctly to any knowledge questions on a 10-item knowledge survey regarding breast cancer risk assessment, and the majority (71%) of NPs felt uncomfortable or a low level of comfort in conducting breast cancer risk assessment (Edwards, Maradiegue, Seibert, Saunders-Goldson, & Humphreys, 2009). Significant variation existed among 175 NP survey respondents in another U.S. study regarding breast cancer screening approaches, in which agreement with the accepted answer for individual breast cancer screening items ranged from 51% to 80%, and overall, only 54% demonstrated agreement with three or more of the four items (Lawvere et al., 2004). In another study, NPs demonstrated adequate knowledge about malignant melanoma but conducted general skin and malignant melanoma assessments less than half of the time and provided patient teaching about preventive measures and risk factors only occasionally (Furfaro, Bernaix, Schmidt, & Clement, 2008). NP behaviours in oral cancer prevention and early detection were significantly affected by their attitudes, with NPs less likely to provide an oral cancer exam to their new patients if they felt less confident in their oral cancer-related knowledge and training (Meng & Tomar, 2008). These gaps in knowledge and the discrepancies between knowledge, attitudes and behaviours demonstrate the need for knowledge translation products to prompt and support NPs in providing evidence-based care.
External factors influencing guideline implementation in primary care.

In the primary care setting, information overload is one of the key barriers to accessing the best evidence for practice (Davis, Ciurea, Flanagan, Perrier, & Ontario Guidelines Advisory Committee, 2004). Lack of time, lack of medical resources, inadequate search skills, lack of information-seeking behaviours, lack of access to technology or journals, and the inapplicable format of information are additional barriers identified by primary care MDs to accessing research evidence (Andrews, Pearce, Ireson, & Love, 2005; Taba et al., 2012). Primary care MDs rarely access primary sources of scientific information and favour indirect sources such as CME activities, popular media, online sources, experience, pharmaceutical representatives and online subscription services that summarize new research (Beaulieu et al., 2008; Warren-Findlow, Price, Hochhalter, & Laditka, 2010). Factors that positively influenced the attractiveness of online continuing medical education (CME) aimed at facilitating implementation of evidence-based CPGs included the credibility of the content, as indicated by affiliations with medical organizations and accreditation, and the ability to control the depth of learning and time spent (Young, Kim, Yeung, Sit, & Tobe, 2011). Factors that influenced a preference for face-to-face CME included the need for discussion of the content (Young et al., 2011). However, results of a study of CME programs suggest that the presentation of research data in most CME programs is inadequate to allow practitioners to make fully informed clinical decisions (Allen, MacLeod, Handfield-Jones, Sinclair, & Fleming, 2010). Physicians in another study suggested that an easy-to-find online database of guidelines would facilitate use (Taba et al., 2012). NPs have reported a preference for in-person conferences, workshops, print-based self-study, interactive video conferences, learning in practice settings, lectures, interactive online case studies, and direct mail and email newsletters from professional organizations that provide
short pieces emphasizing the important facts (Charles & Mamary, 2002; Green, Westwood, Smith, Peniston-Bird, & Holloway, 2009; Newman, Buckley, Dunn, & Cashin, 2009; Warren-Findlow et al., 2010).

**Knowledge translation for primary care providers**

To provide high-quality evidence-based care to patients, primary care providers must keep up with latest knowledge and skills; however, ensuring the most current evidence is available and used by primary care providers is a challenge. There is new evidence being produced all the time and busy clinicians have limited time to devote to updating their knowledge related to the wide variety of health care issues relevant to primary care practice. Knowledge translation (KT) is a relatively new field that addresses these demands.

Knowledge translation or implementation research is the study of the determinants of knowledge use and methods to promote the uptake of research findings by knowledge users such as healthcare providers (Foy, Eccles, & Grimshaw, 2001). The Canadian Institutes of Health Research (CIHR) defines KT as a “dynamic and iterative process that includes synthesis, dissemination, exchange and ethically-sound application of knowledge to improve the health of Canadians, provide more effective health services and products and strengthen the health care system” (Straus, Tetroe, & Graham, 2009, p. 4). Knowledge translation addresses the gap between research and practice through the knowledge-to-action (KTA) process as described in the conceptual framework developed by Graham and colleagues (Graham et al., 2006). This framework has been adopted by the CIHR as the model for promoting the application of research (Straus et al., 2009). Components of the framework are knowledge creation and the action cycle, which involves identifying a problem, selecting and adapting knowledge to local context, assessing barriers to knowledge use and tailoring interventions appropriately. Monitoring
knowledge use and evaluating outcomes informs sustained knowledge use, the identification of new problems and the creation of further knowledge.

Traditional approaches to disseminating research findings have failed to achieve optimal healthcare (Grimshaw & Eccles, 2004). Studies suggest 30-40% of patients do not receive treatments with proven effectiveness (Grol, 2001) and 20-25% of patients receive unnecessary or potentially harmful treatments (McGlynn et al., 2003). Failure to use research evidence to inform decision making is apparent in all health care settings including primary care (Straus et al., 2009). This gap between evidence and practice is referred to as a “knowledge-to-action gap” within the KTA framework (Kitson & Straus, 2009).

The gap between research and clinical practice is often wider in underserved communities (Ousley, Swarz, Milliken, & Ellis, 2010). Primary care practitioners in a rural practice-based research network reported more frequent use of print and interpersonal sources compared to online sources (Andrews et al., 2005). In Canada, NPs play a particularly important role in rural, northern and remote communities; however access to continuing education for these NPs is limited due to barriers such as travel, cost, and work and family obligations (Tilleczek, Pong, & Caty, 2005). Although more than 80% of cancer care practitioners in a U.S. study including primary care MDs and NPs report adequate access to research, only one third feel they have enough time to access the information (Ousley et al., 2010).

Several reviews have evaluated effectiveness of KT interventions. In 1997, results of a review of CPG implementation described interventions as weak (didactic, traditional continuing medical education, and mailings), moderately effective (audit and feedback, and opinion leaders), or relatively strong (reminder systems, academic detailing and multiple interventions) (Davis & Taylor-Vaisey, 1997). Although this review focused on results from RCTs and three
previous reviews, the methodological quality of the included studies was not reported. In 2001, Grimshaw and colleagues conducted a rigorous overview of 41 systematic reviews of interventions to change professional behaviour and concluded passive approaches were generally ineffective and unlikely to result in behaviour change but most other interventions were effective under some circumstances, with the most promising interventions including educational outreach, reminders and multifaceted interventions (Grimshaw et al., 2001). However, they found the methodological quality of the included reviews to be variable, and on average rated as moderate risk of bias. Also in 2001, Grol reviewed implementation of 70 evidence-based guidelines and reported a multifaceted approach with written (scientific journals & support materials) and personal approaches (local consensus discussions, contact with colleagues, outreach visits by peers) was an effective dissemination strategy (Grol, 2001). In 2004, Grimshaw and colleagues reviewed 235 original studies evaluating effectiveness and efficiency of guideline dissemination and implementation strategies and found: the majority of interventions produced modest to moderate improvements in care, with considerable variation both within and across interventions; there was no relationship between the number of components and the effects of multifaceted interventions; and evidence was inadequate to support which guideline dissemination and implementation strategies are likely to be efficient under different circumstances (Grimshaw et al., 2004).

More recently, a series of Cochrane reviews have evaluated various knowledge translation interventions on professional practice and health outcomes. Continuing education meetings and workshops alone or combined with other interventions were found to result in small improvements in professional practice and healthcare outcomes for patients (Forsetlund et al., 2009). Educational outreach visits alone or combined with other interventions also had small
but consistent and potentially important effects on prescribing; improvements on other types of professional practice vary from small to modest (O’Brien et al., 2007). Printed educational materials when used alone may have had a beneficial effect on process outcomes but not on patient outcomes (Farmer et al., 2008). And finally, opinion leaders alone or in combination with other interventions may have successfully promoted evidence-based practice, but effectiveness varied (Flodgren et al., 2011).

Innovative strategies such as online confidence-based learning CME have demonstrated that practitioners not only enhanced their knowledge, but their confidence in their knowledge and their clinical competence, with content mastery achieved through formative assessment, targeted feedback and remediation work (Cash, Mitchner, & Ravyn, 2011). Characteristics of the guidelines themselves that contribute to effective implementation are that they are evidence-based, compatible with existing norms and values, easy to follow, and not requiring new knowledge or skills (Burgers et al., 2003).

**Knowledge translation best practices for primary care**

Efforts to change clinical practice through implementation of evidence-based CPGs tend to be successful only to the extent to which they address the real world in which clinicians operate (Koutsavlis, 2001). Thus an understanding of KT interventions and best practices that have been proven effective in the primary care setting are essential. As lack of time is perceived to be the major barrier to practicing evidence-based medicine in primary care, historically, a number of studies have aimed to address this issue in particular. A group of researchers in the U.K. concluded that improving access to evidence summaries would be a more appropriate method of promoting evidence-based practice than teaching all primary care MDs literature searching and critical appraisal, and that practitioners who are skilled in accessing and
interpreting evidence should be encouraged to develop local evidence-based CPGs (McColl, Smith, White, & Field, 1998). In 1997, Hayward and colleagues conducted a survey of a random sample of over 1800 Canadian physicians that included primary care MDs and found that user friendliness of the guideline format was very important, and that MDs found pocket cards, concise pamphlets and journal article summaries most useful, and that more discursive formats, workshops and computer databases were not considered useful (Hayward, Guyatt, Moore, McKibbon, & Carter, 1997).

As well, several reviews of the literature have outlined best practices for disseminating research evidence to physicians including primary care providers. In 2001, a group of Canadian researchers published a review of best practices entitled Disseminating Practice Guidelines to Physicians which targeted first line health professionals to increase health promotion and prevention efforts for cardiovascular health using evidence-based practice guidelines (Koutsavlis, 2001). They concluded that CPG dissemination and implementation is a complex problem and recommended a multifaceted approach, using theoretical and practical means, and new technologies, to achieve success. In 2005, a review funded by the Canadian Population Health Initiative (CPHI) formed the basis for five general best practice guidelines for translating knowledge to primary care MDs: (1) choose goals (effect researchers want to see from dissemination of their research; (2) develop a multi-faceted plan (more than one approach and communication vehicle to reach MDs with varied learning and working styles); (3) affiliate to gain credibility (recognized partners or agencies that MDs trust); (4) choose collegial and small group learning (MDs learn and apply learning better when information is acquired in interactive, personal way); and (5) respond to existing problems (tailor messages to the practice environment
and take organizational barriers and resources into account to increase likelihood of implementation) (McColl, Dent, & Churchman, 2005).

Similarly, researchers in Sweden recommended that several factors be taken into account when planning implementation of innovations in primary care: assessment of expectations and perceived need for the innovation and its potential compatibility with existing routines, and avoiding implementation concurrently with other major organizational changes (Carlfjord, Lindberg, Bendtsen, Nilsen, & Andersson, 2010). More recently, Unverzag and colleagues conducted a systematic review of 84 RCTs about guideline implementation strategies on cardiovascular disease CPGs, and concluded that both unimodal or multimodal implementation strategies could be effective on physician adherence, and that three distinct strategies should be considered in designing CPG implementation for primary care: organizational changes in the primary care team, patient education, and provider education.

Knowledge translation interventions for primary care

Recently, additional innovative KT strategies have been tested in primary care settings such as practice facilitation, financial incentives, technology-based innovations, decision-support tools and multifaceted approaches. Practice facilitation, in which a health professional, usually external to the practice, regularly visits the practice to provide support in change management that targets improvements in care delivery, has been shown to be more effective in improving uptake (>10%) of preventive care guidelines in primary care than traditional didactic and passive dissemination efforts, and audit and feedback (Liddy et al., 2013). A recent rigorous meta-analysis of 23 studies involving 1,398 primary care practices found that primary care MDs supported by a practice facilitator were nearly three times as likely to implement evidence-based CPGs; however the methodological quality of the included studies were rated as poor to
moderate (Baskerville, Liddy, & Hogg, 2016). Adoption of a CPG was positively influenced by positive expectations, perceptions of compatibility with existing routines, perceived advantages, use of an explicit implementation strategy and positive opinions on change and innovation suggesting the need to assess and address provider attitudes when designing KT strategies.

Financial incentives (and/or disincentives) for health professionals layered on top of or alongside existing funding mechanisms have been used in Ontario with variable results, including modest absolute increase in provision of four of five preventive services and three recommended diabetes assessments, and large relative increase in the planned management of diabetes (Lavis, Wilson, Grimshaw, & Hurley, 2015).

Technology-enabled knowledge translation (TEKT), which involves the use of modern information and communication technologies, can be an effective tool for collecting, processing, and distributing targeted information to health care providers (Ho et al., 2004). Increased use of electronic patient records provides opportunities for incorporating electronic decision-support tools that synchronize patient management with documentation, and improve adherence to evidence-based CPGs (Ho, Ferdinands, Jarvis-Selinger, Bluman, & Hardwick, 2008). In a U.S. study, Stoner and colleagues evaluated a Web-based multimedia training for primary care providers, including MDs (n=37) and NPs (n=20), in screening, brief intervention, and referral to treatment (SBIRT) for unhealthy use of alcohol, tobacco, and other drugs, which resulted in significant increases in SBIRT-related knowledge, self-efficacy, and clinical practices (Stoner, Mikko, & Carpenter, 2014). A systematic review of online CME for primary care MDs found a significant improvement in at least one of the following outcomes: satisfaction, knowledge or practice change in eight of eleven included studies, however there was little impact on patient outcomes (Thepwongsa, Kirby, Schattner, & Piterman, 2014). Souza and colleagues conducted a
decision-maker-researcher partnership systematic review of 41 RCTS assessing computerized clinical decision support systems (CCDSSs) on care processes, patient outcomes, harms and costs, and found strong evidence supporting effectiveness of CCDSSs for care processes related to screening and treatment of dyslipidemia in primary care, but less consistent evidence for CCDSSs used in screening for cancer and other preventive care, with effects on patient outcomes, safety, costs of care, and provider satisfaction poorly supported (Souza et al., 2011).

Several Canadian initiatives have evaluated a variety of TEKT interventions for primary care. Minard and colleagues demonstrated the feasibility of implementing an electronic asthma record for primary care that integrated evidence-based CPGs into practice and permitted monitoring of patient outcomes (Minard et al., 2014). Grad and colleagues explored retrieval of email alerts by primary care MDs and found that email alerts containing research-based synopses were seldom retrieved (Grad et al., 2011). Badran and colleagues further evaluated the use of educational email alerts and found that primary care MDs reported several advantages such as saving time, convenience and valid information, as well as disadvantages such as an overwhelming number of emails and irrelevance; however the advantages of email alerts seem to compensate for their disadvantages, and participants made suggestions for improving educational email such as enabling links to a discussion board (Badran, Pluye, & Grad, 2015). Eng and colleagues demonstrated that a web-based knowledge resource increased access to and knowledge of evidence-based information related to spinal cord injury rehabilitation and informed health care providers (n=101) practices and clinical decision making (Eng et al., 2014).

Two novel Canadian KT products for primary care that can be delivered electronically are Decision boxes and Actionable Nuggets. Decision boxes (Dboxes), developed by Giguere and colleagues, are 2-page clinical summaries that provide clinicians with research evidence by
weekly emails about management options for medical questions that have no single best answer (Giguere et al., 2014). Although Dboxes were valued, some primary care providers would have liked a clear recommendation statement for each Dbox and access to print versions of the Dboxes in consultation rooms, whereas others suggested that patient decision aids and training in shared decision-making would facilitate use of the Dbox information. Actionable Nuggets, are postcards that can be delivered either in hard copy or electronically and were developed by McColl and colleagues to provide primary care MDs with concise, practical information about the most prevalent and pressing primary care needs of patients with spinal cord injury (SCI) (McColl et al., 2015). Pilot testing demonstrated that MD knowledge increased and the tool was highly rated for usefulness and acceptability, with participants indicating a strong preference for hard-copy postcards with email prompts. The SCI Nuggets were subsequently updated and adapted for distribution by the Canadian Medical Association to approximately 50,000 primary care physicians in Canada, in both English and French.

Other Canadian-based KT strategies that are available on the internet include evidence-based clinical forms, and evidence-based librarian services. One specific KT tool that has proven successful in primary care in Canada is the Rourke Baby Record (RBR) which is a freely available evidence-based structured form for pediatric health prevention and surveillance; the RBR was widely used, helpful to primary care MD users, and promoted a high rate of documentation of many aspects of well-baby care (Rourke, Godwin, Rourke, Pearce, & Bean, 2009). The Web-based Just-in-Time Librarian Consultation Service is a point-of-care reference service, accessed by computer or hand-held devices, in which librarians answer primary care providers’ questions within minutes (McGowan et al., 2009). The service was well-received and
evaluation showed it was possible to provide evidence-based answers to clinical questions in 15 minutes or less, and had a positive impact on clinical decision-making.

Use of a multi-faceted KT approach is a recurrent theme in historical reviews previously mentioned, as well as emerging research. In Australia, Dadich & Hosseinzadeh evaluated the effect of six relatively inexpensive evidence-based sexual healthcare resources for primary care providers that included online learning modules and testing tools and placards, and found the resources improved delivery of evidence-based sexual healthcare (Dadich & Hosseinzadeh, 2013). In Canada, Licskai and colleagues used the KTA framework to guide a multi-step, multi-level approach that targeted patients, primary care practices, and the local health system, and facilitated implementation of six asthma CPG recommendations, resulting in improved health outcomes (Licskai, Sands, Ong, Paolatto, & Nicoletti, 2012). Also in Canada, Kastner and colleagues developed a multi-component osteoporosis knowledge translation (Op-KT) tool involving a patient-initiated risk assessment questionnaire (RAQ), which generates individualized best practice recommendations for MDs and customized patient education for patients at the point of care, and significantly increased osteoporosis investigations in three primary care practices (Kastner et al., 2016)

**Knowledge translation interventions for breast cancer survivorship care**

Although numerous KT strategies have been implemented and evaluated in primary care settings, fewer studies have focused on cancer or cancer survivorship care in general or breast cancer survivorship care specifically. Some evidence and practice guidelines exist for provision of survivorship care following breast cancer treatment; however, it is unclear what strategies would be most effective to promote evidence-based survivorship care by primary care practitioners. One randomized controlled trial described an intensive multimodal intervention
for rural primary care providers to improve knowledge about cancer practice including breast cancer (Elliott et al., 2001). The intervention included eight components including CPGs faxed from regional cancer centers to the primary care providers. The CPGs were designed for quick review by users, and were supported by best evidence and references, clinical algorithms and checklists to assist in the application to actual practice. Knowledge scores for providers in the experimental group increased significantly from pretest (66/100) to post-test (79/100) for MDs (p=0.02), and providers in the experimental group performed significantly better (p=.008) on the post-test knowledge scores (79/100) than those in the control groups (68/100, 67/100). However, improving primary care provider knowledge does not necessarily improve their practice performance (Elliott et al., 2002). In a second report, the researchers reported the multimodal intervention significantly improved only 5 of the 37 cancer practice end points measured in the study related to cancer diagnosis, staging, treatment, clinical trial participation, and post-treatment surveillance.

A controlled before and after study evaluated a CPG implementation strategy on medical practice in a cancer network; the strategy involved monthly meetings in which local opinion leaders from the cancer center presented CPGs on cancer management including, breast cancer specific guidelines (Ray-Coquard et al., 2002). The information presented was then discussed, modified and/or validated by the participating MDs from 26 hospitals to obtain a regional consensus. Validated CPGs were then sent to all participating MDs who were expected to use them in their practice. Compliance rates were significantly higher in the experimental group with the breast cancer guidelines improving from 12% to 36% following the intervention, suggesting that involvement of MDs in the KT process can facilitate translation of guideline recommendations into practice.
Evaluation of an educational tool that addressed topics including lifestyle changes, enhanced screening, and psychosocial issues in treating women at risk for breast cancer indicated that primary care MDs are interested in identifying and treating patients at increased risk for breast cancer, but may be reluctant to do so due to lack of sufficient knowledge (Gabram et al., 2009). Participant knowledge increased significantly following the session and may influence their future practices. Similarly workshops for NPs significantly increased knowledge related to hereditary colorectal cancer, (Edwards, Maradiegue, Seibert, & Jasperson, 2011) and breast cancer risk assessment (Edwards & Seibert, 2010). Publishing CPGs does not change provider behaviour; however, introduction of a CPG with a resource kit that included documentation tools, handouts and worksheets resulted in significant improvements in NP knowledge, intent to change behaviour and increased confidence in ability to address barriers to helping patients maintain a healthy weight (Gance-Cleveland, Sidora-Arcoleo, Keesing, Gottesman, & Brady, 2009).

Results from these few studies suggest KT strategies can effectively increase primary care provider knowledge of breast cancer care but may have limited success with changing practice. Knowledge translation identifies best evidence and creates pathways or tools to facilitate use of evidence in practice (DiCenso & Bryant-Lukosius, 2010). For example, algorithms might facilitate adherence to complex recommendations (Burgers et al., 2003). Tools to facilitate translation of evidence on breast cancer survivorship care are needed. However, a thorough understanding of the practice context is essential to the effective implementation of new interventions or practices in health care settings (Sandelowski & Leeman, 2012). Variables related to the providers themselves may influence implementation in different settings (Durlak & DuPre, 2008). Findings from qualitative research with health care providers can provide
contextual information on the feasibility of different approaches and characteristics of providers that might influence implementation (Sandelowski & Leeman, 2012). A qualitative exploration may reveal that MD and NP experiences of providing breast cancer survivorship care are different which would suggest that different approaches may be required to promote evidence-based practices by these two provider groups.

**Summary**

**The problem**

It is apparent that breast cancer survivors continue to have a broad range of physical and psychosocial primary health care needs after breast cancer treatment. Pain, lymphedema, fatigue, sleep disturbances, depression and anxiety are the most commonly reported issues. Survivors may continue to experience long-term effects of their treatment or develop late effects months or years later. Research suggests that primary care providers are willing to provide breast cancer survivorship care but many lack the knowledge and confidence to provide evidence-based care.

**What was known**

Recent CPGs were available applicable to follow-up care of breast cancer survivors in primary care, however, primary care provider practices related to implementing CPGs are known to be influenced by their knowledge and attitudes, as well as the resources available to them and their patients. Knowledge translation best practices for primary care have been suggested by researchers. Numerous KT strategies have been evaluated with MDs, and in some cases NPs, in primary care settings that address known barriers to evidence-based practice, with varied success.
The gaps

Despite availability of numerous CPGs, there was no single guideline that addressed all of the essential components of breast cancer survivorship care and it was unclear which guideline recommendations were relevant to the primary care practice setting. As well, it was unknown which guidelines were actually being accessed and which recommendations were being applied in primary care settings within the South East LHIN, and what were the gaps.

Numerous KT strategies have been studied in the primary care setting with varying effect. Many improved primary care provider knowledge but not always their practices, and few specifically addressed challenges related to providing survivorship care. Thus, it was unclear which strategies would be most effective to promote evidence-based breast cancer survivorship care in the primary care setting within the Canadian context and specifically within Ontario where the population of primary care NPs is growing, and where many primary care providers are practicing in team-based models such as Family Health Teams. However, a thorough understanding of the practice context would first be essential prior to the design and implementation of effective KT interventions to support evidence-based breast cancer survivorship care.

The plan

The South East LHIN in Ontario provided an appropriate research setting for exploring these issues in both rural and urban primary practice settings and family health teams. Thus, through this dissertation I proposed to (1) determine which existing breast cancer survivorship care guideline recommendations are perceived to be relevant to our local context by oncology specialists, primary care providers and breast cancer survivors from our region, through a modified Delphi process; (2) determine the current knowledge and practice gaps of primary care...
MDs and NPs from our region, through a quantitative survey; and (3) determine the challenges, strengths and opportunities related to providing evidence-based breast cancer survivorship care as perceived by primary care MDs and NPs from our region, through qualitative interviews. Results of this dissertation will thus inform future development of targeted KT strategies to address the identified knowledge and practice gaps and the factors influencing them.
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CHAPTER THREE

A comprehensive framework and key guideline recommendations for the provision of evidence-based breast cancer survivorship care within the primary care setting
Abstract

Background

Breast cancer survivors continue to experience physical and psychosocial healthcare needs post-treatment. Primary care involvement is increasing as cancer centres move forward with earlier discharge of stable breast cancer survivors to primary care follow-up. Research suggests primary care providers (PCPs) are willing to provide survivorship care but many lack knowledge and confidence to provide evidence-based care. Although clinical practice guidelines (CPGs) exist for follow-up surveillance and certain aspects of survivorship care, no single comprehensive guideline addresses all significant breast cancer survivorship issues encountered in primary care.

Purpose

The purpose of this research was to create a comprehensive clinical practice framework to guide the provision of breast cancer survivorship care in primary care settings.

Methods

This study consisted of an extensive search, appraisal and synthesis of CPGs for post-treatment breast cancer care using a modified Delphi method. Breast cancer survivorship issues and relevant CPGs were mapped to four essential components of survivorship care to create a comprehensive clinical practice framework to guide provision of breast cancer survivorship care.

