
by

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Abstract

Objective: To describe pain self-management behaviours (PSMB), and barriers and facilitators to PSMB in breast cancer (BC) survivors following primary cancer treatment. Methods: This study used a sequential explanatory mixed-methods design. BC survivors (n=53) who were 6 months (±2 months) post-treatment for BC completed measures assessing pain catastrophizing, fear of cancer recurrence (FCR), and pain self-efficacy. Participants also completed the Barriers Questionnaire II (BQ-II) to assess barriers to pain management, and the Pain Self-Care Behaviours Questionnaire (PSCBQ) to assess engagement in PSMB. Interviews were conducted with a subset of participants (n=10) to further describe PSMB and barriers and facilitators to PSMB. Results: The most common PSMB participants reported via the PSCBQ were walking, distraction strategies, other exercise, and relaxation. Barriers and facilitators to PSMB included those identified by the BQ-II, as well as novel barriers and facilitators such as pain acceptance, information, and social support. Conclusion: BC survivors engage in a variety of PSMB and encounter many barriers and facilitators to PSMB not identified by existing quantitative measures. Future research should acknowledge the importance of barriers and facilitators such as pain acceptance, information (on what to expect and on PSMB in general), and social support.
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Contributions

The data from this study comes from a larger longitudinal study, “Pain and its management in the first year after breast cancer treatment” which was developed by Dr. Jennifer Jones, Dr. Lynn Gauthier, and Dr. Lucia Gagliese. Other larger study team members include Dr. David Warr, Dr. Alex Jadad, Dr. Christine Elser, Dr. Doris Howell, Dr. David McCready, and Dr. Pamela Catton. I completed the Research Ethics Board renewal for this study in 2017. I recruited participants for the present study, administered all study questionnaires, and conducted all interviews. I conducted all data analysis with input from Dr. Jennifer Jones, my program advisory committee members Dr. Doris Howell and Dr. Gary Rodin, and Dr. Lynn Gauthier. Interviews were constructed collaboratively between Dr. Lynn Gauthier, Dr. Jennifer Jones, and myself. Cheryl Pritlove and Beth Edwards, who have expertise in qualitative analysis, were consulted for feedback on our qualitative interview guide. Participants were recruited from the breast clinics at Princess Margaret Cancer Centre.
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**List of Abbreviations**

BC: Breast Cancer

CTP: Chronic Treatment-Related Pain

HCP: Heath Care Provider

PSMB: Pain Self-Management Behaviours

FCR: Fear of Cancer Recurrence

AI: Aromatase Inhibitor

CCM: Chronic Care Model

PCS: Pain Catastrophizing Scale

BPI: Brief Pain Inventory

PSCBQ: Pain Self-Care Behaviors Questionnaire

BQ-II: Barriers Questionnaire II

CPSE: Chronic Pain Self-Efficacy Scale

DRS: Quality of Life of Adults Cancer Survivors Scale, Distress-Recurrence subscale
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Chapter 1: Background

1.1 Introduction

Breast cancer (BC) is the most commonly diagnosed cancer in women worldwide (Ferlay et al., 2015) and approximately 1 in 8 Canadian women will be diagnosed with BC in their lifetime (Canadian Cancer Statistics, 2017). Treatment for BC has become increasingly sophisticated and as a result, more disease-free BC survivors are living long after treatment completion (Canadian Cancer Statistics, 2017). A cancer survivor refers to any individual who has been diagnosed with cancer, from the time of their diagnosis onward (National Cancer Institute, 2017), and in the context of this study, a BC survivor refers to any individual with BC who is disease-free and post-primary treatment for BC.

Approximately 25-60% of BC survivors experience chronic treatment-related pain (CTP) from cancer treatment such as surgery, chemotherapy, radiation, and/or hormone therapy (Gartner et al., 2009). CTP refers to any pain that persists beyond 3 months post-surgery for BC, and includes pain categorized as post-mastectomy pain syndrome (Andersen & Kehlet, 2011), phantom breast pain, intercostobrachial neuralgia, neuroma pain, and other nerve injury due to BC treatment (Jung et al., 2003). The definition of CTP used in this study also includes joint pain and painful menopausal symptoms, due to adjuvant hormone therapy such as aromatase inhibitors and Tamoxifen (Mao et al., 2009; Crew et al., 2007; Glaus et al., 2006; Garreau et al., 2006). CTP can have a significant impact on quality of life and has been correlated with poorer physical and psychological outcomes in BC survivors (Belfer et al., 2013).

CTP often occurs outside of the regular follow-up period for BC survivors (i.e. post-primary cancer treatment) who may lack access to specialized pain management resources in the survivorship phase of cancer. The end of cancer treatment means less communication and follow-
ups with health-care providers (HCPs) (Aziz, 2007) and CTP may require more active involvement and self-management by the patient, as is the case with other chronic conditions (Barlow et al., 2002).

No standardized definition for chronic pain self-management exists (Stewart et al., 2014) and the wide spectrum of pain self-management behaviours (PSMB) that BC survivors engage in remains unknown. Self-management behaviours in general are directed at managing the medical, emotional, and role-related factors associated with chronic illnesses (Lorig & Holman, 2003), and PSMB specifically may include activities like taking pain medication and communicating effectively with HCPs about pain (Gunnarsdottir et al., 2002).

Although there is a large body of literature exploring pain and other symptom self-management in advanced cancer patients (see Marie et al. 2013; Koller et al., 2013; McCorkle et al., 2011; Bennett et al., 2009), little is known about what disease-free BC survivors who are post-treatment do to self-manage CTP. Studies that have explored pain in BC survivors, tend to focus on pain early in the cancer trajectory and/or during active treatment such as radiation or chemotherapy (see Howell et al., 2016). Further, Stewart et al. (2014) report that pain self-management tends to be explored in one of three ways including as an intervention, as an outcome, or in terms of everyday behaviours. The literature on chronic cancer pain has explored PSMB in the context of interventions and outcomes (see Marie et al. 2013; Koller et al., 2012; McCorkle et al., 2011; Bennett et al., 2009) however, little research has explored PSMB in the context of everyday behaviours. Thus, much of what is known about PSMB has been reported from the perspective of HCPs and it is unknown what PSMB cancer survivors choose to engage in on their own. There is also an absence of mixed-methods and qualitative research on PSMB for cancer
pain, and most studies use the same quantitative measures to evaluate barriers to PSMB (see Marie et al. 2013; Koller et al., 2013; McCorkle et al., 2011; Bennett et al., 2009).

This presents an issue for several reasons. BC survivors may evaluate pain differently than patients with advanced disease or patients undergoing treatment (Gauthier et al., 2015), and variables such as fear of cancer recurrence (FCR) and pain catastrophizing may play an important role in pain evaluation (Belfer et al., 2013; Edwards et al., 2013; Janz et al., 2011; Matulonis et al., 2008; van den Beuken-van Everdingen et al., 2008; Bishop & Warr, 2003). The onset of CTP may also occur long after treatment completion (Forsythe et al., 2013), in the absence of regular follow-up with cancer specialists. Further, neglecting the patient perspective and examining PSMB solely from the HCP perspective presents the risk of overlooking PSMB, and barriers and facilitators to PSMB unknown to HCPs that may be common among patients with cancer pain.

It is important to understand the PSMB that BC survivors may engage in on a daily basis. It is also important to understand the barriers and facilitators to PSMB that BC survivors face from a patient perspective. This will allow for the creation of appropriate pain management interventions that could contribute to better quality of care, higher quality of life, and lower reported morbidity post-treatment.
1.2 Breast Cancer Treatment and Treatment-Related Pain

1.2.1 Breast Cancer Statistics

1 in 8 Canadian women will develop BC in her lifetime and 1 in 30 will die from the disease (Canadian Cancer Statistics, 2017). Since the mid-1980s, the death rate for BC has declined significantly due largely in part to improvements in screening and treatment (Canadian Cancer Statistics, 2017), and the number of BC survivors continues to rise. Most often, BC is diagnosed at a localized stage (DeSantis et al., 2014). The 5-year survival rate for BC, according to aggregated estimates from 2004-2008, is 87% and the majority of women diagnosed with BC will die from other causes (Canadian Cancer Society's Advisory Committee on Cancer Statistics, 2016). The median age at BC diagnosis is 61 years, and over 70% of BC survivors are 60 years of age or older. Less than 10% of BC survivors are younger than 50 years old (DeSantis et al., 2014). Factors associated with BC mortality include younger age, race, tumor grade, hormone-receptor status, and human epidermal growth factor receptor (HER2) status (DeSantis et al., 2014).

1.2.2 Breast Cancer Treatment Overview

Treatment for BC may include surgery, chemotherapy, radiation, and/or hormone treatment, many of which may influence the development of CTP in BC survivors (Andersen & Kehlet, 2011; Jung et al., 2005). Most commonly, BC patients first undergo surgery to remove their tumor(s) and adjuvant radiation and/or chemotherapy will follow. In some instances, BC patients receive intraoperative radiation during surgery and some BC patients may complete chemotherapy before surgery.

Surgery, radiation, and chemotherapy are considered primary treatment for BC. Following primary treatment, BC survivors may be prescribed hormone therapy to reduce their risk of cancer recurrence. The various treatments for BC are discussed in this section.
Surgery

Surgical treatments for BC include lumpectomy or mastectomy, with or without sentinel node biopsy or axillary node dissection (Jung et al., 2003). Lumpectomy, also referred to as breast-conserving surgery, involves removing the breast cancer tumor itself and some of the surrounding breast tissue, and mastectomy involves the entire removal of the breast and surrounding tissue (Jung et al., 2003). The type of surgery that BC patients received is determined in part by the stage of their BC and more extensive surgery is generally recommended for more advanced disease (DeSantis et al., 2014). However, the decision to undergo mastectomy may also be related to demographic factors such as younger age (18 to 49), higher travel time to cancer center, and residence in a less affluent neighborhood (Canadian Institute for Health Information, 2012), and psychological factors such as fear of cancer (Nold et al., 2000).

In Ontario, 37% of women with unilateral, invasive BC, and 28% of women with ductal carcinoma in situ underwent mastectomy between 2007 and 2010 (Canadian Institute for Health Information, 2012). In a large sample of over 189,000 BC survivors who had been diagnosed with Stage 0-III BC between 1998 and 2011 in the US, Kurian et al. (2014) report that 6.2% of their study participants underwent bilateral mastectomy, 38.8% underwent unilateral mastectomy, and 55% underwent lumpectomy with radiation. They found that from 1998 to 2011, there was a substantial increase (from 2%-12.3%), in the rate of bilateral mastectomies however, bilateral mastectomy was not associated with lower mortality, and lumpectomy plus radiation has been shown to offer the same long-term survival as mastectomy (Canadian Institute for Health Information, 2012).
**Adjuvant Treatment**

Most BC survivors also complete some form of adjuvant treatment in addition to surgery such as radiation, chemotherapy, and/or hormone therapy, and studies tend to report on adjuvant treatment prevalence according to stage or type of surgery.

Most women with early-stage BC receive radiation only (56%) after surgery, and a minority receive both radiation and chemotherapy (DeSantis et al., 2014). Studies that look at adjuvant treatment prevalence according to type of surgery report that among BC survivors who undergo bilateral mastectomy, approximately 15.6% complete radiation and 45.3% complete chemotherapy. Among those who undergo unilateral mastectomy, 16.0% complete radiation and 39.8% complete chemotherapy (Kurian et al., 2014). Among BC survivors who undergo lumpectomy (also referred to as breast-conserving surgery) plus radiation, 31.6% complete chemotherapy. Langballe et al. (2016) report slightly higher rates of radiation and chemotherapy among their sample of BC survivors from the US, Denmark, and Canada.

**Hormone Therapy**

Hormone therapy may be recommended for BC survivors during and following the completion of their primary cancer treatment (i.e. surgery, chemotherapy, and/or radiation), depending on the type of BC they are diagnosed with. Hormone therapy includes Tamoxifen and Aromastase inhibitors such as Letrozole, Anastrozole, and Exemestane. Hormone therapy is used to suppress the production of estrogen and reduce the risk of recurrence in some BC survivors. Langballe et al. (2016) report that approximately 36% of BC survivors with unilateral BC take adjuvant Tamoxifen following primary BC treatment, and about 6% report taking other types of endocrine therapy (i.e. aromatase inhibitors (AI) or other anti-estrogens).
1.2.3 Chronic Treatment-Related Pain (CTP) in Breast Cancer Survivors

Prevalence of CTP

According to Levy et al. (2008), CTP is ‘underreported, underdiagnosed, and undertreated.’ In general, CTP is reported to occur in 25-60% of BC survivors (Gartner et al., 2009) and can persist indefinitely after treatment. One study found that almost one-third of BC survivors reported ‘above average’ pain 10 years following primary treatment (Forsythe et al., 2013). Studies that examine pain earlier in the treatment trajectory have found that approximately 10% of BC survivors report ‘severe’ pain anywhere from 6 months to three years post-surgery (Fecho et al. 2009; Gartner et al., 2009). In their study of over 3500 BC survivors, Gartner et al. (2009) found that 47% of participants who were an average of 26 months post-surgery reported some pain in the breast, arm, and surrounding area, and the majority of those who reported pain (52%) rated it as moderate-severe.

The Relationship between Type of Treatment and CTP

Studies reporting on the impact of type of surgical procedure (i.e. lumpectomy or mastectomy) on reported pain in BC survivors, have generally found no relationship (Gartner et al., 2009; Vilholm et al., 2008; Kuehn et al., 2000; Tasmuth et al., 1999; Hack et al., 1999; Tasmuth et al., 1996; Stevens et al., 1995) however, a minority of studies have found a higher incidence of reported pain in the arm following lumpectomy (Karki et al., 2005; Tasmuth et al., 1997). For example, Karki et al. (2005) found that pain in the axilla region and breast pain were higher among BC survivors who had undergone lumpectomy than in BC survivors who had undergone mastectomy. Similarly, Tasmuth et al. (1997) found that type of surgery was related to pain in the ipsilateral arm and pain in the breast. Instead of implicating lumpectomy, the authors speculate
that higher pain may be reported because radiation, which has been linked to the development of CTP, is standard treatment following lumpectomy and less common following mastectomy.

In terms of sentinel node biopsy and axillary node dissection, which both involve making an incision in the underarm to remove lymph nodes (Jung et al., 2003), axillary node dissection has been associated with higher reported pain than sentinel node biopsy or lumpectomy alone (Andersen & Kehlet, 2011).

In terms of adjuvant BC treatment, radiation, which is indicated in most women who undergo lumpectomy and, less often, in women who undergo mastectomy (Jung et al., 2005) has also been implicated in the development of neuropathic CTP (Andersen & Kehlet, 2011; Jung et al., 2005), while the relationship between chemotherapy and CTP is less well understood. Most studies exploring the relationship between chemotherapy and CTP do not examine dose, patients who withdraw due to side effects, or timing in terms of pain measurement (Gartner et al., 2009), making it difficult to draw conclusions about the impact of chemotherapy on pain. In one study that did account for these variables, no effect of chemotherapy on CTP was found (Gartner et al., 2009).

Hormonal therapy for hormone receptor positive BC has also been linked to adverse side effects including menopausal symptoms and joint pain (Mao et al., 2009; Crew et al., 2007; Glaus et al., 2006; Garreau et al., 2006).

Types of CTP

Chronic cancer pain can be due to cancer itself (primary tumor or metastases) or due to pain caused by cancer treatment (i.e. CTP) (Treede et al., 2015). CTP due to primary cancer treatment (surgery, radiation, chemotherapy) is usually neuropathic in nature (Andersen & Kehlet, 2011; Jung et al., 2003), and may be described by patients as numbness, burning, tingling,
stabbing, pins and needles, or electric-like sensations (Paice & Ferrell, 2011; Tofthagen & McMillan, 2010). Neuropathic pain is distinct from nociceptive pain, which may be described as gnawing or aching, and pain from hormone therapy is generally not neuropathic in nature (see Mao et al., 2007).

The International Association for the Study of Pain (IASP) defines neuropathic pain as “pain caused by a lesion or disease of the somatosensory nervous system” (Jensen et al., 2011), distinct from nociceptive pain which they define as “the actual or threatened damage to non-neural tissue... due to the activation of nociceptors.” Both types of pain involve different treatment approaches, and neuropathic pain is a risk factor for the under-treatment of pain (Paice & Ferrell, 2011). Neuropathic pain has been reported as more severe than nociceptive pain (Tofthagen & McMillan, 2010) and less responsive to opioids (McNicol et al., 2013). Pain from hormone therapy on the other hand, is very responsive to pain medication (e.g. Crew et al., 2007). Neuropathic pain may be more difficult to treat because it often occurs spontaneously, without warning and may peak several times throughout the day (Fallon, 2013).

Cancer pain is often of mixed-etiologia (Fallon, 2013) and may occur alongside other comorbidities. Therefore, it may be difficult for patients to identify the origins of their pain, and BC survivors may experience both neuropathic and nociceptive CTP.

**Etiology and Manifestation of CTP**

In a review on neuropathic pain related to BC surgery, Jung et al. (2003) report that postsurgical neuropathic pain may manifest as phantom breast pain, neuroma pain, damage to the intercostobrachial nerve, or pain due to other nerve injury. Phantom breast pain may occur after mastectomy and refers to the sensation that the breast is present and painful. It is distinct from non-painful phantom breast sensations. Neuromas can form when peripheral nerves are severed or
injured, and occur after both mastectomy and lumpectomy. Neuroma pain may also be referred to as ‘scar pain’ and is exacerbated by touch. Pain due to damage to the intercostobrachial nerve may occur as a result of mastectomy or axillary node dissection, and can affect the axilla, medical upper arm, and anterior chest wall. Other nerve injuries after BC surgery include damage to the medical and lateral pectoral, long thoracic, thoracodorsal, and other intercostal nerves. In the absence of axillary node dissection, injury to small branches of the intercostobrachial nerve may also occur.

In a review of non-surgical treatments for BC, Jung et al. (2005) report that radiation, chemotherapy, and hormone therapy may also cause CTP. Radiation can leave skin lesions at the site of radiation during treatment, and cervical or brachial plexopathy can develop over time (Bajrovic et al., 2004; Kori et al., 1981). Pain from radiation is usually neuropathic in nature and can appear up to several years after treatment (Delanian et al., 2012). It may manifest in cancer patients as numbness, tingling, burning, weakness, or other abnormal sensations in shoulder, arm, wrist, or hand region (Bajrovic et al., 2004; Kori et al., 1981). Pain from chemotherapy is also neuropathic in nature (Jung et al., 2005) and has been linked to the development of peripheral neuropathy, which may be described as tingling or burning in the hands and feet (Andersen & Kehlet, 2011). CTP due to chemotherapy is influenced by age, dose, type of chemo, and co-morbidities (Andersen & Kehlet, 2011).

Hormone therapy has been linked to menopausal symptoms such as fatigue, hot flashes, weight gain, vaginal dryness, and low libido (Glaus et al., 2006; Garreau et al., 2006), as well as joint pain in BC survivors (Mao et al., 2009; Crew et al., 2007). In a study of over 700 BC survivors who had been taking Tamoxifen for a mean duration of 33 months, Moon et al. (2017) found that over 40% of participants reported pain and other symptoms such as hot flashes and fatigue. In a study among Stage 0-III BC survivors taking an aromatase inhibitor, 47% reported having AI-
related joint pain and the most common joints affected were the hands, knees, and back (Crew et al., 2007). Most BC survivors report symptoms related to hormone therapy use within 3 months of initiation (Mao et al., 2009). In BC survivors taking an AI, being overweight and prior Tamoxifen use have been negatively correlated with AI-related joint symptoms (Crew et al., 2007).

1.2.4 Section Summary

BC is the most commonly diagnosed cancer in women worldwide and the number of BC survivors continues to rise. Although estimates vary, there is consensus that CTP is a significant problem facing BC survivors. Much of the research on cancer pain has examined the impact of cancer treatment on pain (Heathcote & Eccleston, 2017), and a large body of evidence suggests that axillary node dissection, radiation, and hormone therapy may be implicated in the development of CTP. Biological factors like cancer treatment do not fully explain pain experience and pain-related behaviour (Heathcote & Eccleston, 2017) however, and emotional and psychological factors related to pain have been understudied (Syrjala et al., 2014).

1.3 Self-Management

In cancer and other chronic illnesses alike, innovations in treatment and screening have increased survivability. This increase in the number of people living with chronic illnesses has been met with a corresponding shift in healthcare towards an emphasis on self-management for patients living with chronic illnesses (Bodenheimer et al., 2002).

Self-management has been explored in many chronic illnesses including asthma, arthritis, and diabetes (Barlow et al., 2002). Self-management skills relevant to diabetes for example, include monitoring one’s blood glucose level, making healthy diet decisions, and taking medication appropriately (Bodenheimer et al., 2002). Although a plethora of literature refers to self-management in the context of coping with chronic health conditions, the term lacks a
standardized definition (Barlow et al., 2002). Lorig and Holman (2003) report that ‘self-management’ was first used in the 1960s by Thomas Creer to denote a patient’s active participation in their treatment. Lorig and Holman (2003) propose that self-management tasks fall into one of three categories: 1. Medical management, which involves behaviors such as adhering to one’s medication; 2. Role management, which involves recognizing one’s limitations and engaging in less strenuous activity; and 3. Emotional management, which involves coping with the psychological correlates of disease such as anxiety and/or depression. Lorig and Holman (2003) also list five skills central to self-management including problem solving, decision-making, resource utilization, forming patient-HCP partnerships, and taking action. Problem solving involves defining a problem, generating potential solutions, implementing a solution, and evaluating it. Decision-making involves choosing a solution and is based on having enough appropriate information. For example, back pain patients who may ask when they should seek medical attention as a result of their back pain might be taught to identify “red flags” such as loss of bladder control. Such an accompanying symptom may indicate that an individual with back pain should see a health care professional. Resource utilization involves the skill of knowing how to access and navigate various healthcare resources. Forming patient-HCP partnerships is another important skill for self-management, and may include talking to HCPs about symptom management. Lastly, taking action involves actually engaging in a given self-management behavior.

1.3.1 Pain Self-Management Behaviours (PSMB)

Much of what is known about cancer PSMB comes from HCP-led interventions and little is known about PSMB from the patient perspective (see Howell et al., 2016; Marie et al., 2013; Bennett et al., 2009). Further, although many studies have explored pain self-management in
cancer survivors, no standardized definition of PSMB exists (Stewart et al., 2014; Nicholas et al., 2012) and it is therefore difficult to summarize findings about PSMB. The full range of PSMB that cancer survivors may engage in to manage their pain remains unclear.

The definition of PSMB used in this study is informed by the definition of self-management put forth by Lorig and Holman (2003) and McCorkle et al. (2011) to include the medical, role, and emotional aspects involved in the self-management of pain. For the purposes of this study, PSMB refer to activities (medical, role, or emotional) undertaken by BC survivors with the goal of maximizing wellness and minimizing pain.

In women with advanced BC, self-management behaviors in general include symptom management (i.e. taking analgesics for pain), exercise, healthy nutrition regimens, adhering to medication, and education (Schulman-Green et al., 2011). Other self-management behaviors include evaluating and ensuring support in the home (i.e. housekeeping), keeping home life as normal as possible, managing financial resources, coordinating medical services, searching for cancer resources, and advanced care planning with HCPs (Schulman-Green et al., 2011). Examples of PSMB specifically include activities such as exercise, relaxation, seeing a chiropractor or acupuncturist, attending psychotherapy, and/or asking for assistance (Miaskowski Pain Self-Care Behaviors Questionnaire, 2015).

