THE EXPERIENCES OF WOMEN LIVING WITH BREAST CANCER

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by

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Abstract

Beyond relying on friends and family, several factors may influence the distress that occurs with a breast cancer diagnosis. These include the trust women have in their oncologist, the coping styles endorsed, satisfaction with the support received, as well as the unsupport encountered. Women in treatment for breast cancer ($n = 40$), women in remission ($n = 74$), and a control group ($n = 146$) were asked about (a) satisfaction with social support, (b) experiences of unsupport, (c) trust in physician, (d) coping styles (e) blame for negative events during treatment, (f) decision making regarding treatment, (g) regret regarding treatment decisions, and (h) depressive symptoms. Social support, unsupport and blame were related to variations in depressive symptoms. Different coping styles dominated at different stages of a cancer experience, and interacted with experiences of unsupport. Though trust was highest in women with a cancer experience, it was not related to any factors other than blame. The implications for a woman's well-being during a breast cancer experience are discussed.

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The Experiences of Women Living with Breast Cancer

The Canadian Cancer Society estimates that 171,000 incidences of cancer will occur in 2009, and approximately 75,300 people will die due to the disease. Of these, it is predicted that 22,700 women will be diagnosed with breast cancer, and 5,400 will die from the illness (Canadian Cancer Society, June 2009). Though these numbers are disconcerting, mortality rates from breast cancer have declined since the mid 80's and are now at the lowest point since 1950 (Canadian Cancer Society, 2009). These statistics are certainly encouraging, but it is clear that a cure for the disease is still in the distant future, and many factors surrounding the development and progression of cancer remain largely unattended. Accumulating evidence has supported the view that psycho-social factors ought to be considered in cancer therapy, particularly as this might be of direct relevance to well-being associated with a cancer diagnosis (Shapiro, Lopez, Schwartz, Bootzin, Figueredo, Braden, & Kurker, 2001).

Understandably, many women experience distress and depression when they are diagnosed with breast cancer, and coping with this challenge is exceedingly difficult. In this regard, the social support received from friends and family plays a prominent role in how females cope with the disease (Friedman, Kalidas, Elledge, Chang, Romero, Husain, Dulay, & Liscum, 2006; Gray, Fitch, Davis, & Phillips, 1997; Waxler-Morrison, Hislop, Mears, & Kan, 1991). As well, it appears that the relationship a patient has with her treating medical professional may also influence how well she is able to cope with her breast cancer experience (Han, Collie, Koopman, Azarow, Classen, Morrow, Michel, Brennan-O'Neill & Spiegel, 2005; Parker, Davidson, Tishelman, & Brundage, 2005; Wright, Holcombe, & Salmon, 2004). To be sure, faced with this daunting situation, a

woman must make overwhelming, and often intimidating decisions about medical treatment options. In order to do so, she must rely on the information provided by her treating physician, and despite medical advances there are no guarantees that a cancer treatment will be successful. Thus, a woman living with breast cancer must also contend with the looming uncertainty about her future.

The present study examined several psychosocial factors that may independently or interactively influence well-being among women living with breast cancer. In particular, the overarching theme of this work was to determine, among women with breast cancer, the factors that interact with coping styles in relation to depressive symptoms. In this regard, coping is broadly defined not only to include those strategies that are most often considered as part of individuals' coping repertoires, such as emotion- and problem-focused coping and social support resources, but also to assess the impact of trust in the physician. Moreover, the effects of negative factors in determining well-being, particularly how unsupport impacts mood state as well as the role of blame and regret in determining psychological well-being were examined. A greater understanding of the intricate and complicated relationship in a therapeutic alliance between doctor and patient may help to position women living with breast cancer, and their treating physician, to combat the disease.

Coping

The prevalence of stress and depression in individuals diagnosed with breast cancer is very high. Specifically, 70 percent of women diagnosed with Stage I or II breast cancer suffered mild or moderate depression, and 44 percent had high levels of intrusive anxiety (Tjemsland, Soreide, Matre, & Malt, 1997), suggesting a need to examine how

women are dealing with these negative mood states. Coping has been described in various ways, and it appears that the effectiveness of various forms of coping fluctuate over time and across situations (Folkman, Lazarus, Dunkel-Schetter, DeLongis, & Gruen, 2000). According to Folkman and Lazarus (1980) coping with a stressor begins with primary appraisal in which a potential threat is assessed. In the context of breast cancer, primary appraisal would begin when a female detects symptoms and evaluates the risks that these symptoms might reflect the presence of a tumor. This would be followed by secondary appraisals, in which a woman would evaluate whether she has an effective way of dealing with the distress of a cancer diagnosis. This evaluation, in turn, influences the strategies that individuals would use to cope with the stressor. As breast cancer is a somatic disease, this secondary appraisal would be largely dependent on the informational and educational support provided by the woman's treating physician, the treatment team, or information she gathers independently. Of course, how a woman copes with a stressor, including her appraisal of having breast cancer, is defined by the continuously changing management of external and internal demands, some of which may exceed the individual's own resources (Folkman et al., 2000). Thus, although women may have a range of coping strategies that can be used in most situations (e.g. work place stress, family disagreements), coping in the case of a cancer diagnosis may be greatly dependent on the woman's doctor and also the support that comes from her family and friends.

Coping styles and strategies have frequently been subdivided into two broad categories (Folkman, Lazarus, Gruen, & DeLongis, 1986). The first involves problem-focused coping, whereas the latter entails emotion-focused coping and includes such

behaviours as self-controlling, distancing, seeking social support, escape-avoidance, accepting responsibility and positive reappraisal (Folkman et al., 1986). Other investigators have divided emotion-focused coping as those that entail emotional approach versus emotional avoidance, as these may have different implications for well-being (Stanton & Franz, 1999). Carver (2000) identified wishful thinking, escapist fantasies, denial, turning to alcohol, and overeating as examples of emotional avoidance. Behaviours such as emotional expression, emotional processing, acknowledging and validating feelings, and expressing emotions are examples of emotional approach (Stanton & Franz, 1999).

It has been suggested that emotion-focused coping is utilized to a greater degree than problem-focused coping in relation to health stressors as these situations required the management of anxiety, fear, dread, and concern regarding interpersonal relationships, and in situations where the individual appraises the situation as being one over which they have no control (Folkman & Lazarus, 1980). In contrast, problem-focused coping is often more effective when stressors are presented that can be altered, such as rehabilitations after an injury (Folkman & Lazarus, 1980). Thus, it should not be surprising to find that emotion-focused coping might predominate when a woman is diagnosed with an illness over which she perceives herself to have little control. Based on a meta-analysis, Franks and Roesch (2006) concluded that variations in individuals' perception of their cancer were directly related to the coping strategy they employed such that individuals who viewed their cancer to be a challenge for them to overcome were more likely to use problem-focused or emotional approach coping, and those who viewed

a cancer diagnosis as something that causes harm and/or loss were more likely to utilize emotional avoidance coping.

As depression is frequently associated with elevated levels of emotional expression and lower levels of problem-focused coping, it has often been considered that problem-focused coping is adaptive, whereas emotional oriented coping is maladaptive (Anisman, Merali, & Hayley, 2008). For example, the use of denial and behavioural disengagement as emotional avoidance coping was inversely correlated with optimism and acceptance of breast cancer (Carver, Pozo, Harris, Noriega, Scheier, Robinson, Ketcham, Moffat, & Clark, 1993). Although emotion-focused coping has often been portrayed as being an ineffective and even counterproductive strategy, Stanton and Franz (1999) suggested that under some conditions emotion-focused coping might actually be beneficial. Austenfeld and Stanton (2004) proposed that emotion-focused coping may be related to negative psychological outcomes simply due to the wide and often poor operational definition of emotional coping used in various studies, coupled with a departure from the original measures designed to assess emotional coping. An examination of women with breast cancer using emotion expressive coping at baseline revealed that three months later they were less likely to have medical appointments regarding cancer-related morbidities, had enhanced self-reported physical health, greater vigor, and experienced less distress than women who reported that they used less emotion-focused coping at baseline (Austenfeld & Stanton, 2004). Emotion-focused coping was also found to be used when individuals in a stressful situation were not provided with a significant amount of informational support (Dunkel-Schetter, Folkman, & Lazarus, 1987). This suggests that when women are not fully informed of the details

regarding breast cancer risks and treatment, they may use emotion-focused coping to deal with the overwhelming feelings associated with the diagnosis.

The ability of an individual to cope with their cancer diagnosis also affects their quality of life. Of the various factors that facilitate coping, social support has been found to be especially important. Women often rely on close family members and friends to aid them in working through the copious emotions experienced in a breast cancer diagnosis, and this social support may play a role in their coping abilities and strategies used. While participating in breast cancer support groups, women reported benefits in both the long and short term from interacting with others in the same situation (Gray et al., 1997). Conversely, experiences of unsupport, such as others' withdrawal behaviours, hinder the ability to cope effectively (Grange, Matsuyama, Ingram, Lyckholm, & Smith, 2008).

Social Support

Social support, the reliance on others to buffer individuals them from the adverse effects of stressors and negative life experiences, is of great importance to women living with breast cancer (Bottomley & Jones, 1997). The social support desired by individuals living with cancer is often something tangible such as practical assistance (rides to appointments, prescription pick-up), or housing (living with a family member to provide daily care) (Grange et al., 2008). However, social support may also be more abstract or involve emotional components, such as having someone listen to the concerns and realities of living with cancer, express a positive attitude, or pray on the individuals behalf (Grange et al., 2008).

Higher levels of social support have been correlated with lower levels of depression in a cancer population, and it was reported that satisfaction with social support might predict

women's well-being (Hann, Baker, Denniston, Gesme, Reding, Flynn, Kennedy, & Kieltyka, 2002; Friedman et al., 2006). Conversely, social isolation has been found to be correlated with poor health related quality of life (Michael, Berkman, Colditz, Holmes, & Kawachi, 2002). Social support not only comes from family and friends; many women find support groups helpful in dealing with the stress of breast cancer. Women living with breast cancer reported gaining informational support and learning how to be more assertive when interacting with medical professionals to demand answers to their questions (Grey et al., 1997). Additionally, women also reported that connecting with other survivors, sharing laughter, feeling understood, sharing experiences and providing hope were among the benefits of social support (Gray et al., 1997). Other than the psychological benefits, social support may also have beneficial effects on the somatic functioning of women living with breast cancer. In the short term, individuals who received two sessions of psychosocial intervention (to learn relaxation techniques, problem-solving skills, crisis management, and discuss with other women) prior to a surgery to treat their breast cancer did not experience the immune suppression that members of the control group exhibited (Larson, Duberstein, Talbot, Caldwell, & Moynihan, 2000). Further, the importance of social support is exemplified in studies where social support was found to be a significant predictor of mortality (Berkman & Syme, 1979). Waxler-Morrison et al., (1991) identified being married, support and contact from friends, total support, being employed, and having a strong social network to be significant predictors of survival over four years in women living with breast cancer. Of these factors, the ability for a woman living with breast cancer to call on three

or more friends for support was the most strongly associated with survival (Waxler-Morrison et al., 1991).

It has also been found among women living with breast cancer that reluctance to engage in social disclosure of problems and concerns was negatively correlated with emotional well-being and positively correlated with unsupportive social interactions (Figueiredo, Fries, & Ingram, 2004). This suggests that unsupport might also play a crucial role in the well-being of a woman living with breast cancer.