Results

The completed framework consists of a one-page checklist outlining breast cancer survivorship issues relevant to primary care, a three-page summary of key recommendations, and a one-page list of guideline sources. The framework and key guideline recommendations were verified by a panel of experts for comprehensiveness, importance and relevance to primary care.
Conclusions

This framework may serve as a tool to remind PCPs about issues impacting breast cancer survivors, as well as the evidence-based recommendations and resources to provide the associated care.

Keywords: breast neoplasms; aftercare; practice guideline; primary health care; nurse practitioners; physicians, primary care
**Introduction**

Breast cancer is the most common cancer affecting women worldwide representing 25% of all new cancer cases, with 1.67 million new cases diagnosed in 2012 (1). With aging of the population and improved cancer treatment the number of women who have survived breast cancer is increasing. Many of these women have multiple, complex and unique health care needs and may experience debilitating physical and psychosocial consequences such as pain, fatigue, depression, and lymphedema (2). Primary care involvement in post-treatment follow-up is evolving as increasing healthcare costs, increasing patient numbers and limited supply of oncologists are impacting accessibility to follow-up care (3-6). Researchers and cancer agencies are recommending breast cancer survivors without ongoing treatment issues be discharged from specialist-led care to community-based family physician-led care (7;8). However, survivors often describe feeling “abandoned” as they transition from intensive specialist care to primary care follow-up (9) and often report their health care needs are not being sufficiently met (10). This is a significant problem impacting the lives of breast cancer survivors and their families.

Unfortunately primary care providers (PCPs), by their own admission, lack knowledge about consequences of cancer treatment and optimal care for cancer survivors (11;12). Although clinical practice guidelines (CPGs) exist for follow-up surveillance and certain aspects of survivorship care, no single comprehensive guideline covers the wide spectrum of breast cancer survivorship issues commonly encountered during the post-treatment phase. As cancer programs are moving forward with earlier discharge of stable, early-stage breast cancer survivors to primary care follow-up after completion of primary treatment, each PCP may only be seeing one to two newly discharged breast cancer survivors per year, and it may prove challenging for these
providers to remain up to date about best practices in breast cancer survivorship care (13). Lack of comprehensive guidelines may limit ability of PCPs to implement evidence-based care.

**Purpose of the study**

The purpose of this study was to create a comprehensive clinical practice framework to guide the provision of breast cancer survivorship care in primary care settings.

**Research Question:** What evidence-based CPGs are available for post-treatment breast cancer survivorship care that are relevant to the primary care setting?

**Conceptual Framework**

In terms of a clinical framework for provision of survivorship care, the seminal report from the Institute of Medicine (IOM) *From Cancer Patient to Cancer Survivors: Lost in Transition* (14), is the most frequently reported in the literature providing guidance to cancer survivorship care and research (15-18). Several of the consensus report recommendations have recently been adapted in a pan-Canadian guideline for the organization of cancer survivorship services (19). The IOM report synthesizes what is known about cancer survivorship and establishes the survivorship period as an important new focus for care extending beyond long-term surveillance to include many previously unaddressed medical and psychosocial needs of survivors (18). The IOM report specifically outlines four essential components of survivorship care: 1) prevention of recurrent and new cancers, and other late effects; 2) surveillance for cancer spread, recurrence, second cancers, and medical and psychosocial late effects; 3) intervention for consequences of cancer and its treatment; and 4) coordination between specialists and PCPs to ensure that all of the survivor’s health needs are met (14).

The IOM report definition of survivorship focuses on the individual following the acute treatment phase until treatment is needed again or death occurs (20). This definition will be
understood when referring to cancer survivorship throughout this study. Breast cancer patients may experience difficulties while transitioning to the survivorship phase (21). The Canadian Partnership Against Cancer describes survivorship care to be patchy, and overall, not of high quality and suggests guidelines and care plans are needed, and promoting survivorship research and ensuring effective Knowledge translation (KT) are key priorities of the Canadian agenda for cancer survivorship (11). KT is the study of the determinants of knowledge use and methods to promote uptake of research findings by knowledge users such as healthcare providers (22).

**Review of the Literature**

A key recommendation of the IOM report was to raise awareness of the needs of cancer survivors to ensure delivery of appropriate survivorship care (14). Acute physical toxicities may appear during cancer treatment and continue after treatment as long-term chronic effects, or emerge as late effects following treatment (23). An abundance of studies have identified physical symptoms that may persist for years following breast cancer treatment. A recent, comprehensive review described both physical and psychosocial late effects such as pain, lymphedema, fatigue and sleep disturbances, and identified a need for screening instruments and guidelines for rehabilitation and interventions for alleviating symptoms in breast cancer survivors (24). Similarly, a study examining needs and preferences of breast cancer survivors found the most common treatment-related sequelae reported were fatigue, neuropathy, pain and lymphedema; and aspects of follow-up care rated as important included: screening, educational materials, physical therapy, diet and exercise counselling, and complementary/alternative medicine information (25). Management of postmenopausal symptoms and premature menopause were often cited in the literature (26;27). Older breast cancer survivors may be particularly vulnerable
to physical symptoms and functional decline due to comorbid conditions compounding treatment effects (28;29).

In addition to physical symptoms, breast cancer survivors continue to experience psychosocial effects during long-term survivorship. A cancer diagnosis may result in significant psychological distress and disruption of quality of life (30), particularly in women aged 40 years and younger (28). Adjuvant chemotherapy results in impaired cognitive function, with residual effects after treatment completion (31;32). Residual non-life threatening physical symptoms can result in decreased physical functioning which in turn impacts occupational and social functioning, contributing to isolation and financial strain which are risk factors for development of psychosocial distress (33). Psychological consequences of cancer diagnosis include depression, anxiety and posttraumatic stress disorder (34;35). Survivor concerns related to sexuality and body image can lead to reduced intimacy and sexual activity, and anxiety about resuming or establishing sexual relationships (33). A review by Vivar and McQueen (36) suggested women with breast cancer continue to experience informational and emotional needs during long-term survivorship which are often unmet by oncology teams. Hawkins and colleagues (37) similarly concluded that many cancer survivors’ lifestyle, social, and financial needs are often addressed inadequately, and that unmet informational needs may contribute to depression and anxiety.

An additional psychosocial concern commonly reported is fear and anxiety related to cancer recurrence, which has been identified as the highest unmet supportive care need even up to 10 years after diagnosis (33;35;38;39). An overview of randomised trials revealed about three-quarters of eventual local recurrence risk occurred during the first five years (40). In fact, most
existing cancer-related practice guidelines focus on detection, treatment and surveillance of cancer (41).

A scoping review and validation study by Young (2011) identified eleven broad categories related to the post-treatment primary health care needs of women with breast cancer: surgical complications, fatigue, lymphedema, gynecologic and menopausal symptoms, psychosocial issues, additional primary cancers, cardiovascular issues, osteoporosis, lifestyle changes, cognitive dysfunction, and pregnancy (42). Results of interviews with post-treatment breast cancer patients and primary care physicians (MDs) validated some of these findings in terms of post-treatment complications and demonstrated a gap between research findings and clinical practice as MDs were not aware of certain research findings or published guidelines for care of post-treatment breast cancer patients (42). These results are consistent with the literature in suggesting a need for translation of evidence-based guidelines into primary care practice, specifically focused on survivorship needs of women following breast cancer treatment.

Differentiating between symptoms related to cancer progression or recurrence, treatment-related issues, and non-cancer-related problems is challenging for PCPs (43). Another recommendation of the IOM report is use of evidence-based CPGs, assessment tools, and other screening instruments to identify and manage late effects of cancer treatment (14). Although research in the area of best practices in survivorship care is lacking (44;45), there are evidence-based guidelines available on follow-up surveillance for detection of recurrent breast cancer (46-48). However, optimal cancer survivorship care involves more than surveillance tests (18). Several reviews are available to guide general primary care follow-up of complications related to local and systemic treatment for breast cancer (49-51), including psychosocial care (52). There
are also guidelines available related to specific survivorship issues such as nutrition (53),
physical activity (54), and cancer fatigue (55).

Available Canadian guidelines have not been updated since 2005 (46). These guidelines,
published in the Canadian Medical Association Journal, provided recommendations to patients
and physicians regarding follow-up after treatment for breast cancer. These guidelines included
general recommendations for surveillance, and specific recommendations related to the
following health concerns frequently experienced by breast cancer survivors: cognitive
functioning, fatigue, weight management, osteoporosis, sexual functioning and pregnancy.
Cancer Care Ontario (CCO) continues to endorse these recommendations (56). It is unclear
which sources and guidelines are currently being accessed and/or utilized by primary care MDs
and NPs. Further it is unclear what strategies would be most effective to promote awareness and
use of evidence-based guidelines on breast cancer survivorship care by PCPs.

Methods

This study consisted of the appraisal, synthesis and validation of relevant CPGs to
determine key best practice guideline recommendations to create a comprehensive clinical
practice framework to guide the provision of post-treatment breast cancer survivorship care in
primary care settings.

Search for clinical practice guidelines

A search of the literature including the grey literature through online databases and
websites of national and international cancer care organizations was conducted to identify
current CPGs from 2005-2013 that outlined evidence-based care for post-treatment breast cancer
survivors. CPGs were retrieved from the U.S., Canada, Australia, New Zealand, and Europe,
including the U.K. The most recent Canadian guidelines for primary care follow-up care were
published in 2005, thus 2005 was chosen as the starting point for guideline inclusion. A
description of the search strategy can be found in Table 1. Due to the limited number of
guidelines related solely to breast cancer, guidelines related to generic cancer survivorship were
also reviewed.

**Appraisal of clinical practice guidelines**

Guideline quality was assessed by two reviewers using the AGREE II (Appraisal of
Guidelines, Research and Evaluation) tool, which comprises 23 items within 6 domains (57),
prior to selection of key recommendations. Overall quality of each guideline was assessed on a
scale from 1 (lowest possible quality) to 7 (highest possible quality). Each guideline may report
methods for rating the evidence and grading the recommendations in the guidelines. Practitioners
are referred back to the original sources to obtain this level of detail.

**Creation of a clinical practice framework**

Breast cancer survivorship issues and recommendations identified in the CPGs were mapped to
the four essential domains of cancer survivorship care as described in the seminal IOM report
*From Cancer Patient to Cancer Survivor: Lost in Transition* to create a provisional clinical
practice framework (Final version presented in Table 2. Guideline recommendations were
chosen from the most recent, highest quality guidelines available for each survivorship issue that
were potentially relevant to the primary care setting i.e. recommendations from the CPGs with
the highest AGREE ratings were chosen first. The clinical practice framework was used as an
outline for the synthesis of key guideline recommendations for comprehensive breast cancer
survivorship care.
Validation of the framework and guideline recommendations

The proposed clinical practice framework and recommendations for breast cancer survivorship care were verified for comprehensiveness, importance and relevance to primary care through external review with an expert panel of oncologists, MDs, Nurse Practitioners (NPs) and breast cancer survivors recruited based on their experience with breast cancer and/or primary care. Panel members were known to the principal investigator or recommended by other panel members; breast cancer survivors were recruited through a breast cancer support group. A consensus process using a two-round modified Delphi method was employed. The Delphi technique consists of a series of questionnaires or “rounds” of feedback that aim to obtain the most reliable consensus of opinion of an expert panel (58). In this study experts were asked to confirm that the individual issues in the draft framework were relevant and to identify additional issues for primary care practice. Panel members were also asked to rate the specific guideline recommendations as “need to know” (high importance/essential/must do), “nice to know” (important/relevant/nice to do) or “not relevant to primary care” (not important/not relevant/doesn’t need to be done within the primary care setting).

Essential and relevant issues and guideline recommendations were retained in the framework. Feedback from the panel members was obtained through informal individual interviews, email communications, as well as formal surveys.

Results

This purpose of this study was not to synthesize or appraise evidence from different studies, but to identify existing CPGs with recommendations relevant to issues commonly encountered in the post-treatment breast cancer survivorship phase that could be managed in the primary care setting. A total of 25 categories of issues potentially relevant to primary care
follow-up were identified through the review of the CPGs. These issues were mapped to the four essential domains of survivorship care as outlined by the IOM to create a framework for breast cancer survivorship care as presented in Table 2. Intervention issues were organized according to treatment type as many long-term effects are related to the treatment modalities used. Within the intervention section, several issues (e.g. fatigue) were included more than once as they were applicable to more than one treatment modality.

A total of 30 CPGs relevant to primary care were retrieved and mapped to the four essential domains of survivorship care (see Table 3). None of the retrieved CPGs addressed all of the domains. Each of the guidelines addressed some of the individual survivorship care issues but none of the guidelines addressed all of them. Each of the issues was addressed by at least one of the identified guidelines.

Methodological quality of the guidelines was assessed using the AGREE II tool (see Table 3). Only 3 of the 30 CPGs were rated as high quality (59-61). Fifteen guidelines were rated as moderate (46;55;62-74), and 12 were rated as low quality (5;75-85). The majority of retrieved guidelines, 26 out of 30, were published between 2009 and 2013, and four were published between 2005 and 2008. Recognizing that guidelines developed more than five years ago may be outdated, these recommendations were considered only if there were no more recent guidelines addressing a specific issue. Although most guidelines were developed for use by healthcare professionals, only five targeted PCPs specifically (5;59;61;63;72).

Following appraisal of guideline quality, a comprehensive list of recommendations from all of the guidelines was extracted based on potential relevance to the primary care setting. A total of 113 recommendations were summarized in a table and organized according to the breast care survivorship issue addressed: exercise (11 recommendations), lymphedema (10), specialist
referrals (10), fatigue (8), distress (7), menopausal symptoms (7), sexual dysfunction (7),
immunizations (6), osteoporosis (6), history & physical (5), fertility, pregnancy and
contraception (5), pain (5), pelvic exam (4), cognitive dysfunction (4), nutrition (3), weight
management (3), mammography (2), breast self-exam (1), non-routine tests (3), survivorship
care plan (3), peripheral neuropathy (1), cardiovascular complications (1), and alcohol
consumption (1).

A total of 15 individuals were recruited to review and provide expert feedback on the
preliminary framework and guideline recommendations. Expert panel members included a breast
cancer oncologist, a breast cancer NP, 3 primary care MDs (2 with oncology focus), 3 primary
care NPs (2 with previous oncology experience), and 7 breast cancer survivors (see
Acknowledgements). Healthcare providers on the expert panel were asked to review the
framework and to indicate if there were any breast cancer survivorship issues that should be
added to or removed from the framework. None of the panel members suggested that any of the
issues should be removed from the framework. Eleven new issues were identified: smoking
cessation, sun exposure, calcium and vitamin D intake, PAP, lipid and cholesterol testing,
depression, frozen shoulder, breast reconstruction, second malignancy leukemia, second
malignancy endometrial cancer and skin changes.

Breast cancer survivor panel members were asked to evaluate the original framework and
the additional issues. Two more issues were identified by the breast cancer survivors: family
issues and work issues. A second round of feedback was requested from panel members to
evaluate relevance of the additional issues and identify appropriate guideline recommendations
and sources to address them.
All panel members were also asked to rate the specific guideline recommendations as “need to know” (high importance/essential/must do), “nice to know” (important/relevant/nice to do) or “not relevant to primary care” (not important/not relevant/doesn’t need to be done). Of the original 113 guideline recommendations, 72 were rated as “need to know” and the remaining 41 were rated as “nice to know” by over 50% of the panel members following the first round of feedback.

Following the second round of feedback, four additional items (smoking cessation, sun exposure, cholesterol and lipid screening, family and work) and one intervention category (targeted therapy) were added to the framework (see Table 2). Items were added only if the majority of panel members rated the item as relevant to primary care, and at least one related guideline recommendation was retrieved. Although family and work were identified as separate issues, a single guideline recommendation was retrieved that addressed both issues, and therefore they were grouped together in the framework.

During each round of feedback panel members were invited to enter additional comments, suggestions or clarifications related to their responses. Feedback from the panel members was generally positive with most agreeing the framework was relevant and comprehensive: “very comprehensive and laid out in an intuitive manner,” “I commend you on your thoroughness,” and “agree with the order in which they are presented and the grouping of the chart.” Some PCPs also commented on the usefulness of the framework and summary of recommendations: “the flow of the chart allows clinicians to cue discussion topics relevant to breast cancer survivorship care,” “I learned something in terms of recommendations,” I was able to use your framework with a new patient recently, it provided a nice reminder,” and “I was able to identify issues I probably wouldn’t have without it, for example sexuality, I may not have
discussed this, and it was an issue.” Healthcare panel members liked the brevity of the framework and recommendations: “a simple care plan will be followed by primary care, while a complex one may seem overwhelming,” and “I really like your summary page—so succinct. Just what a GP likes! And then the ability to dig deeper into references as needed.” Constructive feedback included comments that some guideline recommendations, particularly those related to prevention, were normal practice: “some of the things were certainly valid, but no different from the general population,” “many of the recommendations I would expect to be part of routine family practice regardless if patient is breast cancer survivor,” and “some of these recommendations are simply common sense.” As well, breast cancer survivors on the panel suggested patients get a copy of the framework because “patients have to look after their own health,” and “patients should probably be responsible for this.”

The completed and validated Comprehensive Framework for Evidence-based Breast Cancer Survivorship Care consists of a one-page checklist outlining breast cancer survivorship issues relevant to primary care, a three page summary of key guideline recommendations pertaining to these issues, and a one-page list of the guideline sources (see Supplemental Data File in Appendix I).

Discussion

A rigourous process was followed to identify existing CPGs relevant to provision of breast cancer survivorship care in primary care settings. The importance of context to the success of knowledge translation (KT) strategies implies the need for involvement of end-users in the research process. Integrated KT refers to collaboration of researchers and knowledge users throughout the entire research cycle including research design, interpretation and dissemination of findings (86). Informal consultation with an oncologist, two primary care MDs and three
primary care NPs informed the design of the study. Formal consultation with a panel of oncology and primary care experts and breast cancer survivors validated the content and structure of the clinical practice framework for breast cancer survivorship care.

Results of the study confirm there are numerous existing CPGs addressing one or more post-treatment healthcare needs of breast cancer survivors, however, no single guideline addresses the four essential components of comprehensive survivorship care: prevention, surveillance, intervention and coordination. The completed and validated *Comprehensive Framework for Evidence-based Breast Cancer Survivorship Care* may be the first to consolidate the evidence pertaining to provision of breast cancer survivorship care in the primary care setting.

Research suggests only a subset of primary care MDs provide multidimensional survivorship care including management of late effects, mental health and monitoring for cancer recurrence; 47% of primary care MDs surveyed by Bober and colleagues (87) cited inadequate preparation and lack of formal training in cancer survivorship as a problem in providing this care. In one study, only 40% of primary care MDs reported confidence in their knowledge of testing for recurrence, and only 23% reported confidence in their knowledge of caring for late physical effects of cancer (88). In another study, only 50% of breast cancer survivors surveyed perceived their PCP as knowledgeable about cancer follow-up and only 41% perceived them as knowledgeable treating symptoms related to cancer or cancer treatment (89). Although primary care MDs report a willingness to provide follow-up survivorship care, they report a need for resources including printed guidelines (16). These results suggest that with appropriate information and support in place, PCPs would be able to provide evidence-based breast cancer survivorship care.
Information overload is one of the key barriers to accessing the best evidence for primary practice (90). Lack of time and resources, inadequate search skills, lack of information-seeking behaviours, lack of access to technology/journals, and the inapplicable format of information are additional barriers (91;92). Primary care MDs rarely access primary sources of scientific information and favour indirect sources that summarize new research (93;94). NP preferences include sources that provide short pieces emphasizing important facts (94-97). These studies suggest the comprehensive framework and guideline recommendations for primary care breast cancer survivorship care could be a relevant and timely resource for PCPs in addition to providing a guiding framework and content for future KT research.

Feedback from expert panel members supports the comprehensiveness and relevance of the framework and guideline recommendations for the primary care setting. Additionally, anecdotal evidence from PCPs on the panel indicates the framework has been useful to them in highlighting survivorship needs and prompting discussion of these points. Although the “prevention” guideline recommendations may be considered to be common sense, prevention is one of the four “essential” domains of survivorship care outlined by the IOM report. Although prevention is very important for all individuals, it is particularly important for cancer survivors who are at increased risk for recurrent and new cancers as well as long-term and late effects of cancer and its treatment such as cardiovascular problems. Thus the expert panel recommended leaving these items in the framework to remind primary care providers of the importance of discussing them with their cancer survivor clients.

Distribution of the framework and guideline recommendations should be evaluated further in larger samples of primary care MDs and NPs. Evaluation of the usefulness of the framework to breast cancer survivors themselves should also occur.
Limitations of the study

Limitations to this study include recruitment of expert panel members from a limited geographical area. Thus findings may not be generalized to other geographical areas. Research findings could also be strongly influenced by the types of PCPs and breast cancer survivors who agreed to participate as expert panel members. Only 3 out of 30 CPGs reviewed received a high AGREE II rating, thus the majority of the guideline recommendations were selected from CPGs with moderate ratings; however, these provide the best evidence available on the given topics.

Conclusions

The completed Comprehensive Framework for Evidence-based Breast Cancer Survivorship Care (Supplemental Data File 2) consists of a one-page checklist outlining breast cancer survivorship issues relevant to primary care, a three page summary of key guideline recommendations, and a one-page list of guideline sources. The framework and recommendations were verified by a panel of experts for comprehensiveness, importance and relevance to primary care. This framework may serve as a tool to remind PCPs about issues that may impact breast cancer survivors in their practices, as well as the evidence-based recommendations and resources to provide the associated care. Further testing of the framework through empirical research is recommended to establish its utility for primary care education, practice and research. Specifically, now that a comprehensive set of guideline recommendations for breast cancer survivorship care has been identified, the next steps for this research will be to determine to what extent these recommendations are currently being implemented in primary care practice, and to identify the challenges and opportunities related to their implementation as perceived by primary care MDs and NPs.
Supplemental Data File

The following supplemental data file is available online: Comprehensive Framework for Breast Cancer Survivorship Care and Key Guideline Recommendations.

Acknowledgements

We would like to thank the members of the expert panel for providing feedback on the framework and guideline recommendations: Dr. Hugh Langley, Regional Primary Care Lead, Southeast Regional Cancer Program; Dr. Yolanda Madarnas, Medical Oncologist; Dr. Arawn Therrien, Primary Care MD; Dianne Batchelor, Primary Care NP with oncology experience; Colleen Mackulin, Primary Care NP; Susan Peters, Primary Care NP with oncology experience; and breast cancer survivors Dianne Johnston, Tracey Smith, Sandra Chopping, and Michelle Methot. Five additional panel members who did not wish to be acknowledged included a General Practitioner in Oncology (GPO), an Oncology NP, and three breast cancer survivors.

Declaration

Ethical approval: Ethical approval was obtained from the Queen’s University Health Sciences and Affiliated Teaching Hospitals Research Ethics Board (File # 6009937).

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Conflict of interest: none
References


(42) Young TK. Understanding the primary health care needs and current care guidelines for women following breast cancer treatment. Kingston ON: Queen's University; 2011.


