EXAMINING PERCEPTIONS OF ADJUSTMENT, COMMUNICATION, AND RELATIONSHIP QUALITY BETWEEN MOTHERS AND DAUGHTERS WHEN A MOTHER HAS BREAST CANCER

by

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ABSTRACT

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Previous research has indicated that parents may be poor perceivers of their children’s coping and adjustment to parental cancer. However, it is unclear as to whether children have accurate perceptions of their parents’ adjustment during this time, or if parents and children have similar perceptions of their communication and their relationship. Additionally, adolescent daughters of mothers with cancer have been identified as a group of children at risk for developing psychosocial problems following a mothers’ diagnosis. Differences in perceptions of adjustment, communication, and relationship quality were investigated between mothers and daughters when a mother has breast cancer. Twenty-three mother-daughter pairs completed a cross-sectional survey. Results indicated that daughters had accurate perceptions of their mothers’ adjustment; however, significant discrepancies were identified in mothers’ perceptions of their daughters’ adjustment. Mothers and daughters also indicated similar perceptions of their relationship and communication. Limitations, implications, and recommendations for future research are discussed.
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Chapter One: Literature Review

Introduction to Breast Cancer

In 2010 an estimated 23,200 women in Canada were diagnosed with breast cancer (Canadian Cancer Society, 2010). Approximately 1 in 9 women will develop breast cancer in their lifetime, making breast cancer the most commonly diagnosed cancer in Canadian women. Incident rates have steadily increased since the 1980s, which is thought to be associated with the increase in routine mammography screening and the aging population. Breast cancer is the second leading cause of cancer mortality in women with 1 in 28 Canadian women dying of this disease (Canadian Cancer Society, 2010).

Risk factors associated with high to moderate risk of developing breast cancer include a family history of breast cancer, such as a mother or sister with breast cancer, and age at diagnosis, with older age associated with higher risk. Minor risk factors include obesity, with a body mass index greater than 30, and menopause occurring at 55 years of age or older (Kelsey, 1993). According to Canadian clinical practice guidelines, the standard treatment for patients with stage I or II breast cancer is a lumpectomy in combination with radiation therapy (Scarth, Cantin, & Levine, 2002). For patients with stage III or IV breast cancer standard treatment is a single or double mastectomy in addition to radiation therapy and/or chemotherapy (Shenkier et al., 2004). The rate of survival for breast cancer patients varies by age and stage of cancer. Younger women are more likely to survive 10 years after diagnosis than are older women. More than 50% of women with stage I or II breast cancer can expect to live at least 10 years after diagnosis, whereas less than 30% of women with stage III or IV survive for 10 years or more (Gaudette, 1996).
Approximately 19% of breast cancer cases occur in women 50 years old and younger, and 53% of cases occur in women between 50 and 69 years of age (Canadian Cancer Society, 2010). Many women may face the difficult challenge of continuing to raise children or adolescents while also managing the physical and emotional demands associated with a breast cancer diagnosis. Coping with a breast cancer diagnosis can be very difficult. Although breast cancer patients may struggle with the psychological and social aspects of adjusting to their diagnosis, it is important to recognize that there may also be significant impacts for other members of the family, including the spouse and children, as well as significant impacts to relationships within the family.

**Psychosocial Impact of Breast Cancer**

A cancer diagnosis can be a highly disruptive experience for both the patient and family members. The psychosocial impact of breast cancer on the patient, spouse, and children has been well documented (e.g., Compas & Luecken, 2002; Grabiak, Bender, & Puskar, 2007; Hilton, Crawford, & Tarko, 2000; Visser, Huizinga, van der Graaf, Hoekstra, & Hoekstra-Weebers, 2004). However, this is not a homogenous group and various members of the family may experience different psychosocial problems.

**Patient**

Patients with cancer have identified the need for help in coping with both the psychological and social aspects of their diagnosis and treatment. The psychological component may include symptoms of psychiatric disorders such as anxiety, depression, posttraumatic stress, and changes in quality of life. Twenty to 40% of cancer patients report clinically high levels of anxious and depressive symptoms during the time of their diagnosis and treatment (Burgess et al., 2004; Preyde, Chevalier, Hatton-Bauer, &
Barksey, 2010). For many women these symptoms decline with time. In the year following initial diagnosis and treatment the prevalence of clinically high levels of anxiety and depression is approximately 15-24%. Women who are in remission (showing no signs or symptoms of the disease) have been shown to experience similar levels of anxiety and depression to that of the general female population (Burgess et al., 2004).

Breast cancer and its diagnosis are also associated with posttraumatic stress disorder (PTSD). PTSD is characterized by recurrent and intrusive thoughts about the event, persistent avoidance of event related stimuli, and persistent symptoms of arousal (American Psychiatric Association, 1994). Although it appears that only a very small proportion of women (2-5%) meet the criteria for a diagnosis of cancer-related PTSD, many women may experience PTSD symptoms (Green et al., 1998). For example, reports suggest that approximately a third of women with breast cancer experience at least three or more PTSD symptoms including, intrusive thoughts (36% of women), avoidant behaviours (41%), and arousal symptoms (27%) (Green et al., 1998).

Additionally, some women experience changes to their quality of life. Quality of life refers to an individual’s subjective sense of well-being and satisfaction or dissatisfaction with the physical, social, functional, and emotional domains of life (Cella, 1994). Patients with cancer have identified quality of life concerns such as fatigue, pain, nausea, and fear of disease recurrence. Women with breast cancer have identified impacts directly related to their breast cancer, which include arm swelling and pain, and changes in femininity, including feelings of attractiveness and change in weight (Brady et al., 1997; Knobf, 1990). Only minor differences have been identified in quality of life ratings between women receiving different surgical procedures. In the year following surgery,
women receiving mastectomies have reported similar quality of life ratings as women receiving breast-conserving surgeries (Ganz, Schag, Lee, Polinsky, & Tan, 1992). Quality of life is often used as a measure of adjustment to cancer in supportive care and clinical practice settings for cancer patients (Cella, 1994), and is recommended as an end-point measure in clinical trials for cancer treatments (Nayfield, Ganz, Moinpour, Cella, & Hailey, 1992).

Finally, the social component of coping with breast cancer includes coping with changes in relationships, and changes to the routines, roles, and responsibilities within the family (Spira & Kenemore, 2000). Additional problems reported by women with breast cancer include gathering and understanding health related information, managing symptoms and treatment side effects, managing money, and dealing with work (Liang, Dunn, Gorman, & Stuart-Harris, 1990; McIlmurray et al., 2001). Coping with these psychological and social aspects of breast cancer can be difficult for some women and may result in poor psychosocial adjustment.

*Spouse*

Partners of breast cancer patients may also experience psychosocial problems. Partners have reported symptoms of anxiety and depression, and in some cases have reported a greater number of psychosocial problems than their spouses with cancer (Baider & De-Nour, 1988; Ben-Zur, Gilbar, & Lev, 2001). Some couples report difficulties with marital adjustment and experience increased conflict, trouble communicating, and disagreements associated with the cancer (Lewis, Woods, Hough, & Bensley, 1989). As an integral member of the family, partners may also experience significant changes with respect to roles and responsibilities, and may have to find a new
balance between maintaining a job, being the sole caregiver of the children, as well as a primary support system for their ill spouse.

Children and Adolescents

Many investigators have examined the impact of breast cancer on children and adolescents within the family (Brown et al., 2007; Edwards et al., 2008; Forrest, Plumb, Ziebland, & Stein, 2006; Hoke, 2001; Kristjanson, Chalmers, & Woodgate, 2004; Lewis & Darby, 2003; Lewis & Hammond, 1996; Lichtman et al., 1984; Sigal, Perry, Robbins, Gange, & Nassif, 2003; Watson et al., 2006; Wellisch, Gritz, Schain, Wang, & Siau, 1991; Wellisch, Gritz, Schain, Wang, & Siau, 1992; Wellisch, Schains, Gritz, & Wang, 1996). The results have indicated that children of women with breast cancer may also face significant psychosocial stressors. During this time, children may have to cope with the threat of the potential death of their parent, the temporary absence of the ill parent and often the healthy parent during the treatment and recovery phase, as well as significant changes in daily routines, responsibilities, and family rules (Davey, Askew, & Godette, 2003). As a result, some children present with psychosocial difficulties. For example, children have reported experiencing internalizing and externalizing problems (Watson et al., 2006). Internalizing problems are a cluster of behaviours that are expressed internally rather than being acted out in the environment, and include anxiety, depressed mood, and withdrawal behaviours. Externalizing problems are a cluster of behaviours that are directed outward, usually toward other people or the environment, and include aggressive and delinquent behaviours. Children have also reported high levels of posttraumatic stress symptoms including intrusive thoughts, avoidant behaviours, and arousal symptoms (Compas et al., 1994).
Not all children experience adjustment difficulties in response to their mothers’ breast cancer (e.g., Hoke, 2001), however, investigators that have identified children with psychosocial problems have also noted important differences between subgroups of children. For example, the degree of psychological and social difficulty appears to vary as a function of children’s age, gender, and whether their mother or father is ill (e.g., Compas et al., 1994). More specifically, with regard to children of different age groups it is repeatedly adolescent children who report the highest levels of distress (e.g., Compas et al., 1994; Visser et al., 2005; Welch et al., 1996; Wellisch et al., 1992). These findings may be best understood by also considering the specific demands of this developmental stage and the interaction and influence of development with illness in the family. For example, adolescents may face stressors that are very specific to growing up and becoming a young adult, while at the same time having to cope with their mothers’ cancer. Adolescents may also be vulnerable when dealing with parental cancer as they are cognitively more advanced than younger children and have a greater ability to assess and understand the potential impact of this disease (Keating, 1990).

**Parental Cancer During Adolescence**

During the developmental period of adolescence cognitive capacities such as logical and abstract thinking further develop, enabling some adolescents to understand both the implications of parental illness for themselves and for their families (Keating, 1990). Adolescence is also characterized by significant changes to the physical, psychological, and social being. These changes may create specific needs for extra support, attention, and communication from parents, all which may be heightened during stressful periods such as parental illness (Kristjanson et al., 2004; Spira & Kenemore, 1990).
However, this illness may interfere with parents’ ability to provide this support, and adolescents may be less willing or able to ask for help during this time. Additionally, parents may experience difficulty in communicating with their adolescents about their illness (Kristjanson et al., 2004; Stiffler, Haase, Hosei, & Barada, 2008), and with greater autonomy adolescents are able to withdraw or distance themselves from illness related situations in ways that younger children may be unable to do (Lichtman et al., 1984). Finally, at a time when adolescents are developing their own sense of self separate from the family, and rules and responsibilities are being renegotiated, illness may command a need for more family cohesion rather than less, and a coming together of all family members to provide support. There may be an increased expectation of taking on family responsibilities, such as caring for siblings and managing the house in the absence of parents during the course of illness (Grant & Compas, 1995). Adolescents may feel guilt and shame in wanting and seeking independence, and enjoying peer and romantic relationships (Armsden & Lewis, 1993). This dissonance between normative adolescent development and illness demands may create feelings of guilt, anger, and resentment, or at a minimum create some psychosocial distress.

Although the impact of parental cancer is experienced by and investigated in both adolescent sons and daughters, many investigators examining self-reports and parent-reports of adolescent coping and adjustment to parental cancer have reported daughters as the most negatively impacted group (Brown et al., 2007; Compas et al., 1994; Grant & Compas, 1995; Edwards et al., 2008; Huizinga, Visser, van der Graaf, Hoekstra, & Hoekstra-Weebers, 2005a; Huizinga et al., 2005b; Lichtman, 1984; Visser et al, 2005; Welch, Wadsworth, & Compas, 1996).
Daughters of Women with Breast Cancer

Investigators have used several psychosocial factors, including internalizing and externalizing problems, and PTSD symptoms, as indicators of daughters’ adjustment to their mothers’ cancer. Adolescent daughters have reported clinically high levels of internalizing problems including anxious and depressive symptoms (Grant & Compas, 1995; Visser et al., 2005; Watson et al., 2006; Welch et al., 1996), posttraumatic stress symptoms including intrusive thoughts, avoidant and withdrawal behaviours, irritability and hyper arousal (Boyer et al., 2002; Huizinga et al., 2005), and various other psychosocial concerns such as poor school performance, feelings of guilt, shame, anger, resentment, and abandonment (Wellisch et al., 1991, 1992). More specifically, the greatest impact of parental cancer has been reported for daughters of a mother with cancer (Brown et al., 2007; Compas et al., 1994; Grant & Compas, 1995; Watson et al., 2006; Welch et al., 1996). The highest frequency of self-reported psychosocial problems has been found in daughters of mothers with cancer when compared to daughters of fathers with cancer, or sons of mothers or fathers with cancer (Grant & Compass, 1995). This possibly suggests an interaction between the gender of the adolescent and the gender of the parent, with female children having the most difficult time when the female parent is ill (Compas et al., 1994).

In addition to measuring psychosocial factors associated with coping and adjustment several investigators have conducted interviews with daughters to gain an in-depth understanding of the potential reasons why it is distressing to have a mother with cancer as an adolescent female (Davey, et al., 2003; Spira & Kenemore, 2000). Spira & Kenemore (2000) interviewed adolescent daughters between 12-19 years old about their
concerns for both themselves and their mothers. Some daughters discussed worries about developing breast cancer themselves. For example, one 17-year-old daughter expressed somatic complaints of pain in her underarms and breasts, and feared she already had cancer. Spira and Kenemore suggested that adolescent females may be particularly distressed by their mothers’ breast cancer as their physical and sexual development may coincide with their mothers’ illness, fostering a cognitive association between physical development and the potential to become ill themselves. Daughters also reported concerns about disease recurrence in their mothers, the death of their mothers, and the loss of the mother-daughter relationship. Some daughters also expressed concerns about changes in family roles. Finally, daughters discussed the importance of communication and reported that the more the disease was discussed with them the less they had feelings of resentment, anger, and guilt.

Davey and colleagues (2003) interviewed parents and adolescents when a parent had cancer. Again, daughters of mothers with breast cancer expressed fears of inheriting the disease and concerns about one day experiencing the same pain and discomfort as their mothers. Additionally, some adolescents reported that the most difficult period of time was following their mothers’ diagnosis when they had to help care for both the ill and healthy parent, as well as cook, clean, and take care of younger children.

The Mother-Daughter Relationship During Breast Cancer

In addition to the measuring the psychosocial factors associated with adjustment in daughters, several investigators have examined the mother-daughter relationship during this time. This relationship can be difficult to navigate during normal adolescent development for both mothers and daughters, and may be even more complex during
periods of stress. This potentially vulnerable relationship has been studied by a number of investigators. Lichtman and colleagues (1984) contributed one of the initial studies examining the mother-child relationship when a mother had breast cancer. Mothers who had adolescent daughters or sons were interviewed about perceived changes in their relationships. Some mothers reported the mother-daughter relationship to be at higher risk for change than the mother-son relationship, with 44% of women indicating changes in the mother-daughter relationship. Of these women, 40% felt their daughters had become more distant, and exhibited fearful, hostile, and withdrawal behaviours, and 60% indicated that they had grown closer to their daughters. Important age differences were also noted, with mothers reporting that adolescent daughters expressed the most rejecting and dramatic responses, and mothers experienced feelings of betrayal and injury from these reactions.

Daughters have also reported change in the mother-daughter relationship. In a series of studies Wellisch and colleagues (1991; 1992; 1996) used retrospective reports from 60 daughters of mothers with breast cancer to examine adjustment. At the time of their mothers’ diagnosis daughters’ ages ranged from less than one year to 20 years old. The adolescent group of daughters (11-20 years old) reported significant feelings of discomfort with their mothers’ illness, and approximately 47% felt that there were illness related changes in the mother-daughter relationship. These findings are limited by the retrospective nature of the reports as memories may be impaired or distorted as time passes, and may not accurately represent those experiences. Additionally, only 25% of the sample were adolescents at the time of their mothers’ diagnosis. However, other reports have suggested that these changes may not all be negative, with some daughters
reporting improvement of the mother-daughter relationship following their mothers’ mastectomies (Rosenfeld et al., 1983). Taken together these results suggest that there may be changes in the relationship between mothers and daughters, both positive and negative, as reported separately by mothers and daughters.

**Mother-Daughter Communication During Breast Cancer**

In addition to changes in the relationship there also appears to be changes in the way mothers and children communicate with one another during this time. Having discussions about the cancer and its treatment can be difficult for the patient and children, and there may be different ways in which mothers and children cope with this difficulty. In a study of mothers’ experiences of parenting during their breast cancer Stiffler and colleagues (2008) reported that mothers struggled with whether or not to talk to their adolescent daughters about the cancer. A great deal of decision-making and uncertainty was involved in deciding how much, when, and how to communicate with their daughters. Some mothers expressed a desire to protect their daughters from the distress of the cancer and keep life as normal as possible, while still including their daughters in discussions and giving them enough information to understand, cope with, and adjust to the change. Another important concern was that of expressing hope. Some mothers reported that above all the most significant part of speaking with their daughters was conveying hope and a positive perspective by ‘acting normal’. Some mothers were concerned about permanently scarring their children with the stress of the disease and not being a good mother to their children.

Elmberger and colleagues (2000) reported that mothers were the primary family members to discuss treatment, illness, and its outcomes with children; however, it was
common for mothers to feel that they lacked knowledge and information about their cancer, and felt that they often left their children confused and insecure. Reactions of insecurity and fearfulness in children left some mothers feeling exhausted. When children responded in this way some mothers reported attempting to hide their feelings and not engaging in open communication.

Additionally, adolescents have reported being aware of their parents’ difficulty in communicating, and have perceived them to be restricting or withholding information about their mothers’ cancer (Kristjanson et al., 2004). Kristjanson and colleagues examined the self-reported information and support needs of adolescents of mothers with breast cancer. Parents were seen as the most frequent source of information. However, some mothers were perceived as “guardians of information” and controlled adolescents’ access to information. Daughters expressed a need for information and support to reduce their anxiety.

Finally, in addition to the restricted or reduced communication on the part of the parents, it is possible that adolescents may also be withholding information about their distress and coping (Davey et al., 2003). Davey and colleagues found that adolescents of parents with cancer did not want to disclose their feelings of fear and worry as not to worry their parents. Adolescents felt that their parents had enough to worry about, and it was the adolescents’ responsibility to protect them from more distress. Together these findings suggest that both mothers and daughters may be refraining from sharing information and communicating with each other about the cancer.
**Disparity Between Parent-Adolescent Reports**

Although many daughters have reported experiencing significant psychosocial problems, three groups of investigators (Davey et al., 2003; Forrest et al., 2006; Welch et al., 1996) have identified disparity between parent and adolescent reports regarding adolescent coping and adjustment. The results indicate that some parents may be unaware of the difficulties their children are experiencing. For example, Welch and colleagues (1996) found that parental reports of adolescents’ adjustment to parental cancer were significantly different than the adolescents’ self-reports. The greatest discrepancy was between parents’ and adolescent daughters’ reports, with daughters of mothers with cancer self-reporting the highest levels of anxiety, depression, and aggressive symptoms. However, only 37% of parents with cancer were mothers with breast cancer, and comparisons between parent and child reports did not always include the parent with cancer, as some spouse reports were used to identify disparity. Although daughters reported that their distress declined with time, parents reported adolescents’ adjustment as both good and stable throughout the cancer process. This discrepancy suggests that parents may be insensitive to changes in their children’s mood throughout the cancer experience, and that parents may be poor perceivers of their children’s psychosocial functioning during this time.

