

## Review

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

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## Abstract

**Background.** Breast cancer survivors continue to experience physical and psychosocial health care 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.

**Key words:** Aftercare, breast neoplasms, nurse practitioners, physicians, practice guideline, primary care, primary health 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 health care 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 programmes 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: (i) prevention of recurrent and new cancers, and other late effects; (ii) surveillance for cancer spread, recurrence, second cancers, and medical and psychosocial late effects; (iii) intervention for consequences of cancer and its treatment and (iv) 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 health care 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 post-menopausal 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 post-traumatic 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 *et al.* (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 randomized trials revealed about three-quarters of eventual local recurrence risk occurred during the first five years (40). And 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 (42) identified 11 broad categories related to the post-treatment primary health care needs of women with breast cancer: surgical complications,

fatigue, lymphedema, gynaecologic and menopausal symptoms, psychosocial issues, additional primary cancers, cardiovascular issues, osteoporosis, lifestyle changes, cognitive dysfunction and pregnancy. Results of interviews with post-treatment breast cancer patients and primary care medical doctors (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 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 nurse practitioners (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 CPGs

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 to 2013 that outlined evidence-based care for post-treatment breast cancer survivors. CPGs were retrieved from the USA, Canada, Australia, New Zealand and Europe, including the UK. 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 CPGs

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, NPs and breast cancer survivors recruited based on their experience with breast cancer and/or primary care. Panel members were known to the principle 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/does not 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

**Table 1.** Breast cancer survivorship literature review search strategy

Research question	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?
Sources to identify relevant clinical practice guidelines	<ol style="list-style-type: none"> <li>1. Electronic search of databases: Medline, EMBASE, Cochrane Collection, CINAHL, HealthStar</li> <li>2. Hand search of journals: Canadian Family Physician, Canadian Medical Association Journal, Journal for Nurse Practitioners</li> <li>3. Hand search of grey literature through online databases: National Guideline Clearinghouse, Canadian Medical Association, Cancer Care Ontario, Canadian Cancer Society, Canadian Breast Cancer Foundation, Canadian Partnership Against Cancer, National Comprehensive Cancer Network, Institute for Clinical and Evaluative Sciences, Standards and Guidelines Evidence (SAGE), US Preventive Services Task Force, American Cancer Society, Alberta Health Services, American Society of Clinical Oncology, British Columbia Cancer Agency, EORTC, ESMO, National Health and Medical Research Council, NHS, SIGN</li> <li>4. Hand search of reference lists of key articles</li> <li>5. Cited reference searching of 'key articles' to identify other potentially relevant articles which may have cited the 'key articles' as references</li> </ol>
Keyword search strategy	<p>Sets of systematically combined keywords will be used to identify relevant CPGs</p> <ol style="list-style-type: none"> <li>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</li> <li>2. Practice guidelines</li> <li>3. Key findings from previous scoping review: surgical complications; lymphedema; gynaecologic and reproductive implications; psychosocial issues; additional primary cancers; cardiovascular implications; osteoporosis; lifestyle changes; fatigue; cognitive dysfunction; pregnancy</li> </ol>
Sample search of Medline database	<p>Database: Ovid MEDLINE(R) without Revisions &lt;1996 to Present with Daily Update&gt; Search strategy:</p> <p>-----</p> <ol style="list-style-type: none"> <li>1 exp Primary Health Care/ (51780)</li> <li>2 exp Physicians, Primary Care/ (617)</li> <li>3 exp Patient Care Team/ (31275)</li> <li>4 exp Nurse Practitioners/ (9448)</li> <li>5 exp Physicians, Family/ (8768)</li> <li>6 primary care provider\$.ti,ab. (3235)</li> <li>7 primary care physician\$.ti,ab. (9121)</li> <li>8 primary care practition\$.ti,ab. (695)</li> <li>9 exp Aftercare/ (2945)</li> <li>10 (after care or aftercare).ti,ab. (1379)</li> <li>11 (followup care or follow up care).ti,ab. (1552)</li> <li>12 (after treatment or aftertreatment).ti,ab. (66849)</li> <li>13 (health care need\$ or healthcare need\$).ti,ab. (2883)</li> <li>14 survivor\$ care plan\$.ti,ab. (73)</li> <li>15 or/1-14 (174086)</li> <li>16 exp Breast Neoplasms/ (124640)</li> <li>17 ((breast cancer adj3 post) or (breast cancer adj3 after)).ti,ab. (3568)</li> <li>18 ((post treatment adj4 breast) or (posttreatment adj4 breast)).ti,ab. (84)</li> <li>19 (surviv\$ adj3 breast).ti,ab. (4307)</li> <li>20 or/16-19 (125064)</li> <li>21 15 and 20 (2925)</li> <li>22 limit 21 to practice guideline (23)</li> <li>23 exp Guideline/ (18169)</li> <li>24 exp Guidelines as Topic/ (93518)</li> <li>25 exp Guideline Adherence/ (16996)</li> <li>26 guid\$.ti,ab. (264145)</li> <li>27 exp Evidence-Based Medicine/ (47252)</li> <li>28 or/22-27 (363037)</li> <li>29 21 and 28 (349)</li> </ol>