Table 1: Breast Cancer Survivorship Literature Review Search Strategy

<table>
<thead>
<tr>
<th>Research Question:</th>
<th>What are the current clinical practice guidelines in primary care that family physicians and primary health care nurse practitioners need to know in order to provide optimal, evidence-based care to post-treatment breast cancer patients?</th>
</tr>
</thead>
<tbody>
<tr>
<td>Sources to Identify Relevant Clinical Practice Guidelines:</td>
<td>1. Electronic search of databases: Medline, EMBASE, Cochrane Collection, CINAHL, HealthStar</td>
</tr>
<tr>
<td>Keyword Search Strategy:</td>
<td>Sets of systematically combined keywords will be used to identify relevant CPGs</td>
</tr>
<tr>
<td></td>
<td>1. Aftercare; continuity of patient care; survivors; cancer survivorship; primary health care; primary care physician, family practice; family physician; general practice; family health team; nurse practitioner</td>
</tr>
</tbody>
</table>
2. Practice guidelines

3. Key findings from previous scoping review: surgical complications; lymphedema; gynecologic and reproductive implications; psychosocial issues; additional primary cancers; cardiovascular implications; osteoporosis; lifestyle changes; fatigue; cognitive dysfunction; pregnancy

Sample Search of Medline Database:

Database: Ovid MEDLINE(R) without Revisions <1996 to Present with Daily Update>

Search Strategy:

1 exp Primary Health Care/ (51780)
2 exp Physicians, Primary Care/ (617)
3 exp Patient Care Team/ (31275)
4 exp Nurse Practitioners/ (9448)
5 exp Physicians, Family/ (8768)
6 primary care provider$.ti,ab. (3235)
7 primary care physician$.ti,ab. (9121)
8 primary care practitioner$.ti,ab. (695)
9 exp Aftercare/ (2945)
10 (after care or aftercare).ti,ab. (1379)
11 (followup care or follow up care).ti,ab. (1552)
12 (after treatment or aftertreatment).ti,ab. (66849)
13 (health care need$ or healthcare need$).ti,ab. (2883)
survivor$ care plan$.ti,ab. (73)
or/1-14 (174086)
exp Breast Neoplasms/ (124640)
((breast cancer adj3 post) or (breast cancer adj3 after)).ti,ab. (3568)
((post treatment adj4 breast) or (posttreatment adj4 breast)).ti,ab. (84)
(surviv$ adj3 breast).ti,ab. (4307)
or/16-19 (125064)
15 and 20 (2925)
limit 21 to practice guideline (23)
exp Guideline/ (18169)
exp Guidelines as Topic/ (93518)
exp Guideline Adherence/ (16996)
guid$.ti,ab. (264145)
exp Evidence-Based Medicine/ (47252)
or/22-27 (363037)
21 and 28 (349)
Table 2: A Framework for Comprehensive Breast Cancer Survivorship Care in the Primary Care Setting

<table>
<thead>
<tr>
<th>PREVENTION</th>
<th>INTERVENTION</th>
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<tr>
<td>Prevention of recurrent &amp; new cancers &amp; late effects</td>
<td>Intervention for long-term effects of cancer (Grouped by treatment)</td>
</tr>
<tr>
<td>□ Exercise</td>
<td>Surgery</td>
</tr>
<tr>
<td>□ Nutrition</td>
<td>□ Pain</td>
</tr>
<tr>
<td>□ Weight management</td>
<td>□ Lymphedema</td>
</tr>
<tr>
<td>□ Alcohol consumption</td>
<td>Chemotherapy</td>
</tr>
<tr>
<td>□ Immunizations</td>
<td>□ Peripheral neuropathy</td>
</tr>
<tr>
<td>□ Smoking cessation*</td>
<td>□ Cardiovascular complications</td>
</tr>
<tr>
<td>□ Sun exposure*</td>
<td>□ Cognitive dysfunction</td>
</tr>
<tr>
<td></td>
<td>□ Fertility, pregnancy &amp; contraception</td>
</tr>
<tr>
<td></td>
<td>□ Fatigue</td>
</tr>
<tr>
<td></td>
<td>□ Menopausal symptoms</td>
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<table>
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<tr>
<th>SURVEILLANCE</th>
<th>Targeted Therapy*</th>
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<tbody>
<tr>
<td>Surveillance for recurrent or new cancers &amp; assessment of physical &amp; psychosocial late effects</td>
<td>Cardiovascular complications</td>
</tr>
<tr>
<td>□ History and physical</td>
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<tr>
<td>□ Mammography</td>
<td></td>
</tr>
<tr>
<td>□ Breast self-exam</td>
<td></td>
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<tr>
<td>□ Pelvic exam</td>
<td></td>
</tr>
<tr>
<td>□ Non-routine tests</td>
<td></td>
</tr>
<tr>
<td>□ Cholesterol and lipid screening*</td>
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</table>

<table>
<thead>
<tr>
<th>COORDINATION</th>
<th>Radiation therapy</th>
<th>Hormonal therapy</th>
<th>Psychosocial Issues</th>
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</thead>
<tbody>
<tr>
<td>Coordination between primary care providers and specialists to ensure all health care needs are met</td>
<td>Radiation therapy</td>
<td>Hormonal therapy</td>
<td>Psychosocial Issues</td>
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<td>□ Menopausal symptoms</td>
<td>□ Distress, anxiety &amp; depression</td>
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<tr>
<td>□ Specialist referrals</td>
<td>□ Fertility, pregnancy &amp; contraception</td>
<td>□ Osteoporosis</td>
<td>□ Sexual dysfunction</td>
</tr>
<tr>
<td></td>
<td>□ Arthralgias &amp; myalgias</td>
<td></td>
<td>□ Family &amp; work*</td>
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</tbody>
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*items suggested for addition by expert panel members
<table>
<thead>
<tr>
<th>#</th>
<th>Agency/ Authors</th>
<th>Guideline Title</th>
<th>Retrieved From</th>
<th>Target Audience</th>
<th>Cancer Survivorship Domains &amp; Issues Addressed</th>
<th>AGREE II Rating</th>
</tr>
</thead>
<tbody>
<tr>
<td>5</td>
<td>Alberta Health Services (2012) (76)</td>
<td>Magnetic resonance imaging (MRI) for breast cancer screening, pre-operative assessment, and follow-up</td>
<td>SAGE Directory of Cancer Guidelines, Alberta Health Services</td>
<td>Clinicians</td>
<td>Non-routine tests: MRI</td>
<td>Low (1)</td>
</tr>
<tr>
<td>7</td>
<td>Saskatchewan Cancer Agency (2012) (78)</td>
<td>Follow-up guidelines: Breast cancer</td>
<td>Saskatchewan Cancer Agency</td>
<td>Physicians</td>
<td>Physical, mammography, breast self-exam, non-routine tests</td>
<td>Low (1)</td>
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<td>8</td>
<td>American Cancer Society (ACS), Kushi et al. (2013) (62)</td>
<td>Guidelines on nutrition and physical activity for cancer</td>
<td>National Guideline</td>
<td>Cancer specialists, general</td>
<td>Exercise, nutrition,</td>
<td>Moderate</td>
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<td>Agency/Authors</td>
<td>Guideline Title</td>
<td>Retrieved From</td>
<td>Target Audience</td>
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<td>al.(2012) (64)</td>
<td>Cancer Survivorship Domains &amp; Issues Addressed</td>
<td>Prevention, Surveillance, Intervention, Coordination</td>
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<td>12</td>
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<td>Pain, lymphedema, osteoporosis, fatigue, cardiovascular complications, peripheral neuropathy</td>
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<td>15</td>
<td>MacMillan Cancer Support, Campbell et al.(2012) (80)</td>
<td>Physical Activity for People Living with and Beyond Cancer</td>
<td>MacMillan Cancer Support (U.K.) &amp; EMBASE</td>
<td>Healthcare professionals</td>
<td>Exercise</td>
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<td>Guideline Title</td>
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<td>Target Audience</td>
<td>Cancer Survivorship Domains &amp; Issues Addressed</td>
<td>AGREE II Rating</td>
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<td>16</td>
<td>Canadian Association of Psychosocial Oncology/Canadian Partnership Against Cancer, Howell et al.(2011) (59)</td>
<td>Screening, Assessment and care of cancer-related fatigue in adults with cancer</td>
<td>SAGE</td>
<td>Inter-professional health care team including primary care providers</td>
<td>Fatigue</td>
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<td>European Society for Medical Oncology (ESMO), Aebi et al.(2011) (81)</td>
<td>Primary breast cancer: ESMO Clinical Practice Guidelines for diagnosis, treatment and follow-up.</td>
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<td>Physical, mammography, non-routine tests</td>
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<td>American College of Sports Medicine (ACSM), Schmitz et al.(2011) (70)</td>
<td>ACSM Roundtable on Exercise guidelines for Cancer Survivors</td>
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<td>Canadian Breast Cancer Foundation</td>
<td>Breast cancer survivors</td>
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<td>Recommendations for follow-up of women with early breast cancer</td>
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<td>History, physical, mammography, non-routine tests</td>
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<td>National Institute for Health and Clinical Excellence (NICE), Smallwood et al.(2009) (60)</td>
<td>Early and locally advanced breast cancer: Diagnosis and treatment</td>
<td>NICE (U.K.) &amp; SAGE</td>
<td>Healthcare professionals</td>
<td>Mammography</td>
<td>Survivorship care plans</td>
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<td>Cancer Journey Action Group/Canadian</td>
<td>Guide to implementing screening for distress, the</td>
<td>Canadian Partnership</td>
<td>Clinicians</td>
<td>Psychosocial issues</td>
<td>Moderate</td>
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<td>Cancer Journey Action Group/Canadian Partnership Against Cancer, Howell et al. (2009) (61)</td>
<td>A Pan-Canadian clinical practice guideline: Assessment of psychosocial health care needs of the adult cancer patient</td>
<td>Canadian Partnership against Cancer</td>
<td>Inter-professional health care team including primary care providers</td>
<td>Psychosocial issues</td>
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<td>26</td>
<td>Society of Obstetricians and Gynaecologists of Canada (SOGC), Reid et al. (2009) (83)</td>
<td>Menopause and Osteoporosis Update 2009: Hormone therapy and breast cancer</td>
<td>Canadian Medical Association CPG Infobase &amp; SAGE</td>
<td>Gynecologists</td>
<td>Menopausal symptoms</td>
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<td>27</td>
<td>Oncology Nursing Society, Poage et al. (2008) (84)</td>
<td>Demystifying lymphedema: Putting evidence into practice® card</td>
<td>SAGE &amp; Medline</td>
<td>Nurses</td>
<td>Lymphedema</td>
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<td>28</td>
<td>SOGC, McNaught et al. (2006)* (85)</td>
<td>Progesterone-only and non-hormonal contraception in the breast cancer survivor</td>
<td>SAGE &amp; Medline</td>
<td>Gynecologists</td>
<td>Fertility &amp; pregnancy</td>
<td>Low (2)</td>
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<td>29</td>
<td>Health Canada, Grunfeld et al. (2005)* (46)</td>
<td>Health Canada Steering Committee on Clinical Practice Guidelines for the care and treatment of breast cancer: Follow-up after treatment for breast cancer</td>
<td>SAGE &amp; Medline</td>
<td>Practitioners, patients</td>
<td>History, physical, mammography, non-routine tests, breast self-exam</td>
<td>Moderate (4)</td>
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<td>30</td>
<td>Scottish Intercollegiate Guidelines Network (SIGN), Adamson et al. (2005)* (74)</td>
<td>Management of breast cancer in women: A national clinical guideline</td>
<td>SIGN &amp; SAGE</td>
<td>Health professionals</td>
<td>Psychosocial issues</td>
<td>Moderate (5)</td>
</tr>
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*Guidelines developed more than 5 years ago may contain outdated recommendations*
CHAPTER FOUR

*Are primary care providers implementing evidence-based care for breast cancer survivors?*
**ABSTRACT**

**Objective**
To describe the implementation of key best practice guideline recommendations for post-treatment breast cancer survivorship care by primary care providers (PCPs) in southeastern Ontario.

**Design**
Descriptive cross-sectional survey.

**Setting**
South East Ontario.

**Participants**
Eighty-two primary care providers (PCPs): 62 family physicians (FPs) and 20 primary health care nurse practitioners (PHCNPs).

**Main outcome measures**
Twenty-one “need-to-know” breast cancer survivorship care guideline recommendations rated by participants as “implemented routinely,” “aware of guideline recommendation but not implemented routinely,” or “not aware of guideline recommendation.”

**Results**
Overall, FPs and PHCNPs in our sample reported similar practice patterns in terms of implementation of breast cancer survivorship guideline recommendations. Primary care providers (PCPs) reported routinely implementing approximately half (46%, n=10/21) of the key guideline recommendations with breast cancer survivors in their practices. Implementation rates were higher for recommendations related to prevention and surveillance aspects of survivorship care such as mammography and weight management. Knowledge and practice gaps were highest
for recommendations related to screening for and management of long-term effects such as fatigue and distress. There were few minor differences reported between FPs and PHCNPs.

Conclusions

Our findings show there are knowledge and practice gaps related to implementation of the key guideline recommendations for breast cancer survivorship care in the primary care setting which could be targeted for improvement through educational or other interventions.

Key words: Primary Health Care; Breast Neoplasms; Aftercare; Guideline

Key Points:

1 Primary care providers routinely implement about half of the key guideline recommendations for breast cancer survivorship care.

2 Primary care providers were unaware of almost a third of key guideline recommendations for comprehensive breast cancer survivorship care.

3 Knowledge and practice gaps were greatest for screening and management of consequences of cancer and its treatment such as fatigue and distress.
INTRODUCTION

Breast cancer is the most common cancer affecting Canadian women representing 26% of all new cancer cases, with 24,400 new cases expected to be diagnosed in 2014\(^1\). Primary care involvement in post-treatment follow-up is evolving as growing patient numbers, health care costs and limited supply of oncologists impact accessibility to follow-up care.\(^2\)\(^-\)\(^5\) Breast cancer patients may experience difficulties transitioning to survivorship.\(^6\) Following cancer treatment, they are at risk for numerous debilitating physical and psychosocial consequences such as pain, fatigue, depression, and lymphedema.\(^7\) Survivors may continue to experience long-term effects of their treatment or develop late effects months or years later. Unfortunately primary care providers (PCPs) may lack knowledge about consequences of cancer treatment and optimal care for cancer survivors.\(^8,\)^\(^9\)

The seminal report from the Institute of Medicine (IOM) *From Cancer Patient to Cancer Survivors: Lost in Transition* synthesized what is known about cancer survivorship and established the survivorship period as an important new focus for care extending beyond long-term surveillance to include many previously unaddressed medical and psychosocial needs of survivors.\(^10\) The IOM report specifically outlines four essential components of survivorship care: (1) prevention of recurrent and new cancers, and other late effects; (2) surveillance for cancer spread, recurrence, second cancers, and medical and psychosocial late effects; (3) intervention for consequences of cancer and its treatment; and (4) coordination between specialists and PCPs to ensure all health needs are met.\(^11\)

Many cancer programs are moving forward with earlier discharge of stable early-stage breast cancer survivors from oncology to primary care follow-up within two years of cancer diagnosis and following completion of primary treatment.\(^12\) As each PCP may only be seeing one
to two newly discharged breast cancer survivors per year, it may prove challenging for them to remain up to date about best practices in breast cancer survivorship care. At a minimum, primary care providers need to know that clinical practice guidelines (CPGs) applicable to follow-up care of breast cancer survivors are available and how to access them. However, no single guideline addresses all essential components of survivorship care; thus, it is unclear which guidelines are currently being accessed and applied in primary care settings.

As a result, our research team previously conducted an extensive search, appraisal and synthesis of CPGs for post-treatment breast cancer care using a modified Delphi method. Our Comprehensive Framework and Key Guideline Recommendations for the Provision of Evidence-Based Breast Cancer Survivorship Care were published along with a five-page supplemental data file that provides a comprehensive synthesis for primary care providers. The key guideline recommendations were verified by an expert panel consisting of an oncologist, an oncology nurse practitioner (NP), 3 family physicians (FPs), 3 primary health care nurse practitioners (PHCNPs) and 7 breast cancer survivors who rated the recommendations as “need to know” (high importance/essential/must do), “nice to know” (important/relevant/nice to do) or “not relevant to primary care” (not important/doesn’t need to be done). Panel members also ranked the most important recommendations for each of 21 identified survivorship issues. Top-ranking recommendations for each issue were included as survey items for the current study.

The objective of the current study was to describe implementation of key best practice guideline recommendations for post-treatment breast cancer survivorship care by FPs and PHCNPs in southeastern Ontario. Specific research questions are the following:

1) Which of 21 key guideline recommendations for post-treatment breast cancer survivorship care are currently being implemented by PCPs?
2) What are the knowledge gaps among PCPs related to 21 key guideline recommendations for post-treatment breast cancer survivorship care?

3) Are there any differences between FP and PHCNP practices and knowledge gaps related to 21 key guideline recommendations for post-treatment breast cancer survivorship care?

METHODS

Study design and sample

This study consisted of a cross-sectional survey of FPs and PHCNPs within the South East Local Health Integration Network (SE LHIN). A list of PCPs was generated from the College of Physicians and Surgeons of Ontario and individual family health team (FHT)/community health centre (CHC) websites. Practitioners who were retired, had less than one year primary care experience, had moved or were practicing in a specialty role/setting were excluded, leaving a total of 321 FPs and 45 PHCNPs eligible to participate.

Data collection

This study received ethical approval from the Queen’s University Health Sciences and Affiliated Teaching Hospitals Research Ethics Board. A multimodal recruitment strategy and incentive was employed to address known barriers to recruitment of PCPs. A sub-sample of 15 PCPs pilot-tested the survey at two professional meetings. No changes were required prior to electronic distribution through the Office of Continuing Professional Development at Queen’s University. Subsequently, hard copies of the survey were mailed to eligible individuals who had not already completed the survey. Data collection occurred prior to the commencement of the early discharge of breast cancer patients in the South East LHIN, and prior to the publication of our guideline synthesis.
Demographic data were collected regarding PCPs’ age, sex, years in primary practice, practice setting, practice type, and caseload size. Twenty-one “need-to-know” breast cancer survivorship care guideline recommendations were rated by participants as: “implemented routinely” (with 50% or more of breast cancer survivors in their practice), “aware of guideline recommendation but not implemented routinely”, or “not aware of guideline recommendation.”

**Data analysis**

Study variables were described with standard univariate statistics (frequencies/percentages, means/standard deviations). Group comparisons were conducted using independent t tests, Mann-Whitney U and Chi-square tests.

**RESULTS**

Surveys were completed by 82 PCPs (62 FPs and 20 PHCNPs) representing an overall response rate of 22.4%. Response rates varied significantly by profession with 44.4% of eligible PHCNPs completing the survey versus 19.3% of eligible FPs (Chi-square=14.34; df=1; p=.001). There were no significant differences between FP participants and nonparticipants in terms of sex, practice setting, practice type or primary care experience. NP participants were more likely to practice in urban settings than nonparticipants; however statistical testing was not possible due to the small sample size.

Characteristics of study participants are presented in Table 1. Overall, more participants were female (59.8%), practiced in urban settings (69.5%) and in interdisciplinary teams (59.8%). FPs in the sample were significantly older (51.8 years) than PHCNPs (45.0 years; p=.018), and FPs had more experience in primary care (21.9 years) than PHCNPs (5.2 years) in the sample (p=.001).
Survey results are presented in Table 2. Routine guideline implementation rates ranged from 87.8% for annual mammography to only 11.0% for fatigue screening. Overall, only 8 of the 21 key guideline recommendations were routinely implemented by the majority of PCPs in the sample. Individual PCPs reported routinely implementing an average of 46.4% (9.7/21) of key guideline recommendations with breast cancer survivors in their practices. Overall, FPs and PHCNPs did not differ in their implementation rates, and significant practice differences were found for only 2 out of the 21 items: non-routine tests, 59.7% vs 25.0% respectively, (Chi-Square=7.28; df=1; p=.007), and hot flashes, 53.2% vs 10.90% (Chi-Square=11.55; df=1; p=.001).

Knowledge gaps related to individual recommendations ranged from 6.1% for mammography to 53.7% for fatigue screening. On average, PCPs reported they were unaware of 28.5% of the recommendations. Significant knowledge differences between FPs and PHCNPs were noted for four guideline recommendations: vaccines, 30.6% vs 55.0% (Chi-Square=3.87; df=1; p=.049), follow-up, 16.1% vs 45.0% (Chi-square=7.08; df=1; p=.008), non-routine tests, 27.4% vs 75.0% (Chi-square=14.9; df=1; p=.001), and hot flashes 14.5% vs 55.0% (Chi-square=13.5; df=1; p=.001).

**DISCUSSION**

Overall, FPs and PHCNPs in our sample reported similar practice patterns in terms of implementation of breast cancer survivorship guideline recommendations. Less than half of these recommendations (46.4%) were routinely implemented with the majority of breast cancer survivors and overall PCPs were not aware of 28.5% of key guideline recommendations. Implementation rates were higher for recommendations related to prevention and surveillance aspects of survivorship care such as mammography and weight management. These results align
with results from a survey of PCPs from North East Ontario indicating they were most confident with screening for recurrence and counselling on nutrition and exercise.\textsuperscript{18} Knowledge and practice gaps were highest for recommendations related to screening for and management of long-term effects such as fatigue and distress. Similarly PCPs from North East Ontario were less confident with management of treatment-related side effects.\textsuperscript{18}

Higher knowledge/practice rates for prevention guidelines were expected as these should be familiar to PCPs due to relevance to the general population; however, almost a quarter of participants reported they were not aware of these guidelines which have particular significance for breast cancer survivors who are at increased risk for morbidity and mortality as a result of their cancer diagnosis.\textsuperscript{19} In our region, following completion of our survey study, surveillance guidelines based on the American Society of Clinical Oncology (ASCO) follow-up guidelines have been provided to PCPs upon discharge of breast cancer survivors.\textsuperscript{20} Thus PCPs may become familiar with these guidelines as they accept more breast cancer survivors for follow-up care. As the PHCNPs in our sample reported fewer years in primary care, they would have less experience providing this care, which may account for their larger knowledge gap related to surveillance aspects of survivorship care.

Similar to reports in the literature, our sample of PCPs reported larger knowledge/practice gaps related to screening for and managing long-term symptoms such as fatigue and distress. Research suggests only a small subset of FPs provide multidimensional survivorship care including management of late effects and mental health, with inadequate preparation and lack of formal training cited as a problem in providing this care.\textsuperscript{21} In one study, only 23\% reported confidence caring for late physical effects of cancer.\textsuperscript{22} In another study, only 41\% of breast cancer survivors perceived their PCP as knowledgeable treating cancer-related
symptoms.23 A large proportion of breast cancer patients in a randomized controlled trial reported difficulty discussing their concerns and wanted the doctor to tell them more about their problem and treatment.24

Consequences of lack of knowledge of guidelines may be reflected in attitudes towards survivorship care. For example, PCPs were less likely than specialists to strongly agree the purpose of follow-up was to detect late effects of treatment (18% vs. 33%) and to provide psychological support for patients and carers (27% vs. 39%).25 This is concerning as these are two key foci for survivorship follow-up, and attitudes may influence willingness to provide this care. It is also concerning that clinicians valued clinical reasons for follow-up more highly than supportive reasons (p<0.001) in another study.26 However, some PCPs may feel survivorship care is mostly to detect recurrences and new cancers but at the same time be very willing to address late effects and psychosocial concerns, whereas others may not. Experience is another factor that may influence attitudes. For example, in a recent Canadian study, FPs who followed more breast cancer survivors in their practice reported higher confidence in managing their follow-up.27 NPs in North East Ontario have reported lower confidence levels than FPs18 which may reflect having less primary care experience.

The number of PHCNPs is increasing in Ontario and across Canada.28,29 Survivorship care provided by NPs has been found analogous to care provided by FPs, as they manage comorbidities and long-term treatment sequelae and provide specialist referrals.30 Several studies describe various roles that NPs play in providing survivorship care.31-33 Few studies specifically examine NP knowledge and practices of survivorship care; however, some have described gaps in NP knowledge of cancer risk assessment34-36
Limitations

Limitations to this study include self-report data and recruitment from a limited geographical area; thus findings may not generalize to other regions. Findings could also be influenced by the types of PCPs who self-selected to participate. The sample was overrepresented by PHCNPs; however, comparative analyses revealed few differences between the two professions. As well, our sample of FPs was not significantly different from the population of eligible FPs in terms of demographic characteristics. The overall response rate of 22.4% was low but in keeping with other clinician surveys.\(^{37,38}\) Although some research suggests there is limited or no response bias in physician surveys,\(^{39}\) low response rates increase the potential for bias,\(^{40}\) which might actually mean that knowledge and practice gaps are even greater than reported.

Conclusions

Our results enhance understanding of current knowledge and practices of PCPs related to implementation of evidence-based recommendations for post-treatment breast cancer survivorship care. We identify knowledge and practice gaps which could be targeted through educational or other multi-component interventions addressing the challenges of providing survivorship care in primary care settings. Medical school, FP residency, and PHCNP training programs also need to address primary care-based survivorship care; primary care practices could include strategies such as care plans and reminders. Future research needs to determine how to best provide support and education to improve PCP knowledge and practices related to providing breast cancer survivorship care, and translate into enhanced long-term health and quality of life outcomes for breast cancer survivors.
References


(3) Campbell NC, MacLeod U, Weller D. Primary care oncology: essential if high quality cancer care is to be achieved for all. *Fam Pract* 2002;19(6):577-578.


(20) South East Regional Cancer Program. Breast cancer well follow-up care. 2014.


(39) Flanigan TS, McFarlane E, Cook S. Conducting survey research among physicians and other medical professionals--A review of current literature. 2008 4136-4147.