Forrest and colleagues (2006) examined children’s perceptions of their mothers’ breast cancer and treatment in contrast to mothers’ perception of their children’s understanding of her cancer. Interviews were conducted with children between 6-18 years of age and their mothers with early breast cancer. It was found that mothers’ awareness of what their children knew about their cancer was not in accord with what the children
reported knowing. For example, some mothers did not feel that their children were aware that cancer could be a life threatening disease, and were surprised when their children expressed concerns about death and losing their mothers. Additionally, there was disparity between mothers’ and children’s recount of their children’s reaction to learning of the cancer. Many children described feelings upset, shocked, fearful, and anxious. However, some mothers perceived their children as lacking an emotional response and interpreted this reaction as them not caring. Even responses of anger and upset were sometimes perceived by mothers as children being selfish and inconsiderate of their situation.

Finally, Davey and colleagues (2003) reported that during interviews with parents and adolescents about parental cancer, parents were often surprised to hear about their children’s feelings of stress and worry about the cancer. This occurred when adolescents expressed that they often hid their feelings to protect their parents from extra worry or concern, and parents expressed that they were not fully aware of these feelings of sadness and worry experienced by their children.

These results suggest that parents may not be aware of how their children are coping and adjusting to parental cancer and there may be disparity between children’s coping and adjustment and parents’ perceptions of this coping and adjustment during illness. Greater knowledge of how individuals appraise situations of stress, and the development of individual perceptions during this time, may contribute to an understanding of why disparities exist in parents’ and children’s perceptions of one another.
Theoretical Perspectives: Coping, Adjustment, and Perceptions of Illness

In order to examine how mothers and daughters perceive one another during this time a better understanding of the relationship between coping, adjustment, and perceptions of illness is needed. The cognitively oriented theory of stress, coping, and appraisal by Lazarus and Folkman (1984) provides an appropriate theoretical framework for understanding perceptions of illness and individual adjustment. According to this theory coping refers to the cognitive and behavioural efforts directed at managing the demands arising from an appraisal of stress. Lazarus and Folkman have identified two major types of coping strategies. Problem focused coping is aimed at changing the environment that is causing distress, whereas emotion focused coping is aimed at reducing the emotional distress itself. Current research indicates that individuals tend to use both types of coping efforts to manage a situation and that previously used strategies are often employed across different stressful situations (Terry, 1994). Lazarus (1993) argued that there are no correct or incorrect ways to cope with stress, and whether a coping strategy results in a good or poor outcome is context-dependent and person-dependent. Certain coping efforts may be more useful in some circumstances and damaging in others.

There is an important distinction between coping and adjustment; coping refers to the cognitive and behaviour strategies used to manage a situation and are independent of outcome; adjustment refers to psychological and social adaptation or outcomes. For this reason the two constructs are measured separately. A coping measurement would describe what a person is thinking and doing in a stressful situation, whereas an adjustment measurement would describe feelings and states of psychological and social
being in a situation (Lazarus, 1993). Although both coping and adjustment are used to study illness, no causal relationship can be drawn between coping strategies and later adjustment. For the purposes of the current study the strategies used by mothers and daughters to cope with the illness were not of primary interest. Instead, adjustment was measured as an indicator of current feelings or states of well-being in response to breast cancer.

How perceptions of illness are formed is also an important concept. It is thought that an individual’s appraisal or perceptions of a situation determine the stress associated with it and the behaviours directed at managing the stress. Psychological stress occurs when an individual appraises an event as taxing or exceeding resources and endangering well-being. According to Lazarus and Folkman (1984) this appraisal occurs in two forms. Primary appraisal occurs when individuals evaluate the personal relevance of the situation to their well-being. This appraisal can lead to the evaluation of an event as being irrelevant, benign, or stressful. Two types of beliefs held by an individual guide evaluation of an event as stressful: general beliefs about control (the degree to which an individual believes he or she can control or influence a situation), and commitments (beliefs about what is important to an individual, such as values, ideals, and goals). For example, an individual who perceives an illness related situation to significantly impact the future, but has little influence in changing the perceived outcome, would likely experience psychological stress. Secondary appraisal occurs when an individual evaluates personal coping resources. Coping resources can be physical, psychological, social, and material. Appraisal of an illness event as taxing or exceeding these resources may also lead to the experience of stress. Together, primary and secondary appraisals form an
individual’s personal perception of an event. This perception shapes the meaning and impact of the event, and will determine the amount of stress associated with it.

Similarly, a cognitive theory developed by Leventhal and colleagues (1980) suggests that in illness related situations, individuals create personal perceptions of the illness. Individuals are active problem solvers that seek information about the meaning of the illness in order manage it. Information about illness is gathered, interpreted, and perceptions or representations are developed. Mental representations of illness are developed when health related stimuli elicit individuals to incorporate previous social and cultural knowledge of the illness, with information from their external environment including information from clinicians, family, friends and the media, as well as information from previous and current personal experiences of illness. In gathering and appraising this information individuals develop illness representations or perceptions that are thought to guide coping efforts and procedures. For example, if communication between mothers and daughters is reduced during illness, daughters may form perceptions of their mothers’ illness, as well as perceptions of their mothers’ adjustment, by gathering information from friends, the media, and recalling previous experiences when their mothers were ill, and their own experiences of being ill. Altogether this information combines to form daughters’ perceptions of illness, and determines the amount of stress experienced and informs coping efforts.

This cognitively oriented perspective of coping and adjustment is an important theoretical framework for understanding perceptions of illness and individual adjustment; however, this perspective is not often used to examine adolescent coping with parental illness. More commonly, investigators have taken a family context approach, recognizing
the impact of cancer on more than just the patient, and have studied changes in the family as a unit and changes in individuals within the family (Compas et al., 1994; Lewis & Hammond, 1996). Other investigators have taken a more explicit focus, examining changes in specific relationships, for example by using attachment theory (Morris, 2007; Quinn-Beers, 2001). It appears, however, that individual’s appraisal of illness is primary in determining the stress experienced and later adjustment, and that these perceptions may be impacted by multiple sources of influence. It is, therefore, important to recognize this cognitive framework when examining perceptions of illness and adjustment, and for investigators to work towards a greater understanding of how these perceptions are formed, and the potential relationship between perceptions of illness and individual adjustment.

**Study Rationale and Research Questions**

In summary, findings from the current literature suggest that there may be changes in both the mother-daughter relationship and communication during this time, and despite daughters reporting high levels of psychosocial problems some parents may underestimate their children’s emotional and behavioural difficulties. Mothers may perceive their daughters to be asymptomatic, or underestimate their difficulties, despite high levels of distress reported by daughters. This discrepancy may have significant implications for the future psychosocial adjustment of daughters. If mothers do not perceive their children to be having difficulty adjusting mothers may provide less support and be less inclined to seek additional help. Despite the potential impact of this parent-child disparity, only three known studies have been conducted in which parent and child reports regarding children’s coping and adjustment to parental cancer were examined. In
all three of these studies this disparity was examined as only a small part of the larger purpose of the study, and no studies could be located that have directly focused on parents’ and children’s perceptions of one another, or specifically focused on mothers with breast cancer and their daughters. Additionally, no current studies could be located that have compared parent and child reports regarding parents’ coping and adjustment. It remains unclear as to whether mothers and daughters accurately perceive how one another are adjusting to the mothers’ breast cancer.

The purpose of the current study was to examine differences in perceptions between mothers and daughters when a mother has breast cancer. A cross-sectional survey design was used to address the following questions:

1. Are there differences in perceptions of adjustment between mothers and daughters when a mother has breast cancer?
2. Are there differences in perceptions of the mother-daughter relationship when a mother has breast cancer?
3. Are there differences in perceptions of communication between mothers and daughters when a mother has breast cancer?

**Chapter Two: Methods**

**Participants**

Participants were dyads of mothers with breast cancer and their daughters. Mothers were included if they had stage I, II, III, or IV breast cancer, and daughters were included if they were between the ages of 12-25 years old, or were turning 12 in the calendar year of 2011. Mothers who did not have a daughter between 12-25 years old
were not included in the study. Mother-daughter dyads were limited to one daughter per mother included.

**Participant Recruitment**

Mothers were recruited through the Juravinski Cancer Centre in Hamilton, Ontario. This Juravinski Cancer Centre treats approximately 7,000 new patients a year. 750 of these cases are breast cancer patients, with approximately 60 new patients each month. The site supervisor was a registered social worker in Supportive Care at the cancer centre. Ethical approval was obtained from the University of Guelph and from Hamilton Health Sciences through McMaster University (Appendix A).

**Procedure**

Women with breast cancer were first identified or introduced to the student researcher by individuals within their circle of care and included: registered nurses, oncologists, social workers, genetic counsellors, dieticians, advanced practice nurses, and radiation therapists. The student researcher then inquired about whether they had a daughter between 12 and 25 years of age. Mothers who qualified were invited to participate, given more information about the study, allowed to ask questions, and were then asked to complete a consent form (Appendix B). Mothers were informed that participants in this study had the right to withdraw at any time, without penalty. Mothers were given a pencil and paper version of the survey that they completed at the Juravinski Cancer Centre. Mothers with a daughter between 12-15 years old, who believed their daughters might be interested in participating were also asked to read and sign a consent form for their daughters. Once mothers completed the survey they were given an information sheet that contained a website and an identification code for their daughters
Mothers were asked to give this information to their daughters. Daughters accessed the survey through an online survey provider (fluidsurveys.com) and were asked to read and give consent (consent for daughters between 16-25 years of age, and assent for daughters between 12-15 years of age) before starting the survey (Appendix B).

Additionally, recruitment advertisements were posted around the Juravinski Cancer Centre and contained a phone number and email address for the student researcher (Appendix D). Interested participants were able the contact the researcher and information regarding the study was communicated through email or telephone conversations. In these cases both mothers and daughters were given access to the survey through the online version.

The survey took approximately 25-30 minutes to complete. In cases where daughters had accompanied their mothers to the Juravinski Cancer Centre, or in cases where mothers and daughters were completing the survey online at home, both mothers and daughters were asked to complete the survey separately and not to converse with one another regarding any questions or answers. Mothers could answer their daughters’ questions, but were asked to allow their daughters to complete the survey in privacy and at their own discretion. No identifying information was collected, and in order to keep mother-daughter dyad information connected mothers and daughters were given an identification code that differed only by the last letter (e.g., 401m and 401d).

Measures

*Quality of Life Measure.* The Functional Assessment of Cancer Therapy-Breast (FACT-B, Version 4; Brady et al., 1997) was used to measure self-reported quality of life in mothers, and perceptions of quality of life of mothers as rated by daughters. The
FACT-B consists of the FACT-G, a general measure of quality of life for patients with cancer, and the Breast cancer subscale, which when added to the FACT-G creates a more sensitive measure for breast cancer patients. There are 37 items in five subscales measuring Physical well-being, Emotional well-being, Social well-being, Functional well-being, and the Breast cancer subscale. Summing the Physical, Emotional, Social, and Functional subscales gives a FACT-G total score; a FACT-B total score is obtained by adding the Breast cancer subscale to the FACT-G total. Items are rated on a five-point Likert scale of ‘not at all’, ‘a little bit’, ‘somewhat’, ‘quite a bit’, and ‘very much’. Total scores range from 0 to 116 with higher scores reflecting a better quality of life. Due to the young age of daughter participants two questions about feeling sexually attractive and sexual activity were deemed inappropriate and removed from the Breast cancer and Social well-being subscales respectively, resulting in a total of 35 items.

A modified version of the FACT-B was given to daughters. Only the subject in each statement was changed from “I” to “My mother”. For example, mothers completed a question that read, “I worry about dying”. Daughters completed the same question, however, the wording was modified to read, “My mother worries about dying”. Daughters were asked to complete the questions as they perceived they pertained to their mothers.

The FACT-B has demonstrated high internal consistency with Cronbach alpha values of .90 for both the FACT-G and FACT-B total scores, as well as values between .63 and .86 for the five subscales (Brady et al., 1997). Good test-retest reliability and convergent and divergent validity have also been reported (Brady et al., 1997). The scale
was written at a grade six reading level, and therefore, was deemed appropriate to be used with daughters as young as 12 years of age.

*Emotional and Behavioural Problems Measure.* The syndrome scale of the Youth Self-Report (YSR; Achenbach, 1991) was used to measure self-reported emotional and behavioural problems in daughters, and mothers’ perceptions of these emotional and behavioural problems in daughters. The YSR was designed for youth between 11 and 18 years old. The syndrome scale portion of the YSR contains 102 items that are rated on a three-point Likert scale of ‘not true’, ‘somewhat or sometimes true’ and ‘very true or often true’. The items are organized into nine subscales, which include Somatic Complaints, Withdrawn Behaviour, Anxious/Depressed, Social Problems, Thought Problems, Attention Problems, Delinquent Behaviour, Aggressive Behaviour, and Other Problems. Additionally, internalizing behaviours are examined by summing the scores on the Withdrawn, Somatic Complaints, and Anxious/Depressed subscales, to make the Internalizing subscale. Externalizing behaviours are examined by summing the scores on the Delinquent Behaviour and Aggressive Behaviour subscales, to make the Externalizing subscale. Finally, a Total Problems score is calculated by adding the nine original subscales, and total scores range from 0 to 202. A higher score indicates higher total emotional and behavioural problems.

Modifications were also made on the YSR with the subject in each statement changed from “I” to “My daughter”. For example, daughters completed a question that read, “I cry a lot”, and the wording was modified for mothers to read, “*My daughter* cries a lot”. Mothers were asked to complete the questions as they perceived they pertained to their daughters.
The YSR has previously been used to measure emotional and behavioural problems in adolescents of mothers with breast cancer in several studies (Cappelli et al., 2005; Hoke, 2001; Visser et al., 2005; Watson et al., 2006; Welch et al., 1996). This scale has demonstrated good internal consistency with Cronbach alpha values for Total Problems between 0.84 and 0.94 (Achenbach, 1991; Visser et al., 2005). Cronbach alpha values of .91 have been reported for the Internalizing subscale, and .89 for the Externalizing subscale. Values between .59 and .90 have been reported for the nine subscales (Achenbach, 1991). Good validity has also been established (Achenbach, 1991).

Quality of the Relationship Measure. The Quality of Relationships Inventory (QRI; Pierce, Sarason & Sarason, 1991) was used to measure the self-reported quality of the mother-daughter relationship. Mothers and daughters were asked to rate the relationship twice, once reflecting on the relationship prior to the breast cancer diagnosis, and once considering the relationship now (at the time of completing the survey). This allowed for examination of whether mothers and daughters perceived a change in the relationship following the cancer diagnosis, as well as examination of whether there were differences in how mothers and daughters perceived the quality of the relationship.

The QRI contains 25 items rated on a 4-point Likert scale of ‘not at all’ ‘a little bit’, ‘quite a bit’ and ‘very much’. There are three subscales including Support, which measures the perceived availability of the other individual to provide support and assistance; Depth, which measures the extent to which the relationship is viewed as committed, secure, and positive; and Conflict, which measures the extent to which the relationship is a source of conflict and the individual is viewed with ambivalence or
anger. A total score is not computed, and instead the three subscales are used to measure three separate factors related to quality of the relationship. These three factors have been assessed with confirmatory factor analysis on a sample of male and female couples (Verhofstadt, Buysse, Rosseel, & Peene, 2006). Analysis confirmed factorial validity of the three-factor structure purposed by the scales’ developers. Additionally, full metric invariance was demonstrated across males and females (Verhofstadt et al., 2006). Total scores range from 0 to 21, 36, and 18 for the Support, Conflict, and Depth subscales respectively.

The QRI has been used to measure relationships between young adults and their mothers, and has demonstrated good internal consistency with Cronbach alpha values of .83, .88, and .83 for the Support, Conflict, and Depth subscales respectively (Pierce et al., 1991).

**Anxiety Measure.** The State scale of the State Trait Anxiety Inventory, Form Y (STAI Y-2; Spielberger, 1983) was used to measure state anxiety in mothers and daughters. State anxiety refers to an emotional state at a given moment in time, rather than anxiety as a stable personality trait, and is characterized by feelings of apprehension, tension, and nervousness experienced in a moment (Spielberger, 1983). The STAI contains 20 items in which participants are asked to rate how they feel ‘right now’ on a 4-point Likert scale of ‘not at all’, ‘somewhat’, ‘moderately’, and ‘very much so’. Total scores range from 20 to 80, and higher scores indicate higher levels of state anxiety.

This scale has been used to measure anxiety in adolescents of mothers with breast cancer (Lewis & Darby, 2003), and has demonstrated high internal consistency with a
Cronbach alpha value of .93, as well as good test-retest reliability and good validity (Spielberger, 1983).

Open-ended questions. The following four open ended questions were asked to both mothers and daughters:

1. What have you and your mother/daughter discussed about the breast cancer?
2. Who do you speak to about the breast cancer and what do you speak about?
3. Is there any information and/or support that you have not received yet but you feel would be helpful?
4. Have you received any form of psychological or social treatment or help? E.g., counselling, therapy, group therapy etc.? If so, please give details about where this treatment was received, the type of treatment, and the amount of time you received it.

Data Analysis

Descriptive statistics were computed for demographic and psychosocial variables for mothers and daughters. The assumption of normal distribution of difference scores for the paired-test was not met for the four measures; therefore, the non-parametric Wilcoxon signed-ranks test was used to compare responses between mothers and daughters (Wilcoxon, 1945). Non-normal distribution was identified with tests of skewness and kurtosis, Kolmorgorov-Smirnov statistics, and histograms. This non-normal distribution may be related to the very small sample size; according to the central limit theorem (Williams, 1974) larger sample sizes are more likely to demonstrate approximate normal distribution. The non-parametric Wilcoxon signed-ranks test was selected because it does
not assume normal distribution and is recommend for use with small sample sizes (Wilcoxon, 1945).

According to Cohen (1992) in order to detect a large effect size with a power of 80% at an alpha of $p = .05$ a sample size of 26 mother-daughter pairs would be required. Acknowledging that access to a large number of participants would be limited due to the relatively small number of breast cancer patients treated at the Juravinski Cancer Centre each month, and the restrictive inclusion criteria for participants, the small sample size of 26 pairs was a realistically obtainable size for the scope of the current study. A power of 80% confers a fairly high probability of obtaining a significant result; however, this power calculation is based on the paired t-test, not the Wilcoxon test. Debate existed regarding whether parametric tests are more powerful than non-parametric tests. It has been suggested that this only occurs when the assumptions of the parametric test are perfectly met (e.g., perfect normal distribution). When comparing the power of paired t-tests to that of Wilcoxon singed-ranks tests, Blair and Higgins (1985) reported that in samples with various types of non-normal distribution there was relatively similar power for both tests. In several cases the t-test demonstrated such a tiny power advantage that it was not of practical importance, and in the remaining cases the Wilcoxon test was vastly more powerful than the paired t-test. Therefore, the power of the Wilcoxon test was determined to be approximately 80% with a sample size of 26 pairs, and less than 80% with fewer participants. Additionally, to assess reliability Cronbach’s alpha values were computed for all four scales and their associated subscales separately for mother and daughter groups. Adequate to high internal consistency was found for many of the subscales and total scores (Appendix E).
Responses to the open-ended questions were analyzed using content analysis. Content analysis is a process of systematically reducing many words of text into fewer categories and making inferences about the patterns or themes within these categories (Weber, 1990). Conventional content analysis is an inductive form of content analysis where themes emerge from data rather than using preconceived categories into which the data are fit (Hsieh & Shannon, 2005). The process of conventional content analysis involves repeatedly reading all of the data, and highlighting words and text that represent themes or concepts. Often this analysis includes conducting a word-frequency count where frequently mentioned words are thought to reflect the greatest concerns or most important themes (Webber, 1990). However, relying on single words may not account for important synonyms and may underestimate the importance of a particular theme. Therefore, for the purposes of the current study, topic-frequency counts were performed with the most frequently reported topics of discussions constituting important themes. The prevalence of these topics in mothers’ and daughters’ responses was reported, and meaning was inferred from these topics. To verify these results intercoder reliability was assessed. A random number generator was used to separately identify a sample of 10 responses from mothers, and 10 responses from daughters. These responses were then analyzed by an additional member of the research team using the same methods of analysis, and the percentage agreement between the two raters was calculated.