**Table 2.** A framework for comprehensive breast cancer survivorship care in the primary care setting

<p>PREVENTION of recurrent and new cancers and late effects</p> <ul style="list-style-type: none"> <li>•Exercise</li> <li>•Nutrition</li> <li>•Weight management</li> <li>•Alcohol consumption</li> <li>•Immunizations</li> <li>•Smoking cessation<sup>a</sup></li> <li>•Sun exposure<sup>a</sup></li> </ul> <p>SURVEILLANCE for recurrent or new cancers and assessment of physical and psychosocial late effects</p> <ul style="list-style-type: none"> <li>•History and physical</li> <li>•Mammography</li> <li>•Breast self-exam</li> <li>•Pelvic exam</li> <li>•Non-routine tests</li> <li>•Cholesterol and lipid screening<sup>a</sup></li> </ul> <p>COORDINATION between primary care providers and specialists to ensure all health care needs are met</p> <ul style="list-style-type: none"> <li>•Survivorship care plan</li> <li>•Specialist referrals</li> </ul>	<p>INTERVENTION for long-term effects of cancer (grouped by treatment)</p> <p>Surgery</p> <ul style="list-style-type: none"> <li>• Pain</li> <li>• Lymphedema</li> </ul> <p>Chemotherapy</p> <ul style="list-style-type: none"> <li>• Peripheral neuropathy</li> <li>• Cardiovascular complications</li> <li>• Cognitive dysfunction</li> <li>• Fertility, pregnancy and contraception</li> <li>• Fatigue</li> <li>• Menopausal symptoms</li> </ul> <p>Targeted therapy<sup>a</sup></p> <ul style="list-style-type: none"> <li>• Cardiovascular complications</li> </ul> <p>Radiation therapy</p> <ul style="list-style-type: none"> <li>• Cardiovascular complications</li> <li>• Lymphedema</li> <li>• Fatigue</li> </ul> <p>Hormonal therapy</p> <ul style="list-style-type: none"> <li>• Menopausal symptoms</li> <li>• Fertility, pregnancy and contraception</li> <li>• Osteoporosis</li> <li>• Arthralgias and myalgias</li> </ul> <p>Psychosocial issues</p> <ul style="list-style-type: none"> <li>• Distress, anxiety and depression</li> <li>• Sexual dysfunction</li> <li>• Family and work<sup>a</sup></li> </ul>
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<sup>a</sup>Items suggested for addition by expert panel members.

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 (46,54,55,62–73), and 12 were rated as low quality (5,74–84). 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 >5 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 health care professionals, only five targeted PCPs specifically (5,59,61,63,71).

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 and 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, three primary care MDs (two with oncology focus), three primary care NPs (two with previous oncology experience) and seven breast cancer survivors (see Acknowledgements). Health care 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, Papanicolaou test, 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/does not 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