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<tr>
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<td>physicians</td>
<td>nurse</td>
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<td></td>
<td>(N=62)</td>
<td>practitioners</td>
<td>(N=82)</td>
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<tr>
<td><strong>Sex</strong></td>
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<td></td>
<td></td>
</tr>
<tr>
<td>Male</td>
<td>30 (48.4%)</td>
<td>3 (15.0%)</td>
<td>33 (40.2%)</td>
</tr>
<tr>
<td>Female</td>
<td>32 (51.6%)</td>
<td>17 (85.0%)</td>
<td>49 (59.8%)</td>
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<td>Urban total</td>
<td>42 (67.7%)</td>
<td>15 (75.0%)</td>
<td>57 (69.5%)</td>
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<td>Rural total</td>
<td>20 (32.3%)</td>
<td>5 (25.0%)</td>
<td>25 (30.5%)</td>
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<td><strong>Practice type</strong></td>
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<tr>
<td>Interdisciplinary team total</td>
<td>30 (48.4%)</td>
<td>19 (95.0%)</td>
<td>49 (59.8%)</td>
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<td>25 (40.3%)</td>
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<td>Community Health Centre</td>
<td>5 (8.1%)</td>
<td>3 (15.0%)</td>
<td>8 (9.8%)</td>
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<tr>
<td>Physician group total</td>
<td>25 (40.3%)</td>
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<td>1 (5.0%)</td>
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<td>7 (8.5%)</td>
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<td>Physician solo practice</td>
<td>7 (11.3%)</td>
<td>0 (0%)</td>
<td>7 (8.5%)</td>
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<td>------------------------------</td>
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<td></td>
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<tr>
<td>Years in primary care practice*</td>
<td>21.9 (11.8)</td>
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<td>[1-46]</td>
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<tr>
<td>Estimated breast cancer survivor case load</td>
<td>15.8 (11.9)</td>
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<td>[1-50]</td>
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<tr>
<td>Estimated breast cancer survivor visits per year</td>
<td>2.2 (1.1)</td>
<td></td>
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<td>[1-5]</td>
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* t-test=2.49; df=32; p=.018  
**Mann Whitney U =122.5; p=.001
<table>
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<tr>
<th>Issue/Topic</th>
<th>Key Guideline Recommendation</th>
<th>Number (%)</th>
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<tbody>
<tr>
<td><strong>Mammogram</strong></td>
<td>Recommend annual bilateral mammogram, or in case of unilateral mastectomy, annual mammogram of the contralateral breast</td>
<td>Routinely implements guideline recommendation: 72 (87.8%)</td>
</tr>
<tr>
<td><strong>Contraception</strong></td>
<td>Hormonal contraceptive is not recommended for women with breast cancer; barrier methods are preferred (condoms, diaphragms, intrauterine devices, tubal ligation, or vasectomy for the partner)</td>
<td>Routinely implements guideline recommendation: 71 (86.6%)</td>
</tr>
<tr>
<td><strong>Osteoporosis</strong></td>
<td>Postmenopausal, or premenopausal survivors with risk factors for osteoporosis, or taking aromatase inhibitors should undergo a bone mineral density test (by DEXA scan) at baseline and then every 1-2 years</td>
<td>Routinely implements guideline recommendation: 55 (67.1%)</td>
</tr>
<tr>
<td><strong>Weight management</strong></td>
<td>Encourage breast cancer survivors to achieve and maintain a healthy weight (20-25 BMI)</td>
<td>Routinely implements guideline recommendation: 55 (67.1%)</td>
</tr>
<tr>
<td><strong>Nutrition</strong></td>
<td>Encourage breast cancer survivors to obtain needed nutrients through dietary sources; Consider supplements only if nutrient deficiency demonstrated</td>
<td>Routinely implements guideline recommendation: 53 (64.6%)</td>
</tr>
<tr>
<td><strong>Alcohol consumption</strong></td>
<td>Encourage cancer survivors to limit alcohol consumption to no more than 1 drink per day for women or 2 per day for men</td>
<td>Routinely implements guideline recommendation: 49 (59.8%)</td>
</tr>
<tr>
<td><strong>Breast self-exam</strong></td>
<td>Counsel breast cancer survivors to perform monthly breast self-examination and inform them that BSE does not replace mammography as a breast cancer surveillance tool</td>
<td>Routinely implements guideline recommendation: 42 (51.2%)</td>
</tr>
<tr>
<td><strong>Non-routine tests</strong></td>
<td>In the absence of clinical findings, the following tests are not recommended for routine follow-up: CBC; liver/kidney function tests; chest x-ray; bone scan; liver/abdominal ultrasound; CT scan; FDG-PET scan; breast MRI; breast cancer tumor markers, such as CA 15-3, CA 27.29, CEA</td>
<td>Routinely implements guideline recommendation: 42 (51.2%)</td>
</tr>
<tr>
<td><strong>Vaccines</strong></td>
<td>Encourage the following vaccines, following usual doses/schedules: trivalent inactivated influenza (TIV); pneumococcal (PPSV-23/PCV-13); tetanus, diphtheria, pertussis (Tdap); and human papillomavirus (HPV)</td>
<td>Routinely implements guideline recommendation: 40 (48.8%)</td>
</tr>
<tr>
<td>Topic</td>
<td>Intervention</td>
<td>39 (47.6%)</td>
</tr>
<tr>
<td>---------------</td>
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</tr>
<tr>
<td>Pain</td>
<td>Consider nonpharmacologic interventions for pain in conjunction with pharmacologic ones: bed/bath/walking supports; TENS; positioning; energy conservation; acupuncture/acupressure; physical therapy; exercise; psychosocial/behavioural/interventional procedures</td>
<td>39 (47.6%)</td>
</tr>
<tr>
<td>Hot flashes</td>
<td>Consider selective serotonin reuptake inhibitors (SSRIs), serotonin-norepinephrine reuptake inhibitors (SNRIs) to reduce severity of hot flushes in patients with breast cancer; caution must be used when using these agents in conjunction with tamoxifen; gabapentin and clonidine are other options for management of hot flushes</td>
<td>35 (42.7%)</td>
</tr>
<tr>
<td>Exercise</td>
<td>Recommend weekly exercise for cancer survivors: at least 150 minutes of moderate-intensity activity, strength training and stretching of major muscle groups and tendons</td>
<td>34 (41.5%)</td>
</tr>
<tr>
<td>Follow-up</td>
<td>All breast cancer survivors should have a careful history and physical exam every 3-6 months for the first 3 years after primary treatment; every 6-12 months for years 4 and 5, and then annually</td>
<td>34 (41.5%)</td>
</tr>
<tr>
<td>Fatigue</td>
<td>Recommend engaging in 30 minutes of moderate-intensity physical activity most days unless contraindicated (e.g., fast walking, cycling, swimming and resistance training)</td>
<td>31 (37.8%)</td>
</tr>
<tr>
<td>Lymphedema</td>
<td>Strength training has been shown to be safe for survivors with lymphedema and may improve lymphedema symptoms</td>
<td>27 (32.9%)</td>
</tr>
<tr>
<td>Cognitive dysfunction</td>
<td>Consider instruction in self-management and coping strategies, relaxation, stress management and routine exercise</td>
<td>27 (32.9%)</td>
</tr>
<tr>
<td>Gynecologic exam</td>
<td>Women on tamoxifen should have a gynecologic assessment every 12 months if uterus present</td>
<td>26 (31.7%)</td>
</tr>
<tr>
<td>Screening</td>
<td>Screen all survivors periodically to determine needs and interventions related to symptoms experienced over the past 4 months: (1) anxiety/depression; (2) cognitive function; (3) exercise; (4) fatigue; (5) immunizations/infections; (6) pain; (7) sexual function; and (8) sleep disorders</td>
<td>23 (28.0%)</td>
</tr>
<tr>
<td>Sexual functioning</td>
<td>Ask survivors about their sexual function at regular intervals, including their sexual functioning before cancer treatment, their present activity, and how cancer treatment has impacted their sexual functioning &amp; intimacy</td>
<td>23 (28.0%)</td>
</tr>
<tr>
<td></td>
<td>Description</td>
<td>Count (Percentage)</td>
</tr>
<tr>
<td>------------------------</td>
<td>------------------------------------------------------------------------------</td>
<td>--------------------</td>
</tr>
<tr>
<td>Distress screening</td>
<td>Screen all survivors for anxiety and depression at transition to survivorship and regular intervals using a 0-10 severity rating scale (0= no anxiety or depression; 10=worst you can imagine) or NCCN brief distress screening tool</td>
<td>12 (14.6%) 27 (32.9%) 43 (52.4%)</td>
</tr>
<tr>
<td>Fatigue screening</td>
<td>Screen all survivors for fatigue at regular intervals using a 0-10 severity rating scale such as ESAS (0= no fatigue; 10=worst fatigue you can imagine) or have survivors rate their fatigue as none, mild, moderate or severe</td>
<td>9 (11.0%) 29 (35.4%) 44 (53.7%)</td>
</tr>
</tbody>
</table>
CHAPTER FIVE

Challenges, Strengths and Opportunities Related to Implementing Comprehensive Evidence-Based Breast Cancer Survivorship Care:

Perceptions of Primary Care Physicians and Nurse Practitioners in Southeastern Ontario
Abstract

Purpose
As cancer centres move forward with earlier discharge of stable, early-stage breast cancer survivors to primary care follow-up it is important to address known primary care provider knowledge and practice gaps. This qualitative descriptive study examined the practice context that influences the implementation of existing clinical practice guidelines for providing this care. The purpose was to determine the challenges, strengths and opportunities related to implementing comprehensive evidence-based breast cancer survivorship care guidelines by primary care providers.

Methods
A qualitative descriptive study was undertaken. Semi-structured interviews were conducted with 19 primary care providers: 10 physicians and 9 nurse practitioners.

Results
Thematic analysis revealed six themes across the broad categories of knowledge, attitudes and resources. Participants highlighted three major challenges related to providing breast cancer survivorship care: inconsistent educational preparation, provider anxieties, and primary care burden. They also described three major strengths or opportunities to facilitate implementation of survivorship care guidelines: tools and technology, empowering survivors, and optimizing nursing roles.

Conclusions
We identified several important challenges to implementation of comprehensive evidence-based survivorship care for breast cancer survivors, as well as several strengths and opportunities that could be built upon to address these barriers. Findings from this research could inform targeted
knowledge translation interventions to provide support and education for primary care providers and breast cancer survivors.

**Implications for Cancer Survivors**

Breast cancer survivors should be aware of current survivorship care guidelines and share responsibility for managing their own care.

**Keywords:** Breast cancer; evidence-based; survivorship care; primary care; challenges; qualitative study
Background

Breast cancer is the most common cancer affecting Canadian women with 25,000 new cases expected to be diagnosed in 2015\(^1\). A large majority, 88\% of women, will be alive five years after their breast cancer diagnosis,\(^2\) and many will continue to experience physical and psychosocial healthcare needs following acute treatment. Cancer centres in Ontario, Canada are moving forward with earlier discharge of stable early-stage breast cancer survivors to primary care follow-up. Even before this change, survivors often described feeling “abandoned” as they transitioned from oncology specialist care to primary care\(^3\) and reported their health care needs were not being sufficiently met.\(^4\) The Institute of Medicine (IOM) report, *From Cancer Patient to Cancer Survivors: Lost in Transition*, specifically outlined four essential components of survivorship care: (1) prevention of cancers and late effects; (2) surveillance for cancers and medical and psychosocial effects; (3) intervention for consequences of cancer treatment; and (4) coordination between specialists and primary care providers.\(^5\) Our research team recently synthesized existing breast cancer survivorship care clinical practice guidelines (CPGs) within these four domains that were relevant to primary care.\(^6\) We also identified self-reported gaps in primary care provider knowledge and practices related to implementing these guidelines that could be targeted through educational or other multi-component interventions addressing the challenges of providing survivorship care in primary care settings.\(^7\)

Knowledge translation (KT) aims to improve patient outcomes through better integration of research evidence into health professional practices.\(^8\) Existing KT strategies have shown some effectiveness in improving primary care provider knowledge but not always their practices.\(^9\) It is unclear what strategies would be most effective to promote evidence-based breast cancer survivorship care in the primary care setting within the Canadian context and specifically within
Ontario where the population of primary health care nurse practitioners (NPs) is growing, and where many primary care providers are practicing in team-based models such as Family Health Teams (FHTs) and Community Health Centres (CHCs). A thorough understanding of the practice context is essential to effective implementation of new interventions or practices in health care settings. In Ontario, Local Health Integration Networks (LHINs) are the regional health authorities that plan, integrate and fund local health care. Thus, the South East LHIN in Ontario provided an appropriate research setting for exploring these issues in both rural and urban primary practice settings and FHTs.

**Objectives**

The overall purpose of this qualitative descriptive study was to determine the challenges, strengths and subsequent opportunities related to implementing evidence-based guidelines on breast cancer survivorship care by primary care medical doctors (MDs) and NPs. The specific research questions of the study were the following:

1. What are primary care providers’ perceptions of the existing challenges related to the provision of comprehensive evidence-based post-treatment breast cancer survivorship care within the primary care practice setting?

2. What are primary care providers’ perceptions of the existing strengths and potential opportunities to enhance the provision of comprehensive evidence-based post-treatment breast cancer survivorship care within the primary care practice setting?

This research will inform the future development of KT interventions for primary care practice related to evidence-based breast cancer survivorship care.
Theoretical framework

As the long-term goal of this research is to contribute to development of KT interventions for primary care, this study was guided by the Knowledge to Action (KTA) Framework which provides a guiding and organizing framework to influence uptake of research and evidence-based CPGs into practice and subsequently incite clinical change. We previously identified knowledge-to-action gaps related to provision of breast cancer survivorship care through a survey of primary care MDs and NPs from across southeastern Ontario, in which participants reported on their knowledge and practices related to 21 key guideline recommendations for post-treatment breast cancer survivorship care. Interventions are more likely to be successful if the choice of KT strategies are informed by an assessment of likely barriers and facilitators. Thus, further assessment from the perspective of primary care providers was required to understand how to best address these gaps and facilitate adapting knowledge to ensure it is relevant to intended users and feasible within the intended practice setting.

A key conceptual model for assessing barriers to knowledge use by physicians is Cabana’s Clinical Practice Guidelines Framework for Improvement. This framework describes physician behaviours as being influenced by their knowledge and attitudes, with knowledge, attitudes and behaviours further influenced by external barriers such as patient factors, guideline factors and environmental factors. Légaré’s extension of Cabana’s framework included potential facilitators of knowledge use, as any factor can be perceived as both a barrier and a facilitator. Thus primary care provider practices (behaviours) related to implementing CPGs can be seen to be influenced by internal factors (knowledge and attitudes) and external factors (resources) available at the individual, practice and systems levels. Our study described factors perceived to be the most important barriers to and/or facilitators of knowledge use (implementation of
research evidence or CPGs) related to breast cancer survivorship care by primary care providers within our region.

Methods
This study was conducted as one component of a broader KT program of research with the aim to improve outcomes for breast cancer survivors. Enhancing translation of evidence-based guidelines to primary care requires an understanding of the practice context, specifically the challenges, strengths and subsequent opportunities as perceived by the primary care providers themselves, in order to develop strategies with the greatest potential for successful implementation. The Consolidated Criteria for Reporting Qualitative Research (COREQ) has guided reporting of the study methods and results.14

Research Team and Reflexivity
All interviews were conducted by the primary author (MLF), a Registered Nurse, PhD candidate, and faculty member at Queen’s University. The interviewer had a previous professional relationship with two of the NP participants. The interviewer explained the study purpose and that it was part of her graduate thesis work. The interviewer’s interest in this work stemmed from previous research with cancer survivors and a desire to improve the comprehensiveness of survivorship care within the primary care setting. The second author (AA) reviewed all aspects of the data analysis.

Study Design
A qualitative descriptive method was used to explore primary care providers’ perceptions of challenges, strengths and opportunities related to providing effective evidence-based breast cancer survivorship care, which will inform recommendations for KT strategies. The goal of qualitative descriptive studies is to provide a comprehensive summary of events or description of
phenomena, thus qualitative description is particularly applicable to answering questions of relevance to health professionals and policy makers.\textsuperscript{15}

**Participants and Setting**

Participants were recruited from the South East LHIN of Ontario, Canada. A combination of purposive and snowball sampling was employed, resulting in recruitment of 19 primary care providers. Two NPs were known to the researcher and were recruited through email invitations. An additional 4 NPs and 3 MDs were referred to the researcher by colleagues or other study participants. The remaining participants were contacted by email or telephone after indicating interest on a related survey distributed to primary care MDs and NPs across the region.\textsuperscript{7}

Five of the interviews were conducted face-to-face, and the remaining interviews were conducted by telephone.

**Data Collection**

Semi-structured interviews were guided by an interview guide developed and informally pilot tested with one NP and one MD (See Appendix G). Additional prompts and probing questions were improvised at the discretion of the interviewer. Repeat interviews were not required. Interviews were digitally recorded with the participant’s permission. Three face-to-face interviews were not recorded and the researcher took detailed notes on the respondents’ answers. Field notes were completed during or following each interview. Interview recordings were transcribed verbatim by the primary researcher who listened to each recording at least twice. The study received ethics approval from the Queen’s University Health Sciences and Affiliated Teaching Hospitals Research Ethics Board. Informed consent was obtained from all study participants.
Data Analysis

Thematic analysis was employed as this is a flexible approach that can be used in any qualitative research tradition to process and interpret qualitative data.\textsuperscript{16} Data analysis was guided by the principles and steps of qualitative data analysis described by Creswell\textsuperscript{17}, and the phases of thematic analysis described by Braun and Clarke.\textsuperscript{18} A blended approach to coding using both deductive and inductive procedures was employed,\textsuperscript{16,17} and a variety of activities were undertaken to maintain study rigour, specifically peer review, member checking and triangulation.\textsuperscript{19}

A review of the literature suggested that barriers and facilitators to guideline implementation are related to knowledge, attitudes and resources available to primary care providers and breast cancer survivors, thus interview data were partitioned a priori into these three categories which provided the framework for analysis. A fourth category, “other” was included to capture any data that did not fall within these categories. Categories and subcategories were placed into a matrix table upon which emerging data codes could be mapped. Similar codes were combined to create subthemes using emerging, process and theoretical coding, and subthemes were grouped and regrouped to generate analytic themes. Data mapped to each theme were interpreted as challenges or strengths/opportunities. A detailed audit trail was kept throughout data collection and analysis to promote dependability and confirmability. Appendix H provides a detailed description of the analysis plan and procedures.

Results

Participants

Interviews were conducted with 19 primary care providers between July 2013 and July 2014. Of these, 10 were primary care MDs and 9 were primary health care NPs. Participant characteristics
are shown in Table 1. The majority of participants were female. MDs and NPs were similar in age, practice location and practice type. The MDs had significantly more primary care experience ($M=21.8$ years; $SD=13.0$) than the NPs ($M=6.1$ years; $SD=4.7$), however, NPs reported additional experience as Registered Nurses (RNs) ($M=15.6$ years; $SD=9.3$) in a variety of settings. Additionally, three NPs reported previous experience in oncology, and one of the MDs was a cancer survivor. Interview duration ranged from 10 to 47 minutes ($M=24.9$ min; $SD=9.5$).

**Identification of Themes**

Preliminary analysis resulted in 38 subthemes mapped to the categories of knowledge, attitudes and resources. No codes or themes fell into the “other” category, thus this category was dropped from the analysis. The final in-depth analysis revealed six overarching themes (see Table 2) representing three major barriers and three major strengths and opportunities related to implementing breast cancer survivorship care, which will be described below.

**Perceived challenges**

**Inconsistent educational preparation.** Analysis of the 19 interview transcripts highlighted the diversity of primary care provider education, experience and knowledge related to breast cancer survivorship care, challenges with keeping up to date with guidelines, and a diversity of learning needs and preferences. Both MDs and NPs stressed they had no formal education on this topic and that ongoing education was “hit and miss.” Most described knowledge gaps, lack of experience and challenges related to “knowing the system.” A few providers had previously worked in cancer clinics, but most reported “learning on the job” and “learning from patients.”

“I would say none, I trained 20 years ago. Most of what I do I’ve learned along the way through just doing, so, learn as you go, not because of specific education.” (MD-10)
“I think I learned the most about survivorship just from the patients really, on the job learning.” (NP-4)

Primary care providers described the volume of information, and associated time, energy and costs to access guidelines, as contributing to their feeling “overwhelmed” by “keeping up to date” on a variety of topics relevant to primary care, not just breast cancer survivorship care. Perceived lack of relevance of guidelines to primary care was also seen as a barrier to accessing and using CPGs. Some providers, mostly NPs, described their comfort with accessing guidelines and conducting literature searches to answer clinical questions, particularly those with academic appointments and access to university library databases. Both MDs and NPs wanted more information/education about survivorship CPGs.

“So many time constraints…it’s a tough job in primary care because GPs need to know a little about everything, you can’t be an expert on everything…it’s overwhelming to look for guidelines, there are so many.” (MD-7)

In terms of accessing guidelines and educational updates it was clear that “one size does not fit all.” Providers indicated a preference for a wide range of educational formats such as online webinars, workplace “lunch and learns” and continuing medical education (CME) events. Barriers to attending CME events included time, costs, and family obligations, particularly for rural practitioners. Barriers to accessing online resources included questioning reliability and the lack of Canadian guidelines. Many relied on Google searches, whereas others used subscription services such as Up-to-Date which summarize the latest research evidence, to inform practice. Others reported relying on colleagues or specialists for clinical information. Overall, there was a desire for guidelines that were “short and sweet” and resources that were centralized for “one stop shopping.”
“I feel like getting it both ways, email and mail…something published on some card stock, laminated, with the protocol for follow-up…something to refer to for the first little while, until we get used to it.” (MD-10)

“Team-based education, short, over lunch…we’re all learning the same content at the same time…even a video we can watch ourselves.” (NP-2)

**Provider anxieties.** Similarly providers were divided in their confidence to provide survivorship care. While many described this falling within their “comfort zone,” these were mainly individuals who had some previous experience with cancer survivors either in oncology settings or within their own practices. Others expressed some anxiety over their lack of expertise and felt this care would be easier for experts. Many described “feeling like a beginner” or simply stated “tell me what to look for” or “tell me what to do.”

“Maybe physician anxieties...there are a lot of things that I think can get dealt with pretty easily by someone who has expertise and is doing this all day long.” (MD-4)

“Not very confident, I don’t know where to start to be honest, I’d have to go online I guess and search for cancer surveillance guidelines…I wouldn’t know where to begin.” (NP-9)

Providers were divided in their attitudes towards assuming responsibility for survivorship care. Many felt that it was not their responsibility and described a fear of patients “falling through the cracks” if follow-up care was missed, as well as fear of legal consequences if a recurrent cancer diagnosis was missed. Others suggested that primary care providers were ideally positioned to assume this care due to their ongoing relationships with their patients.
“My fear is having people fall through the cracks...we need to clearly know what medically-legally we’ll be held responsible for...to ensure the patient doesn’t get lost in our 1700 patient mix.” (MD-5)

**Primary care burden.** Many participants, particularly physicians with large caseloads, were concerned about the workload impact of “downloading” survivorship care. They were also concerned about the increased burden on their administrative support staff if additional infrastructure or funding is not provided. Use of technologies such as EMRs still required time and manpower to flag patient conditions and generate recall lists. Issues with the reliability of technology in rural settings, as well as needing to update or migrate to new systems were also described.

“We’ve got EMRs but without some structure things may not get done. Someone in the practice has to go into the program deliberately, run lists, set up appointments, call people.” (MD-3)

Although many providers regarded breast cancer survivors as similar to non-cancer patients and reported no differences in their management, others perceived breast cancer survivors “bring more to a visit” in terms of their “cancer mindset” or “focus on their cancer” and higher levels of anxiety and uncertainty which required more time and more frequent visits, involving multiple issues and multiple questions. They were also seen as “higher risks” and requiring “special considerations” related to psychosocial concerns and the need to provide reassurance.

“Usually these patients have more complaints, and they’re hard to manage. It takes a bit longer. It’s not easy things either where there’s a quick fix. It often involves counselling and support.” (MD-10)
The primary care burden was further challenged by inconsistencies in access to specialists and community resources for their patients. Most MDs described oncologists as accessible and approachable and wouldn’t hesitate to call them for advice about a patient; however, NPs were more likely to report challenges accessing the same specialists. Overall, and particularly in rural practices, providers reported lack of access or prolonged wait times to supportive resources such as diagnostic imaging, physiotherapists (PTs), lymphedema specialists, cancer psychiatrists and community support groups. Time, costs, transportation and in some cases illiteracy were barriers to rural patients accessing resources, however home visits and volunteer drivers were available in most settings to support delivery of care.

“I certainly wouldn’t hesitate to call an oncologist to get advice...they’re happy to answer family doctor’s questions...they’re all really approachable. I know I’ve got somebody at my back if I don’t know what’s going on, they will always help me.” (MD-2)

“We don’t have all the resources we need to provide the care breast cancer survivors need...there is no specialist or physiotherapy to treat lymphedema...there’s only one cancer psychiatrist, so patients are waiting for care they need, care I can’t give or don’t have time to give.” (MD-7)

Perceived strengths and opportunities

Tools and technology. Many providers described how current infrastructure and technology could support tracking the survivors and facilitate implementation of CPGs. Guidelines could be built into the EMR by creating fillable templates that cue practitioners to provide the care and document it.
“We can build templates in our EMR which correspond to guidelines we’re given...we can find the stamp in our system and fill in the blanks specific to each patient...I just have to type over them.” (MD-10)

Although many providers were satisfied with communication from the cancer centre, many described feeling “out of the loop” once a referral was made, and expressed a desire for “post-therapy protocols,” “patient-specific survivorship care plans” and tools to enhance communication and embed CPGs into routine practices.

“A care plan or outline of specific screening and interventions for each patient would be helpful...something simple and easy to follow and specific to my patient.” (MD-7)

“You don’t always get great notes back about patients. Pediatric oncology is very different...we had better post therapy protocols about what you should be doing. In the adult world there seems to be more variability depending on the practitioner organizing it.” (NP-8)

**Empowering survivors.** Providers saw survivors on a continuum from those who lacked responsibility or were “not very good advocates” for their own care, to those who were well-informed, positive and engaged in their care. Some providers believed that patients expected them to be “up-to-date” and play an intermediary role with oncology. Some reported that patients preferred to be seen in primary care for their follow-up; whereas others believed that patients lacked confidence in primary care providers when it came to cancer. Thus many providers were interested in empowering survivors to share responsibility or even coordinate their own care and suggested that guidelines or care plans be provided to both the patient and the provider.
“Some of it has to be cooperation. The patient has to have some responsibility to ensure the follow-up happens appropriately…not to sit back if they don’t hear back from my office in 6 months.” (MD-10)

“Having something like a care plan shared with the patient, like we have for asthma, where the patient’s in charge…especially in survivorship, engagement of the client in their own care to give them more of a sense of control… and with something like cancer you can feel pretty not in charge. My suggestion would be to empower patients to take this on.” (NP-7)

**Optimizing nursing roles.** Team practices offered opportunities to collaborate and access to specialty services and expertise such as pharmacists, dieticians, social workers and PTs; however, many NPs described further opportunities to optimize survivorship care if NPs were able to practice to their full scope of practice. They described “role frustration” related to restrictions on prescribing and diagnostics that led to delays in care delivery. Others perceived “role confusion” related to NP scope of practice and “lack of respect” for the NP role.