1.3.2 PSMB in Breast Cancer Survivors

There is no standardized definition of PSMB (Stewart et al., 2014) and there is limited information on what disease-free BC survivors do to manage CTP. Studies that do explore pain self-management in this population generally look at pain during treatment (see Howell et al., 2016), post-operative pain (Andersen & Kehlet, 2011; Poleshuck et al., 2006; Jung et al., 2003), or pain in advanced cancer patients (Marie et al., 2013; Bennet et al., 2009). Further, most studies
that look at cancer pain management use quantitative methods and do so in the context of an intervention as opposed to asking patients directly what they do to self-manage pain. PSMB for cancer pain known in the existing literature fall broadly into six categories: pharmacological, emotional, physical, informational, communication-based, and complementary and alternative medicine strategies (CAM).

**Pharmacological PSMB**

Advanced BC patients and cancer survivors in general may take a variety of pain medications to cope with cancer pain including gabapentin, pregabalin, anti-depressants, and opioids (Satija et al., 2014; Fallon, 2013). Unfortunately, many pain medications are associated with significant side effects and cancer patients may endorse misconceptions about pain medication that can act as a barrier to treatment (Oldemenger et al., 2009; Gunnarsdottir et al., 2002). The majority of BC survivors who do use pain medication report moderate-complete pain relief (Crew et al., 2007) however, in studies that have reported on use of pain medication in BC survivors with joint pain related to hormone therapy, results showed that only half of participants with pain reported actually taking pain medication (Crew et al., 2007; Garraeu et al., 2006).

**Emotional or Psychological PSMB**

Emotional or psychological PSMB interventions for cancer survivors in general and BC patients undergoing active treatment include relaxation exercises (Jahn et al., 2014; Dolbeault et al., 2009), psychotherapy (Ell et al., 2011), stress management (Boesen et al., 2011), enhancing self-efficacy (Risendal et al., 2014), and sharing experiences with other cancer survivors (Risendael et al., 2014; Boesen et al., 2011). There is strong evidence that emotional and psychological PSMB are effective for cancer pain (Syrjala et al., 2014) however, most studies looking at the impact of emotional or psychological interventions for cancer patients do not
examine pain as a primary outcome (see Howell et al., 2016; Syrjala et al., 2014). When studies do look at pain as a primary outcome, effect sizes are larger (Sheinfeld Gorin et al., 2012).

**Physical Pain Self-Management**

Physical PSMB in BC survivors include shoulder and arm exercises to increase mobility and nurse training in lymphedema avoidance (Boesen et al., 2011), and physical PSMB for cancer survivors in general include individualized home-based exercise programs (van Waart et al., 2015; Dodd et al., 2010). The evidence regarding the effectiveness of exercise on pain in BC survivors is mixed with some studies showing improved pain post-intervention (Van Waart et al., 2015) and others showing no impact (Dodd et al., 2010).

**Informational Pain Self-Management**

Educational PSMB interventions for cancer pain may include information about cancer pain in general; address barriers to pain medication and other pain management strategies; and/or provide information on PSMB in general (Jahn et al., 2014; Risendal et al., 2014; Koller et al., 2013; Rustoen et al., 2012; Boesen et al., 2011; Dolbeault et al., 2009). There is convincing evidence that patient education is effective in reducing pain intensity and interference in cancer survivors (Lovell et al., 2014), and education may even be more effective than some coanalgesics (Bennett et al., 2009). In a sample of BC survivors and metastatic BC patients, Bender et al. (2008) found that participants reported unmet needs related to information on what to expect from cancer pain, options for pain control, help managing pain, understanding cancer pain, and how to describe cancer pain to HCPs. Educational interventions have been shown to have a modest but significant impact on cancer pain (Bennett et al., 2009) however, there is a risk of overwhelming patients with too much information (Barlow et al., 2002) and it may be important to find a balance between too much and too little information.
Communication with Health Care Providers (HCPs)

Communication with HCPs is integral to adequate pain management. HCPs are the gatekeepers to pain management referrals and pain medication, and effective communication about pain is the focus of many pain self-management interventions (e.g. Rustoen et al., 2014; Koller et al., 2013; Kravitz et al., 2011; Dolbeault et al., 2009). Although communication with HCPs is never the sole focus of interventional studies, there is strong evidence to suggest that effective communication can improve pain and pain-related outcomes (see Marie et al., 2013; Bennett et al., 2009).

Complementary and Alternative Medicine (CAM)

Complementary and alternative medicine (CAM) includes treatment that is used alongside or instead of standard medical treatment (National Cancer Institute, 2015). CAM strategies used for cancer pain include massage, acupuncture, fitness regimens, herbs, dietary supplements, and psychological techniques such as music therapy, meditation, and hypnosis (Cassileth & Keefe, 2010; Burstein et al., 1999). BC survivors who report using CAM strategies also report higher dissatisfaction with their primary care providers (Montazeri et al., 2007) and higher FCR (Montazeri et al., 2007; Burstein et al., 1999). Use of CAM strategies post-surgery in early-stage BC survivors has been linked to younger age and higher education (Burstein et al., 1999).

1.3.3 Under-Treatment of Cancer Pain

Although there is evidence to suggest that cancer pain self-management interventions can be effective in helping to minimize pain, as many as one third of all cancer patients do not receive adequate pain medication (Greco et al., 2014). A review by Fairchild (2010) found that the most at-risk group for undertreated cancer pain was women 65 years of age and older who identify as ethnic minorities and have earlier-stage cancer and a high school education. BC survivors with
CTP may be at an increased risk of undertreated cancer pain, as BC mainly affects older women and is usually diagnosed at a localized stage (DeSantis et al., 2014). Women are also more likely than men to experience inadequate cancer pain management (Green et al., 2011; Cleeland et al., 1994), and to report higher levels of pain severity and depression, and disability due to pain (Green et al., 2011).

1.3.4 Section Summary

Self-management is an important aspect of cancer survivorship post-treatment and involves medical, role, and emotional management. PSMB are activities aimed at minimizing pain and PSMB known in the existing literature include pharmacological, emotional, physical, informational, communication-based, and CAM-related strategies. More research is needed on whether or not these PSMB are effective for disease-free BC survivors, and what barriers and facilitators to PSMB are relevant in this population.

1.4 Barriers and Facilitators to PSMB

Barriers and facilitators have not been extensively explored in disease-free BC survivors, and most studies that explore barriers and facilitators to cancer pain management do so among advanced cancer patients of mixed site and stage, with varying treatment modalities. Further, most studies looking at barriers and facilitators to PSMB often list moderate-severe pain scores in their inclusion criteria (see Marie et al., 2013; Bennett et al., 2009), meaning cancer survivors who are effectively self-managing their pain and who have lower pain scores as a result, may not be represented in these studies.

In a qualitative study among advanced cancer patients of mixed site, Schumacher et al. (2002) identified several barriers to PSMB. At the patient, professional, and systematic levels, participants reported barriers such as side effects from pain medication, difficulty accessing
information and finding a pain regimen that was tailored to their individual needs, difficulty obtaining prescription medication due to reimbursement issues or lack of medication availability at pharmacies, difficulty managing new or unusual pain, and managing multiple symptoms simultaneously.

It is important to identify barriers and facilitators to PSMB so that pain management interventions can be tailored to patient needs, and so that it is easier for patients to engage in self-management in the first place. Luckett et al. (2013) propose that barriers to PSMB occur at the patient, HCP, and health care system levels. The present study focuses on barriers at the patient and HCP levels.

1.4.1 Patient-Related Barriers

Demographic Factors

Demographic factors have not been extensively explored in relation to engagement in PSMB, but there is an established relationship between age, education, and CTP. Several studies that have looked at CTP in BC survivors two months to several years post-surgery have found age to be negatively associated with CTP (see Wang et al., 2016; Gartner et al., 2009), and lower levels of education have been linked to undertreated pain (Fairchild, 2010).

Cognitive Barriers

Cognitive barriers to PSMB include an individual’s negative beliefs about pain medication, the belief that good patients do not complain about pain or that it will distract their doctor from treating the underlying disease, and fatalistic beliefs about pain (i.e. the idea that pain is inevitable, uncontrollable, or indicative of disease progression) (Kwon, 2014; Oldenmenger et al., 2009; Gunnarsdottir et al., 2002). Many studies have found that among advanced cancer patients of mixed site, beliefs about pain medication that may act as barriers to pain management include fear
of addiction and fear of side effects (Torresan et al., 2015; Kwon et al., 2014; Oldenmenger et al., 2009; Pargeon et al., 1999).

In advanced cancer patients, lack of knowledge about pain management, patient reluctance to report pain, or poor communication with one’s HCP (Koller et al., 2012; Oldenmenger et al., 2009; Pargeon et al., 1999), may also act as barriers to PSMB. In terms of fatalistic beliefs about pain, cancer survivors may interpret changes in their pain to mean that their cancer has returned or progressed, for example (Kwon et al., 2014), which may influence pain severity and likelihood to engage in PSMB. Other patient-related cognitive barriers to PSMB in advanced cancer patients include difficulty processing complex information, uncertainty regarding how to manage new or unusual pain (i.e. whether or not to alter a dose of pain medication), and difficulty managing multiple symptoms simultaneously (Schumacher et al., 2002).

**Psychological Barriers**

Affective variables can also act as barriers to PSMB, and may influence the types of pain management strategies that individuals choose to engage in (Simard et al., 2013; Damush et al., 2008). For example, depressed patients with musculoskeletal pain have been found to exercise less to manage pain and instead use more mental self-management strategies such as visualization, progressive muscle relaxation, and positive self-talk (Damush et al., 2008). More than half of patients with chronic pain may experience depression (Rayner et al., 2016), and depressed patients are three times more likely to be noncompliant with medical treatment recommendations (DiMatteo et al., 2000).

Among cancer patients specifically, pain-related distress may impact engagement in PSMB, and lower levels of symptom-related distress and higher self-efficacy in BC survivors with lymphedema has been linked to higher rates of adherence to lymphedema pain management
strategies (Sherman et al., 2016). Psychological factors such as FCR and pain catastrophizing have been found to influence reported pain severity (Novy & Aigner, 2014; Simard et al., 2013), and higher pain severity in turn has been correlated with less engagement in self-management behaviors in BC survivors (Miaskowski et al., 2012).

The fear-avoidance (FA) model (Lothem et al., 1983) seeks to explain why some individuals develop chronic pain and others do not (Gauthier et al., 2015; Leeuw et al., 2007). This model suggests that fear of pain may lead to avoidance behaviors (Lothem et al., 1983) that involve avoiding activities assumed to increase pain or risk of reinjury (Leeuw et al., 2007). Central to the FA model is the belief that pain means harm or injury and how patients frame their pain may influence subsequent pain relief efforts (Crombez et al., 2012). This model has been applied to individuals with chronic non-malignant pain but has not been tested in people with cancer (Gauthier et al., 2015).

FCR is one of the most commonly reported problems by cancer survivors (Baker et al., 2005). Although there is no consensus among researchers on a concrete definition of FCR, Simard et al. (2013) define it as the “fear that cancer could return or progress in the same place or in another part of the body.” Studies have found FCR to remain stable over time, and it has been correlated with younger age, higher reported physical symptoms including pain, and higher psychological distress (Simard et al., 2013). FCR involves a heightened vigilance and can have a positive effect on health behaviors (Simard et al., 2013) however, when FCR becomes excessive, it may have detrimental effects (Lee-Jones et al., 1997). Higher FCR is hypothesized to occur in women who believe their pain is chronic with negative consequences that are uncontrollable (Lee-Jones et al, 1997). Pain is a constant reminder of cancer, and heightened levels of pain-related fear are associated with disability (Leeuw et al., 2007). Although limited studies have explored the
relationship between FCR and engagement in self-management, some evidence exists to suggest that FCR may have an impact on PSMB. For example, FCR may predict the use of complementary and alternative medicine (CAM) related activities in BC survivors (Simard et al., 2013; Montazeri et al., 2007; Burstein et al., 1999), and may also impact decisions regarding the type of BC surgery women undergo (Nold et al., 2000). Thewes et al. (2016) suggest that further research on the association between FCR and health behaviours is needed.

Pain catastrophizing is another important affective barrier to PSMB and involves an exaggerated and negative evaluation of actual or anticipated pain (Sullivan et al., 2001). Pain catastrophizing has not been extensively explored in cancer survivors however, evidence suggests that pain catastrophizing may influence pain severity and engagement in PSMB. High pain catastrophizing has been found to predict higher pain intensity and disability in individuals with non-malignant pain (Picavet et al., 2002) and in BC survivors, pain catastrophizing has been linked to post-mastectomy pain syndrome (Belfer et al., 2013). Pain catastrophizing in BC survivors has also been linked to disability, less use of active coping strategies (Bishop & Warr, 2003), higher use of analgesics and over-the-counter medications, and more frequent visits to HCPs (Sullivan et al., 2001).

Self-efficacy also plays an important role in self-management behaviors (Lorig & Holman, 2003) and high self-efficacy has been correlated with engagement in more health promoting behaviors among chronic pain patients (Gatchel et al., 2007) and BC survivors (Sherman et al., 2016).

**Social Barriers**

Similarly, social support has been found to exhibit a significant impact on the experience of pain in cancer patients, with those patients who report receiving less social support also
reporting increased pain (Novy & Aigner, 2014). Social factors such as reported marital quality (Boeding et al., 2014) and spousal response to pain (Kerns et al., 1985) may also affect the experience of pain. Existing studies exploring cancer pain interventions often exclude family caregivers (see Bennett et al., 2009) despite evidence suggesting that social variables may play an important role in engagement in PSMB (Kerns et al., 1985). Newton-John (2013) suggests that although the biopsychosocial model has gained widespread acceptance in the pain literature, the social component of this model has been largely neglected. The biopsychosocial model posits that biological factors such as type of cancer treatment, psychological factors such as negative mood, and social factors such as social support interact to influence the experience of pain (Novy & Aigner, 2014).

1.4.2 Health Care Provider and Systematic Barriers

Barriers on behalf of HCPs include lack of knowledge regarding pain management (Koller et al., 2012; Pargeon et al., 1999) especially in terms of neuropathic pain (Kwon, 2014), inadequate assessment tools for pain (Kwon, 2014; Oldenmenger et al., 2009), and reluctance to administer opioids (Kwon, 2014).

System barriers to PSMB have been studied mostly in US-based populations and Canadian cancer survivors may not face the same systematic barriers. System barriers that have been identified include low referral to pain services (Kwon et al., 2014), lack of continuity in care (Luckett et al., 2013), and difficulty obtaining prescription medications due to reimbursement issues or lack of availability of analgesics at pharmacies (Schumacher et al., 2002).

1.4.3 Facilitators to PSMB

Facilitators to PSMB include variables that make engaging in PSMB easier. In BC patients, facilitators to PSMB may include access to a supportive network (Schulman-Green et al., 2011),
information on pain and PSMB (Bender et al., 2008), and self-efficacy regarding pain control (Sherman et al., 2016).

1.4.4 Section Summary

Barriers and facilitators to PSMB occur at the patient, HCP, and system level. Patient barriers, which are the focus of this study, include biological, cognitive, and affective factors. Barriers and facilitators among advanced cancer patients have been well established however, there are gaps in the existing literature. Most studies looking at barriers to cancer pain management use quantitative measures and list moderate-severe pain as inclusion criteria (see Marie et al., 2013; Bennett et al., 2009). Further, most studies do not look at pain self-management in disease-free BC survivors specifically. It is unknown whether barriers to PSMB are fully captured by existing quantitative measures, and whether or not BC survivors face the same barriers and facilitators to PSMB as advanced cancer patients.

1.5 Challenges Facing Breast Cancer Survivors

The transition from the treatment phase of cancer into the survivorship phase is often a challenging one for women with BC, who report many unmet informational and support needs post-treatment (Cappiello et al., 2007). Although cancer treatment is associated with significant morbidity (see Andersen & Kehlet, 2011), there is no standardized model of follow-up care for cancer survivors (Aziz, 2007). The survivorship phase of cancer generally means less frequent and intense monitoring by HCPs (Aziz, 2007), and BC survivors are often left to self-manage symptoms on their own (Capiello et al., 2007). Nonetheless, follow-up care is an essential part of cancer survivorship as it allows for the detection of cancer recurrence (Earle et al., 2006) and provides patients with the opportunity to communicate their physical and psychosocial concerns. Although BC survivors with active disease see cancer specialists throughout their treatment, a
study by Keating et al. (2007) found that among BCS ≥ 65 years old, most did not see a cancer specialist for annual follow-up. Instead, the majority of BC survivors of all ages return to their primary care physicians (Mao et al., 2009b). This has proven to be problematic as many primary care physicians indicate that they are not adequately informed about a patient’s cancer treatment course or cancer surveillance guidelines (Nissen et al., 2007). When asked to rate their level of satisfaction with primary care delivery in a study by Mao et al. (2009), BC survivors gave a score of 65 out of 100 for overall care and less than half believed that their primary care physicians were knowledgeable about symptoms related to cancer and cancer treatment. Even fewer BC survivors (28%) were satisfied with the communication that occurred between their primary care physicians and oncologists. In accordance with these findings, BC survivors report feeling unprepared to deal with the side effects they experience from cancer treatment and express a desire for information on persistent treatment side effects, emotional distress, and lifestyle changes (Capiello et al., 2007).

1.6 Gaps in the Literature

Much of the literature on cancer pain self-management has been conducted with advanced cancer patients (see Marie et al., 2013; Bennett et al., 2009), and studies that explore pain self-management in disease-free cancer survivors tend to aggregate their study findings such that treatment modalities and cancer site are unaccounted for (Gartner et al., 2009). Many studies on cancer pain self-management also list inclusion criteria that specify that participants must be experiencing at least moderate pain or taking analgesics to manage their pain in order to participate (see Marie et al., 2013; Koller et al., 2012; Bennett et al., 2009). This criterion excludes cancer survivors who may be experiencing low pain or no pain as a result of effective self-management. Further, few studies look at PSMB from the patient perspective and most of the literature is focused
on exploring cancer PSMB from an HCP perspective using quantitative methods (Marie et al., 2013; Bennett et al., 2009).

1.7 Rationale

Breast cancer is the most commonly diagnosed cancer in women worldwide and the number of BC survivors will continue to rise. Unfortunately, a significant proportion of BC survivors experience CTP following cancer treatment, which has a negative impact on quality of life. It is unknown what disease-free BC survivors do to self-manage their pain or what barriers and facilitators to PSMB they face. Although cancer pain has been studied in relation to biological factors, more research is needed on psychosocial factors related to cancer pain and pain self-management. It is critical to explore these gaps in the literature in order to improve quality of care and facilitate the creation of appropriate pain self-management interventions.
1.8 Study Objectives and Hypotheses

1.8.1 Objectives

The primary objectives of this study were to:

1. Describe the pain self-management behaviours (PSMB) that BC survivors were engaging in
2. Describe barriers and facilitators to PSMB

The secondary objectives of this study were to:

1. Determine correlates of pain intensity and interference
2. Determine correlates of engagement in PSMB

1.8.2 Hypotheses

1. Pain intensity and interference will be negatively correlated with engagement in PSMB, chronic pain self-efficacy, and education. Pain intensity and interference will be positively correlated with younger age, pain catastrophizing, FCR, and barriers to pain self-management.

2. Engagement in PSMB will be positively correlated with self-efficacy and education. Engagement in PSMB will be negatively correlated with pain intensity and interference, pain catastrophizing, FCR, and barriers to pain self-management. It is unknown how engagement in PSMB will be related to age.
Chapter 2: Theoretical Framework

2.1 The Chronic Care Model

The model most commonly used to look at self-management for chronic conditions is the Chronic Care Model (Wagner et al., 2001). The CCM positions the health system in the larger community and includes six interrelated elements; health care organization, community resources, self-management support, delivery system design, decision support, and clinical information systems (Wagner et al., 2001).

According to the CCM, in order to improve chronic care, health care organizations must visibly support and promote chronic illness management (Wagner et al., 2001). Chronic illness support must be represented in the organization’s goals and business plan and should be encouraged by organization leaders (Wagner et al., 2001). Chronic illness support also occurs through community resources including senior centers, self-help groups, and exercise programs (Bodenheimer et al., 2002), and in order to increase access to programs in the community, it is important to have linkages with relevant agencies (Wagner et al., 2001).

Self-management as defined by the CCM involves actions on behalf of the patient aimed at maintaining health and it is integral to optimizing chronic care. Support for self-management may include emphasizing the patient’s role in maintaining their health and functionality, encouraging patients to establish action plans and set goals, identifying barriers to self-management, and problem solving to overcome barriers (Wagner et al., 2001). Increasing patient self-efficacy, providing self-management tools such as diets, blood pressure cuffs, or glucose monitors (in the case of diabetes) and assessing patient progress are all ways in which an organization can support patient self-management (Bodenheimer et al., 2002).
Optimal chronic care delivery also involves the coordinated actions of multiple caregivers (Wagner et al., 2001). It involves practice teams with clear divisions of labor, and separation of acute and chronic care teams (Bodeheimer et al., 2002). Effective chronic care delivery according to the CCM, involves effective and efficient clinical care and self-management supports (i.e. ensuring that non-clinical staff are fully utilized, assuring follow-up, and planning visits to meet patient needs) (Coleman et al., 2009).

Decision support in the CCM involves promoting clinical care that is consistent with scientific evidence and patient preferences (Coleman et al., 2009). Decision support can be promoted by embedding guidelines into daily practice through the use of electronic alerts and flow sheets (Coleman et al., 2009). Effective training to increase the relevant skills of practice team members, and increased communication with specialty groups and mental health centers may further contribute to promoting effective decision support (Wagner et al., 2001).

Lastly, clinical information systems such as an online patient registry organize patient and population data to facilitate efficient and effective care (Coleman et al., 2009). Clinical information system act as a reminder system to help primary care teams comply with guidelines, provide feedback to physicians, and as registries for planning individual patient care and conducting population-based care (Bodenheimer et al., 2002).

The CCM suggests that self-management support involves promoting confidence in patients and teaching them the skills necessary for self-management (Budhuani, 2013). Central to the CCM is communication between health-care providers and patients (Budhuani, 2013).

Despite commonly being used to explore self-management in chronic conditions, the CCM was not used to inform the present study. The CCM has received criticism for emphasizing the role of health-care providers and organizations, while overlooking the patient perspective
Further, the CCM does not help elucidate the relationship between self-management support and actual engagement in self-management behaviours (Budhuani, 2013). The present study was concerned more specifically with patient-related factors associated with pain self-management therefore, we chose to guide this study according to the Symptom Management Model, outlined below.

### 2.2 The University of California, San Francisco School of Nursing Symptom Management Model

The University of California, San Francisco School of Nursing Adapted Symptom Management Model (SMT)

The conceptual framework used to guide this study was adapted from the *University of California, San Francisco School of Nursing Symptom Management Model* (SMT). The SMT (Dodd et al., 2001) seeks to explain how symptom management occurs in the context of the individual experiencing the symptom, their environment, and health and illness factors. Individual (or ‘person’) factors include demographic, psychological, and physiological variables. Environmental factors include physical (home, work, hospital), social (support network, interpersonal relationship), and cultural (beliefs, values, practices unique to ethnic, racial, or religious group) variables. Health and illness factors include risk factors, health status, injuries, and disabilities. In the context of these variables, the SMT posits that symptom management occurs through three interrelated dimensions; symptom experience, outcomes, and components of symptom management strategies.