Chapter Three: Results

Participant Recruitment

The student researcher approached 232 women receiving treatment for breast cancer during four months of on-site recruitment at the cancer centre. Of this group, only
43 women qualified for the study. The remaining women either had no children, no daughter, or a daughter who was too young or too old to participate. Therefore, approximately 19% of women approached qualified for the study. Only two women who qualified for the study declined to participate. The participation rate of mothers was 95% (or 41 of 43 women). However, of the 41 mothers who completed the survey only 23 of their daughters also completed the survey, with the participant rate of daughters at approximately 56% (or 23 of 41 daughters). Four mothers completed the survey online, and the remainder completed it at the cancer centre. Four daughters had accompanied mothers to their appointments and completed the survey at the cancer centre, and the remainder completed it online.

Since dyadic information was of interest in this study, only data from the complete 23 pairs were included in the analysis, although demographic and psychosocial variables are also presented for the larger sample of 41 mothers (Table 1 and 2). No statistically significant differences between the group of mothers whose daughters participated \((n = 23)\) and the group of mothers whose daughters did not participate \((n = 18)\) were identified.

**Participant Characteristics**

Mothers were asked to complete questions regarding marital status, paid employment status, highest level of education completed, self-identified ethnicity, age, total annual household income, and whether their daughters were currently living with them. Health related information collected included stage of breast cancer, approximate date of breast cancer diagnosis, type(s) of surgery, and type(s) of treatment (Appendix F). Daughters were asked to complete questions regarding ethnicity, employment status,
current age, age when mother was diagnosed, and current level of education (Appendix G).

Mothers’ ages ranged from 41-57 years, with an average age of 48.5 years ($SD=4.38$) (Table 1). The majority of mothers reported they were married (82%), and employed full time (74%). Many mothers indicated they went to college/university (61%), or graduate school (13%), and the remainder indicated high school as their highest level of achieved education (26%). Seventy-eight percent of the sample identified as Caucasian, with only a small minority being of Asian/Pacific Islander or Native American/Alaskan decent. The majority of mothers stated their average annual household income was between $25,000 and $125,000 (70%). The majority of mothers had stage II (44%, 10 women) or stage III (30%, 7 women) breast cancer, however, both stage I (1 woman) and stage IV (2 women) were also represented (Table 2). Three women reported that they did not know the stage of their cancer. Seventy-eight percent of mothers had been diagnosed with breast cancer within the last 2 years, and 9% in the last 3-6 years. Lumpectomies were the primary type of surgery (56%), and chemotherapy was done by all 23 women, with 87% of women having some additional treatment such as radiation, hormonal therapy, or a combination of all three. The mean score for mothers on the FACT-B was 93.41 ($SD=13.79$), and on average mothers indicated their quality of life to be similar to other samples of women (Brucker, Yost, Cashy, Webster, & Cella, 2005), and to other samples of women with breast cancer (Hack et al., 2010), with no statistically significant differences (Appendix H). Mothers’ mean score on the STAI was 35.22 ($SD=8.56$), suggesting that overall mothers in the current sample did not indicate poor psychosocial adjustment.
Daughters’ self-identified ethnicity was the same as their mothers with 78% of the sample identifying as Caucasian, and only a small minority of other decent (Table 1). The average age at the time of sampling was 19.6 years old ($SD= 4.39$), whereas the average age at the time of their mothers’ diagnosis was 18 years old ($SD= 4.57$), with an age range of 9-23 years old. Many daughters were either employed part-time (22%) or not at all (48%). Fifty-two percent of daughters were living at home full-time with their mothers at the time of completing the survey, with 22% only part-time, and 26% not living with their mothers at all. The average score for daughters was 50.39 ($SD= 9.74$) on the YSR, and 37.00 ($SD= 12.32$) on the STAI, suggesting that overall daughters in the current sample did not report poor psychosocial adjustment.

Additionally, scores on the four measures were compared between the two samples of mothers. No statistically significant differences were found, with the exception of ratings of the depth of the relationships with mothers whose daughters participated in the study rating the relationship to be significantly deeper than mothers whose daughters did not participate (Table 2).
<table>
<thead>
<tr>
<th></th>
<th>Daughters n= 23</th>
<th>Mothers n= 23</th>
<th>Mothers n= 18</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Participant Characteristics</strong></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Mean age (years)</td>
<td>19.6</td>
<td>48.5</td>
<td>48.1</td>
</tr>
<tr>
<td>Age range (years)</td>
<td>12-25</td>
<td>41-57</td>
<td>35-59</td>
</tr>
<tr>
<td>Mean age at mothers' diagnosis</td>
<td>18</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Age range (years)</td>
<td>9-23</td>
<td></td>
<td></td>
</tr>
<tr>
<td><strong>Ethnicity</strong></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Caucasian</td>
<td>18 (78%)</td>
<td>18 (78%)</td>
<td>14 (78%)</td>
</tr>
<tr>
<td>Asian/Pacific Islander</td>
<td>4 (17%)</td>
<td>4 (17%)</td>
<td>3 (17%)</td>
</tr>
<tr>
<td>Hispanic</td>
<td>0</td>
<td>0</td>
<td>1 (5%)</td>
</tr>
<tr>
<td>Native American/Alaskan Native</td>
<td>1 (4%)</td>
<td>1 (4%)</td>
<td>0</td>
</tr>
<tr>
<td><strong>Level of education</strong></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Less than high school</td>
<td>4 (7%)</td>
<td>0</td>
<td>0</td>
</tr>
<tr>
<td>High school</td>
<td>8 (35%)</td>
<td>6 (26%)</td>
<td>7 (39%)</td>
</tr>
<tr>
<td>College/University</td>
<td>8 (35%)</td>
<td>14 (61%)</td>
<td>8 (44%)</td>
</tr>
<tr>
<td>Graduate school</td>
<td>3 (13%)</td>
<td>3 (13%)</td>
<td>3 (17%)</td>
</tr>
<tr>
<td><strong>Paid employment status</strong></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Employed</td>
<td>7 (30%)</td>
<td>17 (74%)</td>
<td>8 (44%)</td>
</tr>
<tr>
<td>Unemployed</td>
<td>11 (48%)</td>
<td>5 (22%)</td>
<td>6 (33%)</td>
</tr>
<tr>
<td>Part-time employed</td>
<td>5 (22%)</td>
<td>1 (4%)</td>
<td>4 (22%)</td>
</tr>
<tr>
<td><strong>Daughter lives at home:</strong></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Full-time</td>
<td>12 (52%)</td>
<td>9 (50%)</td>
<td></td>
</tr>
<tr>
<td>Part-time</td>
<td>5 (22%)</td>
<td>4 (22%)</td>
<td></td>
</tr>
<tr>
<td>Not at all</td>
<td>6 (26%)</td>
<td>5 (28%)</td>
<td></td>
</tr>
<tr>
<td><strong>Marital status</strong></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Married</td>
<td>19 (82%)</td>
<td>11 (61%)</td>
<td></td>
</tr>
<tr>
<td>Common Law</td>
<td>2 (9%)</td>
<td>1 (5%)</td>
<td></td>
</tr>
<tr>
<td>Divorced or Separated</td>
<td>2 (9%)</td>
<td>3 (17%)</td>
<td></td>
</tr>
<tr>
<td>Single/Widowed</td>
<td>0</td>
<td>3 (17%)</td>
<td></td>
</tr>
<tr>
<td><strong>Annual household income</strong></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Less than $25,000</td>
<td>0</td>
<td>4 (22%)</td>
<td></td>
</tr>
<tr>
<td>$25,001-$75,000</td>
<td>6 (26%)</td>
<td>6 (33%)</td>
<td></td>
</tr>
<tr>
<td>$75,001-$125,000</td>
<td>10 (44%)</td>
<td>3 (17%)</td>
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<td>$125,001-$175,000</td>
<td>4 (17%)</td>
<td>2 (11%)</td>
<td></td>
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<tr>
<td>Greater than $175,000</td>
<td>2 (9%)</td>
<td>3 (17%)</td>
<td></td>
</tr>
<tr>
<td>No response</td>
<td>1 (4%)</td>
<td>0</td>
<td></td>
</tr>
<tr>
<td><strong>Average number of children</strong></td>
<td>2.5</td>
<td>2.2</td>
<td></td>
</tr>
</tbody>
</table>
Table 2

*Health Related Variables and Average Scores*

<table>
<thead>
<tr>
<th>Stage of breast cancer</th>
<th>Mothers n=23</th>
<th>Mothers n=18</th>
</tr>
</thead>
<tbody>
<tr>
<td>I</td>
<td>1 (4%)</td>
<td>4 (22%)</td>
</tr>
<tr>
<td>II</td>
<td>10 (44%)</td>
<td>4 (22%)</td>
</tr>
<tr>
<td>III</td>
<td>7 (30%)</td>
<td>7 (39%)</td>
</tr>
<tr>
<td>IV</td>
<td>2 (9%)</td>
<td>1 (5%)</td>
</tr>
<tr>
<td>Do not know/Missing</td>
<td>3 (13%)</td>
<td>2 (11%)</td>
</tr>
<tr>
<td>Time since initial diagnosis</td>
<td></td>
<td></td>
</tr>
<tr>
<td>0-2 years</td>
<td>18 (78%)</td>
<td>11 (61%)</td>
</tr>
<tr>
<td>3-6 years</td>
<td>2 (9%)</td>
<td>4 (22%)</td>
</tr>
<tr>
<td>&gt; 6 years</td>
<td>2 (9%)</td>
<td>3 (17%)</td>
</tr>
<tr>
<td>Did not report</td>
<td>1 (4%)</td>
<td>0</td>
</tr>
<tr>
<td>Type of surgery</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Lumpectomy</td>
<td>13 (56%)</td>
<td>5 (28%)</td>
</tr>
<tr>
<td>Bilateral mastectomy</td>
<td>5 (22%)</td>
<td>7 (39%)</td>
</tr>
<tr>
<td>Lumpectomy and bilateral mastectomy</td>
<td>2 (9%)</td>
<td>3 (17%)</td>
</tr>
<tr>
<td>Double mastectomy</td>
<td>1 (4%)</td>
<td>2 (11%)</td>
</tr>
<tr>
<td>No surgery</td>
<td>2 (9%)</td>
<td>1 (5%)</td>
</tr>
<tr>
<td>Type of treatment</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Radiation</td>
<td>0</td>
<td>1 (5%)</td>
</tr>
<tr>
<td>Just chemotherapy</td>
<td>3 (13%)</td>
<td>2 (11%)</td>
</tr>
<tr>
<td>Chemotherapy + radiation</td>
<td>5 (22%)</td>
<td>2 (11%)</td>
</tr>
<tr>
<td>Chemotherapy + hormonal</td>
<td>2 (9%)</td>
<td>0</td>
</tr>
<tr>
<td>Chemotherapy + radiation + hormonal</td>
<td>13 (56%)</td>
<td>12 (67%)</td>
</tr>
<tr>
<td>Have not started yet</td>
<td>0</td>
<td>1 (5%)</td>
</tr>
<tr>
<td>FACT-B</td>
<td>93.41 (13.79)</td>
<td>89.42 (21.13)</td>
</tr>
<tr>
<td>YSR</td>
<td>41.48 (8.18)</td>
<td>46.83 (10.19)</td>
</tr>
<tr>
<td>STAI</td>
<td>35.22 (8.56)</td>
<td>37.78 (12.71)</td>
</tr>
<tr>
<td>QRI suppression *</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Support</td>
<td>12.61 (3.87)</td>
<td>11.25 (3.86)</td>
</tr>
<tr>
<td>Conflict</td>
<td>7.39 (5.24)</td>
<td>11.53 (7.81)</td>
</tr>
<tr>
<td>Depth</td>
<td>16.07 (1.62)</td>
<td>14.28 (3.35)</td>
</tr>
</tbody>
</table>

*a Average of scores as rated before the cancer and currently

* Significant difference at p < .05 between mother groups
Analysis of Group Differences

FACT-B Questionnaire. Overall, mothers rated themselves to have a slightly higher quality of life ($M=93.41$, $SD=13.79$) than their daughters rated them ($M=89.02$, $SD=17.84$), however, this differences did not reach statistical significance with $z=-1.28$, $p=.20$. The only statistically significant difference between mothers’ and daughters’ ratings of mothers’ quality of life was found on the Physical subscale. Mothers rated themselves significantly higher ($M=19.91$, $SD=3.96$) than daughters rated them ($M=15.45$, $SD=6.15$; $z=-3.20$, $p<.001$), indicating that mothers reported better physical quality of life than their daughters reported them to have (Table 3).
<table>
<thead>
<tr>
<th></th>
<th>Mothers</th>
<th>Daughters</th>
<th>Wilcoxon signed-ranks test</th>
<th></th>
<th></th>
<th></th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>Mean (SD)</td>
<td>Mean (SD)</td>
<td>z</td>
<td>p value</td>
<td>r</td>
<td></td>
</tr>
<tr>
<td><strong>FACT-B</strong></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Physical</td>
<td>19.91 (3.96)</td>
<td>15.45 (6.15)</td>
<td>-3.2</td>
<td>&lt; .001*</td>
<td>-0.47</td>
<td></td>
</tr>
<tr>
<td>Social</td>
<td>20.04 (3.51)</td>
<td>19.78 (2.92)</td>
<td>-0.38</td>
<td>.70</td>
<td>-0.06</td>
<td></td>
</tr>
<tr>
<td>Emotional</td>
<td>16.62 (3.70)</td>
<td>17.17 (4.00)</td>
<td>-0.69</td>
<td>.49</td>
<td>-0.1</td>
<td></td>
</tr>
<tr>
<td>Functional</td>
<td>17.35 (5.53)</td>
<td>16.26 (6.86)</td>
<td>-0.49</td>
<td>.63</td>
<td>-0.07</td>
<td></td>
</tr>
<tr>
<td>Breast</td>
<td>19.49 (5.19)</td>
<td>20.35 (5.18)</td>
<td>-0.35</td>
<td>.73</td>
<td>-0.05</td>
<td></td>
</tr>
<tr>
<td><strong>Total</strong></td>
<td>93.41 (13.79)</td>
<td>89.02 (17.84)</td>
<td>-1.28</td>
<td>.20</td>
<td>-0.19</td>
<td></td>
</tr>
<tr>
<td><strong>YSR</strong></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Withdrawn</td>
<td>50.78 (1.70)</td>
<td>53.57 (6.05)</td>
<td>-2.29</td>
<td>.02*</td>
<td>-0.34</td>
<td></td>
</tr>
<tr>
<td>Anxious/Depressed</td>
<td>51.04 (2.51)</td>
<td>54.87 (13.80)</td>
<td>-2.51</td>
<td>.01*</td>
<td>-0.37</td>
<td></td>
</tr>
<tr>
<td>Somatic Complaints</td>
<td>52.30 (4.69)</td>
<td>55.78 (6.22)</td>
<td>-2.6</td>
<td>.01*</td>
<td>-0.38</td>
<td></td>
</tr>
<tr>
<td>Social Problems</td>
<td>51.13 (2.80)</td>
<td>51.48 (2.89)</td>
<td>-0.7</td>
<td>.48</td>
<td>-0.1</td>
<td></td>
</tr>
<tr>
<td>Thought Problems</td>
<td>50.48 (1.08)</td>
<td>51.52 (3.65)</td>
<td>-0.89</td>
<td>.37</td>
<td>-0.13</td>
<td></td>
</tr>
<tr>
<td>Attention Problems</td>
<td>50.96 (2.14)</td>
<td>53.43 (5.14)</td>
<td>-2</td>
<td>.05*</td>
<td>-0.29</td>
<td></td>
</tr>
<tr>
<td>Delinquent Behaviours</td>
<td>51.74 (3.72)</td>
<td>56.09 (6.54)</td>
<td>-2.81</td>
<td>.01*</td>
<td>-0.41</td>
<td></td>
</tr>
<tr>
<td>Aggressive Behaviours</td>
<td>52.48 (5.15)</td>
<td>53.43 (5.12)</td>
<td>-0.71</td>
<td>.48</td>
<td>-0.11</td>
<td></td>
</tr>
<tr>
<td>Internal</td>
<td>44.57 (7.15)</td>
<td>50.22 (8.61)</td>
<td>-2.96</td>
<td>&lt; .001*</td>
<td>-0.44</td>
<td></td>
</tr>
<tr>
<td>External</td>
<td>43.87 (10.06)</td>
<td>52.61 (11.61)</td>
<td>-2.61</td>
<td>.01*</td>
<td>-0.39</td>
<td></td>
</tr>
<tr>
<td><strong>Total Problems</strong></td>
<td>41.48 (8.18)</td>
<td>50.39 (9.74)</td>
<td>-3.59</td>
<td>&lt; .001*</td>
<td>-0.53</td>
<td></td>
</tr>
<tr>
<td><strong>QRI</strong></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Before Support</td>
<td>12.26 (4.13)</td>
<td>15.00 (3.46)</td>
<td>-2.36</td>
<td>.02*</td>
<td>-0.35</td>
<td></td>
</tr>
<tr>
<td>Conflict</td>
<td>7.74 (5.63)</td>
<td>7.26 (7.18)</td>
<td>-0.88</td>
<td>.38</td>
<td>-0.13</td>
<td></td>
</tr>
<tr>
<td>Depth</td>
<td>15.96 (1.72)</td>
<td>15.09 (2.81)</td>
<td>-1.03</td>
<td>.30</td>
<td>-0.15</td>
<td></td>
</tr>
<tr>
<td>Now Support</td>
<td>12.96 (3.78)</td>
<td>13.78 (3.16)</td>
<td>-0.99</td>
<td>.32</td>
<td>-0.15</td>
<td></td>
</tr>
<tr>
<td>Conflict</td>
<td>7.04 (5.25)</td>
<td>7.61 (8.09)</td>
<td>-0.15</td>
<td>.88</td>
<td>-0.02</td>
<td></td>
</tr>
<tr>
<td>Depth</td>
<td>16.17 (1.64)</td>
<td>15.96 (2.18)</td>
<td>-0.02</td>
<td>.98</td>
<td>0.00</td>
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</table>
YSR Questionnaire. The raw subscale scores and Total Problems scores for mothers and daughters were assigned normalized T-scores, as provided by Achenbach (1991), so that direct comparisons could be made between mother and daughter dyad scores. Mothers rated their daughters to have a statistically significant lower Total Problems ($M=41.48$, $SD=8.18$) than daughters rated themselves to have ($M=50.39$, $SD=9.74$; $z=-3.59$, $p<.001$, $r=-.53$). A statistically significant difference was also found for five of the subscales including Withdrawn ($z=-2.29$, $p=.02$), Anxious/Depressed ($z=-2.51$, $p=.01$), Somatic Complaints ($z=-2.60$, $p=.01$), Attention Problems ($z=-2.00$, $p=.05$), and Delinquent Behaviours ($z=-2.81$, $p=.01$). Finally, there was a statistically significant difference found between mothers’ and daughters’ scores on the Internalizing ($z=-2.96$, $p<.001$) and Externalizing subscales ($z=-2.61$, $p=.01$) (Table 3).