“Pain management….we can’t prescribe controlled substances. Another issue is diagnostics…if we’re worried about a recurrence, we can’t order CT or MRI, so getting them done in a timely fashion.” (NP-3)

“Sometimes specialists want to hear from the physician as opposed to the NP…90% of the time I’ll get a letter back from the specialist directed to the physician, with no mention of my name. That’s a barrier that the NP is out of the communication equation…it’s part of the role frustration” (NP-9)

There was much support, particularly from MDs, to optimize RN roles to include aspects of survivorship care. Many providers commented positively on the current nurse navigator role in
the breast cancer assessment clinics and suggested expanding that role to include the survivorship period. Others suggested survivorship care could be part of the primary care nurse role as they are already involved in chronic disease management; however barriers included time and funding to do this, and MD and RN comfort level having nurses take on this additional role.

“*We’re going to be getting some additional nursing support, and that could be a role that as part of some chronic disease management they could be doing.*” (MD-3)

“The breast assessment RN navigator, she’s been great. I don’t know whether it’s reasonable to use her to do survivorship follow-up as well, or someone like her, or could there be two parts to her role?” (NP-8)

Some providers questioned the relevance of some guideline recommendations such as screening for fatigue, or felt the role of primary care in survivorship care was diagnostic follow-up or surveillance for recurrent cancer. Some didn’t feel psychosocial concerns were well-addressed, whereas others described providing comprehensive care including prevention; however, the NP role was seen as a facilitator to providing “holistic care” due to a focus on health promotion and longer scheduled visits which afforded the time to provide screening and counselling.

“*Well some of these guidelines I don’t do, for example asking about their sexual function...what can be done about it anyway?*” (MD-8)

“A breast cancer patient comes to see me and I’m looking at the entire picture. Breast cancer is only one aspect of their health.” (NP-3)

**Discussion**

Organizing emerging themes according to the categories of knowledge, attitudes and resources provided a useful framework for analyzing study findings so that they may be used in a practical manner to inform development of strategies to improve translation of evidence-based breast
cancer survivorship care CPGs into primary care practice. The current study identified three major challenges and three major strengths and opportunities that provide insight into multiple level factors influencing guideline implementation. Several findings are consistent with known barriers and facilitators whereas others add to our knowledge of this topic specific to breast cancer survivorship care.

**Perceived Challenges**

The inconsistency and inadequacy of primary care provider knowledge, education and experience related to cancer survivorship care reported in our study is a major challenge that is well documented in the literature. Our previous survey of primary care providers demonstrated significant knowledge gaps related to breast cancer survivorship care amongst both MDs and NPs across our region. Other studies have found similar gaps in oncology and primary care settings. Cancer survivorship care is a relatively new construct that has not generally been integrated within health professional schools’ curricula which confirms a significant need for updating health professional curricula and continuing education for primary care providers to address this gap. It is also well known that time constraints and an overwhelming volume of information contribute to lack of awareness of CPGs by healthcare professionals; and that even when healthcare providers are aware of guidelines, they may lack familiarity with specific guideline recommendations which leads to nonadherence. Primary care providers may not have enough opportunities to develop expertise in survivorship care, in addition to competing demands on their time related to keeping up to date on care for other speciality conditions.

Participants in our study reported a diversity of learning needs and preferences for delivery of education on survivorship care. Research on implementation of CPGs supports use of a variety of strategies and multidimensional interventions to effect change, as what works with
one individual or group may not work with another. Primary care physicians in a recent Canadian study preferred CME events and online resources to obtain knowledge about breast cancer and survivorship care, which were also popular with our study participants. Overwhelmingly, our participants desired guidelines that were short and succinct. Similarly, family physicians participating in a recent RCT conducted in Ontario and Nova Scotia reported that full versions of breast cancer follow-up CPGs were not useful because they were too long, could not be easily input into the EMR or contained information that was already known. Participants also requested access to reliable, Canadian guidelines housed in one place to facilitate access. Family physicians in another Canadian study preferred a single access point website with links to CPGs, resources, support services, lists of common treatments, side effects and management, and a few key articles.

Although traditional CME remains more popular, online webinars and courses are increasingly being used to deliver education for healthcare providers. Research suggests that webinars, videoconferencing and other forms of electronic CME are a feasible and acceptable manner to deliver quality health education on survivorship care to multidisciplinary groups and specifically primary care providers. Online CME offers particular benefit in rural and remote areas, such as flexibility and convenience of availability and reduced time and costs associated with travel. Systematic reviews of trials of provider education including educational workshops, meetings, lectures, educational outreach and distribution of educational materials have demonstrated small-to-modest benefits to physician adherence to guidelines. Some of our study participants suggested team-based education could ensure all team members are aware of CPGs, and facilitate discussion of how individual teams might implement specific recommendations. Other studies have highlighted the importance of targeting the whole primary
care team with guideline implementation strategies and have demonstrated positive changes in attitudes and practices related to other practice issues such as caring for patients with cardiovascular disease, and prescribing antibiotics.\textsuperscript{26, 40}

Provider anxieties were a second major challenge perceived by our participants. Although it was encouraging that many embraced the primary care role in survivorship care as appropriate or ideal, it was concerning that many perceived this new role as a burden and expressed fears about survivors falling through the cracks, and the legal implications. A fear of missing a cancer recurrence may distract primary care providers from attending to matters perceived as less urgent such as cancer-related fatigue. The chronic disease literature, suggests physicians’ fear of missing a diagnosis of a serious illness may divert attention from important prevention and counseling activities.\textsuperscript{41, 42} Physician fear of litigation is supported by reports that failure or delayed diagnosis are the most common malpractice claims in primary care, with cancer one of the most frequently cited diagnoses.\textsuperscript{43}

Although some participants reported a comfort zone related to providing survivorship care, most expressed some anxiety owing to the previously described hit and miss nature of their knowledge, education and experience, and expressed a need for explicit direction from experts. Similarly, primary care providers in studies conducted in the U.S. and Canada reported a level of comfort providing follow-up care but reported challenges in managing complications of cancer, promoting risk reduction behaviours, and providing psychosocial care.\textsuperscript{44, 45} Experience is a key factor promoting comfort, as primary care MDs who followed more breast cancer survivors in their practice reported higher confidence in managing their follow-up.\textsuperscript{29} However, owing to relatively small caseloads of cancer survivors in primary care, it is difficult for most primary care MDs to acquire this experience and subsequent confidence.\textsuperscript{46} Thus, primary care providers desire
support and clear direction from oncologists regarding expectations for follow-up care and potential problems that could develop.\textsuperscript{25, 30, 47}

The third major challenge identified in this study was the primary care burden. Even when primary care providers have appropriate knowledge and attitudes, practice constraints may limit guideline implementation.\textsuperscript{48} Insufficient time, competing demands, staff shortages, unreliable reminder systems and lack of compensation have been cited as significant barriers to guideline adherence in primary care.\textsuperscript{44, 45, 49} In terms of practice level resources, MDs in our study also reported lack of time, lack of funding, and workload burden for themselves and their staff as barriers to CPG implementation. Inputting EMR data and running lists also contributed to administrative burden.

Many study participants described a subset of survivors who brought more to a visit in terms of multiple questions and multiple needs including increased anxiety. Thus these survivors often required more visits, time and resources. It is well documented that breast cancer survivors often experience significant distress, and in particular related to uncertainty and fear of cancer recurrence.\textsuperscript{50, 51} These findings highlight the importance of comprehensive survivorship care for breast cancer survivors that includes provision of psychosocial support, as well as the challenge of providing this care in the primary care setting where time and other resources may be limited.

Primary care providers in our study reported inequities in access to specialists and supportive care services for breast cancer survivors, particularly those living in rural areas. NPs were more likely to report challenges accessing oncology specialists, a problem that may resolve with new funding reimbursements for specialists consulting with NPs.\textsuperscript{52} MDs in our study already felt access was very good which may be a result of working in a smaller urban centre; whereas MDs in a larger urban Canadian city reported limited contact with oncologists compared
to those working in smaller cities.\textsuperscript{30} Rural breast cancer survivors report limited access to medical and allied health professional follow-up care, and psychosocial and lifestyle support programmes, which predisposes them to higher levels of unmet needs.\textsuperscript{53-55} In Canada, access to some specialized services for breast cancer survivors, such as lymphedema therapists, PTs and rehabilitation is limited by need for more certified therapists, and lack of funding for treatment.\textsuperscript{56, 57} Addressing access inequities will be important for primary care providers to fully implement guideline recommendations for survivors with ongoing physical or psychosocial needs. As well, KT interventions will need to better connect primary care providers and breast cancer survivors to existing resources.

**Perceived Strengths and Opportunities**

In our study, tools and technology were seen as important facilitators to address primary care burden. Facilitators cited in the literature at the practice level include integrated EMR, computerized reminder systems, guidelines available at point of care, protocols to streamline care and scheduling, and dedicated resources such as time, funding and personnel.\textsuperscript{48, 58} Unlike follow-up care for pediatric cancer survivors, care for adult survivors has not been driven by specific protocols or CPGs, has focused on surveillance for cancer recurrence, and has not consistently addressed health promotion or symptom management.\textsuperscript{59} Release of breast cancer survivorship CPGs for primary care now provides sufficient evidence for comprehensive protocol development.\textsuperscript{6, 60} The potential to build protocols, guideline templates, prompts and reminders into EMRs, and electronic charts that could be shared across organizations were seen as opportunities to improve tracking survivors and delivering evidence-based care.

Our study participants identified communication gaps between oncologists and primary care and a desire for tools and protocols that would embed post-treatment CPGs into routine
practices. Patient-specific survivorship care plans (SCPs) detailing treatments, follow-up care and resources were proposed as a three-way communication tool provided by oncology specialists to keep both providers and patients in the loop and improve guideline adherence.

SCPs have been endorsed by the American Society for Clinical Oncology (ASCO), and the Canadian Partnership Against Cancer (CPAC) as important communication tools to enhance post-treatment transition care. A Canadian pilot-study of a multi-component SCP with both tailored web and paper-based materials has shown promise in addressing information needs of both breast cancer survivors and MDs. Similarly, primary care providers in a U.S. study indicated SCPs increased their knowledge and confidence, and resulted in changes in patient care. Primary care providers and survivors have reported high levels of satisfaction with SCPs; however, evidence shows few measurable patient outcome benefits, whereas time, resources, costs and incompatibilities with existing EMRs were seen as significant barriers. Further evaluation of SCPs is needed. Research should also continue to explore which components of SCPs or other tools are most effective and efficient. Evidence suggests primary care providers want understandable, easy to follow CPGs and algorithms. Primary care physicians in one Canadian study indicated that a 1-page record of care was the only useful SCP component and that full versions of survivorship CPGs were too long, contained information already known, and could not be easily incorporated into EMRs. Similarly, in the U.K., the treatment summary of the SCP has been well received and is reported to be useful to MDs. In another Canadian study, MDs preferred paper-based formats for receiving patient-specific treatment information, and printable resources such as patient information and checklists of topics to be addressed during follow-up. Patient preferences for SCP content and format should also be considered.
A second major strength and opportunity was interest in empowering breast cancer survivors. The fact that people with cancer are living longer, and recognition of the impact of fragmented survivorship care has resulted in efforts to engage cancer survivors in self-management, similar to other chronic conditions. Research suggests empowering patients with a personal health record and access to a “transition coach” may improve quality of care transitions and ensure patient needs are being met. Chronic disease self-management programs for people with heart and lung disease, stroke and arthritis have demonstrated improved self-efficacy, reduced distress, and reduced use of emergency services. Cancer survivors report that many physical and psychosocial effects of cancer, and health promotion topics are not addressed in follow-up. Although many survivors in a Canadian study described follow-up care as their responsibility, they felt unprepared to manage it. Thus, tools, interventions and support that empower survivors to take an active role in managing their survivorship care may be a strategy to ensure these issues are addressed. Similar to our results, several physicians in another Canadian study believed the patient should be an active partner or leader in follow-up care, and a number reported incorporating self-management strategies. However, participants in our study indicated that some patients are not reliable, and may not be appropriate candidates for self-management. Likewise, providers may feel reluctant to provide counseling if they perceive patients are unlikely to adhere to recommendations. Almost half of primary care providers in a large U.S. reported that patients are sometimes noncompliant with recommended survivorship care. In addition to SCPs or passports as suggested by our study participants, innovative tools that could be used to support survivorship self-management include eHealth interventions such as web-based programs or apps for mobile devices. Work done in other chronic disease settings can provide a basis for design of eHealth strategies for cancer survivors.
The third significant strength and opportunity perceived by our participants was optimization of nursing roles at the practice and systems level in provision of survivorship care. Since 2005, 184 FHTs have been established across Ontario to improve access, and efficiency and quality of primary healthcare. Most of our study participants belonged to FHTs that included collaborative IP teams of MDs, NPs, registered nurses (RNs) and other professionals. Previous Canadian studies have identified issues related to collaboration, including lack of role clarity, expectations, trust, scope of practice, and conflicting values and beliefs. Many NPs in our study described role frustration and confusion as barriers to collaborative care that impacted their ability to implement CPGs. A major role frustration was inability to order certain diagnostic tests such as CT scans or MRIs. In previous Canadian studies, NPs have reported their roles were hindered by inability to perform tasks that should fall into their scope of practice such as prescribing medications and ordering diagnostic tests. Another major frustration was lack of direct communication from oncologists, which was perceived as lack of respect for the NP role. New amendments to the Schedule of Benefits for Physicians Services have removed barriers for NPs to directly refer patients to specialists in Ontario; thus oncologists may now bill for consultations from NPs, and are required to provide a report back to the referring NP. Although provincial legislation allows NPs to order additional diagnostic tests such as CTs, and MRIs, and to prescribe medications including controlled substances, the provisions will only take effect once relevant regulations are amended and approved by the government. Measures to facilitate NPs practicing to full scope may enhance their ability to provide comprehensive survivorship care in a timely manner.

Although the transition to survivorship care following cancer treatment is recognized as a “teachable moment” to promote lifestyle changes, research suggests oncology follow-up
models often result in missed opportunities to optimize general health of cancer survivors, and that follow-up in the primary care setting results in more non-cancer preventive services provided to breast cancer survivors. NPs are recognized for their focus on psychosocial issues related to cancer, and in one study were more likely to recommend healthy lifestyles than MDs. Similarly, in a Canadian study of rural primary care practices, MDs practiced mainly within the illness care model, whereas, NPs made time to include prevention and health promotion. Many MDs and NPs in our study reported providing holistic survivorship care including preventive care, but many acknowledged screening and psychosocial care were not routine, citing time as a major barrier. Previous research shows cancer survivors have unmet psychosocial needs, and primary care providers may lack resources to deal with complex psychosocial issues. In one Canadian study, MDs seldom described initiating conversations about psychosocial issues, but said they would refer patients for support if needed. Similarly, cancer survivors may have unmet needs related to health promotion such as meeting exercise recommendations. Within a medical system focused on acute illness, it may be difficult for physicians to develop new routines for counseling and preventive care; however, psychosocial and health behaviour assessment and counseling could be delegated to nurses or allied health professionals. Many aspects of comprehensive survivorship care such as health promotion, rehabilitation and chronic disease management could be performed by PTs and occupational therapists (OTs) that have been integrated into some FHTs and CHCs, or who have collaborative relationships with individual primary care MDs.

Our study participants identified optimization and expansion of existing nursing roles in patient navigation and chronic disease management. Regionally, the breast assessment nurse navigator coordinates pre-treatment assessment, diagnosis and referral activities for women with
breast cancer, and primary care nurses are often involved in chronic disease management activities for health conditions such as diabetes and hypertension; however, these roles are not standardized and there is potential for optimization. Many study participants proposed expanding these existing nursing roles to include coordination and provision of survivorship care, as many aspects of this care fall within the scopes of practice of RNs and/or Registered Practical Nurses (RPNs). Breast cancer survivors in one Canadian study emphasized importance of human resources such as patient navigators as sources of support. Professional patient navigators assess and address clinical & supportive care needs of cancer patients, however, at present most navigation programs in Canada concentrate on the diagnostic or treatment phases. Nurse navigators could be integrated in the community to facilitate transition to survivorship, promote self-management and enhance supportive care access. Having one person responsible for coordinating follow-up across the region would allow for centralised recall systems, reducing need for individual primary care practices expending resources on this. There may be opportunities to expand current nurse navigator roles in our region to include survivorship, or training could be provided to primary care nurses to assume this role within a FHT or other collaborative practice model. The “lead physician” model introduced in Manitoba, Canada could be appropriate for team-based practices such as FHTs in Ontario, with each team choosing to nominate an interested MD, NP, RN or other health professional to become the “clinician lead” for survivorship care. Similar initiatives that included nurses as primary care cancer leaders have been trialed in the U.S. and U.K. with positive effects on knowledge and practices. 

Due to ongoing and late effects associated with treatment, cancer can be viewed as a chronic disease; a conceptual framework published in a recent IOM report, Delivering High-Quality Cancer Care, positions survivorship within the chronic phase of cancer care.
post-treatment cancer follow-up could be managed using a chronic care model such as Ontario’s Chronic Disease Prevention and Management (CDPM) Framework. Primary care interventions based on chronic care model components have improved processes and outcomes for patients with chronic illness, and reduced health care costs and service use. Effective chronic disease management includes measures to prevent disease progress, complications and co-morbidities, which is in keeping with the IOM recommendation for preventive measures for cancer survivors. Effective chronic disease teams delegate tasks and responsibilities, and rely heavily on nurses to lead care and implement specific protocols. It may be appropriate and cost-effective to delegate aspects of survivorship care to trained primary care nurses who have time to provide assessment and counseling to support prevention and management of chronic disease. Primary care nurses have had better client outcomes with provision of self-management support than other healthcare professionals. However, a cross-sectional survey of Ontario primary care nurses determined chronic disease management was not uniform across primary care practices, and there was potential to optimize this role and improve implementation of chronic disease management strategies. Results of another study suggest primary care RNs’ involvement in cancer survivorship care in Ontario is limited but generally involves care coordination and system navigation, emotional support, and facilitating access to community resources; expansion of the primary care RN’s role in cancer survivorship care is proposed as a practical approach to improve survivorship care quality.

**Strengths and limitations of the research study**

Strategies employed to establish dependability and credibility of our research findings included clear descriptions of research design and methods, focused data immersion activities including transcription accuracy, and code/recoding procedures. Analytic rigor of the study was also
strengthened by independent coding of a subset of transcripts by professional and academic peers, and by including the voice of participants through verbatim quotes. We also employed multiple methods of triangulation or convergence of multiple perspectives for confirmation of data: triangulation of (1) data methods; (2) data sources; (3) theories; and (4) investigators.114 We employed multiple methods and sources of data collection such as qualitative interview transcripts, qualitative survey question responses and field notes. Results of survey responses echoed many of the themes that emerged from the analysis of the interview transcripts.

Theoretical triangulation involved examining how well results aligned with existing theories and research findings. Our results aligned with existing models and factors known to influence physician adherence to CPGs, and extended these to include NPs. Our analysis additionally identified challenges and strengths relevant to our regional context. Researcher triangulation involved peer review of methods, analysis and results at various stages by faculty and NP colleagues, as well as by the thesis supervisor. Interview participants were invited to provide feedback on the data analysis and emerging themes, and three MDs and three NPs responded to the request. This member checking validated interpretation of thematic findings and provided minor clarifications.

Our detailed description of study context and methods enables readers to judge whether findings may be transferable to their own care contexts. Our sample was representative in that it included MDs and NPs, rural and urban, male and female, and experienced and novice practitioners; however, the majority (68%) practiced in team-based practices such as FHTs which limits ability to also generalize findings to solo PCPs. Findings also could have been influenced by the primary care providers who self-selected to participate. Individual participants may have had particularly positive or negative feelings towards implementation of breast cancer
survivorship care which motivated them to participate; however, for the most part, participants provided balanced perspectives of their challenges and strengths. As data consisted of subjective experiences, there was potential for recall bias or failure to disclose, however, participants’ tone and responses reflected a genuine willingness to share both their positive and negative experiences.

Although measures were taken to reduce bias and increase credibility, qualitative research involves data gathering and analysis performed and interpreted by the researcher; thus, there is a risk of researcher bias. Strategies employed to establish confirmability included a detailed audit trail, and peer debriefing. Although use of an a priori framework to guide qualitative analysis is appropriate when there is significant knowledge related to a field of study, there is a risk that data will be forced into the framework and new themes may be missed. Thus, we were careful to ensure findings emerged directly from the data, and subsequently found no data that fell outside the framework.

**Implications for development of knowledge translation interventions**

Results of this qualitative study of barriers and facilitators to implementing evidence-based breast cancer survivorship care as perceived by primary care providers are important because they provide relevant information for educators, clinicians and researchers about challenges and strengths associated with providing evidence-based survivorship care. Our findings, and the findings of others, support the need for KT interventions to address knowledge gaps, provider anxieties and system barriers identified in this study. The growing involvement of primary care providers in cancer survivorship care also suggests a need for formal educational programs to prepare them to assume this role. Education should encompass comprehensive health care needs of breast cancer survivors, in addition to surveillance for recurrent cancer. In the meantime, gaps
in survivorship education suggest a significant need for continuing education for primary care providers, and updates to undergraduate curricular for those in training. Online CME is a strategy that may address needs and time constraints of primary care practice, in particular for rural practices, and several existing online courses on survivorship care are available in the U.S. and Canada.\textsuperscript{115-117} However, this study contributes to a better understanding of the provider-perceived challenges and preferences for delivery of education on evidence-based CPGs, suggesting a multidimensional approach that includes webinars, workshops, outreach, email and mail notifications with links to dedicated websites with succinct user-friendly CPGs, along with tools and templates easily incorporated into EMRs to facilitate guideline implementation while addressing the primary care burden.

Successful implementation of CPGs requires tailoring to individual practice contexts. Team-based practices could examine existing staff development and education sessions as opportunities to introduce survivorship CPGs.\textsuperscript{27} Primary care providers should explore their own practice contexts, and optimize roles and existing resources such as EMRs for tracking cancer survivors and embedding recommended guidelines and protocols. Primary care burden and provider anxieties related to fear of patients falling through the cracks could be addressed by survivorship care facilitated by nurse navigators or primary care nurses using a chronic disease model. Thus, KT interventions should also target primary care RNs and RPNs. Interventions should also be developed to support self-management by breast cancer survivors. Trials of guideline implementation interventions typically report changes in provider knowledge or practices, with patient outcomes not reported or underpowered to detect changes.\textsuperscript{26, 35} Future KT intervention studies for breast cancer survivorship care should be designed to evaluate effects on patient outcomes such as symptom burden and quality of life.
Implications for cancer survivors

The numerous challenges experienced by primary care providers as described by our study participants have implications for cancer survivors. Acknowledged provider knowledge and practice gaps suggest a need for breast cancer survivors to be aware of current guidelines for breast cancer survivorship care. Thus, survivors should receive information about their specific cancer and treatment and recommendations for follow-up to support them in assuming shared responsibility for their survivorship care. Similarly, breast cancer survivors should be provided with information about the changing role of primary care providers in survivorship care, as well as existing community resources that will support their successful transition from cancer patient to cancer survivor, including self-management support workshops for chronic disease and/or cancer.

Conclusions

This study identified several important challenges to implementation of comprehensive evidence-based survivorship care for breast cancer survivors, as well as several strengths and opportunities that could be built upon to address these barriers. Findings reveal primary care providers are striving to provide comprehensive care to breast cancer survivors but are doing so with limited educational preparation, few survivorship protocols or tools, and strained practice resources. Primary care providers are prepared to assume responsibility for follow-up surveillance but may lack knowledge and resources to provide comprehensive survivorship care including prevention and intervention strategies for ongoing and late effects of treatment. Addressing barriers to implementation with concrete interventions at the levels at which they occur, and building on the identified strengths and opportunities, informed by the KTA framework, will ultimately improve quality of breast cancer survivorship care.
Our study explored primary care MD and NP perceptions of the challenges related to implementing post-treatment breast cancer survivorship care guideline recommendations, and provides local context for the development of KT strategies and interventions. Additionally, our study may be the first to include perceptions of primary health care NPs which is important within the Canadian context and elsewhere where NPs are a growing group providing primary care. The role of the primary care nurse in cancer survivorship care is a promising opportunity to enhance survivorship care that deserves further attention. With appropriate education and tools, primary care nurses could provide efficient, effective and comprehensive survivorship care in collaboration with primary care MDs and NPs and breast cancer survivors. This research will inform development of targeted KT interventions to provide support and education for primary care providers and breast cancer survivors.

Acknowledgements

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Conflict of Interest

None of the authors have any conflicts of interest to disclose.