Unsupport

Unsupport refers to any negative social interaction, or behaviour, where an individual receives an upsetting reaction from others during a time of need or stress (Figueiredo et al., 2004; Ingram, Jones, Fass, Neidig, & Song, 1999). These unsupportive responses range from being very blatant, such as criticizing how an individual is dealing with her cancer diagnosis, or more subtle, such as exhibiting discomfort while a woman discusses her illness, or avoiding the topic of cancer altogether (Grange et al., 2008; Manne, Winkel, Ostroff, Grana, & Fox, 2005). Unsupport has been found to be particularly strong in the form of distancing oneself from the individual living with cancer, or minimizing the trauma by encouraging the woman living with breast cancer to “cheer up” or “look on the bright side” (Figueiredo et al., 2004).

Individuals living with cancer identified that the physical presence of social support is of little benefit if their friends and family are not willing to be emotionally available (Grange et al., 2008). Individuals living with cancer also reported experiences of unsupport when they felt it was not appropriate to share their concerns or worries (Grange et al., 2008). Common themes in focus groups were reports that those living

with cancer felt they had to be strong and pretend not to be scared so that they could assure their children; or felt unsupported when they had to provide comfort in an effort to help family members and friends cope while upset about their illness (Grange et al., 2008). Of course, unsupportive interactions are not limited to breast cancer, but are typically apparent in association with numerous illnesses. For instance, in a sample of 271 individuals living with HIV, 96% reported experiencing some form of unsupportive behaviour from an individual in their lives (Ingram et al., 1999). Of these individuals, 90% reported unsupport occurring in the form of insensitive responses or forced optimism, 87% reported disconnecting responses such as disengaging or refusal to provide support, and 70% reported blaming interactions (Ingram et al., 1999). Unsupportive social interactions such as insensitivity, disconnecting, and blaming were all significantly correlated with increased levels of depression in individuals living with HIV (Ingram et al., 1999).

Encountering unsupportive behaviors may be a stressor in its own right, but in addition, these behaviours may interact with the way in which a woman copes with her breast cancer. Individuals who receive a large amount of social support are significantly more likely to report coping by directly confronting the problem/stressor (Dunkel-Schetter et al., 1987). In contrast, females with early stage breast cancer perception of unsupportive behaviour from their partner was related to the use of avoidant coping, and was a significant predictor of the distress being experienced by the woman (Manne et al., 2005). The females' partners' reports of their unsupportive behaviours, however, were not predictors of distress in this study (Manne et al., 2005). Therefore, suggesting that it is not the actions of a partner, but rather, a woman's perception of her partners'

behaviours that have implications for her well-being. Additionally, unsupportive behaviours have been shown to predict depression and psychological distress, beyond the effects of stress and social support (Ingram, Betz, Mindes, Schmitt, & Smith, 2001). Thus, perceptions of unsupportive behaviours may be important for women living with breast cancer in that they not only reflect a negative social interaction, but may also be a contributing factor to a depressed mood state.

The Doctor-Patient Relationship

Trust in a physician has two aspects, namely (a) trust in a physician's technical skills or their expertise on the matter, and (b) interpersonal trust, which comprises the belief that a woman's doctor respects her and that she may communicate openly (Kraetschmer, Sharpe, Urowitz, & Deber, 2004). Attesting to the psychological importance of the treating physician, women treated for a pre-cancerous cervical cell abnormality stated that their doctor had been the most effective source for reducing their distress regarding the prospect of cancer (Juraskova, Butow, Sharpe, & Campion, 2006). Likewise, women reported that hearing their doctor talk confidently about their treatment and the patient's ability to cope with the disease was often the most effective cause of reducing distress and making cancer less frightening (Henman, Butow, Brown, Boyle & Tattersall, 2002). Individuals who were most trusting tended to report a greater amount of social support (Dunkel-Schetter et al., 1987). Thus, it seems that women who are more open to trusting others may be more likely to have a good relationship with their doctor, and receive a larger amount of informational support than those individuals who are more cautious in placing trust. In a sense, trust in the treating physician has potent

effects relevant to the woman's ability to cope with the ongoing distress, but this trust is based on characteristics of the individual as well as those of the treating physician.

Communication and clarity regarding the patients' situation appears to be an important component of trust, and hence their well-being. It has been suggested that although family members and other caregivers play a role in health care communication, it is the patient-physician dyad that is most crucial in this process (Feldman-Stewart, Brundage, & Tishelman, 2005; Parker et al., 2005). In the framework proposed by Feldman-Stewart et al. (2005) both the physician and the patient have goals representing their needs, and communication is used to explain and react to one another's aims. Typical goals of a female diagnosed with breast cancer may be comprehension of health risks, creating a course of treatment, and planning for the future. Physicians' goals may involve enacting a treatment for the patient, or enrolling the patient in clinical trials. Feldman-Stewart et al. (2005) argued that successful communication occurs when it works towards reaching the patient's goals, even if they may not be realized. Successful communication often cannot occur because the information that patients are willing to receive or acknowledge differs from the information being provided by the treating physician. Alternatively, physicians' beliefs that they are the best judge of the information to report to a patient, coupled with their busy schedule, can lead to physician dominated consultations where the patient is left dissatisfied (Hack, Degner, & Parker, 2005). Another potential problem in doctor-patient communication is the dichotomous opinions of the parties involved in the amount and quality of information provided. Keating, Weeks, Borbas, and Guadagnoli (2003) surveyed women with the option of breast-conserving surgery or mastectomy for their early stage breast cancer. Only 71% of

the females reported that their doctors had discussed both treatment options with them, yet 82% of the physicians reported discussing both treatments. Better educated patients were more likely to report their physician discussing both options (in agreement with their physician) (Keating et al., 2003). The authors recognized that if treatment options were discussed in the same meeting that the female was diagnosed with breast cancer, she might have been too overwhelmed to comprehend all the information provided to her. Yet, in qualitative interviews of women living with breast cancer, when asked what they valued in their interaction with their physician, all women stated that trust in their doctor's expertise greatly outweighed concerns over communication skills (Wright et al., 2004). This trust was determined by the doctors' efficiency, and frankness, and was enhanced by his or her reputation and acclaim (Wright et al., 2004).

Trust was found to be directly related to the amount of information provided to women with cancer. When women were forewarned about what they might expect during treatment and what they could do to aid their recovery, women had a heightened sense that their doctor could be trusted to look after them (Henman et al., 2002). Women also claimed, not surprisingly, that if a doctor hesitated to answer a question, or if they suspected that the physician did not answer honestly, distrust was increased (Wright et al., 2004). These findings suggest that the way in which medical procedures are described to a woman and comprehension of the information provided may be directly related to a female's perception and evaluation of the interaction with her treating doctor.

Although considerable research has examined the communication relationship and informational support provided by physicians, there is a large gap regarding analysis of the role that trust plays when a female with breast cancer must place her health in the

hands of an oncologist and how she copes with the process and resulting outcomes of treatment. Still less information is available as to whether trust serves as a coping response to certain stressors. In this sense, trust may act as a substitute for problem-focused coping in situations where the patient has little or no control over her own destiny.

The Role Women Want to Play in Their Cancer Experience/Decision Making

Coping factors might not only be important in dealing with the threat of cancer, but may also facilitate decision making necessary in the treatment of the disease. Luce (2005) acknowledged that an individual might have to cope with the negative emotions that arise when they realize they must make an important decision. Thus, Luce (2005) proposed the emotional trade-off difficulty model in which a women living with cancer may choose to focus only on the long-term survival rates predicted by various treatments and implicitly ignore the short-term detriments of the various procedures in order to protect herself from, and cope with, the negative emotions that may arise in considering other factors. This view corresponds with other findings that in making decisions, women cited their main focus to be that of extending their lives (Henman et al., 2002). In a qualitative study of twenty women with various cancers, fifteen reported wanting as much information as possible in order to “gain a sense of control over their situation, reduce their anxiety, change their behaviour, and predict and plan for the future” (Henman et al., 2002). When these same women were asked about factors crucial to ‘correct’ decision making the women cited, among other things, their doctors’ knowledge, whether or not they felt listened to by their doctor, whether they felt included in their decision making with their doctor, and whether or not they trusted their doctor

(Henman et al., 2002). Individuals at a breast cancer, a prostate cancer, and a bone fracture clinic were examined to provide indices of trust variations across a range of ages and with differing severity of illnesses. The degree of trust reported was directly related to the role the individual wanted to play in their treatment. Those with blind trust opted for a passive role, whereas this preference decreased as trust in the physician decreased (Kraetschmer et al., 2004).

Although diagnosis and treatment is often the domain of a multi-faceted medical team, a woman may rely more on her own beliefs than medical input in making health decisions. In fact, women with a BRCA mutation (which is associated with an exceedingly high genetic risk for cancer; Bourret, 2005) relied more on their family history of cancer when estimating their risk of cancer development than on the guidance of genetic counselors and medical doctors (Werner-Lin, 2007). Of these women, 75% indicated that despite medical discoveries they were bound to follow family trends rather than match the statistics of the general population. Thus, women with a strong family history of cancer diagnosis are more likely to trust themselves in making cancer decisions rather than relying on the input of doctors. In contrast, Kraetschmer et al. (2004) found that 67.3% of individuals being treated for breast cancer, prostate cancer or an arm fracture wished to have a shared approach in treating their current medical problem, whereas 29.7% preferred a passive role, and only 2.9% wanted an autonomous role. Those who wanted autonomy in making medical decisions perceived themselves to be very knowledgeable about their condition, and those who wanted to take a passive role perceived themselves to be significantly less knowledgeable about their medical affliction (Kraetschmer et al., 2004). Similarly, Keating, Guadagnoli, Landrum, Borbas, and

Weeks (2002) found that 64% of women with early stage breast cancer wanted to share the decision making with their doctors, but in actuality only 40% of women experienced this; 24% wanted their doctors to provide them with the options so that they could make the final decision, and 40% experienced this; 9% desired the doctor to state their optimum option which the female could then accept or reject, 18% experienced this; and 3% desired the doctor to make the final decision without consulting them at all, while 9% experienced this (Keating et al., 2002). Thus, there appears to be a discrepancy in the role women desired to play in the treatment of their illness, and that which truly occurred. The women who had desired and possessed roles that corresponded with one another were most likely to be receiving breast conserving surgery, were more likely to be satisfied with their chance of a positive therapeutic outcome, and more likely to agree that they had received enough information about treatment options, when compared to women whose desired roles did not match their actual involvement (Keating et al., 2002).

The importance of including a woman in treatment decisions was apparent in studies showing that women who were given a choice in the treatment for their breast cancer had lower pathological scores and higher positive scores on the mental adjustment to cancer scale (MAC) four and nine months post treatment, relative to women who had been told what their best treatment option was (Deadman, Leinster, Owens, Dewey, & Slade, 2001). Deadman et al., (2001) indicated that there is often a dichotomy in the role that women wish to play. Many women wish to decide their treatment so they may obtain their preferred choice; however, they are not interested in taking responsibility for the decision. In contrast, Henman et al., (2002) found that women who valued autonomy and wanted to determine their treatment were willing to accept responsibility for the

decisions they made regarding their cancer therapy. Luce (2005) also indicated that forcing a women living with breast cancer to make a treatment decision on her own may cause her great levels of distress, and overwhelm her coping abilities.

It is possible that women take a diminished role in medical decisions because they feel that control is no longer in their hands. More severe procedures, such as prophylactic mastectomy, require the skills of doctors and as such, women may feel that it is then up to the doctor to make the decision that the procedure is in her best interest. Women may also feel that their physicians do not permit them to be involved in making their own medical decisions. Focus groups with women conducted throughout the United States concluded that their doctors were poor communicators and listeners, and that their physicians often coerced and intimidated them into making decisions (Covello, & Peters, 2002).