Additionally, both daughters’ and mothers’ scores were compared to cutoff scores that distinguish youth scoring in the ‘normal’, ‘borderline clinical’ and ‘clinical’ range on the subscales and Total Problems, as provided by Achenbach (1991) (Figure 1, 2 and 3). Youth in the borderline clinical range are considered to be in the 95-97th percentile, and youth in the clinical range are considered to be in the 98th percentile as compared to a normative sample of 11-18 year old females.

In Figure 1 mothers’ and daughters’ scores are graphed on the Internalizing subscale. Four of the 23 daughters ranked in the borderline clinical range (pair # 8, 10, 12, and 15), and three daughters ranked in the clinical range (# 2, 5, and 18). In contrast, none of the mothers ranked their daughters in the either of the two clinical status groups. Scores on the Externalizing subscale are graphed in Figure 2. Two daughters ranked in the clinical range (# 2, 8) and two mothers ranked their daughters in the borderline
clinical range (mothers from pair # 7, 23); however, as seen in Figure 2 these did not represent mother-daughter dyads. Finally, Figure 3 illustrates Total Problem scores. Three daughters ranked in the borderline clinical range (# 8, 10, 18), and one in the clinical range (#2). None of the mothers ranked their daughters in either of the two clinical status groups.

In all three Figures the average score for mothers and the average score for daughters are also indicated. On average daughters scored in the normal range and did not indicate poor adjustment. The vertical bars represent differences between mothers’ and daughters’ scores within pairs. For several pairs there is only a small difference between mothers’ and daughters’ scores; however, the majority of pairs show medium to large differences in their ratings.
Figure 1

*Mother and Daughter Scores on the Internalizing Subscale*

YSR Internalizing Subscale

- **Daughters**
- **Mothers**

Vertical bars represent differences between scores for individual pairs.

* Daughters average score ($M=50.22$, $SD=8.61$)

* Mothers average score ($M=44.57$, $SD=7.15$)

* Vertical bars represent differences between scorers for individual pairs
Figure 2

Mother and Daughter Scores on the Externalizing Subscale

YSR Externalizing Subscale

* Daughters average score ($M = 52.61, SD = 11.61$)
* Mothers average score ($M = 43.87, SD = 10.06$)

Vertical bars represent differences between scorers for individual pairs
Figure 3

*Mother and Daughter Scores for Total Problems*

**YSR Total Problems**

- Daughters average score ($M = 50.93, SD = 9.74$)
- Mothers average score ($M = 41.48, SD = 8.18$)

Vertical bars represent differences between scorers for individual pairs.
**QRI Questionnaire.** There were no statistically significant differences between mothers’ and daughters’ ratings of the relationship with regard to the Conflict and Depth subscales; however, there was a statistically significant difference on the Support subscale, with daughters rating the relationship to be significantly more supportive \((M=15.00, SD=3.46)\) than mothers reported it to be before the cancer \((M=12.26, SD=4.13; z=-2.36, p=.02)\) (Table 3).

Additionally, mothers and daughters did not report many significant changes in the quality of the relationship following the cancer (Appendix I). Mothers did not indicate any statistically significant differences in their ratings of the relationship before the cancer as compared to following the cancer. The same was found for daughters, with the exception of the depth of the relationship. Daughters indicated a statistically significant difference in the depth of the relationship currently \((M=15.96, SD=2.18)\) versus before the breast cancer \((M=15.09, SD=2.81; z=-2.06 at p=.04)\), suggesting that daughters perceived there to be some change in the relationship following the cancer, with the relationship becoming deeper following the breast cancer diagnosis.

**STAI Questionnaire.** There was no statistically significant difference between mothers \((M=35.22, SD=8.56)\) and daughters ratings \((M=37.00, SD=12.32)\) of their individual anxiety with \(z=-.69, p=.49\). Mothers \((M=35.22, SD=8.56)\) reported lower state anxiety than a normative sample of females \((M=36.03, SD=11.07)\), and daughters \((M=37.00, SD=12.32)\) reported lower state anxiety than a normative sample of female high school students \((M=40.54, SD=12.86; Spielberger, 1983)\); however, neither or these differences were statistically significant. Although normative data have been provided, clinical cutoffs have not been established. In Figure 4 and Figure 5 mother and
daughter scores are graphed and percentile marks of $\geq 80$ and $\geq 90$ are depicted.

Additionally, a third and fourth dotted line represents the average score of the normative sample and the average score for the current sample.
Figure 4

*Mothers’ Scores on the STAI*

STAI Score for Mothers

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\(^a\) Average score for normative sample of women \((M=36.03, SD=11.07)\)

\(^b\) Average score for current sample \((M=35.22, SD=8.56)\)
Figure 5

Daughters’ Scores on the STAI

STAI Score for Daughters

\[ a \] Average score for normative sample of adolescent females \((M = 40.54, SD = 12.86)\)

\[ b \] Average score for current sample \((M = 37.00, SD = 12.32)\)
Content Analysis

Topics Discussed by Mothers and Daughters

The most frequently reported topics of discussions between mothers and daughters included: the nature of breast cancer, daughter’s risk of developing breast cancer, openness and honesty, and how mothers were feeling. Table 4 identifies each of the themes and the corresponding pairs, or single mothers and single daughters, who reported these topics in their responses. Intercoder reliability was adequate (Neuendorf, 2002), with 80% agreement between the two raters.
The nature of breast cancer. Twenty mothers and 18 daughters reported speaking about one or more of the following topics: diagnosis, stage, surgery, treatment plan, radiation/chemotherapy, side effects, hair loss, nutrition, prognosis, and progress or change in the cancer. For example, one mother stated, “We have discussed everything, from my biopsy, surgery, chemotherapy, radiation, and Herceptin, to my doctor visits and follow-up appointments”. Her daughter stated, “We discussed what treatments she would go through, some of the side effects I should expect (hair loss, weight gain)”.

For 16 pairs both mothers and daughters similarly reported openly speaking about these cancer related details. In many cases these topics accounted for the majority of the content in respondents’ answers, and there was relatively little other information reported by some pairs. In only one pair neither mother nor daughter reported speaking about these topics, but demonstrated similarity in their responses regarding other topics. For the remaining six pairs either only mothers or only daughters reported speaking about these topics.
Openness and Honesty. Seven mothers and four daughters spoke about being open and honest when discussing the breast cancer. For example, one mother stated, “I have never sheltered my children from my illness and I have always been as open as I could at the time, and answered any questions as honestly as I could”. Another mother reported, “We discussed everything. She came to many of my appointments and both surgeries. She calls after every chemo and comes home on many weekends”. Her daughter reported, “Almost everything I would say. Her surgeries, her treatments, her pain.” One mother-daughter pair simply stated “everything” and “absolutely everything” in response to this question. Of these mothers and daughters three constituted mother-daughter pairs. The corresponding four daughters of the mothers who reported this topic spoke less directly about honesty and openness, however, the majority of them had similar responses to their mothers’ and suggested that they spoke about many different things in an open and honest way.

Daughter’s risk. Four mothers and three daughters reported speaking about the potential risk of daughters also developing breast cancer in the future, although none of these constituted a mother-daughter pair. Topics included hereditary factors, life-style and medical precautions, when to get tested, and how to tell if it is cancer. Very little details were reported regarding these conversations and in many cases it was only listed as one of many topics discussed.

How mothers are feeling. Nine daughters reported having some discussion about their mothers’ feelings, however, none of the 23 mothers directly reported speaking about their own feelings, or their daughters’ feelings. Of these nine daughters, five reported speaking about their mothers’ emotional feelings, such as emotions she experienced in
coping with the cancer. For example, one daughter stated, “We have discussed feelings and emotions in regards to her diagnosis”. Two daughters reported speaking to their mothers about physical feelings, such as treatment side effects, and pain. For example, one daughter reported, “[We speak about] how she feels after her chemotherapy treatment”. And finally two daughters reported speaking about both their mothers’ emotional and physical feelings, with one daughter reporting, “[We speak about] how it makes her feel physically, mentally, and emotionally”. All nine daughters specifically reported speaking about ‘her feelings’ with regard to their mothers’ feelings, and did not report information regarding whether they were discussing their own feelings with their mothers.

Additionally, three other daughters (2, 5, 12) reported a lack of discussion around feelings and not speaking to their mothers about this topic. In two cases daughters reported that their mothers did not like to get emotional or speak about the cancer, and that their mothers kept many of their thoughts and feelings to themselves. Finally, one daughter reported that it was she who did not like to hear about her mother’s feelings regarding anything related to the cancer. She stated, “I don’t like to hear about my mom’s pain she’s feeling after treatments or anything similar. I want everything to go back to the way it was and she agrees that is sucks right now”. Although feelings were commonly reported by the daughters, none of the 23 mothers directly reported speaking about feelings, either their own, or their daughters’ feelings.

*Discussing the Cancer with Others*

Including the larger sample of 41 mothers, 36 mothers and 18 daughters reported speaking to at least one of these groups of individuals: family (husbands, children,
siblings, parents, grandparents, cousins, aunts), friends, and boyfriends. The topics they reported discussing were very similar to the topics reported in the first question, such as, cancer related information, treatment, progression of the cancer, the future, and feelings about the cancer. One mother-daughter pair and one single daughter did not list any individuals.

Three mothers and three daughters reported that they did not like to speak anyone about the cancer; however, these did not constitute any mother-daughter pairs. The three mothers reported that, although they speak to one or two individuals, they prefer to keep their feelings to themselves. One daughter stated that the cancer is not something she would like to be talking to other people about; another daughter reiterated that although she would like to discuss the cancer with her mother, her family does not like to talk about the emotional aspect of the illness; the final daughter simply stated she speaks to no one about her mother’s cancer.

Additional Support Needs and Resources Accessed

Thirty-two of 41 mothers indicated that they did not require additional information and support, and nine responded that they did. Of those who responded yes, five indicated that they needed additional support needs, such as support from counsellors, social workers, or nutritionists, and four indicated they required additional information needs, such as surgical and genetic information.

Seventeen of 41 mothers indicated that they had received some form of psychological or social treatment or help. Thirteen mothers reported that support was obtained through the Juravinski Cancer Centre and was in the form of counselling, ranging between 45 minutes to 10 hours in total. Of the 17 that received counselling 14
mothers indicated it was helpful, and generally speaking they stated that it was helpful to speak to someone about their concerns. One mother indicated it was only somewhat helpful and two indicated it was not helpful at all, stating that the information they gained was also available on the Internet or through other resources, or that their friends and community members were more helpful.

In contrast, a much larger number of daughters reported that there were additional information and/or support needs that they had not yet received. Ten daughters reported needing additional support or information. The responses can be categorized generally into three areas: information needs concerning the breast cancer; additional support for individual coping; and finally, additional support from, or for, their families. With regard to information needs, four daughters stated that they would like more information related to the breast cancer diagnosis. More specifically questions were asked about the treatment (e.g., what happens if the treatment does not work? Are the side effects life threatening?), the future (e.g., what happens if she gets it again?), and about the risk of developing breast cancer themselves (e.g., there is a history in my family, is there a chance I may get it?). With regard to additional support for individual coping, three daughters indicated they needed more support in dealing with their mothers’ cancer, and included requests such as having a group of people their age to speak to, having counselling available for the patient and family with information regarding ways to better support an individual with cancer, and lastly, having someone to talk to about the emotional side of her mother’s cancer. Finally, three daughters indicated that they would like more support from their family or for their families, such as needing more support
from siblings, or being unsure about how to support their mothers and/or their fathers, and requiring help in coping with this aspect.

Only four daughters indicated that they had received some form of psychological or social treatment or help. One daughter indicated this was received through the Juravinski Cancer Centre, and the other three indicated some external support (family doctor, social worker). Two of the four daughters indicated it was helpful to them, and two indicated it was not really helpful.

Chapter Four: Discussion

Overview

Mothers’ and daughters’ perceptions of one another’s adjustment were found to be different with regard to daughters’ adjustment, and similar with regard to mothers’ adjustment. Daughters demonstrated consistency in their ratings for many aspects of their mothers’ quality of life, suggesting that overall daughters may have accurate understandings of their mothers’ adjustment during this time. In contrast, mothers perceived statistically fewer emotional and behavioural problems than daughters reported experiencing, and this difference was found for internalizing behaviours, externalizing behaviours, as well as for total problems.

It was also found that mothers and daughters may experience only minimal changes in their relationship following a cancer diagnosis, which is contrary to previous reports of both positive and negative changes in parent-child relationships during parental cancer (Lichtman et al. 1984; Rosenfeld et al., 1983; Wellisch et al., 1996). Additionally, mothers and daughters reported only small differences in their perceptions of the quality of their relationship, with some daughters perceiving the relationship to be more
supportive than some mothers perceived it to be. Overall the findings in the current study both support and dispute findings from previous studies, as well contribute to areas that have not been previously investigated with respect to mothers’ and daughters’ adjustment to a breast cancer diagnosis in mothers.

**Disparity**

*Mother’s Adjustment*

The only statistically significant difference between mothers’ and daughters’ ratings of mothers’ adjustment was on the Physical subscale of the FACT-B. Items on the Physical subscale addressed issues concerning lack of energy, nausea, pain, being bothered by side effects, feeling ill, and being forced to spend time in bed (Appendix E). Overall, it appears that daughters were accurate in perceiving their mothers’ quality of life; however, the low physical quality of life ratings possibly suggest that daughters do not accurately perceive their mothers’ physical well-being, and overestimate their mothers’ difficulties with these issues. Previous reports suggest that parents often underestimate their children’s difficulties (Welch et al., 1996), whereas the current findings suggest that children may overestimate their parents’ difficulties.

These differences in ratings of physical quality of life appear to be incongruent with what mothers and daughters reported discussing with one another. More specifically, the most commonly reported topics of discussions were some of the same topics addressed in items on the Physical subscale (such as experiencing side effects, and feelings of pain and well-being following treatments). It is therefore, somewhat surprising that despite reports of speaking frequently about these topics, and showing consistency in dyadic reports of these discussions, some daughters may still be
overestimating their mothers’ difficulties in adjusting to the physical aspects of their cancer.

Conversely, there were no statistically significant differences between mothers’ and daughters’ ratings on any of the other subscales or total scores; however, topics on these subscales were not commonly reported as discussions between mothers and daughters. For example, items on the Breast cancer subscale pertain to issues experienced by breast cancer patients such as arm swelling, and changes in femininity, including feelings of attractiveness and change in weight. Although daughters demonstrated accuracy in rating their mothers on the Breast cancer subscale, neither mothers nor daughters reported speaking about topics covered in these items with any great frequency. The same pattern was found for the other subscales of Emotional, Functional, and Social well-being. The Emotional subscale covers topics including feeling sad, worrying about death, losing hope in fighting this disease, feeling nervous, and worrying that the disease will progress. Although some mothers and daughters reported speaking about how their mothers were feeling, these discussions were more often regarding feelings of pain related to symptoms and side effects, and not focused on feelings of worry, death, sadness, and nervousness. This is not to assume that these topics were not discussed between mothers and daughters, only that they were not frequently reported in the current study.

The question remains as to why daughters in the current sample demonstrated accuracy in many ratings, with discrepancies in only one aspect of their mothers’ well-being. These finding may best understood through Lazarus and Folkman’s (1984), and Leventhal and colleagues’ (1980) cognitive theories, which suggest that in an effort to
cope individuals become active problem solvers, and seek information from their environment, combing multiple sources of information to develop representations of the illness. Presumably, the accuracy seen in daughters’ ratings may be in part attributable to some daughters actively seeking out information during this time. Some daughters may manage their stress by diligently attuning to their mothers’ actions, moods, and behaviours during this time. For example, it has been reported by Forrest and colleagues (2006) that children of mothers with breast cancer often suspected that there was something wrong even before they were told of their mothers’ diagnosis. Children reported relying on information about their mothers’ mood and behaviours, as well as overhearing conversations including hospital correspondences, to assess changes in their mothers.

It is also conceivable that this vigilant attention to their mothers, in combination with the instability or fluctuation in physical well-being throughout cancer treatment, contributes to the inaccuracy of daughters’ perceptions of their mothers’ physical well-being. All 23 women received at least chemotherapy as part of their treatment. Chemotherapy is often administered bi-weekly or tri-weekly for multiple weeks and is associated with numerous physical symptoms including nausea, pain, feeling ill, fatigue, and hair loss. These symptoms often cycle with the treatments, with the most symptoms experienced in the several days following treatment, and fewer symptoms experienced in the days leading up to the next treatment. As a result women’s physical well-being can change quite frequently throughout the cancer process. These physical symptoms may also be difficult to hide and may generate discussions between parents and children. In contrast, although distress appears to be highest around the diagnosis and initial treatment
consultations, it often declines as time passes for both the patient and children, and appears to be quite stable following decline of the initial distress (Welch et al., 1996). These frequent changes in physical well-being may contribute to the disparity between mothers’ and daughters’ reports, with mothers and daughters reflecting on different experiences of mothers’ physical well-being, or daughters reflecting on experiences of witnessing a very high number of side effects at one time (e.g., nausea, feeling ill), whereas mothers may be able to generalize across their breast cancer experience and report fewer physical well-being problems. Again these findings may support the cognitive theories of appraisal and illness perceptions (Lazarus & Folkman, 1984, Leventhal et al., 1980). Although mothers and daughters may be sharing information about physical well-being through various conversations and observations, perceptions of these interactions develop individually and separately, as mothers and daughters incorporate different aspects of the illness and different sources of information to form their own perceptions of the illness, and appraise its impact on mothers, and can be seen by differences in mothers’ and daughters’ scores.

Overall, the results suggest that daughters may be more aware of their mothers’ well-being during this time than mothers are aware of their daughters’ well-being. It may be possible that, although mothers and daughters do not engage in discussions directly related to these topics, some daughters may be hyper-vigilant in attuning to their mothers’ well-being, and develop perceptions of their mothers’ adjustment and illness by diligently observing their actions and behaviours. Unfortunately, at this time it remains unclear as to whether there is a potential benefit, or a potential detriment, to being aware of mothers’ well-being on individual adjustment in daughters. It may be hypothesized that
daughters who have mothers that experience poor adjustment, and are aware of this adjustment, may also experience poor adjustment themselves. This would be supported by results from previous studies linking depression in mothers with breast cancer to poor psychosocial adjustment in daughters (Watson et al., 2006). Or daughters who have mothers that are experiencing good adjustment, but are not accurate in their understandings of this adjustment, may also have poor adjustment themselves. Unfortunately, these relationships were not examined in the current study.