*Symptom experience* includes an individual’s perception, evaluation, and response to their symptom, or in the context of this study, pain. Perception involves whether an individual has symptoms (pain) or not.
Evaluation involves the meaning that individuals attribute to their pain and includes a judgment about the cause, intensity, frequency, treatability, impact, threat, and effect of pain on their life. Inherent in a cancer survivor’s judgment about pain is the question of what the pain means. For example, pain could indicate the return or progression of BC, or it could indicate a complication of surgery or treatment. Evaluation of cancer pain may play an important role in PSMB. In a qualitative study exploring met and unmet needs in BC survivors 6-24 months post-treatment, participants expressed a desire for reassurance that their symptoms were normal, and not a sign of recurrence (Thewes et al., 2004). High fear of cancer recurrence has been associated with higher reported pain severity (Simard et al. 2013) and functional impairments, and has also been found to predict the use of complementary alternative medicine and positive behavior change in cancer survivors (Simard et al., 2013). Pain catastrophizing may also influence the evaluation of pain in cancer survivors and has been associated with higher levels of disability and emotional distress, and less engagement in active coping strategies in BC survivors (Bishop & Warr, 2003). Pain catastrophizing has also been associated with higher consumption of analgesic use and higher reported post-operative pain in BC survivors (Jacobsen & Butler 1996). The impact of fear of cancer recurrence and pain catastrophizing on engagement in PSMB should be explored in light of evidence suggesting that these variables may influence health behaviors in cancer survivors.

The last component of symptom experience, response to symptoms (pain) may include physiological, psychological, sociocultural, and/or behavioral elements. Symptom experience may change over time and can be complicated by other closely related symptoms.

**Symptom management strategies** include biomedical, professional, and self-care interventions. Symptom management includes assessing a symptom, identifying focus for intervention, and action taken to achieve a desired outcome. The SMT asks what, when, why, how
much (dose), to whom, and how a given symptom management intervention is delivered. Pain self-management has been explored mostly in the context of interventions facilitated by health care providers (Bennett et al., 2009) and it is unknown what BC survivors do to self-manage pain in the absence of regular follow-up.

**Outcomes** in this model include symptom status (i.e. pain or no pain), functional and emotional status, self-care, costs, QoL, morbidity & co-morbidities, and mortality.

The modified SMT used for this study will look at PSMB on outcomes of Worst Pain severity and psychosocial barriers and facilitators to PSMB. Table 1 shows the measures in the present study applied to the SMT model.

Table 1. Study Measures Applied to the Symptom Management Model (SMT)

<table>
<thead>
<tr>
<th>Symptom (Pain) Experience</th>
<th>Perception</th>
<th>Evaluation</th>
<th>Response</th>
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<tbody>
<tr>
<td></td>
<td>▪ Presence or absence of pain&lt;br&gt;▪ Pain intensity and interference</td>
<td>▪ FCR&lt;br&gt;▪ Pain&lt;br&gt;▪ Catastrophizing&lt;br&gt;▪ Age&lt;br&gt;▪ Education&lt;br&gt;▪ Pain intensity and interference</td>
<td>▪ Pain Self-Efficacy&lt;br&gt;▪ Barriers to pain self-management&lt;br&gt;▪ Pain intensity and interference</td>
</tr>
<tr>
<td>Symptom Management</td>
<td>▪ Pain Self-Management Behaviours</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Outcomes</td>
<td>▪ Engagement in PSMB&lt;br&gt;▪ Pain intensity and interference</td>
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Chapter 3: Methods

3.1 Study Design

The present study used a sequential explanatory mixed-methods (Creswell, 2015; Creswell et al., 2003) cross-sectional design. Mixed-methods studies include both quantitative and qualitative data and “involve integration of the data at one or more stages in the process of research” (Creswell et al., 2003). Sequential explanatory studies usually involve the collection of quantitative data first, followed by the collection of qualitative data, which aim to help explain quantitative findings (Creswell, 2015; Creswell et al., 2003). Sequential explanatory studies integrate data at the interpretation phase of the study, and may formally integrate findings in the study discussion (Creswell et al., 2003).

This study was a sub-study of a larger longitudinal study that followed BC survivors for 1 year post-treatment (see Figure 1). The first follow-up of the larger study (T0) captured participants at their first post-operative appointment following BC surgery and the second follow-up (T1) occurred before radiation and/or after chemotherapy completion (± 1 month). This study analyzed data from T2, which occurred 6 months after T1 (± 2 months), following primary cancer treatment (i.e. surgery plus radiation and/or chemotherapy). Quantitative data was collected through questionnaires and determined eligibility for participation in one-on-one qualitative interviews which took place after T2 questionnaires were returned at the participant’s earliest convenience.

A mixed-method study design was used for several reasons. There are a lack of mixed-methods studies in the existing literature, which is mostly limited to quantitative studies that look at PSMB in advanced cancer patients (see Marie et al., 2013; Bennet et al., 2009). BC survivors may differ from advanced cancer patients in functional status and their ability to engage in different PSMB, and BC survivors may evaluate their pain differently, and factors such as FCR and pain
catastrophizing can influence pain intensity (Simard et al. 2013; Belfer et al., 2013; Bishop & Warr, 2003). BC survivors may also lack appropriate resources for pain management (Aziz, 2007) and availability of support may influence engagement in PSMB (Stewart et al., 2014). Quantitative studies fail to fully elucidate the relationship between these variables, and also do not identify preferences for PSMB, what PSMB are most effective, why they are effective, and how patients come engage in them. Further, there is no validated quantitative measure to evaluate PSMB in BC survivors, and it was unknown if all of the PSMB that BC survivors engage in would be captured by the PSCBQ used in this study.

A qualitative descriptive method (as described by Colorafi & Evans, 2016; Kim et al., 2016; Sandelowski, 2010; Sandelowski, 2000) was used to collect and analyze qualitative data. Qualitative description involves low inference in analysis and is not as highly interpretive as other qualitative methods (Sandelowski, 2010; Sandelowski, 2000). Instead, findings stay closer to the data but are not free from interpretation (Sandelowski, 2010). Features characteristic of qualitative description include a naturalistic perspective, minimally to semi-structured interviews, purposive sampling, and straightforward data representation (Kim et al., 2016; Sandelowski, 2000).

3.2 Inclusion/Exclusion Criteria

Quantitative

This sub-study used the same inclusion criteria as the larger longitudinal study. Women ≥18 years old who underwent BC surgery at Princess Margaret Cancer Centre (± chemotherapy, radiation, tamoxifen, AI, raloxifene, trastuzumab) and who had sufficient English language were eligible to participate in this study. Women with documented cognitive impairment or who scored below a cut-off on a cognitive screen (<20) were ineligible so as to ensure that all participants were capable of providing informed consent.
Qualitative

Purposive sampling was used to identify eligible participants for qualitative interviews based on scores on the Brief Pain Inventory (BPI) and the Pain Self-Care Behaviors Questionnaire (PSCBQ). Eligible participants were categorized into one of four groups based on Worst Pain intensity and the Total Number of PSMB reported via the PSCBQ (see Figure 2). High pain intensity was pain reported as ≥4/10 (moderate to severe pain), and low pain intensity was reported as ≤3/10 (mild pain) (Gartner et al., 2009). The mean number of PSMB across participants was calculated and high/low Total Number of PSMB were considered to be above or below the overall sample mean, respectively.

Participants were categorized by pain intensity and engagement in PSMB in order to ensure diversity in pain intensity and level of engagement in PSMB. Division of participants on these measures was also made based on evidence showing that BC survivors with lower functional status (and presumably less ability to engage in physical PSMB) are at higher risk of experiencing moderate-severe pain (Miaskowski et al., 2012). Care was taken to try and ensure equal distribution of participants across the four categories. Participants were ineligible to participate in interviews if they reported not engaging in any PSMB (a score of zero via the PSCBQ).
3.3 Procedure

Eligible BC patients attending their first follow-up appointment post-surgery at Princess Margaret Cancer Centre in Toronto, Ontario were identified through the Pathways Healthcare Scheduling (PHS) system. Patient medical charts were then accessed through Electronic Patient Records (EPR) in order to confirm eligibility (i.e. post-op status and planned for further treatment). Eligible patients were first informed about the study by a member of their health care team such as their surgeon or nurse, who asked patients if they would be willing to speak to a research assistant (RA). Patients who expressed an interest in participating were approached by a RA who described the study to them in further detail and completed informed consent with those patients who agreed to participate. Consenting participants completed a short cognitive screen at the time of their initial meeting to confirm their ability to provide informed consent and complete study measures. Participants were mailed questionnaires with return postage to complete at home and send back via mail. Participants completed measures of pain, pain self-management, and physical and psychosocial wellbeing (see measures below). There was also a brief demographics and pain assessment questionnaire that took place over the phone at every follow-up.

Purposive sampling based on Total Number of PSMB (PSCBQ) and Worst Pain intensity (BPI) identified a smaller subset of study participants who participated in semi-structured interviews exploring PSMB and barriers and facilitators to PSMB (see Interview Guide, Appendix A). The interview guide was informed by the University of California, San Francisco Symptom Management Model, and existing literature on barriers (Gunnarsdottir et al., 2002) and facilitators (Novy & Aigner, 2014; Gatchel et al., 2007, Lorig & Holman, 2003) to PSMB. The interview guide was created with the explanatory study design in mind and sought to expand on quantitative findings in terms of how, what, why, where, and when participants engaged in PSMB. The
interview guide was developed collaboratively between study team members and two researchers with expertise in qualitative data collection were consulted.

Participants indicated their interest in participating in an interview at the initial meeting (T0) and were contacted by a RA after returning T2 questionnaires if they met the eligibility criteria outlined above. Participants who agreed to an interview signed a separate informed consent informing them that their interview would be audio-recorded and transcribed. Interviews were transcribed by a RA in Microsoft Word. Interviews took place over the phone or in-person when possible, and were approximately 30 minutes in length. Telephone interviews are common in qualitative data collection and there is little evidence to suggest they are produce less quality data than in-person interviews (Novick, 2008).

3.4 Quantitative Measures

Demographics

Demographic information collected from participants included age, marital and employment status, living arrangement, level of education, and type of surgery and treatment.

Short Orientation-Memory-Concentration Test (SOMC)

The SOMC is a validated 6-item assessment aimed at detecting cognitive impairment. Items include questions such as ‘What year is it now?’ and ‘Count backwards from 20 to 1.’ This study used a cutoff of <20 to indicate cognitive impairment that excluded participants from the study. The SOMC is a validated tool (Katzman et al., 1983) and has been used with cancer patients (e.g. Rodin et al., 2007).

Brief Pain Inventory (BPI)

The BPI is a valid and reliable tool (Cleeland & Ryan, 1994) used to measure pain intensity (Worst, Least, and Average Pain over the past 24 hours) and interference with daily living on a
scale from 0-10. It includes a pain map which asks participants to indicate where they are experiencing pain, and a question that asks participants to rate how much relief from pain treatments and medications they experience on a scale from 0-100%. It has been used extensively with cancer patients (see Bennett et al., 2009). Cronbach’s alphas for the BPI Interference subscale and the BPI Pain Intensity subscale in the present study were .940 and .927 respectively.

Pain Catastrophizing Scale (PCS)

The PCS is a valid and reliable tool (Sullivan et al., 1995) used to assess pain catastrophizing. It includes a Total Score, and three subscales that evaluate rumination, helplessness, and magnification. The PCS asks participants to rate their level of agreement with each item on a scale from 0-4. PCS Total Scores range from 0-52. The PCS has been used with breast cancer patients (e.g. Bishop & Warr, 2003). Cronbach’s alpha was .903 for PCS Total Score in the present study.

Quality of Life in Adult Cancer Survivors Distress-Recurrence Subscale (DRS)

The DRS is a valid and reliable subscale of the Quality of Life in Adult Cancer Survivors scale used to assess fear of cancer recurrence (Avis et al., 2005). It asks participants to indicate their level of agreement on a 7-point Likert scale on statements such as ‘You worried about dying from cancer.’ The DRS has been found to possess good psychometric properties in BC survivors (Avis et al., 2006) and is calculated as a Total Score (possible range 4-28). Cronbach’s alpha for the DRS was .916 in the present study.

Barriers Questionnaire II (BQ-II)

The BQ-II is a valid and reliable 27-item tool (Gunnarsdottir et al., 2002) that evaluates barriers to pain management such as misconceptions about analgesics, fatalistic beliefs about cancer pain, poor communication with health care providers, and fears of addiction. Participants
are asked to rate their level of agreement with each item on a scale from 0-5. The BQ-II has been used with cancer patients (Gunnarsdottir et al., 2002) and includes a Total Score and four subscale scores. Cronbach’s alpha for the BQ-II Total Score was .903 in the present study.

Chronic Pain Self Efficacy Scale (CPSE)

The CPSE is a validated and reliable 22-item scale (Anderson et al., 1995) that measures pain self-efficacy in managing chronic pain. It has been used with lung cancer patients (Porter et al., 2008) and involves calculation of three subscales: Physical Functioning, Pain Management, and Coping with Symptoms. Mean CPSE scores ranged from 0-100. Cronbach’s alphas for the CPSE subscales were as follows: .870 (Physical Functioning), .823 (Pain Management), and .870 (Coping with Symptoms).

Pain Self-Care Behaviors Questionnaire (PSCBQ)

The PSCBQ (Miaskowski, written communication) is a 25 item, non-validated questionnaire that identifies what PSMB participants are engaging in, as well as how effective those PSMB are for pain relief (see Appendix B). Items ask participants to indicate ‘yes’ or ‘no’ as to whether or not they have engaged in a given PSMB in the past week (e.g. exercise). For endorsed items, participants are asked to rate how effective that PSMB is in helping with pain on a scale from 0-10. The PSCBQ has been used with cancer patients (Koller et al., 2013) and in patients with end-stage liver disease (Hansen et al., 2014). Three subscale scores were calculated via the PSCBQ: Total Number of PSMB (sum of all endorsed PSCBQ items), Mean Effectiveness (average effectiveness of endorsed PSCBQ items), and Maximum Effectiveness (highest recorded effectiveness score on PSCBQ). Cronbach’s alpha for the Total Number of PSMB was .773. There were too few cases to analyze the Cronbach’s alpha value for Mean Effectiveness.
3.5 Data Analysis

3.5.1 Quantitative Analysis

Quantitative data analysis was conducted using SPSS Version 20.0 for Windows. Data was checked for normality using the Shapiro-Wilk test. Bivariate analysis was conducted using Pearson correlation when data was normally distributed, and using Spearman’s rank order correlation when it was not.

Descriptive statistics were used to describe participant demographic and treatment factors. Descriptive statistics were also used to describe participant pain intensity and interference. Means, medians, and standard deviations were calculated for the Worst, Least, and Average Pain scores, and Pain Interference via the BPI.

Descriptive statistics were further calculated in order to identify the PSMB that BC survivors were engaging in. The proportion of participants engaging in each individual item on the PSCBQ was calculated and individual PSCBQ items were ranked from most to least common. Means and standard deviations were also calculated for the Total Number of PSMB reported, and for Mean and Maximum reported ‘Effectiveness’ via the PSCBQ. Mean Effectiveness was calculated as the average effectiveness of every endorsed item on the PSCBQ. Maximum Effectiveness was the highest Effectiveness rating assigned to an endorsed PSMB via the PSCBQ.

Descriptive statistics were calculated for all psychosocial measures including the BQ-II, the PCS, FCR, and the CPSE. Means, medians, and standard deviations were calculated for each subscale and Total Score of the BQ-II (Gunnarsdottir et al., 2002). A Total Score was calculated for the PCS (Sullivan et al., 1995) and FCR Total (Avis et al., 2005). Three subscales (Pain Management, Physical Functioning, and Coping with Symptoms) were calculated via the CPSE (Anderson et al., 1995).
Correlations between pain intensity (Worst, Least, and Average Pain), Pain Interference, and independent variables (BQ-II, PCS, FCR, and CPSE subscales) were calculated. Results were reported according to strength of the correlation (low >±0.1, moderate >±0.3, high >±0.5; Field, 2009).

Correlations were also calculated between engagement in PSMB and pain intensity/interference, and engagement in PSMB and independent variables (BQ-II, PCS, FCR, and CPSE subscales). Engagement in PSMB was operationalized as the Total Number of PSMB, Mean Effectiveness, and Maximum Effectiveness reported via the PSCBQ. First, correlations were calculated between BPI items and the Total Number of PSMB reported via the PSCBQ. Next, correlations were calculated between BPI items and Mean Effectiveness and lastly, correlations were calculated between BPI items and Maximum Effectiveness.

3.5.2 Qualitative Analysis

Qualitative descriptive studies are generally analyzed using thematic or content analysis (Colorafi & Evans, 2016; Kim et al., 2017; Sandelowski, 2010; Sandelowski, 2000). The present study used directed content analysis (as described by Vaismoradi et al., 2013; Elo & Kyngas, 2008; Hshieh & Shannon, 2005) to analyze findings and identify themes and subthemes related to PSMB and barriers and facilitators to PSMB within the data.

First, interview data was analyzed deductively (Hshieh & Shannon, 2005) using a preliminary codebook that was based on evidence from the existing literature and theory on PSMB (see Appendix C). Initial categories included known PSMB such as taking pain medication, distraction strategies, and exercise (Pain Self-Care Behaviours Questionnaire). Known barriers to PSMB included beliefs about pain medication and poor communication with health care providers (Gunnarsdottir et al., 2002), and known facilitators included self-efficacy (Torresean et al., 2015;
Gatchel et al., 2007) and social support (see Novy & Aigner, 2014). Interviews were revisited after preliminary coding and analyzed using inductive analysis (Hshieh & Shannon, 2005), and new categories and codes were added to the existing codebook as they emerged. Frequency of PSMB and barriers/facilitators was recorded in order to provide insight into how commonly they were reported by participants.

Interviews were conducted until saturation was reached and no new themes continued to emerge. Kim et al. (2017) found the majority of qualitative studies using content or thematic analysis published in 2014 included 8-30 participants, and many studies that used content analysis included 10 participants or less (e.g. Ahlin et al., 2014; Gaughan et al., 2014; Sturesson & Ziegert et al., 2014).

Qualitative rigor was established in several ways. Credibility was established through peer debriefing and member-checking among the research team. Regular meetings between the author and thesis supervisor, and between the author and program advisory committee members were held to discuss any challenges that arose during qualitative data collection. Further, the preliminary codebook used in this study was informed by the existing literature and agreed upon by all members of the research team. Dependability was established through external audit and a researcher with qualitative expertise who was not a member of the research team reviewed the first two interviews transcribed for the present study and provided feedback regarding question probes and overall interviewing style. Interviews were also fully or partially transcribed by the author and read several times before coding began.

3.6 Integration of Findings

The quantitative and qualitative data collected for this study were analyzed separately. The quantitative results of this study are reported followed by the qualitative results (Creswell, 2015).
Integration of findings occurred during the purposive sampling phase of qualitative data collection. Integration also occurred during the description phase of this study and can be found in the discussion (Creswell et al., 2003).

3.7 Ethics

The present study was reviewed and approved by the Research Ethics Board at the University Health Network in February 2014, and approved for renewal from 2015-2017 (see Appendix D).

3.8 Role as Researcher

Bias or skewedness in a research study are sometimes viewed as undesirable however, researchers approach problems with different perspectives which can lead to the development of different but equally valid findings (Cohen & Crabtree, 2006). It is important to state that my interest in pain self-management in BC survivors comes from my broader interest in psychosocial oncology and psychosocial predictors and correlates of pain. I entered into this study with the assumption that pain is a multidimensional experience that includes biopsychosocial components. I chose to focus primarily on psychosocial variables related to pain self-management in part because of my own interest in these phenomena but largely due to lack of research in this area. Most research on cancer pain has looked at biological factors related to pain experience such as type of cancer treatment (surgery, chemotherapy, radiation) but these variables only tell part of the story (Heathcote & Eccleston, 2017).
Figure 1

Figure 1. Study Design

*T2=data collection timepoint
Figure 2

Figure 2. Qualitative Data Collection Purposive Sampling Criteria

*Worst Pain score on the Brief Pain Inventory was used to measure pain intensity; #PSMB (overall sample mean of Total Number of PSMB via the Pain Self-Care Behaviors Questionnaire); X=mean*
Chapter 4: Results

4.1 Quantitative Results

4.1.1 Participant Demographics

Participant demographic factors are displayed in Table 2. Participants (n=53) were disease-free, female BC survivors who were 6 months (±2 months) post-treatment (surgery ± radiation, and/or chemotherapy) for BC, and were a mean age of 60.69 (±10.15).

Table 2. Participant Demographics

<table>
<thead>
<tr>
<th></th>
<th>n (%)</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Age</strong></td>
<td>Mean ± SD (range) 60.09 ± 10.15 (38-79 yrs)</td>
</tr>
<tr>
<td>≥ 60 years old</td>
<td>29 (54.7)</td>
</tr>
<tr>
<td>&lt; 60 years old</td>
<td>24 (45.3)</td>
</tr>
<tr>
<td><strong>Education</strong></td>
<td></td>
</tr>
<tr>
<td>High School</td>
<td>7 (13.2)</td>
</tr>
<tr>
<td>College</td>
<td>14 (26.4)</td>
</tr>
<tr>
<td>University</td>
<td>18 (34.0)</td>
</tr>
<tr>
<td>Master’s Degree</td>
<td>9 (17.0)</td>
</tr>
<tr>
<td>Doctoral Degree</td>
<td>1 (1.9)</td>
</tr>
<tr>
<td>Professional Degree</td>
<td>4 (7.5)</td>
</tr>
<tr>
<td><strong>Race</strong></td>
<td></td>
</tr>
<tr>
<td>White</td>
<td>47 (88.7)</td>
</tr>
<tr>
<td>Black</td>
<td>1 (1.9)</td>
</tr>
<tr>
<td>Asian</td>
<td>5 (9.4)</td>
</tr>
<tr>
<td>Other</td>
<td>0 (0)</td>
</tr>
<tr>
<td><strong>Marital Status</strong></td>
<td></td>
</tr>
<tr>
<td>Single</td>
<td>13 (24.5)</td>
</tr>
<tr>
<td>Married or Common Law</td>
<td>26 (49.1)</td>
</tr>
<tr>
<td>Separated or Divorced</td>
<td>10 (18.9)</td>
</tr>
<tr>
<td>Widowed</td>
<td>4 (7.5)</td>
</tr>
<tr>
<td><strong>Employment Status</strong></td>
<td></td>
</tr>
<tr>
<td>Working</td>
<td>23 (43.4)</td>
</tr>
<tr>
<td>Not working</td>
<td>30 (56.6)</td>
</tr>
<tr>
<td><strong>Living Arrangement</strong></td>
<td></td>
</tr>
<tr>
<td>Alone</td>
<td>19 (35.8)</td>
</tr>
<tr>
<td>w/ Partner Alone</td>
<td>15 (28.3)</td>
</tr>
<tr>
<td>w/ Partner + Children</td>
<td>11 (20.8)</td>
</tr>
<tr>
<td>w/ Children Alone</td>
<td>5 (9.4)</td>
</tr>
<tr>
<td>Other</td>
<td>3 (5.7)</td>
</tr>
</tbody>
</table>

*SD (standard deviation); n=total number of participants
Most participants were white (88.7%) and highly educated (86.8% had a college degree or higher). Most were not working (56.6%), married or in common law relationships (49.0%), and most lived with family (58.5%).

