

Motherhood and Well-Being in Young Breast Cancer Survivors

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To Geoff, who promised to love me in thesis and in health

Abstract

Parenting is a primary role for many young breast cancer survivors and the combined effect of parenting while coping with this disease can be problematic for many of them.

Despite this, little is known about the impact of parenting on the well-being of young breast cancer survivors. This thesis, comprising two studies in article format, explores this question.

In the first study, we identified elements of well-being that are salient for all young women with breast cancer, and which also captured some of the unique challenges associated with parenting as a survivor. Using factor analysis techniques, we determined how these elements interrelated in separate groups of young survivors with children and without, and identified differences between the two groups based on the patterns observed. We found that the interrelationship among elements of well-being varied between these two groups: psychological distress (representing mental health and perceived stress), illness intrusiveness, and fear of cancer recurrence were found to co-occur more frequently in mothers than in young survivors without children, thus compromising their well-being.

Our second study had two objectives. The first part examined differences in perceived stress, illness intrusiveness, and fear of cancer recurrence between young breast cancer survivors with and without children in two separate timeframes (0-5 and 5-15 years since diagnosis). The second part identified predictors for these elements of well-being in young mothers exclusively. Compared to survivors without children, young mothers reported higher levels of fear of cancer recurrence and illness intrusiveness in intimate life domains during both timeframes, suggesting that disruptions in these areas persist over time. Part two revealed that mothers with adolescent children and high levels of parenting stress were most likely to report perceived stress and illness intrusiveness. A mother's age and the time since her diagnosis predicted fear of cancer recurrence and illness intrusiveness, respectively.

Results from this thesis indicate that young mothers with breast cancer need screening and interventions to manage psychological distress, fear of cancer recurrence, and illness intrusiveness, particularly in intimate life domains. This thesis also identifies the most vulnerable groups of mothers and has important implications for future research.

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Content of the thesis and contribution of authors

This thesis comprises a general introduction, two articles which have been submitted for publication, and a general discussion. The first article titled *Motherhood and Well-Being in Young Breast Cancer Survivors* is currently under review for consideration at the *Journal of Psychosocial Oncology*. The second article, titled *The Impact of Motherhood on Perceived Stress, Illness Intrusiveness, and Fear of Cancer Recurrence in Young Breast Cancer Survivors Over Time*, is under review for consideration at *Psychology & Health*.

The author of this thesis, Isabelle Arès, appears as main author on both articles. I participated in every step involved in the realisation of the research projects and the preparation of the manuscript, including the literature review, conceptualisation of the studies, the ethic approval procedures, survey creation, recruitment, testing of participants, data analysis, and the writing of the manuscripts. The thesis supervisor, Dr. Catherine Bielajew, oversaw the entire process and acted as an advisor over the course of the research projects. Dr. Sophie Lebel and Ms. Katherine Collins acted as consultants for this thesis. Dr. Lebel was consulted for the conceptualization and editing of both articles and Ms. Collins assisted with the statistical analyses for the first article.

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General Introduction

One in nine North American women will be diagnosed with breast cancer at some point in her life. In 2013 alone, it is estimated that 23,800 Canadian women will develop breast cancer (Canadian Cancer Society, 2013a). With advances in early detection and treatment, women diagnosed with this disease now have an 88% chance of a five-year survival. Breast cancer survivors, defined as women living with or beyond a breast cancer diagnosis, represent 40% of all female cancer survivors (Canadian Cancer Society, 2013a).

As the population of breast cancer survivors in Canada, now estimated at over 158,000 women, continues to grow, researchers have begun to look beyond treatment and consider issues that affect adjustment during remission and long-term survivorship (Alfano & Rowland, 2006; Canadian Cancer Society, 2013a). One area that has received relatively little attention is the impact of cancer on the well-being of families with dependent children (Alfano & Rowland, 2006; Rauch & Muriel, 2004; Schmitt et al., 2008). Breast cancer is by far the most common cancer among women aged 30 to 49 (Canadian Cancer Society, 2013a), and the issue of parenting is especially relevant to this population. The challenges associated with parenting while coping with this disease is the focus of this thesis.

While cancer is certainly not the only serious illness to affect young mothers, it presents substantial and unique challenges. Researchers agree that a diagnosis of cancer elicits greater distress than any other disease (Shapiro et al., 2001). Recent data from the National Health Interview Survey (NHIS) showed that the prevalence of clinically significant distress was higher in cancer survivors than in those with other chronic health conditions (Kaiser, Hartoonian, & Owen, 2010). Similarly, in a nationally representative sample of over 90,000 adults, Hewitt and Rowland (2002) demonstrated that cancer survivors were more likely to use mental health services compared to individuals with other chronic illnesses.

What is perhaps more difficult about having cancer is the concern surrounding mortality, disease recurrence, and greater overall life disruption (Black & White, 2005; Hewitt, Rowland, & Yancik, 2003; Longo, Fitch, Deber, & Williams, 2006; Mehta, Lubeck, Pasta, & Litwin, 2003). Cancer is described as representing an existential disruption of a person's expected life trajectory (Fawzy & Fawzy, 1994) and can result in substantial changes to short- and long-term life plans (Bellizzi, Miller, Arora, & Rowland, 2007).

Breast cancer is no exception. Studies show that 30 to 50% of women with breast cancer report clinically significant distress upon diagnosis (Knobf, 2011), and for 15 to 30% of them, problems with physical and psychological well-being can persist for years after treatment, even among those who do not experience a recurrence of the disease (Ahles et al., 2005; Kornblith & Ligibel, 2003; Mols, Vingerhoets, Coebergh, & van de Poll-Franse, 2005). In addition to the usual challenges faced by those with cancer, issues related to body image and womanhood in women with breast cancer add significantly to their psychological distress (Helms, O'Hea, & Corso, 2008). Treatments for breast cancer can cause marked changes with respect to weight gain, loss or mutilation of the breast, and hair loss. The loss and mutilation of the breast, in particular, has unique implications on women's sense of femininity, motherhood, and sexuality (Helms et al., 2008). This distress has important repercussions on women's well-being, their treatment outcomes, and even survival (Chida, Hamer, Wardle, & Steptoe, 2008; Falagas et al., 2007; Fann et al., 2008).

Of the variables examined as predictors of well-being in breast cancer survivors, studies show that younger age at diagnosis has consistently been associated with worse physical and psychological well-being (Baucom, Porter, Kirby, Gremore, & Keefe, 2005; Cimprich, Ronis, & Martinez-Ramos, 2002; Kroenke et al., 2004). Women of this age group believe that they are too young to have cancer and the side effects of treatment such as

premature menopause and infertility can be particularly devastating for them (Baucom et al., 2005; Mosher & Danoff-Burg, 2005).

For young women, a diagnosis of breast cancer interferes with the many demands of early adulthood such as family planning and career development (Knobf, 2011), and for many of these young survivors, parenting is already a primary role. The challenges associated with parenting while at the same time coping with this disease may compound the difficulties experienced by this vulnerable group. Although young mothers describe parenting in the context of breast cancer as difficult and emotionally demanding (Connell, Patterson, & Newman, 2006; Rauch & Muriel, 2004; Schmitt et al., 2008; Semple & McCance, 2010b) and evidence suggests that those responsible for young children are at increased risk of psychological distress and poor quality of life (Bloom, Stewart, Chang, & Banks, 2004; Mols et al., 2005; Schlegel, Manning, Molix, Talley, & Bettencourt, 2012), studies also show that they often feel unsupported by health professionals with matters related to parenting (Semple & McCance, 2010b). Furthermore, there are few clear research findings on how parenting affects the well-being of young breast cancer survivors (Semple & McCance, 2010b; Visser, Huizinga, van der Graaf, Hoekstra, & Hoekstra-Weebers, 2004). With young mothers representing a quarter of *all* women with this disease (Rauch, Muriel, & Cassem, 2002; Weaver, Rowland, Alfano, & McNeel, 2010), understanding how breast cancer impacts mothers differently than survivors without children is necessary in order to guide future research and tailor interventions that would be most beneficial to each group.

This thesis, comprising two studies in article format, will explore the impact of parenting children on the well-being of young breast cancer survivors over time and it will identify predictors of well-being in young mothers exclusively. Prior to discussing each article's objectives, information about breast cancer and treatment is presented, followed by

research on adjustment and well-being in breast cancer survivors and the challenges faced by younger women. The literature on parenting while coping with breast cancer and how this relates to well-being is then introduced. Finally, a discussion of the limitations of the current literature is presented and the objectives of the two articles are defined.

Breast Cancer

Breast cancer refers to a condition in which the first site of a cancerous growth is in the breast tissue (American Cancer Society, 2011). Breast tissue is made up of glands for milk production, called lobules, and the ducts that connect the lobules to the nipple. This tissue extends up to the collarbone and from the armpit to the breastbone. Breast cancer is said to have metastasized when cancer cells travel to other parts of the body through the blood stream or lymphatic system.

Breast cancer is labelled as in-situ, or stage 0, if the cancer is confined to the milk ducts or lobules. It is termed “invasive” when the cancer has spread to surrounding breast tissue (stages 1-3) and possibly other parts of the body (stage 4). According to the American Cancer Society (2011), 20% of newly diagnosed cases are in-situ and the remaining 80% are invasive. Approximately 22% of breast cancer cases occur in women under the age of 50, 37% of cases occur in women between the ages of 50 and 64, and 41% of cases occur in women over the age of 65 (American Cancer Society, 2011).

The severity of breast cancer is determined based on the stage of the disease and the grade of the tumour (Canadian Cancer Society, 2013b). The stage of the disease indicates the extent or spread of the cancer when it is first diagnosed, ranging from stage 0 (in situ) to stage 4 (metastasized cancer). The grade of the tumour indicates how quickly the cancer may be growing and its likelihood of spreading. The grades range from grade 1 (slow growing, less likely to spread) to grade 3 (fast growing, more likely to spread).

Treatment for Breast Cancer

Treatment for breast cancer typically involves surgery when the tumour is localized, with the possibility of radiation therapy, chemotherapy, hormonal therapy, and/or biological therapy (American Cancer Society, 2011; Canadian Cancer Society, 2013b).

Surgery. The purpose of surgery is to remove the cancerous tissue and to assess the stage of the disease. Women may undergo one of three types of surgery depending on the size of the tumour and its location. Breast-conserving surgery, also known as lumpectomy, involves the removal of the tumour and a small portion of surrounding healthy tissue. Simple or total mastectomy involves the removal of the entire breast, whereas modified radical mastectomy involves the removal of the entire breast and lymph nodes in the armpit.

It is common to remove lymph nodes during surgery in order to determine whether the cancer has spread to other parts of the body. This process is referred to as an axillary dissection and may result in lymphedema, a painful condition that involves lymph fluid buildup and swelling in the arm and hands. Lymphedema is considered incurable and may occur soon after surgery, or months, and even years later. The risk of developing lymphedema is higher in patients undergoing mastectomies because this surgery is associated with greater lymph node removal (Rowland et al., 2000). Problems with arm morbidity can be longstanding and affect physical functioning and overall well-being in breast cancer survivors (Kornblith et al., 2003; Schou, Ekeberg, Sandvik, Hjerstad, & Ruland, 2005).

Studies examining well-being in breast cancer survivors who have undergone different surgical procedures suggest that the type of surgery (mastectomy versus breast-conserving surgery) has little effect on their long-term well-being (Arora et al., 2001; Cocquyt et al., 2003; Harcourt et al., 2003; Janni et al., 2001; Parker et al., 2007). It appears, however, that women who receive mastectomies report worse body image compared to those

who underwent breast-conserving surgery (Hartl et al., 2003; Janni et al., 2001; Janz et al., 2005), but they worry less about having a recurrence of breast cancer (Connell et al., 2006; Hartl et al., 2003).

Radiation therapy. Radiation therapy is almost always given after breast-conserving surgery and sometimes after a mastectomy. There are two forms of radiation therapy and some patients are treated with both types. External radiation therapy involves aiming a beam of radiation at the tumour to destroy cancer cells and is typically administered over a period of five to six weeks, whereas internal radiation therapy introduces a radioactive substance directly to the cancer site and may take as little as five days.

The side effects of radiation typically involve skin reactions (dryness, redness and itchiness), fatigue, and soreness in the breasts (Buchholz, 2009). These side effects usually dissipate after treatment, although there is a risk of developing lymphedema when radiation is targeted at the armpit (American Cancer Society, 2011). Less common side effects include heart disease (Giordano et al., 2005) and a second malignancy (Holt et al., 2006; Yap et al., 2002).

Studies examining well-being in breast cancer patients undergoing radiation therapy indicate that the side effects are transient in nature and do not affect well-being in a significant way (Buchholz, 2009; T. S. Lee et al., 2008). In their seven-month prospective study, Lee and colleagues (2008) found no differences in well-being between women who received radiation therapy and those who did not, although women who were most fatigued during radiation therapy had worse outcomes. Similar findings were reported in two prospective studies of six weeks and 12 months duration (Back et al., 2005; Rayan et al., 2003).

Systemic therapy. Chemotherapy, hormonal therapy, and biological therapy belong to a treatment category called “systemic therapy” because these drugs invade all parts of the body. Systemic treatment may be given to patients before and/or after surgery. In most cases, combinations of drugs (chemotherapy, hormonal therapy, and biological therapy) are more effective than one drug alone in the treatment of breast cancer (American Cancer Society, 2011).

Chemotherapy. Chemotherapy works by attacking cells that multiply quickly, such as cancerous cells, but it also damages healthy cells. It is usually administered to patients once every second to third week for a period of three to six months. Chemotherapy has greater impact on well-being in breast cancer survivors, both in the short- and long-term, compared to hormonal therapy, radiation therapy, and all types of surgical procedures (Bower et al., 2000; Ganz et al., 2002; Ganz et al., 2004). In the short-term, this drug is associated with hair loss, fatigue, and general malaise that can persist for months after treatment (Janz et al., 2005). In the long-term, chemotherapy can lead to premature menopause, infertility, and a host of physical symptoms, such as pain, fatigue, weight gain, and cognitive symptoms, all of which impact on well-being (Avis, Crawford, & Manuel, 2004; Bower et al., 2006; Ganz et al., 2002; Ganz et al., 2004; Janz et al., 2005). Longitudinal studies indicate that ongoing physical symptoms associated with chemotherapy show little improvement over time (Ganz, Kwan, Stanton, Bower, & Belin, 2011).

The risk of premature menopause is greater for women undergoing chemotherapy over the age of 35 (Fornier, Modi, Panageas, Norton, & Hudis, 2005; Okanami et al., 2011). Menopausal symptoms associated with chemotherapy, such as hot flashes, vaginal dryness and osteoporosis appear to be more pronounced than those related to naturally-occurring menopause (Carpenter, Johnson, Wagner, & Andrykowski, 2002). Premature menopause

resulting in infertility is most devastating for young women who have not yet started or completed their families (Schnipper, 2001). These symptoms are associated with significant psychological distress in breast cancer survivors and with worse physical, social, and sexual functioning (Barton, Wilwerding, Carpenter, & Loprinzi, 2004; Ganz, Greendale, Petersen, Kahn, & Bower, 2003; Ganz et al., 2011; Knobf, 2006a, 2006b).

Hormonal therapy. Hormonal therapy is given to women whose tumours are responsive to estrogen, a hormone produced by the ovaries. The purpose of hormonal therapy is to lower estrogen levels or to block the effect of estrogen on the growth of breast cancer cells. Hormonal drugs are usually taken over a period of five years and the side effects may include menopausal symptoms, such as irregular periods, hot flashes, and vaginal discharge. These side effects usually dissipate after treatment, but sometimes result in permanent menopause. For pre-menopausal women, surgical removal of the ovaries is another form of hormonal treatment, one that induces premature menopause.

Studies suggest that the side effects associated with hormonal therapy are usually well-tolerated (Day, Ganz, & Costantino, 2001; Ganz, Rowland, Meyerowitz, & Desmond, 1998), and that patient-perceived side effects from hormonal therapy, such as weight gain, hair loss, pain, fatigue, depression, vaginal dryness, vasomotor symptoms (i.e., hot flashes and sweats), and diminished sexual functioning, are more directly related to chemotherapy, menopause, or to withdrawal of hormone replacement therapy than to hormonal therapy per se (Ganz, 2001).

Biological therapy. Biological therapy is a relatively new treatment that uses the body's immune system to eradicate cancer cells and/or interfere with their ability to grow (American Cancer Society, 2011; Cancer Research UK, 2013). The most commonly used biological treatment for breast cancer is Herceptin, a drug which is administered through a

drip every three weeks for a year. Most biological therapies are associated with flu-like symptoms, fatigue, pain, and cardiovascular complications (American Cancer Society, 2011; Cancer Research UK, 2013; Wysocki & Wysocki, 2008).

Adjustment to Breast Cancer

Adjustment in breast cancer patients is said to vary over time and is marked by important transitions, such as the periods before, during, and after treatment (Institute of Medicine, 2006). Most women who are diagnosed with breast cancer describe their reaction as intense fear, helplessness, or a sense of horror (Mehnert & Koch, 2007). Breast cancer is a life-threatening disease and nearly half of women report clinically significant distress following diagnosis (Hegel et al., 2006). The nature of women's distress at this time is mostly related to worry, nervousness, uncertainty, depression, and practical problems. The diagnostic period is also marked by important decisions regarding treatment.

Undergoing treatment is challenging for many breast cancer patients. Although women describe a fighting spirit that helps them get through this time (Knobf, 2002), many experience feelings of vulnerability and existential concerns (Beatty, Oxlad, Koczwara, & Wade, 2008; Cowley, Heyman, Stanton, & Milner, 2000). Their lives are greatly disrupted by their treatment schedules (Wallace, Priestman, Dunn, & Priestman, 1993) and the increase in physical side effects (Bower et al., 2000; Ganz et al., 2004; Glaus et al., 2006). In a large sample of breast cancer patients in the midst of treatment, Janz and colleagues (2007) found that the most troublesome side effects included systemic effects of treatment (e.g., hot flashes, dry mouth, headaches), fatigue, breast symptoms (e.g., pain, tenderness, skin irritations), sleep disturbance, and arm morbidity (e.g., pain, mobility, swelling).

Physical symptoms are often at their worst at the end of treatment and contribute to worse physical and overall well-being (Deshields et al., 2005; Ganz et al., 2004). The end of

treatment can be emotionally distressing as well. Treatment is viewed as actively fighting cancer and ending treatment can bring about feelings of uncertainty and vulnerability. Visits to the oncologist become less frequent and women miss the reassurance they provide (Lethborg, Kissane, Burns, & Snyder, 2000; Schnipper, 2001). Furthermore, it is not uncommon for women to feel pressured to resume their family, work, and social roles (Costanzo et al., 2007; Holzner et al., 2001) while at the same time experiencing a decrease in social support (Stanton et al., 2005). As such, women have expressed feeling abandoned by friends, family, and health care providers during this period (Allen, Savadatti, & Levy, 2009; Lethborg et al., 2000).

Problems with physical and psychological functioning can persist long after treatment completion, and women are often taken aback by the intensity and persistence of these difficulties (Knobf, 2011). Three to six months after treatment, women report ongoing problems with pain, fatigue, sleep disturbance, hair loss, weight gain, lymphedema, and menopausal symptoms, all of which challenge their recovery (Byar, Berger, Bakken, & Cetak, 2006; Deshields et al., 2005; Fortner, Stepanski, Wang, Kasprovicz, & Durrence, 2002; Ganz et al., 2011; Land et al., 2004). Of the physical symptoms examined, fatigue level appears to be the strongest predictor of well-being in women with breast cancer (Arndt, Stegmaier, Ziegler, & Brenner, 2006; Byar et al., 2006; de Jong, Courtens, Abu-Saad, & Schouten, 2002; Janz et al., 2007).

Most breast cancer survivors show a gradual improvement in physical and psychological well-being within the first six to 12 months after treatment (Ganz et al., 2011; Ganz et al., 2004; Land et al., 2004; Stanton, Danoff-Burg, & Huggins, 2002). However, further improvements beyond this point rarely occur (Ganz et al., 1996; Helgeson, Snyder, & Seltman, 2004). Long-term survivorship, defined as greater than five years since diagnosis,

can be marked by ongoing problems in physical, psychological, and social well-being for 15 to 30% of survivors, even among those who have not experienced a recurrence (Alfano & Rowland, 2006; Knobf, 2011; Kornblith et al., 2003; Mols et al., 2005).

Psychological Adjustment

Although prevalence rates vary, studies using clinical interviews demonstrate that the most common psychological disorders in breast cancer patients include adjustment disorder (7%), major depressive disorder (5-15%), dysthymic disorder (3%), generalized anxiety disorder (6-10%), acute stress disorder (2.5%), and post-traumatic stress disorder (2.5-19%) (Coyne, Palmer, Shapiro, Thompson, & DeMichele, 2004; Fann et al., 2008; Hegel et al., 2006; Knobf, 2011; Mehnert & Koch, 2007). Many of these conditions are comorbid in breast cancer survivors, and they are often undiagnosed, undertreated, and can persist for years (Fann et al., 2008; Jones, 2001; Mehnert & Koch, 2007). A larger proportion of breast cancer survivors have symptoms of anxiety and depression that do not meet criteria for a diagnosable disorder according to the *Diagnostic and Statistical Manual of Mental Disorders* (American Psychiatric Association, 2000).

A diagnosis of breast cancer is a life-threatening condition that evokes a strong emotional reaction and is now considered a potential traumatic event according to the *Diagnostic and Statistical Manual of Mental Disorders* (American Psychiatric Association, 2000). Golden-Kreutz and colleagues (2005) found that 40% of breast cancer patients experienced clinically significant traumatic stress at the time of their diagnosis, which they described as “the worst days of their lives.” Longitudinal studies demonstrate elevated rates of traumatic stress in 16 to 18% of long-term breast cancer survivors (Foster, Wright, Hill, Hopkinson, & Roffe, 2009).

A recent review suggests that anxiety is the most common manifestation of psychological distress during the diagnostic period, with 16 to 50% of women reporting significant anxiety (Montgomery & McCrone, 2010). Longitudinal studies reveal only a modest decrease in anxiety levels over time (Hopwood et al., 2010), with nearly 20% of breast cancer survivors reporting significant anxiety four years after treatment (Karakoyun-Celik et al., 2010). Similarly, clinically significant depression is found in 15 to 30% of breast cancer patients (Fann et al., 2008), and this depression can persist well into long-term survivorship for approximately 20% of female survivors (Hopwood et al., 2010; Karakoyun-Celik et al., 2010; Vahdaninia, Omidvari, & Montazeri, 2010).

Psychological distress compromises adjustment to breast cancer. Badger and colleagues (2001) found that depression influenced the number and severity of side effects reported by patients after their treatment. Likewise, Fann and colleagues (2008) observed that physical symptoms, such as pain, fatigue, sleep problems, and functional impairments, were exacerbated by psychological distress. Distress in breast cancer survivors is associated with decreased satisfaction with health care, failure to comply with medical treatments, and lower immune function (Fann et al., 2008; Witek-Janusek, Gabram, & Mathews, 2007), all of which can impact disease outcomes and possibly survival (Chida et al., 2008; Falagas et al., 2007).

Patterns of Adjustment

Research on adjustment to breast cancer has identified different patterns of recovery over time (Knobf, 2011). As illustrated in Figure 1 below, the four patterns are: *persistent* (5-30% with ongoing disruptions in physical and psychological well-being), *progressive* (0-15% who do well at first but later have problems), *recovery* (15-25% who experience

temporary disruptions and then recover), and *resilience* (35-65% who experience temporary disruptions but are able to maintain healthy levels of psychological and physical well-being).