**Daughters’ Adjustment**

There were statistically significant differences between mothers’ and daughters’ ratings of daughters’ emotional and behavioural problems for both the Internalizing and Externalizing subscales, and for Total Problems. Mothers rated their daughters to have a lower number of problems than daughters rated themselves, possibly suggesting that mothers do not have accurate perceptions of their daughters’ emotional and behavioural problems, and underestimate their daughters’ difficulty in adjusting to breast cancer.

These findings are consistent with previous reports of disparity. For example, Welch and colleagues (1996) conducted a similar investigation of parent reports of children’s emotional and behavioural problems by comparing children’s reports on the YSR to parents’ reports on the Child Behaviour Checklist (CBCL; Achenbach, 1991). The CBCL is a parent version of the YSR, however, several of the questions differ between the two scales, and standardized T-scores are used to compare between the two respondents. Only two of the subscales were used (Anxious/Depressed and Aggressive Behaviours). Overall, adolescents reported higher rates of anxiety/depression and aggressive behaviours than their parents reported, and this greatest disparity was found
between reports from daughters of mothers with breast cancer and their parents. Therefore, it may not be surprising that there were statistically significant differences between mothers’ and daughters’ reports in the current sample. In fact, Achenbach and colleagues (1987) have reported that in general parents show only modest correspondence in their judgments of their children’s emotional and behavioural problems across different situations. In a meta analysis Achenbach and colleagues (1987) identified 11 studies in which parent and child reports regarding problems experienced by children were compared (with children 6-17 years old). These studies varied in the psychosocial factor measured, with some focusing on depression, and emotional and behavioural problems in children, as well as varying in the subjects sampled with some children coming from inpatient facilities, some from outpatient facilities, and some from families of parents with psychiatric disorders. Overall, the mean Pearson correlation between parent and child reports was statistically significant but small at $r=.25$, demonstrating only moderate consistency between parent and child reports. These results suggest that even in cases with varying psychosocial well-being in parents and in children, parents do not perceive, or perhaps report, the same difficulties as children report experiencing. Overall, it may be appropriate to state that parents in general (both healthy parents and ill parents) may not accurately report their children’s emotional and behavioural problems, and that the results from the current study further support these findings.

With regard to the current sample, there may be various reasons for these disparities. It is possible that daughters may not be communicating with their parents about their difficulties or disclosing their feelings at this time, and may not feel that it is
possible or appropriate to share their distress; mothers may have difficulty identifying or recognizing these problems, as they are focused on coping with their own difficulties. It may be possible that fewer discrepancies are seen in pairs with mothers who have older children and have more experience raising adolescent children, or that even greater discrepancies are seen in pairs where other adults, or other family members, have taken over the care of children and adolescents during this time. However, in general, it may be unrealistic to expect that throughout development parents will have clear understandings of their children’s emotional and behavioural problems, and even more unrealistic to expect this during stressful experiences such as coping with one’s own cancer diagnosis. Although at this time it remains unclear as to what may be at the root of these discrepancies, the results from the current study further contribute to, and support previous findings, that parents may not be aware of their children’s psychosocial problems.

Quality of the Relationship

Overall, there was relatively little difference between mothers’ and daughters’ perceptions of their relationship with one another. Mothers and daughters rated the depth and conflict in the relationship, both before the cancer and following the cancer, to be very similar, as well as the support of the relationship following the cancer. The only statistically significant difference was on ratings of the support of the relationship before the cancer, with daughters rating the relationship to be more supportive than mothers perceived it to be.

It is conceivable that the degree of support in the mother-daughter relationship during adolescence and young adulthood is not always reciprocal. For example, items on
the Support subscale ask mothers and daughters to rate one another with questions such as, ‘To what extent can you really count on this person to distract you from your worries when you feel under stress?’ Although daughters may feel that their mothers provide a great deal of support and assistance, it is possible that daughters are not able to, or willing to, provide the same degree of support to their mothers, and it may be unrealistic to expect this amount of support considering daughters’ developmental stage and level of maturity. The same could be said about the degree of conflict and depth in the relationship. Therefore, it may be more surprising that mothers’ and daughters’ ratings were found to be so similar in the current study.

It is also important to recognize that daughters who completed the survey may have very different relationships with their mothers than the daughters who chose not to participate in the study, and that this relationship may in fact impact daughters’ decisions to participate. Mothers were asked to pass an information sheet on to their daughters regarding the study, and approximately 44% of daughters who qualified to participate did not complete the survey. It is conceivable that in cases in which the relationship was perceived to have high conflict, or there were significant changes towards lower support and depth, and higher conflict, daughters may not be as inclined to fulfill their mothers’ requests and expectations, or to engage in activities that require reflecting on the relationship. This would impact the results found in the current study, with relationships experiencing higher conflict and more change not represented in the current sample. Although it was not possible to obtain any information from daughters who chose not to participate, reports from the 18 mothers whose daughters did not participate suggests that these mothers perceived the mother-daughter relationship to be statistically less deep than
mothers whose daughters did participate. This possibly supports the suggestion that the
good of the mother-daughter relationship may have some impact on daughters’ choice
of whether or not to participate in the study, and that the current sample of daughters may
have different relationships with their mothers than the group of daughters who did not
participate.

Communication

In addition to identifying frequently reported topics of conversations between
mothers and daughters, significant discrepancies were also found between mother and
daughter reports for several pairs (# 2, 5, 8, 12). In all four cases mothers reported at a
very minimum speaking to their daughters about health and disease related information,
however, daughters’ responses described a very different perspective. For example, one
mother reported her and her daughter spoke about “My diagnosis… Always hopeful.
Hope is important. Trust my doctor, my mother is a survivor. We all try to focus on the
positive and today”. In contrast her daughter reported, “My mother does not like to
discuss the details of her cancer or her treatment. My mother does not like to get overly
emotional, and does so when talking about her illness”. Another mother reported, “[We
speak about] treatments, hair loss, nutrition and health, daughter’s risk of breast cancer”.
In contrast her daughter reported “To be honest, barely anything. She keeps a lot of her
emotions and information to herself, or between her and my father”. Similar
discrepancies were found in the other two pairs. For the remaining 19 pairs, although not
identical in their responses, both mothers and daughters spoke about topics that were
generally related and no significant differences were apparent.
There may be several reasons for these disparities. They may be in part attributable to differences in what some mothers and daughters perceived to be the most important responses to the question asked. Additionally, if mothers and daughters were encouraged to write more, or to expand on their answers, it is possible that a greater number of discrepancies would be identified due to differences in how individuals approach their responses to the question. It is also possible that discrepancies exist because one or both of mothers’ and daughters’ responses were biased towards what they believed were the most correct answers, and gave the most socially desirable responses. Therefore, mothers’ and daughters’ responses may not be entirely representative of differences in mother-daughter perceptions, but do contribute some information about possible discrepancies between how mothers and daughters view their communication during breast cancer. Finally, although it is unclear as to what impact these discrepancies may have, and whether they are associated with poor adjustment in daughters, all four of the daughters in pairs that demonstrated discrepancies also indicated poor adjustment on measures of emotional and behavioural problems, and constituted the three daughters that stated they did not discuss feelings with their mothers.

**Impact of Parent-Child Disparity**

Some understanding of the potential impact of these disparities may come from Grusec and colleagues’ research on parenting cognitions (Grusec, Hastings, & Mammone, 1994), and the relationship between parents’ accuracy in predicting children’s distress and children’s coping behaviours (Vinik, Almas, & Grusec, 2011). For example, in a study examining mothers’ knowledge of the degree of distress experienced by their children in various hypothetical situations, mothers’ accuracy in rating this distress
significantly predicted children’s positive coping behaviours (Vinik et al., 2011). Mothers who showed high accuracy in rating their children’s degree of distress had children who reported positive coping behaviours, such as self-reliant coping and seeking social support, suggesting that knowledge of children’s distress may be linked to positive outcomes in children. Additionally, mothers’ accuracy in rating appropriate comforting interventions for their children, such as engaging in conversations about their emotions, providing distractions, or being sympathetic also predicted children’s coping and prosocial behaviour. The investigators speculated that mothers who are aware of their children’s distress are more likely to engage in discussions with their children about emotions, leading to greater knowledge of emotional expression and emotional regulation in children, as well as greater knowledge of what comforts children in mothers. There may also be other explanations. For example, children who are more open and emotionally expressive may engage in more conversations around emotions with their mothers, such that personal characteristics of children contribute to mothers’ knowledge of children’s experiences of emotion. Or it may be a combination of these explanations, and it remains unclear as to how parents become knowledgeable about their children’s emotions; only that greater knowledge may be associated with positive outcomes in children.

With respect to disparities during parental illness, it is possible that some parents may have this knowledge base of their children’s emotional responses and experiences of distress, but are limited in their ability to respond to the needs of their children during illness, and may not be able to provide appropriate comforts at that time. As a result, children may internalize this lack of attention to their emotional needs and become less
upfront or expressive, and parents may become less accurate in perceiving their needs, possibly accounting for some of the discrepancies seen in the current study. It may be speculated that under circumstances outside of serious parental illness (or situations causing similar distress) parents may be more accurate in their perceptions, suggesting that situations of illness may create transitory cases of disparities. However transitory this disparity may be, Grusec and colleagues’ research may suggest that inaccuracy in perceiving children’s distress may lead to problematic coping strategies during that time. Further examinations of accuracy during parental illness may reveal the casual link between disparity and adjustment during illness, and longitudinal examination may reveal the possible transitory nature of these disparities.

**Prevalence of Poor Adjustment**

*Daughters*

In the current study emotional and behavioural problems, and levels of anxiety, were used to assess psychosocial adjustment in daughters. Eight of 23 daughters, or approximately 35% of daughters reported poor adjustment on one of both measures of emotional and behavioural problems or anxiety. This rate is similar to that found in a previous study of daughters of mothers with breast cancer, with 32% of daughters reporting psychosocial problems on the YSR (Edwards et al., 2008).

Although the current sample size was not large enough to statistically identify factors associated with adjustment in daughters, individual examination of several factors suggests possible risk factors, which either support previous findings or warrant further examination in future studies. For example, five of the eight daughters or 63% of those who reported poor adjustment were older than 20 years of age. No studies could be
located that have examined this young adult population of daughters as compared with adolescent daughters on measures of psychosocial adjustment when a mother has breast cancer. With regard to stage of cancer, daughters who reported poor adjustment had mothers with stage I, II, or III breast cancer. A greater number of daughters who reported poor adjustment had mothers with stage III than any other stage. Previous reports have suggested that children’s adjustment to mothers’ breast cancer is not related to the severity of the illness, or the treatment received (Hoke et al., 2001), however, no conclusions can be made from this sample. Finally, in the sample of daughters who had poor adjustment the proportion of daughters living with their mothers full-time was similar to that of the larger sample, with a smaller proportion living with their mothers part-time or not at all, suggesting there may not be a significant relationship between living with mothers during the time of cancer and poor adjustment in the current sample. However, no previous investigations could be located that have examined residency in this sample of daughters.

**Mothers**

Seventeen of 41 mothers or approximately 41% of the sample reported poor adjustment on one or both measures of quality of life or anxiety. These results are similar to previous reports of psychosocial adjustment in women with breast cancer (Burgess et al., 2004; Epping-Jordan et al., 1999). Mothers who reported poor adjustment had stage I to IV breast cancer. The type of surgeries performed on women in the poorly adjusted group was similar to that of the larger sample, with the majority of women receiving a lumpectomy and a smaller proportion receiving a mastectomy. Overall, it appears that
mothers who reported poor adjustment were similar to the larger sample of women in the current study.

Support Needs and Resources Accessed

Overall 43% of daughters reported that they had additional information or support needs that had not been met at the time of completing the survey. Only 22% of mothers reported needing additional information and support, suggesting that daughters in the current sample required more assistance in coping with the breast cancer than their mothers reported needing. This may be in part due to the larger number of mothers (41%) who indicated that they had received additional psychosocial support, whereas only 17% of daughters indicated that they had accessed some form of psychosocial assistance. With 35% of daughters in the current sample reporting poor psychosocial adjustment, 43% indicating that they required more psychosocial help, and only 17% accessing additional support, it appears that some daughters coping with a mothers’ breast cancer may be in need of more assistance than they are receiving, and that some daughters may not be accessing the support they require for good psychosocial adjustment during this time.

Limitations

There were several significant limitations in the current study that may impact both the significance of the results and the conclusions that can be drawn. The current study was significantly limited by the sample size. Although the Juravinski Cancer Centre treats approximately 60 new breast cancer patients a month, only 19% of the women approached met the inclusion criteria and were invited to participate. The participation rate of daughters was also low with just over half of daughters who qualified
to participate completing the survey, resulting in only a small sample of mothers and daughters.

The small sample size limited both the power of the analyses, as well as the type of analyses that could be performed. A sample size of less than 26 pairs reduced the power associated with the Wilcoxon test to below 80%, which is the conventional value used in power analyses; anything below this value incurs a greater risk of a Type II error, or the risk of not identifying a significant result when one exists (Cohen, 1992). Finally, the small sample size limited the statistical examination of the potential relationship between adjustment and disparity. For example, it remains unclear as to whether a relationship exists between showing correspondence in mother-daughter reports and individual adjustment to breast cancer.

Additionally, the study may be limited by the fallible nature of collecting self-reports through survey instruments. Systematic errors, including socially desirable and acquiescent responses (Phillips & Clancy, 1972), as well as random measurement errors, such as temporary variations in the subjects’ health or mood (Singleton & Straits, 1988), may have introduced some bias into subjects’ responses. For example, in the current study problems may have occurred when respondents reported the most socially desirable answers. Mothers may have underreported daughters’ emotional and behavioural problems out of a conscious or unconscious desire to present themselves and their daughters in a favorable light, and may have contributed to the reported discrepancies in mothers’ perceptions of their daughters’ adjustment. Additionally, variability in sampling some women during their chemotherapy or radiation treatments, versus sampling some
women during routine appointments, may have contributed to variability in the health or mood of subjects and may have introduced some measurement error.

The recruitment process of speaking to mothers with breast cancer, but having no direct contact with their daughters, was also a significant limitation in the current study. In addition to some daughters simply not being interested in participating in the current study, there may be several other reasons for the low participation rate of daughters. It is possible that the information sheet was not passed from mothers to daughters, that the information sheet was lost or forgotten by mothers or by daughters, or that after completing their own surveys some mothers chose not to have their daughters participate and never informed them of the study. Finally, and possibly most importantly, it is also possible that daughters who experience difficulties in coping with their mothers’ breast cancer may be less inclined to engage in any activities that require them to reflect on their experience, and thus chose not to participate when they were informed of the study by their mothers. This may have limited the collection of important data from a sample of daughters who may be experiencing significant distress in adjusting to their mothers’ cancer. As no identifying or contact information was collected from mothers, further information could not be obtained from daughters. However, some information may be gained from the 18 mothers whose daughters did not participate. Mothers in this group rated their daughters to have similar scores on the YSR to those scores from mothers whose daughters did participate, and no statistically significant difference was identified. This suggests that daughters in the current sample had similar psychosocial adjustment as those who did not participate, but caution should be taken when relying on mothers’
reports of their daughters, because, as seen in the current study, mothers may not be accurate in their perceptions of their daughters’ psychosocial problems.

Finally, the results are significantly limited in their generalizability due to a lack of heterogeneity with regard to participant characteristics, including stage of cancer, age, ethnicity, socioeconomic status, marital status, employment status, and level of education, in both mothers and daughters and, therefore, group differences could not be examined. For example it has been reported that higher socioeconomic status is associated with higher quality of life in breast cancer patients, and variations exist in level of quality of life among different ethnicities in women with breast cancer (Ashing-Giwa & Lim, 2009). Having only a small number of participants of different ethnicities and socioeconomic statuses limits conclusions about any of these minorities based on results from the current sample.

**Implications for Future Research**

Although statistically significant differences between parents’ understandings of their children’s adjustment to parental cancer and children’s actual adjustment were identified in the current study, this does not imply that blame should be placed on parents or children for these discrepancies, or that parents who show little correspondence are poor parents. There are a multitude of reasons why parents may not be fully aware of their children’s difficulties, ranging from the complexities of adolescence and children seeking autonomy, to the very difficult task of coping with one’s own diagnosis of cancer and all that accompanies it. It appears that during this time, parents and children may have different perceptions of their distress, and this may be both common and expected during periods of high stress such as illness.
Further research examining children’s adjustment to parental cancer should recognize that relying on a single informant’s report of a child’s emotional and behavioural problems may not constitute a complete picture of a child’s well-being at that time. Achenbach and colleagues (1987) have suggested that disparity between different respondents should not be interpreted as one or both informants contributing invalid or unreliable information, and instead, information gathered from multiple respondents should be preserved as meaningful information, even if there is only moderate correspondence between responses. Therefore, reports from a single individual involved in a child’s life may not be a substitute for reports from other respondents, as there may be only moderate agreement between reporters, and other important perspectives could be missed, such as the children’s or teachers’ perspectives. During the scientific study of children’s adjustment to parental cancer, relying on parents’ reports alone, or children’s reports alone, may not produce an accurate measure of children’s psychosocial difficulties and instead multiple perspectives may contribute helpful information.

Additionally, care may be taken when comparing studies in which investigators have examined only parental reports of children’s adjustment to those that have examined only children’s reports, or to those that have examined both parents’ and children’s reports, as there may be little similarity between findings that rely on different sources for information about a single child. Future research examining children’s coping and adjustment to parental illness should at a minimum collect both parent and child reports, and recognize that both reports may contribute important and valid information to what is being studied.
Implications for Practice

The same recommendations may apply in practice when working with families coping with parental cancer, such that information from only parents may not contribute a clear picture of children’s psychosocial state. It should be recognized that if parents are unaware of their children’s psychosocial problems, they may not actively seek help for their children. As a result, during meetings with oncology professionals parents may not address concerns regarding their children, as they do not perceive there to be any urgency or additional assistance needed. Even when oncology professionals address issues of psychosocial well-being and possibly inquire about patients’ children, parental reports of children’s coping and adjustment may not provide the most reliable assessment of children’s well-being. In practice this means that in order to provide support and direct patients and families to appropriate resources, healthcare professionals may have to rely on reports from parents that may not be accurate; although parents may not perceive the need for information regarding supports for their children, this information should still be conveyed and parents should be educated about the possible responses they may see in their children.

There also may be an important place for professional family conferences that include the patient and their family members, as well oncology professionals including doctors, genetic counsellors, and social workers. Issues concerning hereditary factors, family problems, as well as psychosocial impacts may be addressed with both the patient and their children, and may contribute to family discussions about the cancer and communication about the well-being or various family members. Further links to additional resources, should they be needed at some point, can be identified during these
conferences, and children and adolescents may gain knowledge of ways to advocate for themselves and ask for help when they require it.

**Knowledge Translation**

Psychosocial oncology professionals, such as registered social workers, can provide additional information and support needs to patients and their families experiencing coping and adjustment problems. Unfortunately, these professionals often do not have access to patients without first receiving a referral from another oncology professional. Therefore, focusing screening programs aimed identifying children at risk for poor psychosocial adjustment may best be implemented by oncologists, as they have the most frequent contact with patients. Additionally, training programs for oncology professionals may provide them with knowledge and the self-efficacy required to address issues concerning patients’ children, such that they are able to educate parents about possible responses they may see in children, and that even lack of responses may be an indication of potential problems. This education will support a greater awareness of the resources that exist if parents wish to seek additional assistance for their children.