4.1.2 Participant Treatment Factors

Participant treatment factors are summarized in Table 3. Most participants underwent lumpectomy plus sentinel node biopsy (52.8%), and received radiation (50.9%). The majority (67.9%) of participants reported taking some form of hormone therapy at the time of follow-up with Tamoxifen being the most commonly reported treatment.

Table 3. Participant Treatment Factors

<table>
<thead>
<tr>
<th>Type of Sx</th>
<th>Alone</th>
<th>+SNB</th>
<th>+AND</th>
<th>+SNB/AND</th>
</tr>
</thead>
<tbody>
<tr>
<td>Lumpectomy</td>
<td>6 (11.3)</td>
<td>28 (52.8)</td>
<td>1 (1.9)</td>
<td>1 (1.9)</td>
</tr>
<tr>
<td>Mastectomy</td>
<td>2 (3.8)</td>
<td>10 (18.9)</td>
<td>3 (5.7)</td>
<td>1 (1.9)</td>
</tr>
<tr>
<td>Other</td>
<td>-</td>
<td>1 (1.9)</td>
<td>-</td>
<td>-</td>
</tr>
<tr>
<td>Radiation</td>
<td>27 (50.9)</td>
<td>-</td>
<td>-</td>
<td>-</td>
</tr>
<tr>
<td>Chemotherapy</td>
<td>2 (3.8)</td>
<td>-</td>
<td>-</td>
<td>-</td>
</tr>
<tr>
<td>Both</td>
<td>14 (26.4)</td>
<td>-</td>
<td>-</td>
<td>-</td>
</tr>
<tr>
<td>None</td>
<td>10 (18.9)</td>
<td>-</td>
<td>-</td>
<td>-</td>
</tr>
<tr>
<td>Tamoxifen</td>
<td>22 (41.5)</td>
<td>-</td>
<td>-</td>
<td>-</td>
</tr>
<tr>
<td>Letrozole</td>
<td>9 (17.0)</td>
<td>-</td>
<td>-</td>
<td>-</td>
</tr>
<tr>
<td>Other</td>
<td>5 (9.4)</td>
<td>-</td>
<td>-</td>
<td>-</td>
</tr>
<tr>
<td>None</td>
<td>16 (30.2)</td>
<td>-</td>
<td>-</td>
<td>-</td>
</tr>
<tr>
<td>Unknown</td>
<td>1 (1.9)</td>
<td></td>
<td></td>
<td></td>
</tr>
</tbody>
</table>

*Sx (surgery); SNB (Sentinel Node Biopsy); AND (Axillary Node Dissection)

**Note: When participants reported having more than one sx, the more invasive sx of the two was reported. Prevalence was reported as n (%).
4.1.3 Participant Pain Intensity

BPI Worst, Least, and Average Pain, and BPI Interference scores were not normally distributed according to the Shapiro-Wilk test (p<0.01). Mean and median participant pain intensity scores reported via the Brief Pain Inventory (BPI) are displayed in Table 4.

The majority of participants (69.8%) reported having some pain in the past 24 hours (BPI Worst Pain > 0) and about one-third of participants (30.2%) reported no pain (BPI Worst Pain score of 0). Of the participants who reported pain (n=37), 19 (51.4%) rated their pain as mild (BPI Worst Pain ≥1≤3), 13 (35.1%) rated their pain as moderate (≥4≤6), and 5 (13.5%) rated their pain as severe (≥7≤10). Mean Pain Interference was 1.53 ± 1.98.

Table 4. Participant Pain Intensity

<table>
<thead>
<tr>
<th>BPI Item</th>
<th>Mean</th>
<th>SD</th>
<th>Median</th>
</tr>
</thead>
<tbody>
<tr>
<td>BPI Worst</td>
<td>2.58</td>
<td>2.51</td>
<td>2.00</td>
</tr>
<tr>
<td>BPI Least</td>
<td>1.23</td>
<td>1.75</td>
<td>1.00</td>
</tr>
<tr>
<td>BPI Average</td>
<td>1.94</td>
<td>2.12</td>
<td>1.00</td>
</tr>
<tr>
<td>BPI Interference</td>
<td>1.53</td>
<td>1.98</td>
<td>0.57</td>
</tr>
</tbody>
</table>

*BPI (Brief Pain Inventory); SD (Standard Deviation); n=53 for BPI Worst, Least, and Average Pain; n=51 for BPI Interference

4.1.4 Objective 1: Descriptive Statistics of the PSCBQ

The proportions of participants who reported engaging in each individual item of the PSCBQ are listed in Table 5, listed from highest to lowest endorsed item. The most commonly reported PSMB were going for a walk (71.7%), distraction strategies such as listening to music/radio (69.9%), watching TV (67.9%), and reading (67.9%), other exercise such as jogging or swimming (58.5%), and relaxation exercises (47.2%).

The mean Total Number of PSMB (sum of all items endorsed via the PSCBQ) reported by participants was 6.55±3.51 out of a possible 25, and Mean Effectiveness (average effectiveness of all endorsed items on the PSCBQ) was 4.83±2.51 out of 10. The mean ‘Maximum Effectiveness’
The highest rated ‘Effectiveness’ item for each participant via the PSCBQ was 6.69±2.63 out of 10.

### Table 5. Descriptive Statistics of the Pain Self-Care Behaviours Questionnaire (PSCBQ)

<table>
<thead>
<tr>
<th>Pain Self-Care Behavior</th>
<th>n (%)</th>
<th>Mean Effectiveness (SD)</th>
</tr>
</thead>
<tbody>
<tr>
<td>Went for a walk</td>
<td>38 (71.7)</td>
<td>4.95 (3.51)</td>
</tr>
<tr>
<td>Listened to radio, music</td>
<td>37 (69.9)</td>
<td>4.46 (2.99)</td>
</tr>
<tr>
<td>Watched TV</td>
<td>36 (67.9)</td>
<td>4.68 (2.93)</td>
</tr>
<tr>
<td>Read a book, newspaper, or magazine</td>
<td>36 (67.9)</td>
<td>4.34 (2.96)</td>
</tr>
<tr>
<td>Did exercises (jogging, swimming etc.)</td>
<td>31 (58.5)</td>
<td>4.83 (2.82)</td>
</tr>
<tr>
<td>Did relaxation exercises, meditated</td>
<td>25 (47.2)</td>
<td>5.00 (2.66)</td>
</tr>
<tr>
<td>Took a nap</td>
<td>24 (45.3)</td>
<td>5.09 (2.70)</td>
</tr>
<tr>
<td>Reduced my level of activity</td>
<td>19 (35.8)</td>
<td>4.80 (2.78)</td>
</tr>
<tr>
<td>Drank beer, wine, or other alcohol</td>
<td>17 (32.1)</td>
<td>3.57 (3.16)</td>
</tr>
<tr>
<td>Took a hot bath</td>
<td>15 (28.3)</td>
<td>5.13 (2.42)</td>
</tr>
<tr>
<td>Had a massage</td>
<td>13 (24.5)</td>
<td>7.33 (1.30)</td>
</tr>
<tr>
<td>Used a heating pad or hot water bottle</td>
<td>10 (18.9)</td>
<td>5.11 (2.67)</td>
</tr>
<tr>
<td>Reduced my work hours</td>
<td>10 (18.9)</td>
<td>4.18 (3.43)</td>
</tr>
<tr>
<td>Asked for help</td>
<td>9 (17.0)</td>
<td>4.56 (2.92)</td>
</tr>
<tr>
<td>Used assistive devices</td>
<td>5 (9.4)</td>
<td>6.00 (2.12)</td>
</tr>
<tr>
<td>Went to a chiropractor</td>
<td>4 (7.5)</td>
<td>7.00 (1.83)</td>
</tr>
<tr>
<td>Used an ice pack</td>
<td>4 (7.5)</td>
<td>4.00 (2.45)</td>
</tr>
<tr>
<td>Used a transcutaneous electrical stimulator (TENS)</td>
<td>3 (5.7)</td>
<td>7.50 (0.71)</td>
</tr>
<tr>
<td>Went for acupuncture treatment</td>
<td>3 (5.7)</td>
<td>5.33 (1.16)</td>
</tr>
<tr>
<td>Went for counseling</td>
<td>3 (5.7)</td>
<td>4.67 (4.16)</td>
</tr>
<tr>
<td>Took tranquilizers</td>
<td>2 (3.8)</td>
<td>6.50 (2.12)</td>
</tr>
<tr>
<td>Ultrasonic stimulation treatment</td>
<td>1 (1.9)</td>
<td>6.00</td>
</tr>
<tr>
<td>Used magnets</td>
<td>1 (1.9)</td>
<td>1.00</td>
</tr>
<tr>
<td>Had a trigger point injection</td>
<td>0 (0)</td>
<td>-</td>
</tr>
<tr>
<td>Did hypnosis</td>
<td>0 (0)</td>
<td>-</td>
</tr>
</tbody>
</table>

*PSCBQ (Pain Self-Care Behaviours Questionnaire); n (total number of participants); SD (Standard Deviation)

**Note: Participants endorsed items they had engaged in ‘over the past week’
The most effective PSMB rated on a 0-10 scale, were massage (7.33±1.30), seeing a chiropractor (7.00±1.83), and using the TENS machine (7.50±0.71). Of the PSMB items that were endorsed by ≥30 participants, walking was rated as most effective (4.95±3.15), followed by distraction activities such as watching TV (4.68±2.93), listening to radio/music (4.46±2.99), and reading (4.34±2.96), and general exercise (4.83±2.82).

When tested for normality using the Shapiro-Wilk test, Total Number of PSMB and Mean Effectiveness were normally distributed (p>0.05). Maximum Effectiveness was not normally distributed (p<0.01).

4.1.5 Descriptive Statistics of the BQ-II

Means, medians, and standard deviations for each subscale of the BQ-II (Physiological Effects, Fatalism, Communication, Harmful Effects) and the BQ-II Total Score are reported in Table 6. The BQ-II Total Score, Physiological Effects, and Harmful Effects subscales were normally distributed (p>0.05) however, the Fatalism and Communication subscales were not (p<0.05 and p<0.01 respectively) according to the Shapiro-Wilk test.

Table 6. Descriptive Statistics of the Barriers Questionnaire-II (BQ-II)

<table>
<thead>
<tr>
<th>BQ-II subscale</th>
<th>Mean</th>
<th>SD</th>
<th>Median</th>
</tr>
</thead>
<tbody>
<tr>
<td>BQ-II Harmful Effects</td>
<td>2.19</td>
<td>1.16</td>
<td>2.17</td>
</tr>
<tr>
<td>BQ-II Communication</td>
<td>1.14</td>
<td>0.98</td>
<td>1.00</td>
</tr>
<tr>
<td>BQ-II Physiological Effects</td>
<td>1.89</td>
<td>1.04</td>
<td>2.08</td>
</tr>
<tr>
<td>BQ-II Fatalism</td>
<td>1.38</td>
<td>1.05</td>
<td>1.33</td>
</tr>
<tr>
<td>BQ-II Total Score</td>
<td>1.73</td>
<td>0.82</td>
<td>1.86</td>
</tr>
</tbody>
</table>

*SD (Standard Deviation); n=53 for all subscales and Total Score
4.1.6 Descriptive Statistics of Independent Variables

The Shapiro-Wilk test of normality was computed to determine the distribution of all independent variables including FCR (DRS), PCS, and CPSE (Coping with Symptoms, Physical Functioning, and Pain Management). Results found that all independent variables were not normally distributed (p<.001). Means, medians, and standard deviations for all psychosocial measures are displayed in Table 7.

Table 7. Descriptive Statistics of Independent Variables

<table>
<thead>
<tr>
<th>Measure</th>
<th>Mean</th>
<th>SD</th>
<th>Median</th>
</tr>
</thead>
<tbody>
<tr>
<td>Pain Catastrophizing</td>
<td>7.77</td>
<td>7.97</td>
<td>5.00</td>
</tr>
<tr>
<td>Fear of Cancer Recurrence</td>
<td>11.09</td>
<td>5.74</td>
<td>10.00</td>
</tr>
<tr>
<td>Coping with Symptoms (CPSE)</td>
<td>75.39</td>
<td>16.93</td>
<td>76.25</td>
</tr>
<tr>
<td>Physical Functioning (CPSE)</td>
<td>88.49</td>
<td>13.61</td>
<td>94.44</td>
</tr>
<tr>
<td>Pain Management (CPSE)</td>
<td>71.55</td>
<td>20.41</td>
<td>74.00</td>
</tr>
</tbody>
</table>

*CPSE (Chronic Pain Self-Efficacy Scale); SD (Standard Deviation); n=53 for all subscales

4.1.7 Objective 3: Correlates of Pain Intensity and Pain Interference

Psychosocial Measures

Spearman’s rank-order correlations were calculated between BPI Interference, BPI Worst, Least, and Average pain, and overall PCS, FCR (DRS), and CPSE subscales. Results are displayed in Table 8.

High correlations were found between BPI Interference and PCS Total (r=.511, p<.001), and BPI Interference and CPSE Physical Functioning (r= -.736, p<.001). Moderate correlations were found between BPI Interference and CPSE Pain Management (r= -.490, p<.001), CPSE Coping with Symptoms (r= -.439, p<.01), and FCR Total (r=.379, p<.01).

Moderate correlations (0.3-0.5) were found between BPI Worst Pain score and PCS Total (r=.401, p<.01), CPSE Physical Functioning subscale (r= -.484, p<.001), and CPSE Pain
Management subscale ($r = -0.343, p<0.05$). No significant correlation were found between BPI Worst Pain and FCR Total or CPSE Coping with Symptoms.

Moderate correlations were also found between BPI Least Pain score and PCS Total ($r = 0.419, p<0.01$), CPSE Physical Functioning ($r = -0.421, p<0.01$), and CPSE Pain Management ($r = -0.315, p<0.05$). A low correlation was found between BPI Least Pain and CPSE Coping with Symptoms subscale ($r = -0.276, p<0.05$). No correlation was found between BPI Least Pain and FCR Total.

Table 8. Correlations between Pain Intensity and Independent Variables

<table>
<thead>
<tr>
<th></th>
<th>Spearman’s Rank-Order Correlations</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>PCS Total</td>
</tr>
<tr>
<td><strong>BPI Worst</strong></td>
<td>Spearman’s rho</td>
</tr>
<tr>
<td></td>
<td>.401</td>
</tr>
<tr>
<td></td>
<td>p-value</td>
</tr>
<tr>
<td></td>
<td>.003</td>
</tr>
<tr>
<td></td>
<td>n</td>
</tr>
<tr>
<td></td>
<td>53</td>
</tr>
<tr>
<td><strong>BPI Least</strong></td>
<td>Spearman’s rho</td>
</tr>
<tr>
<td></td>
<td>.419</td>
</tr>
<tr>
<td></td>
<td>p-value</td>
</tr>
<tr>
<td></td>
<td>.002</td>
</tr>
<tr>
<td></td>
<td>n</td>
</tr>
<tr>
<td></td>
<td>53</td>
</tr>
<tr>
<td><strong>BPI Average</strong></td>
<td>Spearman’s rho</td>
</tr>
<tr>
<td></td>
<td>.440</td>
</tr>
<tr>
<td></td>
<td>p-value</td>
</tr>
<tr>
<td></td>
<td>.001</td>
</tr>
<tr>
<td></td>
<td>n</td>
</tr>
<tr>
<td></td>
<td>53</td>
</tr>
<tr>
<td><strong>BPI Interference</strong></td>
<td>Spearman’s rho</td>
</tr>
<tr>
<td></td>
<td>.511</td>
</tr>
<tr>
<td></td>
<td>p-value</td>
</tr>
<tr>
<td></td>
<td>&lt;.001</td>
</tr>
<tr>
<td></td>
<td>n</td>
</tr>
<tr>
<td></td>
<td>51</td>
</tr>
</tbody>
</table>

*BPI (Brief Pain Inventory); PCS Total (Pain Catastrophizing Scale Total Score); FCR Total (Quality of Life in Adult Cancer Survivors Fear of Cancer Recurrence subscale Total); CPSE (Chronic Pain Self-Efficacy Scale); Pain Manage (CPSE Pain Management subscale); Coping (CPSE Coping with Symptoms subscale); Physical (CPSE Physical Functioning subscale); n (Total number of participants included in analysis)
Moderate correlations were further found between BPI Average Pain and PCS Total (r=.440, p<.01), CPSE Physical Functioning subscale (r= -.488, p<.001), and CPSE Pain Management subscale (r= -.374, p<.01). A low correlation was found between BPI Average Pain and CPSE Coping with Symptoms subscale (r= -.282, p<.05). No correlation was found between BPI Average Pain and FCR Total.

Barriers Questionnaire II

Spearman’s rank-order correlations were also calculated between BPI Interference, BPI Worst, Least, and Average pain, and the BQ-II subscales and Total Score. Results are displayed in Table 9.

Table 9. Correlations between Pain Intensity and the Barriers Questionnaire II

<table>
<thead>
<tr>
<th></th>
<th>BQ-II Comm</th>
<th>BQ-II Harmful Effects</th>
<th>BQ-II Physiological</th>
<th>BQ-II Fatalism</th>
<th>BQ-II Total Score</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>BPI Worst</strong></td>
<td>Spearman’s rho .141</td>
<td>.071</td>
<td>.141</td>
<td>-.078</td>
<td>.099</td>
</tr>
<tr>
<td></td>
<td>p-value    .313</td>
<td>.615</td>
<td>.313</td>
<td>.581</td>
<td>.480</td>
</tr>
<tr>
<td></td>
<td>n          53</td>
<td>53</td>
<td>53</td>
<td>53</td>
<td>53</td>
</tr>
<tr>
<td><strong>BPI Least</strong></td>
<td>Spearman’s rho .224</td>
<td>.046</td>
<td>.224</td>
<td>.136</td>
<td>.165</td>
</tr>
<tr>
<td></td>
<td>p-value    .107</td>
<td>.742</td>
<td>.107</td>
<td>.332</td>
<td>.238</td>
</tr>
<tr>
<td></td>
<td>n          53</td>
<td>53</td>
<td>53</td>
<td>53</td>
<td>53</td>
</tr>
<tr>
<td><strong>BPI Avg</strong></td>
<td>Spearman’s rho .166</td>
<td>.033</td>
<td>.166</td>
<td>-.036</td>
<td>.112</td>
</tr>
<tr>
<td></td>
<td>p-value    .235</td>
<td>.815</td>
<td>.235</td>
<td>.795</td>
<td>.425</td>
</tr>
<tr>
<td></td>
<td>n          53</td>
<td>53</td>
<td>53</td>
<td>53</td>
<td>53</td>
</tr>
<tr>
<td><strong>BPI Interference</strong></td>
<td>Spearman’s rho .255</td>
<td>.143</td>
<td>.314</td>
<td>.107</td>
<td>.300</td>
</tr>
<tr>
<td></td>
<td>p-value    .071</td>
<td>.317</td>
<td>.025</td>
<td>.454</td>
<td>.032</td>
</tr>
<tr>
<td></td>
<td>n          51</td>
<td>51</td>
<td>51</td>
<td>51</td>
<td>51</td>
</tr>
</tbody>
</table>

*BPI (Brief Pain Inventory); BQ-II (Barriers Questionnaire II); Avg (BPI Average Pain Score); Comm (BQ-II Communication subscale); BQ-II (BQ-II Physiological Effects subscale); n (Total number of participants included in analysis)
Moderate correlations were found between BPI Interference and BQ-II Total Score ($r=.300$, $p<.05$), and BPI Interference and BQ-II Physiological Effects subscale ($r=.314$, $p<.05$). BPI Interference was not significantly correlated with any other BQ-II subscale. No significant correlations were found between pain intensity and any dimension of the BQ-II.

Demographic Variables

Spearman’s rank-order correlations were calculated between demographic factors (age, education) and BPI Worst, Least, Average Pain, and BPI Pain Interference. No significant correlations were found between any BPI item and age or education ($p>.05$).

4.1.8 Objective 4: Correlates of Engagement in PSMB

Pain Intensity

Spearman’s rank-order correlations were calculated between BPI Interference, BPI Worst, Least, and Average Pain and engagement in PSMB (Total Number of PSMB, Mean Effectiveness, Maximum Effectiveness). Results are displayed in Table 10.

Table 10. Correlations between Pain Intensity and Engagement in PSMB

<table>
<thead>
<tr>
<th></th>
<th>PSCBQ Total Number</th>
<th>PSCBQ Max Effectiveness</th>
<th>PSCBQ Mean Effectiveness</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>BPI Worst</strong></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Spearman’s rho</td>
<td>.110</td>
<td>-.080</td>
<td>-.126</td>
</tr>
<tr>
<td>p-value</td>
<td>.431</td>
<td>.584</td>
<td>.387</td>
</tr>
<tr>
<td>n</td>
<td>53</td>
<td>49</td>
<td>49</td>
</tr>
<tr>
<td><strong>BPI Least</strong></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Spearman’s rho</td>
<td>.091</td>
<td>.038</td>
<td>-.071</td>
</tr>
<tr>
<td>p-value</td>
<td>.518</td>
<td>.795</td>
<td>.630</td>
</tr>
<tr>
<td>n</td>
<td>53</td>
<td>49</td>
<td>49</td>
</tr>
<tr>
<td><strong>BPI Avg</strong></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Spearman’s rho</td>
<td>.120</td>
<td>-.024</td>
<td>-.089</td>
</tr>
<tr>
<td>p-value</td>
<td>.393</td>
<td>.870</td>
<td>.545</td>
</tr>
<tr>
<td>n</td>
<td>53</td>
<td>49</td>
<td>49</td>
</tr>
<tr>
<td>BPI Interference</td>
<td>Spearman’s rho</td>
<td>p-value</td>
<td>n</td>
</tr>
<tr>
<td>------------------</td>
<td>----------------</td>
<td>---------</td>
<td>---</td>
</tr>
<tr>
<td></td>
<td>.320</td>
<td>.022</td>
<td>51</td>
</tr>
<tr>
<td></td>
<td>-.081</td>
<td>.586</td>
<td>48</td>
</tr>
<tr>
<td></td>
<td>-.063</td>
<td>.673</td>
<td>48</td>
</tr>
</tbody>
</table>

*BPI (Brief Pain Inventory); PSCBQ (Pain Self-Care Behaviors Questionnaire); Avg (BPI Average Pain Score)

A moderate significant correlation was found between BPI Interference and Total Number of PSMB (r=.320, p<.05). BPI Interference was not significantly correlated with Mean or Max Effectiveness. No significant correlations between pain intensity (Worst, Least, Average) and any dimension of engagement in PSMB via the PSCBQ were found.

**Psychosocial Variables**

Spearman’s Rank-Order correlations were calculated between psychosocial variables (PCS, FCR, and CPSE subscales) and engagement in PSMB (Total Number of PSMB, Mean Effectiveness, Maximum Effectiveness).