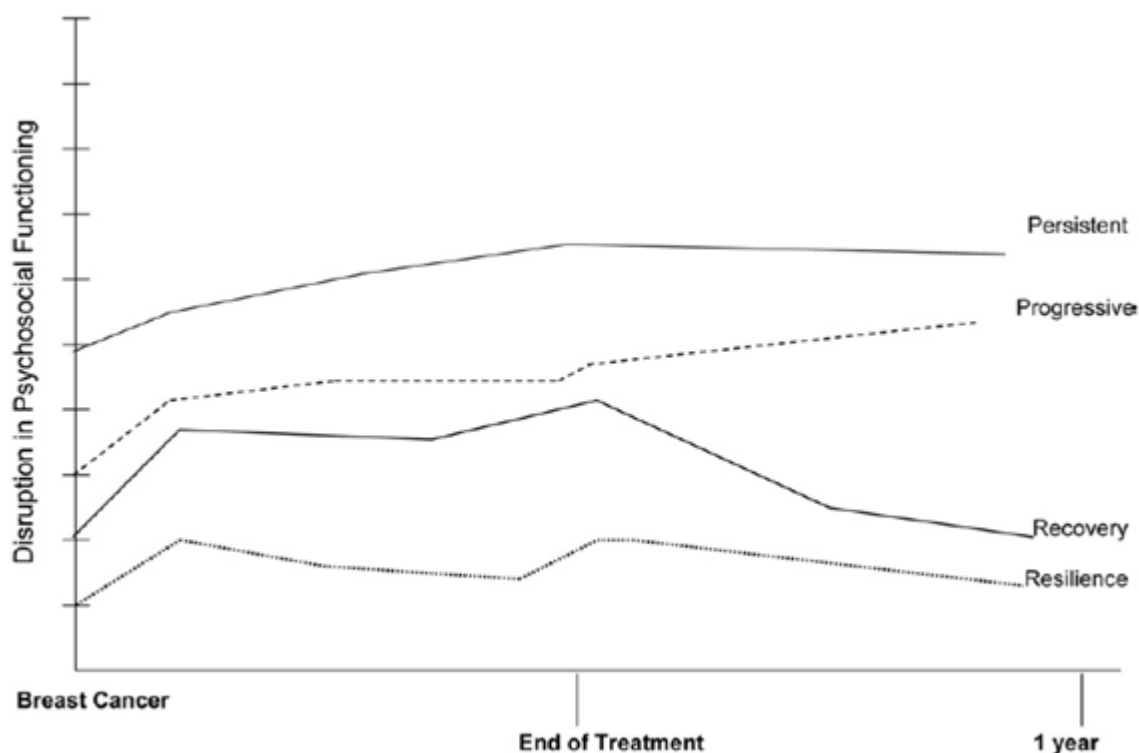


Figure 1. An illustration of the four proposed patterns of adjustment to breast cancer, including persistent, progressive, recovery, and resilience (Knobf, 2011). The level of disruption in psychosocial functioning is presented for each of the proposed patterns over the course of breast cancer diagnosis, treatment, and one-year recovery.

This theoretical model is consistent with research findings pertaining to adjustment to breast cancer (Deshields, Tibbs, Fan, & Taylor, 2006; Helgeson et al., 2004; Knobf, 2008) and other traumatic events (Bonanno, 2004). It demonstrates that a significant proportion of breast cancer survivors experience difficulties in their physical and psychological well-being long after treatment completion. The observed differences in adjustment to breast cancer have served as an impetus for studies to examine the factors associated with recovery from this disease. One such factor is the age at which women are diagnosed with breast cancer.

Younger Breast Cancer Survivors

Compared to older breast cancer survivors, younger women report more short- and long-term disturbances in their physical, psychological, and social well-being (Baucom et al., 2005; Bloom et al., 2004; Burgess et al., 2005; Cimprich et al., 2002; Ganz et al., 2003; Gorman, Malcarne, Roesch, Madlensky, & Pierce, 2010; Kroenke et al., 2004; Osborne, Elsworth, & Hopper, 2003). For example, in a prospective study of over 1,000 women who developed breast cancer during a 5-year period, Kroenke and colleagues (2004) found that women who were diagnosed before the age of 40 experienced the greatest declines in physical roles, bodily pain, social functioning, and mental health compared to middle-aged (41 to 64 years) and elderly (65+ years) women. These group differences were significant after controlling for multiple covariates in the analyses and they remained significant even after 4 years post-diagnosis.

Studies examined whether disease and treatment variables could explain these findings, and while younger women are often diagnosed with more severe forms of the disease and receive more aggressive treatments (Dirier, Burhanedtin-Zincircioglu, Karadayi, Isikdogan, & Aksu, 2009; Maggard et al., 2003), the differences between younger and older women persisted independent of disease severity and treatment extent (Kroenke et al., 2004; Wenzel et al., 1999). This suggests that breast cancer impacts younger women differently than it does their older counterparts.

Research supports this notion. The side effects of breast cancer treatment have been shown to be particularly distressing for young women. Poor body image following surgery is an important concern for many in this group (Baucom et al., 2005), and the sudden onset of menopause and potential infertility can be devastating for those who have not yet started or completed their families (Schnipper, 2001). Treatment-induced menopausal symptoms also

tend to be more pronounced and persistent for younger women (Carpenter et al., 2002; Ganz et al., 2011). Such symptoms can lead to enduring problems in sexual functioning, which is a source of considerable distress for them (Avis et al., 2004; Avis, Crawford, & Manuel, 2005; Baucom et al., 2005; Bloom et al., 2004; Ganz et al., 2003).

Being diagnosed with breast cancer at a young age also has unique implications at this stage of life. Breast cancer interferes greatly with the role demands of early adulthood, including family planning, childcare responsibilities, and career development (Connell et al., 2006; Devins, Bezjak, Mah, Loblaw, & Gotowiec, 2006; Ganz et al., 2002; Mosher & Danoff-Burg, 2005; Rauch et al., 2002). The financial burdens associated with this disease are also substantial (Knobf, 2011). In addition, young women believe that they are too young to have cancer and many feel alone in their experience. It is not uncommon for young women to feel unsupported by their peers who may be less experienced in providing support to those with serious health problems or unavailable due to their own personal and career demands (Ashida, Palmquist, Basen-Engquist, Singletary, & Koehly, 2009).

For many young breast cancer survivors, parenting is a primary role, and the challenges associated with parenting while at the same time coping with this disease may compound the difficulties experienced by this vulnerable group.

Parenting in Young Breast Cancer Survivors

Approximately a quarter of all women with breast cancer are parenting young children at the time of their diagnosis and treatment, and this is considered a conservative estimate (Lewis, 2011; Rauch et al., 2002; Weaver et al., 2010). There is overwhelming consensus in the literature that young mothers feel unequipped to cope with the challenges associated with parenting in the context of breast cancer (Rauch & Muriel, 2004; Semple & McCance, 2010b). Often overlooked by clinical and research teams (Rauch & Muriel, 2004),

issues related to parenting in mothers with breast cancer have consequently been identified as a research priority (Alfano & Rowland, 2006; Schmitt et al., 2008).

Being a parent of young children adds a different dimension to having breast cancer. Young mothers are aware that this illness not only has an impact on them as individuals, but also on the entire family, and they are often overwhelmed by thoughts and feelings about their children throughout the cancer journey (Semple & McCance, 2010b). In a recent review of the qualitative literature on parenting and cancer, three overarching themes that reflect the challenges experienced by young mothers were identified: being a good parent; maintaining a routine at home; and communicating with children (Semple & McCance, 2010b).

Being a Good Parent

Young mothers express a strong drive to be a “good” parent in the face of cancer. They want to meet their children’s needs for care, spend quality time with them, maintain normalcy in their lives, and protect them from cancer-related worries (Elmberger, Bolund, Magnusson, Lutzen, & Andershed, 2008; Helseth & Ulfsaet, 2005; Walsh, Manuel, & Avis, 2005). Despite their best intentions, however, the challenges associated with breast cancer and treatment, such as nausea, fatigue, and disruptive treatment schedules, make it difficult for mothers to live up to what they see as the standards of good parenting (Billhult & Segesten, 2003; Helseth & Ulfsaet, 2005; Ohlen & Holm, 2006; Stiffler, Haase, Hosei, & Barada, 2008). Mothers often feel that they are unable to respond adequately to their children’s needs (Connell et al., 2006), and that they are letting their children down (Ohlen & Holm, 2006; Walsh et al., 2005). A common experience among young breast cancer survivors surveyed by Walsh and colleagues (2005) was a decrease in quality time with their children and a sense that their illness had negatively impacted their relationship with them.

In addition, young mothers worry about their children's future in the event that they should die (Fisher & O'Connor, 2012). Interviews with young breast cancer survivors revealed important concerns for the future welfare of their children and grief related to potential loss of opportunities to engage in their upbringing (Connell et al., 2006). Many mothers worry about the possibility of never seeing their children grow up and several of them feel guilty about potentially abandoning their children (Northouse, Mellon, Harden, & Schafenacker, 2009; Rauch & Muriel, 2004).

Maintaining Routine at Home

Mothers often try to maintain a routine at home to foster a sense of normalcy and safety for their children (Semple & McCance, 2010b). Qualitative studies suggest that maintaining this routine is a useful coping strategy for mothers, in that it provides a necessary distraction from their breast cancer (Billhult & Segesten, 2003; Helseth & Ulfset, 2005; Ohlen & Holm, 2006). However, this too becomes difficult in the face of cancer and treatment, which leads many mothers to sacrifice their own needs for care (Billhult & Segesten, 2003). When maintaining a routine at home ultimately becomes too difficult because of the debilitating effects of treatment, mothers seek help from their friends and families to keep their homes functioning (Fisher & O'Connor, 2012). This has important consequences for mothers as they experience a loss in their maternal and caretaking role (Ohlen & Holm, 2006; Stiffler et al., 2008; Walsh et al., 2005). In families with adolescent children, this caretaking role may shift onto the children, especially adolescent daughters (Walsh et al., 2005), and this shift can be a source of conflict in the mother-daughter relationship (Fitch, Bunston, & Elliot, 1999).

Communicating with Children

Although studies demonstrate that communicating with children is essential to helping them cope with a parent's cancer (Russell & Rauch, 2012a), mothers struggle with this decision (Semple & McCance, 2010b). Some mothers choose to deliberately withhold information, to avoid questions about cancer and death, in an effort to protect their children or because they do not believe their children would understand, while others insist on informing their children to help them cope and foster trust (Barnes et al., 2000; Stiffler et al., 2008).

Choosing whether or not to tell children about breast cancer is only part of the problem; mothers also struggle with *how* to talk to their children about their illness (Barnes et al., 2000; Davis Kirsch, Brandt, & Lewis, 2003; Helseth & Ulfsaet, 2005). They are often unsure as to when to tell their children, how much information to give them, and how to respond to their reactions (Shands, Lewis, & Zahlis, 2000; Stiffler et al., 2008). They attempt to strike a balance between being truthful and open about their cancer on the one hand, and protecting their children on the other. Overriding evidence indicates that parents report a lack of confidence in what to say or do to help their children, even as they admit to watching their children struggle (Lewis, 2011). Difficulties communicating about breast cancer with children are often cited as a source of distress for young mothers (Muriel et al., 2012).

Distress in Mothers with Breast Cancer

Parenting while coping with breast cancer has therefore been construed as a major stressor (Semple & McCance, 2010b) and high levels of distress have been reported in this group (Davis Kirsch et al., 2003; Grabiak, Bender, & Puskar, 2007; Schmitt et al., 2008). For example, in their multinational study, Schmitt and colleagues (2008) reported clinically significant depression in 35% of mothers with cancer. Similarly, in a study examining

predictors of depression in breast cancer patients in the year following treatment, Schlegel and colleagues (2012) found that women with at least one child in the home reported elevated depressive symptoms over the course of that year relative to their counterparts without children.

Distress in mothers with cancer has important consequences on parenting, family functioning, and the well-being of all family members (Grunfeld et al., 2004; Osborn, 2007; Pitceathly & Maguire, 2003; Schmitt et al., 2008; Visser et al., 2004; Watson et al., 2006). Mothers who are distressed tend to be less psychologically available and communicative with their children. They display more hostility, irritability, and coerciveness toward their children, and provide them with less supervision and consistency of discipline (Billhult & Segesten, 2003; Hoke, 2001; Lewis, 2006, 2007). The emotional state of mothers with breast cancer has been shown to impact on the well-being of all family members. Lewis and Darby (2004) found that maternal depressed mood during treatment for breast cancer influenced the emotional adjustment of her adolescent children. Likewise, in a study of 166 cancer patients and their families, a significant relationship was found between maternal psychological functioning and that of their spouses and children (Gazendam-Donofrio et al., 2008).

Families in which mothers with breast cancer are distressed are at greater risk of familial dysfunction. For example, Schmitt and colleagues (2008) found that depression in mothers with breast cancer was a strong predictor of family dysfunction, including difficulties with problem-solving, role functioning, communication, and affective involvement. Similar results were found in two studies examining the relationship between family functioning and anxiety and depression in mothers with breast cancer (B. Edwards & Clarke, 2004; Mantani et al., 2007).

Other than reporting high levels of distress in mothers with breast cancer, there are few clear findings on how parenting children while coping with breast cancer impacts the well-being of young survivors. An important limitation in the existing research has been the absence of a comparison group of young survivors who do not have children, making it difficult to determine whether the experiences of young mothers with breast cancer differ from those of young survivors without children. A comparison of these two groups would contribute to the understanding of how parenting children while coping with breast cancer in young adulthood affects well-being. This research question is addressed here by examining differences in well-being between the two groups, young breast cancer survivors with children and those without. The specific elements of well-being selected were: quality of life; illness intrusiveness; perceived stress; fear of cancer recurrence; and social support. These elements were selected to capture not only the challenges that all young breast cancer survivors face in the short- and long-term, but also the unique challenges associated with parenting.

Elements of Well-Being in Young Breast Cancer Survivors

Quality of Life

Quality of life is a broad multidimensional concept that includes subjective evaluations of both positive and negative aspects of life. A more restricted definition is used when considering the interaction of illness and quality of life. Health-related quality of life refers to the perception of both physical and psychological health, including their perceived effects on physical and social functioning. In breast cancer survivors, health-related quality of life encompasses physical, psychological, and social well-being (Ferrell et al., 1996). Physical well-being takes into account physical symptoms (e.g., fatigue, infertility, pain, and sleep) and functional limitations. Psychological well-being includes positive emotions (e.g.

hope, spiritual growth), as well as psychological distress (e.g. depression and anxiety). Social well-being refers to roles and relationships, family functioning, sexual functioning, and work and finances. For readability in this thesis, health-related quality of life will be referred to simply as quality of life.

Compared to older breast cancer survivors, younger women have consistently been shown to fare worse on a broad range of quality of life domains (Bardwell et al., 2006; Baucom et al., 2005; Bloom et al., 2004; Foster et al., 2009; Knopf, 2011; Kroenke et al., 2004). In the short-term, younger women report more disturbances in their overall quality of life, including difficulties with pain, psychological distress, social functioning, and role functioning (Janz et al., 2005; King, Kenny, Shiell, Hall, & Boyages, 2000; Kroenke et al., 2004; Wenzel et al., 1999). Differences in physical, psychological, and social well-being between younger and older survivors persist in the long-term (Cimprich et al., 2002; Engel, Kerr, Schlesinger-Raab, Sauer, & Holzel, 2004; Ganz et al., 2003; Osborne et al., 2003). For example, in a five-year longitudinal study of breast cancer survivors, Burgess and colleagues (2005) found that younger women were more likely to report longstanding problems with anxiety and depressive disorders.

Parenting children while coping with the effects of breast cancer could potentially amplify the quality of life difficulties experienced in this group. In fact, a recent review found some evidence that breast cancer survivors with children under the age of 18 living at home had worse overall quality of life (Mols et al., 2005). From a physical standpoint, childrearing requires a significant amount of stamina, and the process of balancing the physical side effects from treatment with childcare responsibilities can be problematic (Elmberger et al., 2008; Fisher & O'Connor, 2012). A longitudinal study by Bloom and colleagues (2004) supports this notion. They found that the physical well-being of young

mothers with breast cancer was less likely to improve over time compared to survivors who did not have children. From a psychological and social standpoint, elevated levels of psychological distress and family dysfunction reported among young mothers with breast cancer (Osborn, 2007; Schlegel et al., 2012; Schmitt et al., 2008; Visser et al., 2004), may very well impact on these areas of quality of life.

Illness Intrusiveness

Studies examining the relationship between disease severity, treatment extent, and well-being in adults with acute and chronic health problems have yielded inconsistent results (Devins et al., 1983). Individuals with the same disease and treatment were shown to have widely different patterns of adjustment. In the breast cancer literature, research findings suggest that disease and treatment variables in early-stage breast cancer (stages 0 to 3) are weak predictors of short- and long-term well-being (Arndt et al., 2006; Avis et al., 2005; Carver, Smith, Petronis, & Antoni, 2006; Janni et al., 2001; Janz et al., 2007; Janz et al., 2005; Rakovitch et al., 2003). According to the illness intrusiveness framework, well-being is more strongly related to whether individuals perceive their illness to interfere with different domains of life and/or valued activities, rather than to the disease and treatment variables per se (Devins et al., 1983). In this framework, disease and treatment variables are said to affect well-being indirectly through their impact on illness intrusiveness.

There is considerable evidence that illness intrusiveness is problematic for short- and long-term cancer survivors, which in turn compromises their well-being (Beanlands et al., 2003; Cameron, Franche, Cheung, & Stewart, 2002; Devins et al., 2006; Mah, Bezjak, Loblaw, Gotowiec, & Devins, 2011). Among breast cancer survivors who were on average five years post-diagnosis, illness intrusiveness was found to be highest in instrumental life domains (e.g., work, active recreation), moderate for intimacy (e.g., relationship with spouse,

sex life), and lowest for relationships and personal development (e.g., social relations, religious expression) (Devins et al., 2006; Mah et al., 2011). Studies suggest that illness intrusiveness in long-term breast cancer survivors reflects ongoing side effects from treatment, including pain, fatigue, weakness, sexual dysfunction, and functional limitations (Avis et al., 2005; Chang, Hwang, Feuerman, & Kasimis, 2000; Howell, Radford, Smets, & Shalet, 2000).

Illness intrusiveness appears to be both greater and more detrimental for young adult survivors compared to their older counterparts, particularly in instrumental life domains (Devins et al., 2006). Higher levels of illness intrusiveness reported by young adults may be due to their implicit belief that cancer is not expected to occur at their age and/or because young adults must negotiate developmental tasks that are more dependent on physical strength and stamina (e.g. establishing a career, family and child-rearing responsibilities) (Devins, Edworthy, Guthrie, & Martin, 1992). Given that parenting children requires physical stamina, it is possible that the physical consequences of breast cancer are graver for young mothers. Studies show that the physical impact of breast cancer, such as pain, fatigue, and general malaise, is especially disruptive to their ability to parent (Elmberger et al., 2008; Fisher & O'Connor, 2012). Indeed, fatigue has been described as one of the most common and intrusive symptoms for young mothers with breast cancer, especially as it relates to balancing their children's needs for care with the demands of their illness (Billhult & Segesten, 2003; Fisher & O'Connor, 2012; Semple & McCance, 2010b). Furthermore, in a qualitative study of mothers with cancer on average four years post-diagnosis, Elmberger and colleagues (2008) noted that, much like mothers with fibromyalgia, cancer survivors had to adjust their approach to parenting to compensate for their physical limitations.

Perceived Stress

It is well-known that the occurrence of major life-events does not automatically lead to stress, and that stress levels can be high in the absence of such events. The transactional model of stress (Lazarus & Folkman, 1987) predicts that the impact of major life events depends on one's appraisal of threat and on one's capacity to respond effectively. Thus, the same objective life-event can be expected to lead to varying levels of perceived stress (Pretzer, Beck, & Newman, 2002). Studies suggest that it is this perceived stress, or the extent to which life is perceived as unpredictable, uncontrollable, and overwhelming, that impacts on well-being. In fact, in a longitudinal study of 140 breast cancer survivors, perceived stress was found to fully mediate the relationship between stressful life-events and well-being (Beatty, Lee, & Wade, 2009).

Perceived stress is common among breast cancer survivors and it has important repercussions for their physical and psychological well-being (Beatty et al., 2009; Golden-Kreutz & Andersen, 2004; Golden-Kreutz et al., 2005; Von Ah & Kang, 2008). Younger women are more at risk of experiencing stress in response to breast cancer (Bowman, Deimling, Smerglass, Sage, & Kahana, 2003), compared to older women with this disease, in part because they are less likely to have had life experiences with illness and to have developed coping strategies to manage these health problems.

The added challenge of parenting while coping with the effects of breast cancer may exacerbate perceived stress for younger women. Mothers with breast cancer have described parenting as an important source of stress (Semple & McCance, 2010b) and the overriding evidence indicates that they feel unequipped to cope with the parenting challenges associated with their disease, including how to communicate with children about cancer, how to help their children cope, and how to balance the demands of their illness with their children's

needs for care (Elmberger et al., 2008; Lewis, 2011; Rauch & Muriel, 2004; Semple & McCance, 2010b).

Fear of Cancer Recurrence

Fear of cancer recurrence is the fear or worry that the cancer will return or progress in the same organ or in another part of the body (Vickberg, 2003). It is one of the most universal and durable legacies of surviving cancer and is prevalent among breast cancer survivors (Deimling, Bowman, Sterns, Wagner, & Kahana, 2006; Mehnert, Berg, Henrich, & Herschbach, 2009; van den Beuken-van Everdingen et al., 2008; Vickberg, 2003). Fear of cancer recurrence has been ranked as the largest concern in this group (Armes et al., 2009; Baker, Denniston, Smith, & West, 2005; Herschbach et al., 2004; Lebel, Rosberger, Edgar, & Devins, 2007), with approximately 30 to 60% of breast cancer survivors experiencing moderate to severe fears (Deimling et al., 2006; van den Beuken-van Everdingen et al., 2008; Vickberg, 2003).

Fear of cancer recurrence may be triggered for a number of reasons including visits to doctors, ongoing physical symptoms, reports of cancer in the media, death of fellow survivors, and environmental reminders of the experience (e.g., sights, sounds, and smells associated with the period surrounding breast cancer treatment) (Gill et al., 2004). Fears revolve around the possibility of death, loss of the breast, further treatment, pain, emotional difficulties, suffering of family members, and relying on others to help with daily activities (Mehnert et al., 2009; Vickberg, 2001). The impact of these fears on overall well-being is pronounced, particularly in the psychological domain (Deimling et al., 2006; van den Beuken-van Everdingen et al., 2008). Fear of cancer recurrence may result in debilitating worry and anxiety, and highly disruptive behaviours such as frequent body checking for symptoms (Alfano & Rowland, 2006). Most studies show that these fears remain relatively

stable over time, even five years or more after diagnosis of breast cancer (Koch, Jansen, Brenner, & Arndt, 2013).

Younger women are especially vulnerable to experiencing high levels of fear of cancer recurrence (Koch et al., 2013; Liu et al., 2011). Although the reasons for this are not well understood, it is likely that age-related factors such as less psychological resilience and greater life disruption as a result of cancer play a role (Lebel, Beattie, Ares, & Bielajew, 2013). Fear of cancer recurrence is thought to be higher in those who construe their illness as bearing many negative consequences (Lee-Jones, Humphris, Dixon, & Hatcher, 1997), such as the financial burdens associated with cancer and disruptions to career plans and family responsibilities. It is therefore possible that young mothers experience greater fears of having a recurrence because of the impact a recurrence would have on their families and their ability to parent (Connell et al., 2006; Mehnert et al., 2009; Melchior et al., 2013). Mothers worry about the possibility of not seeing their children grow up in the event that they should die, and they are concerned about the impact this would have on their children's well-being (Billhult & Segesten, 2003; Connell et al., 2006; Fisher & O'Connor, 2012). Indeed, preliminary evidence suggests that mothers with breast cancer experience greater fears of cancer progression and cancer recurrence compared to survivors without children (Connell et al., 2006; Mehnert et al., 2009; Melchior et al., 2013), making this an important area for further exploration.

Social Support

Researchers have underscored the importance of social support in negotiating the stressors associated with a chronic illness (R. T. Brown, 2005; Fuemmeler, Mullins, & Carpentier, 2006). According to the stress-buffering hypothesis proposed by Cohen and Wills (1985), social support reduces one's vulnerability to psychological distress in difficult

situations. In the breast cancer literature, findings are unanimous in that social support from family, friends, and healthcare providers leads to better well-being, both in the short-term and up to 10 years after treatment (Bloom, Stewart, Johnston, Banks, & Fobair, 2001; Friedman et al., 2006; Kornblith et al., 2001; Michael, Berkman, Colditz, Holmes, & Kawachi, 2002). For example, in a study of 100 breast cancer survivors, social support was directly related to well-being and it mediated the extent to which women were distressed by their symptoms (Manning-Walsh, 2005). According to the findings of two longitudinal studies, social support has a protective effect only if it is present at the time of diagnosis and if it remains stable over time (Kornblith et al., 2001; Michael et al., 2002). Lack of social support in breast cancer survivors is a known risk factor for anxiety, depression, and traumatic stress (Amir & Ramati, 2002; Burgess et al., 2005; M. K. Lee et al., 2011; Trunzo & Pinto, 2003; Von Ah & Kang, 2008), and it has been associated with decreased survival (Kroenke, Kubzansky, Schernhammer, Holmes, & Kawachi, 2006; Weihs, Enright, & Simmens, 2008).