Decision Making - Regret

In the treatment of breast cancer, there is rarely one 'correct' option, but rather many options that involve different benefits and risks (Brehaut, O'Connor, Wood, Hack, Siminoff, Gordon, & Feldman-Stewart, 2003). As medical decisions have such a great bearing on a woman's current and future health, it is understandable that they might feel distress in making a decision, and may experience remorse after the decision has been made. Decision making regret often involves counterfactual thinking in which an event that has already occurred is compared with an alternative, and assumedly more optimal, option (Connolly & Reb 2005). A review of regret in decision making shows that most definitions conclude that regret is unfavorable and is therefore evaded as much as possible, is the result of a continuous interaction between cognition and emotion, is

discernable from disappointment, and occurs when a decision is compared in the context of an alternative choice regarding what could have optimally occurred (Connolly & Reb, 2005). Regret can be distinguished from disappointment, as the latter occurs when an optimal result would have been obtained not by making a decision, but rather, if one had been luckier (Connolly & Reb, 2005).

Low satisfaction in a meeting with a doctor, a change in decision, high decisional conflict, and satisfaction with a decision accounted for 44% of the variance in participants' medical decision regret scores (Brehaut et al., 2003). Exhibiting the possible importance of a hindsight bias, low overall quality of life and poor physical and psychological outcome health also contributed to increased regret (Brehaut et al., 2003; Sheehan, Sherman, Lam, & Boyages, 2008). Regret after breast reconstruction has been found to correlate significantly with dissatisfaction with information received, increased depression, anxiety, and general distress (Sheehan, Sherman, Lam, & Boyages, 2007). Among women who reported having a choice in treatment options, decision regret was significantly higher in women who had less than high school education, were middle or low income earners, and were women of colour (Lantz, Janz, Fagerlin, Schwartz, Liu, Lakhani, Salem, & Katz, 2005). These findings suggest that the level of comprehension one has about their situation before making a medical decision may impact the regret or satisfaction they feel about a decision. Likewise, individuals who had primarily allowed their doctors to make the final decisions about their treatment were significantly more likely to regret the decision nine months later (Brehaut et al., 2003). In line with this, as indicated earlier, decision regret was higher in individuals who had played a greater or lesser role in their decision making than that which they desired (Lantz et al., 2005).

The Present Study

There is reason to believe that satisfaction with the social support a woman received (from family, friends and medical professionals), the perceived unsupport experienced, as well as trust in the physician, are all intricately tied with her ability to cope with a cancer experience. Furthermore, these factors may play a role in the medical decisions she makes, and the regret she feels regarding these decisions, as well as her psychological well-being.

It was predicted that:

1. Women still in treatment would have higher levels of depressive symptoms than women in remission or women in the control group.
2. Greater satisfaction with social support would be associated with diminished levels of depression; however, greater perceived unsupport would predict greater depression. Although it was predicted that this would be true for all women, the amount of variance in depressive symptoms accounted for by support and unsupport would be highest in women still in treatment.
3. For all women, the link between coping styles and depressive symptoms would be moderated by satisfaction with social support and experiences of unsupport. Specifically, higher levels of emotion-focused and avoidance coping would relate to greater depressive symptoms. Furthermore, high satisfaction with social support would be associated with attenuation of the relation between emotion-focused or avoidance coping and depressive symptoms. Conversely, unsupport together with these coping styles would be associated with greater symptoms of depression.

4. Among women in treatment, greater trust in one's physician would be related to reduced depressive symptoms. Additionally, greater trust would moderate the endorsement of coping strategies (increased problem-solving and decreased emotion-focused and avoidance coping) and might thereby be associated with reduced depressive symptoms.
5. For women who had/have cancer, low levels of trust would relate to increased blame in the physician for adverse events. High levels of trust, however, could predict one of two outcomes. It is possible that high levels of trust would be associated with low blame, as the women will believe their physician treated them as best s/he could. Alternatively, it is equally conceivable that in women with high trust in their physician, adverse events would be associated with increase blame of the physician as, in a sense, the physician might be perceived as having let the patient down.
6. For women in treatment and in remission, trust in the physician would be related to who made the final decisions regarding treatment. This, in turn, may be associated with regret and/or depression.

Methods

Participants

Women ($N = 260$) over the age of 20, living in Canada participated in this study. Approximately half of the women, ranging in age from 20 to 70 years ($M = 41.30$, $SD = 9.55$), had never had breast cancer ($n = 146$, 56.15%), whereas the remaining women, ranging in age from 23 to 76 years ($M = 47.24$, $SD = 10.20$), had had, or were currently living with, breast cancer ($n = 114$, 43.85%). Of the women with breast cancer, 40 were

still being treated and 74 were in remission. Of the women still in treatment, diagnosis dates varied from being within the past year ($n = 26$, 65.00%), one to two years ago ($n = 9$, 22.50%), and more than five years ago ($n = 5$, 12.50%). Of the women in remission, diagnosis dates ranged from being within the past year ($n = 8$, 10.81%), one to two years ago, ($n = 18$, 24.32%), three to five years ago ($n = 20$, 27.03%), and more than five years ago ($n = 28$, 37.84%).

A majority of women were married ($n = 189$, 72.70%), relatively equal proportions were separated/divorced ($n = 33$, 12.70%) or single ($n = 35$, 13.46%), and the remainder was widowed ($n = 3$, 1.15%). The highest level of education completed varied from obtaining a university degree ($n = 103$, 39.62%), some university schooling ($n = 14$, 5.38%), college diploma ($n = 49$, 18.85%), some college ($n = 33$, 12.69%), trade certificate/diploma ($n = 14$, 5.38%), high school diploma ($n = 36$, 13.85%), some high school ($n = 9$, 3.46%), and grade school ($n = 2$, 0.77%).

Procedure

Participant data were collected during the summer and fall of 2008. Advertisements were placed in on-line chat groups, facebook groups, community posters, and cancer support centres to encourage women to participate in the on-line study. Participants could also request a paper copy of the study, although none did. After obtaining informed consent (Appendix A), the participants created an ID and password that was used to identify their data. Women were able to do the study in sections by using their ID and password to return to the website at a later date and continue the study from where they previously left off. Upon completion of the study, all women received a debriefing explaining the purpose of the study, and women in the cancer group were

provided with contact information for cancer support services, should they have wished to partake (Appendix B). Once validity of responses was confirmed, participants were mailed a \$10.00 gift card to their choice of HMV, Famous Players, Second Cup, Tim Horton's or Chapters/Indigo.

Measures

Women living with breast cancer currently, or in the past, completed the following measures on-line:

1. *Demographics and Medical History*: this scale collected demographic information regarding education, marital status, employment, and living arrangements. The medical history portion of the scale investigated details about the woman's breast cancer, the treatments she had or was considering having, as well as information regarding cancer occurrences in family members (Appendix C).
2. *Trust-In-Physician Scale*: this scale assessed the trust a woman had in the primary physician treating her breast cancer (Anderson & Dedrick, 1990; Appendix D). Participants were asked to indicate on a five point scale (from strongly agree (1) to strongly disagree (5)) how much they concurred with statements about the care their doctor had provided to them. The total score was taken by calculating the mean across all items. The reliability for this scale was very good (Table 1).
3. *Blame Questionnaire*: this scale was composed of three stand alone questions that assessed who made the decision about a woman's cancer treatment, who is to be held responsible for possible metastases, and who is held responsible for other problems or negative outcomes which may have occurred (Appendix E). The participants identified who made the final decision about their cancer treatment:

themselves, their doctor, or that the decision was made together. The participants also identified whom they would blame if their cancer were to metastasize, and whom they would blame for things that had gone wrong during treatment: themselves, their doctor, or no one was responsible. This measure was created for this study, and as each issue involved only one item, reliability estimates could not be obtained.

4. *Survey of Coping Profile Endorsement*: this scale assessed the means individuals use to cope (Matheson & Anisman, 2003; Appendix F). Women indicated on a five point scale how often (from never (0) to almost always (4)) they used the provided strategies to cope with recent stressors. This scale quantified how often the individual used problem-solving, cognitive restructuring, active distraction, cognitive distraction, rumination, humour, social support seeking, wishful thinking, emotional expression, other blame, self blame, emotional containment, religion, or passive resignation as a method of coping. A principal component analysis with a varimax rotation was performed to determine the factors this scale could be organized along. Based on a scree plot, these coping styles could be grouped into three factors. Items were included on a factor when loadings were greater than 0.40. Cognitive distraction loaded onto both problem-focused coping and avoidance coping, but was retained in the latter due to theoretical relevance. Emotion-focused coping comprised self blame, other blame, rumination, wishful thinking, and emotional expression and had very good reliability. Problem-focused coping comprised problem solving, cognitive restructuring, social support seeking, active distraction, humour, and religion and had good reliability.

Avoidance coping comprised emotional containment, passive resignation, and cognitive distraction and had moderate reliability (Table 1).

5. *Social Support Questionnaire*: this questionnaire assessed the number of individuals that women could turn to for social support, and how satisfied women were with the support they had received on a six point scale (from very dissatisfied (1) to very satisfied (6)) (Sarason, Sarason, Shearin, & Pierce, 1987; Appendix G). The total satisfaction score was calculated by taking the mean across all items. The reliability for this measure was very good (Table 1).
6. *Unsupportive Social Interactions Inventory*: this inventory assessed on a five point scale how frequently (none (0) to a lot (4)) a woman's partner or close friend had responded in an unsupportive way when she had turned to them for support (Ingram et al., 2001; Appendix H). The scale is comprised of four subscales identifying the different types of unsupport that may be received: distancing, bumbling, minimizing, and blaming. Distancing is perceived as behavioural or emotional disengagement and had moderate reliability. Bumbling is perceived as awkward, uncomfortable, intrusive, or inappropriately focused behaviours and had moderate reliability. Minimizing is perceived as forced optimism or downplaying the importance of the situation and had good reliability. Blaming is perceived as criticism and finding fault and had very good reliability. The reliability of the overall scale was very good (Table 1). As the subscales were highly inter-correlated for both women in the control group and women with a breast cancer experiences (Table 2), the total unsupport scale was calculated by taking the mean for all items and was used in the analyses.

7. *Decision Regret Scale*: this scale asked women living with breast cancer to indicate on a five point scale (from strongly agree (1) to strongly disagree (5)) how much she concurred with statements regarding regret pertaining to her breast cancer treatment decisions (Brehaut et al., 2003; Appendix I). The total scores for this scale were calculated by taking the mean across all items. The reliability for this scale was very good (Table 1).
8. *Beck Depression Inventory*: this inventory assessed depressive symptoms by asking participants to choose one of four options for the way they currently felt (Beck, Ward, Mendelson, Mock, & Erbaugh, 1961; Appendix J). The responses range from low to high depressive symptomology. The total score for this scale was calculated by summing across all items. Individuals who indicated that they were considering harming themselves or who received a summative score indicating high symptomology immediately received a debriefing pertaining to distress that provided contact information for services that may help them (Appendix K). The reliability of this scale was very good (Table 1).

Appendices provided are those used for the women living with breast cancer currently or in the past. Any alterations in the method for the control group are explained in the following procedure section.

Women in the control group completed the following measures on-line:

1. *Demographics and Medical History*: the medical history portion of the scale was not given to the control group, however information regarding cancer occurrences in family members was collected.