Results found a significant correlation between all three CPSE subscales and Total Number of PSMB reported via the PSCBQ. The Total Number of PSMB was negatively and moderately correlated with all three CPSE subscales including Pain Management (r=-.301, p<.05), Coping with Symptoms (r=-.422, p<.01), and Physical Functioning (r=-.484, p<0.01). The results of the Spearman’s Rank-Order correlation analysis are displayed in Table 11.

**Demographic Variables**

Bivariate analysis was also conducted between participant demographic factors and engagement in PSMB (Total Number of PSMB, Mean Effectiveness, Max Effectiveness) however, no significant correlations were found.
Table 11. Correlations between Engagement in PSMB and Psychosocial Variables

<table>
<thead>
<tr>
<th></th>
<th>PCS Total</th>
<th>FCR Total</th>
<th>CPSE Pain Manage</th>
<th>CPSE Coping</th>
<th>CPSE Phys</th>
</tr>
</thead>
<tbody>
<tr>
<td>PSCBQ Total</td>
<td>Spearman’s rho</td>
<td>.175</td>
<td>.249</td>
<td>-.301</td>
<td>-.422</td>
</tr>
<tr>
<td></td>
<td>p-value</td>
<td>.210</td>
<td>.072</td>
<td>.029</td>
<td>.002</td>
</tr>
<tr>
<td></td>
<td>n</td>
<td>53</td>
<td>53</td>
<td>53</td>
<td>53</td>
</tr>
<tr>
<td>PSCBQ Max Eff</td>
<td>Spearman’s rho</td>
<td>-.182</td>
<td>-.084</td>
<td>.035</td>
<td>.093</td>
</tr>
<tr>
<td></td>
<td>p-value</td>
<td>.212</td>
<td>.568</td>
<td>.813</td>
<td>.527</td>
</tr>
<tr>
<td></td>
<td>n</td>
<td>49</td>
<td>49</td>
<td>49</td>
<td>49</td>
</tr>
<tr>
<td>PSCBQ Mean Eff</td>
<td>Spearman’s rho</td>
<td>-.163</td>
<td>-.221</td>
<td>.013</td>
<td>.244</td>
</tr>
<tr>
<td></td>
<td>p-value</td>
<td>.263</td>
<td>.127</td>
<td>.932</td>
<td>.092</td>
</tr>
<tr>
<td></td>
<td>n</td>
<td>49</td>
<td>49</td>
<td>49</td>
<td>49</td>
</tr>
</tbody>
</table>

*PSCBQ (Pain Self-Care Behaviors Questionnaire); PCS (Pain Catastrophizing Scale); FCR (Quality of Life in Adult Cancer Survivors Fear of Cancer Recurrence subscale); CPSE (Chronic Pain Self-Efficacy Scale); CPSE Pain Manage (CPSE Pain Management subscale); CPSE Phys (CPSE Physical Functioning subscale); PSCBQ Max Eff (Maximum Effectiveness); PSCBQ Mean Eff (Mean Effectiveness); n (Total number of participants included in analysis)

**Note: Significant correlations are bolded.
4.2 Qualitative Results

4.2.1 Qualitative Sample

10 participants from the larger sample participated in an interview. 11 participants were approached to participate in an interview after initially indicating their interest at the time of consent. One participant declined to participate citing other responsibilities. Saturation of themes occurred at Interview 8 and two interviews were conducted thereafter. Participants were represented across all four purposive sampling categories (see Figure 3).

Figure 3. Participant Representation via Purposive Sampling

<table>
<thead>
<tr>
<th>HIGH PAIN</th>
<th>LOW PAIN</th>
</tr>
</thead>
<tbody>
<tr>
<td>(≥4/10)</td>
<td>(≤3/10)</td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>HIGH #PSMB</th>
<th>LOW #PSMB</th>
</tr>
</thead>
<tbody>
<tr>
<td>(&gt;X)</td>
<td>(≥0/&lt;X)</td>
</tr>
</tbody>
</table>

- HIGH-HIGH: n=3
- HIGH-LOW: n=3
- LOW-HIGH: n=2
- LOW-LOW: n=2

Qualitative participant demographic data is displayed in Table 12. Qualitative participants were a mean age of 56.40 ± 11.06 and most were University educated (60%). Mean BPI Worst Pain Score was 4.70 ± 2.90 and mean Total Number of PSMB was 7.40±2.32. Most qualitative participants underwent lumpectomy plus radiation (50%), and the majority (60%) were taking Tamoxifen at the time of interview.
Table 12. Qualitative Participant Demographic Factors

<table>
<thead>
<tr>
<th></th>
<th>Mean</th>
<th>SD</th>
</tr>
</thead>
<tbody>
<tr>
<td>Age</td>
<td>56.40</td>
<td>11.06</td>
</tr>
<tr>
<td>BPI Worst Pain</td>
<td>4.70</td>
<td>2.90</td>
</tr>
<tr>
<td>BPI Average Pain</td>
<td>4.00</td>
<td>2.58</td>
</tr>
<tr>
<td>BPI Least Pain</td>
<td>2.70</td>
<td>2.67</td>
</tr>
<tr>
<td>Total Number of PSMB</td>
<td>7.40</td>
<td>2.32</td>
</tr>
<tr>
<td>Mean Effectiveness</td>
<td>4.09</td>
<td>2.54</td>
</tr>
<tr>
<td>Maximum Effectiveness</td>
<td>6.40</td>
<td>2.95</td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>Education</th>
<th>n (%)</th>
<th>-</th>
</tr>
</thead>
<tbody>
<tr>
<td>University</td>
<td>6 (60%)</td>
<td>-</td>
</tr>
<tr>
<td>College</td>
<td>3 (30%)</td>
<td>-</td>
</tr>
<tr>
<td>High School</td>
<td>1 (10%)</td>
<td>-</td>
</tr>
</tbody>
</table>

*BPI (Brief Pain Inventory); SD (Standard Deviation)

4.2.2 Objective 1: Description of Pain Self-Management Behaviours (PSMB)

Participants described engaging in a number of PSMB that fell broadly under the categories of Physical-Exercise, Emotional, Pain Medication, Medical-Professional, Distraction, Complementary Alternative Medicine (CAM), Avoidance, and Assistive Devices. Additional categories and codes were added to the preliminary codebook as they appeared in interviews and the final codebook is displayed in Table 13.
Table 13. Pain Self-Management Behaviours (PSMB) Coding Guide

<table>
<thead>
<tr>
<th>PSMB</th>
<th>Definition</th>
<th>Examples from Participants</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Physical</strong></td>
<td>Physical or exercise-related PSMB aimed at physical rehabilitation or overall physical wellbeing</td>
<td>▪ Breast self-massage</td>
</tr>
<tr>
<td></td>
<td></td>
<td>▪ Yoga</td>
</tr>
<tr>
<td></td>
<td></td>
<td>▪ Walking</td>
</tr>
<tr>
<td></td>
<td></td>
<td>▪ Strengthening exercises/Weight training</td>
</tr>
<tr>
<td></td>
<td></td>
<td>▪ Cancer Exercise Programs</td>
</tr>
<tr>
<td></td>
<td></td>
<td>▪ Arm exercises</td>
</tr>
<tr>
<td></td>
<td></td>
<td>▪ Jogging</td>
</tr>
<tr>
<td><strong>Emotional</strong></td>
<td>Minimized the emotional impact of pain</td>
<td>▪ Meditation</td>
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<td></td>
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<td>▪ Heating pad</td>
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<td></td>
<td></td>
<td>▪ Deep breathing</td>
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<td></td>
<td></td>
<td>▪ Laugh therapy</td>
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<td></td>
<td></td>
<td>▪ Positive thinking</td>
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<tr>
<td><strong>Pain Medication</strong></td>
<td></td>
<td>▪ Prescribed</td>
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<td></td>
<td></td>
<td>▪ Over-The-Counter (OTC)</td>
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<tr>
<td><strong>Medical-Professional</strong></td>
<td>Health care providers with expertise in pain management, seen for the purpose of pain management</td>
<td>▪ Physiotherapist</td>
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<td></td>
<td></td>
<td>▪ Lymphedema clinic</td>
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<td></td>
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<td>▪ Physiatrist</td>
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<td></td>
<td></td>
<td>▪ Massage therapist</td>
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<tr>
<td><strong>Distraction</strong></td>
<td>Activities done with the primary purpose of shifting focus from pain</td>
<td>▪ Going out w friends</td>
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<td></td>
<td>▪ Activity just a good distraction</td>
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<td></td>
<td></td>
<td>▪ Walking</td>
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<tr>
<td><strong>CAM</strong></td>
<td>PSMB that are not part of standard medical cancer (National Cancer Institute)</td>
<td>▪ Acupuncture</td>
</tr>
<tr>
<td></td>
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<td>▪ Vitamin B</td>
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<td>▪ TENS</td>
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<td></td>
<td></td>
<td>▪ A535 cream</td>
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<tr>
<td></td>
<td></td>
<td>▪ Cream</td>
</tr>
<tr>
<td><strong>Avoidance</strong></td>
<td>Of activities involving upper chest, arm, or other area affected by breast cancer treatment</td>
<td>▪ Not using arm on side of breast cancer surgery</td>
</tr>
<tr>
<td><strong>Assistive Devices</strong></td>
<td>Devices used to manage pain</td>
<td>▪ Wearing a bra</td>
</tr>
<tr>
<td></td>
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<td>▪ Compression stockings</td>
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<td></td>
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<td>▪ Cervical collar</td>
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<td></td>
<td></td>
<td>▪ Sit-stand desk</td>
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Physical

The most commonly reported PSMB were physical or exercise related. The majority of participants (n=8) reported engaging in some form of physical PSMB including arm or other stretching exercises recommended by HCPs (n=5), breast self-massage (n=4), yoga (n=3), walking (n=3), strengthening exercises/weight training (n=2), cancer-related exercise programs (n=2), and/or jogging (n=1).

Arm/other stretching exercises were described with varying degrees of efficacy. Two participants reported them to be ineffective for pain, two participants reported that they were helpful, and one participant did not comment on their efficacy. Breast self-massage also worked for some participants (n=2) and was ineffective for others (n=2) in terms of pain relief.

Yoga and walking were described as effective for pain by all of the participants who reported engaging in them. Strengthening exercises/weight training were also described as effective (n=2), as was jogging (n=1). Participants did not describe the efficacy of cancer-related exercise programs during interviews.

Participants sometimes attributed the efficacy of physical-exercise to the release of muscle tension (n=1) and better blood circulation (n=2).

*I feel better if I’m jogging. I think it’s because of the circulation. I don’t know. Because after jogging I feel like my body feels better.* –Participant 5

Another participant described engaging in arm stretching exercises recommended by her HCPs that she undertook regularly to deal with what she referred to as ‘discomfort’.

*And I’ll, you know, I might be in the kitchen and sort of walk my arm up the cupboard and down. Just to sort of release and stretch...* –Participant 6

Many participants also described engaging in breast self-massage taught by a HCPs to relieve breast pain mostly secondary to lymphedema (n=4). Participants who described breast self-
massage as helpful for pain reported that it relieved tension (n=1) and distributed fluid buildup (n=1). One participant explained that breast self-massage was the most helpful PSMB she engaged in because she could see the results immediately.

    Because you can see the results immediately. Around the breast, you can see the water going away right after the massage. –Participant 5

**Emotional**

Five participants reported engaging in emotional PSMB including meditation (n=1), deep breathing (n=2), laugh therapy (n=1), positive thinking (n=1), and use of a heating pad (n=1). Meditation was also reported by one participant who used it to manage anxiety unrelated to pain.

    Meditation as a PSMB was described as helping to create gaps in thinking about pain and helped one participant to connect more fully with her body, and identify the origin of her pain which facilitated appropriate PSMB (breast self-massage). When asked about the efficacy of emotional PSMB, participants described them as very effective.

    Oh yah! On so many levels [laughs]. Especially, the meditation... it creates gaps in your thinking... when you mediate and you have a focus - you focus on your breath, you focus on your body. It starts to break the thoughts and create gaps in your thoughts, and then you can start, slowly over time, to become more aware of your thoughts and the quality of your thoughts... And, so I refer my thoughts to the positive which for me, really helps me cope with all situations, and in particular, it really gave me the tools to get through this process as well as I did. –Participant 4

Deep breathing was used as an acute PSMB that participants utilized immediately at pain onset. The way in which deep breathing helped minimize pain was not fully elucidated in interviews.

    Laugh therapy and positive thinking helped one participant to stay positive and lessened her pain by shifting her focus to positive thoughts.
The heating pad used by one participant in this sample was described as soothing and facilitated relaxation and comfort, as well as decreased pain. This participant described how use of a heating pad helped her pain when asked by the interviewer.

*Actually, a little bit. I mean they’re not getting rid of it but, particularly the heating pad, when I’m sitting, I don’t use it in bed. But when I’m sitting in a chair reading, I put it at the base of my spine and, yah, it makes me feel comfortable.* –Participant 7

This quote from Participant 7 highlights the intersection between pain relief and emotional comfort during pain management.

**Pain Medication**

Four participants reported taking pain medication at the time of interview however, the majority of participants (n=6) were not taking pain medication. One participant reported taking prescribed pain medication daily, and the other three reported taking over-the-counter (OTC) pain medication as needed.

Participants taking pain medication (n=4) described it as effective in minimizing their pain but most reported that pain medication did not entirely eliminate it (n=3), and some participants took pain medication only once their pain became severe enough to interfere with activities such as sleep and work-life (n=2).

*... I’ll only take the Advil after the pain has been severe enough. And usually never at home, I don’t usually take it at home. Usually if I have to take the Advil it’s while I’m at the office. And that only happens when the pain is such that it actually interferes with me being able to do my job. So if I’m sitting and the pain is just too much that I can’t sit for too long or I can’t concentrate on my work because of the pain. And it could be just that the pain has been there for a couple of days and it’s now just beginning to wear me down. So you know, if I can ease it up a little bit then my body can heal quicker.* –Participant 3

All participants (n=10) reported being prescribed pain medication after their BC surgery or during treatment such as chemotherapy however, most participants chose not to take pain medication or discontinued it early (n=6). Participants reported not taking pain medication when
they felt that their pain intensity was not severe enough or they didn’t need it (n=4) and two discontinued pain medication due to side effects (see Barriers to Pain Medication). Of the participants who chose not take pain medication post-operatively or discontinued it early (n=6), half underwent lumpectomy and half underwent mastectomy. Participants who did take pain medication post-op without bothersome side effects (n=4) generally took pain medication for up to three weeks following surgery.

Medical-Professional

Three participants reported seeing HCPs for BC-related pain. HCPs included physiotherapists, HCPs specializing in lymphedema treatment, physiatrists, and massage therapists.

Participants reported seeking HCPs 2-4 months post-surgery on their own (n=2) and one participant described being referred to a HCP during treatment by a member of her oncology team after she experienced swelling in the breast. Participants described HCPs as helpful in teaching them exercises to restore range of motion, mobility, and arm strength (n=1), as well as breast self-massage to decrease swelling due to lymphedema (n=2).

When asked what PSMB were particularly helpful in terms of pain relief, one participant described the exercises given to her by a physiotherapist.

*Exercising. Doing the exercises the physiotherapist gave me. It was very helpful. Just in terms of slowly increasing the range of motion and the strength in that arm.* –Participant 10

Distraction

At least three participants referred to activities they engaged in to distract themselves from pain. Participants described activities such as going out with friends, talking, and walking that
helped to distract them from pain. PSMB were categorized under ‘distraction’ when participants
described distraction as the primary reason for why the behaviour was effective.

*The strategy, believe it or not, it’s exercise... it’s [getting] up and walking... Keep yourself
moving. And I find the exercise, or just the moving, also helps me not concentrate on the
pain as much. So that also helps me.* –Participant 4

One participant also mentioned going out with friends and described why this activity was
helpful in minimizing pain.

*But I do go out with pain and I do have a good time because it takes my mind off myself.
So, you know - I do like to socialize. You know, people come here or I go somewhere. And
it takes my mind off of everything for a while... and that relieves it for a bit, whatever time
I’m with somebody, you know, a couple of hours or whatever. The conversation is totally
off of any illness - or we go to the theatre or you know, lunch or dinner.* –Participant 7

**Complementary Alternative Medicine (CAM)**

Three participants reported engaging in CAM for pain relief. CAM strategies included use
of a Transcutaneous Electric Nerve Stimulator (TENS) (n=1), A535 cream (n=1), Vitamin B (n=1),
and Vitamin E (n=1). The TENS device was described as ineffective by the one participant who
used it, and A535 cream made the one participant who used it more comfortable but it did not
improve pain. The effectiveness of Vitamin B was not described.

The one participant who did find CAM to be directly effective in minimizing her pain used
Vitamin E oil in combination with cream for lymphedema breast self-massage.

*My oncologist asked me to - after the radiation right? After treatment, I have to use the
vitamin E oil. But it’s because the vitamin E oil that I bought is really hard to spread. So I
use the vitamin E cream instead of the oil. But I found that the tissue still gets hard
underneath, you know, my muscle [unintelligible]... So after I spoke to my oncologist, he
told me that maybe I could try the vitamin E oil, so I bought the vitamin E oil, and after I
put the vitamin E cream on top to massage, so it’s easy to spread. Then, I found that after
the week, all the hard tissue [was] gone.* –Participant 5
Although no participants reported actively seeing an acupuncturist, one participant did discuss seeing one in the past for migraine headache pain and discussed desire to see one again in the future for cancer-related pain.

Avoidance

Two participants reported avoiding PSMB. Both participants described avoiding certain movements or activities involving their upper chest and arm area in an effort to avoid pain.

Assistive Devices

Two participants reported using assistive devices to cope with pain including compression stockings (n=1), a cervical collar (n=1), a sit-stand desk (n=1), and wearing a bra (n=1), all of which were rated as effective for pain relief. Participants used assistive devices to help with pain secondary to or exacerbated by BC treatment, such as hormone therapy and radiation.

*But other than that, I’ve changed my work station at work. When I’m home, I wear a cervical collar to sleep, which the doctor recommended to take the pressure off the neck. And just stuff like that. For me, right now, it’s a - I can’t even say lifestyle - it’s just things that I know to do and it’s gotten a lot better.* –Participant 3
4.2.3 Objective 2: Description of Barriers to PSMB

Participants described several barriers to PSMB including Barriers to Pain Medication, Pain Characteristics, Lack of Information, Lack of Communication with HCPs, HCP Bias, Pain Catastrophizing, Fear of Creating a New Problem, Stigma around Pain Medication, Kinesiophobia, Lack of Progress, and Co-morbidities. Additional categories and codes were added to preliminary codes and are displayed in Table 14.

Table 14. Barriers to Pain Self-Management Behaviours Coding Guide

<table>
<thead>
<tr>
<th>Barrier</th>
<th>Sub-Category/ Definition</th>
<th>Examples from Study Participants</th>
</tr>
</thead>
</table>
| **Barriers to Pain Medication** | Side Effects (experienced) | ▪ Nausea, Vomiting  
▪ Disorientation/foggy thinking  
▪ Dizziness  
▪ Hallucinations  
▪ Drowsiness  
▪ Panic attacks  
▪ Weird dreams  
▪ Constipation |
| | Beliefs about pain medication | ▪ Fear of Addiction  
▪ Fear of Side Effects  
▪ Pain medication is unnatural  
▪ Long-term use of medication may cause harm  
▪ Pain medication masks pain, body is trying to tell me something |
| | Dislike or distrust of pain medication | ▪ Does not like taking pills/pain medication  
▪ Eager to ween off after starting  
▪ Did not want to be on the pain meds but really helped  
▪ Pain medication as last resort  
▪ Not a big drug person |
| Lack of Information | Where it otherwise would have been helpful | On Behalf of HCPs  
- About cording  
- About pain management strategies in general  
On Behalf of Patients  
- About prescription renewal  
- How to get out of bed  
- Who to talk to about pain  
- Balance between too much/too little information |
|---------------------|----------------------------------------|-------------------------------------------------|
| Lack of Communication | Or ineffective communication, where it otherwise would have been helpful | With HCPs  
- Uncomfortable taking up doctor’s time  
- Not much they can do |
| HCP bias | Pain undertreatment as a result of HCP beliefs about pain treatment |  
- Wanted stronger pain meds |
| Pain catastrophizing | An exaggerated negative mental set brought to bear during actual or anticipated painful experience (Sullivan et al., 2001) |  
- Afraid of doing damage  
- Is pain permanent damage from surgery |
| Pain Characteristics | Pain intensity, type of pain |  
- Cording pain (a.k.a. axillary web syndrome)  
- Severe Pain  
- Mild pain |
| Lack of Progress | Lack of observable progress or change from PSMB |  
- Exercises recommended by HCPs not breaking up scar tissue |
| Co-morbidities | That made it more difficult or impossible to engage in PSMB |  
- Osteoarthritis  
- Spinal stenosis  
- Rotator cuff injury  
- Right hand injury |
| Fear of creating a new problem by engaging in PSMB | Belief that engaging in a given PSMB will cause additional problems |  
- Past experience with allergies to pain treatment |
| Stigma around Pain Medication | On behalf of patients, that impedes the likelihood of obtaining pain medication |  
- Didn’t want to ask for more pain meds  
- Thought there was a reason they only prescribed a certain amount |
<table>
<thead>
<tr>
<th>Kinesiophobia</th>
<th>Fear of movement</th>
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<td></td>
<td>• Avoiding use of arm in anticipation of pain</td>
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</table>

**Barriers to Pain Medication**

Participants described many barriers to pain medication including side effects, a general dislike/distrust for pain medication, and negative beliefs about pain medication.

Seven participants reported experiencing side effects from pain medication and five of those participants reported side effects severe enough to discontinue pain medication. Side effects included feeling disoriented, dizziness, drowsiness, panic attacks, nausea, vomiting, fatigue, strange dreams, and hallucinations.

Dislike and distrust of pain medication was described by six participants. Many reported that they simply did not like taking pain medication (n=5) and several participants described taking it as a last resort.

*I have always been the personality who’s reluctant to take medications if I can help it. I prefer to try relieving pain in a more natural way... that’s just how I’ve always kind of functioned... I just sort of feel that long-term use of drugs – as much as they may benefit one area - they could cause harm in another. And I think that just comes from childhood when I had tonsillitis basically 24/7 and they still didn’t want to remove them and I was practically living off amoxicillin. And you start wondering, how is this healthy? How is this not harming other areas of me? So it’s been honestly since then that kind of made me go – as my absolute last resort, I will take something.* -Participant 6

Four participants reported beliefs about pain medication that acted as a barrier to taking it. Beliefs about pain medication included fears of addiction (n=2), fear of side effects (n=3), the belief that pain medication is unnatural and can cause harm in other areas of the body (n=1), and the belief that pain medication masks changes in the body (n=1).
Lack of Information

Lack of information acted as a barrier to PSMB for the majority participants (n=6). This included a lack of information on behalf of both HCPs and patients.

Participants described HCPs as lacking information about PSMB and post-treatment pain in general (n=2), and one participant emphasized the distress associated with lack of information.

...particularly before I knew what it was, that was when it was most distressing, emotionally... And I guess if it had been recognized sooner, then I would have been able to not have that sort of despair feeling that I had... But knowing what it was and then finding a treatment path to fully resolve it has been great. So just, if we could have skipped that step, it would have been good. –Participant 10

This participant was referring to lack of information about cording (a pain condition she developed secondary to breast cancer surgery), which caused significant distress. She described how information eventually led her to develop an appropriate treatment plan.