The literature distinguishes between different types of social support, including structural support, such as network size and frequency of interaction, and functional support, such as emotional, informational, and practical support (Rose, 1990; Thoits, 1986). It is believed that emotional support is the strongest predictor of psychological well-being in breast cancer survivors (Arora, Finney Rutten, Gustafson, Moser, & Hawkins, 2007; Bloom et al., 2001; Kornblith et al., 2001; M. K. Lee et al., 2011).

A woman's age appears to be related to the level of support received during breast cancer. While some authors have suggested that older cancer survivors have limited social networks (Ajrouch, Antonucci, & Janevic, 2001), several others assert that they have larger and more stable networks compared to their younger peers, and that consequently they

receive more support (Ashida et al., 2009; Novotny et al., 2010). Indeed, younger survivors have been found to experience a greater decrease both in emotional support, and in the size of their social networks as a result of cancer (Ashida et al., 2009; Bloom et al., 2004). Many of them feel unsupported by their peers who may be less experienced in providing support to those with serious health problems or unavailable due to their own personal and career demands.

Social support may be especially important to young mothers who are known to depend on others to help them manage their parenting responsibilities (Russell & Rauch, 2012a; Semple & McCance, 2010b). Furthermore, young mothers have reported unmet needs for support from health professionals on matters related to parenting (Rauch & Muriel, 2004; Semple & McCance, 2010b). Difficulties accessing this support may place this group at risk for poor adjustment (M. K. Lee et al., 2011).

Predictors of Diminished Well-Being in Young Mothers

Most studies on adjustment in families in which a parent has cancer have focused on well-being in children, whereas the variables that contribute to diminished well-being in mothers have not received as much attention (Schmitt et al., 2008). Results from these investigations suggest that mothers report worse psychological adjustment when their children are distressed and when family functioning is low (M. Cohen & Pollack, 2005; B. Edwards & Clarke, 2004; Gazendam-Donofrio et al., 2008; Mantani et al., 2007). This line of research has typically used a systems-based approach that encompasses children, spouses, and family functioning to predict well-being in mothers. Although this approach is certainly valuable, it is also important to understand the factors that contribute independently to a mother's well-being, so as to capture their unique circumstances and further develop these systemic models.

Based on existing literature, a number of psychosocial, demographic, and medical characteristics have been shown to predict diminished well-being in women with breast cancer. Characteristics such as coping, life stress, and social support are frequently cited, as are demographic predictors like age, level of education, and ethnicity (Knobf, 2011). Medical characteristics including physical functioning, physical symptoms, and treatment modality are also considered to be determinants of well-being (Knobf, 2011). Undoubtedly, these characteristics are important; however, none of them are unique to young mothers.

To specifically address some of the fundamental aspects of being a mother in the context of breast cancer, we chose to explore potential predictors such as a mother's age, the age of her children, her level of parenting stress, and the time since her diagnosis. In addition, we designed the studies reported in this thesis to determine whether these potential predictors have an additive effect on well-being. Research of this nature generally does not consider the possibility that predictors might have an additive effect on outcomes, yet this could help to identify the most vulnerable group of young mothers with breast cancer.

Mother's Age and Time Since Diagnosis

Although age and time since diagnosis are certainly not unique to mothers, and we know that women who are younger and newly diagnosed are at greater risk of diminished well-being (Knobf, 2011; Mosher & Danoff-Burg, 2005), the impact of these two predictors has not been examined in the context of parenting or in combination with other potential predictors. For example, are younger mothers with the youngest children most at risk, or could it be newly diagnosed mothers with the highest levels of parenting stress.

We chose to examine these two characteristics as they have been shown to exert a strong influence across several elements of well-being in breast cancer survivors. For example, research indicates that younger age is a determinant of fear of cancer recurrence

(Liu et al., 2011; Mehnert et al., 2009; Simard & Savard, 2009), illness intrusiveness (Devins et al., 2006), and quality of life (Baucom et al., 2005), particularly in the psychological domain (Ganz et al., 2003). Meanwhile, time since diagnosis has been shown to predict illness intrusiveness (Mah, Bezjak, Loblaw, Gotowiec, & Devins, 2005), quality of life (Knobf, 2011), mental health (Burgess et al., 2005), as well as other elements of well-being. As two of the strongest predictors of well-being in breast cancer survivors, we deemed it important to evaluate their influence in the context of parenting and in combination with other potential predictors.

Age of Children

The age of children and associated parenting challenges could conceivably impact well-being in young mothers with breast cancer; however, most studies on motherhood and breast cancer have combined the age ranges of dependent children, making it difficult to draw conclusions regarding the age of children on a mother's experience of breast cancer (Semple & McCance, 2010b). Nevertheless, these studies suggest that parenting while coping with cancer poses different challenges depending on the age of children (Russell & Rauch, 2012a).

Younger children are more distressed by changes in family rhythms such as having new caregivers in the home or a mother's absence at key parts of the day like dinnertime or bedtime. Maintaining a normal routine at home and being physically and emotionally available are therefore more important when children are younger (Thastum, Johansen, Gubba, Olesen, & Romer, 2008; Visser, Huizinga, Hoekstra, van der Graaf, & Hoekstra-Weebers, 2006). This may be problematic for mothers undergoing disruptive treatment schedules or experiencing physical and psychological symptoms common during and after treatment. In addition, some authors suggest that mothers worry more about having a breast

cancer recurrence when their children are younger (Ziner et al., 2012), potentially diminishing their well-being.

Parenting adolescents brings its own set of difficulties even without the added burden of this disease (Bornstein, 2002), and these difficulties may be magnified in families in which a mother has breast cancer. Adolescents experience higher levels of distress as a result of their parent's cancer (Grabiak et al., 2007; Osborn, 2007; Visser et al., 2004), in part because they can understand the consequences of cancer and death. In addition, normal adolescent needs for greater independence are in direct opposition with parental needs and expectations in the context of breast cancer (Russell & Rauch, 2012a). Conflicts over additional household and caretaking responsibilities are common and can bring about important tensions between mothers and their adolescent children (Russell & Rauch, 2012a).

To capture the influence of age of children on the well-being of mothers with cancer, we believed it was important to examine the predictive value of children's ages as a continuous variable on well-being. Age of children was therefore measured in months and ranged from 1 to 240 months (20 years).

Parenting Stress

While some mothers find that parenting children is a source of strength during their cancer experience, others are overwhelmed by it. The extent to which young mothers feel burdened and overwhelmed by parenting, or feel incompetent in their parenting role, could therefore impact their well-being. Parenting stress, or the disparity between the demands of parenting and the resources available to deal with these demands (Abidin, 1995), was selected to capture the experience of young mothers who describe feeling ill-equipped and unprepared to cope with these challenges. To date, no study has examined the impact of parenting stress on the well-being of young mothers with breast cancer.

Although parenting stress is generally studied in families in which children are diagnosed with physical or mental illnesses, evidence suggests that parenting stress in mothers of sick children is strongly related to other aspects of their well-being. To our knowledge, only one study has examined parenting stress in individuals with cancer and it demonstrated that parenting stress was associated with higher levels of depression and anxiety in parents with haematological cancer (Fernandes, Muller, & Rodin, 2012).

In this thesis, parenting stress referred to both the positive and negative aspects of parenting. It addressed the extent to which parenting was viewed as overwhelming and exhausting, but it also assessed the rewarding and satisfying aspects of parenting. This balanced view of parenting reflects how rearing children can be a source of strength (protective factor) and/or vulnerability (risk factor), which takes into account a greater range of parenting experiences.

Although the predictors of well-being identified in this thesis do not represent an exhaustive list of the factors that contribute to poor adjustment in mothers, they address some of the most fundamental questions we have about parenting in the context of breast cancer. Identifying predictors of well-being in young mothers is important in order to recognize and treat those who are most vulnerable to poor adjustment, and it is also a step towards developing a model of adjustment to breast cancer that takes into account their unique circumstances.

Objectives of the Thesis

This thesis was designed to address gaps in the literature on motherhood and breast cancer through two studies presented as separate articles. Both studies focused on the experiences of young breast cancer survivors, defined as women diagnosed with breast cancer before the age of 45 and who are living with or beyond their disease. A decision was

made to only include women who had not experienced a recurrence of the disease so as to limit the variables that could potentially confound our findings.

As mentioned previously, most studies on breast cancer and motherhood have not examined differences in well-being between young survivors with and without children. Although a handful of studies have compared these two groups in one or two areas, none have examined differences across a range of elements of well-being. A comparison of this nature would contribute to the understanding of how parenting children while coping with this disease in young adulthood affects overall well-being.

Thus, the objective of the first study was to uncover the unique influence that being a young mother has on adjusting to breast cancer. To achieve this, we examined differences in overall well-being between young breast cancer survivors with children and without. First, we identified elements of overall well-being that are salient for both groups. We then determined how these elements interrelated within each group using factor analysis techniques (see Appendix A), and finally we identified differences between the two groups based on the patterns observed. We found support for our hypothesis that the interrelationship among elements of well-being varied between young breast cancer survivors with and without children, in such a way so as to reflect their different struggles. Psychological distress (a composite variable representing mental health and perceived stress), illness intrusiveness, and fear of cancer recurrence were found to co-occur more frequently in mothers than in young survivors without children, thus compromising their overall well-being.

Results from our first study revealed elements of well-being that were especially problematic for young mothers with breast cancer compared to survivors without children. However, our study did not reveal the extent to which young mothers struggled, or whether

differences between these two groups were more or less pronounced during the short-term or long-term.

Most studies on motherhood and breast cancer focus on the diagnostic and treatment period, yet evidence suggests that parenting poses distinct challenges over the course of the cancer experience (Russell & Rauch, 2012b) and that family distress can persist into long-term survivorship for many young mothers (Alfano & Rowland, 2006). In the short term, mothers with breast cancer struggle to balance the demands of their illness with being a “good” parent (Semple & McCance, 2010b). After treatment, the pressures of resuming social and work roles may be compounded by parenting responsibilities. During long-term survivorship, ongoing physical symptoms such as lymphedema, fatigue and pain, may be especially burdensome for young mothers because of the high energy demands of parenting. Indeed, preliminary findings demonstrate that having dependent children can be detrimental to long-term well-being in young breast cancer survivors (Bloom et al., 2004; Elmberger et al., 2008; Mols et al., 2005).

Young mothers may therefore face distinct challenges during short- and long-term survivorship compared to survivors without children, representing an important and overlooked area of study. In addition to examining differences in well-being between these two groups over time, another important gap in the literature involves identifying predictors of diminished well-being in young mothers exclusively. Consequently, the purpose of our second study was to address these shortcomings, by (1) examining whether or not parenting children affected the well-being of young women with breast cancer over time; and (2) identifying the predictors for these elements of well-being in young mothers exclusively.

In the first part, young survivors with and without children were examined in three areas of well-being which, in our first study, had been identified as especially problematic

for young mothers: perceived stress, illness intrusiveness, and fear of cancer recurrence. These two groups were compared during two timeframes: short-term (0 to 5 years) and long-term survivorship (5 to 15 years since diagnosis). The second part of the study focused exclusively on young mothers and aimed to identify predictors that impacted on these areas of well-being, namely a mother's age, the age of her children, her level of parenting stress, and the time since her diagnosis. Our goal was to identify the most vulnerable group of mothers with breast cancer and determine whether these predictors, alone or in combination, affected these three elements of well-being.

Research Design

A single survey was chosen to address the research questions for both studies. A survey design was deemed ideal given our interest in exploring differences between young breast cancer survivors with and without children across a range of elements of well-being using standardized questionnaires, and to gather relevant information pertaining to demographic and medical data. The information gathered using this approach allowed us to test a number of different hypotheses and causal relations.

We designed our survey using the recommendations outlined in *Designing Surveys: A Guide to Decisions and Procedures* by Czaja and Blair (2005) which describes the steps involved in drafting survey items and response options, selecting questionnaires, coding survey items, and pre-testing the survey. A literature review was conducted to determine which items and questionnaires were most appropriate for our research questions. Items in the demographic and medical portion of the survey were developed based on previous studies (e.g., Wenzel et al., 1999) and additional items were included for future laboratory studies. Questionnaires were selected that have strong psychometric properties and that were

deemed appropriate for studies with cancer survivors (Montazeri, 2008, 2009; Perry, Kowalski, & Chang, 2007).

The survey was pre-tested online by 250 participants in 2008-2009. Participants were asked to provide feedback about the survey through open-ended questions. The survey underwent three revisions and the final version was launched in April 2009. Please refer to Appendices B through D for a copy of the informed consent, complete demographic and medical history questionnaire, and standardized questionnaires used in studies one and two.

Online Recruitment and Data Collection

We chose to recruit young breast cancer survivors using online methods because this age group is most likely to use the internet as a source of information and support compared to older survivors (Fogel, Albert, Schnabel, Ditkoff, & Neugut, 2002; Pereira, Koski, Hanson, Bruera, & Mackey, 2000; Satterlund, McCaul, & Sandgren, 2003). This method of recruitment also enabled us to reach a sufficiently large sample size to carry out the proposed analyses.

Data collection was also conducted online. Online surveys now represent a common method of collecting data across disciplines (Czaja & Blair, 2005), as well as in breast cancer research (Partridge et al., 2004; Schmidt & Andrykowski, 2004). Studies suggest that online surveys yield larger and more demographically diverse samples, which in turn increases the generalizability of findings (Gosling, Vazire, Srivastava, & John, 2004). This method also encourages participation from those who would otherwise be unable to take part in more traditional research because of physical limitations (Reips, 2002). Evidence suggests that participants in online surveys are motivated to participate, produce results that are consistent with traditional methods, and are no more anxious or depressed than participants in traditional studies (Gosling et al., 2004). Furthermore, research shows that participants in

breast cancer studies actually prefer completing questionnaires electronically (Perry et al., 2007).

Implications of Thesis Findings

Research on motherhood and breast cancer has expanded in recent years. The overriding evidence suggests that young mothers struggle with matters related to parenting and that they feel unsupported by health professionals in this regard (Russell & Rauch, 2012a; Semple & McCance, 2010b). Understanding how breast cancer impacts mothers differently than survivors without children is necessary in order to guide future research and tailor interventions to their specific circumstances. The two studies presented here contribute to an improved understanding of the areas that are most problematic in a mother's breast cancer recovery. This has important implications for future research, as well as for screening and intervention to manage distress in this group, which will be further elaborated in the General Discussion.

Motherhood and Well-Being in Young Breast Cancer Survivors

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Abstract

Parenting while coping with breast cancer is challenging for young women, yet little is known about the impact of parenting on their well-being. This exploratory study examined differences in well-being among 816 young breast cancer survivors with and without children. Exploratory and confirmatory factor analyses were performed on questionnaires measuring various elements of well-being in separate groups of survivors with children and without. Results indicated that psychological distress, illness intrusiveness, and fear of cancer recurrence co-occurred more frequently in young survivors with children than in those without. These findings reveal areas that are especially problematic to a mother's cancer recovery.

Keywords: breast cancer; children; well-being; illness intrusiveness; fear of cancer recurrence; distress

Background

Young breast cancer survivors, broadly defined as young women who are living with or beyond their cancer (Canadian Cancer Society, 2013a), consistently experience poorer physical and psychological well-being compared to older survivors (Baucom et al., 2005; Cimprich et al., 2002; Kroenke et al., 2004). A diagnosis of breast cancer at a young age interferes with the demands of early adulthood, and the short- and long-term side effects of treatment can be especially aversive for this group (Knobf, 2011).

Parenting children while also coping with the effects of breast cancer is both challenging and distressing for young women (Connell et al., 2006; Davis Kirsch et al., 2003; Rauch & Muriel, 2004; Schmitt et al., 2008; Semple & McCance, 2010b; Walsh et al., 2005), potentially compounding difficulties experienced in this vulnerable group. Despite this, there are few clear findings on how parenting children affects the well-being of young survivors (Semple & McCance, 2010b; Visser et al., 2004). With young mothers representing roughly a quarter of all women with this disease (Rauch et al., 2002; Weaver et al., 2010), understanding how breast cancer impacts mothers differently than survivors without children is necessary in order to tailor interventions to their specific circumstances.

This exploratory study is the first to focus specifically on uncovering the unique influence that being a young mother has on adjusting to breast cancer. To achieve this, we examined differences in overall well-being between young breast cancer survivors with children and without. First, we identified elements of well-being that are salient for both groups. We then determined how these elements interrelate within each group, and subsequently explored differences between the two groups based on the patterns observed. This study identifies areas that are especially problematic to a mother's cancer recovery, enabling health professionals to better meet their needs.

Breast Cancer and Motherhood

Mothers with breast cancer often have difficulty fulfilling their parental roles as the demands of illness add significantly to the usual challenges of family life. They tend to sacrifice their own need for care and rely heavily on social support in an effort to meet their children's needs (Billhult & Segesten, 2003; Stiffler et al., 2008). Ultimately though, mothers describe a sense of loss in the quality time spent with their children and feel guilty for being unavailable (Stiffler et al., 2008; Walsh et al., 2005). In addition, mothers worry about their children's well-being in the event that they should die (Billhult & Segesten, 2003; Connell et al., 2006; Fisher & O'Connor, 2012; Rauch & Muriel, 2004). It is no surprise that high levels of psychological distress have been reported in this group (Davis Kirsch et al., 2003; Rauch & Muriel, 2004; Schmitt et al., 2008). Maternal distress in breast cancer survivors has important consequences on marital relationships, family functioning, and the ability of children to cope (Osborn, 2007; Schmitt et al., 2008; Visser et al., 2004).

Well-Being in Young Breast Cancer Survivors

A literature review identified elements of short- and long-term well-being that are salient to all young breast cancer survivors, and which captured some of the unique challenges associated with parenting as a survivor. Based on this review, we designed our study to examine quality of life, perceived stress, illness intrusiveness, fear of cancer recurrence, and social support in young survivors with children and without.

Quality of life. Young women often report disturbances in their short- and long-term quality of life involving their physical, psychological and social well-being (Baucom et al., 2005; Bloom et al., 2004; Cimprich et al., 2002; Kroenke et al., 2004). Young mothers may be especially vulnerable to such disturbances given the elevated rates of distress and physical exhaustion reported in this group (Davis Kirsch et al., 2003; Fisher & O'Connor, 2012;

Rauch & Muriel, 2004; Schmitt et al., 2008). Evidence indicates that breast cancer survivors with dependent children have a worse quality of life than those without children (Bloom et al., 2004; Mols et al., 2005).

Perceived stress. Stress is common among young breast cancer survivors (Beatty et al., 2009; Golden-Kreutz et al., 2005), but not all survivors react to stressful events in the same way. Studies suggest that perceived stress, or the degree to which situations in one's life are appraised as stressful, has a direct bearing on well-being in breast cancer survivors (Beatty et al., 2009; Von Ah & Kang, 2008). Perceived stress may be exacerbated when the survivor is a young mother as parenting can pose an added source of stress, especially with respect to balancing the demands of their illness, work responsibilities, and their children's needs for care (Billhult & Segesten, 2003; Elmberger et al., 2008; Semple & McCance, 2010b).

Illness intrusiveness. Illness intrusiveness, defined as the interference of disease and treatment with various life domains, is detrimental to the well-being of young breast cancer survivors (Devins et al., 2006). Young survivors report that their illness interferes with the demands of early adulthood (Knobf, 2011), and for young mothers, the physical impact of cancer, such as pain, fatigue, and general malaise are especially disruptive to their ability to parent (Fisher & O'Connor, 2012).

Fear of cancer recurrence. Fear of cancer recurrence is prevalent among young breast cancer survivors (Mehnert et al., 2009; Vickberg, 2003). Ranked in this group as the area of greatest concern (Baker et al., 2005), it may result in debilitating worry and anxiety, and frequent body checking for symptoms (Alfano & Rowland, 2006). Studies indicate that mothers with breast cancer report greater fears of cancer progression and cancer recurrence

than survivors without children (Connell et al., 2006; Lebel, Beattie, et al., 2013; Mehnert et al., 2009; Melchior et al., 2013).

Social support. Emotional and practical support from family, friends, and health providers, is essential to the well-being of breast cancer survivors (Bloom et al., 2001; Michael et al., 2002). Studies show that young survivors experience a decline in their social support over the course of their illness (Ashida et al., 2009; Bloom et al., 2004; Bloom et al., 2001). Many young survivors feel unsupported by their peers who may be less experienced in providing support to those with serious health problems or limited by their own personal and career demands (Ashida et al., 2009). Young mothers, in particular, rely heavily on others to help manage their parenting responsibilities (Fisher & O'Connor, 2012; Semple & McCance, 2010b), and many have reported unmet needs for support from health providers with matters related to parenting (Rauch & Muriel, 2004; Semple & McCance, 2010b). Difficulties accessing this support may place this group at risk for poor adjustment (M. K. Lee et al., 2011).

Statistical Approach

Exploratory and confirmatory factor analyses were chosen to analyse the pattern of interaction among elements of well-being or indicator variables. The purpose of these analyses is to determine whether this pattern of interaction can be explained by a smaller number of variables called factors (Bandalos & Finney, 2010). Exploratory factor analysis (EFA) is a hypothesis-generating approach used to identify a factor structure, that is, factors and the relationships between factors and indicator variables, whereas confirmatory factor analysis (CFA) involves testing hypothesized factor structures. In this study, we first performed an EFA on our selected elements of well-being in a group of young mothers with breast cancer in order to obtain a factor structure or model. We then conducted individual

CFAs to test whether this model fit with a separate group of young mothers with breast cancer, as well as a group of young survivors without children. Upon establishing a model that converged well for both groups, we used multiple-group CFA to compare the factor structures between groups (T. A. Brown, 2006).

Hypotheses

The factor analyses will cluster the elements of well-being into main themes, also known as a factor structure. Although we expect this structure to be similar between young breast cancer survivors with children and those without, we hypothesize that the interrelationship among factors and/or elements of well-being will vary between these two groups in such a way so as to reflect their different preoccupations. For example, we expect a stronger relationship between social support and the physical and psychological well-being of mothers because of their heavy reliance on support systems to keep their families functioning. Similarly, we anticipate a stronger relationship between physical well-being and illness intrusiveness for mothers because of the physical demands involved in parenting. Finally, we expect fear of cancer recurrence to be more closely related to psychological well-being in mothers given the potential consequences a recurrence could have on their families.

Methods

Participants

Young women in this study were defined as being younger than 45 years old at the time of their diagnosis, a cut-off that has been used in other research of this nature (Cimprich et al., 2002). Participants were also eligible for this study if they had the ability to read and comprehend English and were older than 18 years old. The following exclusion criteria applied: 1) advanced disease (i.e. stage 4); 2) recurrence of breast cancer; 3) previous history of cancer (other than breast cancer); 4) previous history of chemotherapy or radiation (other

than for breast cancer); and 5) unstable psychiatric, neurological, or substance use disorders. These exclusion criteria were selected so as to limit the number of confounding variables that could potentially influence our findings.

Recruitment for this research was performed online by Avon Army of Women (www.armyofwomen.org) and through advertisements on the websites of Canadian and American breast cancer support organizations. Our initial sample consisted of 1,113 English-speaking North American women diagnosed with breast cancer before the age of 45. Participants were divided at random into three groups: (1) an exploratory sample of young mothers; (2) a confirmatory sample of young mothers; and (3) a confirmatory sample of young women without children. Participants who did not fully complete the questionnaires were excluded from the analyses, as were those whose data recorded as univariate or multivariate outliers ($\alpha = .001$).