2. *Trust-In-Physician Scale*: individuals were asked to answer based on thinking about the last thing their doctor treated them for.
3. *Blame Questionnaire*: the women were asked to imagine that they had breast cancer and answer the questions accordingly.
4. *Survey of Coping Profiles Endorsed*
5. *Social Support Questionnaire*
6. *Unsupportive Social Interactions Survey*
7. *Beck Depression Inventory*

Table 1.

Descriptive statistics and inter-item reliabilities of measures.

Measure	<i>n</i>	Mean	SD	Number of items	α
Trust in physician	260	3.48	0.27	11	0.90
Coping					
Emotion-focused	260	1.67	0.47	17	0.92
Problem-focused	260	2.34	0.34	22	0.88
Avoidant	260	2.01	0.23	11	0.77
Social Support	260	4.94	0.11	6	0.95
Unsupport	260	1.03	0.40	24	0.94
Distancing	260	0.93	0.28	6	0.77
Bumblng	260	1.24	0.31	6	0.72
Minimizing	260	1.46	0.21	6	0.84
Blaming	260	0.61	0.22	6	0.91
Regret	114	2.08	0.09	5	0.95
Beck Depression	260	10.56	8.64	21	0.91

Table 2.

Pearson correlations among unsupport subscales (control group above the diagonal, women with a cancer experience below the diagonal).

Variable	1.	2.	3.	4.
1. Distancing	---	0.62**	0.60**	0.83**
2. Bumbling	0.53**	---	0.66**	0.58**
3. Minimizing	0.63**	0.64**	---	0.58**
4. Blaming	0.70**	0.41**	0.55**	---

** $p < 0.01$

Results

Social Support, Unsupport and Depressive Symptoms

As hypothesized, a one-way ANOVA indicated that depressive symptoms varied as a function of cancer status, $F(2, 257) = 4.97, p < 0.01, \eta^2 = 0.037$. Tukey follow-up comparisons revealed that levels of depressive symptoms among women in treatment were higher than among women in remission, and women who had never had cancer, but did not differ between women in remission and women in the control group (Figure 1).

One-way ANOVAs also revealed that there was no significant difference in satisfaction with social support, $F(2, 257) = 1.43, ns$, whereas experiences of unsupport differed with cancer status, $F(2, 257) = 5.92, p < 0.01, \eta^2 = 0.044$. The follow up test indicated that women in the control group experienced unsupport more often than women in remission (Figure 2). Women in treatment did not differ from either of the other groups.

Correlational analyses indicated that for women in the control group, satisfaction with social support was negatively related to experiences of unsupport, emotion-focused and avoidant coping, and depressive symptoms; and positively related to problem-focused coping and trust in the physician. Unsupport was positively related to emotion-focused and avoidant coping as well as depressive symptoms; and negatively related to problem-focused coping (Table 3). Among women in remission, the correlations were in most respects similar to those of women in the control group. In particular, satisfaction with social support was positively related to problem-focused and negatively related to experiences of unsupport, emotion-focused and avoidant coping, and depressive symptoms (Table 4).

Figure 1. Mean ($\pm$ SE) depressive symptoms as a function of cancer status.

* $p < 0.05$

Figure 2. Mean ($\pm$ SE) experiences of unsupport as a function of cancer status.

* $p < 0.05$

Table 3.

Pearson correlations among social support, unsupport, coping styles, trust in physician, and depressive symptoms within the control group.

Variable	1.	2.	3.	4.	5.	6.	7.	8.
1. Support								
2. Unsupport	-0.40**							
Coping								
3. Emotion-focused	-0.42**	0.39**						
4. Problem-focused	0.33**	-0.17*	0.07					
5. Avoidant	-0.20*	0.18*	0.45**	0.08				
6. Trust in physician	0.29**	-0.14	-0.20*	0.08	-0.16			
7. Beck Depression	-0.49**	0.38**	0.57**	-0.32**	0.36**	-0.25**		
8. Regret	—	—	—	—	—	—	—	

Note. Single dashes indicate that women in the control group did not complete the regret scale.

* $p < 0.05$; ** $p < 0.01$

Table 4.

Pearson correlations among social support, unsupport, coping styles, trust in physician, depressive symptoms and regret within women in remission.

Variable	1.	2.	3.	4.	5.	6.	7.	8.
1. Support								
2. Unsupport	-0.35**							
Coping								
3. Emotion-focused	-0.23*	0.36**						
4. Problem-focused	0.37**	-0.13	0.16					
5. Avoidant	-0.28*	0.24*	0.41**	0.11				
6. Trust in physician	0.10	-0.14	-0.03	0.20	0.09			
7. Beck Depression	-0.31**	0.40**	0.46**	-0.31**	0.33**	-0.13		
8. Regret	-0.05	0.27*	0.09	-0.12	0.02	-0.19	0.23*	

* $p < 0.05$; ** $p < 0.01$

Unsupport was positively related to emotion-focused and avoidant coping, depressive symptoms and regret (Table 4). Among women in treatment, the relations between support and other variables were different from women in the control condition and women in remission. Specifically, satisfaction with social support was positively related to problem-focused coping and trust in physician. Conversely, unsupport was positively related to emotion-focused and avoidant coping (Table 5).

It was hypothesized that greater satisfaction with social support, and fewer unsupportive interactions, would be associated with lower depressive symptoms. To examine this, cancer status was dummy coded into two variables: the first comparing women who have/had cancer to the control group, and the second comparing women in treatment to women in remission. A hierarchical regression with the cancer status dummy variables entered on the first step, dimensions of support and unsupport entered on the second step, and interactions between the cancer status dummy variables and support/unsupport entered on the third step, were used to examine the variance in depressive symptoms. As hypothesized, after controlling for cancer status, greater satisfaction with social support was linked with decreased depressive symptoms, $B = -2.58, t = -5.08, p < 0.01$, and greater experiences of unsupport were related to increased depressive symptoms, $B = 2.19, t = 4.24, p < 0.01, R^2_{cha} = 0.204, F_{cha}(2, 255) = 34.19, p < 0.01$. The interactions between social support and cancer status, as well as unsupport and cancer status did not account for a significant proportion of the variance in depressive symptoms, $F_{cha}(4, 251) = 1.36, ns$.

Table 5.

Pearson correlations among social support, unsupport, coping styles, trust in physician, depressive symptoms and regret within women in treatment.

Variable	1.	2.	3.	4.	5.	6.	7.	8.
1. Support								
2. Unsupport	-0.26							
Coping								
3. Emotion-focused	-0.15	0.39*						
4. Problem-focused	0.56**	-0.02	0.17					
5. Avoidant	-0.15	0.33*	0.50**	0.14				
6. Trust in physician	0.40**	-0.15	-0.07	0.10	0.01			
7. Beck Depression	-0.18	0.26	0.46**	-0.03	0.22	-0.10		
8. Regret	0.05	0.05	0.49**	0.29	0.12	-0.22	0.08	

* $p < 0.05$; ** $p < 0.01$

Coping

When faced with a potentially terminal illness, the coping styles women use may predict well-being. Among women in the control group, emotion-focused coping was positively related to avoidance coping and depressive symptoms, and negatively related to trust in physician. Further to this, problem-focused and avoidance coping were related to depressive symptoms (Table 3). Among women in remission, emotion-focused coping was positively related to avoidant coping and depressive symptoms; both problem-focused and avoidant coping were related only to depressive symptoms (Table 4). Finally, among women in treatment, emotion-focused coping was positively related to avoidance coping, depressive symptoms and regret; problem-focused and avoidant coping were not related to any other variables (Table 5).

A MANOVA revealed that there were significant differences in the coping strategies used by the women, *Pillai's Trace* $F(6, 512) = 5.95, p < 0.01, \eta^2 = 0.065$. These differences were examined in univariate ANOVA's for each type of coping. The endorsement of avoidance coping, as well as emotion-focused coping, varied across the groups, F 's $(2, 257) = 3.95$ and $10.93, p < 0.03$ and $0.01, \eta^2 = 0.030^1$ and 0.078^2 respectively. Tukey follow up comparisons revealed that women in treatment were significantly more likely to use avoidant coping, than women in remission or women in the control group, and that the two latter groups did not differ from one another (Figure

¹ As the time since diagnosis may be related to the coping style a woman with breast cancer was using, it was considered as a covariate. However, this variable was not correlated with the use of avoidant coping, $r = -0.16, ns$, and thus was not included in this analysis.

² As the time since diagnosis was correlated with emotion-focused coping, $r = -0.22, p < 0.05$, an ANCOVA was run. However the same results were observed as in the initial ANOVA, $F(2, 256) = 10.18, p < 0.01, \eta^2 = 0.074$.

3). Furthermore, women in remission were less likely to use emotion-focused coping than women in the other groups; however women in the control group and women in treatment did not differ from one another (Figure 4). In contrast there were no differences across the groups with respect to the use of problem-focused coping, $F(2, 257) = 1.55, ns^3$.

It was hypothesized that greater use of emotion-focused and avoidant coping would be linked to greater depressive symptoms. A hierarchical regression with the cancer status dummy variables entered on the first step, dimensions of coping entered on the second step, and interactions between the cancer status dummy variables and coping styles entered on the third step, were used to examine the variance in depressive symptoms. Over and above cancer status, endorsement of different coping strategies was significantly related to different levels of depressive symptoms, $R^2_{cha} = 0.381, F_{cha}(3, 254) = 55.55, p < 0.01$. Depressive symptoms increased as the endorsement of emotion-focused coping increased, $B = 4.42, t = 9.18, p < 0.01$. Similarly, the increased endorsement of avoidant coping was related to increased depressive symptoms, $B = 1.12, t = 2.45, p < 0.02$. In contrast, the use of problem-focused coping was associated with lower reports of depressive symptoms, $B = -2.86, t = -6.84, p < 0.01$. Interactions between coping styles and a woman's current cancer status did not account for a significant amount of the variance in depressive symptoms, $F_{cha}(6, 248) = 1.24, ns$. It was also hypothesized that satisfaction with social support among women who have/had

³ Time since diagnosis was correlated with problem-focused coping, $r = -0.26, p < 0.01$, thus an ANCOVA was run. The same findings as in the initial ANOVA were observed, $F(2, 256) = 1.07, ns$.

breast cancer would moderate the endorsement of emotion-focused and avoidant coping in relation to depressive symptoms.

Figure 3. Mean ($\pm$ SE) endorsement of avoidant coping as a function of cancer status.

* $p < 0.05$

Figure 4. Mean ($\pm$ SE) endorsement of emotion-focused coping as a function of cancer status.