Participants also discussed being unaware of practical information like the option to renew prescription pain medication (n=1) and described being unsure of who to talk to about pain (n=1).

And there was no information provided either - how long might it go on, is it normal? Zero. I would rather have information than relief, in a way. In a way, I just want to know... Cause if I have that information, I can manage it myself, or know who to go to, to manage it. –Participant 1

This quote from Participant 1 exemplifies the challenge that many participants faced in communicating pain-related concerns to HCPs (see Lack of Communication), and also highlights the importance of information in facilitating PSMB (see Facilitators to PSMB, Information).

Maintaining a balance between too much and too little information was also important to participants (n=3), who discussed feeling oversaturated with information at times and worried that having too much information could lead to hypervigilance.
I didn’t want to put something in my head that wouldn’t have been there if I hadn’t read the book. So, in that respect, I don’t want too, too much information but I also want enough that – this is a surprise, but it wasn’t – it’s not a surprise that’s making me angry. It’s just a surprise that’s making me say, ‘Why?’ - and I haven’t got the answers yet. If I could get the answers, it would probably be better. –Participant 8

This participant described her post-treatment pain as a “surprise” and described her conflicting needs for information and peace of mind.

Lack of Communication with HCPs

Lack of communication with HCPs was a barrier to PSMB for three participants. Participants described being uncomfortable taking up their doctor’s time (n=1), described doctors as very busy and unable to do much in terms of pain (n=1), and discussed being unsure of who to talk to about pain concerns (n=1).

If anything, I guess, to go back to the barriers - I guess it would just be the fact that - for instance, when I went to see the surgeon after and told him I was still having a lot of pain - there seems to be no one in charge of that. I mean you’re studying pain but it’s not your job to relieve it, so. There’s nobody out, there’s nobody in the team that - the surgeons seemed like, so what?... It wasn’t like ‘suck it up’ but it was just a non-issue. Mind you, I was asking the surgeon, maybe it wasn’t his job. I don’t know. I don’t know who I was supposed to ask. –Participant 1

This participant described a challenging interaction with a HCP who did not offer advice on how to deal with pain. On the other hand, some participants maintained that they believed their doctors were doing the best they could (n=2).

Maybe a lot of it may be my fault b/c I haven’t asked the right questions. It’s very difficult you know. I understand all the pressures the healthcare system is under. I know that the doctors are doing their best, they have many, many patients to deal with, they have really poor funding, and they have to maximize what funding they do have and I feel really uncomfortable taking up a lot of their time. –Participant 9
This participant described severe bone pain from hormone therapy and discussed feeling uncomfortable voicing her pain concerns while maintaining her belief that her HCPs were doing their best.

**HCP bias**

Three participants reported undertreated pain due to HCP bias. These participants all described instances of pain in which they felt that the pain medication they were prescribed was too mild for their level of pain (see also Stigma about Pain Medication). One participant described presenting to a hospital Emergency Room because of severe pain due to a degenerative spine condition which was exacerbated by radiation, and being advised to take Advil.

> And it did not work, it didn’t work. So literally the very next day I was back again, and they were a little peeved to see me again. And they said ‘I told you to go home and take Advil’ and like, you’re back again – ‘what do you want?’ And you know, I get that because they had no clue who I was, they had no clue how I deal with pain, and if I’m actually stepping into the ER where I have a 6 hour wait just for you to do something, you’ve got to know that I’m here for a reason. But you know, they don’t know that because they don’t know me. -Participant 3

This participant described what she perceived as HCP bias at the ER. She eventually resolved her pain by seeing her family doctor who recommended appropriate PSMB.

**Pain Catastrophizing**

Two participants engaged in pain catastrophizing that directly impacted their decision to engage in PSMB. Both participants described attributing worst-case scenarios to their pain including permanent damage from surgery.

> I felt - in particular after the mastectomies, I was just so afraid of doing myself damage. I really honestly felt like they had done something during the surgery, or made some kind of
mistake, or pushed the expander too far to the right. You know, so I was a little bit afraid of hurting myself...Yah, and you know, I was sometimes a little bit worried with the fills with the expansions. Because I would feel it in my sternum. In certain parts of my sternum it would feel like there was pulling and it was going to just tear off of my sternum, or like the packages were going to just tear or that there was a tear. I was a little bit worried with that. –Participant 4

This participant described pain catastrophizing that persisted until her pain dissipated. In this participant, pain catastrophizing influenced her decision not to engage in arm stretching exercises recommended by her HCPs for mobility.

**Pain Characteristics**

Pain characteristics such as severe pain or mild pain acted as a barrier to various PSMB for many participants (n=5). Severe pain compounded by multiple co-morbidities directly impacted one participant’s ability to engage in physical PSMB, and cording pain affected another participant’s ability to engage in PSMB by restricting her movement.

Some participants also believed that mild pain did not warrant intervention or that there was nothing that could be done for mild pain (n=3).

*Also, my pain isn’t hugely extreme. If I were in extreme pain, obviously I would do something about it. I would root around and call people, and pester people... it’s not that extreme. But it is there.* –Participant 1

This quote from Participant 1 exemplifies the belief help by some participants that nothing could be done for their pain.

**Stigma around Pain Medication**

Two participants described perceived stigma surrounding pain medication that acted as a barrier to obtaining it. One participant described not wanting to ask for more pain medication after
using up her prescription because she didn’t feel comfortable and feared HCPs would think she was addicted.

> Well, I didn’t know that I could get a renewal, I didn’t know that, that was an option, yah. And then my mom had her pills, and they were the same ones. The exact same ones. But if I hadn’t had access to my mom’s pills I probably would not have called. I just felt like perhaps there was a reason why they only gave me a certain amount and I didn’t want to ask for more. I just felt, I didn’t feel comfortable asking for more. –Participant 4

When asked to explain further, Participant 4 discussed feelings of stigma about pain medication and described fear of being labelled as an addict.

> I didn’t wanna feel like – because you know, there’s this whole big thing about people being addicted to prescription drugs and I didn’t want anyone to think that, that’s what was going on. I mean I really need them. But isn’t that what an addicted person would say anyway? [laughs]. –Participant 4

This participant also described assuming that there was a reason why HCPs only prescribed a certain amount after surgery. Another participant also described stigma related to taking pain medication.

> And every once in a while, I do have to take Advil. I’m not gonna dismiss that, because every once in a while, I do have to take Advil for it. –Participant 3

This participant described taking OTC Advil with some level of shame, presumably because of perceived stigma about pain medication.

**Lack of Progress**

Lack of observable progress or change acted as a barrier to PSMB for two participants who described frustration about engaging in exercises recommended by their HCPs that resulted in little to no change.
They showed me how to do this breast self-massage, which I have been doing, but it hasn’t made any difference, nothing has changed. So, I don’t know what else I can do. I don’t know if it’s going to stay this way forever or what, but it’s not very nice actually. – Participant 9

This participant described her concern over the swelling in her breast that began around the time of her surgery. Despite following recommendations to engage in breast self-massage, this participant observed no progress or change in pain and eventually stopped doing it entirely.

**Co-morbidities**

One participant reported a co-morbidity that acted as a barrier to physical PSMB. This participant also described the emotional impact of co-morbidities and functional limitations.

*Well, I do have other medical issues. And I do, I get depressed by the fact that I’m not able to get around as much as I would like to, and that the pain is constant at some level. So, yah I do, and I worry about these other medical conditions and, so, yah. There is depression… I finally have an appointment to have an MRI done on my left hand… So, the stress – first of all, the MRI - I’m highly claustrophobic, I’m going to have to be sedated. And then I worry about what they’re going to find because it involves an operation on my spine. So I’m worrying about that, I’m worrying about the rotator cuff and what’s happening with that, and then I have another problem with the bladder. So these are all, you know – they’re hitting me all at once.* – Participant 7

Other participants (n=2) reported co-morbidities such as arthritis and pain from other recent surgeries but did not overtly describe them as barriers to PSMB. Co-morbidities did however, impact pain intensity and exacerbated CTP.

**Fear of Creating a New Problem**

One participant reported fear of creating a new problem by engaging in PSMB as a barrier. This participant described past experiences with bad side effects from pain medication and allergies to other types of pain treatment.
So, I try not to do anything as far as pain management is concerned because I often find that if I try to do something, I just create another new problem. –Participant 8

Kinesiophobia

One participant reported kinesiophobia, or fear of movement, as a barrier to PSMB.

I’m not eager to use my arm. I try to minimize that, anticipating pain. –Participant 2

This participant described avoiding use of her arm (on the same side of her breast surgery) because of the expectation of pain.
4.2.4 Objective 2: Description of Facilitators to PSMB

Participants described several facilitators to PSMB including Information, Communication with HCPs, Pain Acceptance, Social Support, Perceived Accessibility, Accommodating Workplace, and Self-Efficacy. Additional categories and codes were added to preliminary codes and are displayed in Table 15.

Table 15. Facilitators to Pain Self-Management Behaviours (PSMB) Coding Guide

<table>
<thead>
<tr>
<th>Facilitator</th>
<th>Definition</th>
<th>Examples from Study Participants</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Information</strong></td>
<td>Information from HCPs</td>
<td>▪ What to do about pain, what to expect post-treatment (via literature, communication)</td>
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<tr>
<td></td>
<td></td>
<td>▪ Encouragement/support to engage in given PSMB (i.e. take pain medication when needed)</td>
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<td>▪ Suggestions for alternatives to pain medication when desired</td>
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<td></td>
<td></td>
<td>▪ On side effects from pain medication</td>
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<tr>
<td></td>
<td>Understanding Rationale for PSMB</td>
<td>▪ The how and why of PSMB</td>
</tr>
<tr>
<td><strong>Communication with HCPs</strong></td>
<td>Communication with HCPs about pain concerns</td>
<td>▪ Bringing pain concerns to the attention of HCPs</td>
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<tr>
<td></td>
<td></td>
<td>▪ Asking questions</td>
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<td>▪ Describing pain concerns thoroughly</td>
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<td><strong>Pain Acceptance</strong></td>
<td>“Process of giving up the struggle w pain and learning to live life despite pain” (LaChapelle et al., 2008); “Acceptance of chronic pain entails that an individual reduce unsuccessful attempts to avoid or control pain and focus instead on participation in valued activities and the pursuit of”</td>
<td>▪ Learning to accept your new normal</td>
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<td>▪ Allowing yourself feel pain</td>
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<td>▪ Learning to live with it</td>
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| Social Support                                                                 | Practical                                                                 | • Social referrals/connections to HCPs with expertise in pain management  
|                                                                              |                                                                                  | • Friends/family with expertise in pain management/physical rehabilitation  
| Shared experience                                                            |                                                                                  | • What others do to relieve pain  
|                                                                              |                                                                                  | • Hearing about other BC survivors’ experiences with pain (i.e. how painful it will be)  
| Perceived Accessibility                                                       | To HCPs or pain treatment that facilitated (or could have facilitated) easier contact/engagement | • Told by HCP to call if needed  
|                                                                              |                                                                                  | • They are still there if I need them  
|                                                                              |                                                                                  | • Pains meds for emergencies  
|                                                                              |                                                                                  | • Information available if I need it  
| Accommodating Workplace                                                      | Physical or emotional boundaries or limitations set or supported by workplace personnel that helped to minimize pain | • Sit-stand desk at work  
|                                                                              |                                                                                  | • Setting limitations with supervisor  
| Self-efficacy                                                                | Confidence in ability to manage pain; “ability to carry out activities even when in pain” (Nicholas et al., 2015) | • I can do this  
|                                                                              |                                                                                  | • My job is to take care of myself  

personally relevant goals” (McCracken et al., 2004)
Information

The most commonly described facilitator to PSMB was information, which was discussed by seven participants.

Five participants described receiving or desiring information from HCPs such as literature on what to do and what to expect after BC treatment.

...I think it’s good. Yah, especially my radiation oncologist, he helped me a lot. – Participant 5

This participant described being taught how to properly engage in breast self-massage for lymphedema by her radiation oncologist post-treatment.

...[they] taught me how to use my hands to move, you know, how to do the right massage. – Participant 5

Two participants who were engaged in many PSMB described how information facilitated peace of mind and minimized distress.

They gave me all the information that I needed. If I did not know any better - if I was not forewarned on the kind of pain - the breast pain, I’ll go back to the breast pain - that I could experience, not necessarily will, but could have experienced and how long it could take, then I actually might be very, very worried that there are parts of my breasts that are still very numb. I may go, ‘well it’s almost a year’, but they told me, ‘this is natural.’ ...So I’m not sitting there worried about if it’s normal or it’s not normal, ‘does this mean the cancer’s back?’ – Participant 3

This participant described how her breast numbness persisted for almost a year post-surgery and how this might have led to distress if she was not expecting it. Because this participant received information that her symptoms were normal however, she was not worried. Another participant expressed a similar sentiment and described how information about pain facilitated appropriate pain treatment.
The only thing I would say is – I’m not sure if there was a lot of awareness on the part of my healthcare team about the cording. And I guess if it had been recognized sooner then I would have been able to not have that sort of despair feeling that I had... But knowing what it was and then finding a treatment path to fully resolve it has been great. –Participant 10

This participant described how information about her pain (i.e. what it was) was integral to facilitating appropriate PSMB.

Participants also described receiving specific information about PSMB from HCPs including alternatives to pain medication after expressing preferences for other treatments (n=1) and support about PSMB from HCPs (n=1).

*I was advised that if I was having pain I should use the medication, and I did that... Just my oncologists were encouraging in saying if you have any pain there’s no problem with taking this. So that was supportive.* –Participant 10

This participant described informational support from HCPs that challenged stigma surrounding pain medication and encouraged her to engage in taking pain medication if needed, which this participant did during her cancer treatment.

Receiving information regarding the rationale for engaging in a given PSMB also acted as a facilitator for some participants (n=2).

*I did go to the rehab people and everything, but at first I didn’t do them because I hate exercising [laughs]. It bores me, totally senseless. So then they start scaring you - ‘you’re going to be like this for the rest of your life if you don’t do them. You will be frozen in your post-surgical position...’ I thought, ‘I better start doing these things.’* –Participant 1

This participant joked about being scared into doing rehabilitative exercises recommend by HCPs post-treatment but also attested to how information on the purpose or rationale of those exercises was effective in promoting engagement in them.
Participants also describing desiring information on side effects from pain medication (n=1) and discussed how side effects like constipation need to be managed preemptively.

**Communication with HCPs**

Communication with HCPs was described as a facilitator to PSMB by five participants. Communication with HCPs acted as a facilitator to PSMB by enabling referral to appropriate pain interventions by HCPs. Communication with HCPs included asking questions (n=1), describing pain thoroughly (n=1), and bringing pain concerns to the attention of HCPs (n=1).

*I’m very open, I’m always very descriptive in letting them know through each treatment if I feel pain or if I don’t or what it is that I’ve been going through. And I feel the more information I can give them, the better the treatment they can give me. And so far, that’s been working.* -Participant 6

This participant described communicating with her healthcare team about pain and exemplified how communication can lead to appropriate pain treatment.

**Pain Acceptance**

Pain acceptance was a facilitator to PSMB in five participants. Participants described living in spite of pain (n=1), learning to live with pain (n=1), accepting a new normal (n=1), accepting the impossibility of being pain-free (n=1), and allowing yourself to feel pain and then letting go (n=1).

*Well, what I do is - I honestly – unless I literally can’t get out of bed – even with pain, I will make myself go out. If I’m invited out for lunch, you know, I’ll take whatever pain medication necessary and I’ll go out. I try not to restrict my associations with people. And so, I really do try and make an effort not to let it get to me. And, I’m human, sometimes it does.* –Participant 7

This participant described experiencing pain from cancer treatment, as well as multiple co-morbidities. This participant described pain acceptance in other parts of her interview by describing pain “that never leaves [her]” and knowing that she “can never get rid of [pain].” Pain
acceptance facilitated taking pain medication in this participant who chose to engage in social activities despite pain.

Social Support

Social support was described by five participants as a facilitator to PSMB. Practical social support included friends who referred participants to relevant HCPs or who were helpful themselves (n=3). For example, one participant described exercises recommended by her son who had expertise in fitness training, and two participants self-referred themselves to social connections who had pain management expertise.

And he highly recommended that as well, so. And he did recommend to find a massage therapist who specialized in fascial release, and I just happened to know one. So, yah. It all kind of worked out that way. –Participant 6

This participant described seeing a HCP who recommended that she see a massage therapist in the community for lymphedema. This participant was able to self-refer to a massage therapist who she knew socially.

Participants also described receiving or desiring social support in the form of shared experience or advice from other cancer survivors (n=4). Advice received or desired included details about what other BC survivors do to relieve pain (n=2), and what to expect from cancer treatment in terms of pain (n=2).

...Would I attend? I don’t know. I probably would. If I was working, it may depend. But when you see what other people say then maybe sometimes you can get an idea or think it through and go, ‘oh, is that what I’ve done? Is that what’s causing it?’ ...or you know, what they do to relieve it. –Participant 8

This participant described a desire for a post-treatment support group and discussed how shared experience could facilitate PSMB.
Participants reported receiving or desiring social support through friends and family (n=5), through a Facebook support group (n=1), and through an in-person support group (n=1).

**Perceived Accessibility**

Three participants described perceived accessibility to HCPs and pain management resources as a facilitator to PSMB. One participant described having prescription pain medication “just for emergencies” (Participant 1) and two participants reported that HCPs were there if needed them.

*I had a wonderful team and they are still there if I need them.* –Participant 3

Perceived accessibility facilitated seeking the help of Medical-Professionals when participants had pain concerns.

**Accommodating Workplace**

An accommodating workplace acted as a facilitator to PSMB for two participants. One participant described being given a sit-stand desk to help alleviate pain from a condition exacerbated by radiation, and another participant described setting physical limitations at work.

*I bear with it. But I do my best to try to limit what I can. It’s hard to do that – to limit – when you’re parenting. But at work - I’ve made it clear to my management, the things that I can and cannot do. And they’re very accommodating about it.* -Participant 6

This participant described having a very physical job and a supervisor who was very understanding of her limitations.

**Self-Efficacy**

Two participants described self-efficacy that acted as a facilitator to PSMB. Both of these participants described engaging in several PSMB.

*And I got through it really, really well, and then bam, this thing came along and I got through this really well. And I felt like my job though all of the treatments and the surgeries and everything, was to take care of myself - emotionally, mentally and my health*
... And I already did that, I already took care of my health. But I amped it up... and that was what I felt like I had control over. –Participant 4

This participant described being diagnosed with a health condition shortly before her BC diagnosis. Her ability to persevere through this health condition gave her confidence in her ability to manage her health through BC.

4.2.5 Additional Insights

Several other themes emerged as relevant to PSMB in the course of interviews including Goals for Pain Relief, Preferences for Receiving Information on PSMB, Using PSMB in Combination with one another, and not expecting pain post-treatment.

Goals for Pain Relief

Seven participants described their goals for pain relief when asked. Participants discussed the goal of minimizing pain (n=3), trying to keep pain from getting worse (n=1), becoming pain-free (n=1), sleeping soundly (n=1), and maintaining independence (n=1).

My goal is it to minimize the pain, but I understand the only way I’m going to do that is by either - there is no healing of degenerative cervical spine, so I guess just to learn to live with it, and learning how to - so that it doesn’t get any worse. So it’s just maintaining. – Participant 3

This participant described her goal to minimize pain and maintain her functional status. She reported engaging in several PSMB throughout her interview. Another participant described the importance of maintaining her independence and not letting pain interfere.

I guess my main goal, the thing that matters the most to me is that I don’t find myself in the situation - either because of pain or because of any other health related reasons - that are going to potentially put my independence at risk. –Participant 9

This participant described pain symptoms due mostly to hormone therapy and described pain as threatening her independence, the maintenance of which was her primary goal for pain relief.
Receiving Information on PSMB

Six participants expressed a desire for more information on PSMB when asked and four participants reported no desire for further information. Participants who desired more information about PSMB discussed preferences for information to be delivered in person (n=2), by their doctor (n=1), or in print (n=1). Two participants did not specify a preference for receiving information.

*Just in general, information. A brochure, I mean - anything. ‘This is what you might experience and if you experience this kind of pain, here’s who you should see about it and here’s what you can do about it.’* –Participant 1

Participants not interested in receiving further information on PSMB discussed knowing enough already (n=2), fear of becoming overwhelmed with information (n=1), and feeling that if they needed more information, they could ask for more independently (n=1).

Many participants expressed a dislike for online information (n=4). Participants described disliking online information for various reasons including not knowing how it applies to their particular case (n=1), the impersonality (n=1), the inclination to “diagnose thyself”, and one participant joked that it was the “way to insanity.” One participant did endorse finding information on PSMB online however, and described enjoying the convenience of finding information online.

Using PSMB in Combination

Three participants described using PSMB in combination with one another. These participants described pain management as being most effective when several PSMB were undertaken to cope with pain.

*...I sort of feel like they really go hand in hand. I find if I don’t have one for a while, like I don’t have massage for a while, the physio isn’t really benefiting me as much and vice versa. I really feel that they’re interconnected in that - in being able to open up the area, relieve the tension, minimize the pain.* –Participant 6
This participant described a circular relationship between the PSMB she engaged in including massage and physiotherapy in that one PSMB influenced another and vice versa.

**Did not expect CTP**

Three participants described not expecting pain after treatment. Two of these participants described being prepared for post-op pain but not expecting pain thereafter.

*Well, I didn’t expect it you know because no one had said anything to me. Umm, I was sort of expecting it after the surgery, because they did mention it. They gave me these prescriptions. So after the surgery, yah. But you know, it wasn’t an issue. As I say, I had the medication, and I didn’t have a lot of pain from the surgery. But after that, no. There hasn’t been any discussion of pain control, at all.* –Participant 9

This participant described the expectation of post-op pain and the readiness of HCPs to help manage it. She contrasted that with the pain she experienced on hormone therapy. Other participants also discussed post-treatment pain as a surprise (n=1) and described a preference for knowing what to expect beforehand in terms of pain (n=1) (see also Facilitators to PSMB, Information).
Chapter 5: Discussion

5.1 Summary of Results

The present study is the first to explore PSMB in disease-free BC survivors from a mixed-methods perspective. The primary objectives of this study were to describe PSMB, and barriers and facilitators to PSMB in BC survivors.

Using the PSCBQ, we found that the most common PSMB endorsed by BC survivors were walking (71.7%), distraction strategies (>67.9%), and other exercise (58.5%). The most effective PSMB were massage (7.33/10), seeing a chiropractor (7.00/10), and using the TENS machine (7.50/10). BC survivors reported engaging in a mean number of 6.55 PSMB, and Mean Effectiveness was rated as 4.83 out of 10. Overall, most participants reported adequate efficacy of at least one PSMB and mean Maximum (or highest rated) Effectiveness was 6.69 out of 10.

Qualitative findings corresponded well with quantitative findings and only Avoidance emerged as a new PSMB category in interviews. BC survivors reported engaging in PSMB that fell broadly under the following categories: Physical, Emotional, Pain Medication, Medical-Professional, Distraction, Complementary Alternative Medicine (CAM), and Assistive Devices.