The final sample size for the exploratory group of young mothers was 284 participants, thus exceeding the recommended sample size of 180 for this type of analysis based on a participant-to-variable ratio of 10:1 (Bandalos & Finney, 2010; Costello & Osborne, 2005). The final sample sizes for the confirmatory groups of young women with children and without were 275 and 257 participants, respectively. Although researchers agree that larger sample sizes are better for CFA, there is no universal agreement as to how large is large enough. Common rules of thumb for determining adequate sample size suggest that a sample size greater than 200 can be qualified as large and is acceptable for most models (Kline, 2005).

Procedure

An internet-based survey was used for data collection in this cross-sectional study. The survey was hosted by iSurvey.ca. Participants were directed to a consent form detailing

the purpose, risks, and benefits associated with the study. They were told that the purpose of the study was to address issues related to coping and survival during diagnosis, treatment, and remission of breast cancer and that one of the issues of interest was motherhood. They were informed that agreeing to participate in the survey demonstrated their consent and were advised to complete the survey in a quiet location of their choice. They were told that the survey took approximately 45 minutes to complete and that they could interrupt it at any time and return to it at a later date and time. An electronic message was then sent to participants with a link allowing them to continue the survey where they left off. In the event that participants did not complete the survey, two reminder messages were sent. This study was approved by the University of Ottawa Social Sciences and Humanities Research Ethics Board.

Measures

Demographic and medical variables. Demographic variables included country of origin, ethnicity, age, relationship status, education, working status, and age of children. Medical variables included breast cancer stage, time since diagnosis, type of surgery (e.g. lumpectomy, mastectomy), adjuvant therapy (chemotherapy, hormone therapy and radiation therapy) and presence of chronic (non-cancer) health problems.

The Medical Outcomes Study—Short Form (MOS-SF-36) (Ware, Snow, & Kosinski, 2000). The 36-item MOS-SF-36 measures health-related quality of life across eight domains: physical functioning, social functioning, physical and emotional role limitations, mental health, vitality, pain, and overall health perception. Scores range from 0 to 100 for each scale, with higher scores indicating better health and lower scores reflecting substantial functional impairment, significant social and role limitations, and poor health evaluations. The MOS-SF-36 has been shown to be a reliable and valid instrument across

diagnoses, including cancer (Ware et al., 2000). Cronbach's alphas for the exploratory and confirmatory samples in this study ranged from 0.80 to 0.94, except for the General Health subscale; it had an alpha value of 0.44.

Illness Intrusiveness Ratings Scale (IIRS) (Devins et al., 1983). The 13-item IIRS measures the extent to which an illness and/or its treatment interferes with 13 valued activities and interests using a 7-point scale. The IIRS generates three subscales. The Instrumental subscale measures intrusiveness in health, work, finances, and active recreation. The Intimacy subscale measures intrusiveness in sex life and relationship with one's partner. The Relationships and Personal Development subscale measures intrusiveness in family relations, social relations, religious expression, self-improvement, passive recreation, and community involvement. Scores for each subscale range from 1 to 7, with higher scores reflecting greater illness intrusiveness. The IIRS has shown good internal reliability (Cronbach's alpha > 0.8) and validity across diagnoses, including breast cancer (Bloom, Stewart, Johnston, & Banks, 1998; Devins et al., 1983). Cronbach's alphas for the exploratory and confirmatory samples in this study ranged from 0.81 to 0.91.

Concerns About Recurrence Scale (CARS) (Vickberg, 2003). The 30-item CARS measures women's fears about having a breast cancer recurrence. The first section measures the overall fear of having a recurrence with four questions on the frequency, consistency, potential for upset, and intensity of fears using a 6-point scale. The second section includes four subscales and examines the nature of women's concerns using a 4-point scale: health worries, womanhood worries, role worries, and death worries. Higher scores on each scale indicate higher fears. The CARS has demonstrated strong internal reliability with Cronbach's alphas ranging from 0.87 to 0.94 and there is evidence of its validity (Vickberg, 2003).

Cronbach's alphas for the exploratory and confirmatory samples in this study ranged from 0.88 to 0.94.

Social Support Questionnaire (SSQ) (Northouse, 1988). The 40-item SSQ assesses perceived emotional support from five different sources, including spouses, family members, friends, nurses, and physicians using a 5-point scale. Total scores range from 40 to 200, with higher scores indicating greater levels of perceived support. Participants who indicated that they were not currently in a relationship did not complete the section on spousal support and their scores were adjusted accordingly. The SSQ has shown good reliability (Cronbach's alpha = 0.90) and validity (Northouse, 1988). Cronbach's alphas for the exploratory and confirmatory samples in this study ranged from 0.92 to 0.93.

Perceived Stress Scale (PSS) (S. Cohen, Kamarck, & Mermelstein, 1983). The 10-item PSS measures the perception that life is unpredictable, uncontrollable, and overwhelming in the past month using a 5-point scale. Total scores range from 0 to 40, with higher scores indicating greater overall stress. The PSS has shown good reliability (Cronbach's alphas > 0.86) and validity (S. Cohen et al., 1983), and has been used in studies with breast cancer patients (Beatty et al., 2009). Cronbach's alpha for the exploratory and confirmatory samples in this study was 0.92.

Results

Demographic and Medical Characteristics

Demographic and medical characteristics of the sample are presented in Table 1.

Table 1
Group Differences in Demographic and Medical Characteristics for the Exploratory Factor Analysis (EFA) Sample of Mothers and the Confirmatory Factor Analysis (CFA) Samples of Women With Children and Without

Characteristic	EFA Children	CFA Children	CFA No Children
	n = 284	n = 275	n = 257
	M (SD)	M (SD)	M (SD)
Current age	46 (7.7)*	46 (8.3)	44 (9.2)*
Average age of children	16 (9.3)	16 (9.9)	n/a
Age at diagnosis	39 (4.3)	39 (4.5)	38 (5.9)
Time since diagnosis (in years)	7.3 (6.8)	6.9 (7.0)	6.3 (5.9)
	%	%	%
Education			
≤ High school	27*	24	12*
Associate/technical degree	10	13	12
College/university degree	41	41	46
Graduate school	22	22	30*
Relationship status			
In a relationship	90*	91*	73*
Not in a relationship	10*	9*	27*
Working status			
Working	71	69	73
Not working	29	31	23
Breast cancer stage			
0	16	13	20*
I	34	39	43
II	35	30	28
III	15	18*	9*
Surgery type			
Unilateral mastectomy	36	34	30
Bilateral mastectomy	29*	26	18*
Lumpectomy	35*	40	52*
Chemotherapy			
Yes	72	76*	66*
No	28	24*	34*
Radiation therapy			
Yes	43	45	41
No	57	55	59
Hormone therapy			
Yes	57	55	59
No	43	45	41
Other chronic health condition			
Yes	23	26	25
No	77	74	75

* Significant at $p < 0.05$

ANOVAs and chi-squares examining demographic differences among participants revealed that, compared to mothers in the EFA and CFA groups, women without children in the CFA group were marginally younger and more likely to have achieved higher education and to be single. As for medical differences, women without children in the CFA sample tended to have less severe breast cancer, fewer mastectomies, more lumpectomies, and were less likely to have received chemotherapy compared to both groups of mothers, although effect sizes were small.

Exploratory Factor Analysis

We performed an EFA on a sample of young mothers with breast cancer to model the pattern of interaction among elements of well-being. Numerical transformations were performed on 13 variables in order to meet the statistical assumption of normality underlying EFA. A series of principal axis factor analysis with oblimin rotation were then conducted using PASW Statistics V18. This method was chosen because factors were expected to correlate.

The first analysis involved all 18 variables, including eight subscales of the MOS-SF-36, three subscales of the IIRS, five subscales of the CARS, the SSQ, and the PSS. We determined the number of factors to retain based on Kaiser's criterion of 1 and the inflexion in the scree plot (Costello & Osborne, 2005). A variable was considered to be associated with a factor if its loading was greater than or equal to 0.40 (Tabachnick & Fidell, 2007). Through subsequent analyses, three variables from the MOS-SF-36 (General Health, Role Emotional, and Social Functioning) were eliminated to obtain a parsimonious and pure factor structure with few or no cross-loading items (Bandalos & Finney, 2010; Costello & Osborne, 2005; Tabachnick & Fidell, 2007). The final solution yielded a four-factor structure that accounted for 72% of the variance (see Table 2 for factor loadings).

Table 2
The Pattern Matrix for the Exploratory Factor Analysis (EFA) of Young Mothers

Item	F_1^a	F_2	F_3	F_4	h^2
Health worries (CARS)	0	-1.00	0	0	.99
Role worries (CARS)	0	-.86	0	0	.74
Death worries (CARS)	0	-.78	0	0	.60
Woman worries (CARS)	0	-.72	0	0	.55
Physical functioning (MOS-SF-36)	0	0	.77	0	.60
Role physical (MOS-SF-36)	0	0	.61	0	.55
Bodily pain (MOS-SF-36)	0	0	.57	0	.45
Mental health (MOS-SF-36)	.89	0	0	0	.83
Perceived stress scale	-.77	0	0	0	.71
Vitality (MOS-SF-36)	.68	0	0	0	.75
Social support questionnaire	.45	0	0	0	.25
Instrumental (IIRS)	0	0	0	-.83	.81
Intimacy (IIRS)	0	0	0	-.71	.58
Relationships/personal devlpmt (IIRS)	0	0	0	-.66	.58
Overall fears (CARS)	0	0	0	-.52	.35
Eigenvalue	5.45	2.91	1.36	1.03	
Percent of covariance	36.36	19.39	9.10	6.84	

Note. The pattern matrix identifies the factor structure, or pattern of interaction among elements of well-being (or indicator variables), including pattern loadings, communalities, and the percentage of variance accounted for by each factor. Loadings under 0.40 are replaced by zeros.

^a Factor labels are F_1 (Psychological adjustment), F_2 (Recurrence worries), F_3 (Physical health), and F_4 (Illness intrusiveness)

The first factor, Psychological Adjustment, included mental health, perceived stress (inversely related), vitality, and social support. The strongest loading items on this factor suggest that Psychological Adjustment represents the extent to which women are free of anxiety, depression, and stress. The second factor, Recurrence Worries, included worries related to health, womanhood, roles, and death (the “worries” subscales of the CARS), and represented the extent to which women worried about the negative physical, psychological, and social consequences of having a breast cancer recurrence. This factor did not measure

worries about the *possibility* of having a breast cancer recurrence, but rather the *content* of these worries. The third factor, Physical Health, included bodily pain, physical functioning, and problems with work or other daily activities as a result of physical health. The fourth factor, Illness Intrusiveness, included measures of intrusiveness in instrumental life domains, intimacy, and relationships and personal development, as well as the extent to which women feared having a recurrence.

Confirmatory Factor Analysis

We elected to perform two separate CFAs to determine whether the four-factor structure derived from the EFA could be replicated in a second sample of young breast cancer survivors with children, as well as a sample of young survivors without children. All assumptions underlying CFA were met, and two separate CFAs using maximum likelihood estimation were conducted using EQS 6.1, one for each group: women with children and those without. Our confirmatory model, based on the results of the EFA, included four factors and 15 indicator variables. The four variable regression coefficients that corresponded with each factor in the CFA were fixed according to the strongest loading variables for those factor in the EFA, namely health worries, mental health, physical function, and illness intrusiveness in instrumental life domains.

Several indices were used to assess the model's goodness of fit with the data: (1) the comparative fit index (CFI; values of 0.95 or higher represent a good fit) (Hu & Bentler, 1999); (2) the root-mean-square error of approximation (RMSEA; values between 0.05 and 0.08 indicate a fair fit) (Browne & Cudeck, 1993); and (3) Akaike's information criterion (AIC), a measure of model parsimony where smaller values indicate better parsimony. Post-hoc modifications were performed in an attempt to improve model fit using the results from the Lagrange multiplier test to add or delete paths.

CFA of young mothers. The CFA for our sample of young mothers with breast cancer indicated that the model was a fair fit for the data ($\chi^2(84, N = 275) = 202.41, p < .001, CFI = 0.95, RMSEA = 0.07, AIC = 34.41$). Post-hoc modifications were performed to improve model fit. A path predicting the vitality variable from the Physical Health factor was added, $\chi^2(83, N = 275) = 167.58, p < .001$. A chi-square difference test indicated that the model was significantly improved by the addition of this path ($\chi^2_{diff}(1, N = 275) = 34.83, p < .001$). The decision to add a path connecting vitality to the Physical Health factor was supported by research: vitality measured the extent to which women felt “tired and worn out”, a state closely resembling fatigue which has been associated with worse overall physical well-being (Arndt et al., 2006). The modified model had a CFI value of 0.97, an RMSEA value of 0.06, and an AIC value of 1.58, indicating a good fit.

CFA of young women without children. The CFA for our sample of young survivors without children also indicated that the model was a fair fit for the data ($\chi^2(84, N = 257) = 202.42, p < .001, CFI = 0.94, RMSEA = 0.07, AIC = 34.42$). A path predicting the vitality variable from the Physical Health factor was added ($\chi^2(83, N = 257) = 176.21, p < .001$), and the chi-square difference test indicated that the model was significantly improved by the addition of this path ($\chi^2_{diff}(1, N = 257) = 26.21, p < .001$). The modified model had a CFI value of 0.95, an RMSEA value of 0.07, and an AIC value of 10.21, indicating a fair fit.

Multiple-group CFA. Upon obtaining a model that fit well for both groups (young women with children and without), we compared the factor structures of these groups using multiple-group CFA (Costello & Osborne, 2005). A stepwise procedure was used which followed the recommendations by Brown (2006), including (1) a test of equal form (factor structure); (2) a test of the equality of factor loadings; and (3) a test of the equality of factor variances and covariances. Figure 2 illustrates the results of the multiple-group CFA.

The multiple-group CFA was conducted on the modified models for young survivors with children and without. The first test suggested that the two groups had equivalent factor structures ($\chi^2(166, N = 532) = 343.79, p < .001$). The CFI value was 0.96 and the RMSEA value was 0.06, confirming that the model fit well with both groups. This result was expected given that the same factor structure or model fit well for both groups in our separate CFAs.

The second test suggested that the two groups had equivalent factor loadings ($\chi^2(178, N = 532) = 354.16, p < .001$), indicating that the variables that made up each factor did not differ in their relative contribution to these factors. For example, for the Psychological Adjustment factor, none of social support, perceived stress, mental health, or vitality contributed differently to the psychological adjustment of young mothers with breast cancer. Therefore, all variables carried equal weight in the overall sense of well-being of young women with children and without.

The third test showed that factor variances and correlations were not equivalent between groups ($\chi^2_{\text{diff}}(10, N = 532) = 19.83, p = 0.031$). On the basis of the Lagrange multiplier test, the equality constraint for the Psychological Adjustment–Illness Intrusiveness factor correlations was released ($\chi^2(187, N = 532) = 360.08, p < .001$), allowing these two factors to correlate. A chi-square difference test indicated that the model was significantly improved after releasing this constraint ($\chi^2_{\text{diff}}(1, N = 532) = 11.9, p < .001$). The CFI value was 0.94 and the RMSEA value was 0.07, confirming that the modified model fit well with both groups. This last step demonstrated that young women with children and without differed in the extent to which the Psychological Adjustment factor was inversely related to the Illness Intrusiveness factor. The relationship between these two factors was significantly stronger in mothers ($r = -0.77$) compared to women without children ($r = -0.58$).

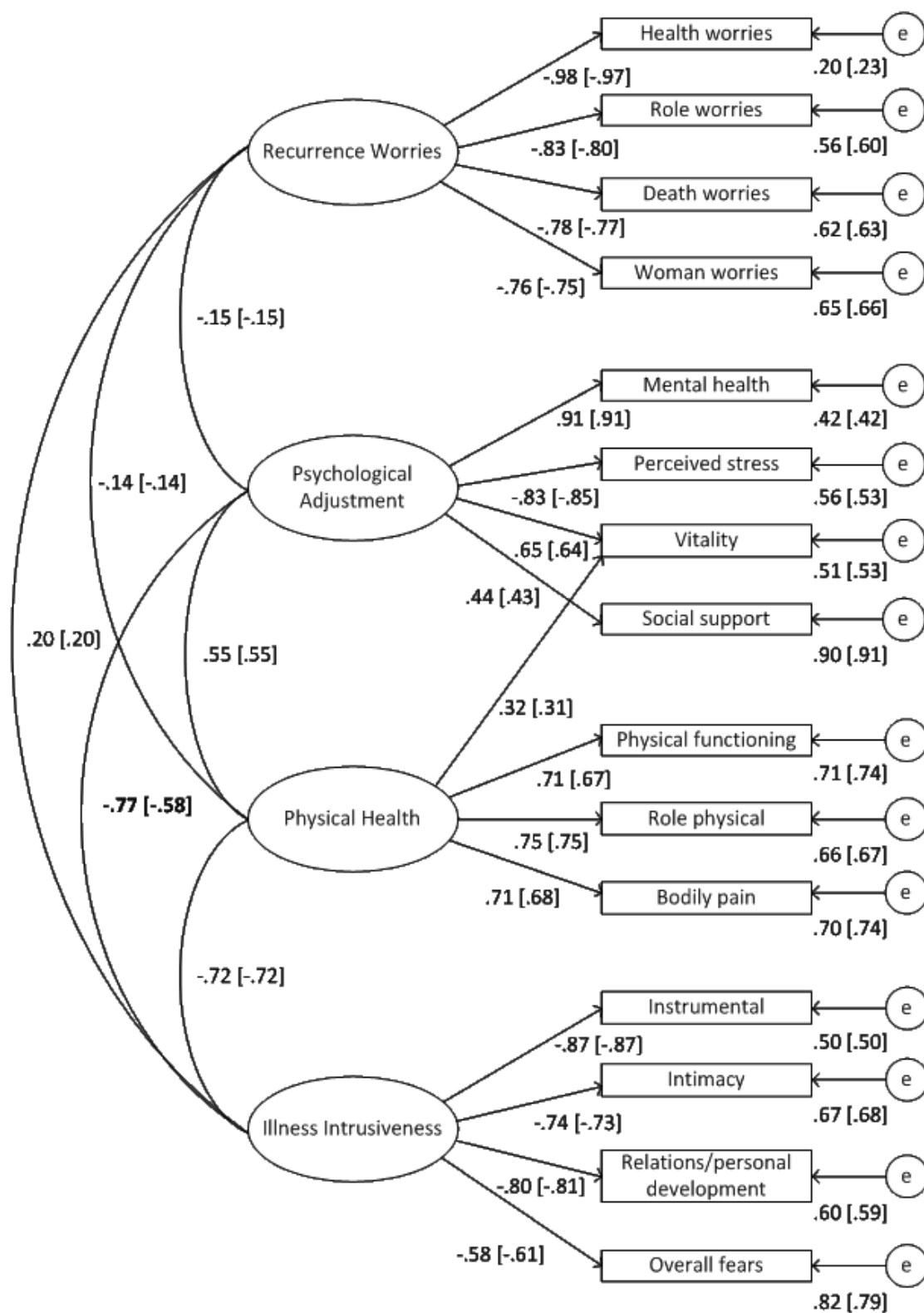


Figure 2. The multiple-group Confirmatory Factor Analysis (CFA) compares the factor structures between young breast cancer survivors with children (N=275) and those without children (N=257), including factor loadings and factor variances and correlations. The ovals

represent the latent factors, including Recurrence Worries, Psychological Adjustment, Physical Health, and Illness Intrusiveness. The rectangles represent the indicator variables, including the subscales for The Medical Outcomes Study—Short Form, Illness Intrusiveness Ratings Scale, Concerns About Recurrence Scale, Social Support Questionnaire, and Perceived Stress Scale. The curved lines represent correlations between factors and the arrows represent factor loadings for each indicator variable. The circles represent error terms. Results for survivors without children are displayed in brackets. Significant differences between groups are bolded.

Discussion

This exploratory study focused on uncovering the unique impact that being a mother has on adjusting to breast cancer. As we had hypothesized, the interrelationship among elements of well-being varied between young breast cancer survivors with children and without.

Four main factors were defined as contributing to the overall sense of well-being for young breast cancer survivors: Psychological Adjustment, Physical Health, Illness Intrusiveness (which includes the presence of fear of cancer recurrence), and Recurrence Worries (which describes the content of these fears). We found a stronger relationship between Psychological Adjustment and Illness Intrusiveness for young survivors who were mothers, suggesting that psychological distress is closely related to illness intrusiveness for this group. Since fear of cancer recurrence was a part of the Illness Intrusiveness factor, it is included in this relationship as well. Consequently, these three elements co-occurred more frequently in young breast cancer survivors with children than in survivors without children. This is the first study to demonstrate that parenting children while coping with breast cancer compromises young mothers' overall sense of well-being by exacerbating the relationship between psychological distress, illness intrusiveness, and fear of cancer recurrence.

The direction of the relationships among these three elements, and how they relate to parenting, is unclear and remains to be tested. It is possible that psychological distress in

young mothers leads to greater illness intrusiveness and fear of cancer recurrence. Indeed, fear of cancer recurrence has been shown to be prospectively influenced by psychological distress (Lebel, Rosberger, Edgar, & Devins, 2009; Liu et al., 2011); however, this may not be the case for illness intrusiveness. Although illness intrusiveness and psychological distress frequently co-occur (Bloom et al., 1998), evidence suggests that illness intrusiveness impacts on psychological well-being, and not the reverse (Devins, 2010).

It is also possible – and, indeed, more likely – that illness intrusiveness and fear of cancer recurrence have the effect of heightening distress in young mothers with breast cancer. Illness intrusiveness, especially in areas requiring physical stamina, may pose particular challenges for young mothers. Fatigue has been described as one of the most common and intrusive symptoms for young mothers with breast cancer, especially as it relates to meeting the demands of their illness as well as their children’s needs for care (Billhult & Segesten, 2003; Fisher & O’Connor, 2012; Semple & McCance, 2010b). Since being unable to care for their children is distressing for young mothers (Semple & McCance, 2010b; Stiffler et al., 2008; Walsh et al., 2005), our finding that illness intrusiveness creates more distress in this group is supported.

Our findings indicate that young mothers may be especially distressed by their fears of having a breast cancer recurrence and there is evidence to support this. Previous research demonstrates that young mothers report greater fears of having a recurrence because of the potential consequences a recurrence could have on their families, their ability to parent, and their children’s well-being (Connell et al., 2006; Mehnert et al., 2009; Melchior et al., 2013). In a study of young breast cancer survivors, the most commonly reported major personal concern in relation to fear of cancer progression and recurrence was for the future welfare of their children (Connell et al., 2006). This research illustrates not only that fear of cancer

recurrence is elevated among young mothers, but that these fears are also a cause of significant concern and distress.

Limitations

Although our use of factor analysis precludes us from drawing firm causal interpretations, the aim of this exploratory study was to identify areas important to the overall sense of well-being of young mothers with breast cancer compared to survivors without children, and to evaluate the degree to which the results were consistent with our hypotheses. Our findings shed light on areas in which young mothers with breast cancer struggle, which has important implications for screening and intervention in this group.

Mothers in our study were diagnosed with more severe cancers and received more aggressive treatments compared to our samples of survivors without children. However, differences were small and studies suggest that disease and treatment variables in early-stage breast cancer are weak predictors of short- and long-term well-being (Arndt et al., 2006; Janz et al., 2005; Rakovitch et al., 2003).

Women in our sample were predominantly Caucasian (over 93%) and highly educated, with approximately 25% having completed graduate school. Questions relating to the representativeness of our sample could be attributed to our use of online methods to recruit participants. However, the relative infrequency of breast cancer among younger women made this method of recruitment ideal to reach this population as younger women are more likely to use the internet as a source of information and support (Pereira et al., 2000; Satterlund et al., 2003). Furthermore, this method enabled us to recruit a sufficiently large sample size to carry out the proposed analyses. Our study will need to be replicated with demographically diverse samples to determine whether our results apply across demographic groups.

Finally, it is possible that our findings are true of all mothers, whether or not they have breast cancer. However, we chose cancer- and illness-specific outcome measures to examine our research question, so that our findings would be specific to mothers with breast cancer.

Clinical and Research Implications

Our findings indicate that this group is especially in need of screening and interventions to manage psychological distress, the fear of having a recurrence of breast cancer, and illness intrusiveness in various life domains. Interveners should consider screening for illness intrusiveness and fear of cancer recurrence when they suspect psychological distress in a young mother with breast cancer which will help identify problematic areas in her recovery. Further research is needed to explore the mechanisms relating these three elements to parenting and the impact on children of young mothers with breast cancer.