* $p < 0.05$

To examine the variance in depressive symptoms, a hierarchical regression was conducted with the standardized social support variable entered on the first step, the standardized coping styles entered on the second step, and interactions between standardized satisfaction with social support and each of the standardized coping styles entered on the third step. This analysis was conducted only on the responses of women currently living with breast cancer, or who were in remission. Among these women, satisfaction with social support did not moderate the relations between coping styles and depressive symptoms, $F_{cha}(3, 106) = 1.43, ns$. Additionally, it was hypothesized that experiences of unsupport would moderate the endorsement of emotion-focused and avoidant coping on depressive symptoms. Again to assess the responses of women contending with breast cancer currently and in the past, a hierarchical regression was run with the standardized unsupport variable entered on the first step, the standardized coping styles entered on the second step, and interactions between standardized experiences of unsupport and standardized coping styles entered on the third step. Experiences of unsupport approached significance in moderating coping styles in relation to depressive symptoms, $R^2_{cha} = 0.045, F_{cha}(3, 106) = 2.59, p = 0.06$. However, the individual interactions between unsupport and emotion-focused coping, $B = -0.06, ns$, unsupport and problem-focused coping, $B = -0.97, ns$, and unsupport and avoidant coping, $B = -1.17, ns$, did not predict the variance in depressive symptoms. To further examine the simple effects of the moderating effect of unsupport in relation to depressive symptoms, separate hierarchical regressions were run for each coping style with standardized unsupport entered on the first step, one of the standardized coping styles entered on the second step, and an interaction between standardized unsupport and the standardized coping style

entered on the third step. The moderating effect of unsupport on emotion-focused coping in relation to depressive symptoms approached significance, $R^2_{cha} = 0.020$, $F_{cha}(1, 110) = 3.19$, $p < 0.08$. To determine the nature of the moderation effect, a simple slopes analysis was conducted by assessing the relation between emotion-focused coping and depressive symptoms at one standard deviation above and below the mean of unsupport. Individuals with low levels of emotion-focused coping had higher depressive scores when they experienced high levels of unsupport relative to individuals with low unsupport. Individuals with high endorsement of emotion-focused coping had reported higher levels of depressive symptoms than did those with low endorsement of emotion-focused coping; however, depressive symptoms in women with high levels of emotion-focused coping did not differ between women with high or low experiences of unsupport (Figure 5). The interaction between unsupport and avoidant coping also accounted for a significant amount of the variance in depressive symptoms, $R^2_{cha} = 0.034$, $F_{cha}(1, 110) = 4.72$, $p < 0.05$. This moderation effect was examined by conducting a simple slopes analysis to assess the relation between avoidance coping and depressive symptoms at one standard deviation above and below the mean of unsupport. Individuals who experienced high amounts of unsupport had higher depressive symptoms, regardless of whether they endorsed high or low avoidant coping. Individuals who had fewer unsupportive experiences had higher depressive scores when they used high levels of avoidance coping relative to individuals who used low levels of avoidance coping (Figure 6). In contrast to these findings, experiences of unsupport did not moderate the use of problem-focused in relation to depressive symptoms, $F_{cha}(1, 110) = 1.45$, *ns*.

Figure 5. The endorsement of emotion-focused coping as moderated by experiences of unsupport in relation to depressive symptoms.

$^{**}p < 0.01$

Figure 6. The endorsement of avoidant coping as moderated by experiences of unsupport in relation to depressive symptoms.

$**p < 0.01$.

Trust

The trust a woman has in her physician might play a role in decreasing the distress she feels regarding her breast cancer. However, trust was not correlated with any factors for women in remission (Table 4) and was only positively correlated with satisfaction with social support among women in treatment (Table 5). For women who have never had a cancer experience, trust was positively related to satisfaction with social support and depressive symptoms, and negatively related to emotion-focused coping (Table 3). A one-way ANOVA revealed that trust in one's physician varied as a function of group membership, $F(2, 257) = 5.84, p < 0.01, \eta^2 = 0.042$. Tukey post hoc comparisons indicated that women in remission had greater trust in their doctor than did women in the control group, but not greater trust than women in treatment. Women in treatment and women in the control group did not differ from one another (Figure 7). It was hypothesized that among women who have/had breast cancer, greater trust in one's physician would relate to diminished depressive symptoms, however a bivariate correlation revealed that trust in the physician was not related to depressive symptoms among women in treatment (Table 5), nor among women in remission (Table 4).

Among women who had/have breast cancer, it was also hypothesized that the relation between trust and depressive symptoms would be moderated by coping styles (i.e. increased trust relating to greater use of problem-focused coping and less use of emotion-focused coping would be associated with lower levels of depressive symptoms).

Figure 7. Mean ($\pm$ SE) trust in physician as a function of cancer status.

* $p < 0.05$.

The variance in depressive symptoms was examined through a hierarchical regression with standardized trust entered on the first step, standardized coping styles entered on the second step, and interactions between standardized trust and each standardized coping style entered on the third step. Trust in physician was not moderated by the use of coping styles, $F_{cha}(3, 106) = 1.00, ns$.

Blame

The role that trust in a physician would play on blame for adverse effects was explored in this study. It was possible that high levels of trust would predict low blame in the physician, as a woman may feel her doctor did everything s/he could to treat her cancer. However, it was equally possible that high levels of trust would predict high levels of blame in the physician, as a woman may feel that her doctor let her down. Thus a directional hypothesis was not formed for this research question. Women who had/have cancer were asked about their cancer metastasizing and a multinomial logistic regression revealed that trust in physician was not a significant predictor of who they would blame in this situation, $\chi^2(3) = 3.64, ns$. Univariate ANOVAs revealed that the individual women would blame if their cancer were to metastasize was not associated with depressive symptoms, $F(3, 110) = 2.37, ns$; nor did it relate to regret for treatment decisions, $F(3, 110) = 1.59, ns$.

Trust in physician was, however, a significant predictor in multinomial logistic regression of whom women blamed for things that had gone wrong in their treatment other than metastases, $\chi^2(3) = 8.70, p < 0.04$; with trust in physician accounting for 8.3% of the variance in blame. With each one unit increase in trust in the physician, a woman was 2.98 times more likely to blame her doctor for negative treatment events as opposed

to blaming no one, $Wald(1) = 7.67, p < 0.01, Exp(B) = 2.98, CI = 1.38-6.47$. Though a majority of women reported that no one was to blame for negative events in their treatment ($n = 68, 60\%$), a one way ANOVA indicated that depressive symptoms were elevated in women who did blame someone ($n = 46, 40\%$) ($M = 12.87, SD = 7.63$), in comparison to women who blamed no one, ($M = 10.01, SD = 8.07$), $F(1, 112) = 3.59, p < 0.07, \eta^2 = 0.031$. However, among women who blamed someone, depressive symptoms did not differ based on who was blamed for negative events (such as one's doctor, one's self, or another source) $F < 1, ns$. Similarly, a one-way ANOVA indicated that blame for negative events during treatment was related to regret in treatment decisions, $F(3, 110) = 3.44, p < 0.02, \eta^2 = 0.086$. Tukey follow up comparisons revealed that women who blamed themselves had higher regret scores than women who blamed others (i.e., wait times, Satan, health care system, MRI machine); no other groups differed from one another (Figure 8).

Decision Making

It was hypothesized that greater trust in the physician would be associated with shared decision making, or the doctor making the final treatment decision. For women with breast cancer currently or in the past, a multinomial logistic regression revealed that trust in physician was not a significant predictor of who made the final decisions regarding treatment, $\chi^2(5) = 7.28, ns$.

Figure 8. Mean ($\pm$ SE) regret as a function of the individual blamed for negative events during treatment.

* $p < 0.05$

Univariate ANOVAs indicated that the individual who made the final decisions regarding a woman's cancer treatment was not linked to depressive symptoms, $F < 1$, nor did it relate to regret in treatment decisions, $F(5, 108) = 1.40$, *ns*.

Discussion

It is widely believed that an individual's relationship with their doctor may have important implications for their well-being during and after the course of therapy. In women with breast cancer specifically, this doctor-patient relationship may influence the way treatment is approached and how the experience is perceived (Han et al., 2005; Parker et al., 2005; Wright et al., 2004). The purpose of the present investigation was to examine the unique role that trust in one's physician has with respect to how women cope with a breast cancer experience and their subsequent levels of depression, as well as the influence of the support or unsupport they may be receiving from their social network. Furthermore, we examined how trust in a physician would relate to decision making concerning treatment and regret/blame regarding negative outcomes that might have occurred.

Social Support and Unsupport in Relation to Depressive Symptoms

Consistent with previous reports (Tjemsland et al., 1997), depressive symptoms were elevated in women in treatment for breast cancer, whereas depressive symptoms of individuals in remission, and those in the control group were approximately equal. Though understandable that women battling a potentially terminal illness had elevated reports of depressive symptoms, it was encouraging that these levels typically did not meet the criteria for clinical depression and were generally within the mild to moderate range (Beck et al., 1961). It seems that once the rigors of treatment or the immediate

threat of a potentially terminal illness has passed, individuals were able to continue their lives with levels of depressive symptoms comparable to that of the general population, despite a five year survival rate of 86% and a twenty year survival rate of only 70% following treatment (Canadian Cancer Society, 2009). This is not to say that these women are not at an increased risk for further depression, particularly as the occurrence of severe distress or depression disposes (sensitizes) women so that further stressful encounters might be more apt to re-induce the depressive symptomatology (Post, 2007).

Consistent with other reports (Hann et al., 2002; Friedman et al., 2006; Grange et al., 2008; Manne et al., 2005), regardless of cancer status, greater satisfaction with social support was related to lower depressive symptoms, and conversely, greater experiences of unsupport were associated with greater depressive symptoms. Importantly, although women in treatment had the highest reports of depressive symptoms, they were not less satisfied with their social support, nor did they have greater experiences of unsupport relative to the other groups, suggesting that their depression was directly related to the health threat and not a result of the reactions of others. In fact, women with a cancer experience had marginally higher satisfaction with their support relative to women in the control group. This finding is especially encouraging for women living with cancer as increased satisfaction with social support has been found to be a predictor of breast cancer survival (Gilbar, 1996; Waxler-Morrison et al., 1991; Funch & Marshall, 1983). In the present sample it appeared that poor support or unsupport was infrequent among women that currently or previously dealt with breast cancer. It remains to be established what depression levels would be like among women with breast cancer who had, indeed, encountered poor support or unsupport.

Coping with a Cancer Diagnosis

As previously reported (Carver et al., 1993), the endorsement of emotion-focused coping and avoidance coping were linked to greater levels of depressive symptoms, and the endorsement of problem-focused coping was associated with lower levels of depressive symptoms. However, on the basis of coping styles reported in response to day-to-day problems, women in treatment and those in remission could be distinguished from one another, and from women who had not been affected by cancer. While still in treatment, women reported elevated levels of avoidance coping, corresponding to the style Franks and Roesch (2006) proposed would be used in the face of a stressor that could cause harm and/or loss. Although this coping method is often considered to be “maladaptive” (Anisman et al., 2008) within the context of women going through the treatment for breast cancer, an avoidance coping style may be a very effective one. Engaging in behaviours such as wishful thinking, and escapist fantasies that characterize avoidance coping (Carver, 2000), may act as a kind of positive visualization in which women can focus on their continued lives without breast cancer, thereby limiting the distress that might otherwise be present. Indeed, although avoidance coping was positively correlated with depressive symptoms in women in remission and in the control group, this was not the case among women still in treatment who used this style most often. In contrast, women in remission generally used less emotion-focused coping than the other groups of women. Though the factors responsible for this are uncertain, it may be that after having experienced the threats and travails associated with a cancer diagnosis and its treatment, the methods of coping with stressors changed. Folkman and Lazarus (1980) suggested that in the face of health related problems, emotion-focused

coping is utilized most as individuals must contend with negative feelings and do not have enough control over the situation to use problem-focused coping. Thus, women who previously used high levels of emotion-focused coping while in treatment, may, by comparison, report lower use of this strategy when they are in remission.