Ethics Statement

Ethical approval was obtained from the Queen’s University Health Sciences and Affiliated Teaching Hospitals Research Ethics Board (File # 6009937). All study procedures were performed in accordance with the ethical standards of the institutional and/or national research committee and with the 1964 Helsinki declaration and its later amendments or comparable ethical standards.
References


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Table 1: *Characteristics of Interview Participants (N=19)*

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<thead>
<tr>
<th>Characteristic</th>
<th>Number</th>
<th>Mean (SD)</th>
<th>Range</th>
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<td>Primary healthcare nurse</td>
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<tr>
<td>practitioner</td>
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<td></td>
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<tr>
<td>Male</td>
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<td></td>
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<tr>
<td><strong>Age (years)</strong></td>
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<tr>
<td><strong>Primary care experience (years)</strong></td>
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<td>14.3 (12.6)</td>
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<tr>
<td>Small urban (10,000-99,999)</td>
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<tr>
<td>Town (3,000-9,999)</td>
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<tr>
<td>Rural (&lt;3000)</td>
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<tr>
<td><strong>Practice type</strong></td>
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<td>Family Health Team (FHT)</td>
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<td>Family Health Organization (FHO)</td>
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<td>Nurse-Led Clinic</td>
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<tr>
<td>Solo Physician</td>
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### Table 2: Perceived Challenges, Strengths and Opportunities

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<tr>
<th>Themes</th>
<th>Subthemes</th>
<th>Recommended Knowledge Translation Strategies</th>
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<tr>
<td><strong>Perceived Challenges</strong></td>
<td>Inconsistent educational preparation</td>
<td>- include survivorship education in undergraduate and postgraduate educational programs</td>
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<td></td>
<td>No formal education</td>
<td>- provide continuing education to current primary care providers</td>
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<td></td>
<td>On the job learning</td>
<td>- offer continuing education in a variety of formats</td>
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<td></td>
<td>Overwhelming to keep up to date</td>
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<td></td>
<td>Diversity of learning needs and preferences</td>
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<tr>
<td>Provider anxieties</td>
<td>Fear of patients falling through the cracks</td>
<td>- provide support to primary care providers as they assume responsibility for survivorship care</td>
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<td></td>
<td>Fear of missing diagnosis</td>
<td>- evaluate the transition to primary care follow-up from the perspective of primary care providers to identify ongoing concerns that may impact guideline implementation</td>
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<tr>
<td></td>
<td>Fear of legal consequences</td>
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<tr>
<td></td>
<td>Comfort zone</td>
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<td></td>
<td>Feeling like a beginner</td>
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<td>Primary care burden</td>
<td>Shifting burden to primary care</td>
<td>- develop EMR templates and processes to facilitate tracking breast cancer survivors and implement recommended guidelines</td>
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<td></td>
<td>Not my responsibility</td>
<td>- provide primary care providers and breast cancer survivors with clear information about what resources, specialists are available to support provision of survivorship care, as well as how to access them</td>
</tr>
<tr>
<td></td>
<td>Breast cancer survivors bring more to a visit</td>
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<td></td>
<td>Primary care workload</td>
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<td>Admin support workload</td>
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<td>Infrastructure &amp; funding</td>
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<td></td>
<td>Access inequities</td>
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<td><strong>Perceived Strengths and Opportunities</strong></td>
<td>Tools and technology</td>
<td>- develop EMR templates and processes to facilitate tracking breast cancer survivors and implement recommended guidelines</td>
</tr>
<tr>
<td></td>
<td>Tracking survivors</td>
<td>- develop tools, protocols and care plans to embed guidelines into routine practices</td>
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<td>Electronic health records</td>
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<td>Communication tools</td>
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<td></td>
<td>Protocols and survivorship care plans</td>
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<td>Empowering survivors</td>
<td>Patient responsibility</td>
<td>- educate survivors about primary care role in survivorship care</td>
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<td></td>
<td>Survivor expectations for follow-up</td>
<td>- educate survivors about survivorship guidelines and provide them with a copy of the survivorship care plan</td>
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<tr>
<td></td>
<td>Positive attitudes &amp; behaviours</td>
<td>- develop self-management support programs for survivors</td>
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<tr>
<td></td>
<td>Providing survivorship care plans</td>
<td>- educate primary care providers about providing self-management support</td>
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<td>Optimizing nursing roles</td>
<td>NP role frustration and scope of practice</td>
<td>- provide education to all primary care team members including RNs and RPNs to support their practicing to full scope of practice in providing comprehensive breast cancer survivorship care</td>
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<tr>
<td></td>
<td>Nurse navigator role</td>
<td>- expand existing RN roles to support provision of comprehensive survivorship care in primary care</td>
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<td></td>
<td>Nursing chronic disease management role</td>
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<td>NP role benefits</td>
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CHAPTER SIX

Discussion

This thesis contributed to our knowledge and understanding of complex processes related to implementing evidence-based breast cancer survivorship care by primary care providers within the South East Local Integration Health Network (SE LHIN). This final chapter summarizes and integrates the results of the three phases of this mixed methods study. In keeping with the underlying pragmatic philosophical framework for this study, practical applications of the research results will be suggested for primary care practice and health policy, as well as areas for future research to advance knowledge in the fields of knowledge translation and breast cancer survivorship care.

Overview of Findings

The overall purpose of this thesis was to determine the challenges, strengths and opportunities related to implementing comprehensive evidence-based guidelines on breast cancer survivorship care by primary care medical doctors (MDs) and nurse practitioners (NPs) in the SE LHIN of Ontario. In Chapter One, the regional context for this study was described, in which stable, early-stage breast cancer survivors are now being discharged from oncology follow-up at the Cancer Centre of Southeastern Ontario to primary care follow-up following completion of their primary treatment (South East Regional Cancer Program, 2011). As each primary care provider may only be seeing one to two newly discharged breast cancer survivors per year, it may prove challenging for these providers to remain up to date about the best practices in breast cancer survivorship care in addition to competing demands from other patient populations. Thus a three-phased, mixed-methods study was proposed to provide foundational knowledge that can be used in the future to tailor knowledge translation (KT) interventions that provide appropriate
education and support to primary care providers as they assume this new role in breast cancer survivorship care. The Knowledge-to-Action (KTA) Framework provided the guiding and organizing framework for the study design and implementation (Graham et al., 2006). Each of the three phases of this thesis incorporated various steps of the KTA Framework. The seminal report from the Institute of Medicine (IOM) *From Cancer Patient to Cancer Survivor: Lost in Transition*, provided the clinical framework for provision of comprehensive survivorship care as described throughout the thesis (Hewitt, Greenfield, & Stovall, 2006).

*Chapter two* provided an extensive narrative review of the literature related to: (1) breast cancer survivorship care, (2) barriers and facilitators to implementing clinical practice guidelines (CPGs), and (3) knowledge translation (KT) for primary care providers. The results of this literature review highlighted what is known about evidence-based breast cancer survivorship care in primary care and provided foundational knowledge for the study. The review demonstrated that some breast cancer survivors continue to have a broad range of physical and psychosocial problems such as pain, lymphedema, fatigue, sleep disturbances, depression and anxiety that may be ongoing or develop months or years after treatment, and suggested that although primary care providers are willing to provide breast cancer survivorship care, many lack the knowledge and confidence to provide evidence-based care. Recent clinical practice guidelines (CPGs) are available that are applicable to follow-up care of breast cancer survivors in primary care; however, no single guideline addressed all of the essential components of survivorship care.

The seminal framework *Clinical Practice Guidelines Framework for Improvement* published by Cabana and colleagues (Cabana et al., 1999) and later updated by Légaré and colleagues (Legare, Ratte, Gravel, & Graham, 2008) was identified through this review and
subsequently used to explore barriers and facilitators to MD adherence to CPGs, with factors organized according to the knowledge, attitudes and external factors that influence MD behaviours. Numerous KT strategies described in the literature were evaluated in the primary care setting with varying effects, but few specifically addressed challenges related to providing survivorship care. Thus, it was unclear what strategies would be most effective to promote evidence-based breast cancer survivorship care in the primary care setting within the Canadian context and specifically within Ontario where the population of primary care NPs is growing, and where many primary care providers are practicing in family health teams. The SE LHIN in Ontario provided an appropriate research setting for exploring these issues in both rural and urban primary practice settings and family health teams.

Thus, as a thorough understanding of the practice context is essential to the effective implementation of new interventions or practices in health care settings, we proposed three objectives that guided the three phases of the research:

1. To describe evidence-based comprehensive breast cancer survivorship care for primary care practice;
2. To determine to what extent the key best practice guideline recommendations for post-treatment breast cancer survivorship care are being implemented by primary care MDs and NPs within the SE LHIN and to describe the gaps in knowledge and care;
3. To determine the challenges (barriers), strengths (facilitators) and opportunities (recommendations) related to provision of comprehensive evidence-based breast cancer survivorship care by primary care providers within the SE LHIN.

**Chapter three** aligns with research objective #1 and describes the development and validation of a comprehensive clinical practice framework for provision of post-treatment breast
cancer survivorship care within the primary care setting. This first phase of the thesis consisted of an extensive search, appraisal and synthesis of CPGs for post-treatment breast cancer care using a modified Delphi method. Breast cancer survivorship issues and relevant CPGs were mapped to the four essential components of survivorship care described in the IOM report: (1) prevention of recurrent and new cancers, and other late effects; (2) surveillance for cancer spread, recurrence, second cancers, and medical and psychosocial late effects; (3) intervention for consequences of cancer and its treatment; and (4) coordination between specialists and PCPs to ensure that all of the survivor’s health needs are met (Hewitt et al., 2006). A comprehensive clinical practice framework was created to guide provision of breast cancer survivorship care. The completed framework consists of a one-page checklist outlining breast cancer survivorship issues relevant to primary care, a three-page summary of key recommendations, and a one-page list of guideline sources. The framework and key guideline recommendations were verified by a panel of experts for comprehensiveness, importance and relevance to primary care (Luctkar-Flude, Aiken, McColl, & Tranmer, 2015).

Chapter four aligns with research objective #2 and describes the results of a brief descriptive cross-sectional survey to determine self-reported practices related to provision of evidence-based post-treatment breast cancer survivorship care by primary care MDs and NPs within the SE LHIN. This second phase of the thesis identified several knowledge-to-action gaps (Straus & Leung, 2011), which are gaps between best practices and actual practices, related to provision of evidence-based breast cancer survivorship care in primary care. Overall, MDs and NPs in our sample reported similar practice patterns in terms of implementation of breast cancer survivorship guideline recommendations, and reported routinely implementing about half (46%, n=10/21) of the key guideline recommendations with breast cancer survivors in their practices.
Implementation rates were higher for recommendations related to prevention and surveillance aspects of survivorship care such as mammography and weight management, and knowledge and practice gaps were highest for recommendations related to screening for and management of long-term effects such as fatigue and distress. These results underscore the need for KT interventions for primary care providers to address these identified knowledge and practice gaps.

**Chapter five** aligns with research objective #3 and describes the results of individual interviews with a subset of primary care MDs and NPs about the challenges, strengths and opportunities related to the provision of comprehensive evidence-based post-treatment breast cancer survivorship care within the SE LHIN. This third phase provided further assessment of the practice context and needs from the perspective of primary care providers which is required in order to understand how to best address the identified knowledge-to-action gaps. Organizing emerging themes according to the broad categories of knowledge, attitudes and resources provided a useful framework for analyzing study findings so that they may be used in a practical manner to inform development of strategies to improve translation of evidence-based breast cancer survivorship care CPGs into primary care practice. Thematic analysis revealed six themes across these three categories. Participants highlighted three major challenges related to providing breast cancer survivorship care: *inconsistent educational preparation, provider anxieties, and primary care burden*. They also described three major strengths or opportunities to facilitate implementation of survivorship care guidelines: *tools and technology, empowering survivors, and optimizing nursing roles*. Addressing these challenges while building on existing strengths can provide opportunities to translate the growing body of research evidence on comprehensive breast cancer survivorship care into primary care practice and enhance the health outcomes and quality of life of breast cancer survivors as they recover from the effects of treatment.
Unique contributions

This research will contribute foundational knowledge that can be used in the future to tailor KT interventions and inform health policies that address identified knowledge and practice gaps related to provision of breast cancer survivorship care within the context of resources available at the local primary care practice and systems levels. As context is essential to the success of KT strategies, this study involved both informal and formal methods to obtain input from primary care providers, oncology specialists, and breast cancer survivors throughout the research process, which is an important strength of this study, as it increases the validity and relevance of findings to the end-users of this research.

The three phases of this thesis make several unique contributions to the growing body of literature on evidence-based breast cancer survivorship care. Although these findings are described in the individual chapters there are five significant contributions that will be highlighted: (1) synthesis of existing CPGs aligning with the four domains of survivorship care that are relevant to primary care; (2) identification of local knowledge and practice gaps related to specific key CPG recommendations for breast cancer survivorship care; (3) highlighting the emotional impact of implementing breast cancer survivorship care CPGs within the context of inconsistent educational preparation and the competing resource demands associated with primary care practice; (4) highlighting promising opportunities to enhance breast cancer survivorship care by empowering survivors and optimizing primary care nursing roles; and (5) incorporating perceptions of primary care NPs.

Our study was the first to synthesize existing CPGs to create a single resource outlining breast cancer survivorship care recommendations for primary care that align with the four domains outlined by the IOM report. The resulting Comprehensive Framework for Evidence-
based Breast Cancer Survivorship Care has been published in the journal *Family Practice* and is freely available online to primary care providers (Luctkar-Flude et al., 2015). Feedback from our expert panel members suggests the framework was comprehensive but succinct enough to be useful in clinical practice to guide consultations and discussions with breast cancer survivors. Subsequent to the publication of our guideline synthesis, the American Cancer Society (ACS) and the American Association of Clinical Oncology (ASCO) released their own comprehensive breast cancer survivorship care guideline for the first time (Runowicz et al., 2016). Previous versions of ASCO breast cancer follow-up guidelines focused on surveillance for recurrent cancers and did not address the other domains of survivorship care (Khatcheressian et al., 2013). Their latest publication supports that there was a need for more comprehensive CPGs to guide breast cancer survivorship care.

Our quantitative survey results enhance understanding of current knowledge and self-reported practices of primary care providers in our region specifically related to implementation of 21 key evidence-based recommendations for post-treatment breast cancer survivorship care. This will facilitate adapting knowledge to the local context to ensure it is relevant to the intended users and feasible within the primary care practice setting.

Through the qualitative component of this research we identified several important challenges to implementation of comprehensive evidence-based survivorship care for breast cancer survivors. Although inadequate knowledge and resources are well-known barriers to CPG implementation, this study highlighted the impact of provider anxieties related to assuming responsibility for survivorship care. In addition to known attitudes such as lack of confidence, many providers expressed strong fears of missing required patient follow-up care or diagnosis of
cancer recurrence. Thus acknowledging provider attitudes and emotions will be important to consider when designing KT strategies.

The qualitative component of this research also identified several strengths and opportunities that could be built upon to address these barriers. Many novel KT strategies employing tools, technology and survivorship care plans have already been piloted in Canadian studies; however, our study results provide specific content that could be incorporated into future trials. The concept of empowering survivors is not new but our study emphasizes that this area deserves renewed and focused attention, given the challenges and demands faced by primary care providers. And finally, the findings supporting optimizing primary care nursing roles, provides a promising option that could relieve the primary care burden related to providing comprehensive survivorship care.

Our study is among the first to explore primary care provider perceptions of the challenges specifically related to implementing post-treatment breast cancer survivorship care guideline recommendations, and provides local context for the development of KT strategies and interventions. Additionally, our study may be the first to include perceptions of primary health care NPs which is important within the Canadian context and elsewhere where NPs are a growing group providing primary care.

**Limitations**

Although specific limitations of each chapter were described in detail, several broad limitations of this research should be considered when interpreting study findings: (1) risk of sampling bias; (2) risk of response bias; and (3) risk of researcher bias.

Study findings may have been influenced by several risks of sampling bias including recruitment of expert panel members, survey participants and interview participants from a
limited geographical area of southeastern Ontario. Thus findings may not be easily generalized to other geographical areas across the province, or beyond. Research findings could also be strongly influenced by the types of primary care providers and breast cancer survivors who agreed to participate as expert panel members. Similarly, the low response rates for the primary care provider survey may limit generalizability of results and increase the potential for bias as findings could be influenced by the types of primary care providers who self-selected to participate; however, this might actually mean that knowledge and practice gaps are even greater than reported. The sample was also overrepresented by primary care NPs; however, comparative analyses revealed few differences between NP and MD survey responses. As well, our sample of MDs was not significantly different from the population of eligible MDs in terms of demographic characteristics. Potential for bias also exists due to the fact that 60% of survey participants practiced in team-based models; however, secondary analysis of data revealed no significant differences in reported knowledge and practice between those PCPs who worked in IP teams and those who did not (see Appendix J). Similarly, the majority of interview participants (68%) practiced in team-based practices such as FHTs, thus the challenges and strengths described by the interview participants may be less generalizable to solo PCPs than those practicing in teams.

The use of self-report data for both the quantitative surveys and the qualitative interviews introduces a risk for response bias in which participants may be reluctant to reveal deficiencies in their own knowledge or practices. Thus, as previously mentioned, knowledge and practice gaps may be even greater than reported. Similarly, participants with strong feelings may have exaggerated positive or negative aspects of the research questions which may skew results of the qualitative interviews; however, for the most part, our study participants provided balanced
perspectives of their challenges and strengths, data saturation was perceived to occur following about 15 interviews, and we included the perspectives of both MDs and NPs, males and females, and experienced and novice practitioners, practicing in a variety of rural and urban primary care practice types.

Although measures were taken to increase credibility, qualitative research involves data gathering and analysis performed and interpreted by the researcher; thus, there is a risk of researcher bias informing the analysis of our qualitative interviews. Strategies employed to establish confirmability included a detailed audit trail, peer debriefing, triangulation, and member checking. Additionally, the use of an a priori framework to guide qualitative analysis could have biased the researcher to force data into the framework and new themes may have been missed; however, we were careful to ensure findings emerged directly from the data, and as the three categories of the framework were interpreted very broadly subsequently found no data that fell outside the framework.

Implications for Practice and Research

While specific implications have been outlined within each chapter, the collective work of this thesis informs recommendations for clinical practice and health policy, as well as directions for future research. Overall the findings underscore the need for KT interventions for primary care and future research that evaluates promising interventions and models of care.

Recommendations for Clinical Practice and Health Policy

The numerous challenges experienced by primary care providers as described by our study participants have implications for practice, health policy and for cancer survivors. As cancer centres move forward with early discharge of stable, early-stage breast cancer survivors to primary care follow-up, it is essential that primary care providers are prepared and supported to
provide comprehensive, evidence-based breast cancer survivorship care. This thesis has identified specific knowledge and practice gaps within our region that have been deemed to be important and relevant by an expert panel of oncology specialists, primary care providers and breast cancer survivors. Thus it will be important to focus KT efforts to address these gaps. Our published *Comprehensive Framework for Evidence-based Breast Cancer Survivorship Care* provides a first step by providing tools that are easily accessible to primary care providers; however, primary care providers need to be aware of the existence of these guidelines and how to access them. This framework provides content that could be incorporated into survivorship care plans, continuing education sessions and/or any of the KT innovations described in the literature. As well, it is recommended that this survivorship content be included in undergraduate and postgraduate educational programs to better prepare future primary care providers to provide comprehensive survivorship care.

As many primary care providers in our study reported considerable anxiety and burden related to providing survivorship care, it is recommended that cancer centres and LHINs explore ways to provide support to primary care providers as they assume responsibility for survivorship care. This support could include survivorship care plans, protocols and processes, as well as tools such as electronic medical record (EMR) templates that embed guidelines into routine practices. Primary care providers should explore their own practice contexts and build on existing resources such as EMRs for tracking cancer survivors. Oncology specialists and primary care providers could empower breast cancer survivors to share responsibility for their survivorship care by providing and educating survivors about survivorship care guidelines and providing self-management support. The primary care burden could further be reduced by building on the strengths of team-based care models and optimizing nursing roles such as the regional nurse...
navigator role to include survivorship care, or to involve primary care Registered Nurses (RNs) and Registered Practical Nurses (RPNs) in providing comprehensive survivorship care using a chronic disease management model.

Directions for Future Research

Findings of this research suggest several directions for future research. Further testing of the *Comprehensive Framework for Evidence-based Breast Cancer Survivorship Care* through empirical research is recommended to establish its utility for primary care education, practice and research. Future research also needs to determine how to best provide support and education to improve PCP knowledge and practices related to providing breast cancer survivorship care, and translate into enhanced long-term health and quality of life outcomes for breast cancer survivors. Thus KT interventions that have been tested in primary care with other patient populations could be adapted and evaluated for implementation of breast cancer survivorship CPGs. Additionally, novel KT interventions that specifically target the challenges and strengths reported by our participants could be developed and tested. Our results suggest that in addition to primary care MDs and NPs, KT interventions need to target primary care nurses (RNs and RPNs), and other primary care health professionals (e.g. PTs, OTs, social workers) as well as breast cancer survivors. As well, the diversity of learning needs and preferences reported by our participants suggests that KT interventions involving multiple strategies will need to be designed and evaluated to enhance knowledge use in primary care. Future KT intervention studies for breast cancer survivorship care should be also be designed to evaluate effects on patient outcomes such as symptom burden and quality of life, and the early discharge transition to primary care follow-up will need to be evaluated from the perspectives of primary care providers and breast cancer survivors to identify ongoing gaps in care.
Knowledge translation activities

This thesis was prepared in a manuscript format to facilitate submission of findings to peer-reviewed clinical journals. Chapters three and four have been published in the peer-reviewed journals *Family Practice* and *Canadian Family Physician* respectively, and chapter five will be submitted to the *Journal of Cancer Survivorship*. Findings have been presented at both regional and national/international scientific conferences. Internal funding has been obtained to evaluate the transition to primary care provider from the perspective of breast cancer survivors in our region, and a research collaboration with members from Breast Cancer Action Kingston (BCAK) is in the planning stages, to determine KT strategies for dissemination of breast cancer survivorship care guidelines to breast cancer survivors. Study results will also be used to inform future research related to the development of knowledge translation interventions for primary care providers. Linkages with the Office of Continuing Professional Development at Queen’s University, the Primary Care Lead of the Southeast Regional Cancer Program, and the Primary Care Lead SE LHIN will provide the opportunity to share results locally and provide a potential vehicle for knowledge translation activities within the SE LHIN and with other LHINs.

Conclusions

This thesis accomplished three objectives. First we described comprehensive evidence-based breast cancer survivorship care for primary care practice and produced a framework to guide this care. Second, we determined self-reported knowledge and practice gaps related to provision of evidence-based breast cancer survivorship care by primary care MDs and NPs within the SE LHIN that could provide a focus for future KT interventions. And third, we identified several important challenges to implementation of comprehensive evidence-based survivorship care for breast cancer survivors, as well as several strengths and opportunities that
could be built upon to address these barriers. Findings reveal primary care providers are striving to provide comprehensive care to breast cancer survivors but are doing so with limited educational preparation, few survivorship protocols or tools, and strained practice resources. Primary care providers are prepared to assume responsibility for follow-up surveillance but may lack knowledge and resources to provide comprehensive survivorship care including prevention and intervention strategies for ongoing and late effects of treatment. Addressing barriers to implementation with concrete interventions at the levels at which they occur, and building on the identified strengths and opportunities, informed by the KTA framework, could ultimately improve quality of breast cancer survivorship care. Additionally, this thesis informs recommendations for clinical practice and health policy, as well as directions for future research. Overall the findings underscore the need for KT interventions for primary care and future research that evaluates promising interventions and models of care.

In the short term, results of this research will contribute to a better understanding of the experiences of primary care MDs and NPs, and the factors that affect their ability to provide high quality, comprehensive evidence-based care to women following primary treatment for breast cancer. In the long term, a better understanding of these challenges, strengths and opportunities will contribute to the development of targeted knowledge translation interventions to provide support and education that can improve primary care provider knowledge, attitudes and practices related to providing breast cancer survivorship care, within the context of resources available at the practice and systems level. This thesis will contribute to a developing program of research with the overall goal to improve health and quality of life outcomes in the growing population of breast cancer survivors.
References


Appendix A

QUEEN'S UNIVERSITY HEALTH SCIENCES & AFFILIATED TEACHING HOSPITALS RESEARCH ETHICS BOARD-DELEGATED REVIEW
June 21, 2013

Ms. Marian Luctkar-Flude
School of Nursing
Queen's University

Dear Ms. Luctkar-Flude

Study Title: NURS-305-13 Challenges and opportunities related to implementing evidence-based guidelines on breast cancer survivorship care by primary care physicians and nurse practitioners in southeastern Ontario
File # 6009937
Co-Investigators: Dr. M.A. McColl, Dr. A. Aiken, Dr. J. Tranmer

I am writing to acknowledge receipt of your recent ethics submission. We have examined the protocol (June 10, 2013), primary care provider demographics and practice data survey, interview guide/questions, research timeline, participant interview information sheet, participant consent form, information sheet – Primary Care Physician and Nurse Practitioner 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 listing 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. Please use event form: HSREB Multi-Use Amendment/Full Board Renewal Form associated with your post review file # 6009937 in your Researcher Portal (https://eservices.queensu.ca/romeo_researcher/)

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. Serious Adverse Event forms are located with your post-review file 6009937 in your Researcher Portal (https://eservices.queensu.ca/romeo_researcher/)

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
June 21, 2013
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.

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

The membership of this Research Ethics Board complies with the membership requirements for Research Ethics Boards and operates in compliance with the Tri-Council Policy Statement; Part C Division 5 of the Food and Drug Regulations, OHRP, and U.S DHHS Code of Federal Regulations Title 45, Part 46 and carries out its functions in a manner consistent with Good Clinical Practices.