Conclusion

Parenting is an important concern for young breast cancer survivors, yet little is known about the impact of having children on their overall sense of well-being. This exploratory study found that psychological distress, illness intrusiveness, and fear of cancer recurrence co-occurred more often in young mothers with breast cancer, thus compromising their well-being. Young mothers with breast cancer are therefore in need of screening and interventions to manage distress in these areas and to reduce their combined impact. These findings suggest new research avenues to explore, including the mechanisms relating these three elements to parenting, and their impact on children of young mothers with breast cancer.

The Impact of Motherhood on Perceived Stress, Illness Intrusiveness, and Fear of Cancer

Recurrence in Young Breast Cancer Survivors Over Time

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Abstract

Objective: Parenting children while coping with breast cancer is challenging for young women, yet little is known about the impact of parenting on their well-being over time. The first part of this study examined differences in stress levels, illness intrusiveness, and fear of cancer recurrence between young breast cancer survivors with and without children in two separate timeframes (0–5 and 5–15 years since diagnosis). The second part identified predictors of diminished well-being in young mothers with breast cancer. *Methods:* 742 young North American women previously diagnosed with breast cancer completed the Perceived Stress Scale, Illness Intrusiveness Ratings Scale, and Concerns About Recurrence Scale via a web-based survey. In part one, multivariate analyses were performed with motherhood status and timeframe since diagnosis as the independent variables, and stress levels, illness intrusiveness, and fear of cancer recurrence as the dependent variables. In part two, hierarchical linear regressions were conducted with age of mother, age of children, time since diagnosis, and parenting stress as predictors of diminished well-being in young mothers only. *Results:* Young mothers reported higher levels of fear of cancer recurrence and illness intrusiveness in intimacy during both timeframes compared to survivors without children. Predictors were found to influence different outcomes. *Conclusions:* Young mothers are in need of screening and intervention to manage their fears of having a recurrence and to cope with problems in intimacy well into remission. This study also reveals how maternal age, age of children, and parenting stress impact on well-being in this group.

Keywords: breast cancer; oncology; children; illness intrusiveness; fear of cancer recurrence; stress

Background

Young breast cancer survivors consistently experience poorer physical and psychological well-being compared to older survivors (Baucom et al., 2005; Cimprich et al., 2002; Kroenke et al., 2004). Parenting is a primary role for many young survivors and the combined effect of parenting while coping with this disease can be distressing for many of them (Connell et al., 2006; Rauch & Muriel, 2004; Schmitt et al., 2008; Semple & McCance, 2010b). This could potentially amplify difficulties experienced in this vulnerable group. Despite this, there are few clear findings on how parenting children affects the well-being of young survivors during or after the cancer treatment experience (Semple & McCance, 2010b; Visser et al., 2004).

Most studies on breast cancer and motherhood have not examined differences between young survivors with and without children, making it difficult to determine whether the experiences of young mothers differ from those of survivors who do not have children. Existing studies have typically focused on the diagnostic and treatment period (Semple & McCance, 2010b), yet problems related to family dysfunction persist well into remission for many young survivors (Alfano & Rowland, 2006). Furthermore, little is known about the variables that contribute to distress in young mothers with breast cancer. With young mothers representing roughly a quarter of all women with this disease (Rauch & Muriel, 2004; Rauch et al., 2002; Weaver et al., 2010), understanding how breast cancer impacts mothers differently than survivors without children is necessary in order to tailor interventions to their specific circumstances.

Part 1: Motherhood and Well-Being in Young Survivors

In an earlier study comparing the well-being of young breast cancer survivors with and without children, we identified three elements that were especially problematic for the

well-being of young mothers, namely perceived stress, illness intrusiveness, and fear of cancer recurrence (Ares, Collins, Lebel, & Bielajew, 2013). Part 1 of the current study was therefore designed to focus in on these three elements in young survivors with and without children.

Perceived Stress

Stress is common among young breast cancer survivors (Beatty et al., 2009; Golden-Kreutz et al., 2005), but not all survivors react to stressful events in the same way. Studies suggest that perceived stress, or the degree to which situations in one's life are appraised as stressful, has a direct bearing on well-being in breast cancer survivors (Beatty et al., 2009; Von Ah & Kang, 2008). Younger women are more likely to perceive cancer as stressful compared to older women (Bowman et al., 2003), and this perceived stress may be exacerbated when the survivor is a young mother (Semple & McCance, 2010b). The overriding evidence indicates that mothers feel unequipped to cope with the parenting challenges associated with their disease, including how to communicate with children about cancer, how to help their children cope, and how to balance the demands of their illness with their children's needs for care (Elmberger et al., 2008; Lewis, 2011; Rauch & Muriel, 2004; Semple & McCance, 2010b).

Illness Intrusiveness

Illness intrusiveness, defined as the interference of disease and treatment with various life domains, is prevalent among breast cancer survivors and detrimental to their well-being (Devins et al., 2006). Illness intrusiveness is higher in younger survivors, particularly in instrumental life domains such as work and active recreation (Devins et al., 2006). Higher levels of illness intrusiveness reported by young survivors may be due to their implicit belief that cancer is not expected to occur at their age and/or because the developmental tasks they

must negotiate are more dependent on physical strength and stamina (e.g. establishing a career, family and child-rearing) (Devins et al., 1992). Parenting children requires a significant amount of stamina and studies show that the physical impact of breast cancer, such as pain, fatigue, and general malaise, is especially disruptive to their ability to parent (Elmberger et al., 2008; Fisher & O'Connor, 2012).

Fear of Cancer Recurrence

Fear of cancer recurrence, one of the most universal and durable legacies of surviving cancer, is pervasive among young breast cancer survivors (Koch et al., 2013; Liu et al., 2011). Ranked in this group as the area of greatest concern (Baker et al., 2005), it may result in debilitating worry, anxiety, and frequent body checking for symptoms (Alfano & Rowland, 2006). Younger women are thought to be more susceptible to these fears because, as a group, they are less psychologically resilient and have greater caregiver and financial responsibilities compared to older survivors (Knobf, 2011). Indeed, breast cancer survivors with children report greater fears of cancer progression and cancer recurrence than survivors without children because of the impact a recurrence would have on their family and their ability to parent (Connell et al., 2006; Mehnert et al., 2009; Melchior et al., 2013). Mothers worry about their children's future well-being in the event that they should die (Billhult & Segesten, 2003; Fisher & O'Connor, 2012), and many feel guilty about potentially abandoning their children (Connell et al., 2006; Northouse et al., 2009; Rauch & Muriel, 2004).

Part 1: Objectives and Hypotheses

Although physical and psychological impairments are most pronounced during and up to a year after treatment, 15 to 30% of breast cancer survivors continue to have difficulties in these areas well into remission (Knobf, 2011). Long-term survivorship, defined as greater

than five years, can be marked by ongoing problems with physical symptoms, psychological functioning, and family distress for many young breast cancer survivors (Alfano & Rowland, 2006), even among those who remain free of cancer (Bloom et al., 2004; Bloom, Stewart, Oakley-Girvan, Banks, & Shema, 2012).

The aim of the first part of this cross-sectional study was to examine whether or not parenting children has an impact on the well-being of young breast cancer survivors during two timeframes: short-term survivorship (0–5 years) and long-term survivorship (5–15 years since diagnosis). Specifically, young survivors with children and without were compared in three areas: perceived stress, illness intrusiveness, and fear of cancer recurrence. Although we expected the well-being of *all* young breast cancer survivors to be worse during short-term survivorship, we hypothesized that this effect would be *most* pronounced for mothers given that parenting children would be more challenging when the physical and psychological demands of breast cancer are at their highest. We also anticipated that any differences between these two groups would dissipate over time as the parenting demands associated with cancer diminish.

Part 2: Predictors of Diminished Well-Being in Young Mothers

Most studies of adjustment in families in which a parent has cancer have focused on distress in children, whereas the variables that contribute to distress in mothers have not received as much attention (Schmitt et al., 2008). Based on the existing literature, four potential predictors were identified which could impact the well-being of mothers, namely mother's age, the age of her children, her level of parenting stress, and the time since her diagnosis. Although research has already demonstrated that women who are younger and newly diagnosed are at greater risk of diminished well-being (Knobf, 2011; Mosher & Danoff-Burg, 2005), the impact of these two predictors have not been examined in the

context of parenting or in combination with other potential predictors. For example, are younger mothers with the youngest children most at risk, or could it be younger mothers with the highest levels of parenting stress?

Furthermore, although there is some speculation that well-being in mothers is most affected when children are younger, most studies on motherhood and breast cancer have combined the age ranges of dependent children, making it difficult to draw conclusions on how the age of children impacts on a mother's experience of breast cancer (Semple & McCance, 2010b). Moreover, to date, no study has examined the impact of parenting stress, or the disparity between the demands of parenting and the resources available to deal with these demands (Abidin, 1995), on the well-being of young mothers with breast cancer.

Part 2: Objectives and Hypotheses

The second part of this study focuses exclusively on young mothers and aims to identify predictors of perceived stress, illness intrusiveness, and fear of cancer recurrence. Our goal was to identify the most vulnerable group of mothers with breast cancer and determine whether these predictors, alone or in combination, affected these three elements of well-being. We hypothesized that younger mothers, younger children, higher levels of parenting stress, and shorter time since diagnosis all represented predictors of diminished well-being. We also expected the combination of more than one predictor to have a greater influence on well-being.

Methods

Participants

Young women in this study were defined as being younger than 45 years of age at the time of diagnosis, a cut-off that has been used in other research of this nature (Cimprich et al., 2002; Janz et al., 2007). To be eligible, participants also had to have been diagnosed with

breast cancer within the past 15 years, have the ability to read and comprehend English, and be older than 18 years of age. The following exclusion criteria applied: 1) advanced disease (i.e. stage 4); 2) recurrence of breast cancer; 3) previous history of cancer (other than breast cancer); 4) previous history of chemotherapy or radiation (other than for breast cancer); and 5) unstable psychiatric, neurological, or substance use disorders. These exclusion criteria were selected so as to limit the number of confounding variables that could potentially influence our findings.

Recruitment for this research was performed online by the Avon Army of Women (www.armyofwomen.org) and through advertisements on the websites of Canadian and American breast cancer support organizations. Our initial sample consisted of 979 participants. Those who did not fully complete the questionnaires were subsequently excluded from the analyses, as were those whose data recorded as univariate or multivariate outliers ($\alpha = .001$).

A final sample of 742 young breast cancer survivors was obtained for the MANOVA analyses, further subdivided into four groups based on timeframe since diagnosis (0–5 and 5–15 years) and motherhood status (yes/no). A final sample size of 531 young mothers was used for the hierarchical linear regression analyses in the second part of this study.

Procedure

An internet-based survey was used for data collection in this cross-sectional study. The survey was approved by the University of Ottawa Social Sciences and Humanities Research Ethics Board and hosted by iSurvey.ca. Participants were directed to a consent form detailing the purpose, risks, and benefits associated with the study. They were told that the purpose of the study was to address issues related to coping and survival during diagnosis, treatment, and remission of breast cancer and that one of the issues of interest was

motherhood. They were informed that agreeing to participate in the survey demonstrated their consent and were advised to complete the survey in a quiet location of their choice. They were told that the survey took approximately 45 minutes to complete and that they could interrupt it at any time and return to it at a later date and time. Participants who interrupted their survey were sent an electronic message with a link allowing them to continue the survey where they left off. In the event of non-completion, two reminder messages were sent.

Measures

Demographic and medical variables. Demographic variables included country of origin, ethnicity, age, relationship status, education, employment status, and age of children. Medical variables included breast cancer stage, time since diagnosis, past and current chemotherapy, and presence of chronic (non-cancer) health problems.

Illness Intrusiveness Ratings Scale (IIRS) (Devins et al., 1983). The 13-item IIRS measures the extent to which an illness and/or its treatment interferes with 13 valued activities and interests using a 7-point scale. The IIRS generates three subscales. The Instrumental subscale measures intrusiveness in health, work, finances, and active recreation. The Intimacy subscale measures intrusiveness in sex life and relationship with one's partner. The Relationships and Personal Development subscale measures intrusiveness in family relations, social relations, religious expression, self-improvement, passive recreation, and community involvement. Scores for each subscale range from 1 to 7, with higher scores reflecting greater illness intrusiveness. The IIRS has shown good internal reliability (Cronbach's $\alpha > 0.8$) and validity across diagnoses, including breast cancer (Devins et al., 1983; Devins et al., 2001). Cronbach's alphas for the three subscales in this study ranged from 0.81 to 0.85.

The Concerns About Recurrence Scale (CARS) (Vickberg, 2003). Fear of cancer recurrence was measured using the 4-item Overall Fear subscale of the CARS, which addresses the frequency, consistency, and intensity of the fear of having a recurrence, as well as the potential for upset caused by these fears. Items are coded on a 6-point scale with higher scores indicating greater fears. The CARS has demonstrated strong internal reliability with Cronbach's alphas ranging from 0.87 to 0.94 and there is preliminary evidence of its validity (Vickberg, 2003). Cronbach's alpha for the Overall Fear subscale in this study was 0.92.

Perceived Stress Scale (PSS) (S. Cohen et al., 1983). The 10-item PSS measures the degree to which situations in one's life are appraised as unpredictable, uncontrollable, and overwhelming in the past month using a 5-point scale. Total scores range from 0 to 40, with higher scores indicating greater overall stress. The PSS has shown good reliability (Cronbach's alphas > 0.86) and validity (S. Cohen et al., 1983), and has been used in studies with breast cancer patients (Beatty et al., 2009). Cronbach's alpha for the PSS in this study was 0.92.

Parental Stress Scale (PaSS) (Berry & Jones, 1995). The 18-item PaSS measures the level of stress associated with parenting by asking about positive (e.g., "I am happy in my role as a parent") and negative (e.g., "I feel overwhelmed by the responsibilities of being a parent") aspects of parenting. Items are coded on a 5-point scale with scores ranging from 0 to 90. Higher scores indicate higher parenting stress. The PaSS has shown good reliability (Cronbach's alphas > 0.81) and validity (Berry & Jones, 1995). Cronbach's alpha for the PaSS in this study was 0.87.

Statistical Methods

In Part 1 of the study, we identified relevant demographic and medical covariates by conducting ANOVAs and chi-squares across different timeframes since diagnosis (0–5 and 5–15 years) and motherhood statuses (yes/no). To test our hypothesis that parenting children affects the well-being of young women with breast cancer during short-term and long-term survivorship, a 2 x 2 MANOVA was conducted on five dependent variables: 1) perceived stress, 2) fear of cancer recurrence, and illness intrusiveness in 3) instrumental life domains, 4) intimacy, and 5) relationships and personal development. Independent variables included timeframe since diagnosis (0–5 and 5–15 years) and motherhood status (yes/no). We controlled for relevant demographic and medical covariates in follow-up MANCOVAs. The Bonferroni correction for multiple comparisons was applied as appropriate. In Part 2, we conducted five hierarchical linear regression analyses on a sample of young mothers to identify the variables that predicted our five dependent variables. Predictor variables tested were time since diagnosis, a mother's age, the age of her children, parenting stress, and all possible two-, three-, and four-way interactions. All analyses were performed using PASW Statistics V18.

Results

Demographic and Medical Characteristics

Demographic and medical characteristics of the sample are presented in Table 3. ANOVAs and chi-squares examining significant differences among participants revealed that women 0 to 5 years since diagnosis were younger, had younger children, and were diagnosed at an earlier age compared to women 5 to 15 years since diagnosis.

Table 3
Demographic and Medical Characteristics of the Sample of Breast Cancer Survivors (n = 742)

Characteristic	0 to 5 Years		5 to 15 Years	
	Children n = 332	No Children n = 123	Children n = 207	No Children n = 80
	M (SD)	M (SD)	M (SD)	M (SD)
Current age	42 (4.2)	41 (4.7)	49 (5.7)	49 (5.9)
Age at diagnosis	40 (4.0)	39 (4.6)	40 (4.8)	40 (5.0)
Time since diagnosis (in years)	2.0 (1.2)	2.2 (1.3)	9.1 (2.9)	9.5 (2.6)
Average age of children	11 (5.9)	n/a	20 (7.9)	n/a
Family income	\$122,375 (\$78,896)	\$96,254 (\$60,544)	\$110,935 (\$68,921)	\$105,462 (\$60,068)
	%	%	%	%
Education				
≤ High school	22	12	29	15
Associate degree	11	11	14	11
College/university degree	44	50	32	46
Graduate school	23	27	25	28
Relationship status				
In a relationship	94	75	87	74
Not in a relationship	6	25	13	26
Working status				
Working	71	82	76	79
Not working	29	18	24	21
Breast cancer stage				
0	13	22	17	17
I	35	39	41	53
II	33	31	30	27
III	19	8	12	3
Previous chemotherapy				
Yes	74	67	70	70
No	26	33	30	30
Other chronic health condition				
Yes	19	20	29	28
No	81	80	71	72

Mothers in both timeframes reported higher incomes than women without children, and mothers 0 to 5 years since diagnosis were diagnosed with more severe breast cancers compared to all other groups. Women without children in both timeframes were more likely to report being single compared to mothers 0 to 5 years since diagnosis, and women without

children 0 to 5 years since diagnosis were more educated compared to mothers 5 to 15 years since diagnosis. We therefore entered income, working status, education, relationship status, chemotherapy treatment (as a measure of cancer severity), and chronic health condition as separate covariates in follow-up MANCOVAs.

Part 1: Does Motherhood Status, Timeframe Since Diagnosis, or Their Interaction Impact on Perceived Stress, Illness Intrusiveness, and Fear of Cancer Recurrence

The means and standard deviations for all dependent variables included in the MANOVA are presented in Table 4. The MANOVA revealed a significant main effect for timeframe since diagnosis ($F(5, 734) = 30.80, p < .001, \text{partial } \eta^2 = 0.173$) and motherhood status ($F(5, 734) = 3.91, p = .002, \text{partial } \eta^2 = 0.026$) on the combined dependent variables, but there was no interaction between timeframe and motherhood status ($F(5, 734) = 2.04, p = .071, \text{partial } \eta^2 = 0.014$). Follow-up ANOVAs were conducted on each dependent variable to understand the source of the significant main effects, using a Bonferroni-adjusted alpha level of .010.

Table 4
Means and Standard Deviations for the Dependent Variables

Dependent variables	0 to 5 Years		5 to 15 Years	
	Children n = 332	No Children n = 123	Children n = 207	No Children n = 80
	M (SD)	M (SD)	M (SD)	M(SD)
Illness Intrusiveness				
Instrumental life domains	2.83 (1.58)	3.13 (1.62)	1.83 (1.18)	1.47 (0.67)
Intimate life domains	3.66 (1.89)	3.60 (1.92)	2.72 (1.99)	1.81 (1.11)
Relationships and personal development	2.35 (1.25)	2.46 (1.20)	1.70 (1.00)	1.40 (0.65)
Overall Fear	3.84 (1.43)	3.72 (1.29)	3.14 (1.19)	2.58 (1.05)
Perceived Stress Scale	16.33 (7.23)	16.49 (6.96)	14.89 (7.01)	12.74 (5.66)

There was a significant main effect for motherhood status on two dependent variables in the follow-up univariate analyses, namely illness intrusiveness in intimate life domains ($F(1, 738) = 9.47, p = .002, \text{partial } \eta^2 = 0.013$) and fear of cancer recurrence ($F(1, 738) = 9.60, p = .002, \text{partial } \eta^2 = 0.013$). Mothers were more likely to report greater intrusiveness in intimate life domains ($M = 3.30, SD = 1.98$) and worse fears ($M = 3.57, SD = 1.38$) compared to women without children (intimacy: $M = 2.90, SD = 1.86$; fears: $M = 3.27, SD = 1.32$).

A significant main effect for timeframe since diagnosis was also found on all dependent variables in the follow-up univariate analyses. Young survivors who were diagnosed in the previous 0 to 5 years reported worse overall well-being compared to survivors 5 to 15 years since diagnosis, including worse perceived stress ($F(1, 738) = 19.49, p < .001, \text{partial } \eta^2 = 0.026$), fear of cancer recurrence ($F(1, 738) = 69.91, p < .001, \text{partial } \eta^2 = 0.087$), and illness intrusiveness in instrumental life domains ($F(1, 738) = 123.73, p < .001, \text{partial } \eta^2 = 0.144$), intimacy ($F(1, 738) = 76.06, p < .001, \text{partial } \eta^2 = 0.093$), and relationships and personal development ($F(1, 738) = 81.44, p < .001, \text{partial } \eta^2 = 0.099$).

Follow-up MANCOVAs using each of the six covariates separately confirmed that none of the covariates significantly impacted the relationships between timeframe since diagnosis or motherhood status and perceived stress, illness intrusiveness, and fear of cancer recurrence, either in the multivariate or univariate analyses.

In summary, the first part of this study showed that all young survivors, regardless of their motherhood status, had worse overall well-being during short-term (0–5 years) compared to long-term survivorship (5–15 years since diagnosis). Furthermore, young mothers with breast cancer experienced worse fear of cancer recurrence and higher levels of illness intrusiveness in intimate life domains across timeframes compared to survivors

without children. The absence of an interaction between motherhood status and timeframe since diagnosis signified that the differences between these two groups did not dissipate over time.

Part 2: Predictors of Perceived Stress, Illness Intrusiveness, and Fear of Cancer

Recurrence in Young Mothers

Five hierarchical linear regression analyses were carried out on a sample of young mothers in order to determine whether the potential predictors influenced our five dependent variables: perceived stress, fear of cancer recurrence, and illness intrusiveness in instrumental life domains, intimacy, and relationships and personal development. Predictors included mother's age, the age of her children, time since diagnosis, parenting stress, and all possible two-, three-, and four-way interactions. Transformations were performed on all abnormally distributed variables as appropriate, and the predictor variables were centered to minimize multicollinearity.

As shown in tables 5 through 9, mother's age, children's age, time since diagnosis, and parenting stress (Step 1) accounted for a significant portion of the variance across all regression analyses; however, the addition of the two-, three-, or four-way interactions in Steps 2 through 4 did not add significantly to the prediction of any of the dependent variables. This means that any interactions between predictor variables, such as between mother's age and the age of her children, did not add significantly to the prediction of any of the dependent variables. As such, we assumed that any higher-order interactions would be relatively inconsequential and the following discussion applies only to the main effects (Step 1) for each regression analysis.

The combined main effects of mother's age, children's age, time since diagnosis, and parenting stress (Step 1) accounted for 24% of the variance for perceived stress ($F_{change} (4,$

526) = 40.71, $p < .001$), 13% for fear of cancer recurrence ($F_{change} (4, 526) = 18.83, p < .001$), 24% for illness intrusiveness in instrumental life domains ($F_{change} (4, 526) = 41.10, p < .001$), 14% for intrusiveness in intimacy ($F_{change} (4, 526) = 21.37, p < .001$), and 19% for intrusiveness in relationships and personal development ($F_{change} (4, 526) = 30.10, p < .001$). Tables 5 through 9 present the hierarchical linear regression analyses for each dependent variable.

In terms of individual predictors, high levels of parenting stress significantly predicted all dependent variables in young mothers with breast cancer, including perceived stress ($\beta = .47, t(515) = 9.08, p < .001$), fear of cancer recurrence ($\beta = .18, t(515) = 3.25, p = .001$), and illness intrusiveness in instrumental life domains ($\beta = .31, t(515) = 6.04, p < .001$), intimacy ($\beta = .27, t(515) = 4.88, p < .001$), and relationships and personal development ($\beta = .35, t(515) = 6.60, p < .001$). Having older children was a significant predictor for perceived stress ($\beta = .13, t(515) = 2.00, p = .046$) and illness intrusiveness in instrumental life domains ($\beta = .22, t(515) = 3.25, p = .001$) and relationships and personal development ($\beta = .15, t(515) = 2.25, p = .025$). Being closer to the time of diagnosis significantly predicted all of the illness intrusiveness subscales: intrusiveness in instrumental life domains ($\beta = -.35, t(515) = -5.98, p < .001$), intimacy ($\beta = -.21, t(515) = -3.43, p = .001$), and relationships and personal development ($\beta = -.22, t(515) = -3.57, p < .001$). Younger age only predicted the extent to which mothers feared having a breast cancer recurrence ($\beta = -.23, t(515) = -2.71, p = .007$).