Though coping was not moderated by satisfaction with social support, experiences of unsupport interacted with emotion-focused coping, and avoidance coping, to predict depressive symptoms. High utilization of emotion-focused coping was associated with greater depressive symptoms regardless of the unsupport experienced, whereas low emotion-focused coping, coupled with high experiences of unsupport, related to higher depression symptoms than the low use of this style in the face of low unsupport. Furthermore, as previously observed among women who favored avoidant styles (Manne et al., 2005), depressive symptoms were evident irrespective of unsupport, whereas among women who used low levels of avoidance coping, depressive symptoms increased with greater unsupport. These findings point to unsupport being associated with poor outcomes (depressive symptoms) even among those women who tended not to use ineffective coping styles (emotion-focused and avoidant coping). In effect, regardless of the individuals coping disposition, unsupport may over-ride even the actions of proper methods of dealing with stressful circumstances. From a practical or clinical vantage, these data point to the possibility that teaching individuals to use effective coping strategies may not promote well-being when individuals support systems are not in place, and more to the point, when the support systems are negative. As unsupport is not simply a lack of support, in the face of unsupport women not only have their cancer experience to deal with, but an additional emotional burden of a disrupted or disturbed

personal relationship. Thus, low endorsement of less desirable coping styles may not necessarily be enough to overcome the detriment caused by others' unsupportive reactions.

Trust, Blame and Regret

The experience of a life threatening disease may have implications for the trust a woman has in her doctor. In fact, trust in physician was lowest in women in the control group, increased for women in treatment, and was highest among women in remission. An inherent component of the present study was that women in remission knew the outcome of their cancer treatment. Thus, they were able, in retrospect, to perceive their physician in a more positive light. Women still in treatment have a need to have high confidence in their physician, as s/he is their main connection to survival. In contrast, women in the control group who might never have had a serious illness may not have had an opportunity to test the boundaries of the trust they have in their doctor. These women were asked to report on trust for their physician in regard to this most recent ailment/condition. Inasmuch as the cause for their last doctor-patient interaction may have involved a relatively mild illness, trust may not have been a particularly germane issue for the patient.

Despite previous reports that trust in physician reduced distress and helped women being treated for cancer cope with their experience (Juraskova et al., 2006; Henman et al., 2002), trust was not correlated with depressive symptoms in the present study. According to the transactional model of stress, a woman's ability to cope with cancer should be largely dependant on the informational support (a component of trust) she receives from her physician (Folkman et al., 2000). However, in the present

investigation trust did not interact with coping styles for any of the women in the sample. It is possible that with the increasing promotion of support groups for breast cancer patients, coupled with the amount of information available on line, women may be turning to social supports more as a source of coping, and looking to their doctors for skill during treatment instead of a source of strength. Previous studies have found that a woman's primary concerns are in her doctor's skill and that the need for a physician to have medical expertise greatly outweighs females concerns about communication abilities (Wright et al., 2004).

Interestingly, it has been reported that women who have greater social support tend to be more trusting (Dunkel-Schetter et al., 1987), and it is equally possible that trust in the physician would be augmented simply by the diminished distress that comes with increased satisfaction with support. Indeed, in the present investigation satisfaction with social support was related to trust among women in treatment. Beyond its relation to depression, trust in one's physician has been implicated in relieving the pressure a woman feels when making decisions regarding treatment. In this regard, it has been shown that feeling one's doctor has listened, and included women in the treatment decision, is fundamental to women believing the 'correct' treatment was chosen (Henman et al., 2002). Contrary to intuition, however, the more trust a woman had in her doctor, the more likely she was to blame her doctor for negative events. This finding may reflect a dichotomy previously reported in which women make their own decisions to obtain the desired treatment, but then do not wish to be accountable for the repercussions of the chosen therapy (Deadman et al., 2001). It is likely that when making life threatening treatment decisions women are overwhelmed by the magnitude of possibilities (Luce

2005). Thus, when negative events occur, women are likely to place the blame elsewhere, even though they agreed to undergo the treatment that they had. Most individuals follow the recommended treatment given their limited knowledge, and hence their control over their own treatment is largely illusory. Accordingly, blaming the physician may not be appropriate, but certainly it would be more reasonable than self-blame (unless, of course, their health-related behaviours contributed to negative outcomes). These data indicate that trust is a two edged sword; with the benefits of trust comes the possibility of blame when adverse events occur.

Curiously, although trust was associated with problems that occurred during the course of treatment, the level of trust a woman had in her doctor did not predict who she would blame if her cancer were to metastasize. This finding suggests that women feel that they are, to a certain extent, putting their health into their doctors' hands, but might be differentiating between negative events in the doctor's control (for which s/he can be blamed) and uncontrollable events, such as metastases, (for which the physician might not be perceived as being responsible).

As previously found, self- and other-blame are frequently observed features among depressed individuals (Matheson & Anisman, 2003). It was likewise detected in the present study that women who blamed their doctor, themselves, or another source for negative events had higher depressive symptoms than individuals who blamed no one. Furthermore, women who blamed themselves had greater levels of regret than women who blamed other sources suggesting that they may be feeling responsibility for, and remorse over, the decision they made. Given that self- and other-blame are common among depressed individuals, the finding that blame over negative events was tied to

depression and regret among women with a cancer experience is not altogether surprising. However, it is uncertain if blame emanated from the depression or the other way around.

Limitations

Although the present investigation may have implications as to how a woman copes with breast cancer and whether this is related to depression, there are limitations of this study that should be acknowledged. Ultimately, to a degree, every woman's cancer experience is unique. Women may have had different types of problems during their treatment that were reflected in their coping and trust appraisals. Furthermore, the women had different kinds of breast cancer and were diagnosed at different stages of cancer. As survival and recurrence rates are dependant on the type and stage of cancer, these factors may have contributed to women's subjective ratings of the various measures.

In the present study, women were asked about the way they cope with stresses in general, but this was time limited to recent weeks. Thus, it is not known if women in treatment were reporting the way they coped with their illness, the treatment, other recent stresses or a combination of factors. It is possible that women in treatment cope with all stresses in the same way, but there is no assurance that similar responses would be obtained if they had specifically been asked about coping with cancer. Indeed, coping strategies that individuals' use have been shown to vary across situations and over time in response to a given stressor (Folkman et al., 2000).

Women with breast cancer typically have a combination of individuals involved in their cancer treatment, including an oncologist, radiologist, surgeon, and family

physician, as well as nurses and technicians. Thus, the trust reported may have been reflective of the primary physician, or may have been an average perception of trust across all doctors (or the entire team). Additionally, women were not asked about facets of the relationship with their doctor other than trust. It is possible that women were displeased with other aspects of their doctor, such as communication skills or time management, and this was reflected in their trust appraisal.

The retrospective design of this study for women in remission may allow them to look back on their cancer experience more positively knowing that they have overcome the disease, at least for the time being. Thus, the responses of women in remission may not be reflective of how they felt about their physician during their treatment. Likewise, women currently battling cancer may be in different mind states from one another when they completed this study, based on their current physical or mental condition. As such, their responses may not reflect how they felt over the entire cancer experience, but were more reflective of their perspective at that given moment.

Finally, the close ended design of the questionnaires may have limited the amount of information gathered from participant responses. It is possible that other aspects of the doctor-patient relationship or social supports were crucial to women and these were not reflected in the questions asked. The sample size was also a concern in this study. Given the number of variables examined, the small sample size may have impeded the power to obtain significant results. Furthermore, not all groups were equally represented, and women in treatment had the least number of participants. Thus, a larger and more equal sample may have yielded stronger results.

It remains to be determined how the trust a woman has in her physician fluctuates over a breast cancer experience. Did women in remission who reported higher trust have this same level of trust during treatment? Or is it the result of a hindsight bias? To increase understanding of these distinctions, women's trust should be examined at various times throughout the cancer treatment process. Ultimately, trust ratings of women in remission should be compared to women who are receiving end of life palliative care, to see whether treatment outcome influences physician ratings. Additionally, while in treatment, women typically experience an influx of attention and aid as friends and family recognize the difficulty of dealing with a potentially terminal illness. What is not known, is how women cope at the critical point when this support suddenly disappears as they are classified as 'cured' or 'cancer free'. In the initial months of remission women are often dealing with lingering side effects from treatment and fear of cancer recurrence; thus a sudden decrease in the amount of support received may have detrimental effects on a woman's mood state and her adjustment to life after cancer. Similarly, it may be important to know how a woman's ability to cope, or her trust in her physician, changes if cancer does reoccur.

Conclusions

A satisfying social network and few experiences of unsupport, coupled with appropriate coping styles and trust in a physician, are some of the key facets to the well-being of a woman dealing with a cancer diagnosis. Women in treatment, like those who are well, may be at risk for negative mood states due to the endorsement of potentially maladaptive emotion-focused coping. Women in remission, however, tend to have levels of depression, coping styles and trust that are similar to women in the control group.

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Appendix A Informed Consent

The purpose of an informed consent is to ensure that you understand the purpose of the study and the nature of your involvement. The informed consent has to provide sufficient information such that you have the opportunity to determine whether you wish to participate in the study.

Study Title: Appraisal of trust, coping and decision making in women living with breast cancer.

Study Personnel: Dr. Hymie Anisman (Faculty Investigator, 520-2600 ext. 2699)
Sheena Aislinn Taha (Graduate Researcher, 520-2600 ext. 7513)

If you have any ethical concerns about how this study was conducted please contact:

Dr. A. Parush, Chair of the Carleton University Ethics Committee for Psychological Research, 613-520-2600 ext. 6026 or Dr. J. Mantler, Chair of the Department of Psychology, 613-520-2600 ext. 4173.

Purpose and Task Requirements: We are interested in understanding how you're coping with breast cancer, and how support from your friend, family members, and medical doctor(s) contribute to your coping abilities. We are also interested in the relationship you have with your medical doctor, how you perceive potentially negative outcomes and your perception of the decisions you have already made regarding your treatment. By gaining an enhanced understanding of how women living with breast cancer appraise their experience we may better comprehend the social services breast cancer patients may benefit from. Similarly, this study may help us understand the role that trust between a medical professional and their patient plays in a woman's cancer experience.

Potential Risk and Discomfort: There are no physical risks in this study. You may experience some emotional pain when reflecting back on your experience living with cancer.

Anonymity/Confidentiality: The data collected in this study will be kept confidential. Your informed consent form will be stored separately from your questionnaire and kept in a secured file by one of the research investigators who will keep this information confidential. It will be associated with a code, and only this code will identify your questionnaire.

Right to Withdraw: Your participation in this study is entirely voluntary. At any point during the study you have the right to contact the study personnel to withdraw your consent.

Please note that you may be contacted after you complete the study to clarify your responses to certain questions.

I have read the above description of the study. The data collected will be used in research publications and/or for teaching purposes. My signature indicates that I agree to participate in the study, and this in no way constitutes a waiver of my rights.

Full name (please print): _____

Participant Signature: _____

Date: _____

Appendix B Debriefing Statement for Women with Breast Cancer

Research has shown that the social support a woman receives while living with breast cancer may affect how well she copes with the disease. This social support may come from friends, family or medical professionals. However, the role that her medical doctor plays in providing support has not been well understood. In most cases, the medical oncologist is the primary provider of medical information and is the individual who provides the treatment opportunities to the women living with breast cancer.

In this study, we are interested in examining the relationship you have with your oncologist and the affect that this has on how you are coping with your disease and how you have made decisions related to your cancer. We are also interested in understanding how the social support you are receiving is affecting how you are coping with living with breast cancer.

Thank you very much for your participation in this study. If you have experienced any distress while completing these measures please consult the directory provided by the Canadian Cancer Society for a support organization in your area (<http://info.cancer.ca/csd/searchcon.aspx?lang=E&id=3172>). We hope that the information gained from this study will help us to understand the therapeutic relationship between a female with breast cancer and her doctor. We also hope to gain a better understanding of the influence that this doctor-patient relationship, along with other social support, has on how a woman copes with her cancer experience. This information will be crucial to improve the interactions between an oncologist and a female to

establish a relationship where both involved are most confident in obtaining a successful outcome in treatment.