Federalwide Assurance Number: #FWA00004184, #IRB00001173

Current 2013 membership of the Queen's University Health Sciences & Affiliated Teaching Hospitals Research Ethics Board:

Dr. A.F. Clark, Emeritus Professor, Department of Biomedical and Molecular Sciences, Queen's University (Chair)

Dr. H. Abdollah, Professor, Department of Medicine, Queen's University

Dr. R. Brison, Professor, Department of Emergency Medicine, Queen's University

Dr. C. Cline, Assistant Professor, Department of Medicine, Director, Office of Bioethics, Queen's University, Clinical Ethicist, Kingston General Hospital

Dr. M. Evans, Community Member

Dr. C. Godfrey, Assistant Professor, School of Nursing, Queen's University

Ms. J. Hudacin, Community Member

Dr. J. MacKenzie, Pediatric Geneticist, Department of Paediatrics, Queen's University

Mr. D. McNaughton, Community Member

Ms. P. Newman, Pharmacist, Clinical Care Specialist and Clinical Lead, Quality and Safety, Pharmacy Services, Kingston General Hospital

Ms. S. Rohland, Privacy Officer, ICES-Queen's Health Services Research Facility, Research Associate, Division of Cancer Care and Epidemiology, Queen's Cancer Research Institute

Dr. B. Simchison, Assistant Professor, Department of Anesthesiology and Perioperative Medicine, Queen's University

Dr. A. Singh, Professor, Department of Psychiatry, Queen's University

Ms. K. Weisbaum, LL.B. and Adjunct Instructor, Department of Family Medicine (Bioethics)
QUEEN'S UNIVERSITY HEALTH SCIENCES AND AFFILIATED TEACHING HOSPITALS RESEARCH ETHICS BOARD ANNUAL RENEWAL

Queen's University, in accordance with the "Tri-Council Policy Statement 2, 2010" prepared by the Interagency Advisory Panel on Research Ethics for the Canadian Institutes of Health Research, Natural Sciences and Engineering Research Council of Canada and Social Sciences and Humanities Research Council of Canada requires that research projects involving human participants be reviewed annually to determine their acceptability on ethical grounds.

A Research Ethics Board composed of:

Dr. A.F. Clark, Emeritus Professor, Department of Biomedical and Molecular Sciences, Queen's University (Chair)
Dr. H. Abdullah, Professor, Department of Medicine, Queen's University
Dr. C. Cline, Assistant Professor, Department of Medicine, Director, Office of Bioethics, Queen's University, Clinical Ethicist, Kingston General Hospital
Dr. R. Brison, Professor, Department of Emergency Medicine, Queen's University
Dr. M. Evans, Community Member
Ms. J. Hudacin, Community Member
Mr. D. McNaughton, Community Member
Ms. S. Rohland, Privacy Officer, ICES-Queen's Health Services Research Facility, Research Associate, Division of Cancer Care and Epidemiology, Queen's Cancer Research Institute
Dr. M. Sawhney, Assistant Professor, School of Nursing, Queen's University
Dr. A. Singh, Professor, Department of Psychiatry, Queen's University
Dr. J. Walia, Assistant Professor and Clinical Geneticist, Department of Paedics, Queen's University and Kingston General Hospital
Ms. K. Weisbaum, LL.B. and Adjunct Instructor, Department of Family Medicine (Bioethics)

has reviewed the request for renewal of Research Ethics Board approval for the project “Challenges and opportunities related to implementing evidence-based guidelines on breast cancer survivorship care by primary care physicians and nurse practitioners in southeastern Ontario” as proposed by Ms. M. Lustkar-Flude of the School of Nursing, at Queen's University. The approval is renewed for one year, effective June 21, 2014. If there are any further amendments or changes to the protocol affecting the participants in this study, it is the responsibility of the principal investigator to notify the Research Ethics Board. Any unexpected serious adverse event occurring locally must be reported within 2 working days or earlier if required by the study sponsor. All other adverse events must be reported within 15 days after becoming aware of the information.

\[\text{Al \textbf{bert} J. \textbf{C}lark.}\]
\[\text{Date: June 19, 2014}\]

Chair, Health Sciences Research Ethics Board

Renewal [x] Renewal 2 [ ] Extension [ ] Code# NURS-305-13 Romeo file# 6009937
Appendix C

Survey Participant Information and Consent Form

Challenges and Opportunities Related to Implementing Evidence-Based Guidelines On Breast Cancer Survivorship Care by Primary Care Physicians and Nurse Practitioners in Southeastern Ontario

You are invited to participate in a research study being conducted by Marian Luctkar-Flude, RN, MScN, PhD (student) under the supervision of Dr. Alice Aiken, in the School of Rehabilitation Therapy at Queen’s University in Kingston, Ontario.

Background: The South East Regional Cancer Program is moving forward with earlier discharge of stable early-stage breast cancer survivors from oncology follow-up to primary care follow-up in the community. A panel of experts has synthesized the key clinical practice guideline recommendations for breast cancer survivorship care that are relevant to the primary care setting.

What is this study about? The purpose of this research is to explore primary care physician and nurse practitioner experiences providing evidence-based care to breast cancer survivors. The purpose of this survey is to determine to what extent the key best practice guideline recommendations for post-treatment breast cancer survivorship care are being implemented by primary care MDs and NPs within the SE LHIN. This information will contribute to the development of targeted knowledge translation interventions to provide support and education that may enhance breast cancer survivorship care within the primary care setting.

What is the extent of my participation? You are being invited to complete a brief survey that should take about 5 minutes to complete.

Is my participation voluntary? Yes. Although it be would be greatly appreciated if you would answer all material as frankly as possible, you should not feel obliged to answer any material that you find objectionable or that makes you feel uncomfortable. You may also withdraw at any time.

What will happen to my responses? We will keep your responses confidential. Only researchers will have access to this information. The data may be published in professional journals or presented at scientific conferences, but any such presentations will be of general findings and will never breach individual confidentiality. Should you be interested, you are entitled to a copy of the findings.

Will I be compensated for my participation? Study participants who complete a survey will be entered into a draw to receive a $100 gift card from Chapters/Indigo.

What should I do if I have any questions, concerns, or complaints? You may contact: the graduate student, Marian Luctkar-Flude at mfl1@queensu.ca or 613-533-6000, Ext. 77383; the thesis supervisor, Dr. Alice Aiken at aa5@queensu.ca or 613-533-6710; or the Director of the School of Rehabilitation Therapy, Dr. Marcia Finlayson at marcia.finlayson@queensu.ca or 613-533-2576. If you have concerns about your rights as a research participant 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.

Please keep this page for your information
SUBJECT STATEMENT AND SIGNATURE SECTION

Challenges and Opportunities Related to Implementing Evidence-Based Guidelines on Breast Cancer Survivorship Care by Primary Care Physicians and Nurse Practitioners in Southeastern Ontario

I have read and understand the consent form for this study. I have had the purposes, procedures and technical language of this study explained to me. I have been given sufficient time to consider the above information and to seek advice if I chose to do so. I have had the opportunity to ask questions which have been answered to my satisfaction. I am voluntarily signing this form. I will receive a copy of this consent form for my information. If at any time I have further questions or problems, I can contact:

Dr. Alice Aiken, the principal investigator, at aa5@queensu.ca or 613-533-6710;
Marian Luctkar-Flude, the project coordinator, at mfl1@queensu.ca or 613-533-6000, Ext. 77383;
Or Dr. Marcia Finlayson, the Director of the School of Rehabilitation Therapy, at marcia.finlayson@queensu.ca or 613-533-2576.

If I have concerns about my rights as a research participant 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.

By signing this consent form, I am indicating that I agree to participate in this study.

_______________________________________________
Name of participant (please print)

_______________________ ___________________
Signature of participant Date

_______________________ ___________________
Signature of witness Date

Name of witness (please print)

STATEMENT OF INVESTIGATOR:
I, or my delegate, have carefully explained to the subject the nature of the above research study. I certify that, to the best of my knowledge, the participant understands clearly the nature of the study and demands, benefits, and risks involved to participants in this study.

_______________________________________________
Signature of Investigator Date

This study has been granted approval by the Queen’s University Health Sciences and Affiliated Teaching Hospitals Research Ethics Board according to the recommended principles of Canadian ethics guidelines, and Queen's policies.
Appendix D

Interview Participant Information Notice

Challenges and Opportunities Related to Implementing Evidence-Based Guidelines on Breast Cancer Survivorship Care by Primary Care Physicians and Nurse Practitioners in Southeastern Ontario

You are invited to participate in a research study being conducted by Marian Lucutkar-Flude, RN, MScN, PhD (student) under the supervision of Dr. Alice Aiken, in the School of Rehabilitation Therapy at Queen’s University in Kingston, Ontario.

What is this study about? The purpose of this research is to explore primary care physician and nurse practitioner experiences providing evidence-based care to breast cancer survivors. The study will require participation in individual face-to-face or telephone interviews. There are no known physical, psychological, economic, or social risks associated with this study.

Is my participation voluntary? Yes. Although it be would be greatly appreciated if you would answer all material as frankly as possible, you should not feel obliged to answer any material that you find objectionable or that makes you feel uncomfortable. You may also withdraw at any time.

What will happen to my responses? We will keep your responses confidential. Only researchers will have access to this information. The data may be published in professional journals or presented at scientific conferences, but any such presentations will be of general findings and will never breach individual confidentiality. Should you be interested, you are entitled to a copy of the findings.

Will I be compensated for my participation? Study participants who complete a 15 minute interview will receive a $10.00 Starbucks gift card. Study participants who complete a 30 minute interview will receive a $20.00 Starbucks gift card. Additionally, study participants who successfully recruit a colleague working in primary care to participate in the study will receive an additional $10.00 gift card in appreciation.

What if I have concerns? Any questions about study participation may be directed to: the graduate student, Marian Lucutkar-Flude at mfl1@queensu.ca or 613-533-6000, Ext. 77383; the thesis supervisor, Dr. Alice Aiken at aa5@queensu.ca or 613-533-6710; or the Director of the School of Rehabilitation Therapy, Dr. Marcia Finlayson at marcia.finlayson@queensu.ca or 613-533-2576. If you have any concerns about your rights as a research participant please contact Dr. Albert Clark, Chair of the Queen’s University Health Sciences and Affiliated Teaching Hospitals Research Ethics Board at 613-533-6081.

Again, thank you. Your interest in participating in this research study is greatly appreciated.

This study has been granted approval by the Queen's University Health Sciences and Affiliated Teaching Hospitals Research Ethics Board according to the recommended principles of Canadian ethics guidelines, and Queen's policies.
Appendix E

Interview Participant Consent Form

Challenges and Opportunities Related to Implementing Evidence-Based Guidelines on Breast Cancer Survivorship Care by Primary Care Physicians and Nurse Practitioners in Southeastern Ontario

Name (please print clearly): ________________________________________

1. I have read the Information Notice and have had any questions answered to my satisfaction.

2. I understand that I will be participating in the study called Challenges and Opportunities Related to Implementing Evidence-Based Guidelines on Breast Cancer Survivorship Care by Primary Care Physicians and Nurse Practitioners in Southeastern Ontario. I understand that this means that I will be asked to participate in one or two individual interviews conducted face-to-face or by telephone.

3. I understand that my participation in this study is voluntary and I may withdraw at any time. I understand that every effort will be made to maintain the confidentiality of the data now and in the future. Only researchers in the School of Rehabilitation Therapy at Queen’s University will have access to this data. The data may also be published in professional journals or presented at scientific conferences, but any such presentations will be of general findings and will never breach individual confidentiality. Should you be interested, you are entitled to a copy of the findings.

4. I am aware that if I have any questions, concerns, or complaints, I may contact: the graduate student, Marian Luutkar-Flude at mfl1@queensu.ca or 613-533-6000, Ext. 77383; the thesis supervisor, Dr. Alice Aiken at aa5@queensu.ca or 613-533-6710; or the Director of the School of Rehabilitation Therapy, Dr. Marcia Finlayson at marcia.finlayson@queensu.ca or 613-533-2576. If I have concerns about my rights as a research participant 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.

I have read the above statements and freely consent to participate in this research:

Signature: ____________________________

Date: ____________________________
Appendix F

Interview Participant Recruitment Notice

Challenges and Opportunities Related to Implementing Evidence-Based Guidelines on Breast Cancer Survivorship Care by Primary Care Physicians and Nurse Practitioners in Southeastern Ontario

Researchers at Queen’s University are interested in speaking with you about your experiences providing care to breast cancer survivors in primary care.

You are invited to participate in a research study exploring primary care provider:
(1) knowledge and use of key evidence-based guideline recommendations for post-treatment breast cancer survivorship care;
(2) perceptions of facilitators and barriers to implementing these guidelines; and
(3) perceptions of educational needs to support provision of post-treatment breast cancer survivorship care

This study involves participating in your choice of one or two 15 or 30 minute interviews via telephone or face-to-face. Participants will receive a $10.00 Starbucks gift card for a 15 minute interview and a $20.00 gift card for a 30 minute interview.

If you are a primary care physician or nurse practitioner working in a private practice, family health team, community clinic or nurse-led clinic you are eligible to participate.

To learn more about this research project please contact:

Marian Luctkar-Flude, RN, MScN, PhD (student in Rehabilitation Sciences)
mfl1@queensu.ca
(613) 533-6000 Ext. 77383

This research study has received ethics approval from the Queen’s University and Affiliated Teaching Hospitals Health Sciences Human Research Ethics Board (REB).
Appendix G

Interview Guide

INTRODUCTION

What you share in this interview will be kept confidential. You may be identified in the study report in a way that will not reveal your individual identity such as, “MD1 said,” so please tell me what you really think and feel; this will be the most helpful in trying to find out how to improve health care delivery for breast cancer survivors. I will be tape recording the interview to try to make sure that we have an accurate record of your views and I also will be taking a few notes for the same purpose.

Do you agree to allow me to tape-record this interview?

If NO: I will be available to meet with you for an individual interview where the audio recorder will be turned off.

If YES: Thank you, I will proceed with the interview.

INTERVIEW INFORMATION

<table>
<thead>
<tr>
<th>Interview Date</th>
</tr>
</thead>
<tbody>
<tr>
<td>Interview Type</td>
</tr>
<tr>
<td>(Face-to-face vs. telephone)</td>
</tr>
<tr>
<td>Interview Start Time</td>
</tr>
<tr>
<td>Interview End Time</td>
</tr>
<tr>
<td>Interview Total Time</td>
</tr>
<tr>
<td>Participant Name</td>
</tr>
<tr>
<td>Participant ID #</td>
</tr>
<tr>
<td>Voice Recorder File #</td>
</tr>
</tbody>
</table>
INTERVIEW QUESTIONS

1. Tell me about your experience of providing care to women following primary treatment for breast cancer
2. What is your perception of the care breast cancer survivors receive in primary practice?

3. What are the challenges and barriers to providing effective care to breast cancer survivors? Related to practicing in a city/town/rural setting? Related to the NP role?
4. How has your experience of caring for breast cancer survivors impacted your confidence in caring for this patient population?
5. Tell me about the education you had to prepare you for working with breast cancer survivors.
6. Tell me about how you access research evidence related to breast cancer survivorship care. Are there any specific guideline sources that you access?
7. Are there any barriers or challenges related to implementing these guidelines? Related to the health care system? To the patients themselves?
8. What are the primary care provider’s educational needs related to caring for breast cancer survivors? How prepared do you feel to assume responsibility for survivorship care following early discharge from the cancer center?
9. What is your choice in educational delivery method that will enhance your ability to provide evidence-based survivorship care?
10. With respect to the four domains of survivorship care: prevention, surveillance, intervention and coordination…which domains do you feel comfortable/confident with? Any domains that you feel less comfortable/confident with?
11. Can you suggest anything else that would facilitate implementation of the key guideline recommendations?
### Appendix H: Qualitative Thematic Analysis Plan and Procedures: A Pragmatic Blended Approach

<table>
<thead>
<tr>
<th>Step</th>
<th>Description</th>
<th>Plan</th>
<th>Procedures</th>
</tr>
</thead>
<tbody>
<tr>
<td>1</td>
<td>Prepare data</td>
<td>- transcribe interviews &amp; arrange data by type/information source</td>
<td>- interviews transcribed &amp; verified</td>
</tr>
<tr>
<td></td>
<td></td>
<td>- briefly memo written after each interview</td>
<td></td>
</tr>
<tr>
<td>2</td>
<td>Read data</td>
<td>- read &amp; reread transcripts</td>
<td>- prolonged engagement with data, noting ideas, questions, major themes &amp; audit trail initiated by collecting all descriptive and analytic notes into a single electronic file</td>
</tr>
<tr>
<td></td>
<td></td>
<td>- obtain a general sense of the data</td>
<td></td>
</tr>
<tr>
<td></td>
<td></td>
<td>- record general thoughts about data</td>
<td></td>
</tr>
<tr>
<td>3</td>
<td>Organize data using a deductive approach</td>
<td>- themes/codes are generated from theory and/or prior research findings</td>
<td>- partitioned data into three main categories of factors identified in the literature: knowledge, attitudes &amp; resources</td>
</tr>
<tr>
<td></td>
<td></td>
<td>- develop a provisional list of codes from the conceptual framework</td>
<td>- identified theory-driven subcategories for each category</td>
</tr>
<tr>
<td></td>
<td></td>
<td>- recorded general thoughts about data</td>
<td>- further partitioned into “challenges” &amp; “strengths”</td>
</tr>
<tr>
<td>4</td>
<td>Conduct initial coding using an inductive approach</td>
<td>- code meaningful chunks of data with descriptive labels that emerge during data collection &amp; analysis</td>
<td>- coded chunks of data using primarily descriptive and in vivo coding to develop an initial list of data-driven codes</td>
</tr>
<tr>
<td></td>
<td></td>
<td>- generate notes/memos to capture analytic thoughts as they occur</td>
<td>- recoded subset of interviews several months apart to ensure consistency of coding by primary author</td>
</tr>
<tr>
<td></td>
<td></td>
<td>- after reviewing several interviews list all topic codes &amp; combine similar codes to eliminate repetition</td>
<td>- analytic memos recorded in the audit trail</td>
</tr>
<tr>
<td></td>
<td></td>
<td>- define elements/parameters of each code as needed</td>
<td></td>
</tr>
<tr>
<td>5</td>
<td>Generate a code list</td>
<td>- after reviewing several interviews list all topic codes &amp; combine similar codes to eliminate repetition</td>
<td>- mapped preliminary codes to a priori categories/subcategories</td>
</tr>
<tr>
<td></td>
<td></td>
<td>- define elements/parameters of each code as needed</td>
<td>- displayed codes &amp; categories on a data display matrix</td>
</tr>
<tr>
<td></td>
<td></td>
<td>- after reviewing several interviews list all topic codes &amp; combine similar codes to eliminate repetition</td>
<td>- combined similar codes to create a code list (subthemes) using emerging, process and theoretical coding</td>
</tr>
<tr>
<td></td>
<td></td>
<td>- define elements/parameters of each code as needed</td>
<td>- grouped codes to suggest preliminary themes</td>
</tr>
<tr>
<td>6</td>
<td>Continue coding using a blended approach</td>
<td>- use combination of predetermined &amp; emerging codes &amp; see if new codes &amp; categories emerge</td>
<td>- coded and recoded transcripts using code list</td>
</tr>
<tr>
<td></td>
<td></td>
<td>- revise codes/recode data as needed</td>
<td>- some similar codes combined, some new codes emerged</td>
</tr>
<tr>
<td>7</td>
<td>Establish intercoder agreement</td>
<td>- compare codes independently derived or coded using code list by different researchers</td>
<td>- subset of transcripts coded by a group of NP colleagues, revealed very similar codes &amp; emerging themes</td>
</tr>
<tr>
<td></td>
<td></td>
<td>- discuss/come to a consensus</td>
<td>- subset of transcripts coded by a PhD nurse with qualitative research experience demonstrated high agreement/consistency</td>
</tr>
<tr>
<td>8</td>
<td>Generate themes</td>
<td>- reduce list of codes by grouping topics meaningfully related</td>
<td>- grouped analytic codes (subthemes) into more general, higher level themes &amp; relabelled themes with more descriptive labels emerging from data</td>
</tr>
<tr>
<td></td>
<td></td>
<td>- use most descriptive labels for themes</td>
<td></td>
</tr>
<tr>
<td>9</td>
<td>Collate data</td>
<td>- collate coded data relevant to each theme &amp; organize data including codes into a matrix or network display</td>
<td>- entered coded data into “collated data” table with the following headings: category, subcategory, themes, supporting data (challenges, strengths &amp; opportunities)</td>
</tr>
<tr>
<td>10</td>
<td>Interrelate themes</td>
<td>- review how themes work in relation to coded extracts &amp; full data-set</td>
<td>- examined relationship between themes in different categories and subcategories as there was some overlap across them</td>
</tr>
<tr>
<td></td>
<td></td>
<td>- examine relationship between themes &amp; collapse/expand as needed</td>
<td>- moved around and merged subcategories and themes to reduce their total number and reduce redundancy</td>
</tr>
<tr>
<td>11</td>
<td>Interpret meaning of themes</td>
<td>- write detailed analysis of each theme and how it relates to the research question</td>
<td>- interview data mapped to one or more themes in a table</td>
</tr>
<tr>
<td></td>
<td></td>
<td>- may use visuals, figures or tables as adjuncts to discussions</td>
<td>- themes described &amp; interpreted as challenges, strengths and/or opportunities related to implementing survivorship guidelines</td>
</tr>
<tr>
<td></td>
<td></td>
<td>- select data extracts that best exemplify each theme</td>
<td>- in keeping with pragmatic nature of inquiry, recommendations emerging from data were aligned with each theme</td>
</tr>
<tr>
<td></td>
<td></td>
<td>- key sample quotes selected and summarized in a table</td>
<td></td>
</tr>
<tr>
<td>12</td>
<td>Peer review or debriefing</td>
<td>- test and defend emergent hypotheses to peers to confirm plausibility</td>
<td>- data analysis, emerging themes &amp; analytic audit trail reviewed by an experienced qualitative researcher &amp; by thesis supervisor</td>
</tr>
<tr>
<td>13</td>
<td>Member checking</td>
<td>- have study participants review analysis &amp; resulting themes for accuracy/validity</td>
<td>- 6 of the 19 interview participants responded to request for feedback on the analysis and resulting themes (3 MDs &amp; 3 NPs)</td>
</tr>
<tr>
<td>14</td>
<td>Triangulation</td>
<td>- compare results to those obtained with other methods to produce comprehensive understanding</td>
<td>- emerging themes were compared to themes derived from qualitative survey results (data methods triangulation)</td>
</tr>
<tr>
<td></td>
<td></td>
<td>- results obtained from MDs and NPs were compared and contrasted (data sources triangulation)</td>
<td>- themes compared to the literature (theoretical triangulation)</td>
</tr>
<tr>
<td>15</td>
<td>Produce report</td>
<td>- write up final discussion/conclusions &amp; compare findings with literature, prior research findings or theories</td>
<td>- discussed resulting themes in relation to prior research findings</td>
</tr>
<tr>
<td></td>
<td></td>
<td></td>
<td>- discussed rigour &amp; limitations</td>
</tr>
<tr>
<td></td>
<td></td>
<td></td>
<td>- discussed implications for practice, education &amp; research</td>
</tr>
</tbody>
</table>

*Creswell, 2009; *Braun & Clarke, 2006; *Miles & Huberman, 1994; *Tesch, 1990; *Boyatzis, 1998; *Bryman, 2008; *Lincoln & Guba, 1985*
Appendix I
Supplemental Data File

A Framework for Comprehensive Breast Cancer Survivorship Care
In the Primary Care Setting

<table>
<thead>
<tr>
<th>PREVENTION</th>
<th>INTERVENTION</th>
</tr>
</thead>
<tbody>
<tr>
<td>of recurrent &amp; new cancers</td>
<td>for long-term effects of cancer &amp; its treatment</td>
</tr>
<tr>
<td>&amp; late effects</td>
<td></td>
</tr>
<tr>
<td>□ Exercise</td>
<td>Surgery</td>
</tr>
<tr>
<td>□ Nutrition</td>
<td>□ Pain</td>
</tr>
<tr>
<td>□ Weight management</td>
<td>□ Lymphedema</td>
</tr>
<tr>
<td>□ Alcohol consumption</td>
<td>□ Peripheral neuropathy</td>
</tr>
<tr>
<td>□ Immunizations</td>
<td>□ Cardiovascular complications</td>
</tr>
<tr>
<td>□ Smoking cessation</td>
<td>□ Cognitive dysfunction</td>
</tr>
<tr>
<td>□ Sun exposure</td>
<td>□ Fertility, pregnancy &amp; contraception</td>
</tr>
<tr>
<td></td>
<td>□ Fatigue</td>
</tr>
<tr>
<td></td>
<td>□ Menopausal symptoms</td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>SURVEILLANCE</th>
<th>Targeted Therapy</th>
</tr>
</thead>
<tbody>
<tr>
<td>for recurrent or new cancers</td>
<td>Cardiovascular complications</td>
</tr>
<tr>
<td>&amp; assessment of physical &amp;</td>
<td></td>
</tr>
<tr>
<td>psychosocial late effects</td>
<td></td>
</tr>
<tr>
<td>□ History and physical</td>
<td>□ Cardiovascular complications</td>
</tr>
<tr>
<td>□ Mammography</td>
<td>□ Lymphedema</td>
</tr>
<tr>
<td>□ Breast self-exam</td>
<td>□ Fatigue</td>
</tr>
<tr>
<td>□ Pelvic exam</td>
<td>□ Menopausal symptoms</td>
</tr>
<tr>
<td>□ Non-routine tests</td>
<td></td>
</tr>
<tr>
<td>□ Cholesterol and lipid</td>
<td></td>
</tr>
<tr>
<td>screening</td>
<td></td>
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</tbody>
</table>