Table 5
Hierarchical Linear Regression (HLR) of Illness Intrusiveness in Instrumental Life Domains

Steps and predictor variables	β	t-value	R ² change	F change
Step 1			.338	41.095***
Mother's age	-.125	-1.576		
Child's age	.215	3.251**		
Time	-.348	-5.976***		
Parenting stress	.310	6.040***		
Step 2			.016	1.837
Mother's age x child's age	.007	.105		
Mother's age x time	.052	.729		
Mother's age x parenting stress	.025	.305		
Child's age x time	.084	1.226		
Child's age x parenting stress	-.097	-1.474		
Time x parenting stress	-.044	-.714		
Step 3			.006	1.055
Mother's age x child's age x parenting stress	-.076	-.903		
Mother's age x time x parenting stress	.031	.332		
Mother's age x child's age x time	-.124	-1.809		
Time x child's age x parenting stress	.006	.069		
Step 4			.001	.650
Mother's age x child's age x time x parenting stress	.058	.806		

* $p < .050$; ** $p < .010$; *** $p < .001$

Table 6
HLR of Illness Intrusiveness in Intimate Life Domains

Steps and predictor variables	β	t-value	R ² change	F change
Step 1			.140	21.368***
Mother's age	-.047	-.555		
Child's age	-.061	-.857		
Time	-.213	-3.429**		
Parenting stress	.267	4.877***		
Step 2			.020	2.047
Mother's age x child's age	-.106	-1.526		
Mother's age x time	.027	.356		
Mother's age x parenting stress	.022	.249		
Child's age x time	.148	2.031*		
Child's age x parenting stress	-.148	-2.110*		
Time x parenting stress	.070	1.070		
Step 3			.000	.051
Mother's age x child's age x parenting stress	-.044	-.488		
Mother's age x time x parenting stress	.008	.086		
Mother's age x child's age x time	.009	.129		
Time x child's age x parenting stress	.017	.204		
Step 4			.000	.154
Mother's age x child's age x time x parenting stress	.030	.392		

* $p < .050$; ** $p < .010$; *** $p < .001$

Table 7
HLR of Illness Intrusiveness in Relationships and Personal Development

Steps and predictor variables	β	t-value	R ² change	F change
Step 1			.186	30.103 ^{***}
Mother's age	-.120	-1.465		
Child's age	.154	2.253 [*]		
Time	-.215	-3.572 ^{***}		
Parenting stress	.350	6.600 ^{***}		
Step 2			.012	1.318
Mother's age x child's age	-.015	-.221		
Mother's age x time	.099	1.335		
Mother's age x parenting stress	.016	.192		
Child's age x time	-.008	-.118		
Child's age x parenting stress	-.094	-1.376		
Time x parenting stress	-.027	-.430		
Step 3			.012	1.937
Mother's age x child's age x parenting stress	-.091	-1.046		
Mother's age x time x parenting stress	-.085	-.888		
Mother's age x child's age x time	-.163	-2.301 [*]		
Time x child's age x parenting stress	.085	1.034		
Step 4			.000	0.139
Mother's age x child's age x time x parenting stress	.028	.373		

* $p < .050$; ** $p < .010$; *** $p < .001$

Table 8
HLR of Overall Fear

Steps and predictor variables	β	t-value	R ² change	F change
Step 1			.125	18.826 ^{***}
Mother's age	-.232	-2.712 ^{**}		
Child's age	.056	.784		
Time	-.116	-1.846		
Parenting stress	.180	3.247 ^{**}		
Step 2			.005	0.481
Mother's age x child's age	-.006	-.081		
Mother's age x time	.006	.080		
Mother's age x parenting stress	-.073	-.822		
Child's age x time	.016	.213		
Child's age x parenting stress	-.081	-1.143		
Time x parenting stress	-.028	-.424		
Step 3			.001	0.134
Mother's age x child's age x parenting stress	-.041	-.448		
Mother's age x time x parenting stress	-.058	-.584		
Mother's age x child's age x time	-.033	-.452		
Time x child's age x parenting stress	.035	.413		
Step 4			.006	3.526
Mother's age x child's age x time x parenting stress	.146	1.878		

* $p < .050$; ** $p < .010$; *** $p < .001$

Table 9
HLR of Perceived Stress

Steps and predictor variables	β	t-value	R ² change	F change
Step 1			.236	40.705***
Mother's age	-.050	-.623		
Child's age	.133	2.001*		
Time	-.059	-1.012		
Parenting stress	.469	9.084***		
Step 2			.007	0.787
Mother's age x child's age	-.036	-.552		
Mother's age x time	.076	1.058		
Mother's age x parenting stress	.012	.145		
Child's age x time	.025	.362		
Child's age x parenting stress	-.117	-1.764		
Time x parenting stress	-.003	-.047		
Step 3			.007	1.255
Mother's age x child's age x parenting stress	-.058	-.692		
Mother's age x time x parenting stress	.039	.414		
Mother's age x child's age x time	-.137	-1.981*		
Time x child's age x parenting stress	.006	.071		
Step 4			.001	0.996
Mother's age x child's age x time x parenting stress	.072	.998		

* $p < .050$; ** $p < .010$; *** $p < .001$

Discussion

This study is the first to examine whether or not parenting children affects perceived stress, illness intrusiveness, and fear of cancer recurrence in young breast cancer survivors over time; and to identify groups of mothers who are most at risk for diminished well-being.

Part 1: Does Parenting Children Impact Well-Being in Young Survivors

Our findings support the notion that parenting children while coping with breast cancer can hinder well-being. Although higher levels of fear of breast cancer recurrence among young mothers have been reported by others (Connell et al., 2006; Mehnert et al., 2009; Melchior et al., 2013); our study is the first to demonstrate that mothers with breast cancer experience greater fears both in the short-term *and* well into long-term survivorship compared to women without children. In addition, young mothers reported that breast cancer

interfered more with their intimate life than survivors without children, and this effect was also found to persist over time.

Illness intrusiveness in intimate life domains may result from problems communicating with partners about emotionally charged issues, as well as difficulties with sexual functioning. Although these problems are common among young breast cancer survivors (Avis et al., 2004; Devins et al., 2006; Knobf, 2011; Manne et al., 2006; Walsh et al., 2005), it is conceivable that these difficulties are compounded by having children. Parenting children while at the same time coping with breast cancer diverts energy away from the couple relationship and may interfere with attempts to resolve these challenges. Indeed, Avis and colleagues (Avis et al., 2004) also found that young breast cancer survivors who had children reported more problems in their relationship with their partner.

It is possible that problems with intimacy as a result of having children may apply to all mothers. Studies show that marital satisfaction suffers in couples who have children, regardless of illness (Twenge, 2003). However, parenting children while also coping with breast cancer likely exacerbates some of these patterns, and to examine this question, we specifically chose illness-related outcome measures as opposed to general measures of marital satisfaction.

A final step in this analysis was to determine whether an interaction existed between motherhood status and timeframe since diagnosis. Although the well-being of *all* young breast cancer survivors improved over time, young mothers continued to experience levels of fear of cancer recurrence and intrusiveness in intimate life domains that surpassed those of survivors without children well into long-term survivorship, suggesting that the impact of motherhood on these areas of well-being was problematic and persisted over time.

Part 2: Predictors of Diminished Well-Being in Young Mothers

Maternal age, age of children, time since diagnosis, and level of parenting stress were all tested as potential predictors of perceived stress, illness intrusiveness, and fear of cancer recurrence in young mothers with breast cancer. The influence of a predictor was examined on its own as a “single predictor” and in combination with others to determine if the combination of more than one predictor had a greater influence on well-being. Surprisingly, we did not find that young mothers were more at risk when these predictors were considered together.

Our study showed that having adolescent children significantly predicted perceived stress and illness intrusiveness, a finding which was contrary to our expectation. Adolescent children are more distressed as a result of their mother’s breast cancer compared to their younger siblings (Gabiak et al., 2007; Osborn, 2007; Visser et al., 2004), and distress in adolescents is closely related to distress in mothers (M. Cohen & Pollack, 2005; B. Edwards & Clarke, 2004; Gazendam-Donofrio et al., 2008). Furthermore, adolescent needs for greater independence are in direct opposition with parental needs and expectations in the context of breast cancer (Russell & Rauch, 2012a). Conflicts over additional household and caretaking responsibilities can bring about important tensions between mothers and their adolescent children (Russell & Rauch, 2012a), thus potentially worsening perceived stress and illness intrusiveness in mothers. Although parenting younger children may be more *physically* demanding, the challenges associated with parenting adolescents may be more *emotionally* demanding.

As expected, age of mother and time since diagnosis significantly influenced well-being. Younger mothers in our study were more fearful of having a breast cancer recurrence, and this is well-supported in the literature (Liu et al., 2011). Similarly, mothers who were

diagnosed more recently reported greater illness intrusiveness, a finding which is also consistent with previous studies (Mah et al., 2005). Our results, however, showed that neither younger age nor time since diagnosis interacted with other predictor variables to significantly influence well-being in mothers.

Similarly, parenting stress significantly predicted all three elements of well-being in mothers. Although we expected that mothers who described parenting as stressful, exhausting, and overwhelming would also report difficulties in these areas of well-being, we were surprised by the absence of interactions between parenting stress and other predictor variables on well-being, such as the age of the mother or the age of her children. Instead, the absence of interaction among predictors speaks to their individual strength.

Limitations

Although the naturalistic and cross-sectional design of this study precludes us from drawing firm causal interpretations, we were able to evaluate the degree to which the results were consistent with our hypotheses. This is the first study to demonstrate that young mothers with breast cancer experience higher levels of fear of cancer recurrence and greater illness intrusiveness in intimate life domains compared to survivors without children, both during short- *and* long-term survivorship, and to identify groups of mothers who are most at risk for diminished well-being.

Women in our sample were predominantly Caucasian (over 92%) and highly educated, with approximately 25% having completed graduate school. Questions relating to the representativeness of our sample could be attributed to our use of online methods to recruit participants. However, the relative infrequency of breast cancer among younger women made this method of recruitment ideal to reach this population as younger women are more likely to use the internet as a source of information and support (Pereira et al., 2000;

Satterlund et al., 2003). Furthermore, this method enabled us to recruit a sufficiently large sample size to carry out the proposed analyses. Our study will need to be replicated with more diverse samples to determine whether our results apply across demographic groups.

Implications and Future Directions

Our results suggest that young mothers are in need of screening and intervention to manage their fears of having a recurrence and to cope with problems in intimacy both during treatment and well into remission. Further research should identify the unique needs of mothers in these contexts. In addition, predictors of diminished well-being among young mothers with breast cancer were identified as experiencing high levels of parenting stress, having adolescent children, and being younger and closer to the time of diagnosis. Contrary to popular belief that younger children pose a significant stressor for young mothers with breast cancer, this study showed that parenting adolescent children worsens stress and illness intrusiveness in mothers. Future research should investigate the challenges associated with parenting adolescents in the context of breast cancer, as well as the role played by parenting stress.

General Discussion

This section presents an overview of the two studies included in this thesis and the how the main findings relate to the current literature. It provides a discussion of the limitations of this thesis, its clinical and research implications, and recommendations for further research.

Overview of the Studies

The purpose of the work reported in this thesis was to examine differences in well-being between young breast cancer survivors with children and those without. The objective of the first study was to uncover the specific ways that being a young mother impacts on the process of adjusting to breast cancer. To achieve this, we identified elements of overall well-being that are salient for all young women with breast cancer, and which also captured some of the unique challenges associated with parenting as a survivor. Using factor analysis techniques, we then determined how these elements interrelated in separate groups of young survivors with children and without, and finally we identified differences between the two groups based on the patterns observed.

In the first study, we found support for our hypothesis that the interrelationship among elements of well-being varied between young breast cancer survivors with children and those without, in such a way so as to reflect their different struggles. Psychological distress (a composite variable representing mental health and perceived stress), illness intrusiveness, and fear of cancer recurrence were found to co-occur more frequently among young mothers than in young survivors without children, thus compromising their overall well-being.

The second study was divided into two parts, reflecting its two objectives. The first was to determine whether or not having children affected levels of perceived stress, illness

intrusiveness, and fear of cancer recurrence in young women with breast cancer during two time intervals, short-term (0 to 5 years) and long-term survivorship (5 to 15 years since diagnosis). The second objective was to identify the predictors for these elements of well-being in young mothers exclusively.

Related to the first objective, we found higher levels of fear of cancer recurrence and illness intrusiveness in intimate life domains for young mothers during both timeframes compared to survivors without children, which partially supported our hypotheses. Furthermore, differences between these two groups did not dissipate with time, suggesting that disruptions in these areas of well-being are prevalent among young mothers and persistent over time.

To answer the second question, we focused exclusively on young mothers and examined whether a mother's age, the age of her children, her level of parenting stress, and the time since her diagnosis influenced her well-being. Our goal was to identify the most vulnerable group of mothers with breast cancer and determine whether these predictors, alone or in combination, influenced levels of perceived stress, illness intrusiveness, and fear of cancer recurrence. Our findings indicated that each predictor influenced different outcomes; however, we did not find that young mothers were more at risk of poor adjustment when these predictor variables were considered together. For example, neither younger age nor parenting stress interacted with other predictors, such as the age of children or the time since diagnosis, to significantly influence well-being in mothers. Instead, the absence of interaction among predictors speaks to their individual strength.

Main Findings and the Current Literature

Our main findings are presented in four sections: (1) illness intrusiveness in young mothers; (2) fear of cancer recurrence in young mothers; (3) predictors of well-being in young mothers; and (4) unexpected findings.

Illness Intrusiveness in Young Mothers

Findings from our first study indicated that illness intrusiveness and psychological distress co-occurred more frequently in young breast cancer survivors with children than in those without children, signifying that illness intrusiveness in young mothers could have the effect of heightening their psychological distress. In our second study, young mothers with breast cancer were found to experience greater illness intrusiveness in intimate life domains over time compared to young survivors without children. Illness intrusiveness and its impact on psychological well-being are therefore important elements to consider in the adjustment of young mothers with breast cancer.

Illness intrusiveness and psychological distress in mothers. Although illness intrusiveness and psychological distress co-occurred more frequently in our sample of young mothers with breast cancer, the direction of the relationship between these two elements is unclear. Evidence suggests, however, that illness intrusiveness impacts on psychological well-being and not the reverse (Devins, 2010). In a study of young breast cancer survivors, Bloom and colleagues (1998) confirmed that illness intrusiveness mediated the relationship between disease and treatment factors and psychological well-being. In a more recent study comparing breast cancer survivors of different ages, Avis and colleagues (2012) showed that illness intrusiveness accounted for higher rates of depression among younger women with the disease.

The impact of illness intrusiveness on psychological well-being is said to be moderated by psychological, social and contextual factors, such as younger age, female gender and developmental life stage (Devins, 2010). Parenting children while coping with breast cancer can be problematic for young survivors due to ongoing physical symptoms and side effects from treatment, such as pain, fatigue and lymphedema (Fisher & O'Connor, 2012). This presents a contextual challenge that could exacerbate the relationship between illness intrusiveness and psychological distress.

Indeed, the extent to which breast cancer interferes with parental roles and responsibilities is difficult for many young mothers. In a qualitative study of women with breast cancer who had dependent children, Fisher and O'Connor (2012) found that the physical impact of cancer, such as fatigue and nausea, was particularly disruptive to their roles and identities as mothers. They observed that a mother's identity was based on her capacity to meet the emotional, social, and physical needs of her children. Their inability to continue their mothering role, as they had prior to their diagnosis, caused considerable anxiety. Similarly, Walsh and colleagues (2005) found that mothers in their study were clearly frustrated by their inability to do as much for and with their children as before and this shift in roles and family responsibilities was a source of considerable distress for them.

In a study of young mothers who were on average four years post-diagnosis, Elmberger and colleagues (2008) noted that, much like mothers with fibromyalgia, cancer survivors had to adjust their approach to parenting to compensate for their physical limitations and decreased energy levels. There was a need for them to redefine what it meant to be a "good" mother and come to terms with their limits, a process described as challenging for many in this study.

Illness intrusiveness in intimate life domains in mothers over time. In our second study, young mothers reported that breast cancer interfered more with their intimate life compared to young survivors without children, both during the short- and long-term. Illness intrusiveness in intimate life domains may result from difficulties with sexual functioning and communicating with partners about emotionally-charged issues (Devins et al., 2006). Although problems in these areas are common for young breast cancer survivors (Melisko, Goldman, & Rugo, 2010; Walsh et al., 2005), we argue that having children likely compounds these difficulties.

Some cancers and their treatments involve sites with direct physiological or psychological associations to sexuality and may therefore affect sexual functioning and the couple relationship. For example, in a study comparing illness intrusiveness across genders and cancer sites, Mah and colleagues (2011) found that adult men with prostate cancer reported the highest scores in intrusiveness into intimacy with a mean of 3.4. There is a growing body of literature suggesting that sexual dysfunction is a common and persistent problem experienced by breast cancer survivors, including changes in body image associated with the loss of breasts, weight gain, decreased libido, and vaginal dryness (Alder et al., 2008; Ganz et al., 2003; Melisko et al., 2010; Speer et al., 2005). Also common among young breast cancer survivors are difficulties communicating with partners about emotionally-charged issues (Devins et al., 2006) such as feelings and fears related to cancer, the future, financial arrangements, and what may happen in the event of death (Walsh et al., 2005), with over 22% of women reporting at least one communication difficulty (Avis et al., 2004; Walsh et al., 2005).

Young mothers in our study reported levels of illness intrusiveness in intimate life domains comparable to adult men with prostate cancer, with a mean of 3.7 on the intimacy

subscale in the short-term and 2.7 in the long-term (scores ranged from 1 to 7). These levels were higher than those reported by women without children during both time intervals (short-term: 3.6; long-term: 1.8). Having children may therefore compound problems of sexual functioning and communication that may already exist among young breast cancer survivors. In healthy couples, an increase in stress and fatigue related to parenting has been shown to interfere with a couple's sex life and companionship (Twenge, 2003). Parenting in the context of breast cancer brings about additional challenges such as helping children cope with their mother's disease, adjusting to changes in family roles and routines and dealing with uncertainty about the future. These added challenges could exacerbate illness intrusiveness in intimate life domains by diverting energy away from the couple relationship and interfering with attempts to resolve difficulties in sexual functioning and communication.

A study of young breast cancer survivors by Avis and colleagues (2004) found that women who had children reported more problems in their relationship with their partner than women without children. Although it is possible that problems with intimacy may be generally true of mothers, regardless of their health status, parenting children while also coping with breast cancer likely exacerbates some of these patterns. To examine this specific question, we chose an illness-related outcome measure as opposed to a general measure of marital satisfaction.

Fear of Cancer Recurrence in Young Mothers

Findings from our first study revealed that fear of cancer recurrence was associated with illness intrusiveness for all young breast cancer survivors in our sample, and that these two elements were more closely related to psychological distress in young mothers. Our second study demonstrated that young mothers experienced greater fears of having a breast

cancer recurrence both during short-term (0 to 5 years) and long-term (5 to 15 years) survivorship. Fear of cancer recurrence and its impact on psychological well-being is therefore a pervasive and persistent concern for young mothers.

Fear of cancer recurrence, illness intrusiveness, and psychological distress in mothers. Using factor analysis techniques, our first study established a relationship between fear of cancer recurrence and illness intrusiveness for all young breast cancer survivors. The model presented by Lee-Jones and colleagues (1997) explains why these two elements are so closely related. They proposed that fear of cancer recurrence is higher in those who construe their illness as bearing many negative consequences. Given that illness intrusiveness measures the negative consequences associated with breast cancer and its treatment, higher levels of illness intrusiveness could increase the fear of having a recurrence. This notion was supported in a recent study examining four possible mechanisms governing the association between younger age and fear of cancer recurrence. Lebel and colleagues (2013) found that illness intrusiveness mediated the relationship between age and fear of cancer recurrence, such that younger women were more prone to these fears because they experienced more illness intrusiveness.

The association between fear of cancer recurrence and illness intrusiveness in our first study also included psychological distress and we found that these three elements co-occurred more frequently in young mothers compared to survivors without children.

Fear of cancer recurrence has frequently been associated with psychological outcomes (Deimling et al., 2006; Mehnert et al., 2009; van den Beuken-van Everdingen et al., 2008); however, the direction of this relationship is less clear. It is possible that distress in mothers has the effect of heightening their fear of having a recurrence. In a longitudinal study of women with breast cancer, Liu and colleagues (2011) found that elevated anxiety at

4-6 weeks and 6 months post-surgery predicted greater fears of having a recurrence two years later. Similarly, in a study of women followed over the first 15 months after a breast cancer diagnosis, psychological distress was found to prospectively influence fear of the future (a concept closely related to fear of cancer recurrence) and not the reverse: as distress decreased over time, so did fear of the future (Lebel et al., 2009). For mothers, elevated levels of distress reported during the cancer experience could in turn exacerbate their fears of having a recurrence, and evidence suggests that young mothers are at greater risk of psychological distress (Deshields et al., 2006; Schmitt et al., 2008).

On the other hand, young mothers may be especially distressed by their fears of having a breast cancer recurrence and there is evidence to support this proposition as well. In a study of young breast cancer survivors, the most commonly reported major personal concern in relation to the fear of having a breast cancer recurrence, second only to mortality issues, was for the future welfare of their children (Connell et al., 2006). Approximately 20% of young women reported such concerns and described feeling emotionally distressed by them.

Fear of cancer recurrence in mothers over time. Results from our second study confirmed findings from other researchers that young mothers experience greater fears of having a breast cancer recurrence (Connell et al., 2006; Mehnert et al., 2009; Melchior et al., 2013). In addition, however, our study is the first to demonstrate that a young mother's increased vulnerability persists over time. Young mothers continued to report moderate levels of fears of having a breast cancer recurrence 5 to 15 years post-diagnosis, whereas survivors without children reported low levels of fears during this timeframe.

Young mothers are said to experience greater fears because of the potential consequences a recurrence could have on their families, their ability to parent, and their

children's well-being (Mehnert et al., 2009; Melchior et al., 2013). Concerns related to parenting in relation to the fear of having a recurrence are so prevalent that Ziner and colleagues (2012) added a fifth subscale to the Concerns About Recurrence Scale (CARS) named "parenting worries." This subscale measured women's concerns that a breast cancer recurrence would (a) harm their ability to be the parent they want to be, and (b) cause them to leave their children without a mother. In their study comparing younger (≤ 45 years old) and older (≥ 55 years old) women who were 3 to 8 years post-diagnosis, Ziner and colleagues (2012) found that the greatest difference between younger and older women on the Concerns About Recurrence Scale (CARS) was seen on the parenting worries subscale, signifying that parenting concerns are prevalent among younger women and that these contribute to their fears of having a recurrence.

Fear of cancer recurrence has been associated with poorer quality of life (Avis et al., 2005; van den Beuken-van Everdingen et al., 2008) and worse psychological well-being (Deimling et al., 2006) in women with breast cancer. In addition to the impact on women's adjustment, fear of cancer recurrence in mothers influences their family's adjustment and quality of life as well (Mellon & Northouse, 2001; Mellon, Northouse, & Weiss, 2006). For example, in a study of cancer survivors and their families 1 to 5 years post-diagnosis, survivors and family caregivers were found to influence one another's fear of cancer recurrence (Mellon, Kershaw, Northouse, & Freeman-Gibb, 2007).

Predictors of Diminished Well-Being in Young Mothers

As part of our second study, we aimed to identify young mothers who were most at risk for diminished well-being by testing the influence of different predictor variables on perceived stress, illness intrusiveness, and fear of cancer recurrence. We found that mothers with adolescent children were most susceptible to stress and to feeling as though their illness

was intrusive, as were mothers with high levels of parenting stress. The youngest mothers were most vulnerable to the fear of having a recurrence of breast cancer, and those who were closer to their time of diagnosis were more likely to report illness intrusiveness. None of the interactions, or combinations, between predictor variables significantly influenced well-being in young mothers, which speaks to the strength of individual predictor variables in determining well-being.