**Table 3.** Summary of CPGs for breast cancer survivorship care

Number	Agency/authors/year	Guideline title	Retrieved from	Target audience	Cancer survivorship domains and issues addressed				AGREE II rating
					Prevention	Surveillance	Intervention	Coordination	
1	National Comprehensive Cancer Network (NCCN), Denlinger <i>et al.</i> , 2013 (62)	Survivorship	NCCN	Clinicians	Exercise, immunizations		Pain, sexuality, fatigue, cognitive dysfunction, anxiety and depression	Survivorship care plans, specialist referrals	Moderate (5)
2	American Society of Clinical Oncology (ASCO), Khatcheressian <i>et al.</i> , 2013 (63)	Breast cancer follow-up and management after primary treatment: American Society of Clinical Oncology CPG update	National Guideline Clearinghouse, ASCO, Standards and Guidelines Evidence (SAGE) Directory of Cancer Guidelines, Medline	Oncologists, primary care providers, oncology nurses		History, physical, mammography, breast self-exam, pelvic exam, non-routine tests			Moderate (5)
3	British Columbia (B.C.) Cancer Agency, 2013 (74)	Cancer management guidelines, breast: follow-up	B.C. Cancer Agency, SAGE	Health professionals	Exercise	Physical, mammography, breast self-exam, non-routine tests	Lymphedema		Low (2)
4	NCCN, Holland <i>et al.</i> , 2013 (66)	CPGs in Oncology: Distress	NCCN and SAGE	Clinicians		Distress, anxiety and depression, family and work, physical problems	Distress, anxiety and depression		Moderate (5)
5	Alberta Health Services, 2012 (75)	Magnetic resonance imaging (MRI) for breast cancer screening, pre-operative assessment and follow-up	SAGE Directory of Cancer Guidelines, Alberta Health Services	Clinicians		Non-routine tests: MRI			Low (1)
6	B.C. Cancer Agency, 2012 (76)	Patient/public info: Lymphedema	B.C. Cancer Agency	Patients, public			Lymphedema		Low (1)
7	Saskatchewan Cancer Agency, 2012 (77)	Follow-up guidelines: Breast cancer	Saskatchewan Cancer Agency SAGE	Physicians		Physical, mammography, breast self-exam, non-routine tests	Menopausal symptoms, fertility and pregnancy, osteoporosis		Low (1)
8	American Cancer Society (ACS), Kushi <i>et al.</i> , 2012 (64)	Guidelines on nutrition and physical activity for cancer prevention	National Guideline Clearinghouse, SAGE Medline	Cancer specialists, GPs, advanced practice nurses	Exercise, nutrition, weight management, alcohol consumption				Moderate (5)
9	Canadian Breast Cancer Foundation (CBCF), 2012 (78)	After treatment: Follow-up care	CBCF	Breast cancer survivors		Physical, mammography	Lymphedema, fatigue, menopausal symptoms		Low (1)
10	NCCN, Carlson <i>et al.</i> , 2012 (65)	CPGs in Oncology: Breast Cancer	NCCN and SAGE	Clinicians (patient versions available)		History, physical, mammography	Fertility and pregnancy		Moderate (5)
11	NCCN, Berger <i>et al.</i> , 2012 (55)	CPGs in Oncology: Cancer-Related Fatigue	NCCN and SAGE	Clinicians			Fatigue		Moderate (5)

(Continued)

Table 3. Continued

Number	Agency/authors/year	Guideline title	Retrieved from	Target audience	Cancer survivorship domains and issues addressed				AGREE II rating
					Prevention	Surveillance	Intervention	Coordination	
12	Harris <i>et al.</i> , 2012 (67)	CPGs for Breast Cancer Rehabilitation	Medline	Clinicians			Pain, lymphedema, osteoporosis, fatigue, cardiovascular complications, peripheral neuropathy	Specialist referrals	Moderate (4)
13	ACS, Rock <i>et al.</i> , 2012 (68)	Nutrition and Physical Activity Guidelines for Cancer Survivors	National Guideline Clearinghouse, SAGE and Medline	Physicians and nurses	Exercise, nutrition, weight management, alcohol consumption				Moderate (5)
14	American College of Obstetricians and Gynecologists, 2012 (69)	Management of Gynaecologic Issues in Women with Breast Cancer	Medline	Advanced practice nurses, nurses			Menopausal symptoms, fertility and pregnancy, osteoporosis		Moderate (4.5)
15	MacMillan Cancer Support, Campbell <i>et al.</i> , 2012 (79)	Physical Activity for People Living with and Beyond Cancer	MacMillan Cancer Support (UK) and EMBASE	Health care professionals	Exercise				Low (2)
16	Canadian Association of Psychosocial Oncology/Canadian Partnership Against Cancer, Howell <i>et al.</i> , 2011 (59)	Screening, Assessment and care of cancer-related fatigue in adults with cancer	SAGE	Inter-professional health care team including primary care providers			Fatigue		High (6)
17	European Society for Medical Oncology (ESMO), Aebi <i>et al.</i> , 2011 (80)	Primary breast cancer: ESMO CPGs for diagnosis, treatment and follow-up	ESMO, SAGE and Medline	Clinicians		Physical, mammography, non-routine tests			Low (2)
18	Madarnas <i>et al.</i> , 2011 (5)	Models of Care for Early-Stage Breast Cancer in Canada	PUBMED	Primary care providers		Physical, mammography, non-routine tests		Specialist referrals	Low (3)
19	American College of Sports Medicine (ACSM), Schmitz <i>et al.</i> , 2011 (54)	ACSM Roundtable on Exercise guidelines for Cancer Survivors	SAGE and Medline		Exercise				Moderate (4)
20	CBCF (81)	After treatment: Lymphedema	CBCF	Breast cancer survivors			Lymphedema		Low (1)
21	Australian Government, Cancer Australia, 2010 (70)	Recommendations for follow-up of women with early breast cancer	Cancer Australia and SAGE	Health professionals		History, physical, mammography, non-routine tests			Moderate (4)