Unfortunately, even before recommendations can be made for knowledge translation interventions, high-quality research is needed to guide the development of evidence-based programs for improving psychosocial adjustment in children. Although it is now clear that children of parents with cancer are at risk for developing serious psychological and social problems, there is still a significant need for evidence to support intervention programs for children of parents with cancer. For example, Niemela and colleagues (2010) conducted a systematic review of child-centered interventions for children of parents with cancer, and identified only 11 studies that have evaluated the
effectiveness of structured family interventions and peer interventions. Although both children and parents reported positive impacts following interventions, there were very few statistically significant effects, and it remains unknown as to whether these interventions lead to better psychosocial adjustment. The authors also identified a lack of valid and reliable methods used to evaluate the interventions, concluding that there is still a significant need for high quality research evaluating the effectiveness of intervention programs for children coping with parental cancer. Only then can recommendations be made for the implementation of appropriate programs in clinical practice, and the dissemination of evidence-based training programs for staff working with oncology patients and their families.

In conclusion, the results of the current study support previous findings of disparity between child and parent reports regarding children’s adjustment, and contribute new findings that suggest that children may have accurate perceptions of their parents’ adjustment during this time. Few disparities were found regarding mothers’ and daughters’ perceptions of their relationships, however, there were several disparities noted in mothers’ and daughters’ reports of their communication during this time. Overall, mothers and daughters in the current sample did not indicate poor psychosocial adjustment; however several mothers and daughters indicated high anxiety, or a high number of emotional and behavioural problems, and several mothers and daughters reported the need for additional psychosocial assistance in coping with the breast cancer diagnosis.
References


Appendix A: University of Guelph Ethics Approval Certificate

RESEARCH ETHICS BOARD
Certification of Ethical Acceptability of Research Involving Human Participants

APPROVAL PERIOD: November 22, 2010 to November 22, 2011
REB NUMBER: 100G033
TYPE OF REVIEW: Full Board
RESPONSIBLE FACULTY: MICHELLE PREYDE
DEPARTMENT: Family Relations & Applied Nutrition
SPONSOR: N/A
TITLE OF PROJECT: Examining Adolescent Daughters’ Perception of Their Mother’s Adjustment to Breast Cancer

CHANGES: 11 Jan 11: B.10 Methodology; B.13 Recruitment; D.17 Consent

The members of the University of Guelph Research Ethics Board have examined the protocol which describes the participation of the human subjects in the above-named research project and considers the procedures, as described by the applicant, to conform to the University's ethical standards and the Tri-Council Policy Statement.

The REB requires that you adhere to the protocol as last reviewed and approved by the REB. The REB must approve any modifications before they can be implemented. If you wish to modify your research project, please complete the Change Request Form. If there is a change in your source of funding, or a previously unfunded project receives funding, you must report this as a change to the protocol.

Adverse or unexpected events must be reported to the REB as soon as possible with an indication of how these events affect, in the view of the Responsible Faculty, the safety of the participants, and the continuation of the protocol.

If research participants are in the care of a health facility, at a school, or other institution or community organization, it is the responsibility of the Principal Investigator to ensure that the ethical guidelines and approvals of these facilities or institutions are obtained and filed with the REB prior to the initiation of any research protocols.

The Tri-council Policy Statement requires that ongoing research be monitored by, at a minimum, a final report and, if the approval period is longer than one year, annual reports. Continued approval is contingent on timely submission of reports.

Membership of the Research Ethics Board: M. Bowring, CME; F. Caldwell, Physician (alt); J. Clark, PolSci (alt); J. Dwyer, FRAN; M. Dwyer, Legal; D. Dyck, CBS; D. Emslie, Physician; M. Fairburn, Ext.; J. Hacker-Wright, Ethics; G. Holloway, CBS (alt); V. Kanetkar, CME (alt); L. Kuczynski, FRAN (alt); S. Lachapelle, COA; L. Mann, Ext.; J. Minogue, EHS; P. Saunders, Alter. Health Care; S. Singer, COA (alt); L. Son Hing, Psychology; V. Shalla, SOAN (alt); L. Spriet, CBS; L. Trick, Chair; T. Turner, SOAN, L. Vallis; CBS (alt).

Approved: _______________________________ Date: _______________________________
Chair, Research Ethics Board
Appendix B: Informed Consent Forms

CONSENT TO PARTICIPATE IN RESEARCH
Participant Form (Mother)

Adolescent daughters’ perceptions of their mothers’ adjustment to breast cancer

The Local Primary Investigator for this study is Linda Learn (MSW, RSW) from Supportive Care at the Juravinski Hospital and Cancer Centre. This is a student project and will contribute to the Master’s Thesis of Gillian Marit (student) from the Family Relations and Applied Nutrition Department at the University of Guelph.

INVITATION TO PARTICIPATE
You are asked to participate in a research study. You are eligible for this study if you are a woman with breast cancer, who has a daughter between the ages of 12-25 years old. Your participation in this project is greatly appreciated.

PURPOSE OF THE STUDY
We are interested in learning more about how individuals and their families cope with and adjust to a cancer diagnosis. We are interested in looking at how mothers and daughters understand each other’s experience of coping with a mother’s breast cancer and how mothers and daughters communicate about the cancer.

NUMBER OF PARTICIPANTS
We are hoping to have at least 26 mother participants in this study, and at least 26 daughter participants, for a total of 52 participants.

PROCEDURES
If you volunteer to participate in this study, we would ask you to fill out a survey either by pencil and paper at the hospital, or online at your home (your choice). It will take approximately 25-30 minutes to complete the survey. You will only be asked to complete the survey once.

POTENTIAL RISKS AND DISCOMFORTS
We would be asking you to complete a survey reflecting on your experience of breast cancer and there is a chance you may feel some distress. If this occurs at any time and you would like to speak to someone there is an oncology social worker available at the hospital (905-387-9711 ext. 64315), or you may contact a toll-free support line through the Canadian Cancer Society (1-800-263-6750).

POTENTIAL BENEFITS TO PARTICIPANTS
The potential benefit of participating is the knowledge that you are contributing to our understanding of how individuals and their families cope with cancer. There is no monetary compensation for participating in this study.

CONFIDENTIALITY
Every effort will be made to ensure confidentiality of any identifying information that is obtained in connection with this study. You will not be asked to give any contact information. Instead you and your daughter will be given ID codes to complete the survey and therefore, your responses will not be connected to your name or any identifying information. Only the student (Gillian Marit) and her advisor (Dr. Michele Preyde) will have access to your responses. This study data will be kept at the University of Guelph on a password protected
computer for five years, after which point the data will be destroyed.

For confidentiality purposes you will not be informed as to whether your daughter decided to participate or whether she completed the survey. You will also not have access to your daughter’s answers to the survey. Conversely, your daughter will not be given your information.

PARTICIPATION AND WITHDRAWAL

You can choose whether to be in this study or not. If you volunteer to be in this study, you may withdraw at any time without consequences of any kind. You may exercise the option of removing your data from the study by notifying the student Gillian Marit. You may also refuse to answer any questions you don’t want to answer and still remain in the study. The investigator may withdraw you from this research if circumstances arise that warrant doing so.

If either you or your daughter decides that you do not want to participate in the study we will still keep the other person in the study. We do not require participation from both parties, and your data will be included in the study with or without the participation of the other person.

FEEDBACK AND RESULTS OF THE STUDY

The results of this study will be used for completion of Gillian Marit’s Masters Thesis. The results may also be published in a journal article at a later date. If you would like information about the results of this study you can contact Gillian Marit at (905) 387-9711, ext. 64315 or by email at gmarit@uoguelph.ca and she will send you the information (by email or mail).

By returning this consent form, we understand that you have consented to participate in this study.

RIGHTS OF RESEARCH PARTICIPANTS

You may withdraw your consent at any time and discontinue participation without penalty. You are not waiving any legal claims, rights or remedies because of your participation in this research study. This study has been reviewed and received ethics clearance through the University of Guelph Research Ethics Board. If you have questions regarding your rights as a research participant, contact:

Director, Research Ethics
University of Guelph
437 University Centre
Guelph, ON N1G 2W

Telephone: (519) 824-4120, ext. 56606
E-mail: sauld@uoguelph.ca
Fax: (519) 821-5236

If you have any questions or concerns about the research, please feel free to contact:

Gillian Marit
Family Relations and Applied Nutrition
University of Guelph
(905) 387-9711, ext. 64315
gmarit@uoguelph.ca

Michele Preyde, Ph.D.
Family Relations and Applied Nutrition
University of Guelph
(519) 824-4120, ext. 58599
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Linda Learn, MSW, RSW
Supportive Care
Juravinski Cancer Centre
(905) 387-9711 ext. 64304
linda.learn@jcc.hhsc.ca

SIGNATURE OF RESEARCH PARTICIPANT/LEGAL REPRESENTATIVE

I have read the information provided for the study “Adolescent daughters’ perceptions of their mothers’ adjustment to breast cancer” as described herein. My questions have been answered to my satisfaction, and I agree to participate in this study. I will be given a signed copy of this form.

Name of Participant (please print) ____________________________

Signature ____________________________

Date ____________________________
Person Obtaining Consent

_________________________________________________________________
Name, Role in Study (please print) Signature
Date

This study has been reviewed by the Hamilton Health Sciences/McMaster Faculty of Health Sciences Research Ethics Board (HHS/FHS REB). If you have any questions about your rights as a research participant, please call The Office of the Chair, HHS/FHS REB at 905-521-2100 x 42013.
CONSENT TO PARTICIPATE IN RESEARCH
Parent Form (with a daughter 12-15 years old)

Adolescent daughters' perceptions of their mothers' adjustment to breast cancer
The Local Primary Investigator for this study is Linda Learn (MSW, RSW) from Supportive Care at the Juravinski Hospital and Cancer Centre. This is a student project and will contribute to the Master's Thesis of Gillian Marit (student) from the Family Relations and Applied Nutrition Department at the University of Guelph.

INVITATION TO PARTICIPATE
Your daughter is asked to participate in a research study. She is eligible if her mother has breast cancer, and she is between the ages of 12-25 years old.

PURPOSE OF THE STUDY
We are interested in learning more about how individuals and their families cope with and adjust to a cancer diagnosis. We understand that dealing with breast cancer can be a difficult experience for both the patient and children. We are interested in looking at how mothers and daughters understand each other's experience of coping with a mother's breast cancer and how mothers and daughters communicate about the cancer.

NUMBER OF PARTICIPANTS
We are hoping to have at least 26 mother participants in this study, and at least 26 daughter participants, for a total of 52 participants.

PROCEDURES
If your daughter would like to volunteer to participate in this study we would ask that she complete a survey online at home. You will be given a sheet of information to pass onto your daughter that contains all the information she needs to participate. Your daughter will be asked to read and complete a similar form to this one (called an Assent form) online before she begins the survey. It will take approximately 25-30 minutes to complete the survey. She will only be asked to complete the survey once.

POTENTIAL RISKS AND DISCOMFORTS
We would be asking your daughter to complete a survey reflecting on her experience of her mother's breast cancer and it is possible that she may feel some discomfort or distress. If this occurs at any time and she would like to speak to someone there is an oncology social worker available at the hospital (905-387-9711 ext. 64315), or she may contact a toll-free support line through the Canadian Cancer Society (1-800-263-6750). This information will be located on the information sheet you pass on to her and at the beginning and end of completing the survey online.

POTENTIAL BENEFITS TO PARTICIPANTS
The potential benefit to participating is the knowledge that you are contributing to our understanding of how individuals and their families cope with cancer. There is no monetary compensation for participating in this study.

CONFIDENTIALITY
Every effort will be made to ensure confidentiality of any identifying information that is obtained in connection with this study. Your daughter will not be asked to give any contact information. Instead you and your daughter will be given ID codes to complete the survey and
therefore, responses will not be connected to a name or any identifying information.

For confidentially purposes you will not be informed as to whether your daughter decided
to participate or whether she completed the survey. You will also not have access to your
daughter’s answers to the survey.

**PARTICIPATION AND WITHDRAWAL**

Your daughter can choose whether to be in this study or not. If she volunteers to be in
this study, she may withdraw at any time without consequences of any kind. She may exercise
the option of removing her data from the study by notifying the student Gillian Marit. She may
also refuse to answer any questions she does not want to answer and still remain in the study.
The investigator may withdraw her from this research if circumstances arise that warrant doing
so.

If either you or your daughter decides that you do not want to participate in the study we
will still keep the other person in the study. We do not require participation from both parties, and
data will be included in the study with or without the participation of the other person.

**FEEDBACK AND RESULTS OF THE STUDY**

The results of this study will be used for completion of Gillian Marit’s Masters Thesis. The
results may also be published in a journal article at a later date. If your daughter would like
information about the results of this study she may contact Gillian Marit at (519) 824-4120, ext.
56360 or by email at gmarit@uoguelph.ca and she will send the information (by email or mail).

By returning this consent form, we understand that you have consented to have your
daughter participate in this study.

**RIGHTS OF RESEARCH PARTICIPANTS**

You or your daughter may withdraw consent at any time and discontinue participation
without penalty. You are not waiving any legal claims, rights or remedies because of participation
in this research study. This study has been reviewed and received ethics clearance through the
University of Guelph Research Ethics Board. If you have questions regarding your rights as a
research participant, contact:

Director, Research Ethics University of Guelph
437 University Centre Guelph, ON N1G 2W
Telephone: (519) 824-4120, ext. 56606
E-mail: sauld@uoguelph.ca
Fax: (519) 821-5236

If you have any questions or concerns about the research, please feel free to contact:

Gillian Marit Michele Preyde, Ph.D. Linda Learn, MSW, RSW
Family Relations and Applied Nutrition Family Relations and Applied Nutrition Supportive Care
University of Guelph University of Guelph Juravinski Cancer Centre
(905) 387-9711, ext. 64315 (519) 824-4120, ext. 58599 (905) 387-9711 ext. 64304
gmarit@uoguelph.ca mpreyde@uoguelph.ca linda.learn@jcc.hhsc.ca

Legally Authorized Representative (for daughters under 15 years old)

If your daughter is between the ages of 12-15 years old a parent must give consent for
her to participate. In order to be fully informed you are able to review the survey that will be
administered to your daughter before giving consent. Your daughter will be required to read and
complete a similar assent form, and you are able to view this form as well.

I have read the preceding information thoroughly. My questions have been
answered to my satisfaction, and I give consent for my daughter to participate in this
study. I will be given a signed copy of this form.
I give my permission for ____________________________ to participate in this study.

<table>
<thead>
<tr>
<th>Name, Relationship to Participant</th>
<th>Signature</th>
</tr>
</thead>
<tbody>
<tr>
<td>Date</td>
<td></td>
</tr>
</tbody>
</table>

**Person Obtaining Consent**

<table>
<thead>
<tr>
<th>Name, Role in Study</th>
<th>Signature</th>
</tr>
</thead>
<tbody>
<tr>
<td>Date</td>
<td></td>
</tr>
</tbody>
</table>

This study has been reviewed by the Hamilton Health Sciences/McMaster Faculty of Health Sciences Research Ethics Board (HHS/FHS REB). If you have any questions about your rights as a research participant, please call The Office of the Chair, HHS/FHS REB at 905-521-2100 x 42013.
ASSENT TO PARTICIPATE IN RESEARCH
Participant Form (Daughter 12-15)

Adolescent daughters’ perceptions of their mothers’ adjustment to breast cancer

The Local Primary Investigator for this study is Linda Learm (MSW, RSW) from Supportive Care at the Juravinski Hospital and Cancer Centre. This is a student project and will contribute to the Master’s Thesis of Gillian Marit (student) from the Family Relations and Applied Nutrition Department at the University of Guelph.

WHY ARE WE DOING THIS STUDY?

We are interested in learning more about how people deal with their feelings about cancer. We understand that breast cancer can be difficult for both the sick person and their children. We are interested in looking at how mothers and daughters understand each other’s feelings when the mother has breast cancer, and how mothers and daughters talk about the cancer.

WHAT ARE WE ASKING YOU TO DO?

If you volunteer to participate in this study, we would ask you to fill out a survey online. All you have to do is answer some questions on the computer. It will take about 25-30 minutes to complete the survey.

WILL I BE HURT IF I AM IN THE STUDY?

We are asking you to think about your feelings about your mom’s breast cancer. It is possible that you may feel upset or hurt when you think about the cancer. If this happens and you would like to talk to someone there is a social worker available at the hospital you may call (905-387-9711 ext. 64315), or you may call a toll-free support line through the Canadian Cancer Society (1-800-263-6750) and speak to someone.

WILL THE STUDY HELP ME OR MY MOM?

If you are in the study it may not help you feel better, and it will not help your mom get better. The study may help us better understand how people deal with their feelings when a family member has cancer.

PRIVACY

We will do everything we can to make sure that the information we get from you is kept safe and not shared with anyone else. We will not ask for any information about your name or contact information like your address or email address.

Your mother will not be told whether you participated or not, and she will never be given any information about what you said in the survey. This information will be kept confident and never shared with your mother.

DO I HAVE TO BE IN THIS STUDY?

You can choose whether to be in this study or not. If you volunteer to be in this study, you can still choose to stop at any time without any consequences. If you do not feel comfortable
answering a question you can skip it. If for any reason you finish the questionnaires and you do not want us to use the information you can tell us and we will take it out.

If either you or your mother decides you don’t want to participate in the study we will still keep the other person in the study. We do not need both you and your mother to agree to do the study, so don’t worry about whether or not you both participate. You can make this decision just for yourself.

WHAT HAPPENS AFTER THE STUDY?

The results of this study will help Gillian Marit complete a study project for school. The results may also be printed in a journal for other people to read about. If you would also like to read about the results of this study you can contact Gillian Marit at (519) 824-4120, ext. 56360 or by email at gmarit@uoguelph.ca and she will send you the information (by email or mail).

RIGHTS OF RESEARCH PARTICIPANTS

You can tell us you do not want to participate anymore at any time or just stop completing the survey and stop participation without penalty. You do not have to participate and no one will make you if you do not want to. This study has been reviewed and received ethics clearance through the University of Guelph Research Ethics Board. If you have questions about your rights as someone participating in this study, contact:

Director, Research Ethics
University of Guelph
437 University Centre
Guelph, ON N1G 2W

Telephone: (519) 824-4120, ext. 56606
E-mail: sauld@uoguelph.ca
Fax: (519) 821-5236

If you have any questions or concerns about the research, please feel free to contact:

Gillian Marit
Family Relations and Applied Nutrition
University of Guelph
(905) 387-9711, ext. 64315
gmarit@uoguelph.ca

Michele Preyde, Ph.D.
Family Relations and Applied Nutrition
University of Guelph
(519) 824-4120, ext. 58599
mpreyde@uoguelph.ca

Linda Learn, MSW, RSW
Supportive Care
Juravinski Cancer Centre
(905) 387-9711 ext. 64304
linda.learn@jcc.hhsc.ca

ASSENT

I have read the information provided for the study “Adolescent daughters’ perceptions of their mothers’ adjustment to breast cancer” as described. My questions have been answered and I agree to participate in this study. I will be given a signed copy of this form.

If you decide you want to be in this study, please print/write your name.

I, _____________________________ (Print your name) would like to be in this research study.