Debriefing Statement for Women in the Control Group

Research has shown that the social support a woman receives while living with breast cancer may affect how well she copes with the disease. This social support may come from friends, family or medical professionals. However, the role that her medical doctor plays in providing support has not been well understood. In most cases, the medical oncologist is the primary provider of medical information and is the individual who provides the treatment opportunities to the women living with breast cancer.

In this study, we are interested in examining the relationship you have with your doctor and how this compares to that of women living with breast cancer. We are also interested in understanding how the social support you are receiving is affecting how you are coping with stress.

If you have experienced any distress while completing these measures please consult the directory provided by the Canadian Cancer Society for a support organization in your area (<http://info.cancer.ca/csd/searchcon.aspx?lang=E&id=3172>). We hope that the information gained from this study will help us to understand the therapeutic relationship between a female with breast cancer and her doctor. We also hope to gain a better understanding of the influence that this doctor-patient relationship, along with other social support, has on how a woman copes with her cancer experience. This information will be crucial to improve the interactions between an oncologist and a

female to establish a relationship where both involved are most confident in obtaining a successful outcome in treatment.

Appendix C Demographics and Medical History

*Questions 6-20 not given to the control group

1. What is your current age? _____
2. What is the highest level of education that you have completed?
 - ☐ Grade school
 - ☐ Some high school
 - ☐ High school diploma
 - ☐ Trade certificate/diploma
 - ☐ Some college
 - ☐ College diploma/degree
 - ☐ Some university
 - ☐ University degree
3. What is your marital status?
 - ☐ Married/with partner
 - ☐ Separated/divorced
 - ☐ Widowed
 - ☐ Single
 - ☐ Other: _____
4. What are your current living arrangements?
 - ☐ Living alone
 - ☐ Living with spouse/significant other
 - ☐ Living with family
 - ☐ Other: _____
5. What is your employment status?
 - ☐ Employed Part-time
 - ☐ Employed Full-time
 - ☐ Unemployed
 - ☐ Retired
 - ☐ Other: _____
6. When were you diagnosed with breast cancer?
 - ☐ within the last year
 - ☐ 1-2 years ago
 - ☐ 3-5 years ago
 - ☐ more than 5 years ago
7. What was your age of the time of your breast cancer diagnosis? _____

8. What was the stage of cancer at the time of your diagnosis?
- ☐ Stage 1
 - ☐ Stage 2
 - ☐ Stage 3
 - ☐ Stage 4
9. At the time of diagnosis, the size of your tumor was?
- ☐ 0-2 cms
 - ☐ 2.1-5 cms
 - ☐ >5.1 cms
10. Were/are there lymph nodes involved in your breast cancer?
- ☐ Yes
 - ☐ No
- If yes, how many nodes were affected?
- ☐ 1-3
 - ☐ 4-7
 - ☐ >7
11. With respect to hormone involvement, were you positive for any of the following? (mark all that apply)
- ☐ Androgen
 - ☐ Progesterone
 - ☐ Don't know
12. Was/is your tumor HER 2 positive?
- ☐ Yes ☐ No
13. The type of cancer you have is? (mark all that apply)
- ☐ infiltrating ductal
 - ☐ invasive lobular
 - ☐ in situ breast cancer
 - ☐ other: _____
14. Which treatments/procedures have you already had? (mark all that apply)
- ☐ Mastectomy
 - ☐ Surgery other than mastectomy
 - ☐ Radiation
 - ☐ Chemotherapy
 - ☐ Hormone therapy
 - ☐ Herceptin
 - ☐ Other: _____

15. Are you still on hormone therapy?

☐ Yes ☐ No

If yes, do you believe you are being protected/helped by hormone therapy?

☐ Yes ☐ No ☐ Don't Know

16. Which treatments/procedures are you considering having or are you going to have? (mark all that apply)

- ☐ Mastectomy
☐ Surgery other than mastectomy
☐ Radiation
☐ Chemotherapy
☐ Hormone therapy
☐ Herceptin
☐ Other: _____

17. What is the current status of your cancer?

- ☐ Still being treated
☐ In remission
☐ Other: _____

18. Has your cancer metastasized (spread) to other areas of your body?

Yes ☐ No ☐

Is so, which area(s)? _____

19. Has your doctor informed you about:

A: prognostic factors (getting better)? ☐ Yes ☐ No

B: benefit of your treatment? ☐ Yes ☐ No

20. Based on prognostic factors and the benefit of your treatment, what is your anticipation of relapsing over the next 5-10 years? (0% = absolutely will not relapse 50% = could happen, could not 100% = definitely will relapse)

_____ %

21. Do you have a relative that is/was diagnosed with cancer?

Yes ☐ No ☐

If so, what was their relationship to you? _____

When was this relative diagnosed? _____

22. Which treatments/procedures did your relative have? (mark all that apply)

- ☐ Mastectomy
- ☐ Surgery other than mastectomy
- ☐ Radiation
- ☐ Chemotherapy
- ☐ Hormone therapy
- ☐ Herceptin
- ☐ Other: _____

23. What was the outcome of their cancer experience?

- ☐ Currently dealing with cancer
- ☐ Cancer in remission
- ☐ Death as a result of cancer

Appendix D Trust in Physician

Thinking about your interaction with your doctor treating your breast cancer, please indicate the degree to which you agree or disagree with the following statements.

	Strongly Agree	Agree	Neither Agree nor Disagree	Disagree	Strongly Disagree
1. I doubt that my doctor really cares about me as a person	1	2	3	4	5
2. My doctor is usually considerate of my needs and puts them first	1	2	3	4	5
3. I trust my doctor so much I always try to follow his/her advice	1	2	3	4	5
4. If my doctor tells me something is so, then it must be true	1	2	3	4	5
5. I sometimes distrust my doctors opinions and would like a second one	1	2	3	4	5
6. I trust my doctors judgments about my medical care	1	2	3	4	5
7. I feel my doctor does not do everything he/she should do for my medical care	1	2	3	4	5
8. I trust my doctor to put my medical needs above all other considerations when treating my medical problems	1	2	3	4	5
9. My doctor is a real expert in taking care of medical problems like mine	1	2	3	4	5
10. I trust my doctor to tell me if a mistake was made about my treatment	1	2	3	4	5
11. I sometimes worry that my doctor may not keep the information we discuss totally private	1	2	3	4	5

Appendix E Blame

1. If your cancer were to metastasize, whom would you hold responsible?

- ☐ my doctor(s)
- ☐ myself
- ☐ no one is responsible
- ☐ other: _____

2. Looking back at things that have gone negatively in your treatment, whom do you hold responsible?

- ☐ my doctor(s)
- ☐ myself
- ☐ no one is responsible
- ☐ other: _____

3. Whom would you say made the final decisions about your breast cancer treatment?

- ☐ I made the final decisions about which treatment options to pursue on my own/with my family
- ☐ My doctor made the final decisions about which treatment options to pursue on his/her own
- ☐ Using my doctors guidance, I made the final decisions about which treatment options to pursue
- ☐ Accounting for my desires, my doctor made the final decisions about which treatment options to pursue
- ☐ My doctor and I made the decision together about which treatment options to pursue
- ☐ Other: _____

Appendix F Survey of Coping Profiles Endorsed (50-item SCOPE)

The purpose of this questionnaire is to find out how people deal with more general problems or stresses in their lives. The following are activities that you may have done. After each activity, please indicate the extent to which you would use this as a way of dealing with problems or stresses in recent weeks.

<i>Ordinarily, in recent weeks have you:</i>	<i>Never</i>	<i>Seldom</i>	<i>Sometimes</i>	<i>Often</i>	<i>Almost always</i>
1. accepted that there was nothing you could do to change your situation?	0	1	2	3	4
2. tried to just take whatever came your way?	0	1	2	3	4
3. talked with friends or relatives about your problems?	0	1	2	3	4
4. tried to do things which you typically enjoy?	0	1	2	3	4
5. sought out information that would help you resolve your problems?	0	1	2	3	4
6. blamed others for creating your problems or making them worse?	0	1	2	3	4
7. sought the advice of others to resolve your problems?	0	1	2	3	4
8. blamed yourself for your problems?	0	1	2	3	4
9. exercised?	0	1	2	3	4
10. fantasized or thought about unreal things (eg., the perfect revenge, or winning a million dollars) to feel better?	0 4	1	2	3	4
11. been very emotional compared to your usual self?	0	1	2	3	4
12. gone over your problem in your mind over and over again?	0 4	1	2	3	
13. asked others for help?	0	1	2	3	4
14. thought about your problem a lot?	0	1	2	3	4
15. became involved in recreation or pleasure activities?	0	1	2	3	4
16. worried about your problem a lot?	0	1	2	3	4
17. tried to keep your mind off things that are upsetting you?	0 4	1	2	3	

18. tried to distract yourself from your troubles?	0	1	2	3	4
19. avoided thinking about your problems?	0	1	2	3	4
20. made plans to overcome your problems?	0	1	2	3	4
21. told jokes about your situation?	0	1	2	3	4
22. thought a lot about who is responsible for your problem (besides yourself)?	0	1	2	3	4
23. shared humorous stories etc. to cheer yourself and others up?	0	1	2	3	4
24. told yourself that other people have dealt with problems such as yours?	0	1	2	3	4
25. thought a lot about how you have brought your problem on yourself?	0	1	2	3	4
26. decided to wait and see how things turn out?	0	1	2	3	4
27. wished the situation would go away or be over with?	0	1	2	3	4
28. decided that your current problems are a result of your own past actions?	0	1	2	3	4
29. gone shopping?	0	1	2	3	4
30. asserted yourself and taken positive action on problems that are getting you down?	0	1	2	3	4
31. sought reassurance and moral support from others?	0	1	2	3	4
32. resigned yourself to your problem?	0	1	2	3	4
33. thought about how your problems have been caused by other people?	0	1	2	3	4
34. daydreamed about how things may turn out?	0	1	2	3	4
35. been very emotional in how you react, even to little things?	0	1	2	3	4
36. decided that you can grow and learn through your problem?	0	1	2	3	4
37. told yourself that other people have problems like your own?	0	1	2	3	4
38. wished I was a stronger person or better at dealing with problems?	0	1	2	3	4
39. looked for how you can learn something out of your bad situation?	0	1	2	3	4

40. asked for God's guidance?	0	1	2	3	4
41. kept your feelings bottled up inside?	0	1	2	3	4
42. found yourself crying more than usual?	0	1	2	3	4
43. tried to act as if you were not upset?	0	1	2	3	4
44. prayed for help?	0	1	2	3	4
45. gone out?	0	1	2	3	4
46. held in your feelings?	0	1	2	3	4
47. tried to act as if you weren't feeling bad?	0	1	2	3	4
48. taken steps to overcome your problems?	0	1	2	3	4
49. made humorous comments or wise cracks?	0	1	2	3	4
50. told others that you were depressed or emotionally upset?	0	1	2	3	4

Appendix G Social Support Questionnaire

For the following questions, please answer with the relationship that the individual has to you, e. g. brother, mother, friend, etc. Please write down all who are applicable.

1. Whom can you really count on to distract you from your worries when you feel under stress? _____

How satisfied are you with support available to you in this situation?

Very Dissatisfied					Very Satisfied
1	2	3	4	5	6

2. Whom can you really count on to help you feel more relaxed when you are under pressure or tense? _____

How satisfied are you with support available to you in this situation?