<table>
<thead>
<tr>
<th>COORDINATION</th>
<th>Hormonal therapy</th>
</tr>
</thead>
<tbody>
<tr>
<td>between primary care</td>
<td>□ Menopausal symptoms</td>
</tr>
<tr>
<td>providers and specialists</td>
<td>□ Fertility, pregnancy &amp; contraception</td>
</tr>
<tr>
<td>to ensure all health care</td>
<td>□ Osteoporosis</td>
</tr>
<tr>
<td>needs are met</td>
<td>□ Arthralgias &amp; myalgias</td>
</tr>
<tr>
<td>□ Survivorship care plan</td>
<td>□ Distress, anxiety &amp; depression</td>
</tr>
<tr>
<td>□ Specialist referrals</td>
<td>□ Sexual dysfunction</td>
</tr>
<tr>
<td></td>
<td>□ Family &amp; work</td>
</tr>
</tbody>
</table>


Comprehensive Breast Cancer Survivorship Care: Key Guideline Recommendations for Primary Care Practice

### Survivorship Care Domain: Prevention

<table>
<thead>
<tr>
<th>Survivorship Care Issue</th>
<th>Guideline Sources</th>
<th>Key Guideline Recommendations</th>
</tr>
</thead>
<tbody>
<tr>
<td>Exercise</td>
<td>NCCN Survivorship 2013; ACS 2012</td>
<td>Encourage all survivors to avoid inactivity and return to daily activities as soon as possible; Exercise is considered safe for the majority of survivors. General exercise recommendations for cancer survivors: (1) at least 150 minutes of moderate-intensity activity or 75 minutes of vigorous-intensity activity or equivalent combination weekly; (2) two to three weekly sessions of strength training that include major muscle groups; and (3) stretch major muscle groups and tendons on days other exercises are performed.</td>
</tr>
<tr>
<td></td>
<td></td>
<td>High-risk survivors (with cardiopulmonary comorbidities or extreme fatigue) should receive medical clearance and referral to trained personnel for a supervised exercise program; start with light intensity/resistance and progress slowly as tolerated.</td>
</tr>
<tr>
<td></td>
<td></td>
<td>Survivors with severe anemia should delay exercise, other than activities of daily living, until the anemia is improved. Survivors with lymphedema may participate in resistance training under the supervision of a trained exercise therapist and using appropriate compression garments.</td>
</tr>
<tr>
<td>Nutrition</td>
<td>ACS, 2012</td>
<td>Encourage survivors to follow a diet high in vegetables, fruits, and whole grains, and limited in processed and red meats.</td>
</tr>
<tr>
<td></td>
<td></td>
<td>Encourage survivors to obtain needed nutrients through dietary sources; Consider supplements only if a nutrient deficiency is demonstrated (e.g., low plasma vitamin D or B12, low bone density).</td>
</tr>
<tr>
<td>Weight management</td>
<td>NCCN 2012; ACS 2012</td>
<td>Encourage survivors to achieve and maintain a healthy weight (20-25 BMI).</td>
</tr>
<tr>
<td>Alcohol consumption</td>
<td>ACS 2012</td>
<td>Encourage survivors to limit alcohol consumption to no more than 1 drink per day for women or 2 per day for men.</td>
</tr>
<tr>
<td>Immunizations</td>
<td>NCCN Survivorship 2013</td>
<td>Encourage the following vaccines for all survivors, following usual doses and schedules: trivalent inactivated influenza (TIV); pneumococcal (PPSV23/PCV13); tetanus, diphtheria, pertussis (Tdap); and human papillomavirus (HPV).</td>
</tr>
<tr>
<td></td>
<td></td>
<td>Vaccines containing live attenuated organisms (e.g. live attenuated influenza vaccine; measles, mumps, rubella [MMR]; oral polio vaccine) are contraindicated in survivors, with the exception of the zoster (shingles) vaccine.</td>
</tr>
<tr>
<td>Smoking cessation</td>
<td>NCI 2014; NCCN 2013</td>
<td>Assess tobacco use, encourage smoking cessation and offer advice/counselling and assistance including pharmacotherapy such as nicotine replacement therapies, antidepressant therapies (e.g. bupropion) and nicotine receptor agonist therapy (e.g. varenicline). Refer to the ASCO Tobacco Cessation and Control Resources, the Canadian Cancer Society Smoker’s Helpline Quit Connection, or the Ottawa Model for Smoking Cessation (Primary Care).</td>
</tr>
<tr>
<td>Sun exposure</td>
<td>Skin Cancer Foundation 2011</td>
<td>Women with breast cancer have an increased risk of developing melanoma; advise breast cancer survivors to follow the Skin Cancer Foundation Prevention Guidelines, to be aware of photosensitivity (due to certain treatments), be screened, perform self-exams and to know the warning signs.</td>
</tr>
</tbody>
</table>

### Survivorship Care Domain: Surveillance

<table>
<thead>
<tr>
<th>Survivorship Care Issue</th>
<th>Source</th>
<th>Key Guideline Recommendations</th>
</tr>
</thead>
<tbody>
<tr>
<td>History &amp; physical</td>
<td>NCCN 2013; ASCO 2013; Madamars et al, 2011; Grunfeld et al, 2005; SIGN, 2005</td>
<td>All breast cancer survivors should have a careful history and physical examination every 3-6 months for the first three years after primary treatment; every 6-12 months for years four and five, and then annually. Examination should include the affected breast or mastectomy site, chest wall, regional lymph node areas (axillary and supraclavicular), contralateral breast, chest auscultation, liver palpation, check for spinal tenderness, check for arm edema. Encourage survivors to report new, persistent symptoms promptly, without waiting for the next scheduled appointment including new lumps, bone pain, chest pain, dyspnea, abdominal pain, persistent headaches, persistent coughing, rash on breast, nipple discharge, abnormal vaginal bleeding, arm or leg swelling. Screen all survivors periodically to determine needs and necessary interventions related to possible symptoms experienced over the past 4 months: (1) anxiety and depression; (2) cognitive function; (3) exercise; (4) fatigue; (5) immunizations and infections; (6) pain; (7) sexual function; and (8) sleep disorder. Assess the following at regular intervals to determine whether reversible or contributing causes for symptoms exist: (1) current disease status; (2) functional/performance status; (3) medications; (4) comorbidities; and (5) prior cancer treatment history and modalities used.</td>
</tr>
<tr>
<td>Mammmogram</td>
<td>ASCO 2013; NCCN Breast 2012; ESMO 2011</td>
<td>Annual bilateral mammogram, or in the case of unilateral mastectomy, annual mammogram of the contralateral breast is recommended. The first post-treatment mammogram should be scheduled 1 year after the initial mammogram that led to diagnosis, but no earlier than six months after radiation therapy; subsequent mammograms should be scheduled every six to twelve months for surveillance of abnormalities.</td>
</tr>
<tr>
<td>Breast self-exam</td>
<td>ASCO, 2013</td>
<td>All breast cancer survivors should be counselled to perform monthly breast self-examination (BSE) and should be informed that BSE does not replace mammography as a breast cancer surveillance tool.</td>
</tr>
<tr>
<td>Pelvic exam</td>
<td>ASCO 2013; NCCN 2012</td>
<td>Women on tamoxifen should have a gynecologic assessment every 12 months if uterus present.</td>
</tr>
<tr>
<td>Non-routine tests</td>
<td>ASCO 2013; NCCN Breast 2012; AHS 2012; Madamars et al, 2011 Mackey et al, 2008</td>
<td>In the absence of clinical findings, the following tests are not recommended for routine follow-up as they have not been shown to lengthen survival: complete blood count (CBC); liver/kidney function tests; chest x-ray; bone scan; liver/abdominal ultrasound; computed tomography (CT or CAT) scan; fluorodeoxyglucose-positron-emission tomography (FDG-PET) scan; breast magnetic resonance imaging (MRI); breast cancer tumor markers, such as CA 15-3, CA 27.29, and CEA. MRT in follow-up screening should generally be considered only in those in a high-risk category (lifetime risk of a second primary cancer greater than 20%). In the absence of cardiac symptoms and no signs of substantial LVEF decline (greater than 10% absolute decrease) further cardiac monitoring is not recommended following completion of chemotherapy and trastuzumab (Herceptin) therapy.</td>
</tr>
</tbody>
</table>
### Survivorship Care Domain: Surveillance

<table>
<thead>
<tr>
<th>Survivorship Care Issue</th>
<th>Source</th>
<th>Key Guideline Recommendations</th>
</tr>
</thead>
<tbody>
<tr>
<td>Cholesterol and lipid screening</td>
<td>Chalasani et al 2010</td>
<td>Monitor lipid profiles and screen for cardiac disease in all breast cancer survivors</td>
</tr>
</tbody>
</table>

### Survivorship Care Domain: Intervention

<table>
<thead>
<tr>
<th>Survivorship Care Issue</th>
<th>Source</th>
<th>Key Guideline Recommendations</th>
</tr>
</thead>
<tbody>
<tr>
<td>Pain</td>
<td>NCCN Survivorship, 2013; Harris et al, 2012</td>
<td>Consult NCCN Guidelines for Adult Cancer Pain for treatment recommendations specific to six categories of cancer pain syndromes; guidelines include information on opioid use and pain treatment agreements, adjuvant analgesics, psychosocial support and behavioural interventions that may be modified to fit the individual circumstances</td>
</tr>
<tr>
<td>Peripheral neuropathy</td>
<td>Harris et al, 2012</td>
<td>Consider nonpharmacologic interventions in conjunction with pharmacologic ones: bed, bath, and walking supports; positioning instruction; energy conservation; pacing of activities; transcutaneous electrical nerve stimulation, acupuncture or acupressure; psychosocial/behavioural interventions; physical therapy/exercise; and interventional procedures</td>
</tr>
<tr>
<td>Cardiovascular complications</td>
<td>Harris et al, 2012; ESMO, 2010</td>
<td>Encourage all survivors to adopt a healthy lifestyle in order to reduce cardiovascular risk including a balanced diet, moderate exercise and smoking cessation</td>
</tr>
<tr>
<td>Lymphedema</td>
<td>NCCN Survivorship 2013; Harris et al, 2012; Pouge et al, 2008</td>
<td>Strength training has been shown to be safe for survivors with lymphedema and may improve lymphedema symptoms</td>
</tr>
<tr>
<td>Fatigue</td>
<td>NCCN Survivorship 2013; NCCN Fatigue 2012; Harris et al, 2012; CAPO/CPAC 2011</td>
<td>Screen all survivors for fatigue at regular intervals using a 0-10 severity rating scale such as ESAS (0=no fatigue; 10=worst fatigue you can imagine) or have survivors rate their fatigue as none, mild, moderate or severe</td>
</tr>
<tr>
<td>Cognitive dysfunction</td>
<td>NCCN Survivorship, 2013</td>
<td>Treatment recommendations for managing cognitive dysfunction include instruction in self-management and coping strategies, relaxation, stress management and routine exercise</td>
</tr>
<tr>
<td>Distress</td>
<td>NCCN Survivorship 2013; NCCN Distress 2012; CAJAC/CPAC, 2009</td>
<td>Screen all survivors for distress at transition to survivorship and regular intervals using a 0-10 severity rating scale such as ESAS anxiety &amp; depression scales (0=no anxiety/depression; 10=worst anxiety/depression you can imagine)</td>
</tr>
<tr>
<td>Sexual dysfunction</td>
<td>NCCN Survivorship, 2013; Grunfeld et al, 2005</td>
<td>Cancer survivors should be asked about how cancer treatment has impacted their sexual functioning &amp; intimacy</td>
</tr>
</tbody>
</table>

The Brief Sexual Symptom Checklist for Women can be used as a primary screening tool; for a more in depth evaluation of sexual dysfunction, the Female Sexual Function Index can be considered. Water, oil or silicone-based lubricants and moisturizers can help alleviate symptoms such as vaginal dryness and sexual pain. Pelvic floor training may improve sexual pain, arousal, lubrication, orgasm, & satisfaction. Vaginal estrogen (pills, rings, or creams) can be effective in treating vaginal dryness, itching, discomfort, and painful intercourse.
### Survivorship Care Domain: Intervention

<table>
<thead>
<tr>
<th>Survivorship Care Issue</th>
<th>Source</th>
<th>Key Guideline Recommendations</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Family &amp; work</strong></td>
<td>NCCN Distress 2013</td>
<td>Social work and counseling services are recommended for psychosocial (e.g. family &amp; social conflict/isolation) and practical problems (e.g. financial and employment concerns)</td>
</tr>
<tr>
<td><strong>Menopausal symptoms</strong></td>
<td>ACOG, 2012; SCA, 2012; NCCN Breast Cancer 2012; Madarnas et al, 2011; SOGC, 2009</td>
<td>Address and encourage adherence to adjuvant endocrine therapy</td>
</tr>
<tr>
<td><strong>Fertility, pregnancy &amp; contraception</strong></td>
<td>ACOG, 2012; NCCN Breast Cancer, 2012</td>
<td>Hormonal contraceptive is not recommended for women with breast cancer; Preferred options include barrier methods, such as condoms and diaphragms, intrauterine devices, tubal ligation, or vasectomy for the partner</td>
</tr>
<tr>
<td><strong>Osteoporosis</strong></td>
<td>SCA, 2012; NCCN Breast Cancer, 2012; NCCN Survivorship, 2013; Harris et al., 2012; Madarnas et al, 2011</td>
<td>Survivors who are postmenopausal, or are premenopausal with risk factors for osteoporosis, or are taking aromatase inhibitors should undergo a screening bone mineral density test (by DEXA scan) at baseline and every 1-2 years thereafter</td>
</tr>
<tr>
<td><strong>Arthralgias &amp; myalgias</strong></td>
<td>NCCN Survivorship 2013</td>
<td>Consider nonpharmacologic interventions (e.g. exercise, heat, cold) and pharmacologic interventions (e.g. NSAIDS, muscle relaxants, anti-epileptic drugs, SSRIs, TCAs) to manage arthralgias and myalgias related to aromatase inhibitors</td>
</tr>
</tbody>
</table>

### Survivorship Care Domain: Coordination

<table>
<thead>
<tr>
<th>Survivorship Care Issue</th>
<th>Source</th>
<th>Key Guideline Recommendations</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Survivorship care plan</strong></td>
<td>NCCN Survivorship, 2013; Madarnas et al, 2011</td>
<td>The oncologist should provide evidence-based recommendations to the primary care provider for surveillance for cancer recurrence, and guidance on appropriate management and referral back to secondary care</td>
</tr>
<tr>
<td><strong>Specialist referrals</strong></td>
<td>NCCN Survivorship, 2013; ASCO, 2013; Harris et al, 2012; Madarnas et al, 2011</td>
<td>Primary care providers need to have easy access to specialists to discuss areas of concern and for referrals as appropriate</td>
</tr>
</tbody>
</table>

- Survivors with focal neurologic deficits should be sent for imaging and neuropsychological evaluation
- Survivors with cognitive dysfunction may be sent for neuropsychological and/or occupational therapy evaluation to clarify nature of impairments to guide rehabilitative efforts
- Survivors experiencing sexual dysfunction may be referred for psychotherapy, sexual/couples counseling, or gynecologic care as appropriate and ongoing partner communication should be encouraged
- Survivors with problems in the breast, a new mass in the breast, rash or nodule on the chest wall, or palpable lymphadenopathy should be referred to the surgeon and not to the oncologist
- Survivors reporting abnormal vaginal bleeding should be referred to a gynecologist
- Survivors with back pain with limb weakness, change in sensation, change in reflexes, or loss of bowel or bladder control should be referred urgently to the radiation oncologist for possible spinal cord compression
- Survivors with new persistent headache (especially with visual changes, nausea, or seizures) should be referred urgently to the radiation oncologist for possible brain metastases
<table>
<thead>
<tr>
<th>Survivorship Care Issue</th>
<th>Source</th>
<th>Key Guideline Recommendations</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td></td>
<td>Survivors with altered level of consciousness, nausea, vomiting or pain associated with hypercalcemia should be referred to the medical oncologist for management of hypercalcemia.</td>
</tr>
<tr>
<td></td>
<td></td>
<td>Survivors at high risk for familial breast cancer syndromes should be referred for familial oncology/genetic counselling.</td>
</tr>
</tbody>
</table>
Appendix J

Correlations between **Primary Care Provider Characteristics and Guideline Implementation Practices and Knowledge Gaps**

<table>
<thead>
<tr>
<th>Practices: Number of guidelines implemented with 50% or more of breast cancer survivors</th>
<th>Age</th>
<th>Sex (Female)</th>
<th>Profession (NP)</th>
<th>Years as PCP</th>
<th>Practice Setting (Urban)</th>
<th>Practice Type (IP)</th>
</tr>
</thead>
<tbody>
<tr>
<td>Correlation coefficient*</td>
<td>.002</td>
<td>.125</td>
<td>-.144</td>
<td>-.007</td>
<td>.072</td>
<td>.019</td>
</tr>
<tr>
<td>Sig (2-tailed)</td>
<td>.984</td>
<td>.264</td>
<td>.195</td>
<td>.949</td>
<td>.521</td>
<td>.864</td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>Knowledge Gaps: Number of guidelines that primary care providers were “not aware of”</th>
<th>Correlation coefficient*</th>
<th>Sig (2-tailed)</th>
</tr>
</thead>
<tbody>
<tr>
<td>-.107</td>
<td>.098</td>
<td>.262</td>
</tr>
<tr>
<td>.342</td>
<td>.383</td>
<td>.018</td>
</tr>
</tbody>
</table>

Note: NP=nurse practitioner; PCP=primary care provider; *Spearman’s rho

Correlations between **Physician Characteristics and Guideline Implementation Practices and Knowledge Gaps**

<table>
<thead>
<tr>
<th>Practices: Number of guidelines implemented with 50% or more of breast cancer survivors</th>
<th>Age</th>
<th>Sex (Female)</th>
<th>Years as PCP</th>
<th>Practice Setting (Urban)</th>
<th>Practice Type (IP)</th>
</tr>
</thead>
<tbody>
<tr>
<td>Correlation coefficient*</td>
<td>-.126</td>
<td>.214</td>
<td>-.144</td>
<td>.177</td>
<td>.062</td>
</tr>
<tr>
<td>Sig (2-tailed)</td>
<td>.339</td>
<td>.098</td>
<td>.272</td>
<td>.172</td>
<td>.634</td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>Knowledge Gaps: Number of guidelines that primary care providers were “not aware of”</th>
<th>Correlation coefficient*</th>
<th>Sig (2-tailed)</th>
</tr>
</thead>
<tbody>
<tr>
<td>-.032</td>
<td>-.058</td>
<td>.042</td>
</tr>
<tr>
<td>.810</td>
<td>.656</td>
<td>.749</td>
</tr>
</tbody>
</table>

Note: PCP=primary care provider; *Spearman’s rho
Appendix K

Reflexivity Statement

My interest in cancer survivorship care arose from my experiences working at the Nursing Research Unit at Kingston General Hospital while I was completing my Master’s Degree. As the RA, I was responsible for recruiting over 400 cancer survivors and 100 breast cancer survivors in two survey studies between 2003 and 2007 examining health and well-being in older persons with cancer. As my name and contact information was on the surveys, I was surprised when I began to be contacted by many elderly cancer survivors who were asking me for healthcare advice related to ongoing effects of their cancer treatment. Many relayed that their healthcare providers were not addressing their needs, both in the oncology and primary care settings. I was saddened by this but did my best to connect these people with any community resources that could be helpful, in addition to encouraging them to contact their oncologist or primary care provider or their nurses. This experience had an impact on me when I decided to do a PhD and I became aware of plans in the region to discharge breast cancer survivors back to primary care earlier than previously. I was concerned about the care that they might receive. This concern has been renewed several times when I have spoken to groups of cancer survivors about cancer fatigue and about my research on survivorship care guidelines. The survivors overwhelmingly thanked me for addressing these unmet needs and simply for acknowledging the existence of their ongoing problems.

Thus as I prepared to interview primary care providers I had to be conscious of the potential for a negative bias towards primary care providers, as a result of my empathy for the distress that many cancer survivors were reporting. As well, as a nurse, I also had to be conscious of the potential for a negative bias towards primary care physicians versus nurse practitioners. However, I also empathized with primary care providers and the overwhelming amount of knowledge they require to manage all of the health and illness concerns that present to primary care. Thus, I sought to be objective and present a balanced report of the challenges and strengths of both professions as they engage in survivorship care.

Another bias that was not apparent to me until after my thesis defense was again related to my role identification as a nurse, although I was completing a PhD in Rehabilitation Sciences. As a nursing faculty member I have a lot of experience with interprofessional collaborations related to developing and delivering interprofessional simulation educational modules. Thus I was quite comfortable to pursue my degree a different but related discipline. In fact, where I was expecting to be the lone outsider in the class, I was pleasantly surprised at the diversity of the group, for example there was a lawyer, a physician, a mental health worker and a nurse who had formerly been one of my students. I also found my first course in the program, Disability in the Community, to be eye-opening, where I learned about the traditional Medical Model of Disability as well as the Social Model of Disability which permitted two different approaches to disability: the Minority Group Approach, and the Universal Approach. I felt that this course broadened my perspectives on chronic illness and disability, as well as deepened my desire to advance the quality and comprehensiveness of care provided to cancer patients after they have completed treatment.
However, when completing my thesis and in particular when conducting my qualitative analysis, although my goal was to describe comprehensive care, I may have displayed a biomedical bias in that I focused on the two traditional primary care providers, the family physician and the primary care nurse practitioner, and did not provide much description or discussion related to team-based models of care or the role of physiotherapists and occupational therapists in provision of survivorship care. This is surprising as I was completing my degree in Rehabilitation Sciences, and my committee members included a physiotherapist, an occupational therapist and a nurse. However, I believe this apparent tunnel vision was the result of the fact that responsibility for survivorship care follow-up is currently being transferred from the oncologist to either a primary care physician or nurse practitioner, which led me to focus on their knowledge, practices and needs, alone. In retrospect I have added some content that addresses the need to consider all primary health care team members when designing knowledge translation interventions, and I anticipate that as I go forward in my program of research I will now be conscious of the need to do so.
Appendix L

Publications, Presentations and Funding Related to My Research

Publications (Peer Reviewed)


Presentations (Peer Reviewed)


Luctkar-Flude, M. Primary health care nurse practitioner knowledge, practices and challenges implementing breast cancer survivorship care guidelines. Poster presentation at the 2015 NPAO Annual Conference, Toronto, ON, September 2015.


Luctkar-Flude, M., Aiken, A., McColl, M.A., & Tranmer, J. Preliminary results of a survey examining the implementation of key breast cancer survivorship care guidelines by primary care providers. Poster presentation at the 17th Annual Meeting for Health Sciences Research Trainees, Queen’s University, Kingston, June 2014.

Luctkar-Flude, M., Aiken, A., McColl, M.A., & Tranmer, J. Development of a comprehensive clinical practice framework to guide evidence-based breast cancer survivorship care within the primary care setting. Poster presentation at the 17th Annual Meeting for Health Sciences Research Trainees, Queen’s University, Kingston, June 2014.


Presentations (Non-Peer Reviewed)

Luctkar-Flude, M. Evidence-based breast cancer survivorship care in the primary care setting. Podium presentation at the Queen’s University, Rehabilitation Sciences Seminar Series, September 2013.

Invited Presentations and Meetings


Luctkar-Flude, M. South East Regional Cancer Plan. Invited panel member at the South East Regional Cancer Program (SERCP)/Cancer Care Ontario (CCO) Planning Workshop, Kingston, Ontario, October 2015.


Luctkar-Flude, M. Primary care physician and nurse practitioner knowledge and practices related to evidence-based breast cancer survivorship care. Invited presentation at the Queen’s University School of Nursing, Academic Series, Kingston, October, 2014.


Media Reports


Winter 2013 de Souza Distinction: Congratulations to the Winners of the 2013 de Souza Scholarship http://www.desouzainstitute.com/files/resources/Newsletter%20%5BWinter%202013%5D.pdf

External Funding

Jul 15  Canadian Institutes of Health Research-Institute of Cancer Research (CIHR-ICR) and Canadian Cancer Society Research Institute (CCSRI), Careers in Cancer Research Development Program (CCRDP) New PI Award ($1200)

Aug 14 Canadian Cancer Society Travel Award ($1935)

Dec 12 de Souza Institute Graduate Scholarship ($20,000)

**Internal Funding**

Apr 15 Queen’s University Faculty Travel Award ($1100)

Dec 14-Mar 16 *Transition to primary care follow-up: A mixed methods study exploring the perspective of early discharge in breast cancer survivors.* Co-Investigators: Marian Luctkar-Flude (PI), Hugh Langley. Funded by the Freda Paltiel Award, Queen’s University, School of Nursing ($2000).