Qualitative findings further revealed several perceived barriers to engagement in PSMB in addition to those identified by the BQ-II. Participants described barriers consistent with the BQ-II such as negative Beliefs about Pain Medication and Lack of communication with HCPs, and interviews provided insight into additional barriers such as Lack of Information, Pain Characteristics, HCP Bias, Pain Catastrophizing, Lack of Progress, Co-morbidities, Fear of Creating a New Problem, Stigma around Pain Medication, and Kinesiophobia.
Facilitators to PSMB described by participants included Information, Communication with HCPs, Pain Acceptance, Social Support, Perceived Accessibility to pain management resources, Accommodating Workplaces, and Self-Efficacy.

The secondary objectives of this study were to determine correlates of Pain Intensity, Pain Interference, and Engagement in PSMB. Bivariate analysis found that Pain Interference was highly correlated with both pain catastrophizing and self-efficacy about Physical Functioning. Pain Interference was also moderately correlated with FCR, self-efficacy about Pain Management and Coping with Symptoms, and barriers to pain management.

Pain intensity (Worst Pain) was moderately correlated with pain catastrophizing and chronic pain self-efficacy (Physical Functioning and Pain Management) however, contrary to hypotheses, pain intensity was not correlated with FCR, barriers to pain self-management (BQ-II), age, or education (p>0.05)

Engagement in PSMB (Total Number of PSMB) was positively correlated with pain interference and negatively correlated pain self-efficacy (all subscales) however, it was not correlated with pain intensity, pain catastrophizing, FCR, demographic factors, or any dimension of the BQ-II, contrary to our hypotheses.

5.2 Pain Self-Management Behaviours

The present study found that on average, BC survivors reported engaging in 6.55 PSMB via the PSCBQ, and Max Effectiveness was moderate (6.69/10). Most PSMB were known in the existing literature and most were identified via the PSCBQ. Interviews provided insight into details such as what, why, where, when, and how participants came to engage in given PSMB.
5.2.1 Physical Activity

The most commonly reported PSMB were physical and exercise-related according to both quantitative and qualitative assessments. The PSCBQ found that walking was the most commonly reported PSMB, endorsed by approximately 72% of participants and in interviews, many participants described walking as a PSMB. The PSCBQ also found that approximately 59% of participants reported engaging in general exercise as a PSMB and in interviews, participants described breast self-massage for lymphedema, stretching, yoga, strengthening/weight training exercises, cancer-related exercises programs, and jogging.

In terms of effectiveness, participants rated walking and general exercise as moderately effective, and in interviews participants described physical and exercise-related PSMB with varying degrees of efficacy. Yoga, walking, jogging, and strengthening exercises were described as effective by all participants who engaged in them. However, arm stretching exercises and breast self-massage improved pain in only half of the participants who reported engaging in them.

Despite how common and effective physical PSMB were in the present study, physical and exercise-related PSMB have received little attention in the BC survivorship literature (Syrjala et al., 2014). In their review on educational cancer pain self-management interventions, Bennett et al. (2009) included no studies that reported giving participants information on physical or exercise-related PSMB. In a similar review by Howell et al. (2016), only three studies included in their results listed physical or exercise-related components. Two of the three studies (Van Waart et al., 2015; Dodd et al., 2010) evaluated the effects of a home-based exercise program on fatigue for cancer patients during chemotherapy. Van Waart et al. (2015) found a significant improvement in pain and Dodd et al. (2010) found no effect. The third study, among early-stage BC survivors who were 10 weeks post-surgery, described integrating information on how to avoid lymphedema and
how to increase arm mobility post-operatively into their primarily psychoeducational intervention but no impact on pain was found (Boesen et al., 2011).

The finding that exercise may be helpful for chronic pain is supported by the chronic non-malignant pain literature. A study by Landmark et al. (2011) for example, found that exercising 2-3 times per week (for at least 30 minutes or at a moderate intensity) was associated with a 10% decrease in chronic pain prevalence. In participants over 65 years old, exercising 2-3 times weekly was associated with a 27% decrease in chronic pain prevalence. Physical activity may improve pain by increasing mood, and decreasing hypervigilance and anxiety, but further research on the exact mechanisms through which physical activity impacts pain is necessary (Hurwitz et al., 2005).

BC survivors may face unique challenges to pain self-management such as breast lymphedema and arm or shoulder mobility issues. Appropriate physical and exercise-related interventions should target this population specifically and tailor exercises accordingly.

5.2.2 Distraction

Distraction involves activities that divert attention away from pain and enhance mood such as listening to music, watching TV, and reading (Porter & Keefe, 2011). Distraction-related activities were the second most commonly reported PSMB via the PSCBQ. Over 67% of participants reported engaging distraction-related PSMB including listening to radio/music, watching TV, and reading. In interviews, participants who reported engaging in distraction described going out with friends, engaging in conversation, and walking.

Distraction strategies were rated as moderately effective via the PSCBQ, and in interviews, all participants who reported engaging in distraction strategies described them as effective for pain.

Reviews on educational pain self-management interventions for cancer pain do not report on distraction strategies (e.g. Howell et al., 2016; Marie et al., 2013; Bennett et al., 2009) and no
studies have evaluated distraction as a PSMB in disease-free BC survivors post-treatment. In postsurgical BC patients, distraction strategies such as listening to music have been found to effectively improve pain and this is thought to occur through reduced attention to pain and increased relaxation (Li et al., 2011). This finding is also supported by the chronic non-malignant pain literature which has found distraction to reduce pain in patients with lower back and neck pain (Schrieber et al., 2014).

Given the high prevalence of engagement in distraction and the moderate effectiveness of distraction in reducing pain in this population, further research on distraction as a PSMB is warranted.

5.2.3 Emotional Pain Self-Management

Emotional and psychological factors play an important role in the evaluation of cancer pain (see Simard et al. 2013; Belfer et al., 2013; Bishop & Warr, 2003) however, they have been “remarkably underconsidered in cancer survivorship research” (Syrjala et al., 2014). Most research on pain experience in cancer survivors has approached cancer pain from a biological perspective, and has focused on pain due to surgery, chemotherapy, and radiation (Heathcote & Eccleston, 2017). The meaning cancer survivors attribute to pain however, may be an important factor in determining pain-related help-seeking and avoidance behavior (Heathcote & Eccleston, 2017).

Preliminary evidence has found that emotional and psychological PSMB such as guided imagery (Arathuzik, 1994), yoga-meditation (Galantino et al., 2012; Ulger et al., 2010; Speed-Andrews et al., 2010; Carson et al., 2009), and mindfulness-based stress reduction (Tehrani et al., 2011; Lengacher et al., 2009) improve pain in advanced BC patients and BC survivors.

Both quantitative and qualitative findings from the present study found that a large proportion of participants reported engaging in some type of emotional-psychological PSMB.
47.2% of participants reported engaging in relaxation exercises and 5.7% of participants reported attending pain-related counseling via the PSCBQ. In interviews, participants described emotional-psychological PSMB such as deep breathing, meditation, laugh therapy, and positive thinking.

Few studies have examined the efficacy of PSMB such as laugh therapy and positive thinking; however, evidence regarding meditation for cancer pain is promising. Bower et al. (2015) suggests that meditation may improve pain by reducing pro-inflammatory signaling in the brain. Participants in the present study rated relaxation exercises and counseling via the PSCBQ as moderately effective (5.00/10 and 4.67/10, respectively) and during interviews, participants described all emotional PSMB as effective. Emotional and psychological factors were particularly relevant for participants in the present study in terms of their evaluation of pain. For example, pain catastrophizing was associated with greater distress about pain during interviews, which led to avoidance of PSMB in some participants.

Most existing studies that look at emotional and psychological PSMB in BC survivors do not examine pain as a primary outcome or look at emotional-psychological PSMB in advanced BC patients or patients undergoing treatment (Syrjala et al., 2014; Johanssen et al., 2013). Future research should examine the impact of emotional-psychological PSMB on pain specifically in BC survivors.

5.2.4 Pain Medication

Pain management guidelines have generally focused on treating pain during active treatment where unrestricted opioid use has been the standard of care; however, opioids may be less suitable for long-term use in cancer survivors with CTP due to adverse effects (Syrjala et al., 2014). Most interventional studies looking at PSMB in cancer patients include information on pain medication and address barriers to pain medication (see Marie et al., 2013; Bennett et al., 2009).
Only 2 out of 53 participants reported taking pain medication via the PSCBQ however, many more participants reported using pain medication in interviews. This discrepancy may have been due in part to the nomenclature used by the PSCBQ (i.e. ‘took tranquilizers’).

In interviews, participants described using both prescribed and over-the-counter pain medication, and all participants described being prescribed pain medication post-surgery. Participants described only taking pain medication if pain intensity was severe, and many participants described stopping pain medication due to side effects. Participants rated ‘tranquilizers’ via the PSCBQ as effective (6.50/10), and in interviews, participants described pain medication as helping but not entirely eliminating pain. The low rate of pain medication use in this population is consistent with other studies (Crew et al., 2007; Garraeu et al., 2006).

Although pain medication helped to ease pain, there were many barriers to pain medication that were often significant enough to cause participants to stop taking pain medication or avoid it all together. Barriers to pain medication are discussed further in section 5.3.

5.2.5 Avoidance

Avoidance of PSMB was described by some participants in interviews, and was often associated with pain catastrophizing and kinesiophobia. Avoidance did not improve pain and participants described being ready to engage in PSMB only once pain dissipated. Consistent with theory proposed by Heathcote & Eccleston (2017), participants reported avoidance of PSMB when they interpreted their pain as threatening.

Few studies have examined avoidance in the context of cancer pain but it may be especially relevant for cancer survivors who are high pain catastrophizers.
5.2.6 Other PSMB

Other PSMB described by participants in interviews included seeing medical professionals such as physiotherapists, physiatrists, and massage therapists, engaging in CAM strategies, and using medical or assistive devices. Of interest, using the TENS machine was the highest rated item in terms of effectiveness (7.50/10) however, it was only endorsed by three participants via the PSCBQ. Massage ranked second highest in terms of effectiveness via the PSCBQ (7.33/10) and breast self-massage for lymphedema was described by many participants during interviews.

5.2.7 Section Summary

In summary, most PSMB described in interviews were listed on the PSCBQ. Physical activities such as walking, breast self-massage for lymphedema, and strengthening exercises recommended by HCPs were very common among participants and were moderately-highly effective in minimizing pain. Distraction and emotional-psychological PSMB were also very common among participants and were moderately effective for pain. In particular, deep breathing and meditation were described as effective for pain and pain-related distress.

Use of pain medication was not common among participants, including those who described moderate-severe pain and some participants described complete avoidance of PSMB, often due to pain-related distress. Although our quantitative measure was adequate in providing data on how many PSMB participants were engaging in and how effective they were, qualitative data provided important insight into how and why participants came to engage in specific PSMB. Section 5.3 discusses barriers and facilitators to PSMB.
5.3 Barriers and Facilitators to PSMB

Barriers to cancer pain self-management have usually been assessed via the BQ-II (e.g. Marie et al., 2013; Bennett et al., 2009) which addresses barriers such as misconceptions about pain medication and lack of communication with HCPs (Gunnarsdottir et al., 2002). Qualitative findings from the present study found barriers addressed by the BQ-II to be common among participants. Qualitative findings from the present study also revealed many additional barriers however, not identified by the BQ-II.

Barriers and facilitators impacted participants at the pain onset, evaluation, and response to pain (Wagner et al., 2001). At pain onset, participants described evaluating their pain and often labelled it as either expected (i.e. normal) or unexpected based on information that they had or had not received. Participants who described their pain as expected based on information received by HCPs or from people in their social network for example, tended to engage in PSMB more often. For those participants whose pain was not entirely eliminated by engagement in PSMB, pain acceptance was critical to engagement in daily activities and to continuing to engage in PSMB.

Participants who described their pain as unexpected or abnormal searched for the cause of their pain which led to one of two outcomes. When participants found answers to the cause of their pain through a facilitator such as communication with HCPs, they were able to engage in PSMB and distress about pain (if present) was minimized. When participants were unable to find the cause for their pain however, distress persisted and participants avoided engagement in PSMB indefinitely or until they found a reason for their pain. Psychological factors such as pain catastrophizing and FCR influenced how participants evaluated their pain. Barriers and facilitators to PSMB are discussed in further detail below.
### 5.3.1 Pain Acceptance

Pain acceptance involves learning to live despite pain (LaChapelle et al., 2008; McCracken et al., 2004) and attempts to avoid controlling pain to focus on participation in valued activities and the pursuit of personal goals (McCracken et al., 2004). Pain acceptance was described by half of study participants during interviews and played a pivotal role in the decision to engage in PSMB.

Participants described pain acceptance as “living in spite of pain”, “accepting a new normal”, and “accepting the impossibility of being pain-free.” Although the objective of PSMB is to minimize pain, when pain is chronic and/or severe, some degree of pain may be inevitable. Pain acceptance has not been explored in cancer survivors but there is strong evidence in the chronic non-malignant pain literature to suggest that pain acceptance may improve pain intensity and pain-related anxiety (e.g. McCracken & Eccleston, 2003), and in advanced cancer patients, pain acceptance has been correlated with better psychological wellbeing (Gauthier et al., 2009). Future research on pain management interventions should examine the important role that pain acceptance may place in facilitating PSMB.

### 5.3.2 Social Support

Social support was described as a facilitator to PSMB by many participants and it acted as a facilitator to PSMB in two distinct ways. Practical social support occurred when participants described people in their social networks who referred them to relevant pain management resources or who were experts in pain management themselves. For example, participants described instances where family members and acquaintances taught them PSMB both formally (i.e. in the setting of a health care center when participants knew HCPs personally) and informally (i.e. at home with family or friends).
Shared experience through social support also acted as a facilitator to PSMB and occurred when participants heard first-hand from other BC survivors about what they did to manage their pain. Participants described obtaining shared experience online and in-person.

Our results correspond with findings from a study by Hughes et al. (2014) that looked at social support in BC survivors who were six months post-treatment. The authors found that social support at time of diagnosis predicted post-treatment pain, depressive symptoms, and inflammation.

### 5.3.3 Barriers to Pain Medication

In the Bennett et al. (2009) review paper on educational PSMB, all of the studies included in their review address barriers proposed by the BQ-II including barriers to pain medication and communication with HCPs (Gunnarsdottir et al., 2002). Barriers to pain medication include beliefs about the physiological effects of pain medication (i.e. the idea that side effects from pain medication are inevitable and unmanageable); beliefs about the harmful effects of pain medications (i.e. fear of addiction); and fatalistic beliefs about pain management. Barriers to communication with HCPs include the belief that good patients do not complain about pain. These barriers have been extensively studied in cancer populations and the results of the present study support many of the barriers proposed by Gunnarsdottir et al. (2002).

Side effects from pain medication were described by most participants during interviews and these side effects were often severe enough to discontinue medication. Participants further described fear of addiction and fear of anticipated side effects from pain medication, as well as the belief that pain medication masks changes in body and the belief that pain medication can harm other areas of the body.
Participants also described barriers to pain medication not supported by Gunnarsdottir et al. (2002). Participants described viewing pain medication as unnatural and taking pain medication only once their pain was severe, despite recommendations to manage pain while it is mild. Further, participants described stigma surrounding pain medication which acted as a significant barrier for some participants who described fear of being labelled as an addict and an overall reluctance associated with taking pain medication. One participant described how a HCP helped facilitate her use of pain medication by encouraging her to take it if needed.

The results of the present study support the barriers proposed by the BQ-II (i.e. in Gunnarsdottir et al., 2002) however, additional barriers such as stigma, preference for more natural treatments, and the idea that pain medication is only for severe pain, warrant further investigation.

**5.3.4 Communication with Health Care Providers (HCPs)**

Communication with HCPs is an important facilitator to appropriate pain management resources. BC survivors may rely on HCPs to educate them about what to expect in terms of pain and PSMB in general, and also rely on HCPs to facilitate referrals to other professionals who specialize in pain management. Without communication, patients cannot receive this information.

Gunnarsdottir et al. (2002) describes barriers to communication to HCPs including the belief that good patients do not complain of pain, and the belief that talking about pain will distract the doctor from treating the underlying disease. Participants in the present study described barriers to communication such as being uncomfortable taking up their doctor’s time, not knowing who to talk to about pain, and the idea that HCPs are unable to help manage pain. Communication with HCPs was facilitated by asking questions and using descriptive language, and participants who described their HCPs as accessible reported more communication with their HCPs and reported a higher number of PSMB.
HCP bias also played a significant role in communication with HCPs. Many participants described undertreatment of pain due to HCP bias, especially in relation to prescription of pain medication. Alternatively, some participants described their HCPs as very knowledgeable about PSMB and some noted that their HCPs were not biased about pain medication or CAM treatment.

Many PSMB require HCP referral or knowledge which highlights the essential nature of effective communication with HCPs. Future interventions looking at communication with HCPs should include both patients and providers.

### 5.3.5 Information

Information (or lack thereof) was described as a barrier or facilitator to PSMB by the majority of participants and lack of information was usually associated with distress.

Participants described receiving or desiring information on what to expect in terms of pain after treatment, and on PSMB in general, consistent with findings from Bender et al., (2008). Participants also described the need for practical information such as who to talk to about pain, how to get a prescription renewal for pain medication, and on side effects from pain medication. Participants further described needing a rationale for engaging in PSMB (i.e. an explanation on how PSMB worked to minimize pain). Participants described HCPs as particularly knowledgeable in terms of lymphedema-related pain and range of motion issues, but desired more from them in terms of what to expect.

Information played an important role in helping participants determine if their pain was normal or not. Abnormal pain warranted further investigation and generally, participants described engaging in PSMB only once they knew why they were having pain. For example, one participant described ‘cording’ pain related to surgery in her interview, and went on to describe the distress
she experienced before knowing what is was and why she had it. When this participant found out that her cord pain was due to surgery, she was able to find appropriate PSMB.

Despite the clearly beneficial role of information in the present study, consistent with Lovell et al. (2014), participants described the importance of maintaining a balance between too much and too little information.

### 5.3.6 Pain Catastrophizing

Pain catastrophizing involves “an exaggerated negative mental set brought to bear during actual or anticipated painful experience” (Sullivan et al., 2001). Consistent with findings from Bishop & Warr (2002), the present study found that BC survivors who described pain catastrophizing avoided engagement in PSMB. Pain catastrophizing centered around fears about damage that may have occurred during surgery and kinesiophobia, or fear of movement, occurred as a result of pain catastrophizing.

Although pain catastrophizing was not reported by many participants during interviews, it was very impactful in the decision to engage in PSMB for those who did describe it. Pain catastrophizing was not correlated with engagement in PSMB as assessed by the PSCBQ, but a positive correlation was found between pain catastrophizing and pain intensity. Future research should look at the role of informational interventions and in particular, information on what to expect in terms of pain, in decreasing pain catastrophizing.

### 5.3.7 Self-Efficacy

Self-efficacy involves confidence in managing pain and the idea that pain will not compromise the ability of the patient to engage in daily activities (Nicholas et al., 2015). Participants who described pain self-efficacy as a facilitator to PSMB in interviews, described confidence in their ability to manage pain, and reported engaging in a higher number of PSMB.
Self-efficacy has not been extensively studied in BC survivors however, one study found that self-efficacy was correlated with greater perceived barriers to pain management in BC survivors (Mosher et al., 2010), and low self-efficacy in cancer survivors in general has been linked to higher reported pain (Foster et al., 2015). Future pain management interventions for cancer survivors should examine ways to promote self-efficacy for symptom management.

5.3.8 Other Barriers and Facilitators

Other barriers and facilitators to PSMB included co-morbidities, an accommodating workplace, and lack of progress. Physical co-morbidities such as arthritis, were sometimes exacerbated by BC treatment and often amplified pain, and made it more difficult to engage in some physical PSMB like walking. Accommodating workplaces facilitated PSMB including the use of medical devices (i.e. a sit-stand desk for a participant with degenerative disc disease) and understanding supervisors who were aware and accepting of physical limitations on the job.

5.3.9 Section Summary

The present study identified many barriers and facilitators to PSMB consistent with existing literature, and also revealed many unique barriers and facilitators to PSMB such as pain acceptance, information on what to expect, and social support.

5.4 Correlates of Engagement in PSMB

5.4.1 Pain intensity and Interference

Pain Interference was positively correlated with Engagement in PSMB (Total Number of PSMB) via the PSCBQ however, Pain Intensity was not, contrary to our hypotheses. Pain was relatively high in terms of prevalence among participants in the present study, the majority of whom (70%) reported some pain (>0 Worst Pain via the BPI). Mean (SD) Worst Pain was 2.58 (2.51) and Median Worst Pain was 2.00. Gartner et al. (2009), in their study of over 3500 BC
survivors who were an average of 26 months post-surgery, reported that 47% of participants reported some level of pain.

Qualitative data did not support the finding that pain intensity was not correlated with engagement in PSMB, and during interviews participants described many PSMB as effective for pain. This was particularly true of walking and emotional-psychosocial PSMB. As noted, psychological factors related to pain may be particularly significant for cancer survivors (Syrjala et al., 2014) in the evaluation process of their pain (Heathcote & Eccleston, 2017), and participants often described engaging in a given PSMB with the goal of minimizing pain-related distress.

5.4.2 Demographic and Psychological Variables

Pain catastrophizing was not correlated with Engagement in PSMB via the PSCBQ however, it was correlated with pain intensity and pain interference, consistent with other literature (Belfer et al., 2013). FCR was significantly correlated with Pain Interference but not with Engagement in PSMB, contrary to our hypotheses.

All dimensions of pain self-efficacy via the CPSE scale were negatively correlated with Engagement in PSMB (p<0.05). Moderate correlations were found between the Total Number of PSMB reported and all subscales of the CPSE, and moderate correlations were found between pain self-efficacy and pain intensity.

No correlations were found between age, education, and engagement in PSMB.

5.5 Implications

Several findings from the present study have implications for future research. We found that a large proportion of BC survivors experience pain after cancer treatment, and they may engage in common, everyday activities such as walking to manage their pain. We also found that
several important barriers and facilitators to PSMB exist outside of those identified by the BQ-II and future studies need to address these other variables.

5.6 Limitations

This study had several limitations. First, we used a non-validated quantitative measure to assess engagement in PSMB. The PSCBQ was first used with a cancer population (Koller et al., 2013) but there was no report on findings from the PSCBQ in this publication. We assessed engagement in PSMB in the same way Hansen et al. (2014) did however, their study looked at PSMB in end-stage liver disease patients. Hansen et al. (2014) looked at the Total Number of PSMB and Mean Effectiveness of PSMB via the PSCBQ.

This study also had a relatively small sample size and it is possible that some correlations could not reach significant based on our sample size. Due to our small sample size, researchers should be cautious in applying the findings from the current study to other BC survivors.

Further, only one coder analyzed qualitative data in the present study and some themes may have been overlooked and were subject to bias.

5.7 Future Directions

5.7.1 Pain Self-Management Interventions

Future research might use the findings from the present study to inform educational pain self-management interventions for BC survivors post-treatment completion. BC survivors in the present study expressed a desire for more information on what to expect in terms of pain after BC treatment, and more about PSMB in general. Participants also described a preference for receiving this information in-person and from a verified source. Consistent with suggestions from Lovell et al. (2014) however, maintaining a balance between too much and too little information is important.
Pain self-management interventions might also take into consideration the importance of emotional distress related to pain and should seek to integrate psychosocial management guidelines into pain self-management programs. Pain acceptance might be a particularly important facilitator to promote in BC survivors.