(Continued)

Table 3. Continued

Number	Agency/authors/year	Guideline title	Retrieved from	Target audience	Cancer survivorship domains and issues addressed				AGREE II rating
					Prevention	Surveillance	Intervention	Coordination	
22	National Institute for Health and Clinical Excellence (NICE), Smallwood <i>et al.</i> , 2009 (60)	Early and locally advanced breast cancer: Diagnosis and treatment	NICE (UK) and SAGE	Health care professionals		Mammography		Survivorship care plans	High (6)
23	New Zealand Guidelines Group, 2009 (71)	Management of early breast cancer: Follow-up	National Guideline Clearinghouse and SAGE	Family practice, advanced practice nurses, allied health personnel, patients		Physical, mammography		Survivorship care plans	Moderate (5)
24	Cancer Journey Action Group/Canadian Partnership Against Cancer, Bultz <i>et al.</i> , 2009 (72)	Guide to implementing screening for distress, the 6th vital sign	Canadian Partnership against Cancer	Clinicians			Psychosocial issues		Moderate (4.5)
25	Cancer Journey Action Group/Canadian Partnership Against Cancer, Howell <i>et al.</i> , 2009 (61)	A Pan-Canadian CPG: Assessment of psychosocial health care needs of the adult cancer patient	Canadian Partnership against Cancer	Inter-professional health care team including primary care providers			Psychosocial issues		High (6)
26	Society of Obstetricians and Gynaecologists of Canada (SOGC), Reid <i>et al.</i> , 2009 (82)	Menopause and Osteoporosis Update 2009: Hormone therapy and breast cancer	Canadian Medical Association CPG Infobase and SAGE	Gynaecologists			Menopausal symptoms		Low (3)
27	Oncology Nursing Society, Poage <i>et al.</i> , 2008 (83)	Demystifying lymphedema: Putting evidence into practice@ card	SAGE and Medline	Nurses			Lymphedema		Low (3)
28	SOGC, McNaught <i>et al.</i> , 2006 <sup>a</sup> (84)	Progesterone-only and non-hormonal contraception in the breast cancer survivor	SAGE and Medline	Gynaecologists			Fertility and pregnancy		Low (2)
29	Health Canada, Grunfeld <i>et al.</i> , 2005 <sup>a</sup> (46)	Health Canada Steering Committee on CPGs for the care and treatment of breast cancer: Follow-up after treatment for breast cancer	SAGE and Medline	Practitioners, patients	Weight management	History, physical, mammography, non-routine tests, breast self-exam	Menopausal symptoms, fertility and pregnancy, osteoporosis, fatigue, sexuality		Moderate (4)

(Continued)

Table 3. Continued

Number	Agency/authors/year	Guideline title	Retrieved from	Target audience	Cancer survivorship domains and issues addressed				AGREE II rating
					Prevention	Surveillance	Intervention	Coordination	
30	Scottish Intercollegiate Guidelines Network (SIGN), Ad-amsen <i>et al.</i> , 2005 <sup>a</sup> (73)	Management of breast cancer in women: A national clinical guideline	SIGN and SAGE	Health professionals			Psychosocial issues		Moderate (5)

<sup>a</sup>Guidelines developed >5 years ago may contain outdated recommendations.

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'. Health care 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 online [supplementary data](#)).

## Discussion

A rigorous 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 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 (85). 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 health care 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 *et al.* (86) 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 (87). 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 (88). 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 (89). 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 (90,91). Primary care MDs rarely access primary sources of scientific information and favour indirect sources that summarize new research (92,93). NP preferences include sources that provide short pieces emphasizing

important facts (93–96). 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 PCPs 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* (see online [supplementary data](#)) 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 have 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.

### Supplementary material

Supplementary material is available at *Family Practice* online.

### Declaration

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