______________________________ (Date of assent)

______________________________ (Name of person who obtained assent)

______________________________ (Signature of person who obtained assent and Date)
This study has been reviewed by the Hamilton Health Sciences/McMaster Faculty of Health Sciences Research Ethics Board (HHS/FHS REB). If you have any questions about your rights as a research participant, please call The Office of the Chair, HHS/FHS REB at 905-521-2100 x 42013.
CONSENT TO PARTICIPATE IN RESEARCH
Participant Form (Daughter 16-25)

Adolescent daughters’ perceptions of their mothers’ adjustment to breast cancer
The Local Primary Investigator for this study is Linda Learn (MSW, RSW) from Supportive Care at the Juravinski Hospital and Cancer Centre. This is a student project and will contribute to the Master’s Thesis of Gillian Marit (student) from the Family Relations and Applied Nutrition Department at the University of Guelph.

INVITATION TO PARTICIPATE
You are asked to participate in a research study. You are eligible for this study if your mother has breast cancer, and you are a female between 12-25 years old. Your participation in this study is completely voluntary and choosing not to participate in this study will not result in any negative consequences. This student project will be supervised by the student’s advisor Dr. Michele Preyde from the University of Guelph. Your participation in this project is greatly appreciated.

PURPOSE OF THE STUDY
We are interested in learning more about how individuals and their families cope with and adjust to a cancer diagnosis. We understand that dealing with breast cancer can be a difficult experience for both the patient and children. We are interested in looking at how mothers and daughters understand each other’s experience of coping with a mother’s breast cancer and how mothers and daughters communicate about the cancer.

NUMBER OF PARTICIPANTS
We are hoping to have at least 26 mother participants in this study, and at least 26 daughter participants, for a total of 52 participants.

PROCEDURES
If you volunteer to participate in this study, we would ask you to fill out a survey online at your home. It will take approximately 25-30 minutes to complete the survey. You will only be asked to complete the survey once.

POTENTIAL RISKS AND DISCOMFORTS
We would be asking you to complete a survey reflecting on your experience of breast cancer and it is possible that you may feel some discomfort or distress. If this occurs at any time and you would like to speak to someone there is an oncology social worker available at the hospital (905-387-9711 ext. 64315), or you may contact a toll-free support line through the Canadian Cancer Society (1-800-263-6750). This information is also available at the beginning and end of completing the survey online.

POTENTIAL BENEFITS TO PARTICIPANTS
The potential benefit to participating is the knowledge that you are contributing to our understanding of how individuals and their families cope with cancer. There is no monetary compensation for participating in this study.

CONFIDENTIALITY
Every effort will be made to ensure confidentiality of any identifying information that is obtained in connection with this study. You will not be asked to give any contact information.
Instead you will be given an ID code to complete the survey and therefore, your responses will not be connected to your name or any identifying information.

Only the student (Gillian Marit) and her advisor (Dr. Michele Preyde) will have access to your responses. This study data will be kept at the University of Guelph on a password protected computer for five years, after which point the data will be destroyed.

For confidential purposes your mother will not be informed as to whether you decided to participate or whether you completed the survey. She will not have access to your answers to the survey.

**PARTICIPATION AND WITHDRAWAL**

You can choose whether to be in this study or not. If you volunteer to be in this study, you may withdraw at any time without consequences of any kind. You may exercise the option of removing your data from the study by notifying the student Gillian Marit. You may also refuse to answer any questions you don't want to answer and still remain in the study. The investigator may withdraw you from this research if circumstances arise that warrant doing so.

If either you or your mother decides that you do not want to participate in the study we will still keep the other person in the study. We do not require participation from both parties, and your data will be included in the study with or without the participation of the other person.

**FEEDBACK AND RESULTS OF THE STUDY**

The results of this study will be used for completion of Gillian Marit’s Masters Thesis. The results may also be published in a journal article at a later date. If you would like information about the results of this study you can contact Gillian Marit at (905) 387-9711, ext. 64315 or by email at gmarit@uoguelph.ca and she will send you the information (by email or mail).

By returning this consent form, we understand that you have consented to participate in this study.

**RIGHTS OF RESEARCH PARTICIPANTS**

You may withdraw your consent at any time and discontinue participation without penalty. You are not waiving any legal claims, rights or remedies because of your participation in this research study. This study has been reviewed and received ethics clearance through the University of Guelph Research Ethics Board. If you have questions regarding your rights as a research participant, contact:

Director, Research Ethics  
University of Guelph  
437 University Centre  
Guelph, ON N1G 2W

Telephone: (519) 824-4120, ext. 56606  
E-mail: sauld@uoguelph.ca  
Fax: (519) 821-5236

If you have any questions or concerns about the research, please feel free to contact:

Gillian Marit  
Michele Preyde, Ph.D.  
Linda Learn, MSW, RSW  
Family Relations and Applied Nutrition  
Family Relations and Applied Nutrition  
Supportive Care  
University of Guelph  
University of Guelph  
Juravinski Cancer Centre  
(905) 387-9711, ext. 64315  
(519) 824-4120, ext. 58599  
(905) 387-9711 ext. 64304  
gmarit@uoguelph.ca  
mpreyde@uoguelph.ca  
lindea.learn@jcc.hhsc.ca

**SIGNATURE OF RESEARCH PARTICIPANT/LEGAL REPRESENTATIVE**

I have read the information provided for the study “Adolescent daughters’ perceptions of their mothers’ adjustment to breast cancer” as described herein. My questions have been answered to my satisfaction, and I agree to participate in this study. I will be given a signed copy of this form.
Name of Participant (please print)       Signature
Date

**Person Obtaining Consent**

<table>
<thead>
<tr>
<th>Name, Role in Study (please print)</th>
<th>Signature</th>
</tr>
</thead>
<tbody>
<tr>
<td>Date</td>
<td></td>
</tr>
</tbody>
</table>

This study has been reviewed by the Hamilton Health Sciences/McMaster Faculty of Health Sciences Research Ethics Board (HHS/FHS REB). If you have any questions about your rights as a research participant, please call The Office of the Chair, HHS/FHS REB at 905-521-2100 x 42013.
Appendix C: Information Sheets

Mother Information Sheet

To start:
1. Start by entering the website listed below, exactly as shown:
   
   http://app.fluidsurveys.com/s/mbc/

2. Enter your ID code:_________________

3. Complete each set of questions

Then you are all done!

Please answer all the questions as best as you can. It would be best if you completed the survey in a quiet space by yourself so you can think about the questions. If you have any questions please don’t hesitate to contact me, Gillian, through email at gmarit@uoguelph.ca. or by telephone at (905) 387-9711, ext. 64315.

Your participation is greatly appreciated

If you feel uncomfortable or upset after answering these questions, and you would like help, or need to speak to someone you can call anytime of the day or night to the:

Canadian Cancer Society            Distress Centre of Hamilton
1 800-263-6750                     905-525-8611

Additional help can be obtained at the Juravinski Cancer Centre through Supportive Care, and can be reached at 905-387-9711 ext. 64315 from 9 a.m. to 5 p.m.
Daughter Information Sheet

We are conducting a study looking at mother’s and daughter’s feelings about how each other are dealing with breast cancer. We understand that breast cancer can be difficult for both the sick person and their children.

How do I participate?
If you would like to participate in this study, we would ask you to fill out a survey online. It will take approximately 25-30 minutes to complete.

To start:
1. Start by entering the website listed below, exactly as shown:
   http://app.fluidsurveys.com/s/dbc/
2. Read, understand, and complete the consent form
3. Enter your ID code:_________________
4. Complete each set of questions
   Then you are all done! Your participation is greatly appreciated.

Please answer all the questions as best as you can. It would be best if you completed the survey in a quiet space by yourself so you can think about the questions. If you have any questions please don’t hesitate to contact me, Gillian, through email at gmarit@uoguelph.ca. or by telephone at (905) 387-9711 x 64315.

*Our hope is to have both you and your mother participate; however, we do not require that both of you agree to participate for you to be included in the study. We welcome anyone who would like to participate. Your mother will never know if you choose to participate or not, and she will not be able to see how you answered the questions. It will all be kept safe and private with us.

<table>
<thead>
<tr>
<th>If you feel uncomfortable or upset after answering these questions, and you would like help, or need to speak to someone you can call anytime of the day or night to the:</th>
</tr>
</thead>
<tbody>
<tr>
<td>Canadian Cancer Society</td>
</tr>
<tr>
<td>1 800-263-6750</td>
</tr>
<tr>
<td>Distress Centre of Hamilton</td>
</tr>
<tr>
<td>905-525-8611</td>
</tr>
<tr>
<td>Additional help can be obtained at the Juravinski Cancer Centre through the Supportive Care, and can be reached at 905-387-9711 ext. 64315 from 9 a.m. to 5 p.m.</td>
</tr>
</tbody>
</table>
Appendix D: Recruitment Poster

Breast Cancer Study

**Do you have a daughter between 12-25 years old?**

We are conducting a study exploring mother’s and daughter’s feelings about how one another are dealing with a breast cancer diagnosis and treatment. The information gathered from this study may help other women and daughters dealing with breast cancer in the future.

**Who can participate?**

**Mothers**
- Women who have **stage I-IV breast cancer**

**Daughters**
- Daughters **aged 12-25 years old**

**How do I participate?**

- You will complete a survey with a **pencil and paper** or **online**. If you choose to complete it online you will be given all the information you need
- You will be given information to pass onto your daughter
- Your daughter may choose to participate at her own discretion
- The survey will take between 25-30 minutes to complete

**Your participation is greatly appreciated!**

This study is being conducted by **Gillian Marit**, a graduate student from the University of Guelph as part of a Masters thesis, and is supervised by **Dr. Preyde** from the University of Guelph, and **Supportive Care** at the Juravinski Cancer Centre. Please feel free to contact **Gillian Marit** at the hospital, or via email at gmarit@uoguelph.ca. or by telephone at (905) 387-9711 x 64315.
# Appendix E: Reliability Analysis

*Alpha Coefficients of the Four Standardized Measures*

<table>
<thead>
<tr>
<th>Measures</th>
<th>Number of items</th>
<th>Mothers Alpha coefficient</th>
<th>Daughters Alpha coefficient</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>FACT-B</strong></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Physical</td>
<td>7</td>
<td>0.67</td>
<td>0.87</td>
</tr>
<tr>
<td>Social</td>
<td>6</td>
<td>0.59</td>
<td>0.47</td>
</tr>
<tr>
<td>Emotional</td>
<td>6</td>
<td>0.60</td>
<td>0.68</td>
</tr>
<tr>
<td>Functional</td>
<td>7</td>
<td>0.82</td>
<td>0.87</td>
</tr>
<tr>
<td>Breast cancer specific</td>
<td>8</td>
<td>0.64</td>
<td>0.62</td>
</tr>
<tr>
<td><strong>Total</strong></td>
<td>34</td>
<td>0.80</td>
<td>0.89</td>
</tr>
<tr>
<td><strong>YSR</strong></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Withdrawn</td>
<td>7</td>
<td>0.24</td>
<td>0.75</td>
</tr>
<tr>
<td>Somatic Complaints</td>
<td>9</td>
<td>0.67</td>
<td>0.71</td>
</tr>
<tr>
<td>Anxious/Depressed</td>
<td>16</td>
<td>0.72</td>
<td>0.89</td>
</tr>
<tr>
<td>Social Problems</td>
<td>8</td>
<td>0.32</td>
<td>0.24</td>
</tr>
<tr>
<td>Thought Problems</td>
<td>7</td>
<td>0.07</td>
<td>0.61</td>
</tr>
<tr>
<td>Attention Problems</td>
<td>9</td>
<td>0.62</td>
<td>0.72</td>
</tr>
<tr>
<td>Delinquent Behaviour</td>
<td>11</td>
<td>0.52</td>
<td>0.61</td>
</tr>
<tr>
<td>Aggressive Behaviour</td>
<td>18</td>
<td>0.84</td>
<td>0.79</td>
</tr>
<tr>
<td>Internalizing scale</td>
<td>31</td>
<td>0.67</td>
<td>0.91</td>
</tr>
<tr>
<td>Externalizing scale</td>
<td>29</td>
<td>0.82</td>
<td>0.79</td>
</tr>
<tr>
<td><strong>Total Problems</strong></td>
<td>101</td>
<td>0.87</td>
<td>0.94</td>
</tr>
<tr>
<td><strong>QRI</strong></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Support</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Before</td>
<td>6</td>
<td>0.80</td>
<td>0.85</td>
</tr>
<tr>
<td>Now</td>
<td>6</td>
<td>0.78</td>
<td>0.72</td>
</tr>
<tr>
<td>Conflict</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Before</td>
<td>12</td>
<td>0.87</td>
<td>0.92</td>
</tr>
<tr>
<td>Now</td>
<td>12</td>
<td>0.86</td>
<td>0.92</td>
</tr>
<tr>
<td>Depth</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Before</td>
<td>6</td>
<td>0.46</td>
<td>0.76</td>
</tr>
<tr>
<td>Now</td>
<td>6</td>
<td>0.49</td>
<td>0.69</td>
</tr>
<tr>
<td><strong>STAI</strong></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Total</td>
<td>20</td>
<td>0.86</td>
<td>0.95</td>
</tr>
</tbody>
</table>
Appendix F: Mother Survey

Mother Survey

ID CODE:__________________

Please complete the following form to the best of your knowledge.

1. Marital status:
   a. Single
   b. Common law relationship
   c. Married
   d. Divorced or separated
   e. Widowed

2. Paid employment status:
   a. Employed
   b. Part-time employed
   c. Unemployed

3. Level of achieved education to date:
   a. Less than high school
   b. High school
   c. College
   d. University
   e. Graduate school

4. Self Identified Ethnicity:
   a. Asian/Pacific Islander
   b. African American
   c. Hispanic
   d. Native American or Alaskan
   e. Caucasian
   f. Other: (please specify)___________________

5. Total annual household income:
   a. Less than $25,000
   b. $25,000- $75,000
   c. $75,001- $125,000
   d. $125,001- $175,000
   e. Greater than $175,001

6. Current age:

7. Does your daughter currently live with you:
   a. Full-time
   b. Part-time
   c. Not at all

8. Please list the gender and age of your children:
   __________________________________________
   __________________________________________

9. Approximate date of breast cancer diagnosis:

   __________________________________________

10. Stage of breast cancer:
    a. I
    b. II
    c. III
    d. Do not know

11. Type of surgery(s) (Check all that apply):
    a. Lumpectomy
    b. Bilateral Mastectomy
    c. Double Mastectomy
    d. No surgery
    e. Other: (please specify)___________________

12. Type of treatment(s) (Check all that apply):
    a. Radiation
    b. Chemotherapy
    c. Hormonal Therapy, Drugs (eg. Tamoxifen)(please specify):
    d. Haven’t started treatment yet
    e. Other: (please specify) _______
Please describe any cases of cancer in your biological family:
1. Relationship to individual: ____________________________
   Type and stage of cancer(s): ____________________________
   Outcome: ____________________________________________
2. Relationship to individual: ____________________________
   Type and stage of cancer(s): ____________________________
   Outcome: ____________________________________________
3. Relationship to individual: ____________________________
   Type and stage of cancer(s): ____________________________
   Outcome: ____________________________________________

Below is a list of statements that other people with your illness have said are important. Please circle or mark one number per line to indicate your response as it applies to you in the **past 7 days**.

<table>
<thead>
<tr>
<th>Statement</th>
<th>Not at all</th>
<th>A little bit</th>
<th>Somewhat</th>
<th>Quite a bit</th>
<th>Very much</th>
</tr>
</thead>
<tbody>
<tr>
<td>I have a lack of energy</td>
<td>0</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
</tr>
<tr>
<td>I have nausea</td>
<td>0</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
</tr>
<tr>
<td>Because of my physical condition, I have trouble meeting the needs of my family</td>
<td>0</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
</tr>
<tr>
<td>I have pain</td>
<td>0</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
</tr>
<tr>
<td>I am bothered by side effects of treatment</td>
<td>0</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
</tr>
<tr>
<td>I feel ill</td>
<td>0</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
</tr>
<tr>
<td>I am forced to spend time in bed</td>
<td>0</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
</tr>
<tr>
<td>I feel close to my friends</td>
<td>0</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
</tr>
<tr>
<td>I get emotional support from my family</td>
<td>0</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
</tr>
<tr>
<td>I get support from my friends</td>
<td>0</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
</tr>
<tr>
<td>My family has accepted my illness</td>
<td>0</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
</tr>
<tr>
<td>I am satisfied with family communication about my illness</td>
<td>0</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
</tr>
<tr>
<td>I feel close to my partner (or the person who is my main support)</td>
<td>0</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
</tr>
<tr>
<td>I feel sad</td>
<td>0</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
</tr>
<tr>
<td>I am satisfied with how I am coping with my illness</td>
<td>0</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
</tr>
<tr>
<td>I am losing hope in the fight against my illness</td>
<td>0</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
</tr>
<tr>
<td>I feel nervous</td>
<td>0</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
</tr>
<tr>
<td>I worry about dying</td>
<td>0</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
</tr>
<tr>
<td>I worry that my condition will get worse</td>
<td>0</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
</tr>
<tr>
<td>I am able to work (include work at home)</td>
<td>0</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
</tr>
<tr>
<td>My work (include work at home) is fulfilling</td>
<td>0</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
</tr>
<tr>
<td>I am able to enjoy life</td>
<td>0</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
</tr>
<tr>
<td>I have accepted my illness</td>
<td>0</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
</tr>
<tr>
<td>I am sleeping well</td>
<td>0</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
</tr>
<tr>
<td>I am enjoying the things I usually do for fun</td>
<td>0</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
</tr>
<tr>
<td>I am content with the quality of my life right now</td>
<td>0</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
</tr>
</tbody>
</table>
I have been short of breath  0  1  2  3  4
I am self-conscious about the way I dress  0  1  2  3  4
One or both of my arms are swollen or tender  0  1  2  3  4
I am bothered by hair loss  0  1  2  3  4
I worry that other members of my family might someday get the same illness I have  0  1  2  3  4
I worry about the effect of stress on my illness  0  1  2  3  4
I am bothered by a change in weight  0  1  2  3  4
I am able to feel like a woman  0  1  2  3  4
I have certain parts of my body where I experience pain  0  1  2  3  4

Read each statement and then circle the appropriate number to the right of the statement to indicate how you feel right now, that is, at this moment.

<table>
<thead>
<tr>
<th></th>
<th>Not at all</th>
<th>Some what</th>
<th>Moderately</th>
<th>Very much</th>
</tr>
</thead>
<tbody>
<tr>
<td>I feel calm</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
</tr>
<tr>
<td>I feel secure (safe)</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
</tr>
<tr>
<td>I am tense</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
</tr>
<tr>
<td>I feel strained</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
</tr>
<tr>
<td>I feel at ease</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
</tr>
</tbody>
</table>

* (The remaining 15 questions cannot be published according to the scale distributor)

Please use the scale below to answer the following questions regarding your relationship with your daughter both before the cancer and now.

<table>
<thead>
<tr>
<th></th>
<th>Before the cancer</th>
<th>Now</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>Not at all</td>
<td>A little bit</td>
</tr>
<tr>
<td>To what extent can you count on this person to listen to you when you are very angry at someone else?</td>
<td>0 1 2 3</td>
<td>0 1 2 3</td>
</tr>
<tr>
<td>To what extent could you turn to this person for advice about problems?</td>
<td>0 1 2 3</td>
<td>0 1 2 3</td>
</tr>
<tr>
<td>To what extent can you really count on this person to distract you from your worries when you feel under stress?</td>
<td>0 1 2 3</td>
<td>0 1 2 3</td>
</tr>
<tr>
<td>To what extent could you count on this person for help with a problem?</td>
<td>0 1 2 3</td>
<td>0 1 2 3</td>
</tr>
</tbody>
</table>
If you wanted to go out and do something this evening, how confident are you that this person would be willing to do something with you?