Lastly, pain self-management interventions should seek to enhance pain self-efficacy in BC survivors, which was significantly correlated with engagement in PSMB in the present study.

5.7.2 New Barriers and Facilitators to PSMB

Future research should also note that BC survivors encountered a number of barriers and facilitators to PSMB in the present study that are not captured by existing quantitative measures. Pain acceptance was of particular relevance and should be assessed in relation pain in to cancer survivors. Further research on pain catastrophizing and FCR is needed to determine the role of these variables in pain evaluation and engagement in PSMB.

5.7.3 Validating the PSCBQ

Future research might also seek to validate the PSCBQ, which may be a time and cost-effective way to assess engagement in PSMB. The present study found that additional PSMB that may be specific to BC survivors include activities such as breast self-massage for lymphedema.

5.8 Conclusion

The present study found that BC survivors commonly engage in every-day PSMB including walking, distraction, and physical exercise such as rehabilitative arm exercises, breast self-massage, and yoga. BC survivors also engage in a number of emotional PSMB such as relaxation exercises and positive thinking aimed at minimizing the distress associated with pain.
The present study also found several barriers and facilitators to PSMB not captured by the BQ-II. These included pain acceptance, social support, lack of information (on what to expect in terms of pain after treatment and who to talk to about pain), stigma surrounding pain medication, pain catastrophizing, co-morbidities, and workplace environment. Pain acceptance and information were particularly important facilitators to engagement in PSMB.

The present study further found that engagement in PSMB was positively correlated with pain interference and negatively correlated with chronic pain self-efficacy, but engagement was not significantly correlated with pain intensity or psychosocial or demographic variables such as pain catastrophizing or FCR, contrary to hypotheses.
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Appendix A

Appendix A. Interview Guide

General questions pertaining to experiences with pain:

1. Can you tell me about your experience with pain.

   Probing points:
   a) When did your pain start?
   b) Where do you have pain?
   c) What does it feel like?
   d) How much does it hurt?

2. Do you feel that the pain you experience affects your day-to-day life and if so, in what ways?
   a) How do you usually deal with these disruptions?

Pain Self-Management Behaviours:

3. Do you use any strategies to help manage your pain? If so, what do these include?
   a) How did you come to know about these strategies?

   b) Are these strategies helping you relieve your pain?

   c) What are your goals for pain relief?

   d) Which of these pain management strategies (if any) did you find particularly helpful in managing your pain? Which did you not find helpful?

      i. Why? (i.e. Did they relieve pain? Decrease stress? Improve daily functioning?)

   e) At what point did you decide to take/engage in (analgesics/X pain management strategy)?

   f) What do you believe about (analgesics/X pain management strategy) and how they/it can help you to feel better?

   g) How do (analgesics/X pain management strategy) make you feel?

If participant takes pain medication…

   a) Do you take pain medication as directed? If yes, why? If no, why not?
   b) Were you given directions on how to take the medication?
Barriers and Facilitators

4. Have you experienced any challenges (barriers) managing your pain?

   Probing for barriers re: strategies:
   a) Have you experienced any difficulty engaging in the strategies you discussed a
      moment ago? If so, what do these difficulties include?
      i. Were there any stress or emotional factors that made using these strategies
         easier or harder for you?
      ii. Were there any physical limitations or illness factors that made using
          these strategies harder?

   Probing for facilitators re: strategies:
   a) What are some of the things that made these strategies easy to use regularly?
      i. Are there social supports or resources in your life that made engaging in
         pain relieving activities easier or more difficult?

Access to Pain Self-Management Interventions

5. Would further information on pain relief strategies be of interest to you?

If YES,

   a) What types of pain relief strategies would you be interested in trying?
   b) What would help to facilitate your participation in them
      Probing point:
      Is there a particular delivery method you would prefer (in person, in groups,
      online, alone, via pamphlets and other printed materials)?

6. If you could tell your health care team how better to treat your pain, what would you tell
   them?
Appendix B

Appendix B. Pain Self-Care Behaviors Questionnaire (PSCBQ)

ID: ___________  Date: __/__/__  Pain after breast cancer treatment

PSCBQ

Below are a list of things people do to help their pain. If you did any of the following things in the past week to help your pain, mark YES; if you did not do any of these activities, answer NO by putting an “X” in the square indicating your answer.

In addition, if you did the activity, place an “X” in the square above the number from the 0-10 scale to indicate how well the activity helped your pain.

1. Took tranquilizers  _______________________________  □ Yes  □ No

   If yes, how effective was this activity in helping your pain?

   □ □ □ □ □ □ □ □ □ □

   0  1  2  3  4  5  6  7  8  9  10
   not at all effective  mildly effective  moderately effective  extremely effective  completely effective

2. Went to a chiropractor  _______________________________  □ Yes  □ No

   If yes, how effective was this activity in helping your pain?

   □ □ □ □ □ □ □ □ □ □

   0  1  2  3  4  5  6  7  8  9  10
   not at all effective  mildly effective  moderately effective  extremely effective  completely effective

3. Did exercises (jogging, swimming, etc.)  _______________________________  □ Yes  □ No

   If yes, how effective was this activity in helping your pain?

   □ □ □ □ □ □ □ □ □ □

   0  1  2  3  4  5  6  7  8  9  10
   not at all effective  mildly effective  moderately effective  extremely effective  completely effective

Version 1
December 18, 2014
ID: ______  Date: __/__/__

4. Did relaxation exercises, meditated ____________________ Yes No

   If yes, how effective was this activity in helping your pain?

   0 1 2 3 4 5 6 7 8 9 10
   not at all effective mildly effective moderately effective extremely effective completely effective

5. Used a transcutaneous electric nerve stimulator ____________________ Yes No

   If yes, how effective was this activity in helping your pain?

   0 1 2 3 4 5 6 7 8 9 10
   not at all effective mildly effective moderately effective extremely effective completely effective

6. Had a massage ____________________ Yes No

   If yes, how effective was this activity in helping your pain?

   0 1 2 3 4 5 6 7 8 9 10
   not at all effective mildly effective moderately effective extremely effective completely effective

7. Had a trigger point injection ____________________ Yes No

   If yes, how effective was this activity in helping your pain?

   0 1 2 3 4 5 6 7 8 9 10
   not at all effective mildly effective moderately effective extremely effective completely effective

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Date: 

Pain after breast cancer treatment

8. Went for counseling ........................................... □ Yes □ No

   If yes, how effective was this activity in helping your pain?
   □ □ □ □ □ □ □ □ □ □ □
   0 1 2 3 4 5 6 7 8 9 10
   not at all effective mildly effective moderately effective extremely effective completely effective

9. Did hypnosis/imagery ........................................... □ Yes □ No

   If yes, how effective was this activity in helping your pain?
   □ □ □ □ □ □ □ □ □ □ □
   0 1 2 3 4 5 6 7 8 9 10
   not at all effective mildly effective moderately effective extremely effective completely effective

10. Went for acupuncture/acupressure treatment ................. □ Yes □ No

    If yes, how effective was this activity in helping your pain?
    □ □ □ □ □ □ □ □ □ □ □
    0 1 2 3 4 5 6 7 8 9 10
    not at all effective mildly effective moderately effective extremely effective completely effective

11. Used a heating pad or hot water bottle ...................... □ Yes □ No

    If yes, how effective was this activity in helping your pain?
    □ □ □ □ □ □ □ □ □ □ □
    0 1 2 3 4 5 6 7 8 9 10
    not at all effective mildly effective moderately effective extremely effective completely effective

Version 1
December 18, 2014
ID: ______
Date: __/__/__

12. Used an ice pack

If yes, how effective was this activity in helping your pain?

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13. Took a hot bath

If yes, how effective was this activity in helping your pain?

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14. Read a book, newspaper, or magazine

If yes, how effective was this activity in helping your pain?

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15. Used magnets

If yes, how effective was this activity in helping your pain?

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16. Listened to radio, music ........................................... Yes No

If yes, how effective was this activity in helping your pain?

0 1 2 3 4 5 6 7 8 9 10
not at all effective mildly effective moderately effective extremely effective completely effective

17. Watched TV ............................................................. Yes No

If yes, how effective was this activity in helping your pain?

0 1 2 3 4 5 6 7 8 9 10
not at all effective mildly effective moderately effective extremely effective completely effective

18. Went for a walk ........................................................ Yes No

If yes, how effective was this activity in helping your pain?

0 1 2 3 4 5 6 7 8 9 10
not at all effective mildly effective moderately effective extremely effective completely effective

19. Drank beer, wine, or other alcohol ................................ Yes No

If yes, how effective was this activity in helping your pain?

0 1 2 3 4 5 6 7 8 9 10
not at all effective mildly effective moderately effective extremely effective completely effective
20. Took a nap ................................................................. □ Yes □ No

If yes, how effective was this activity in helping your pain?

☐ ☐ ☐ ☐ ☐ ☐ ☐ ☐ ☐ ☐ ☐

0 1 2 3 4 5 6 7 8 9 10
not at all effective mildly effective moderately effective extremely effective completely effective

21. Reduced my level of activity ........................................... □ Yes □ No

If yes, how effective was this activity in helping your pain?

☐ ☐ ☐ ☐ ☐ ☐ ☐ ☐ ☐ ☐ ☐

0 1 2 3 4 5 6 7 8 9 10
not at all effective mildly effective moderately effective extremely effective completely effective

22. Asked for help .............................................................. □ Yes □ No

If yes, how effective was this activity in helping your pain?

☐ ☐ ☐ ☐ ☐ ☐ ☐ ☐ ☐ ☐ ☐

0 1 2 3 4 5 6 7 8 9 10
not at all effective mildly effective moderately effective extremely effective completely effective

23. Reduced my hours at work ............................................. □ Yes □ No

If yes, how effective was this activity in helping your pain?

☐ ☐ ☐ ☐ ☐ ☐ ☐ ☐ ☐ ☐ ☐

0 1 2 3 4 5 6 7 8 9 10
not at all effective mildly effective moderately effective extremely effective completely effective
24. Used assistive devices (cane, walker, tub rails) ☐ Yes ☐ No

If yes, how effective was this activity in helping your pain?

☐ ☐ ☐ ☐ ☐ ☐ ☐ ☐ ☐ ☐ ☐ ☐ ☐
0 1 2 3 4 5 6 7 8 9 10
not at all effective mildly effective moderately effective extremely effective completely effective

25. Went for ultrasonic stimulation treatment ☐ Yes ☐ No

If yes, how effective was this activity in helping your pain?

☐ ☐ ☐ ☐ ☐ ☐ ☐ ☐ ☐ ☐ ☐ ☐ ☐
0 1 2 3 4 5 6 7 8 9 10
not at all effective mildly effective moderately effective extremely effective completely effective

Please list any other things you did for your pain:

---

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## Appendix C

### Appendix C. Preliminary Coding Guide

#### Pain Self-Management Behaviours
- **Pain medication**
  - Example: Prescribed, Over-the-counter
- **Seeking Medical-Professional services**
  - i.e. massage therapist (for lymphedema), physiotherapist
- **Assistive Devices**
  - Example: Assistive or medical devices that help minimize/control pain (i.e. cane)
- **Physical Exercise**
  - i.e. jogging, swimming, walking
- **Emotional**
  - i.e. relaxation exercises, meditation, psychotherapy, hypnosis/imagery, taking a hot bath, using a heating pad
- **Complementary Alternative Medicine**
  - i.e. TENS, acupuncture, acupressure
- **Distraction**
  - Reading, watching TV, listening to radio/music, drinking alcohol
- **Work-role accommodation**
  - Reducing level of activity or hours at work, asking for help

#### Barriers to PSMB

- **Barriers to pain medication**
  - **Beliefs about pain medication**
    - Fear of side effects, fear of addiction/tolerance, belief that pain medication can mask changes in the body or harm the immune system
  - **Beliefs about pain management**
    - Fatalistic beliefs about pain management
  - **Poor or absent communication with HCPs**
    - Belief that pain complaints are a distraction to doctors, belief that good patients do not complain about pain
  - **Fear of cancer recurrence**
    - Avoidance of activity related to preoccupation with fear of breast cancer returning
<table>
<thead>
<tr>
<th>Pain catastrophizing</th>
<th>Avoidance of activity related to searching for worst-case origins of pain</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Facilitators to Pain Management</strong></td>
<td></td>
</tr>
<tr>
<td>Self-efficacy</td>
<td>Belief in ability to manage pain</td>
</tr>
<tr>
<td>Social Support</td>
<td>Social networks, shared experience</td>
</tr>
</tbody>
</table>
Appendix D

Appendix D: University Health Network Research Ethics Board (REB) Study Approval and

NOTIFICATION OF REB RENEWAL APPROVAL

Date: January 30, 2017
To: Jennifer M Jones
ELLICSR Centre, B-PMB-148, Toronto General Hospital, 555 University Avenue, M5G 2N2, Toronto, Ontario, Canada

Re: 13-7178
Pain and its management in the first year after breast cancer treatment

REB Review Type: Delegated
REB Initial Approval Date: February 4, 2014
REB Renewal Approval Effective Date: February 4, 2017
Lapse In REB Approval: N/A
REB Expiry Date: February 4, 2018

The University Health Network Research Ethics Board has reviewed and approved the Renewal (13-7178.9) for the above mentioned study.

Best wishes on the successful completion of your project.

Sincerely,
Gillian Goulet
Ethics Coordinator, University Health Network Research Ethics Board

For: Jack Holland
Co-Chair, University Health Network Research Ethics Board

The UHN Research Ethics Board operates in compliance with the Tri-Council Policy Statement, ICH Guideline for Good Clinical Practice E6(R1); Ontario Personal Health Information Protection Act (2004); Part C Division 5 of the Food and Drug Regulations; Part 4 of the Natural Health Products Regulations and the Medical Devices Regulations of Health Canada.
Date: January 26th, 2016
To: Dr. Jennifer Jones
    ELLICSR Centre, B-PMB-148, Toronto General Hospital, 565 University Avenue
    Toronto, Ontario, Canada, M5G 2N2

Re: 13-7178-CE
    Pain and its Management in the First Year After Breast Cancer Treatment

REB Review Type: Expedited
REB Initial Approval Date: February 4th, 2014
REB Annual Approval Date: February 4th, 2016
REB Expiry Date: February 4th, 2017

The UHN Research Ethics Board operates in compliance with the Tri-Council Policy Statement; ICH Guideline for Good Clinical Practice E6(R1); Ontario Personal Health Information Protection Act (2004); Part C Division 5 of the Food and Drug Regulations; Part 4 of the Natural Health Products Regulations and the Medical Device Regulations of Health Canada. The approval and the views of the REB have been documented in writing.

Furthermore, members of the Research Ethics Board who are named as Investigators in research studies do not participate in discussions related to, nor vote on such studies when they are presented to the REB.

Best wishes on the successful completion of your project.

Sincerely,

Gillian Guillet, MSc
Research Ethics Coordinator

For: Jack Holland, MD FRCPC
Co-Chair, University Health Network Research Ethics Board
Notification of REB Continued Approval

Date: January 21st, 2015
To: Dr. Jennifer Jones
    Room BCS045, Basement Floor, New Clinical Services Building, Toronto General Hospital, 505 University Avenue, Toronto, Ontario, Canada, M5G 2N2

Re: 13-7173-CE
    Pain and Its Management in the First Year After Breast Cancer Treatment

REB Review Type: Expedited
REB Initial Approval Date: February 4th, 2014
REB Annual Approval Date: February 4th, 2015
REB Expiry Date: February 4th, 2016

The UHN Research Ethics Board operates in compliance with the Tri-Council Policy Statement; ICH Guideline for Good Clinical Practice E6(R1); Ontario Personal Health Information Protection Act (2004); Part C Division 5 of the Food and Drug Regulations; Part 4 of the Natural Health Products Regulations and the Medical Devices Regulations of Health Canada. The approval and the views of the REB have been documented in writing.

Furthermore, members of the Research Ethics Board who are named as Investigators in research studies do not participate in discussions related to, nor vote on such studies when they are presented to the REB.

Best wishes on the successful completion of your project.

Sincerely,

Gillian Goulet, MSc
Research Ethics Coordinator

For: Jack Holland, MD FRCP
Co-Chair, University Health Network Research Ethics Board
CAPCR-ID: 13-7178

Pain and its management in the first year after breast cancer treatment

Date submitted: 
Study nickname: Pain after breast cancer treatment

PI's name: Dr. Jennifer M Jones 
PI's email: jennifer.jones@uhn.ca
PI's phone #: 416-581-8603
PI's location: Rm BC3045, Basement Floor, Rm BCS045, New Clinical Services Building; Toronto General Hospital; 585 University Avenue, M5G 2N2; Toronto, Ontario, Canada

Submission Contacts: 
Lynn Gauthier, lynn.gauthier@uhn.ca
Jennifer M Jones, jennifer.jones@uhn.ca

Prepared by: 
Lynn Gauthier, lynn.gauthier@uhn.ca

Reviewed by: 
CCRU (Cancer Clinical Research Unit - Impact Assessment) 
REB (Research Ethics Board) 
ROI (Research Quality Integration)
Appendix E

Appendix E: Consent Form

Consent to Participate in a Research Study

TITLE: Pain and its management in the first year after treatment for breast cancer

INVESTIGATOR: Jennifer Jones, PhD (Telephone: 416-581-8603)

CO-ORDINATOR: Lynn Gauthier, PhD (Telephone: 416-581-8468)

You are being asked to take part in a research study. Please read this explanation about the study and its risks and benefits before you decide if you would like to take part. You should take as much time as you need to make your decision. You should ask the study doctor or study staff to explain anything that you do not understand and make sure that all of your questions have been answered before signing this consent form. Before you make your decision, feel free to talk about this study with anyone you wish including your friends, family, and family doctor. Participation in this study is voluntary.

Background and Purpose
Surgery, chemotherapy, radiation and adjuvant hormone therapy are common treatments for breast cancer. Although some women experience pain or other symptoms, very little is known about this during treatment and in the first year after breast cancer treatment. The purpose of this study is to develop an understanding of pain and other symptoms during treatment and in the first year after cancer treatment.

You are being asked to take part in this study because you have received treatment for breast cancer at Princess Margaret Cancer Centre. As someone who has been treated, you can help us understand women’s experiences with cancer treatment. We would like to know who has pain or other symptoms, how people deal with these symptoms, how they affect wellbeing, and what treatments people have tried.

We are interested in your responses to these questions, even if you do not have pain or other symptoms.

Consent form
Version 5
December 18, 2014
If you agree to participate, we will ask you to complete 4 sets of questionnaires:

Assessment 1 will be completed post-surgery. You will be asked to complete this assessment upon your consent to participate in this study.

Assessment 2 will be completed just before your radiation treatment, if you are scheduled to undergo radiation, or just after you have finished chemotherapy, if you are not scheduled to undergo radiation.

Assessment 3 will be completed 6 months after Assessment 2.

Assessment 4 will be completed 6 months after Assessment 3.

A total of 150 people will take part in this study over the next 2 years.

Procedures
If you agree to participate in this study, you will be asked some questions about your memory. You will be given a questionnaire package that takes approximately 45 minutes to complete. This questionnaire asks about pain and other symptoms, your physical and emotional wellbeing, and your general health. Other parts of the questionnaire will ask you about personal information, such as your marital status.

You have the option to complete the questionnaires on your own, or with the help from a research team member. You may complete the questionnaires at the hospital or if you prefer, you may take the questionnaires home and return them by mail once they are completed (we will provide postage and an envelope for this purpose).

If you do choose to participate and take the questionnaire package home, we will contact you in two weeks to remind you to send your completed questionnaire package. You may refuse to answer any question you do not want to answer, or not answer an interview question by saying “pass”. You may feel free to take breaks as required.

We will telephone you for Assessments 2, 3, and 4 to update your background information and to administer the questionnaires. You will have the option to complete the questionnaires over the phone with the research assistant, or via mail. If you choose to complete the questionnaires via mail, we will mail you the questionnaire package with a postage-paid, stamped return envelope. We will contact you 2 and 3 weeks after to follow-up if you have not returned your questionnaire package.
Risks
There are minimal risks to you for participation in this study. Some of the questions
may be sensitive or upsetting. You are under no obligation to answer questions that
you do not wish to answer.

Benefits
This study may not benefit you directly but it may improve pain management in the
future.

Confidentiality
If you agree to join this study, the study doctor and her team will look at your personal
health information and collect only the information they need for the study. Personal
health information is any information that could identify you and includes your:
• Name
• Address
• Year of birth
• New or existing medical records, that includes types, dates and results of
medical tests or procedures.
All information obtained during the study is completely confidential and will be
stored in a secure locked cabinet in a locked office. Your health record will be
reviewed to verify that we have accurate information regarding your health history.
Only the study personnel will look at your personal health information and collect the
information needed for the study. Representatives of the University Health Network
Research Ethics Board may also look at the study records and at your personal health
information to check that the information collected for the study is correct and to
make sure the study followed proper laws and guidelines.

The only form that will have your name and signature is this consent form. You will
be identified with a study number only. This study ID number will be used on the
questionnaire that you will be asked to complete, and the list that links your name to
your code will be kept locked and secured at all times and separate from your study
file.

All information collected during the study, including your personal health
information, will be kept confidential and will not be shared with anyone outside the
study unless required by law. You will not be named in any reports, publications, or
presentations that may come from this study. No information identifying you will be
transferred outside this hospital or to anyone besides the investigators in this study.
Your participation in this study also may be recorded in your medical record at this
hospital. This is for clinical safety purposes. The study doctor will keep any personal
health information about you in a secure and confidential location for a minimum of 10 years.

Voluntary Participation
Your participation in this study is voluntary. You may decide not to be in this study, or to be in the study now and then change your mind later. You may leave the study at any time without affecting your medical care. If you decide to leave the study, the information that was collected before you leave the study will still be used in order to help answer the research question. No new information will be collected without your permission.

Compensation
You will not be compensated for participating in this study.

Rights as a Participant
If you are harmed as a direct result of taking part in this study, all necessary medical treatment will be made available to you at no cost.

By signing this form you do not give up any of your legal rights against the investigators, sponsor or involved institutions for compensation, nor does this form relieve the investigators, sponsor or involved institutions of their legal and professional responsibilities.

Conflict of Interest
Researchers have an interest in completing this study. Their interests should not influence your decision to participate in this study.

Questions
If you suffer any side effects or other injuries during this study, or if you have any general questions about the study, please call Dr. Lynn Gauthier at 416-581-8468 or Dr. Jennifer Jones at 416-581-8603.

If you have any questions about your rights as a research participant, please call the University Health Network Research Ethics Board at 416-581-7849. They are not involved with the research project in any way and calling them will not affect your participation in the study.

Future Contact Consent
You may be contacted about participation in a related study. For this related study, we would ask you to describe, in your own words, your experiences of pain, the things that you have tried to manage your pain, and things that you would like to try to manage your pain in the future. You are under no obligation to agree to participate in this related project if you do not wish to participate.
I voluntarily consent to be contacted for participation in the interview component of this study

YES □
NO □

Consent
This study has been explained to me and any questions I had have been answered. I know that I may leave the study at any time. I agree to take part in this study.

Participant’s Name (Please Print)          Participant’s Signature          Date

(You will be given a signed copy of this consent form)

My signature means that I have explained the study to the participant named above. I have answered all questions.

Print Name of Person          Signature          Date
Obtaining Consent

Consent form
Version 5
December 18, 2014