Very Dissatisfied					Very Satisfied
1	2	3	4	5	6

3. Who accepts you totally, including both your worst and your best points? _____

How satisfied are you with support available to you in this situation?

Very Dissatisfied					Very Satisfied
1	2	3	4	5	6

4. Whom can you really count on to care about you, regardless of what is happening to you? _____

How satisfied are you with support available to you in this situation?

Very Dissatisfied					Very Satisfied
1	2	3	4	5	6

5. Whom can you really count on to help you feel better when you are feeling generally down-in-the-dumps? _____

How satisfied are you with support available to you in this situation?

Very Dissatisfied					Very Satisfied
1	2	3	4	5	6

6. Whom can you count on to console you when you are very upset?

How satisfied are you with support available to you in this situation?

Very Dissatisfied					Very Satisfied
1	2	3	4	5	6

Appendix H Unsupportive Social Interactions Inventory (Modified USII – A)

Please think about times when you've turned to **your partner** for support in regards to dealing with breast cancer. For each of the statements below, **please indicate how frequently your partner responded in this way when you went to him/her for support**. If you do not currently have a partner, please indicate how frequently a close friend has responded in this way.

	<u>None</u>			<u>A lot</u>	
	0	1	2	3	4
1. My partner thought I was over-reacting to the situation	0	1	2	3	4
2. When I was talking about the issue/situation with my partner, he did not give me enough of his time, or made me feel like I should hurry	0	1	2	3	4
3. My partner made "should/shouldn't have" comments about my role in the situation, such as, "You shouldn't have"	0	1	2	3	4
4. My partner didn't seem to know what to say, or seemed afraid of saying/doing the "wrong" thing	0	1	2	3	4
5. My partner refused to provide the type of help or support I was looking for	0	1	2	3	4
6. After becoming aware that I was dealing with something that I found difficult or distressing, my partner responded with uninvited physical touching, such as hugging	0	1	2	3	4
7. My partner said I should look on the bright side	0	1	2	3	4
8. My partner said "I told you so." or made some similar comment to me about my situation	0	1	2	3	4
9. My partner seemed to be telling me what he thought I wanted to hear	0	1	2	3	4
10. In responding to me about my situation, my partner seemed disappointed in me	0	1	2	3	4
11. When I was talking to my partner about my situation, he changed the subject before I wanted to	0	1	2	3	4
12. My partner felt that I should stop worrying about the situation and just forget about it	0	1	2	3	4

13. My partner asked me "why" questions, such as, "Why did/didn't you ..."	0	1	2	3	4
14. My partner felt that I should focus on the present and/or future, and that I should forget about what's happened and get on with my life.	0	1	2	3	4
15. My partner tried to cheer me up when I was not ready to cheer up about the situation	0	1	2	3	4
16. My partner refused to take me seriously	0	1	2	3	4
17. My partner told me to be strong, to keep my chin up, or that I shouldn't let it bother me	0	1	2	3	4
18. When I was talking to my partner about what was bothering me, he did not seem to want to hear about it	0	1	2	3	4
19. My partner told me that I had gotten myself into the situation in the first place, and that now I must deal with the consequences	0	1	2	3	4
20. My partner did something for me that I wanted to do and could have done for myself, as if he thought I was no longer capable	0	1	2	3	4
21. My partner discouraged me from expressing feelings about my situation, such as anger, hurt or sadness	0	1	2	3	4
22. My partner felt that 'it could have been worse' or that 'it was not as bad as I thought'	0	1	2	3	4
23. From my partner's tone of voice, expression, or body language, I got the feeling that he was uncomfortable talking with me about my problem	0	1	2	3	4
24. My partner made comments which blamed me or tried to make me feel responsible	0	1	2	3	4

Appendix I Decision Regret Scale

Please reflect on the decisions made to treat your breast cancer. Please indicate how strongly you agree or disagree with these statements by circling a number from 1 (strongly agree) to 5 (strongly disagree) which bests fits your view about your decision.

	Strongly Agree	Agree	Neither Agree nor Disagree	Disagree	Strongly Disagree
It was the right decision	1	2	3	4	5
I regret the choice that was made	1	2	3	4	5
I would go for the same choice if I had to do it over again	1	2	3	4	5
The choice did me a lot of harm	1	2	3	4	5
The decision was a wise one	1	2	3	4	5

Appendix J Beck Depression Inventory

On this questionnaire are groups of statements. Please read the entire group of statements of each category. Then pick out ONE statement in that group which best describes the way you feel. Check off the number beside the statement you have chosen.

1. ☐ 0 = I do not feel sad
☐ 1 = I feel sad or blue
☐ 2a = I am blue or sad all of the time and I can't snap out of it
☐ 2b = I am so sad or unhappy that it is very painful
☐ 3 = I am so sad or unhappy that I can't stand it

2. ☐ 0 = I am not particularly pessimistic or discouraged about the future
☐ 1 = I feel discouraged about the future
☐ 2a = I feel I have nothing to look forward to
☐ 2b = I feel I won't ever get over my troubles
☐ 3 = I feel that the future is hopeless and things cannot improve

3. ☐ 0 = I do not feel like a failure
☐ 1 = I feel I have failed more than the average person
☐ 2a = I feel I have accomplished very little that is worthwhile or that means anything
☐ 2b = As I look back on my life, all I can see is a lot of failures
☐ 3 = I feel I am a complete failure as a person

4. ☐ 0 = I am not particularly dissatisfied
☐ 1a = I feel bored most of the time
☐ 1b = I don't enjoy things the way I used to
☐ 2 = I don't get satisfaction out of anything anymore
☐ 3 = I am dissatisfied with everything

5. ☐ 0 = I don't feel particularly guilty
☐ 1 = I feel bad or unworthy a good part of the time
☐ 2a = I feel quite guilty
☐ 2b = I feel bad or unworthy practically all of the time now
☐ 3 = I feel as though I am very bad or worthless

6. ☐ 0 = I don't feel I am being punished
☐ 1 = I have a feeling that something bad may happen to me
☐ 2 = I feel I am being punished or will be punished
☐ 3a = I feel I deserve to be punished
☐ 3b = I want to be punished

7. ☐ 0 = I don't feel disappointed in myself
☐ 1a = I am disappointed in myself

- ___ 1b = I don't like myself
 ___ 2 = I am disgusted with myself
 ___ 3 = I hate myself
8. ___ 0 = I do not feel I am any worse than anybody else
 ___ 1 = I am very critical of myself for my weaknesses or mistakes
 ___ 2a = I blame myself for everything that goes wrong
 ___ 2b = I feel I have many bad faults
9. ___ 0 = I don't have thoughts of harming myself
 ___ 1 = I have thoughts of harming myself but I would not carry them out
 ___ 2a = I feel I would be better off dead
 ___ 2b = I have definite plans about committing suicide
 ___ 2c = I feel my family would be better off if I were dead
 ___ 3 = I would kill myself if I could
10. ___ 0 = I don't cry anymore than usual
 ___ 1 = I cry more now than I used to
 ___ 2 = I cry all the time now. I can't stop it
 ___ 3 = I used to be able to cry but now I can't cry at all even though I want to
11. ___ 0 = I am no more irritated now than I ever am
 ___ 1 = I get annoyed or irritated more easily than I used to
 ___ 2 = I get irritated all the time
 ___ 3 = I don't get irritated at all the things that used to irritate me.
12. ___ 0 = I have not lost interest in other people
 ___ 1 = I am less interested in other people than I used to be
 ___ 2 = I have lost most of my interest in other people and I have little feeling for them
 ___ 3 = I have lost all my interest in other people and don't care about them at all
13. ___ 0 = I make decisions about as well as ever
 ___ 1 = I am less sure of myself now and try to put off making decisions
 ___ 2 = I can't make decisions anymore without help
 ___ 3 = I can't make decisions at all anymore
14. ___ 0 = I don't feel I look any worse than I used to
 ___ 1 = I am worried that I am looking old or unattractive
 ___ 2 = I feel that there are permanent changes in my appearance and they make me look unattractive
 ___ 3 = I feel that I am ugly or repulsive looking
15. ___ 0 = I can work about as well as before
 ___ 1a = It takes extra effort to get started at doing something

- ___ 1b = I don't work as well as I used to
 ___ 2 = I have to push myself very hard to do anything
 ___ 3 = I can't do any work at all
16. ___ 0 = I can sleep as well as usual
 ___ 1 = I wake up more tired in the morning than I used to
 ___ 2 = I wake up 1-2 hours earlier than usual and find it hard to get back to sleep
 ___ 3 = I wake up early every day and can't get more than 5 hours sleep
17. ___ 0 = I don't get any more tired than usual
 ___ 1 = I get tired more easily than I used to
 ___ 2 = I get tired from doing anything
 ___ 3 = I get too tired to do anything
18. ___ 0 = My appetite is no worse than usual
 ___ 1 = My appetite is not as good as it used to be
 ___ 2 = My appetite is much worse now
 ___ 3 = I have no appetite at all anymore
19. ___ 0 = I haven't lost much weight, if any, lately
 ___ 1 = I have lost more than 5 pounds
 ___ 2 = I have lost more than 10 pounds
 ___ 3 = I have lost more than 15 pounds
20. ___ 0 = I am no more concerned about my health than usual
 ___ 1 = I am concerned about aches and pains or upset stomach or constipation or other unpleasant feelings in my body
 ___ 2 = I am so concerned with how I feel or what I feel that it's hard to think of much else
 ___ 3 = I am completely absorbed in what I feel
21. ___ 0 = I have not noticed any recent change in my interest in sex
 ___ 1 = I am less interested in sex than I used to be
 ___ 2 = I am much less interested in sex now
 ___ 3 = I have lost interest in sex completely

Appendix K Distress Debriefing

Depression is a stress-related response that can occur for many reasons, including workplace stressors, traumatic life events, as well as discrimination. Approximately 10-15% of people will suffer some degree of depression during their lifetime. With advances in modern medicine, most people can readily be treated for this illness, which if unattended can be long lasting and affect many aspects of one's life. The symptoms of depression comprise:

- Poor or depressed mood, or a reduction in the pleasure gained from otherwise positive experiences
- Sleep disturbances
- Eating disturbances (loss of appetite, or overeating despite not being hungry), which may be linked to weight changes
- Lack of sexual interest
- Fatigue and lethargy (you don't feel like doing anything)
- An inability to focus (e.g., have a hard time reading)
- Reduced interactions with family and friends
- Thoughts of suicide

Someone who is depressed may experience several (3-4), but not necessarily all of the above symptoms.

It is likewise the case that 60% of individuals will encounter a severe traumatic event and of these people, a fair number will develop symptoms that cause severe anxiety. Illnesses of this nature, including posttraumatic stress disorder (PTSD) can be treated. Once again, if unattended, the repercussions can be severe. Symptoms include:

- Hyperarousal (e.g., feelings of anxiety and reactive even to minor situations)
- Intrusive thoughts (the event comes into your head frequently)
- Avoiding thoughts or stimuli related to the event

These symptoms persist for more than a month following the event, and influence your day-to-day functioning.

Your responses to this survey suggest that you may be experiencing one of the above. If you are not already receiving attention for this problem, it is suggested that you contact your family physician. It is not a good idea to allow problems to fester, as ruminating over these problems will typically not make them go away. Your family physician or counsellor will usually be able to help you or to refer you to someone who can. If you do not have a family physician, then you can contact either of the following

Ottawa Distress Centre: (613) 238-1089, Web Site: www.dcottawa.on.ca

Distress Centre of Toronto: (416) 408-HELP, Web Site: www.torontodistresscentre.com