Adolescent children. Mothers with adolescent children were found to be at greater risk of experiencing stress and illness intrusiveness, a finding which was contrary to our expectations. Reviews of this topic indicate that adolescents are more distressed in response to their mother's breast cancer compared to their younger siblings, in part because they can appreciate the consequences of cancer and death (Grabiak et al., 2007; Osborn, 2007; Visser et al., 2004). Elevated rates of internalizing problems, such as anxiety, stress, and depressed mood, are often reported in this group (Osborn, 2007). For example, in a study examining stress response symptoms in adolescents during the first year after a parent's cancer diagnosis, Huizinga and colleagues (2010) found that 14% of adolescents continued to experience clinically significant symptoms 12 months post-diagnosis. Moreover, it appears that psychological distress in adolescent children is closely related to distress in mothers (L. Edwards et al., 2008; Gazendam-Donofrio et al., 2008), supporting our finding that mothers with adolescent children are at greater risk of diminished well-being.

In addition, for adolescents, negotiating a balance between separation and connectedness to their parents is a central developmental task; however, their desires for greater independence are in direct opposition with parental needs and expectations in the context of breast cancer (Russell & Rauch, 2012a). Adolescent children are often caught up in the shifting roles and routines at home and may be expected to help more with younger

siblings. Conflicts over additional household and caretaking responsibilities are common and can bring about important tensions between mothers and their adolescent children (Russell & Rauch, 2012a), potentially leading to more stress and illness intrusiveness in mothers.

We anticipated, however, that mothers with the youngest children would be more vulnerable. Studies show that younger children are more perturbed by changes in family rhythms and routines following a mother's breast cancer diagnosis, such as her absence during key parts of the day like bedtime or dinnertime, or having new caregivers in the home (Russell & Rauch, 2012a). Consequently, we expected that the physical and practical implications of breast cancer would make it difficult for mothers to be emotionally and physically available to their children, thus creating stress and a sense that the illness interfered with parental roles and responsibilities. However, research also demonstrates that maintaining a routine at home for younger children helps mothers cope with their breast cancer, in that it fosters a sense of normalcy and a distraction from their illness (Billhult & Segesten, 2003; Fisher & O'Connor, 2012; Semple & McCance, 2010b). In contrast, adolescent children may not provide this mental escape. Although parenting younger children may be more *physically* demanding, the challenges associated with parenting adolescents may be more *emotionally* demanding.

Similarly, contrary to the popular belief that mothers worry more about having a breast cancer recurrence when their children are younger (Ziner et al., 2012), we found no such association between the age of children and fear of cancer recurrence in mothers. It is likely that mothers with children of all ages worry about the possibility of dying and not seeing their children grow up (Northouse et al., 2009).

Although we could not identify studies on motherhood and breast cancer that would corroborate our finding pertaining to adolescent children, researchers have explored this

question in families in which children are ill. For example, in a study of parents with children diagnosed with juvenile rheumatic diseases, Andrews and colleagues (2009) found that parents with adolescent children were more psychologically distressed by the intrusiveness of their child's illness compared to parents with younger children. It is therefore possible that health-based stressors have more of an impact on the well-being of parents who have adolescent children.

Parenting stress. While some mothers may find that parenting children is a source of strength for them during the cancer experience, others may be completely overwhelmed by it. In our second study, we investigated whether parenting stress, or the extent to which young mothers felt burdened and overwhelmed by parenting or incompetent in their parenting role, impacted on their well-being. We found that high levels of parenting stress were most predictive of perceived stress, followed by illness intrusiveness, and least of all fear of cancer recurrence.

The relationship between parenting stress and perceived stress is clear. Parenting stress, as conceptualized by Abidin (1995), represents the disparity between the demands of parenting and the resources available to deal with these demands. Meanwhile perceived stress refers to the degree to which situations in one's life are appraised as unpredictable, uncontrollable, and overwhelming. It is understandable that mothers who describe feeling ill-equipped and unprepared to cope with the parenting challenges associated with their disease would be more prone to experiencing stress.

The association between parenting stress and illness intrusiveness is perhaps less clear. Parenting stress, as measured in this study, evaluated both positive and negative aspects of parenting. It measured the extent to which parenting was viewed as overwhelming and exhausting, but it also assessed the rewarding and satisfying aspects of parenting, such as

the pleasure derived from spending time with children. A premise underlying the illness intrusiveness framework is that an increase in negative outcomes as a result of illness and treatment, coupled with a decrease in rewarding ones, contribute to higher levels of illness intrusiveness (Devins, 2010). By this logic, high levels of exhaustion reported by mothers who are trying to balance the realities of breast cancer with their children's needs for care (Elmberger et al., 2008; Fisher & O'Connor, 2012), together with a decrease in the amount and quality of time spent with their children (Walsh et al., 2005), could explain why parenting stress predicted illness intrusiveness in young mothers in our study.

Mother's age and time since diagnosis. Younger age and time since diagnosis in breast cancer survivors have both been associated with diminished well-being (Baucom et al., 2005; Knobf, 2011; Mosher & Danoff-Burg, 2005). These two risk factors, however, had not been examined in combination with other potential predictor variables, such as the age of children or level of parenting stress, to identify the most vulnerable group of women. Results from our second study demonstrate that younger age significantly predicted fear of cancer recurrence, a finding which is well-supported in the literature (Liu et al., 2011). Furthermore, shorter time since diagnosis predicted illness intrusiveness, a result which is also consistent with previous studies (Mah et al., 2005). Contrary to our expectations, however, neither younger age nor time since diagnosis predicted any other element of well-being, and they did not interact with other predictors to influence these outcomes. Instead, our study showed that mothers with adolescent children, or those with high levels of parenting stress, are at greater risk of diminished well-being regardless of their age or their time since diagnosis.

Unexpected Findings

Although young mothers in our second study were found to have more ongoing difficulties with fear of cancer recurrence and illness intrusiveness in intimate life domains

compared to women without children, we expected there would be more differences between these two groups. Our original hypotheses stated that young mothers would report higher levels of perceived stress compared to women without children, and that they would find all aspects of their illness more intrusive. Findings from the qualitative literature can help explain our unexpected results.

While several studies emphasize the negative effects of breast cancer on mothers, others have shown that the illness can actually lead to positive outcomes. Mothers can experience a shift in life priorities as a result of their breast cancer, and some have noticed that breast cancer brought their families closer together (Helseth & Ulfset, 2005). In a study of mothers with breast cancer and their school-aged children, Shands and colleagues (2000) found that mothers spent more time with their children following their diagnosis. Similarly, Elmerger and colleagues (2000) reported that mothers with lymphoma formed closer bonds with their children as a result of their cancer. Walsh and colleagues (2005) explained how mothers, through their experience of cancer, became more tolerant of their children's behaviour and had a greater appreciation of the time spent together as a family.

Having children can also be a source of motivation for mothers to live and to fight their cancer, as well as a necessary distraction. In a study of mothers with cancer, Elmerger and colleagues (2008) observed that parenting children was both encouraging and mobilizing, and that it gave mothers the opportunity to forget about their illness.

Interestingly, some studies show that families in which a parent has cancer perceive themselves as functioning in a more positive fashion than the norm; these families feel they are more social, expressive and organized, and less controlling and conflicted than families without parental cancer (Gazendam-Donofrio et al., 2008).

Clinical Implications

Research in the field of psychosocial oncology seeks to identify groups of individuals who are most at risk of poor adjustment to cancer, to understand the essence of their struggles, and to reveal the factors that contribute to their distress. Research of this nature helps clinicians better meet the multifaceted needs of cancer patients. Clinicians and researchers alike have been called upon to attend to the circumstances of young mothers with breast cancer (Rauch & Muriel, 2004; Semple & McCance, 2010b). Findings from this thesis shed light on elements of well-being that are particularly problematic to a young mother's breast cancer recovery, and identify groups of mothers who are most at risk for diminished well-being.

Our results indicate that young mothers with breast cancer are more likely to struggle with psychological distress, the fear of having a breast cancer recurrence, and illness intrusiveness, particularly in intimate life domains, compared to young survivors without children. Furthermore, these difficulties are not only present during the short-term, but they also persist well into long-term survivorship. Given the important role that these elements can exert on a mother's adjustment to breast cancer and on her family's well-being, this group is especially in need of screening and interventions to manage distress in these areas.

Screening for psychological distress, fear of cancer recurrence, and illness intrusiveness should therefore become a routine part of the support provided to breast cancer patients who have young children. Special attention should be paid to mothers who present any of the following risk factors: younger age, having adolescent children, being closer to the time of diagnosis, and expressing high levels of parenting stress.

A number of interventions have been developed to address these issues in cancer survivors. Interventions aimed at reducing illness intrusiveness typically target the lifestyle

domain that is most disrupted for that patient. For young mothers, our study suggests that interventions designed to improve sexual functioning and the couple relationship may be particularly helpful at reducing illness intrusiveness (Baucom et al., 2009; Kayser, Feldman, Borstelmann, & Daniels, 2009). Interventions that address the fear of cancer recurrence typically involve psycho-education, coping skills, uncertainty management, and cognitive restructuring for worrisome thoughts and beliefs about cancer (Herschbach et al., 2010; Humphris & Ozakinci, 2008; Lebel, Maheu, et al., 2013; Mishel et al., 2005). Similarly, there have been a number of interventions designed to alleviate psychological distress and improve mood in this population (Gurevich, Devins, & Rodin, 2002; Kangas, Henry, & Bryant, 2002; Kornblith & Ligibel, 2003; Newell, Sanson-Fisher, & Savolainen, 2002). Our findings indicate that these interventions should consider the role of parenting in these areas of functioning.

Our results also emphasize the need to support young mothers in matters specifically related to parenting, and in this regard, there have been a number of interesting new developments. Muriel and colleagues (2012) developed an instrument to assess parenting concerns among cancer survivors, and to our knowledge, there are two interventions designed to help parents with cancer. The Enhancing Connections Program (Lewis, 2011) is an evidence-based cancer parenting program that focuses on parental mood and anxiety, parenting skills and confidence, the quality of the parent-child relationship, and children's cancer-related concerns. This program has been shown to effectively lessen maternal anxiety and depressed mood, in addition to improving children's emotional and behavioural outcomes. A second program, Parenting at a Challenging Time (PACT) (Russell & Rauch, 2012b), teaches practical strategies for communicating with children about illness, helping children cope, preserving family time, and harnessing support networks. The program PACT

uses a developmental approach to guide parents at different stages of illness, including diagnosis, treatment, survivorship, and end-of-life. These new developments show promise in helping mothers cope with the parenting challenges associated with breast cancer and our findings support this need.

Limitations and Future Research Directions

It is important to acknowledge limitations in research in order to address the generalizability of findings and to consider improvements for future designs. A first limitation of our research relates to our findings pertaining to young mothers and the possibility that they may be true of all mothers, whether or not they have breast cancer. For example, although we found that young mothers experienced more intrusiveness into intimacy than survivors without children, it is well-known that parenting children has a negative impact on the couple relationships of healthy mothers as well (Twenge, 2003). Furthermore, parenting adolescent children is a challenge for many young parents, regardless of their health status (Bornstein, 2002). Although these patterns may be common for all mothers, we propose that they are even more pronounced in those with breast cancer because of the added challenges associated with this disease. To reflect this, we chose several cancer- and illness-related outcome measures to examine this issue, so that our findings would be more specific to mothers with breast cancer.

Whether our findings also apply to women with other severe and chronic illnesses is a possibility that remains to be explored. While research suggests that there is considerable overlap in the risk factors for distress in cancer survivors and those with other chronic health conditions, lending support to a general health model of distress, there are also specific ways in which patterns of risk for distress in cancer survivors differ from those with other chronic illnesses (Kaiser et al., 2010). Results from a recent National Health Interview Survey

(NHIS) indicate that a) the prevalence of clinically significant distress was higher in cancer survivors than those with other health conditions, and b) the patterns of risk identified by a general health model were more pronounced for cancer survivors (Kaiser et al., 2010).

Across all of the risk factors identified, having a cancer diagnosis magnified disparities in distress, and this was particularly true for younger age and having young children living in the household. The pattern of results identified by these authors showed that there is something unique, and more difficult, about having cancer in comparison with other chronic health conditions.

The possibility remains that our findings apply to mothers with other cancers. Most studies of this nature have been conducted with mothers who have breast cancer, making it difficult to determine whether they face distinct challenges compared to mothers with other forms of this illness (Semple & McCance, 2010b). Nevertheless, researchers have cautioned against making assumptions that the experience of parenting following a diagnosis of cancer is similar across different forms of the disease (Semple & McCance, 2010a). Breast cancer poses a real threat of death for women in this age group (Canadian Cancer Society, 2013a), second only to lung cancer, and treatment for breast cancer brings about unique consequences to women's sense of identity, femininity, and motherhood (Helms et al., 2008). Further research should investigate the different experiences of mothers with various forms of cancer.

A second limitation of our research is that women in our sample were predominantly Caucasian and highly educated. Questions relating to the representativeness of our sample could be attributed to our use of online methods to recruit participants. However, the relative infrequency of breast cancer among younger women made this method of recruitment ideal to reach this population as younger women are more likely to use the internet as a source of

information and support (Pereira et al., 2000; Satterlund et al., 2003). Furthermore, this method enabled us to recruit a sufficiently large sample size to carry out our analyses. Our study will need to be replicated with more diverse samples to determine whether our results apply across demographic groups.

Third, young mothers in our samples differed from survivors without children on certain medical and demographic characteristics. For example, young mothers in our first study were diagnosed with more severe cancers and received more aggressive treatments compared to our samples of survivors without children. Although it is possible that these group differences may have influenced our results, the majority of these differences were statistically small, and for many of these characteristics, studies have reported contradictory findings as to their impact on well-being. For example, research on disease and treatment variables in early-stage breast cancer demonstrates that they are weak predictors of short- and long-term well-being (Arndt et al., 2006; Janz et al., 2005; Rakovitch et al., 2003). And, while we were not able to control for some of these group differences in our first study, the statistical approach used in our second study allowed us to control for many of these characteristics and our results remained significant even after making these adjustments.

Finally, the cross-sectional nature of our studies precludes us from drawing firm causal interpretations. Our results will therefore need to be replicated using prospective and longitudinal methods.

Until recently, most studies on adjustment in families in which a parent has cancer focused on well-being in children. Little was known about the impact of parenting on the well-being of young mothers (Rauch & Muriel, 2004; Schmitt et al., 2008). The studies reported in this thesis identify elements of well-being that are most problematic to a young mother's breast cancer recovery, including their fears of having a breast cancer recurrence

and the degree to which illness and treatment interfere with various life domains, and represent a significant contribution to an area of research that had been largely understudied to date. Furthermore, we identified patient characteristics that influence these outcomes.

Further research is needed to explore the nature of women's fears of having a breast cancer recurrence in the context of parenting, as well as to examine the consequences of these fears on young mothers' overall adjustment and on that of their families. The addition of a "parenting worries" subscale to a measure of fear of cancer recurrence in the study by Ziner and colleagues (2012) shows promise and merits further validation.

The association between parenting and problems with intimacy and sexual functioning in young mothers with breast cancer also represents an important area of future study. This line of research should consider the quality of the couple relationship and its role in this dynamic.

Results from this thesis also suggest that psychological distress, illness intrusiveness, and fear of cancer recurrence in young mothers with breast cancer are more closely connected than in survivors without children. Further research is needed to explore the mechanisms relating these three constructs in young mothers, as well as their unique needs in these areas of functioning.

Our findings also extend our understanding of the patient characteristics that influence well-being in young mothers with breast cancer, such as maternal age, age of children, parenting stress, time since diagnosis, and any combination involving these characteristics. Further research is warranted to investigate the challenges associated with parenting adolescents in the context of breast cancer, as well as the impact of parenting stress.

Although the elements and predictors of well-being identified in this thesis do not represent an exhaustive list of the factors that contribute to poor adjustment in mothers, our findings are an important first step toward developing a model of adjustment to breast cancer that is specific to young mothers. Such a model may then be incorporated into more systemic models of adjustment to breast cancer, ones that would encompass family functioning and the adjustment of spouses and children.

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Appendix A: Factor Analysis

Exploratory Factor Analysis (EFA) was used in study one to model the pattern of interaction among elements of well-being in young mothers with breast cancer. Two separate Confirmatory Factor Analyses (CFAs) were then conducted to test whether this model fit with a second group of young mothers with breast cancer, as well as a group of young women without children. Upon establishing a model that converged well for both groups, we used multiple-group CFA to compare the factor structures between groups and observe any differences therein (T. A. Brown, 2006).

The purpose of factor analysis is to examine the patterns in the relationships among variables in order to determine if they can be explained by a smaller number of variables called factors (Fabrigar, Wegener, MacCallum, & Strahan, 1999). In this approach, factors are considered latent constructs because they are not directly observable, such as intelligence or creativity. The goal of factor analysis is to identify the nature of the latent constructs, as well as the relationships between these constructs and the variables of interest (Fabrigar et al., 1999).

Factor analysis differs from principal component analysis, a pure data reduction technique, in that it attempts to identify the latent constructs underlying the variable correlations, whereas principal component analysis does not attempt to model the structure of correlations among variables. As a general rule, principal component analysis is recommended for reducing a large number of variables to a smaller number of components, while factor analysis is recommended when the purpose is to identify latent constructs (Costello & Osborne, 2005).

The two main categories of factor analysis that are widely utilized in the social sciences are EFA and CFA. Although both methods model the correlation among variables

as a function of latent constructs, in EFA the aim of such models is to identify the latent constructs or to generate hypotheses about their possible structures, whereas the aim of CFA is to evaluate hypothesized structures of the latent constructs and/or to develop a better understanding of such structures (T. A. Brown, 2006).

Most experts recommend EFA when minimal research has been conducted regarding the structure of the latent constructs of interest (Fabrigar et al., 1999). EFA is data-driven in that no a priori number of factors is specified and few restrictions are placed on the patterns of relations between the factors and the measured variables (i.e., the factor loadings). In this approach, the number of factors and pattern of factor loadings are derived from the data. In contrast, CFA involves specifying the number of factors as well as the pattern of factor loadings prior to the analysis (T. A. Brown, 2006). When there is no strong basis for identifying a single model or a few competing models for the latent constructs of interest, CFA can be impractical because the number of plausible models may be so large that it would be difficult to specify and test each one separately. Furthermore, this would increase the likelihood of failing to identify a model of best fit altogether. As such, EFA is recommended for situations in which there is little theoretical basis to make assumptions about the structure of latent constructs of interest, whereas CFA is recommended if the structure of latent constructs has previously been studied using EFA with an independent source of data (Bandalos & Finney, 2010).

Both EFA and CFA were chosen for study one because there was insufficient theoretical basis upon which to develop a model for the structure of the latent constructs. EFA was first performed on a group of young mothers with breast cancer. The model obtained in the EFA was then tested on two additional groups using CFAs, including young breast cancer survivors with children and those without. The acceptability of the model was

then evaluated according to a goodness of fit test and the strength of parameter estimates. Upon establishing a model that converged well for both groups we compared the factor structures of these groups using multiple-group CFA (T. A. Brown, 2006). The purpose of this follow-up analysis was to explore differences in the factor structures between young survivors with children and those without.

Multiple-group CFA examines whether different groups are equivalent across a set of measurement and structural parameters. A stepwise procedure was used starting with the least restrictive solution (equal form) and subsequent models were evaluated that entailed increasingly restrictive constraints, that is, equal factor loadings, equal factor variances, equal residual variances, and so on. The recommended sequence for multiple-group CFA according to T. A. Brown (2006) involves (1) a test of equal form (factor structure); (2) a test of the equality of factor loadings; and (3) a test of the equality of factor variances and covariances. It is also possible to test the equality of variable residual variances; however, this is rarely done in practice (Byrne, 2006). Any significant differences in the multiple-group CFA would suggest that young survivors with children responded differently to the questionnaire items than those without children, even if their latent scores were similar.

Appendix B: Informed Consent

Principal Investigator

Dr. Catherine Bielajew
Full Professor
School of Psychology
University of Ottawa

Co-Investigator

Isabelle Ares
Ph.D. Candidate
School of Psychology
University of Ottawa

Eligibility Criteria

You are eligible to participate in our study if you are female and have received a diagnosis of breast cancer. The following exclusion criteria apply:

- Previous history of cancer (other than breast cancer)
- Previous history of chemotherapy or radiation (other than for breast cancer)
- Advanced disease (e.g., stage 4 or metastasis beyond axillary lymph nodes)
- Unstable psychiatric, neurological, or substance use disorders

Purpose of Study

Given that breast cancer survival rates have increased, it has become increasingly important to address the impact of breast cancer on psychosocial issues. The increased survival rate has made it important to focus not only on prevention and treatment, but to also consider issues related to coping and survival during diagnosis, treatment, and remission. Despite this need, there has been little research in this area. One factor that has received little attention in this regard is motherhood. Through the development of a web-based survey, this study will compare mothers with breast cancer to non-mothers with breast cancer and examine the relationship between motherhood and psychosocial and parental measures. With the identification of psychosocial factors and concerns specific to mothers with breast cancer, appropriate interventions for this specific population can be developed to improve coping and quality of life.

Participation

Participation in this study will involve completing a series of questionnaires online in a quiet location of your preference (e.g., home or elsewhere). Participants will first be asked to provide sociodemographic information and medical history. Afterwards, a series of questionnaires will be used to assess psychosocial factors. These questionnaires will measure physical well-being (including perceived health status), functional well-being, social well-being (including social support), and emotional well-being (including depression and anxiety, and fear of cancer recurrence). In sum, these questionnaires will assess quality of life and how having breast cancer has affected different aspects of your life. Two questionnaires at the end will only be completed by mothers. These brief questionnaires will assess parenting self-efficacy and parenting satisfaction, and both positive and negative aspects of parenting. Finally, the study will end with a small number of open-ended questions in order to provide participants with an opportunity to reflect upon their own situation in the context of motherhood and breast cancer. The estimated duration to complete this survey is 45 minutes. Completion of the web-based questionnaires will mark the end of your participation in this study.

Risks

The only foreseeable physical risk while completing the web-based questionnaires is tiredness. A pause function will be available for participants who wish to take breaks while completing the web-based questionnaires. Possible psychological or emotional risks include disclosure of sensitive medical information (e.g. breast cancer history), disclosure of personal information (e.g. parenting behaviours), anxiety or stress due to the nature of the questionnaires (e.g. experience with breast cancer), and boredom. If you feel any discomfort as a result of participating in this study, we recommend that you contact a distress center near you (e.g. in Ottawa, call The Distress Centre of Ottawa & Region).

Canadian Breast Cancer Support Websites

Canadian Breast Cancer Foundation: <http://www.cbcf.org/en-US/home.aspx>

The Breast Cancer Society of Canada: <http://www.bcsc.ca/>

Canadian Breast Cancer Network: <http://www.cbcn.ca/>

Willow Breast Cancer Support Canada: <http://www.willow.org/>

United States Breast Cancer Support Websites

The National Breast Cancer Foundation: <http://www.nationalbreastcancer.org/>

The Young Survival Coalition: <http://www.youngsurvival.org/>

Breast Cancer Network of Strength: <http://www.networkofstrength.org/>

The Susan G Komen Foundation: <http://cms.komen.org/komen/index.htm>

Breast Cancer.Net: <http://www.breastcancer.net/1.php>

The Breast Care Site: <http://www.thebreastcaresite.com/tbcs>

United Kingdom Breast Cancer Support Websites

Breast Cancer Care: <http://www.breastcancercare.org.uk/>

Cancerbackup: <http://www.cancerbackup.org.uk/Home>

The Breast Cancer Campaign: <http://www.breastcancercampaign.org/>

Breakthrough Breast Cancer: <http://www.breakthrough.org.uk/>

Australian Breast Cancer Support Websites

National Breast and Ovarian Cancer Centre: <http://www.nbcc.org.au/>

The National Breast Cancer Foundation: <http://www.nbcf.org.au/>

The Breast Cancer Network Australia: <http://www.bcna.org.au/>

Benefits

There is no direct benefit to participants in this study other than the knowledge that they have contributed to our understanding of how breast cancer affects various psychosocial factors and motherhood. If you wish, you will be given feedback about this at the end of the study.

Compensation

Compensation will be in the form of a draw of four cash prizes of \$250 in June 2009. In order to participate in the draw, you must provide us with your email address at the beginning of the web-based survey.

Questions, Withdrawal, and Confidentiality

Your participation in this study is entirely voluntary and, even if you decide to participate, you are free to withdraw at any time. Your decision to withdraw will not affect your chances of winning the cash prize.