<table>
<thead>
<tr>
<th></th>
<th>Not at all</th>
<th>A little bit</th>
<th>Quite a bit</th>
<th>Very much</th>
<th>Not at all</th>
<th>A little bit</th>
<th>Quite a bit</th>
<th>Very much</th>
</tr>
</thead>
<tbody>
<tr>
<td>To what extent can you count on this person to give you honest feedback, even if you might not want to hear it?</td>
<td>0</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>0</td>
<td>1</td>
<td>2</td>
<td>3</td>
</tr>
<tr>
<td>How angry does this person make you feel?</td>
<td>0</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>0</td>
<td>1</td>
<td>2</td>
<td>3</td>
</tr>
<tr>
<td>How upset does this person sometimes make you feel?</td>
<td>0</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>0</td>
<td>1</td>
<td>2</td>
<td>3</td>
</tr>
<tr>
<td>How often does this person make you feel angry?</td>
<td>0</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>0</td>
<td>1</td>
<td>2</td>
<td>3</td>
</tr>
<tr>
<td>How much do you argue with this person?</td>
<td>0</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>0</td>
<td>1</td>
<td>2</td>
<td>3</td>
</tr>
<tr>
<td>How often do you have to work hard to avoid conflict with this person?</td>
<td>0</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>0</td>
<td>1</td>
<td>2</td>
<td>3</td>
</tr>
<tr>
<td>How much would you like this person to change?</td>
<td>0</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>0</td>
<td>1</td>
<td>2</td>
<td>3</td>
</tr>
<tr>
<td>How much do you have to “give in” in this relationship?</td>
<td>0</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>0</td>
<td>1</td>
<td>2</td>
<td>3</td>
</tr>
<tr>
<td>How much does this person make you feel guilty?</td>
<td>0</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>0</td>
<td>1</td>
<td>2</td>
<td>3</td>
</tr>
<tr>
<td>How much does this person want you to change?</td>
<td>0</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>0</td>
<td>1</td>
<td>2</td>
<td>3</td>
</tr>
<tr>
<td>How often does this person try to control or influence your life?</td>
<td>0</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>0</td>
<td>1</td>
<td>2</td>
<td>3</td>
</tr>
<tr>
<td>How critical of you is this person?</td>
<td>0</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>0</td>
<td>1</td>
<td>2</td>
<td>3</td>
</tr>
<tr>
<td>How much more do you give than you get from this relationship?</td>
<td>0</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>0</td>
<td>1</td>
<td>2</td>
<td>3</td>
</tr>
<tr>
<td>How significant is this relationship in your life?</td>
<td>0</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>0</td>
<td>1</td>
<td>2</td>
<td>3</td>
</tr>
</tbody>
</table>
How much do you depend on this person? 0 1 2 3 0 1 2 3

How close will your relationship be with this person in 10 years? 0 1 2 3 0 1 2 3

How positive a role does this person play in your life? 0 1 2 3 0 1 2 3

How responsible do you feel for this person’s well-being? 0 1 2 3 0 1 2 3

How much would you miss this person if the two of you could not see or talk with each other for a month? 0 1 2 3 0 1 2 3

For each item please identify if the item is not true, somewhat or sometimes true, or very true or often true, of your daughter now or within the past 6 months.

<table>
<thead>
<tr>
<th>Number</th>
<th>Description</th>
<th>0 = Not True</th>
<th>1 = Somewhat or Sometimes True</th>
<th>2 = Very True or Often True</th>
</tr>
</thead>
<tbody>
<tr>
<td>1.</td>
<td>My daughter acts too young for her age</td>
<td>0</td>
<td>1</td>
<td>2</td>
</tr>
<tr>
<td>2.</td>
<td>My daughter has an allergy (describe):</td>
<td>0</td>
<td>1</td>
<td>2</td>
</tr>
<tr>
<td>3.</td>
<td>My daughter argues a lot</td>
<td>0</td>
<td>1</td>
<td>2</td>
</tr>
<tr>
<td>4.</td>
<td>My daughter has asthma</td>
<td>0</td>
<td>1</td>
<td>2</td>
</tr>
<tr>
<td>5.</td>
<td>My daughter acts like the opposite sex</td>
<td>0</td>
<td>1</td>
<td>2</td>
</tr>
<tr>
<td>6.</td>
<td>My daughter likes animals</td>
<td>0</td>
<td>1</td>
<td>2</td>
</tr>
<tr>
<td>7.</td>
<td>My daughter brags</td>
<td>0</td>
<td>1</td>
<td>2</td>
</tr>
<tr>
<td>8.</td>
<td>My daughter has trouble concentrating or paying attention</td>
<td>0</td>
<td>1</td>
<td>2</td>
</tr>
<tr>
<td>9.</td>
<td>My daughter can’t get her mind off certain thoughts (describe):</td>
<td>0</td>
<td>1</td>
<td>2</td>
</tr>
<tr>
<td>10.</td>
<td>My daughter has trouble sitting still</td>
<td>0</td>
<td>1</td>
<td>2</td>
</tr>
</tbody>
</table>

* (The remaining questions cannot be published according to the scale distributor)

1. What have you and your daughter discussed about your breast cancer?
   ________________________________________________________________
   ________________________________________________________________
   ________________________________________________________________
   ________________________________________________________________
   ________________________________________________________________

2. Who do you talk to about your breast cancer and what do you talk about?
   ________________________________________________________________
1. Is there any information and/or support that you have not received yet but feel would be helpful?

______________________________________________________________________________

______________________________________________________________________________

______________________________________________________________________________

______________________________________________________________________________

______________________________________________________________________________

2. Have you received any form of psychological or social treatment or help? E.g., counselling, therapy, group therapy etc.? □ Yes □ No

**If yes:**
Who was this treatment obtained through? E.g., through the Juravinski Cancer Centre, other treatment centre etc.:

______________________________________________________________________________

______________________________________________________________________________

______________________________________________________________________________

______________________________________________________________________________

______________________________________________________________________________

What type of treatment was it? E.g., counselling, therapy, group therapy etc.

______________________________________________________________________________

______________________________________________________________________________

______________________________________________________________________________

______________________________________________________________________________

______________________________________________________________________________

Amount of time:

______________________________________________________________________________

______________________________________________________________________________

______________________________________________________________________________

______________________________________________________________________________

Did you find it helpful? Please explain:

______________________________________________________________________________

______________________________________________________________________________

______________________________________________________________________________

______________________________________________________________________________

______________________________________________________________________________
Appendix G: Daughter Survey

Daughter Survey Package

ID CODE: __________________

Please complete the following form to the best of your knowledge.

1. **Self Identified Ethnicity:**
   - a. Asian/Pacific Islander
   - b. African American
   - c. Hispanic
   - d. Native American or Alaskan Native
   - e. Caucasian
   - f. Other: (please specify) _________________________

2. **Current age:** _________________________

3. **Age at the time of your mother’s diagnosis:** _________________________

4. **Birth order (e.g., are you the 1st (oldest), 2nd, 3rd child?):** _________________________

5. **Current level of education:**
   - a. Less than high school
   - b. High school: Grade ______
   - c. College: Year ______
   - d. University: Year ______
   - e. Graduate school

6. **Paid employment Status:**
   - a. Employed
   - b. Part-time employed
   - c. Unemployed

For each item please identify if the item is not true, somewhat or sometimes true, or very true or
often true of you now or within the past 6 months.

<table>
<thead>
<tr>
<th>0 = Not True</th>
<th>1 = Somewhat or Sometimes True</th>
<th>2 = Very True or Often True</th>
</tr>
</thead>
<tbody>
<tr>
<td>1. I act too young for my age</td>
<td>0</td>
<td>1</td>
</tr>
<tr>
<td>2. I have an allergy (describe):</td>
<td>0</td>
<td>1</td>
</tr>
<tr>
<td>3. I argue a lot</td>
<td>0</td>
<td>1</td>
</tr>
<tr>
<td>4. I have asthma</td>
<td>0</td>
<td>1</td>
</tr>
<tr>
<td>5. I act like the opposite sex</td>
<td>0</td>
<td>1</td>
</tr>
<tr>
<td>6. I like animals</td>
<td>0</td>
<td>1</td>
</tr>
<tr>
<td>7. I brag</td>
<td>0</td>
<td>1</td>
</tr>
<tr>
<td>8. I have trouble concentrating or paying attention</td>
<td>0</td>
<td>1</td>
</tr>
</tbody>
</table>
9. I can’t get my mind off certain thoughts (describe): 0 1 2

10. I have trouble sitting still 0 1 2

* (The remaining questions cannot be published according to the scale distributor)

Read each statement and then circle the appropriate number to the right of the statement to indicate how you feel right now, that is, at this moment.

<table>
<thead>
<tr>
<th></th>
<th>Not at all</th>
<th>Somewhat</th>
<th>Moderately</th>
<th>Very much</th>
</tr>
</thead>
<tbody>
<tr>
<td>I feel calm</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
</tr>
<tr>
<td>I feel secure (safe)</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
</tr>
<tr>
<td>I am tense</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
</tr>
<tr>
<td>I feel strained</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
</tr>
<tr>
<td>I feel at ease</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
</tr>
</tbody>
</table>

*(The remaining 15 questions cannot be published according to the scale distributor)*

Please use the scale below to answer the following questions regarding your relationship with your mother both before the cancer and now.

<table>
<thead>
<tr>
<th></th>
<th>Before the cancer</th>
<th>Now</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>Not at all</td>
<td>A little</td>
</tr>
<tr>
<td>To what extent can you count on this person to listen to you when you are very angry at someone else?</td>
<td>0 1 2 3</td>
<td>0 1 2 3</td>
</tr>
<tr>
<td>To what extent could you turn to this person for advice about problems?</td>
<td>0 1 2 3</td>
<td>0 1 2 3</td>
</tr>
<tr>
<td>To what extent can you really count on this person to distract you from your worries when you feel under stress?</td>
<td>0 1 2 3</td>
<td>0 1 2 3</td>
</tr>
<tr>
<td>To what extent could you count on this person for help with a problem?</td>
<td>0 1 2 3</td>
<td>0 1 2 3</td>
</tr>
<tr>
<td>If you wanted to go out and do something this evening, how confident are you that this person would be willing to do something with you?</td>
<td>0 1 2 3</td>
<td>0 1 2 3</td>
</tr>
<tr>
<td>To what extent can you count on this person to help you if a family member very close to you died?</td>
<td>0 1 2 3</td>
<td>0 1 2 3</td>
</tr>
<tr>
<td>Question</td>
<td>Score</td>
<td></td>
</tr>
<tr>
<td>-------------------------------------------------------------------------</td>
<td>-------</td>
<td></td>
</tr>
<tr>
<td>To what extent can you count on this person to give you honest feedback, even if you might not want to hear it?</td>
<td>0 1 2 3 0 1 2 3</td>
<td></td>
</tr>
<tr>
<td>How angry does this person make you feel?</td>
<td>0 1 2 3 0 1 2 3</td>
<td></td>
</tr>
<tr>
<td>How upset does this person sometimes make you feel?</td>
<td>0 1 2 3 0 1 2 3</td>
<td></td>
</tr>
<tr>
<td>How often does this person make you feel angry?</td>
<td>0 1 2 3 0 1 2 3</td>
<td></td>
</tr>
<tr>
<td>How much do you argue with this person?</td>
<td>0 1 2 3 0 1 2 3</td>
<td></td>
</tr>
<tr>
<td>How often do you have to work hard to avoid conflict with this person?</td>
<td>0 1 2 3 0 1 2 3</td>
<td></td>
</tr>
<tr>
<td>How much would you like this person to change?</td>
<td>0 1 2 3 0 1 2 3</td>
<td></td>
</tr>
<tr>
<td>How much do you have to “give in” in this relationship?</td>
<td>0 1 2 3 0 1 2 3</td>
<td></td>
</tr>
<tr>
<td>How much does this person make you feel guilty?</td>
<td>0 1 2 3 0 1 2 3</td>
<td></td>
</tr>
<tr>
<td>How much does this person want you to change?</td>
<td>0 1 2 3 0 1 2 3</td>
<td></td>
</tr>
<tr>
<td>How often does this person try to control or influence your life?</td>
<td>0 1 2 3 0 1 2 3</td>
<td></td>
</tr>
<tr>
<td>How critical of you is this person?</td>
<td>0 1 2 3 0 1 2 3</td>
<td></td>
</tr>
<tr>
<td>How much more do you give than you get from this relationship?</td>
<td>0 1 2 3 0 1 2 3</td>
<td></td>
</tr>
<tr>
<td>How significant is this relationship in your life?</td>
<td>0 1 2 3 0 1 2 3</td>
<td></td>
</tr>
<tr>
<td>How much do you depend on this person?</td>
<td>0 1 2 3 0 1 2 3</td>
<td></td>
</tr>
<tr>
<td>How close will your relationship be with this person in 10 years?</td>
<td>0 1 2 3 0 1 2 3</td>
<td></td>
</tr>
<tr>
<td>How positive a role does this person play in your life?</td>
<td>0 1 2 3 0 1 2 3</td>
<td></td>
</tr>
<tr>
<td>How responsible do you feel for this person’s well-being?</td>
<td>0 1 2 3 0 1 2 3</td>
<td></td>
</tr>
<tr>
<td>How much would you miss this person if the two of you could not see or talk with each other for a month?</td>
<td>0 1 2 3 0 1 2 3</td>
<td></td>
</tr>
</tbody>
</table>
Below is a list of statements that other people with your mother’s illness have said are important. Please circle or mark one number per line to indicate your response as it applies to your mother in the past 7 days.

<table>
<thead>
<tr>
<th>Statement</th>
<th>Not at all</th>
<th>A little bit</th>
<th>Somewhat</th>
<th>Quite a bit</th>
<th>Very much</th>
</tr>
</thead>
<tbody>
<tr>
<td>My mother has a lack of energy</td>
<td>0</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
</tr>
<tr>
<td>My mother has nausea</td>
<td>0</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
</tr>
<tr>
<td>Because of her physical condition, my mother has trouble meeting the needs of my family</td>
<td>0</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
</tr>
<tr>
<td>My mother has pain</td>
<td>0</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
</tr>
<tr>
<td>My mother is bothered by side effects of treatment</td>
<td>0</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
</tr>
<tr>
<td>My mother feels ill</td>
<td>0</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
</tr>
<tr>
<td>My mother is forced to spend time in bed</td>
<td>0</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
</tr>
<tr>
<td>My mother feels close to her friends</td>
<td>0</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
</tr>
<tr>
<td>My mother gets emotional support from her family</td>
<td>0</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
</tr>
<tr>
<td>My mother gets support from her friends</td>
<td>0</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
</tr>
<tr>
<td>My family has accepted my mother’s illness</td>
<td>0</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
</tr>
<tr>
<td>My mother is satisfied with family communication about her illness</td>
<td>0</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
</tr>
<tr>
<td>My mother feels close to her partner (or the person who is her main support)</td>
<td>0</td>
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<td>4</td>
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<tr>
<td>My mother feels sad</td>
<td>0</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
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<tr>
<td>My mother is satisfied with how she is coping with her illness</td>
<td>0</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
</tr>
<tr>
<td>My mother is losing hope in the fight against her illness</td>
<td>0</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
</tr>
<tr>
<td>My mother feels nervous</td>
<td>0</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
</tr>
<tr>
<td>My mother worries about dying</td>
<td>0</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
</tr>
<tr>
<td>My mother worries that her condition will get worse</td>
<td>0</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
</tr>
<tr>
<td>My mother is able to work (include work at home)</td>
<td>0</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
</tr>
<tr>
<td>My mother’s work (include work at home) is fulfilling</td>
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<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
</tr>
<tr>
<td>My mother is able to enjoy life</td>
<td>0</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
</tr>
<tr>
<td>My mother has accepted her illness</td>
<td>0</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
</tr>
<tr>
<td>My mother is sleeping well</td>
<td>0</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
</tr>
<tr>
<td>My mother is enjoying the things she usually does for fun</td>
<td>0</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
</tr>
<tr>
<td>Statement</td>
<td>0</td>
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<td>2</td>
<td>3</td>
<td>4</td>
</tr>
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<td>--------------------------------------------------------------------------</td>
<td>---</td>
<td>---</td>
<td>---</td>
<td>---</td>
<td>---</td>
</tr>
<tr>
<td>My mother is content with the quality of her life right now</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>My mother has been short of breath</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>My mother is self-conscious about the way she dresses</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>One or both of my mother’s arms are swollen or tender</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>My mother is bothered by hair loss</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>My mother worries that other members of her family might someday get the same illness she has</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>My mother worries about the effect of stress on her illness</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>My mother is bothered by a change in weight</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>My mother is able to feel like a woman</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>My mother has certain parts of her body where she experiences pain</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
</tbody>
</table>

3. What have you and your mother discussed about her breast cancer?
______________________________________________________________________________
______________________________________________________________________________
______________________________________________________________________________
______________________________________________________________________________
______________________________________________________________________________

4. Who do you talk to about your mother’s breast cancer and what do you talk about?
______________________________________________________________________________
______________________________________________________________________________
______________________________________________________________________________
______________________________________________________________________________
______________________________________________________________________________

Is there any information and/or support that you have not received yet but feel would be helpful?
______________________________________________________________________________
______________________________________________________________________________
______________________________________________________________________________
______________________________________________________________________________

Have you received any form of psychological or social treatment or help? E.g., counselling, therapy, group therapy etc.? □ Yes □ No

If yes:
Who was this treatment obtained through? E.g., through the Juravinski Cancer Centre, other treatment centre etc.:

__________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________

What type of treatment was it? Eg., counselling, therapy, group therapy etc.

__________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________

Amount of time:

________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________

Did you find it helpful? Please explain:

__________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________________
Appendix H: Average FACT-B Scores vs. Reference Sample

FACT-B

* Comparison between current sample and average scores from a sample of women with breast cancer receiving chemotherapy from Hack et al., 2010
### Appendix I: Change in the Relationship, QRI Scores

<table>
<thead>
<tr>
<th></th>
<th>Before Mean (SD)</th>
<th>Now Mean (SD)</th>
<th>Wilcoxon signed-ranks test</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Mothers</strong></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Support</td>
<td>12.26 (4.13)</td>
<td>12.96 (3.78)</td>
<td>-1.79</td>
</tr>
<tr>
<td>Conflict</td>
<td>7.74 (5.63)</td>
<td>7.04 (5.25)</td>
<td>-0.99</td>
</tr>
<tr>
<td>Depth</td>
<td>15.96 (1.72)</td>
<td>16.17 (1.64)</td>
<td>-1.09</td>
</tr>
<tr>
<td><strong>Daughters</strong></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Support</td>
<td>15.00 (3.46)</td>
<td>13.78 (3.16)</td>
<td>-1.43</td>
</tr>
<tr>
<td>Conflict</td>
<td>7.26 (7.18)</td>
<td>7.61 (8.09)</td>
<td>-0.38</td>
</tr>
<tr>
<td>Depth</td>
<td>15.09 (2.81)</td>
<td>15.96 (2.18)</td>
<td>-2.06</td>
</tr>
</tbody>
</table>

* Asterisk indicates significance at the 0.05 level.