The information collected from you as part of this study will be held in the strictest confidence. Completed questionnaires will be identified by number—your name will not appear on them. Only those participants who wish to be included in the draw will be asked to provide us with contact information. This information will only be available to the principal investigator who will have the information that links participants' names with their identification numbers. All data will be stored in a locked laboratory on a computer that is password protected for five years, at which time they will be destroyed. Data from this study may be published but these data will not bear your name or any other identifying information.

If you have any questions or concerns about this research, or should you desire further explanation during the course of the study, you are encouraged to contact Dr. Catherine Bielajew, principal investigator.

Any information requests or complaints about the ethical conduct of the project may be addressed to the Social Sciences and Humanities Research Ethic Board or the University of Ottawa or by calling the Protocol Officer for Ethics in Research.

Study Findings

Preliminary findings from this study will be available beginning in June 2009. Please contact Dr. Catherine Bielajew (principal investigator) or Isabelle Ares (co-investigator) for information about study findings.

Consent

I agree to participate in the present study entitled “A web-based survey of psychosocial issues in women diagnosed with breast cancer” that is being conducted by Dr. Catherine Bielajew and Isabelle Ares of the School of Psychology at the University of Ottawa. I have read and understand the information presented above regarding the purpose of the study; participation; risks and benefits; compensation; and questions, withdrawal and confidentiality.

I understand the above information and voluntarily consent to participate in this study. In proceeding to answer this survey, I signify my agreement to participate.

Appendix C: Demographic and Medical History Questionnaire

1. Where do you live and what is your ethnic background?
 - Country: _____
 - City: _____
 - Ethnic background: _____

2. How old are you: _____

3. What is your relationship status?
 1. Single
 2. Dating / in a relationship
 3. Common law
 4. Married / civil union
 5. Separated / divorced
 6. Widowed

4. If you are in a relationship, how long have you been with your partner (months and/or years)? _____

5. What level of education have you completed?
 1. Elementary school
 2. High school
 3. Associate degree
 4. Technical degree
 5. College / university baccalaureate
 6. Masters degree
 7. Doctoral degree
 8. Post-doctoral degree

6. Are you currently employed?
 1. Yes
 2. No
 3. I am on a medical leave of absence
 - If yes: What is your current occupation? _____
 - If yes: Is your employment:
 1. Full-time
 2. Part-time
 - If no: Please indicate which of the following most accurately describes your current status:
 1. I am a student
 2. I am a stay-at-home mother
 3. I am unemployed
 4. I am retired
 - If on medical leave of absence: What is your occupation? _____

7. What is your current annual family income? _____
8. How long has it been since you were first diagnosed with breast cancer (e.g. months, years)?
- Months: _____
 - Years: _____
9. How old were you when you were diagnosed? _____
10. What stage of breast cancer were you diagnosed with?
1. Stage 0 (very early or “in situ”)
 2. Stage I (localized, no spreading)
 3. Stage II (some localized spreading into lymph nodes)
 4. Stage III (some localized spreading into lymph nodes)
 5. Stage IV (metastases, where the cancer has spread to other parts of the body)
 6. Not sure
11. We would like to know more about the treatment you received for your initial breast cancer diagnosis. What type of surgery did you have?
1. Unilateral mastectomy
 2. Bilateral mastectomy
 3. Lumpectomy on one breast
 4. Lumpectomy on both breasts
 5. I did not have surgery
12. Did you receive chemotherapy?
1. Yes
 2. No
- If yes: (*allow to select more than one item*)
 1. I received neoadjuvant chemotherapy (given before surgery to shrink the size of a tumor)
 2. I received adjuvant chemotherapy (given after surgery to reduce the risk of recurrence)
 3. I received palliative chemotherapy (used to control the cancer in settings in which the cancer has spread beyond the breast and localized lymph nodes)
 - If yes: What chemotherapy regimen did you receive?
 - Frequency (e.g. once every three weeks): _____
 - Duration (e.g. 5 months): _____
 - If yes: Are you currently receiving chemotherapy?
 1. Yes
 2. No
13. Did you receive hormone therapy?
1. Yes
 2. No
- If yes:
 - What type of hormone therapy did you receive (i.e. Tamoxifen)? _____

- How long did you receive hormone therapy for? _____
- Are you currently receiving hormone therapy?
 1. Yes
 2. No

14. Did you receive radiation therapy?

1. Yes
2. No
 - If yes:
 - How many sessions or weeks of radiation therapy did you receive?

 - If yes: Are you currently receiving radiation therapy?
 1. Yes
 2. No

15. Have you had breast reconstruction surgery or are you planning on having this surgery?

1. Yes
2. No

16. Have you experienced a recurrence in breast cancer?

1. Yes
2. No
 - If yes: when did you experience a recurrence in breast cancer?
 - Day: _____
 - Month: _____
 - Year: _____

17. Have you been diagnosed with cancer (of any type) before being diagnosed with breast cancer?

1. Yes
2. No
 - If yes:
 - What kind of cancer were you diagnosed with? _____
 - When were you diagnosed? _____
 - How was it treated? Please indicate whether you had surgery, chemotherapy, hormone therapy, radiation therapy, or another treatment: _____

18. Have you been diagnosed with cancer (of any type) after being diagnosed with breast cancer (apart from breast cancer recurrence)?

1. Yes
2. No
 - If yes:
 - What kind of cancer were you diagnosed with? _____
 - When were you diagnosed? _____
 - How was it treated? Please indicate whether you had surgery, chemotherapy, hormone therapy, radiation therapy, or another treatment: _____

19. Have you ever had a chronic medical condition other than breast cancer (e.g. diabetes, high blood pressure, multiple sclerosis, etc.)?
1. Yes
 2. No
 - If yes, please provide details: _____
20. Have you ever had a serious mental illness (such as depression, anxiety attacks, schizophrenia, etc.) that interfered with your ability to carry out your usual social or work activities, required hospitalization, or required treatment?
1. Yes
 2. No
 - If yes, please provide details: _____
21. When did you have your last menstrual period? (If unsure, please give an approximate year, and indicate 01 for day and 01 for month)
- Day: _____
 - Month: _____
 - Year: _____
22. Have you ever had any children?
1. Yes
 2. No

If yes:

- How many children do you have?
 1. One
 2. Two
 3. Three
 4. Four
 5. Five
 6. Six+

What are the ages and gender of your children?

- Child age 1: _____ - Child gender 1: male / female
- Child age 2: _____ - Child gender 2: male / female
- Child age 3: _____ - Child gender 3: male / female
- Child age 4: _____ - Child gender 4: male / female
- Child age 5: _____ - Child gender 5: male / female
- Child age 6: _____ - Child gender 6: male / female

- Who has custody of your child(ren)?

1. My partner and I have full custody of our child(ren)
2. I have full custody of my child(ren) (I am a single mother)
3. I have joint custody of my child(ren)
4. I have no custody of my child(ren)
5. I have adult children

23. How has having breast cancer affected your ability to parent? Please elaborate.

24. On the other hand, how has having children affected your ability to cope with breast cancer? Please elaborate.

25. How would you describe your relationship with your husband/partner during your breast cancer diagnosis, treatment and recovery (e.g., reactions to diagnosis and treatment, communication, support)? Please elaborate.

26. How would you describe your relationship with your children during your breast cancer diagnosis, treatment and recovery (e.g., reactions to diagnosis and treatment, communication, support)? Please elaborate.

Appendix D: Questionnaires for Studies 1 and 2

MOS-SF-36

This set of questions asks for your views about your health. This information will help keep track of how you feel and how well you are able to do your usual activities. Answer every question by marking the answer as indicated. If you are unsure about how to answer a question please give the best answer you can.

1. In general, would you say your health is: (Please select one answer)
 - a. Excellent
 - b. Very good
 - c. Good
 - d. Fair
 - e. Poor

2. Compared to one year ago, how would you rate your health in general now? (Please select one answer)
 - a. Much better than one year ago
 - b. Somewhat better now than one year ago
 - c. About the same as one year ago
 - d. Somewhat worse now than one year ago
 - e. Much worse now than one year ago

3. The following questions are about activities you might do during a typical day. Does your health now limit you in these activities? If so, how much? (Please select one number on each line)

<u>Activities</u>	Yes, limited a lot	Yes, limited a little	Not limited at all
a. Vigorous activities, such as running, lifting heavy objects, participating in strenuous sports	1	2	3
b. Moderate activities, such as moving a table, pushing a vacuum cleaner, bowling, or playing golf	1	2	3
c. Lifting or carrying groceries	1	2	3
d. Climbing several flights of stairs	1	2	3
e. Climbing one flight of stairs	1	2	3
f. Bending, kneeling, or stooping	1	2	3
g. Walking more than a mile	1	2	3
h. Walking several blocks	1	2	3
i. Walking one block	1	2	3
j. Bathing or dressing yourself	1	2	3

4. During the past 4 weeks, have you had any of the following problems with your work or other regular daily activities as a result of your physical health? (Please select one number on each line)

	Yes	No
a. Cut down on the amount of time you spent on work or other activities	1	2
b. Accomplished less than you would like	1	2
c. Were limited in the kind of work or other activities	1	2
d. Had difficulty performing the work or other activities (for example, it took extra effort)	1	2

5. During the past 4 weeks, have you had any of the following problems with your work or other regular daily activities as a result of any emotional problems (e.g. feeling depressed or anxious)? (Please select one number on each line)

	Yes	No
a. Cut down on the amount of time you spent on work or other activities	1	2
b. Accomplished less than you would like	1	2
c. Didn't do work or other activities as carefully as usual	1	2

6. During the past 4 weeks, to what extent has your physical health or emotional problems interfered with your normal social activities with family, friends, neighbours, or groups? (Please select one answer)

- a. Not at all
- b. Slightly
- c. Moderately
- d. Quite a bit
- e. Extremely

7. How much physical pain have you had during the past 4 weeks? (Please select one answer)

- a. None
- b. Very mild
- c. Mild
- d. Moderate
- e. Severe
- f. Very severe

8. During the past 4 weeks, how much did pain interfere with your normal work (including both work outside the home and housework)? (Please select one answer)
- Not at all
 - A little bit
 - Moderately
 - Severe
 - Very severe
9. These questions are about how you feel and how things have been with you during the past 4 weeks. Please give the one answer that is closest to the way you have been feeling for each item. (Please select one number on each line)

	All of the time	Most of the time	A good bit of the time	Some of the time	A little of the time	None of the time
a. Did you feel full of life?	1	2	3	4	5	6
b. Have you been a very nervous person?	1	2	3	4	5	6
c. Have you felt so down in the dumps that nothing could cheer you up?	1	2	3	4	5	6
d. Have you felt calm and peaceful?	1	2	3	4	5	6
e. Did you have a lot of energy?	1	2	3	4	5	6
f. Have you felt downhearted and blue?	1	2	3	4	5	6
g. Did you feel worn out?	1	2	3	4	5	6
h. Have you been a happy person?	1	2	3	4	5	6
i. Did you feel tired?	1	2	3	4	5	6

10. During the past 4 weeks, how much of the time has your physical health or emotional problems interfered with your social activities (like visiting with friends, relatives, etc.) (Please select one answer)
- All of the time
 - Most of the time
 - Some of the time
 - A little of the time
 - None of the time

11. How TRUE or FALSE is each of the following statements for you? (Please select one number on each line)

	Definitely true	Mostly true	Don't know	Mostly false	Definitely false
a. I seem to get sick a little easier than other people	1	2	3	4	5
b. I am as healthy as anybody I know	1	2	3	4	5
c. I expect my health to get worse	1	2	3	4	5
d. My health is excellent	1	2	3	4	5

Illness Intrusiveness Ratings Scale

The following items ask about how much breast cancer and/or its treatment interferes with different aspects of your life. Please select the one number that best describes your current life situation. If an item is not applicable, please select the number one (1) to indicate that this aspect of your life is not affected very much. Please do not leave any item unanswered.

How much does breast cancer and/or its treatment interfere with your:

0. Health

1	2	3	4	5	6	7
Not very much						Very much

1. Diet (i.e., the things you eat and drink)

1	2	3	4	5	6	7
Not very much						Very much

2. Work

1	2	3	4	5	6	7
Not very much						Very much

3. Active Recreation (e.g., sports)

1	2	3	4	5	6	7
Not very much						Very much

4. Passive Recreation (e.g., reading, listening to music)

1	2	3	4	5	6	7
Not very much						Very much

5. Financial Situation

1	2	3	4	5	6	7
Not very much						Very much

6. Relationship with Your Spouse (girlfriend or boyfriend if not married)

1	2	3	4	5	6	7
Not very much						Very much

7. Sex Life

1	2	3	4	5	6	7
Not very much						Very much

How much does breast cancer and/or its treatment interfere with your:

8. Family Relations

1	2	3	4	5	6	7
Not very much						Very much

9. Other Social Relations

1	2	3	4	5	6	7
Not very much						Very much

10. Self-Expression / Self-Improvement

1	2	3	4	5	6	7
Not very much						Very much

11. Religious Expression

1	2	3	4	5	6	7
Not very much						Very much

12. Community and Civic Involvement

1	2	3	4	5	6	7
Not very much						Very much

Concerns About Recurrence Scale

The following questions ask you to tell us about any worries you may have about the possibility of breast cancer recurrence. By recurrence we mean the breast cancer coming back in the same breast or another area of the body, or a new breast cancer in either breast.

Although most women who have been diagnosed with early stage breast cancer will never have another problem with the cancer, we are aware that many women do worry about this possibility. Other women may not worry about recurrence at all. Either way, your answers to these questions are very important to us. We understand that it may be upsetting to think about or answer questions about the possibility of recurrence. However, we need your help to understand how women think about this possibility.

For the following four questions please select the number that comes closest to the way you feel. For example, for the first question you should select "1" if you don't think about recurrence at all, select "6" if you think about recurrence all the time, or select "2", "3", "4" or "5" if the amount of time you spend thinking about recurrence is somewhere in between.

1. How much time do you spend thinking about the possibility that your breast cancer could recur?

1	2	3	4	5	6
I don't think about it at all					I think about it all the time

2. How much does the possibility that your breast cancer could recur upset you?

1	2	3	4	5	6
It does not upset me at all					It makes me extremely upset

3. How often do you worry about the possibility that your breast cancer could recur?

1	2	3	4	5	6
I never worry about it					I worry about it all the time

4. How afraid are you that your breast cancer may recur?

1	2	3	4	5	6
Not at all afraid					Very afraid

Now we are interested in what your concerns are regarding a possible recurrence of breast cancer. When thinking about the possibility of a recurrence what is it about that possibility that you worry about?

Although each of the following items may be a possible consequence of recurrence, we are really interested in whether you actually worry about any of these things occurring. For example, you may believe that a recurrence of breast cancer could require further surgery. We would like to know whether you ever actually worry about this possibility.

For the following questions, please select the number indicating how much you worry about each of the following items. If you do not worry about an item or if you think it does not apply to you, please select “0” for “Not at All”.

I worry that a recurrence of breast cancer would:

	Not at all	A little	Moderately	A lot	Extremely
5. Upset me emotionally	0	1	2	3	4
6. Keep me from doing the things I had planned to do	0	1	2	3	4
7. Threaten my physical health	0	1	2	3	4
8. Make me feel I am less of a woman	0	1	2	3	4
9. Require chemotherapy	0	1	2	3	4
10. Hurt my relationships with friends and family	0	1	2	3	4
11. Make me feel that I don't have control over my life	0	1	2	3	4
12. Threaten my identity (how I see myself)	0	1	2	3	4
13. Interfere with my physical ability to carry out daily activities	0	1	2	3	4
14. Threaten my life	0	1	2	3	4
15. Harm my self-confidence	0	1	2	3	4
16. Be more serious than the first diagnosis	0	1	2	3	4
17. Cause financial problems for me	0	1	2	3	4
18. Interfere with my sense of sexuality	0	1	2	3	4
19. Require radiation treatment	0	1	2	3	4
20. Cause me pain and suffering	0	1	2	3	4
21. Mean losing my breast(s)	0	1	2	3	4
22. Interfere with my ability to plan for the future	0	1	2	3	4
23. Threaten my spirituality or faith	0	1	2	3	4
24. Keep me from fulfilling important roles (in my job or at home)	0	1	2	3	4
25. Lead me to feel less feminine	0	1	2	3	4
26. Require further surgery	0	1	2	3	4
27. Cause me to die	0	1	2	3	4
28. Damage my romantic relationship(s)	0	1	2	3	4
29. Keep me from fulfilling my responsibilities (in my job or at home)	0	1	2	3	4
30. Make me feel badly about how my body looks or feels	0	1	2	3	4

Social Support Questionnaire

People frequently experience different amounts of support from various people in coping with a life stress. The following questions ask about your relationships with various people in your life, such as your spouse (or partner), relatives, friends, and health professionals and the amount of support you perceive from them in regard to the present illness.

Please indicate the extent to which you agree or disagree with each of the statements.

There are no right or wrong answers. This questionnaire is asking for your first impressions to the statements.

The following eight statements ask about your relationship with your spouse (or partner) regarding the present illness. If you are not in a romantic relationship at the moment, please select “skip”.

	Strongly Disagree	Disagree	Neutral	Agree	Strongly Agree
1. My spouse is willing to listen to me when I just need to talk	1	2	3	4	5
2. I feel comfortable discussing my concerns about this situation with my spouse	1	2	3	4	5
3. Sometimes my spouse ignores or makes light of my concerns	1	2	3	4	5
4. My spouse seems to understand what I am going through	1	2	3	4	5
5. I often feel as if I should put up a front around my spouse and pretend that things are going better than they actually are	1	2	3	4	5
6. I am feeling a great deal of affection and warmth from my spouse	1	2	3	4	5
7. I often receive credit from my spouse for my attempts to cope with this situation	1	2	3	4	5
8. My spouse helps me put this experience into perspective	1	2	3	4	5

The following eight statements ask about your relationship with a family member regarding the present illness. Think about one family member or relative (other than your spouse) who is important to you as you respond to these statements.

	Strongly Disagree	Disagree	Neutral	Agree	Strongly Agree
9. My family member is willing to listen to me when I just need to talk	1	2	3	4	5
10. I feel comfortable discussing my concerns about this situation with my family member	1	2	3	4	5
11. Sometimes my family member ignores or makes light of my concerns	1	2	3	4	5
12. My family member seems to understand what I am going through	1	2	3	4	5
13. I often feel as if I should put up a front around my family member and pretend that things are going better than they actually are	1	2	3	4	5
14. I am feeling a great deal of affection and warmth from my family member	1	2	3	4	5
15. I often receive credit from my family member for my attempts to cope with this situation	1	2	3	4	5
16. My family member helps me put this experience into perspective	1	2	3	4	5

The following eight statements ask about your relationships with other people such as a friend (neighbor, work associate, etc.) regarding the present illness. Think about one friend who is important to you as you respond to these statements.

	Strongly Disagree	Disagree	Neutral	Agree	Strongly Agree
17. My friend is willing to listen to me when I just need to talk	1	2	3	4	5
18. I feel comfortable discussing my concerns about this situation with my friend	1	2	3	4	5
19. Sometimes my friend ignores or makes light of my concerns	1	2	3	4	5
20. My friend seems to understand what I am going through	1	2	3	4	5
21. I often feel as if I should put up a front around my friend and pretend that things are going better than they actually are	1	2	3	4	5
22. I am feeling a great deal of affection and warmth from my friend	1	2	3	4	5
23. I often receive credit from my friend for my attempts to cope with this situation	1	2	3	4	5
24. My friend helps me put this experience into perspective	1	2	3	4	5

The following eight statements ask about your relationship with nurses regarding the present illness. In responding to these statements, think about the nurse with whom you have had the most contact.

	Strongly Disagree	Disagree	Neutral	Agree	Strongly Agree
25. The nurse is willing to listen to me when I just need to talk	1	2	3	4	5
26. I feel comfortable discussing my concerns about this situation with this nurse	1	2	3	4	5
27. Sometimes the nurse ignores or makes light of my concerns	1	2	3	4	5
28. The nurse seems to understand what I am going through	1	2	3	4	5
29. I often feel as if I should put up a front around the nurse and pretend that things are going better than they actually are	1	2	3	4	5
30. I am feeling a great deal of affection and warmth from this nurse	1	2	3	4	5
31. I often receive credit from this nurse for my attempts to cope with this situation	1	2	3	4	5
32. The nurse helps me put this experience into perspective	1	2	3	4	5

The following eight statements ask about your relationship with physicians regarding the present illness. In responding to these statements, think about the physician who is treating your illness.

	Strongly Disagree	Disagree	Neutral	Agree	Strongly Agree
33. The physician is willing to listen to me when I just need to talk	1	2	3	4	5
34. I feel comfortable discussing my concerns about this situation with this physician	1	2	3	4	5
35. Sometimes the physician ignores or makes light of my concerns	1	2	3	4	5
36. The physician seems to understand what I am going through	1	2	3	4	5
37. I often feel as if I should put up a front around the physician and pretend that things are going better than they actually are	1	2	3	4	5
38. I am feeling a great deal of affection and warmth from this physician	1	2	3	4	5
39. I often receive credit from this physician for my attempts to cope with this situation	1	2	3	4	5
40. The physician helps me put this experience into perspective	1	2	3	4	5

Perceived Stress Scale

The questions in this scale ask you about your feelings and thoughts during the last month. In each case, please indicate with a check how often you felt or thought a certain way.

1. In the last month, how often have you been upset because of something that happened unexpectedly?

0	2	3	4
Never	Almost never	Sometimes	Very often

2. In the last month, how often have you felt that you were unable to control the important things in your life?

0	2	3	4
Never	Almost never	Sometimes	Very often

3. In the last month, how often have you felt nervous and "stressed"?

0	2	3	4
Never	Almost never	Sometimes	Very often

4. In the last month, how often have you felt confident about your ability to handle your personal problems?

0	2	3	4
Never	Almost never	Sometimes	Very often

5. In the last month, how often have you felt that things were going your way?

0	2	3	4
Never	Almost never	Sometimes	Very often

6. In the last month, how often have you found that you could not cope with all the things that you had to do?

0	2	3	4
Never	Almost never	Sometimes	Very often

7. In the last month, how often have you been able to control irritations in your life?

0	2	3	4
Never	Almost never	Sometimes	Very often

8. In the last month, how often have you felt that you were on top of things?

0	2	3	4
Never	Almost never	Sometimes	Very often

9. In the last month, how often have you been angered because of things that were outside of your control?

0	2	3	4
Never	Almost never	Sometimes	Very often

10. In the last month, how often have you felt difficulties were piling up so high that you could not overcome them?

0	2	3	4
Never	Almost never	Sometimes	Very often

Parental Stress Scale

The following statements describe feelings and perceptions about the experience of being a parent. Think of each of the items in terms of how your relationship with your child or children typically is. Please indicate the degree to which you agree or disagree with the following items by placing the appropriate number in the space provided.

	Strongly Disagree	Disagree	Neutral	Agree	Strongly Agree
1. I am happy in my role as a parent	1	2	3	4	5
2. There is little or nothing I wouldn't do for my child(ren) if it was necessary	1	2	3	4	5
3. Caring for my child(ren) sometimes takes more time and energy than I have to give	1	2	3	4	5
4. I sometimes worry whether I am doing enough for my child(ren)	1	2	3	4	5
5. I feel close to my child(ren)	1	2	3	4	5
6. I enjoy spending time with my child(ren)	1	2	3	4	5
7. My child(ren) is an important source of affection for me	1	2	3	4	5
8. Having child(ren) gives me a more certain and optimistic view for the future	1	2	3	4	5
9. The major source of stress in my life is my child(ren)	1	2	3	4	5
10. Having child(ren) leaves little time and flexibility in my life	1	2	3	4	5
11. Having child(ren) has been a financial burden	1	2	3	4	5

	Strongly Disagree	Disagree	Neutral	Agree	Strongly Agree
12. It is difficult to balance different responsibilities because of my child(ren)	1	2	3	4	5
13. The behavior of my child(ren) is often embarrassing or stressful to me	1	2	3	4	5
14. If I had it to do over again, I might decide not to have child(ren)	1	2	3	4	5
15. I feel overwhelmed by the responsibility of being a parent	1	2	3	4	5
16. Having child(ren) has meant having too few choices and too little control over my life	1	2	3	4	5
17. I am satisfied as a parent	1	2	3	4	5
18. I find my child(ren) enjoyable	1	2	3	4	5